S. HRG. 108–637

STRATEGIES TO IMPROVE ACCESS TO MEDICAID HOME- AND COMMUNITY-BASED SERVICES

HEARING

BEFORE THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDRED EIGHTH CONGRESS

SECOND SESSION

APRIL 7, 2004



Printed for the use of the Committee on Finance

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STRATEGIES TO IMPROVE ACCESS TO MEDICAID HOME- ANDCOMMUNITY-BASED SERVICES

WEDNESDAY, APRIL 7, 2004

U.S. SENATE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at10:08 a.m., in room SD–215, Dirksen Senate OfficeBuilding, Hon. Charles E. Grassley (chairman of thecommittee) presiding.

Also present: Senators Thomas, Smith, Baucus,Breaux, Graham, Bingaman, and Lincoln.

OPENING STATEMENT OF HON. CHARLES E. GRASSLEY, A U.S.SENATOR FROM IOWA, CHAIRMAN, COMMITTEE ON FINANCE

The CHAIRMAN. Good morning, everybody. Thishearing is now called to order.

I thank everybody for attending. This is a very goodturnout. We usually have this room always filled up, andwe often have people in overflow rooms. So, I am alwaysthankful when we have a very major turnout on any hearingthat we have.

I would start by extending a special thanks towitnesses, because they go to a lot of extra work toprepare for this particular hearing, or any hearing. Iwould like to give a special thanks to those who havetraveled long distances to be here today, including twoIowans, Diane Findley and Ray Gerke.

The purpose of today's hearing is to review proposalsto improve access to Medicaid home and community basedservices. One of these proposals is the President's NewFreedom Initiative. Another, is the Medicaid CommunityBased Attendant Services and Support Act of 2003, alsoknown as MiCASSA. We will hear today about aspects ofboth of these proposals.

The President first announced the New FreedomInitiative over 2 years ago. Since that time,government agencies have been busily working together tofind new ways to improve services that we refer to ashome and community based services.

Today, we will take a close look at the variousprograms laid out in the initiative. One demonstrationwould allow individuals who choose to live at home or incommunities to make decisions about not only where theyare going to live, but also how their care is delivered.This is known in the bill as the principle, money followsthe person.

Another concept in the initiative would allowindividuals who rely upon family caretakers the chance toreceive respite care. The respite demonstrationrecognizes that individuals who receive care and theircaretakers occasionally need to step away from theirrespective roles.

A third demonstration would test a proposal to offercommunity-based services to children residing inpsychiatric residential treatment facilities.

Finally, we will discuss the importance of providingadditional support to those who choose the career of adirect care worker. Like nurses, direct care workers arebecoming a scarce resource.

Each of today's witnesses brings a unique backgroundto the issue. The collection of their individualexperiences and perspectives will help us betterunderstand the home- and community-based service system.

For instance, a community-based servicesdemonstration for children receiving care in psychiatricresidential treatment facilities draws attention to anissue that I continue to defend. Current law does notallow States to offer Medicaid home- and community-basedservices as an alternative to inpatient psychiatric care.

Susan, a single mother from Harlan, Iowa, describedher frustration, trying to keep her family together. Herson, Colton, has been diagnosed with bi-polar disorderand depression and is developmentally delayed. One ofhis biggest fears is having to leave his mom. Susanfeels she is willing and able to care for him at home ifshe gets the support services at her community level.

The lack of covered home- and community-based supportmeans that some parents face the impossible decision ofrelinquishing custody of a child to a State institutionso that their child can get necessary lifesavingservices.

A provision in the Family Opportunity Act, which islegislation that I have sponsored for the past threeCongresses, recognizes the hardship that families face incaring for a child with mental health illness. Under mybill, families will no longer have to give up theirchild. These families deserve understanding andcompassionate public policy that addresses the specialneeds of caring for a child with mental illness.

As we consider recommendations regarding thedirection of future policymaking, it is important to keepin mind the legislative history in this area. LikeMedicare, the Medicaid program was first enacted in 1965.Our Nation's service delivery system was vastly differentat that time than it is today. Thanks to the dedicatedadvocacy of consumers and their family members, our long-term care system has seen major improvements over theyears.

That is not to say that our work is finished, orotherwise we would not be having this hearing. Far fromit. Unfortunately, the demand for home and community-based services exceeds current capacity. States,providers, and many others have made great strides inbuilding capacity in consumer demand, but many challengesremain for us.

It is also important to note that not all consumerswant to be cared for in their home. For instance, nearlyone million frail elderly citizens are currently caredfor in a nursing home. The elderly and people withdisabilities and their families deserve choice.

Theyshould have the ability to choose whether they prefer tolive in the community or in a facility.

Home- and community-based services consist of a vastarray of these services. The system is complicatedwhether you are on the inside or the outside. Consumersof the system are the best judge of how well a system isworking, so I welcome their input and suggestions on howto shape current and new policies.

The over-arching goal of our hearing today is tofurther understand the kind of successful, cost-effective, and consumer-friendly systems of providinghome- and community-based services to Medicaidbeneficiaries.

Also, let me ask Senator Bingaman. I did not know ifSenator Baucus was coming. Normally we have one Democratspeak. But if you were not going to speak for him, thenI was going to wait and break in when he comes to let himmake his statement.

Senator BINGAMAN. Mr. Chairman, I do not have anopening statement, so I think, if he does arrive, havinghim give an opening statement is appropriate.

The CHAIRMAN. All right.

Well, then Senator Bingaman, go ahead, becauseSenator Smith has an opening statement. I want to makesure that we have got equal representation from bothsides.

Senator BINGAMAN. Well, Mr. Chairman, I did nothave an opening statement, but I am glad to hear SenatorSmith's.

The CHAIRMAN. All right.

Senator Smith, go ahead.

OPENING STATEMENT OF HON. GORDON SMITH, A U.S. SENATORFROM OREGON

Senator SMITH. Good morning, Mr. Chairman. Thankyou.

First, I would like to express to you my appreciationfor your holding this important hearing on thePresident's New Freedom Initiative, and for the paneltaking its time today to offer their expertise.

I am grateful not only for the panelists taking time,but also for your continued dedication and commitment tohelping the disabled and the elderly.

I particularly want to thank Senator Harkin. He hasbeen a tireless champion on behalf of the disabledcommunity, and I have been privileged to work with him onThe Money Follows the Person Act, which would providegreater flexibility to disabled Medicaid patients,clients who want to remain in their homes and in theircommunities while receiving long-term care.

I have long supported the streamlining of servicesand funding for the elderly and people with disabilitiesso that they have greater opportunities to keep theirindependence, both in here they choose to live and towork.

As we have become aware, Medicaid payments tend tofavor funding of long-term care institutions rather thanhome- and community-based care. These institutionsprovide a valuable service to those who need high levelsof care.

However, our system needs to allow individuals tomake the choice between home and community care or askilled nursing facility rather than having the systemmake that choice for them.

Therefore, I wholeheartedly support the President'seffort to provide a continuum of care for disabledAmericans, and, most importantly, to give them thefreedom to choose.

We can create greater options and opportunities forpeople with disabilities and help ensure that theyreceive quality care in a cost-effective manner byhelping States implement flexible funding systems,dollars follow people to the care setting that best meetstheir individual needs.

Our legislation, S. 1394, would create ademonstration project to test the effectiveness of thisapproach. In my home State of Oregon, we have beensuccessful in providing such a continuum of care for thedisabled and for seniors.

In fact, over half of Oregon's Medicaid long-termcare spending for people with disabilities in community-based care is exactly where they receive it now. Stateslike Oregon who have implemented a person-centeredplanning approach are finding that they serve individualneeds better, while delivering services in a more cost-effective manner.

At the same time, Oregon's excellent skilled nursingfacilities continue to provide quality services toindividuals who require the level of care only a nursingfacility can provide. Long-term care institutions have,and will continue to play, an important role in Oregon'ssystem, and I commend them for the quality services theyprovide.

I believe that disabled persons in every State shouldshare the same long-term care choices as Oregonians do,and the freedom to independently choose where theyreceive their care. We must help States develop programsthat offer new care choices to the elderly and thedisabled.

Again, Mr. Chairman, thank you for holding thishearing. I look forward to working with you and mycolleagues on the President's new initiative.

The CHAIRMAN. Thank you.

I want to thank you, Senator Harkin, for taking timeto appear before the Finance Committee this morning. Ialso want to commend you for working in a bipartisanfashion on this issue, and for supporting a cornerstoneof President Bush's legislative agenda on empoweringindividuals with disabilities.

On February 1, 2001, President Bush announced the NewFreedom Initiative, a comprehensive program to promotethe full participation of people with disabilities in allareas of society, the legislation of which you are anoriginal co-sponsor.

The Money Follows the Person Act of 2003 is one ofthe key pieces of the New Freedom Initiative. We willhear about it in our second panel from Dennis Smith, theDirector of the Centers for Medicaid Services. So, Iwant to thank you for appearing today, wanting to appear,and for your participation.

To my colleague from Iowa, Senator Harkin.

STATEMENT OF HON. TOM HARKIN, A U.S. SENATOR FROM IOWA

Senator HARKIN. Well, thank you very much, Mr.Chairman and members of the committee who are here,especially Senator Smith, for working so closely with uson this legislation.

Before I begin, Mr. Chairman, again, let me thankyour staff, and also the members of our Capitol Policeforce for helping us get the tables out of here so wecould accommodate more people. [Applause]. As you cansee, they did a great job. Thank you.

As you can see when you came in, Mr. Chairman, wehave an overflow group, and some of them are now goingdown to Room 106, I guess, which is the overflow room. Ithink it is going to take some time for them to getthere, so they will probably miss a little bit of this.

But I think you can gather from that that this is anissue of utmost importance, of the highest importance, topeople with disabilities in our country. The questionbefore this committee today is, really, how do we giveolder Americans and Americans with disabilities greaterchoices by expanding access to home- and community-basedservices?

Fourteen years ago, when this Congress passed andPresident Bush signed into law the Americans WithDisabilities Act, we had four goals regarding people withdisabilities. First, was to give equal opportunity inour society to people with disabilities.

Second, to make sure that people with disabilitieswere full participants in all aspects of our society:education, transportation, jobs, everything. The thirdgoal, was to provide independent living for people withdisabilities. Fourth, was to provide economic self-sufficiency for people with disabilities in our country.Those were basically the goals of the Americans WithDisabilities Act.

So where we find ourselves today, I say to my friendson this committee, is we have two sets of laws. We havegot one set of laws telling people with disabilities, wewant you to be self-sufficient, we want you to liveindependently, we want you to be full participants, wewant to give you equal opportunity.

We have another set of laws that are saying, wait aminute, you have to live in an institution, you have tolive in a nursing home, you cannot be a full participant,you cannot have equal opportunity, you cannot have yourown choices. So you have these two conflicting laws.

Well, usually when you have two conflicting laws,which one takes precedence? Well, usually the law thatprovides the money. That takes precedence. So, Medicaidlaw trumps it because, by Medicaid law, you have to livein a nursing home or an institution. So, it is hard tobe a full participant when your only choice is to live ina nursing home or institution.

Mr. Chairman, this situation cries out for quickremediation. It has been 32 years since we passed theRehabilitation Act, and 30 years since we passed IDEA,the Individuals With Disabilities Education Act, 14 yearssince we passed the Americans With Disabilities Act, andyet the Medicaid laws are still in the Dark Ages.

The Congressional Research Service, right now, saysthat 70 percent of Medicaid funding goes to institutionaland nursing home care, and only 30 percent goes tocommunity-based services.

Mr. Chairman, in our home State of Iowa it is evenworse. Eighty-one percent of our Medicaid money goes toinstitutional care, and only 19 percent to community-based services. This is the law. It is not by choice,it is the law. Medicaid must provide institutional

andnursing home care, but does not have to providecommunity-based care.

So in the conflict of these laws, yes, Medicaidtrumps, because that is where the money is. Mr.Chairman, this is simply wrong and we need to rebalancethe system.

There are two bills to address this. The first, isS. 971, called MiCASSA. Now, if you have not heard ofMiCASSA, well, you have not been around people withdisabilities.

There is not a person in this country with adisability who does not know what MiCASSA is. It hasbeen around a long time. MiCASSA stands for MedicaidCommunity Based Attendant Services and Support Act. Itis a long phrase, but we all know it by MiCASSA.

It has one aim: to level the playing field, to give achoice to the person whether that person wants to live inan institution, a nursing home, or whether they want tolive in a community-based setting. Do not leave thatdecision to the government.

I would note for the record, Mr. Chairman, that thisMiCASSA bill that I am talking about was first introducedin the House of Representatives in 1997 by then-SpeakerNewt Gingrich. I remember talking to Newt about it atthe time, and I have talked about it with him since.

He said, Harkin, you may approach it from a liberalstandpoint. I am paraphrasing his words, but basicallyhe said, I am approaching it from a conservativestandpoint.

This has to do with individual freedom and whether ornot an individual has the freedom of choice of whetherthey want to live in an institution or live in acommunity. I said, Newt, I do not care where you arecoming from, you have got the right idea, because that isreally what it is all about.

The second bill, as Senator Smith said, is our bill,S. 1394, Money Follows the Person. This is basically theNew Freedom Initiative of President Bush, which Icompliment him for in introducing. It provides, as youknow, 100 percent Federal funding for 1 year.

It provides 100 percent Federal funding to a Statefor 1 year to cover expanded community-based servicesand settings for people with disabilities. So, a Statecould expand their waiver programs, they could get newwaivers to their Medicaid plans for 1 year. After that1 year, then the State would then go back and get itsregular match after that first year.

The bill provides for $350 million a year, $1.75billion for 5 years. Again, these are the samenumbers that the President had in his New FreedomInitiative.

Mr. Chairman, I have talked about this at length withSecretary Thompson. Secretary Thompson has been helpingus get money for systems change grants to help Statesbegin planning on how they change their systems.

When Secretary Thompson was Governor of Wisconsin, heinstituted a program in Wisconsin to expand access and toexpand community-based services in the State ofWisconsin. The latest figures I have—and I am gettinginto the issue now of cost. A lot of people say, well,it is going to cost a lot more money if you do this.

Well, in the one State where we have seen this work,in Wisconsin, the last year that we have the data for it,according to their Department of Health and HumanServices in Wisconsin, they spent $64 million less oncommunity-based services than they would have if thosepeople had been in nursing homes.

But I guess the bottom line is really not money. Ibelieve an argument can be made that when people are outof the nursing homes and institutions and they are livingin the community and they have the ability toparticipate, get a job, work, be a full participant, be ataxpayer, not just a tax consumer, that that is going tooffset a lot of the costs that we in government spend fornursing home care and institutional care.

So if you just look at the cost thing, I believethat, in the long run, it is going to be cost-effectiveto do this. But I guess I would just hasten to add, Mr.Chairman, that there is much more at stake here than justmoney. We are talking about lost opportunities, lostdreams, lost hopes.

I had a young man in Iowa who is in a nursing home,Joel Justin, uses a wheelchair. He said, I have got totell you what it is like. They get me up in the morning.I have breakfast at a certain time that I have got to goto. After breakfast, I go and watch TV. They put me infront of a TV set and I watch TV for a couple of hours.Then we have some music for an hour.

Then we have someone that reads something for alittle bit, and then we have lunch. Then after lunch,they put me in front of a TV set again for another two orthree hours. He said, I do not want to live like that.He said, I believe I have more to offer to society thansitting in front of a TV set all day in a nursing home.And he is, what, a couple, three hours from his familyand his friends.

So, there is a lot more at stake here than justmoney. It is human dignity. It is whether or not peoplewith disabilities are going to have the same rights andfreedoms as everyone else in our society. That is whatthis is about.

It is time to end this Medicaid system that says youhave got to live in a nursing home or an institution.Give these people here a choice. Let them decide whatthey want to do. [Applause]. Thank you.

The CHAIRMAN. I thank you, Senator Harkin. We callin the order of people coming to the hearing. So, itwould be Senators Smith, Bingaman, Thomas, and Baucus. Iam sorry. You go ahead of Senator Breaux.

So, Senator Smith, a question?

Senator SMITH. No questions. I do not have aquestion, but just another commendation for SenatorHarkin for the passion you bring to the issue. You knowthe needs of the elderly and the people that are here,and I think recognize the system is broken and needs tobe fixed. I think that is the purpose here, and I thankyou, sir, for doing that.

The CHAIRMAN. All right.

Senator Bingaman?

Senator BINGAMAN. Mr. Chairman, thank you. SenatorHarkin, thank you for your leadership on this importantissue. We have a bill that I introduced called Savingour States, the SOS bill, that tries to do many of thesame things that your legislation envisions.

It enhancesthe matching rates for States and provides someadditional State flexibility which we think is importantin getting to the same kind of a place.

Let me just ask about the funding issue. A concern Ihave had all along, is that the general push that we haveseen in the administration budget and in the BudgetResolutions in the past, both the House and Senate, hasbeen to cut back on Medicaid funds that go to the States.

I understand your testimony that more can be donewith less dollars if we build flexibility into thesystem, but I am wondering if some of the things that youare advocating for here are not in jeopardy just likeother parts of Medicaid as those Federal dollars forMedicaid keep getting cut.

Senator HARKIN. Well, Senator, I do not know how torespond to that question. I think a lot of these thingsare in jeopardy now. But we are going to continue tofund Medicaid, I think. I mean, I assume that yourcommittee, and Ways and Means on the House side, has anobligation on Medicaid, I believe, and are going tocontinue to fund it.

I wish I could respond to your question better, butit just seems to me that, once it is funded, how do youspend that money? That is what I am getting to. I amnot arguing a certain level or not. That is something todebate and do yourselves.

I am just saying, once you decide how much, whateverit is ought to go for, as we said, the New FreedomInitiative, to give the person the choice and use some ofthis up-front money.

Now, there may be—and I think I am responsibleenough to recognize this—some transition costs. Iunderstand that. That is why the Money Follows thePerson will give that 1-year 100 percent Federalfunding to do that, to help States, give them a littlebit of a carrot, but also help them kind of get thattransition cost in there. I think that would work.

But regardless of how much money is in there forMedicaid, whatever it is, whatever that level is, itought to be up to the person how they have access tothose dollars, whether it is community-based or nursinghome-based.

Senator BINGAMAN. Well, just as a follow-up, Mr.Chairman, I think Senator Harkin is exactly right in thethrust of his legislation, and I hope we can move aheadwith it. Thank you.

The CHAIRMAN. Thank you.

Senator Thomas, do you have a question?

Senator THOMAS. Thank you, Mr. Chairman. Just ageneral question, I think.

You talked about your Medicaid community-basedattendant service bill, and so on. At the same time, weare talking here today about the New Freedom Initiative.What is the difference? What is it that you are talkingabout that will not be done under the President'sproposal?

Senator HARKIN. Well, the MiCASSA bill is a changein the law, a fundamental change in Medicaid law. Rightnow, as I said, Medicaid law says that you have toprovide institutional care and nursing home care. Itdoes not say that we have to provide community-basedservices.

The New Freedom Initiative is basically to give someup-front money to States to begin to help them changeover to this kind of a system. My argument is, unlessthere is a fundamental change in the law, it is justgoing to be one waiver thing after another.

It is going to be every State trying to get a waiverfor this, and a waiver for that, and a waiver for this,and a waiver for that. Well, why not just change theunderlying law? That is sort of the difference. Onechanges the underlying law, the other sort of helps inthe transition.

Senator THOMAS. But I think in the next testimonyit will say that $68 billion was spent on home communitywaivers. So, the waivers have been there and thatprogram has been able to have been carried out. Is thatnot true?

Senator HARKIN. In some cases, that is true. Therehave been waivers. In fact, what is happening inWisconsin is operating under a waiver. But it is alwaysa burden. It is always something that they have to gothrough. Some States get it, some States do not. Butfor the law, excuse us. That is sort of what a waiveris. But for the law, excuse us.

Senator THOMAS. I guess my point is, I do not thinkanyone disagrees, certainly, with making a choice. Thequestion is whether it is necessary to change the law,what spending is going to be involved that is not alreadyin place, and we will hear more about that from the otherwitnesses.

Senator HARKIN. You will hear from other witnesses.But the point being, unless the underlying, fundamentallaw is changed, there will always be a bias towardsinstitutions, because it says you have to provide themoney for institutional and nursing home care. Untilthat is leveled out, there is always going to be thatbias that way.

Senator THOMAS. I certainly do not disagree withyou. As you know, you and I both work on rural healthcare a great deal.

Senator HARKIN. Yes, we do.

Senator THOMAS. And we have been successful inthat. We have also found some instances in Medicaid thathad to be changed because there was no control over thespending, and so on.

Senator HARKIN. That is true.

Senator THOMAS. So, we have to balance thesethings.

Senator HARKIN. I understand.

Senator THOMAS. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Graham?

Senator GRAHAM. Thank you for meeting with us todayand for holding this important hearing. I might saythat, as a member of the Florida State Senate in the1970's, I introduced, and passed, our first State'sCommunity Care for the Elderly Act, and as Governor,worked for 8 years to see that it was adequatelyincreasing in its funding.

I would offer my State as a role model of 30 years ofaggressive use of community-based services, if you arelooking for specific examples of the effectiveness ofthis program.

But, Mr. Chairman, in deference, I want to talk abouta different subject today which is relevant to thissubject, not only because it is one I know that SenatorHarkin and all the members of this com-

mittee are veryinterested in, but also suggest a way to pay for theprogram that you are presenting.

What I want to talk about today is theadministration's cost estimate of the MedicareModernization and Improvement Act and the circumstancessurrounding the failure to reveal the analysis of thecost of this program to the Congress.

Upon learning of the administration's $534 billioncost estimate, three members of this committee, includingmyself, wrote requesting a hearing of this committee onthe cost estimates and the reason for its latedisclosure. That letter was sent on January 30. Eightweeks later, on March 7, now with seven members of thiscommittee, we requested, again, a hearing to examine thecost discrepancy.

It has now been almost 10 weeks since we found outthat the Medicare bill we thought cost $400 billion over10 years actually cost $534 billion. I want to be clear.It is not the cost, per se, that is troubling to me. Ivoted for a prescription drug benefit that cost more than$400 billion.

I voted for a proposal that cost more than $534billion. But at least we would have provided a reliable,Buick-style benefit to seniors. Now we learn that theYugo benefit that we passed actually is coming at aCadillac cost.

Even more disturbing than the difference in the costestimates, we know that different analysts may arrive atexactly the same, or different, conclusions. But it isthe enormous magnitude of the difference and the effortsapparently taken by the administration to keep the hugedifference from the American people and from theCongress.

Mr. Chairman, this committee has an obligation toinvestigate this deception. We have an obligation to theseniors who are depending upon this drug benefit, many ofwhom I see in this meeting today, and to the taxpayerswho are paying for it, and, frankly, to the members ofthe Congress, and particularly to the members of theFinance Committee who represented the $400 billion numberto our colleagues and now know the consequences of havingbeen kept ignorant.

These are some questions that I think we should askin the hearing on this subject. What did the Presidentknow regarding the much higher cost of the Medicareprescription drug benefit, and when did he know it?

If the President did not know that one of his statedpriorities was estimated by his own actuaries to farexceed the figure that was given to the Congress, whowithin this administration failed to notify the Presidentof this extraordinary cost overrun?

What actions, if any, were taken by the Department ofHealth and Human Services, the Office of Management andBudget, or the White House to prevent the timely andaccurate reporting of information to Congress on the costof the Medicare prescription drug bill?

Mr. Chairman, this is going to be an urgent issue, aswell as an important issue. The Budget Resolution thatthe Senate recently passed assumes that the 5-yearcost of the prescription drug benefit will be $165billion.

The comparable figure, as determined by theadministration's Office of the Actuary, is $231 billion.Senator, that is a difference of $66 billion, which,coincidentally, happens to be approximately the 5-yearcost of the two programs that Senator Harkin hasadvocated so eloquently here today.

This committee needs to look closely and examinethese numbers. One of the major aspects of the costoverrun is the difference estimated to be the cost ofincreasing the number of seniors in managed care. Thisrepresented 25 percent of the cost differential betweenthe Congressional Budget Office and the administration.

Managed care through Medicare has been sold to us asa cost saver. Now, at least in the legislation that wehave recently constructed, it comes at a substantiallyhigher cost than keeping seniors in traditional fee-for-service Medicare.

At the same time, we have recently learned that thetrustees of the Medicare program are projecting that theplan will be exhausted, it will be insolvent, in 2019,7 years earlier than it was predicted just last year.

I question the sense of spending more for eachbeneficiary enrolled in managed care when we should belooking for ways to reduce costs and to save the Medicaretrust fund.

As an aside, I believe one of the devices to reducecost we gave away in this legislation. We prohibitedMedicare from negotiating for better prescription drugprices.

We should reverse that policy in this legislation andwe should immediate authorize hospitals, the source ofexpenditures out of the Medicare trust fund, to commencenegotiation for the prescription drug costs of thehospitals in the United States in exactly the same waythat the Veterans Administration negotiates for all ofits hospitals.

Mr. Chairman, I urge you to hold a hearing before theMemorial Day recess on this critical and urgent issue inorder for us to better understand the differences betweenthe estimates and, importantly, the process by which welearn at such a late date of the administration'sestimate, and what we would recommend be done to reversethis outrage to Medicare beneficiaries and to theAmerican taxpayers. Thank you.

Mr. Chairman, I have the two letters to which Ireferred, the letter of January 30 and of March 26, whichelaborate on my comments, and would ask that they beincluded in the record immediately after my comments.

The CHAIRMAN. They will be included.

[The letters appear in the appendix.]

The CHAIRMAN. Senator Breaux?

Senator BREAUX. It is always good to get back toMedicare.

Let me just make a brief comment on my good friendfrom Florida's comment about the Medicare cost estimates.I think it is important to note that the Congressoperates under the cost estimates of the CongressionalBudget Office, not what OMB thinks, or says, or guesses abill will cost.

If OMB had come back and said that the bill wouldcost $200 billion, we could not have used that criteria.We could not have used that recommendation. We are boundby what the Congressional Budget Office says.

So, we cannot go shopping around to find out whichagency recommends how much a program is going to cost andpick the one we like the most. We are bound by what theCongressional Budget Office says. That is what Congresslegislates on. That is what the Medicare bill was basedon.

We do not know whether either one of them is correct.CBO may be off, OMB may be off. But we do not have achoice to pick and choose which one is more suitable toour particular arguments. And OMB had a cost estimate ofsubstantially more than the Congressional Budget Office.

We cannot pick that estimate any more than we couldpick it if it had come in much lower than CBO. We arebound by what the Congressional Budget Office tells us todo. We cannot pick the Republican administration's orthe Democratic administration's estimate of the cost. Weare bound by he rules of the Senate and by the Congress,and that is what we did.

On the subject on which Senator Harkin is testifying,I am a cosponsor. We had over 13 hearings in the AgingCommittee on the whole question of long-term care. Ithink it is one of the greatest challenges we have as theaging population gets larger and larger and wouldcontinue to grow.

This challenge that we face as Americans is as greatas any challenge that we have. I think that the Senatorhas made a very important point. I am very glad theadministration has come out with, apparently, support forthis demonstration program, because it will show Statesthat they should not have the institutional bias thatthey have.

My State has the fewest number of any State of theUnion of waivers to look at other means of taking care ofpeople other than institutions. The lowest in theNation.

We have been trying very hard to try and convincethem, even to people who run the nursing homes, that theyshould be in the long-term care business. Everybody doesnot need 24-hour-a-day, 7 days a week, 365 days out ofthe year care. But they need help and assistance that isless expensive, less intrusive.

Many times it can be done in a home setting. Fromthe people who make money providing these services, theyjust have to fit the type of services they provide intothe demands of the 21st century. So, I just congratulateyou. This will be a test. Everybody who says it is notgoing to work, this would be a test to see if it couldwork. I commend you for it. I am a co-sponsor of it andI think we should act on it. Thank you.

The CHAIRMAN. Thank you, Senator Harkin.

Senator HARKIN. Mr. Chairman, thank you.[Applause].

The CHAIRMAN. And I also wanted to announce thatSenator Clinton was not able to be here today, but we aredistributing testimony that she has submitted and we aregoing to put it in the written record, obviously. Thisdeals with respite care.

This is a bill that she and Senator Warner haveworked hard to promote through the Respite Life Spanbill. Her testimony is available if anybody wants ithere in the hearing room.

[The prepared statement of Senator Clinton appears inthe appendix.]

Senator HARKIN. Mr. Chairman?

The CHAIRMAN. Yes. Please go ahead.

Senator HARKIN. We all know, to be honest about it,that this is a political year and there are a lot ofthings going on about Medicare and Medicaid, this kind ofstuff.

The two bills we are talking about, S. 971, MiCASSA,and S. 1394, Money Follows the Person, have broadbipartisan support on both the House and the Senate side.They are both long overdue.

This is something I believe this committee and thecommittee in the House could act on this year. I know ofno "politics" on this whatsoever. I really do not see itanywhere. It is just long overdue.

Mr. Chairman, I would just say that we have got twoIowans here, Ray Gerke, who is sitting right here, and DiFindley right behind him over here, who are going to betestifying.

I think if all 100 Senators and 435 members of theHouse could hear their testimony, we would get this billthrough in a hurry and get it down to the President, andI think he would sign it. So, thank you all very much.Thank you for having this hearing. Again, my thanks toyour staff and everyone for helping us get people inhere. Thanks, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Harkin.[Applause]. Senator Baucus is the Ranking Democrat, anda person that cooperates very well in a bipartisan waywith me on this committee, and I call on him now becausehe was necessarily detained and could not make an openingstatement.

OPENING STATEMENT OF HON. MAX BAUCUS, A U.S. SENATOR FROMMONTANA

Senator BAUCUS. Thank you very much, Senator. Ithank you, Mr. Chairman, for holding this hearing.

I would just like to pause for a moment to reflect onthat term that we will undoubtedly hear, and have heardover and over today, that is, home- and community-basedservices. The term sounds clinical. It soundsbureaucratic. It is the kind of term that can become abuzz word.

But when you step back and consider, without thesehome- and community-based services, a person may beforced to leave her home, her family, or her communitysimply to receive care to keep her alive. Then yourealize just how important these services are and thatthey affect real people, with real needs, and realfamilies.

I hope that this hearing will remind us of that,remind members of Congress, remind the administration,State policymakers, and citizens around the world that wesimply must work harder to make home, family, communityavailable to people with severe disabilities.[Applause].

To be sure, making progress this year will bechallenging. The Congressional Budget Office tells usthat providing services in the community cost money, eventhough it may be less costly than providing services ininstitutions.

Money is tight in the Federal budget. States remainin the worst fiscal crisis since World War II. In thePresident's budget, Medicaid is on the chopping block.As the House and Senate move towards conference, Medicaidis at risk in our budget.

But, while we most improve Medicaid to expand accessto home- and community-based services, we must alsopreserve the crucial

support that Medicaid currentlyprovides to so many people with disabilities.

We are fortunate to have excellent witnesses todaywith a wide range of experience and expertise. SenatorHarkin, obviously, has been a tireless advocate here inthe Senate and across the country for people withdisabilities, and I applaud him with that.

Together with Senator Specter, he has introduced, andreintroduced, the MiCASSA legislation to establish thegold standard for improvements in the availability ofhome- and community-based services under Medicaid.

Under MiCASSA, every individual eligible for Medicaidcould receive services in that setting that is mostappropriate for them, whether that setting is at home, ina community-based facility, or in a nursing home.

But Senator Harkin is also pragmatic. He isadvocating bipartisan support for an administrationproposal called Money Follows the Person. The MoneyFollows proposal will set us on the right path in theshort term, giving a few States incentives to allowpeople to return home from nursing homes if they sochoose.

We will also hear from Dennis Smith of the Centersfor Medicare and Medicaid Services, otherwise known asCMS, which has proposed a number of initiatives toimprove choice and independence among individuals withdisabilities who are on Medicaid, and I applaud thateffort.

Some of the proposals are well-known to us on thiscommittee, for example, a similar provision in the FamilyOpportunity Act to allow community-based services forchildren who reside in psychiatric treatment facilities.

The need for change in this area of the Medicaid lawis clear. Under the current law, many families withseriously mentally ill children must impoverishthemselves or literally give up custody of their childrenin order to access appropriate mental health services.

Two families in Montana, one in Hamilton and one inLivingston, shared their heart-breaking stories with mystaff just a few weeks ago. In both cases, they wereadvised to "abandon" their mentally ill children in orderto obtain appropriate psychiatric services for them.

A mother in Hamilton, a nurse with a master's degreein counseling, recently talked to my staff and sheexplained how her son, who was bi-polar and had conductdisorders, alleged that she had abused him, despite alack of evidence.

An attorney suggested that she admit to theallegations, even though they were untrue. Only bylosing custody of her son, she was told, could she ensurehis care. And even after qualifying for Medicaid, he wasunable to receive care in the community and he was placedhundreds of miles away from home.

That story should make us all stop and think: whatchanges can we make to prevent parents from having togive up custody of their children in order for them toreceive appropriate health care services?

I also applaud CMS's efforts to encourage self-directed care that is appropriate. In some rural areasof Montana, individuals with disabilities must be able tochoose neighbors or family members to provide care, sinceother services may simply not be available.

Of course, self-directed care should only be donewith appropriate training, supervision, and oversight. Iam concerned about tradeoffs that might be imposed wherean individual must accept financial risks and servicelimitations in exchange for the freedom to direct theirown care.

These risks must be managed carefully and must bestrictly limited to non-medical services. I alsoappreciate programs that improve our direct care serviceworkforce. Training and support are crucial torecruiting and retraining direct care workers for growingnumbers of elderly and disabled individuals.

I am interested in learning more from our consumerwitnesses about the painful choices that the currentMedicaid system imposes on individuals with disabilitiesand their families. Each story is unique, but there arecrucial lessons to be learned from all of them. Thankyou for sharing your stories and your thoughts with us.

Thank you, Mr. Chairman, for holding this importanthearing.

The CHAIRMAN. Some of what you said reminds me, andI made mention of this in my opening statement, some ofthese problems will be taken care of when we get theFamily Opportunity Act passed that Senator Kennedy and Ihave introduced, and we have got 62 co-sponsors for it.[Applause.]

Also, it would do, on the psychiatric aspect you weretalking about, even more than what the President'sprogram would do, although I do not denigrate thePresident's program because I thank him for hisinitiative.

Now it is my privilege to call Dennis Smith. He iswith us today representing the administration from theCenters for Medicare and Medicaid Services as theDirector.

He has played a critical role in developing the newproposals that are legislatively before us now that arepart of what we call the New Freedom Initiative. I thankhim for his leadership and look forward to hearing histestimony.

Then we also have with us today Hon. CarolNovak, who serves on the National Council on Disabilityas a presidential nominated and Senate confirmedappointee.

As a parent of a 26-year-old who has severe cerebralpalsy, I am sure that she lends a unique perspective tothe policy and personal aspects of disability issues.

I also want to recognize the important work that theNational Council on Disability performs in makingrecommendations to the President and Congress on issuesaffecting Americans with disabilities, and we obviouslylook forward to her testimony.

I am going to start out with you, Mr. Smith.

STATEMENT OF DENNIS SMITH, DIRECTOR OF THE CENTER FORMEDICAID AND STATE OPERATIONS, CENTERS FOR MEDICARE ANDMEDICAID SERVICES, WASHINGTON, DC

Mr. SMITH. Thank you, Mr. Chairman, for inviting metoday. I greatly appreciate your leadership in this areaand appreciate all the support that you have given theadministration in these areas, and look forward tocontinuing to work with you.

The New Freedom Initiative was announced by PresidentBush in February of 2001 and the initiative itself isreally government-wide.

It spreads across all thedifferent departments of the Federal Government.

Today, I would like to talk just about the provisionsrelated to the Medicaid program and the legislativeproposals that we have previously sent to the Congressand the President has re-proposed again this year, and wehave made what we think are some additional improvementsto the New Freedom Initiative. Those are the things thatI would like to focus on today.

In New Freedom, the Medicaid provisions are really apackage of demonstration programs. Money Follows thePerson, the rebalancing initiative, is the largest partof the initiative. Senator Harkin has spoken to this aswell.

It is really very important to focus on bothcomponents of that initiative, the one of the moneyfollowing the individual, but also the idea that thesystem itself needs to be rebalanced.

As Senator Harkin spoke about and I know SenatorBreaux has talked about in the Aging Committee about theinstitutional bias in Medicaid—and we do have aninstitutional-based, provider-driven system—about one-third of all Medicaid expenditures are for long-term careservices.

Nationally, about 70 percent of those long-term careexpenditures are for institutional care, though it varieswidely by State. Only six States spend at least half oftheir long-term care money in community-based services.

We very much believe that the Medicaid program shouldkeep pace with the people that it serves, and it is notjust about health care. This is not the delivery ofacute care that we are talking about.

Home- and community-based services are the supportsystems in the community. What we are really talkingabout is not just health care, but the individualfreedom, independence, the ability to live with one's ownfamily, and the family life itself.

We believe that to change the system, in manyrespects, we have to challenge some of the currentperceptions and assumptions about the program. The heartof the President's proposal is to put the individual atthe center of decision making, to trust individuals andfamilies to make decisions for themselves.

The proposals that we have put before you are alsobuilt on experience. We have a number of States thathave taken on cash and counseling waivers and have beensuccessful and have built on those successes.

Consumer direction. I believe at least 20 differentStates have had at least some element of consumerdirection. The idea of control over decision making issomething that is highly valued and an important measureof quality itself, so we would hope that, as you view ourproposals, that you view them as enhancing quality.

Two important measures of quality themselves areaccess and choice, and we have learned a great deal fromFlorida and other States that have done cash andcounseling that access and choice, in fact, are increasedin those types of waivers.

I would also like to mention a new feature that wehave added this year in the President's budget, andreally is kind of the next generation of what we see asthe next generation and the logical progression of thedifferent proposals.

That is what we call the LIFE accounts, Living withIndependence, Freedom, and Equality accounts. Thesebuild on the successes that we have seen in the Medicaidprogram itself.

Senator Smith was here earlier. Oregon has a programcalled Independent Choices in which families themselvesare self-directing and are using their own decision-making off budgets they have negotiated with the States.

Senator Thomas was here earlier. Wyoming has asimilar program as well. We think it should take it evenone step further, that individuals that control their ownbudgets actually would then be able to roll over into alife account half of the unspent funds into the futureyears. We also see the LIFE accounts as individuals withdisabilities who have gone to work, that the employerswould be able to contribute to those accounts.

Again, the key to those accounts is that, as assetsgrow and are built up, that they would not count againstan individual's Medicaid eligibility or their eligibilityfor SSI. So we believe, again, that that is somethingthat would be very helpful.

I do want to also hasten to mention that these areabout giving choices for individuals. None of theseprovisions have mandates in them. We think that, in thebroad continuum of care, individuals should make theirown choices for themselves of what type of livingarrangement that they want, whether or not they want todo some or part of consumer direction, et cetera.

But we believe that by expanding these choices forindividuals, in particular families where the child hasthe disability, LIFE accounts and consumer direction willreally help them to plan for the lifetime.

I think we have seen experience in a number of Statesof where moving to home- and community-based services, infact, does increase the quality of care for individuals,and, in the long term, saves dollars as well.

Maine is one of the examples I brought today in whatthey have done in terms of increasing the use of home- and community-based services, but their total long-termcare spending is very much below the national average.

So, as the title of our proposal suggests, there is abalancing, a rebalancing, to the system. We dounderstand that that does take time. We believe thatStates themselves are preparing for the changes for thefuture.

We are very happy that with the real choice insystem-change grants, States have accessed over $158million through those grants to States in the lastseveral years.

I believe nine of those States, in particular, in thepast cycle have chosen to submit applications onrebalancing the systems. But we do understand thatrebalancing does take time. It takes work and effort tomove from the system that we have today into a morecommunity-based system.

As I mentioned, there are wide variations of Statesin the percentage of expenditures for long-term carebeing in the home- and community-based setting, so it isgoing to take time.

It is going to take time to recruit the workersthemselves to be in the communities. It is going to taketime to rebalance that system. We think these grants arevery important to help achieve that.

I do not want to overlook the success and progressthat has been made, and Medicaid has played a verycritical role in helping individuals remain in theircommunity or return home to their community.

So, in no way do I want to overlook the importantcontributions that the workers have made, the providershave made to support people in their choices. But wehave made progress. We do want to make progress and wantto make it a little faster than what we are doing.

But to just, again, hopefully give you somebackground on Medicaid to help you understand the growthof the programs, we have had home- and community-basedwaivers for 20 years now. We do believe there is a lotof experience out there to move the system forward and,as I said, for the program itself to keep pace with thepeople it served.

In 1990, 985,000 Medicaid beneficiaries were servedin nursing homes. This is a point in time count. Thisis not all people ever served in a particular year, but asnapshot of a point in time, 858,000 people in nursinghomes.

In 2001, now there are 877,400 Medicaid beneficiariesserved in nursing homes. These are either elderly orpeople with physical disabilities.

Almost 119,000 were served by home- and community-based waivers in 1990. In 2001, 510,000, half a millionpeople, again, elderly and physically disabled, wereserved.

For people served in ICFMRs, the intermediate carefacilities for the mentally retarded or developmentallydisabled, in 1990, 146,900 individuals served in ICFMRs.Only 62,600 served by home- and community-based waivers.In 2001, 113,900 people were now in ICFMRs, 322,200served by home- and community-based waivers.

So, we do want to recognize that progress has beenmade. Our States are the partners who themselves drivethe decision making about waivers, et cetera. It is theStates, in many respects.

What we are trying to do is to help them tounderstand that there are new ways, and better ways ofserving people in the communities, and we believe thatthe President's New Freedom Initiative is an importantstep forward. We very much look forward to working withyou, Mr. Chairman, and all the members of the committee,to make that legislation a reality. Thank you.

[The prepared statement of Mr. Smith appears in theappendix.]

The CHAIRMAN. Ms. Novak?

STATEMENT OF HON. CAROL NOVAK, MEMBER, NATIONAL COUNCILON DISABILITY, WASHINGTON, DC

Ms. NOVAK. Thank you very much. I appreciatedeeply the opportunity to speak at this hearing today.Since you already identified me as a national councilmember, I will go on and clarify that my son is going tobe 28 next Wednesday, so my bio, I guess, is dated.

I want you to know that it is Jonathan's struggle tolive a real life in the community, and by inference themillions of other Americans who live with disabilitiesthat are as limiting as his, that shapes my testimony,which I call "Real Lives for Real People: Seeing the BigPicture."

In our effort to empower Americans with disabilitiesof all ages to live lives with choice, opportunity, anddignity, we face real challenges. One challenge involvesthe coordination of funding and services.

Disability programs and policies are so fragmentedamong administrative agencies and Congressionalcommittees, that it is difficult to achieve thecombination of personal assistant services and accessiblehousing and transportation that are necessary for qualitylife in the community. People have to go to all thesedifferent agencies and try to coordinate services andeligibility criteria.

Another challenge involves the shortage of qualitydirect service providers, which has been mentionedalready several times. Establishing eligibility forpersonal assistant services under Medicaid is just thefirst step. Hiring and keeping qualified, capableworkers is a real challenge and it will continue to beuntil we offer a good wage and health care benefits tothese employees.

In our effort to empower Americans with disabilities,we also face significant opposition to change. One typeof opposition comes from special interests. Those whoprofit from the existing Medicaid long-term carestructure want to maintain the institutional status quo.They are powerful. They cannot be ignored.

In order to achieve real change, these specialinterest concerns must be acknowledged and theiropportunities in a new system that empowers and supportspeople in living the life of their choice must be madeclear to these institutional interests.

Another type of opposition comes from redundantbureaucracies. The separate administrative structuresfor each of the States' Medicaid waivers and forinstitutional long-term care absorb an excessive amountof funding that could be better spent on direct services.These parallel bureaucracies also make it verychallenging and confusing for beneficiaries and theirfamilies when they try to transition from one model oflong-term care to another.

In our effort to empower Americans with disabilities,we also need to recognize and act on opportunities forchange that can enhance people's lives. Currently,people who rely on Medicaid's long-term care services donot have the freedom to move from one State to anotherbecause there is not portability from one State'sMedicaid program to another.

There is also tremendous disparity, as has alreadybeen acknowledged here today, among the States' waiverservices, because each State designs its own waivers withdifferent target populations and different service menus.

Consolidating Medicaid long-term care into a systemadministered by one agency responsible for all models oflong-term services could give people the freedom to movefrom one State to another, eliminate the disparity inservices among the States, make it easier to transitionfrom one model to another, reduce the amount of moneyspent on administration, and make it easier to establishpersonal assistant services as a viable career.

Also, personal assistant services must be madeavailable to adults with disabilities in the workplace ifmeaningful employment for disabled adults is to become areality.

In our effort to empower Americans with disabilities,we also need to take advantage of options for costeffectiveness such as private

long-term care insurance,support for family caregivers, utilizing natural supportsin the community, and early mental health screening andservice delivery.

Most of the people in Medicaid nursing home bedstoday acquired their disability as a consequence ofaging. Despite being productive throughout most of theirlives, their assets were quickly exhausted and theybecame eligible for Medicaid.

Encouraging younger Americans who are not disabled tobuy private long-term care insurance by implementing atax credit for the premium will ultimately save Medicaidbillions of long-term care dollars that can then beallocated to support or provide support services forpersons like my son, who cannot buy private long-termcare insurance.

Family caregivers provide millions of hours of unpaidcare each year. Without our participation, the long-termcare system would crumble. Many States provideinadequate respite services to relieve family caregivers,and this eventually leads to caregiver burnout andinstitutionalization of the disabled individual.

By supplementing our efforts, costlyinstitutionalization can be avoided and impairment ofcaregivers' health can be prevented. When vulnerablepeople live in the community, they have the opportunityto build relationships with family, friends, neighbors,church members called natural supports.

These natural supports complement the paid supportand are what make the difference between living a reallife and just surviving. Far too many children withemotional disturbance cannot get the mental health carethey need. As a result, they often end up in fostercare, juvenile justice, or institutions.

If properly implemented, Medicaid's early periodicscreening, diagnosis and treatment program should assistparents of youth with emotional disturbance inidentifying their disabilities and providing the servicesthey need.

So, in conclusion, I would just like to say that whenvulnerable people require assistance today, the defaultgiven to them through Medicaid is a nursing home or aninstitution. This is the opposite of what we should do.We should enable people to live in their community withsupports and institutional placement should be the lastresort.

People are most productive and have he highestquality of life in an integrated community with friendsand family nearby. Thank you for the opportunity tospeak today. [Applause].

[The prepared statement of Ms. Novak appears in theappendix.]

The CHAIRMAN. I thank each of you for yourtestimony.

Now we will take five-minute rounds of questioning.I would ask my colleagues to stay within the fiveminutes—I will, too—because we have some people thatare on a tight schedule.

First, to Mr. Smith. There has been some concernabout the amount of dollars allocated for the MedicaidNew Freedom program. The question is, this year versuslast year. Has the administration's commitmentdecreased? I would like to have you explain if thataccusation is accurate.

Mr. SMITH. Mr. Chairman, I appreciate the questionbecause there has been some confusion about that. Ourcommitment has not decreased. The issue, as everyone onthe committee would be famil-

iar with, is one of budgetauthority versus outlays. The budget authority is thesame.

The request is the same as what it was last year.But it all depends on the outlays themselves on a real-time basis, how many States, how quickly, will adopt thegrants themselves.

So, over the long term, the money would then all bespent out. It is just a matter of assumptions about howquickly the States will adopt it. But our commitment hasnot changed and has not diminished.

The CHAIRMAN. All right.

Mr. Smith, I hope you remember a letter that SenatorBreaux and I sent to the Department of Health and HumanServices, I believe it was last July, regarding theimportance of quality following the release of theGeneral Accounting Office report that was entitled"Federal Oversight of Growing Medicaid Home and CommunityBased Waivers Should be Strengthened."

This report identified many systemic failures on thepart of the Department of Health and Human Services inensuring quality of care in its waiver program. Failureto provide necessary services, weakness in plans of care,and inadequate case management are just a few of theconcerns that were outlined by the General AccountingOffice. Secretary Thompson has assured us that numeroussteps have been taken by HHS to ensure quality outcomes.

Can you tell me specifically what the administrationhas done to promote quality in these settings?

Mr. SMITH. Thank you, Mr. Chairman. I do recallyour letter. We appreciated the opportunity that yourletter presented because we took a good, hard look atourselves, our procedures, some of the gaps that werecognized that we faced.

We set out an action plan that we described. I amhappy to tell you, we have met 16 out of those 18 actionitems and we have made substantial progress on the othertwo.

You may be interested, on February 29, we releasedthe final version of the "Quality Framework and QualityInventory" report. This was done through collaborationnot only with the Medicaid directors, but also theNational Association of State Units on Aging, and theNational Association of State Directors of DevelopmentalDisability Services. So, this was a collaborative effortof partners across the Nation for promoting qualityassurance.

As I said in my opening remarks, I believe verystrongly that a very important measure of quality isaccess and choice, in themselves. Again, it is very hardto describe, as we have heard previously, how do youmeasure the quality of someone being able to select theirown caregiver.

How do you measure the quality of not having turnoverin staff? Again, caregivers come in and do some of themost personal and intimate things of human nature,bathing someone, cleaning someone, et cetera.

To have a stranger or a different person come throughthe door week after week or month after month, someonenew coming into your house, we believe, again, consumerdirection will be a very, very important measure of whatquality is, and we are working hard to promote that.

But, in particular, on your request on quality, I ampleased to report, and I believe we have follow-upinformation, of meeting the milestones that we pledgedthat we would make to you, Mr. Chairman.

The CHAIRMAN. Thank you. A follow-up to that.This is in regard to the New Freedom Initiative. I seeit as an opportunity to continue to promote theimportance of quality care.

What new policies in this initiative will further thegoals of providing quality care to Medicaid beneficiariesin the home- and community-based settings?

Mr. SMITH. We believe that the LIFE accounts,establishing the LIFE accounts, again, will have a veryimportant improvement in quality as people makedecisions, knowing that they would be able to retainresources without losing them or losing access to them.So, that is a significant change from our proposal lastyear.

And, again, putting the individual, or the familymember on behalf of that individual, at the heart of thatdecision making, we think, will improve access andimprove choice. The LIFE accounts are sort of the nextgeneration of doing that.

The CHAIRMAN. Senator Baucus?

Senator BAUCUS. Thank you very much, Mr. Chairman.

Mr. Smith, I wondered if you could tell us what theadministration's medium- and long-term goals are here.Clearly, the proposal, Money Follows the Person, whichSenator Harkin talked about, is a doable first step.

We all know it is not comprehensive, and States havevery tight budgets, and certainly Medicaid budgets. Ifyou could outline for us the administration's thoughts onmedium- and long-term vision for this program.

Mr. SMITH. Senator, as you say, the proposalsreally are to help us transition more to a community-based system and change what we have today, which is avery institutional-based, provider-driven system.

In our discussions last year on Medicaid reform, wereally wanted to encourage policymakers to start to lookat Medicaid really as two very different programs servingdifferent populations, the acute care side, and, again,the traditional moms and kids, where Medicaid was reallytheir health insurance side, versus the long-term careside. Much of our proposal really was to focus onhelping to move the Medicaid program, the long-term careside of the Medicaid program, to a more community-basedfocus.

Senator BAUCUS. That is just sort of a goal, but doyou have any proposals, medium and long term?

Mr. SMITH. Our immediate proposal is the NewFreedom Initiative itself.

Senator BAUCUS. Medium. Medium and long term.

Mr. SMITH. The long term, we have, again——

Senator BAUCUS. Medium. Let us back up. Medium?

Mr. SMITH. Medium, we did not re-propose anyspecific comprehensive changes to Medicaid this year. Wehave been saying that the President's budget did includelanguage that, again, outlines that we believe long-termchanges to the system do need to be made, but reallyentering a dialogue.

Senator BAUCUS. I appreciate that. I have justsome questions about the New Freedom Initiative, the LIFEaccounts, and self-directed care, generally, especiallysince the administration proposed expanding all this to awider array of services. Here are my questions. One, iscan medical expenses be covered under the capped grantfor individuals?

Mr. SMITH. Senator, we do not see the medicalexpenses, the acute care side, being involved, no. Theseare the support services.

Senator BAUCUS. What about leftover LIFE accountfunds? What can they be used for?

Mr. SMITH. The LIFE account funds? Really, we seethose as the individuals, under their control, to use asthey desire.

Senator BAUCUS. And with the cap, what happens ifnew technologies become available, new hearing aids, newwheelchairs? What if something becomes available, yet itis capped?

Mr. SMITH. Well, again, the medical side would notbe included in that side of home- and community-basedwaivers.

Senator BAUCUS. A wheelchair would not be?

Mr. SMITH. No, Senator.

Senator BAUCUS. That is medical?

Mr. SMITH. That would be medical.

Senator BAUCUS. What if non-medical technologiesbecome available?

Mr. SMITH. Again, non-medical. Just to give you alittle bit more background, we have identified 70different types of services that are categorized as home-and community-based services. These are the supports,respite, as being case management, different things thatare really to the individual. Through our Medicaiddirectors' letter, we told the States that they could useMedicaid home- and community-based services fortransitional costs.

Senator BAUCUS. What happens if a person decides toforego services to save money, that is, save money underthe cap? How can we be certain that that person wouldnot be penalized in future year budgets?

Mr. SMITH. Well, again, Senator, these are notnecessarily for everyone. These are choices that peoplewould want to make for themselves.

Senator BAUCUS. Well, that is not the question Iasked.

Mr. SMITH. All right.

Senator BAUCUS. The question I asked is, how willthis person not be penalized after he or she has madethat choice?

Mr. SMITH. I do not see that as being penalized,Senator.

Senator BAUCUS. Well, how can this person beassured that he or she will not be penalized in thefuture, that is, if a person decides to forego services?

Mr. SMITH. Well, they are not foregoing services,Senator.

Senator BAUCUS. They could. I thought, earlier, aperson might end up with leftover funds they could putinto a LIFE account.

Mr. SMITH. But if they do, they have made thatchoice not to spend all the money in that year. So,these are unspent dollars that go into the account.

Senator BAUCUS. Now, my question is, again, how canwe be sure that that person is not penalized becausethere were unspent dollars?

Mr. SMITH. Well, Senator, again, I see it as achoice that they have made for themselves. I do not seethat as a penalty.

Senator BAUCUS. I am not saying that is a penalty.I am talking about the next year, the next go-around.

Mr. SMITH. Again, the individual budgets are setwithout regard to how much an individual would have intheir LIFE account, so they would still go through thesame process that they did in the previous year based onthat individual's needs.

Senator BAUCUS. I just wanted to make sure that theperson is not penalized.

Mr. SMITH. Yes, Senator.

Senator BAUCUS. How do we know that self-directedcare is going to be entirely optional? Does a personhave to use self-directed care to access Money Followsthe Person?

Mr. SMITH. No, Senator.

Senator BAUCUS. So it is optional?

Mr. SMITH. It is optional to the State and it isoptional to the individual who wants to leave theinstitution.

Senator BAUCUS. I am more concerned about theindividual right now.

Mr. SMITH. The individual? It is their choice.Again, Money Follows the Person is for a person alreadyin an institution who says, I want to leave theinstitution. That is totally optional.

Senator BAUCUS. But is that an entitlement then, ornot?

Mr. SMITH. Still being in the institution——

Senator BAUCUS. Out of the institution. I havedecided I want to get out of the institution. I do notlike it here. I want to try this new program, but I likebeing entitled to get my Medicaid dollars.

Mr. SMITH. Again, the way this works, is these aredemonstration programs, so the States would submitapplications for funding. The Federal Government wouldprovide 100 percent of the funding in the first year.The State itself also would then obviously have to make acommitment to keep that individual in a waiver slot sothey would be able to continue in the future.

Senator BAUCUS. My time is expiring. But if I wantto get out of the nursing home and take this MoneyFollows the Person, can I still accept it as anentitlement?

Mr. SMITH. Again, a home- and community-basedwaiver today, Senator, the States have the ability tocontrol the number of slots. For this particularprogram, moving that individual out of the institution,obviously the State would have to make a commitment tocontinue to support that individual in the community.

Senator BAUCUS. Well, my time has expired. Thankyou very much.

Mr. SMITH. Thank you.

The CHAIRMAN. Senator Lincoln?

Senator LINCOLN. Thank you, Mr. Chairman. Aspecial thanks to you and Senator Baucus for holding ourhearing today.

I also want to applaud my colleague Senator Harkin'scommitment to this very important issue. I think hiscontinued work on behalf of people with disabilities isabsolutely commendable and an example to all of us.

Certainly, I am devoted to what we can do in terms ofensuring that people with disabilities do have access toquality health care in the least restrictive settingspossible. I do think it is a very important issue.

I am very proud of the efforts my State of Arkansashas made to address the needs of older adults and peoplewith disabilities.

Our State has been very progressive in developingservices that promote independence and community living.The Arkansas Division of Aging and Adult Services is aleader in the country, and I am enormously proud of theireffort and the leadership that they have been providedthrough their director, Herb Sanderson, who has done anexcellent job.

I also want to compliment Ms. Novak for bringing upthe issues of dealing with long-term care and providingincentives in the Tax Code to encourage long-term care,as well as early testing, infant screening, all of thosemeasures.

We have certainly found they are great investments inbeing able to not only provide a better quality of life,but also to lower our costs because we know what we aredealing with early on. So, I certainly applaud yourbringing those issues up, and I think they are veryimportant.

Mr. Smith, just a couple of questions. And if I donot get to all of them, I would like to submit them inwriting for your answer.

I have long been a strong proponent of doingeverything possible to provide the highest quality, mostintegrative, and flexible services for people in theleast restrictive settings.

In our experience in Arkansas with the Cash andCounseling demonstration project, it has been a greatsuccess. However, I do want to just add a word ofcaution.

The Arkansas experience has also provided a richexperience of lessons to be learned, and I hope that wewill not jump into too many things without looking atthose things that we have learned in these demonstrationprojects and be able to work through them, and provideeven greater opportunity to offer a program that providesa great deal.

What we have learned, is that there are criticalpolicy issues to be resolved, I think, in order forthese, and other consumer-directed initiatives to reallysuccessfully meet the needs of the consumers who wish todirect their own services.

I just caution us before we open the consumer-directed flood gates that we carefully examine thoselessons learned from our experience.

One of the key elements of the consumer direction isthe ability to hire, fire, train, and supervise personalassistant attendants, and you have mentioned some ofthat.

Is there any kind of information in consumerprotections against the unscrupulous vendors that isavailable for the individual who seeks a personal careattendant?

Mr. SMITH. Senator, I believe, as part of ourtemplate, that the States have to offer to do criminalbackground checks on the caseworkers. Again, there isstill State oversight of the fiscal intermediaries,people that are handling the money, that sort of thing.

Again, consumer direction does have many differentvariations in itself. Some people want to handle themoney, some people do not. This is very critical. Iwould agree, the up-front planning and the identificationof someone who really wants to do it, who understands allof the obligations, it is not something for everybody,but we are trying to expand some choices.

Senator LINCOLN. Well, that kind of leads to mynext question. I would encourage us to make sure that wepoint out that, as individuals are doing more forthemselves, that information and consumer protections aregoing to be critical.

And one of the other lessons that we have learned inArkansas, is that shifting the control to the individualdoes not diminish the need for the State administrativefunctions related to enrollment, financial management,program oversight, you mentioned background checks, andother things like that.

The final report on the Cash and Counseling programfound that the cost of hiring enrollment staff issubstantial and that the administrative functionsassociated with that financial management and programoversights are critical to the successful implementationand to prevent the abuses that might occur.

So my question really is, will there be moniesavailable to States to implement such programs ofmanagement, oversight, and consumer protections?

Mr. SMITH. All of those things would still beMedicaid expenditures that would be matchable. Inparticular, again, on the Systems Change grants, theMoney Follows the Person, it really is to help fund theinfrastructure and the administrative part to help Statesprepare for doing consumer direction and, as youmentioned, all the infrastructure to go to support that.

Senator LINCOLN. So you are reassuring me thatthere is adequate funding for the States to be able tohelp provide these types of services, oversight servicesthat are going to be necessary as people do more and morefor themselves.

Mr. SMITH. Those would continue to be, again. Thisis going on today in the Medicaid system. What we aretrying to do, again, as I said, we are just trying tooffer new ways to promote it to move there faster.

Senator LINCOLN. Well, the Cash and Counselingdemonstration program in our State was designed really togive people greater control over a defined set ofservices, the need for which is likely to remain fairlyconsistent from month to month.

I guess the problem becomes when it does not. TheKaiser Commission on Medicaid and the Uninsured reportsthat the high level of beneficiary satisfaction with theCash and Counseling program appears to result from thefact that the individuals were permitted to manageservices that have a predictable level of need.

Our concern becomes when the consumer direction in anindividual budget may not be appropriate for certainservices, particularly the ones that are less predictableas they move through the concerns that they may have inthe year. I guess it prompts an-

other basic question. Ifthe beneficiary needs change during the plan year, whathappens to them? What are their options?

Mr. SMITH. Again, Senator, States have takendifferent approaches. Wyoming, as I had mentionedearlier, created a reserve account to plan for thosecontingencies, et cetera.

And you are right, it is hard to anticipate. Thedifferent scenarios are as varied as the peoplethemselves are. We think that is good planning, is toanticipate there will be a need, at least for someindividuals.

Senator LINCOLN. Sure.

Mr. SMITH. But I hope that it does not hold us backfor moving forward and simply say, well, you should bethinking about reserve accounts or what you do on anemergency basis. A family situation can change over thatperiod of time, et cetera. But I think that is whatStates are doing through the grants now, sort of learningthese things to be able to prepare for those types ofcontingencies.

Senator LINCOLN. Do you feel like there is a needfor HHS to do more than just encourage? I mean, myconcern is, really, that there is no mandatory safety netplan.

I am just wondering if you think that that might besomething that would be encouraged by HHS of all Statesthat are using these programs in this way so that peopleare not left to fend for themselves in a year where theirneeds may change drastically and they have not plannedfor that.

Mr. SMITH. Well, again, the responsibilities in ahome- and community-based waiver that you are stillobligated to provide for the health and safety of anindividual that you are serving, in our Independence Plustemplate, which is our model waiver in this area, we doprovide certain safeguards in there that we want theStates to meet.

As I said, it is a fine balance between how much isenough and how much is too much, especially, again, whenyou are dealing with someone living in their own home. Ido not think we want to treat it the way we treat aninstitution, where surveyors come in and that sort ofthing.

The CHAIRMAN. Thank you.

Senator LINCOLN. Mine would be more to encouragethe agency to really look towards encouraging States forthose emergency plans and being prepared for that.

Thank you, Mr. Chairman.

The CHAIRMAN. You bet. Thank you, Senator Lincoln.

Thank you, Mr. Smith and Ms. Novak. Thank you verymuch.

I would call the third panel, now. We have RayGerke, Bruce Darling, Jan Moss, and Di Findley. Wouldyou come while I introduce you?

We appreciate all of your work in the disabilitycommunity. Ray Gerke is from Perry, Iowa, a foundingmember of the Olmstead Real Choices Consumer Task Force.His cerebral palsy has existed since infancy, and overthe course of his life he has received care in both thefamily and institutional settings. Mr. Gerke will sharehis experiences from both of these settings, and as anadvocate for the disability community.

Bruce Darling, our second witness, is co-founder andexecutive director of the Center for Disability Rights,Rochester, New York. He

is testifying on behalf of ADAPTCommunity, and brings with him 18 years of experienceworking with individuals with disabilities. Mr. Darlingwill offer testimony on institutional bias and, mostimportantly, how to remove bias from the Medicaidprogram.

Third, Jan Moss, from Oklahoma City, the parent oftwo adult children with serious disabilities. She hasbeen caring for these individuals for the past 36 years,not only for them, but also now she cares for in-laws.She will share her experiences as a family caregiver and,most importantly, the respite need.

Our final witness, Di Findley, is from Mitchellville,Iowa and is executive director of the Iowa CaregiversAssociation. Ms. Findley brings to the committee todaythe voices of direct care workers. She served onnumerous boards, committees, and councils and will focuson the shortage of direct-care workers and its impact onaccess to community-based services.

I would like to have you go in the order that Iintroduced you, so that would be Mr. Gerke, then Bruce,then Jan, then Di.

STATEMENT OF RAY GERKE, MEMBER, IOWA OLMSTEAD REALCHOICES CONSUMER TASK FORCE, PERRY, IOWA, ACCOMPANIED BYRAMONA EDMISTON, A PERSONAL ATTENDANT FROM IOWA

Mr. GERKE. Thank you for allowing me to speak toyou today. I am honored to speak to you to share mystory.

I received, as you said earlier, the diagnosis ofcerebral palsy when I was an infant. At that time, thedoctor gave my parents a choice.

Ms. EDMISTON. Would you like me to read this forhim?

The CHAIRMAN. Whatever is best for the family.

Ms. EDMISTON. I am Ramona Edmiston and I am Ray'spersonal attendant. I have been a friend of the familyfor 20-some years. I will just read you what he has.This is his story.

He received the diagnosis of cerebral palsy when hewas an infant. The doctors gave his parents a choice:either to take him home and raise him like any otherchild, or place him in an institution. They chose totake him home.

His early years were filled with family vacations,road trips with his dad in his truck, games, rivalry andlove between himself and his siblings, and his cousins.But when he was eight, his parents were told they neededmore intensive therapy services than what he could get inthe home community.

They were told the best thing they could do for himwould be to place him in a facility where he could getphysical, occupational, and speech therapy. All of asudden, he found himself in a town two hours from home,alone, without understanding why.

Totally unprepared for this strange setting, insteadof his family and friends, he found himself sharing hislife with 97 other individuals with disabilities. Someof those strangers became his friends, but no one couldreplace what he left at home. Because he did notunderstand, he cried for those first 2 days, and thenmany days off and on for the 2 years he lived therefull-time.

After those first 2 years, he returned to his homeduring the school year and spent summers back in thefacility. It took 3 years

to learn the system, toknow what to expect, and be able to handle things withoutthose childhood tears.

For example, he learned independence. "We were notallowed visitors, as they might upset us." They learnednot to trust people. In a congregate setting, the youngkids get teased and bullied by the more experienced.Kids take things from each other, or worse, if adults seesomething they like, those things often came up missing.

In that same setting, his experience included havingto go along with the demands of an authority figure whohad the power to make his life miserable, even when thatauthority figure's demands included misusing his body tomeet his personal desires.

He got all of the intense therapy he needed, but atwhat cost? When the professional therapy had gone as faras it could, he returned to his family home. Thatexperience over four decades ago has had a lasting impacton his life and his perspectives.

Today, he lives with his wife, who also has cerebralpalsy, in a home they own. He works full-time. Hedrives himself to and from work, and wherever else heneeds to go. He does have many friends, some who havedisabilities, some who do not. He lives a full life, alife that he can direct himself with these supports.

"I also carry with me each and every day the burdenof knowing the burden of knowing that the threat ofinstitutionalization is as real for me today as it everhas been." If he lost the funding sources that providefor him the ability to maintain life as it is, his salarycould not cover the cost of having staff to assist withregularly getting up for work, preparing his meals, orgetting back into bed at night.

Without that support, he has few options but toreturn to this setting, much like the facility he knew inthose early years. "I would then no longer be able todirect a few select personal assistants to assist me withthe choices I make on how I like to live. I would alsono longer have the independence that I know today. Mylife would lack privacy, and when I lose choice,independence, and privacy, I also lose my dignity and myfreedom.

In order for me to maintain my life in the communityand to provide other people of all ages who live withdisabilities today the same opportunity, I ask you toeliminate the institutional bias in Medicaid by requiringStates to include community-based personal assistantservices in their Medicaid plans.

Individuals who qualify for Medicaid shouldautomatically be eligible for community services, notjust services delivered in institutional settings, as incurrent law.

Provide financial incentives for States to helpindividuals transition from institutions to communitysettings, because community settings are typically lesscostly. This benefits not only the individual, but alsothe Federal and State treasuries.

Assist States in developing and implementing astrategy to rebalance their long-term care systems sothat there are more cost-effective choices betweeninstitutional and community options.

Provide financial support and create incentives forStates who develop quality community-based supports andservices, including support to help States find ways torecruit, train, and re-train direct-support workers.

Offer respect to the people whose lives are affectedby disability policy decisions by not just listening tothem, but by having them be a part of the decision makingitself.

Today, I am an active advocate for all people withdisabilities. I serve on many boards and communities,two of which strongly apply to this topic. I am a memberof Iowa's Olmstead Real Choices Consumer Task Force. Weare working to effective implement the Olmstead decisionin Iowa.

This includes advocating for the policies I juststated, as well as working with the Iowa Department ofHuman Services to take advantage of CMS's new progressivepolicy of self-direction which promotes community livingand affords individuals more choice and control over theservices they receive.

I also serve as the co-president self-advocaterepresentative for the National Coalition on Self-Determination, Incorporated, the only national coalitionthat has both parents and consumers working together onissues.

The work of both of these groups focuses on realchoices: the freedom to live the way you want, to self-direct your life, to be able to purchase the services youneed to support you in your life, to live a life withdignity, to have the freedom to make new friends andparticipate in your community, and to support your rightto vote.

Again, I urge you to pass legislation that willincorporate the policies I have mentioned today that helppeople like me have all the right resources that exist inthe community for me to participate fully as an Americancitizen. Your decisions are important to the lives ofmany, many people who are like me that live under athreat that should not be present.

Thank you very much for your time and attention toimproving access to Medicaid home- and community-basedservices." [Applause].

The CHAIRMAN. Thank you, Mr. Gerke. Also, we willhave some questions. If he would like to have you helphim answer questions, that would be appropriate.

[The prepared statement of Mr. Gerke appears in the appendix.]

The CHAIRMAN. I think the next person was Mr.Darling, was it not?

Mr. DARLING. Yes.

The CHAIRMAN. Yes. Mr. Darling, go ahead.

STATEMENT OF BRUCE DARLING, EXECUTIVE DIRECTOR, CENTERFOR DISABILITY RIGHTS, ROCHESTER, NEW YORK

Mr. DARLING. Today I am testifying on behalf ofADAPT and thousands of people like Ray with disabilitieswho want a real choice in long-term care services.

I am the executive director of the Center forDisability Rights, an independent living center inRochester, New York. Over the last 4 years, ourcenter has transitioned over 100 people back into thecommunity. We have also trained people from 37 States inthe territory of Guam in helping people with disabilitiesreturn to the community from institutional settings.

As I have traveled the country, I have heard the samestories again and again about people who have had yearsof their lives stolen by a system that supportsinstitutions over individual rights.

The basic problem is that funding for long-term careservices is tied securely to institutions. According to2002 data, you have heard that 70 percent of that moneyis used for institutional care rather than communityservices.

States must provide institutional care like nursinghomes, while community-based services are entirelyoptional. Because institutional services are mandatory,States cannot cut their funding.

In tough fiscal times, some States have had no otherchoice but to cut community-based services. States thatwant to provide community-based alternatives areprevented from doing so by a Federal policy that mandatesinstitutional services.

There is one extremely important reason we mustchange this system: it is not what people want.According to CMS data collected by the nursing homesthemselves, nearly 19 percent of individuals in nursingfacilities have said they want to return to thecommunity.

From my personal experience, this number should bemuch higher. According to a study conducted by AccessLiving, 64.5 percent of nursing home residents that theyinterviewed said that they wanted to return to communityliving.

Clearly, we need a new model. No longer shouldcommunity-based services be the exception to theinstitutional rule, or the waiver, as it were.Individuals must have real, meaningful choices.

But changing the system is going to take some time.We understand that. But there are things you can doimmediately to address the institutional bias. First,you muss pass Money Follows the Individual legislation.

Under this legislation, the Federal Government willfully fund the first year of community services forindividuals who transition out of institutions. Thislegislation would provide a critical incentive to Statesto get people back into the community.

Senator Harkin introduced the Money Follows thePerson Act of 2003, S. 1394, and the White House hasdistributed its own draft legislation, the New FreedomInitiative Medicaid Demonstration Act of 2003.

We understand that you, Senator Grassley, areconsidering introducing legislation based on theadministration's proposal that would authorize a MoneyFollows the Individual demonstration program and supportother initiatives to promote community-based services.

Thousands of people with disabilities and olderAmericans in nursing homes and other institutions willbenefit if you fund these initiatives.

The CMS data shows that at least 267,000 people withdisabilities and older Americans want to return to thecommunity now. Two hundred and sixty-seven thousandpeople are telling the nursing homes that they want to gohome. Two hundred and sixty-seven thousand people areasking you to help them go home. On behalf of those267,000 people, I am pleading with you not to make themwait one more day. [Applause].

Whether you pass S. 1394 or the administration'sproposal, it is imperative that you take action now.This legislation must be passed this session. There areother steps that you could take to ad-

dress theinstitutional bias. We are looking for medium-rangesolutions earlier.

Create an enhanced Federal Medicaid matching rate forhome- and community-based services. By paying a largerpercentage of the cost of community-based services, youwill create a strong incentive for States to promotecommunity living. Such a step will help our Statesthrough tough fiscal times and send a message that ourNation values the freedom of all its citizens, includingthose with disabilities.

Finally, while programs, demonstration programs, andenhanced Medicaid matches would promote community living,there is still much more work to be done. The ultimatesolution to ending the institutional bias is clear: passMiCASSA. [Applause].

The Medicaid Community Attendant Services andSupports Act, S. 971, gives people real choice in long-term care. MiCASSA provides individuals eligible fornursing facility services, or ICFs, with the opportunityto choose community-based services and supports ratherthan be forced into institutional placement. Peoplewould get assistance in their own homes, not nursinghomes.

Every major national disability organization supportsMiCASSA. In all, 92 national organizations are MiCASSAsupporters; 561 State, regional, and local organizationssupport the bill. The full list is attached to mytestimony.

Notice that advocates for children and seniorssupport MiCASSA. Other organizations represent peoplewith all types of disabilities—cognitive, sensory,mental health, and/or physical—and we are all askingthat you take action now.

Today, we would not be here without the heroicefforts of hundreds of ADAPT members who put their bodieson the line. On their behalf, I would like to thank youfor this hearing. But I must point out that we need morethan hearings, we need action. Take the steps that Ihave outlined today and pass these important pieces oflegislation to free our people.

Thank you. [Applause].

The CHAIRMAN. Thank you.

[The prepared statement of Mr. Darling appears in theappendix.]

The CHAIRMAN. Next, is Mrs. Moss.

STATEMENT OF JAN MOSS, MOTHER OF TWO ADULT CHILDREN WITHDEVELOPMENT DISABILITIES, OKLAHOMA CITY, OKLAHOMA

Ms. MOSS. Mr. Chairman and members of thecommittee, thank you for the opportunity for me totestify today. I especially want to thank you, SenatorGrassley, for the invitation.

I am Jan Moss. I am a family caregiver. I have beenproviding care to both my children, who are adults withdevelopmental disabilities, and my husband's parents fora total of 36 years.

I am a widow now and continue to have the samecaregiving responsibilities that were shared when myhusband was living.

I am here to support the President's proposals forMedicaid respite demonstration for adults and children asoutlined in the proposed New Freedom Initiative MedicaidDemonstration Act. Given the serious funding shortfallsfor respite in most States, and new resources for respitewill be a godsend.

But I am also here to tell you about Oklahoma'sLifespan respite care program, the Oklahoma RespiteResource Network. It has helped thousands of familieswho are not eligible for Medicaid, but in dire need ofrespite.

I want to begin by thanking you and the entire Senatefor its leadership in passing the Lifespan Respite CareAct, which will strengthen Oklahoma's efforts and makesimilar Lifespan programs in respite available in moreStates.

When my children were young, there were no respiteprograms. There was not even information about whetheror not respite was even needed. In recent years, througha home- and community-based waiver, we actually had theopportunity to receive respite services and it has made abig difference in the survival of our family.

My husband and I divided our entire lives into piecesof care. Frequently, our time with each other was themissing piece. We reserved our paid leave for hospitalvacations. We prioritized our employment according towho had the best benefits. The unusual care needs of ourchildren affected every decision in our marriage and ourfamily life.

Except for the birth of my son, I went 18 yearswithout a full day's rest due to illness or injury. Nowonder I have blocks of time for which I have little orno memory. Those years I called my "automizedsuspension." I was suspended in a fatigue fugue, if youwill, that allowed for basic routine and automatedbehavior.

I remember waking on our divan or in one of the kids'rooms, but did not remember going to sleep there. Iremember the year of Jennifer's tendon transfer, the yearof Jason's heart surgery, eye surgery, hernia surgery,oral surgeries, the many heart catheterizations, theEEGs, the EKGs, the ultrasounds, the years ofuncontrolled seizures. But I do not remember some of thebirthday parties and anniversaries.

Now, family pictures prove I was there, but I thinkit is very, very sad now that I do not recall many of thebenchmarks of my family. The most difficult experiencefor me personally has been the sudden death of my husbandand care mate on Father's Day of 2000. He dropped deadfrom an undiagnosed heart problem.

Now I see the importance of those missing pieces,maybe the time that we should have had some rest. Maybeit is heroic to care for our children and not to ask forso much assistance and to be brave. But I will tell you,it is more heroic to live for our family members so thatwe can supervise their care, so that we can see that theyget care, and so that we can have real lives in ourcommunities.

Frightening me now is the loss of his income and myability to maintain my own health responsibilities. Wedo not have a typical day at my house. Jason may be in astupor from some seizures or going into seizures from hisanxiety disorder.

We never know what to expect from Jennifer. Sheunderstands. She is employed. She has tried so hard,and did live independently in the community until recentcutbacks. But she has been forced to move home. So shehas lost her father, she has lost her home, and she hasmoved home.

Jason and Jennifer have disabilities on opposite endsof the spectrum. Their abilities are not complementary,shall we say. I know

that it is difficult for them tounderstand that they, also, need respite from each other,as well as, I need respite occasionally to kind of renewmy batteries.

We have to explain every day to Jennifer, to Jason,and to myself. It is kind of a sharing thing about, itis all right to be who we are, and that is great. I wantJennifer and Jason to be in my life. I want them to behome as long as they want to be there.

But it is true that we do need that kind of naturaldevelopment in our family that typical families have, andthat is the ability to be separate for a little while, tohave some privacy occasionally.

Just recently, I guess it may have been Friday beforelast, I was in a Family Support Committee meeting and Istarted getting these phone calls. My phone is vibratingand it is making all these little noises. Finally,someone said, go ahead and answer it. Well, it is thepolice and they are at my house. Our alarm is going off.

Jason has put his earphones on. Jason would be aperson who is said to have autism, and Jennifer hasdeafness and cerebral palsy. Jason puts his earphones onso the alarm does not bother him, and he lets thepoliceman in the door, but he takes him in the bathroomwhere Jennifer is taking a shower.

Well, the policeman is on the phone and he is saying,would you please come home, because he did not know signlanguage, and I had to go home and quiet Jennifer down.

Well, I tell you what. That evening, Jennifer wasafraid to come home from work by herself because she wasafraid the alarm would go off again.

Now, that whole weekend was so intense that the nextMonday she hardly felt like she could go back to work.But, of course, we stayed with it. We stayed at it. Wekeep staying at it. But there are occasions when weabsolutely have to have reprise, both for our spirits andfor our bodies.

This prolonged kind of fatigue you can get when youare the main and the constant caregiver can produce kindof secondary, ancillary issues. Fatigue-related injuriesand illnesses from prolonged stress can result in, weknow, neglect, and certainly abuse.

Mismanagement of medication. I, myself, suffer fromtypical caregiver issues, serious dental issues. I amtrying to keep, I think, from screaming sometimes. Iclench my teeth so tight, my teeth are disintegrating.

That is not uncommon. I will be visiting with othermoms and we will start talking about our TMJ, which isexpensive and painful.

There are other, kind of autoimmune joint disordersthat families get. Nobody tells families that, withoutproper rest and without proper equipment, you are goingto lose the use of your thumbs eventually from the kindof issues from lifting persons, and transferring persons,and lifting equipment. Nobody shares that informationwith us. Rest is vitally important to kind of preserveour bodies and our health.

When Jennifer was about 19, she became eligible for ahome- and community-based waiver and respite was one ofthe services. The recent budget cutbacks in Oklahomahave forced families to either give up their respite orto lower the amount of respite they were receiving, or,to keep some services, you give some services up.

I am going to have to give up important services andsupports in order for me to be employed if do notcontinue to receive my respite services. It is an awfulchoice to make because I am not going to get any reliefthat way.

I will just go to work. I will have to leave work,go home and check on Jason, and drive back to work. ThenI work with Jennifer and Jason in the evenings. We tryto have a family life. Then if we do not have anyrespite, there is no light at the end of the tunnel.They deserve me to life a long, helpful, and healthylife. They deserve to have one themselves.

Thank goodness, we have Oklahoma's Lifespan RespiteProgram. It is known as the Oklahoma Respite ResourceNetwork, and it is a collaboration. It is a wonderfulmodel of partnering with DHS, Department of Health,Mental Health, caregivers, advocacy agencies.

We network and redirected, at one point, $8 millionto respite care in Oklahoma to serve families across thelifespan, aging families, and families who have childrenwith disabilities.

If families need help in finding a respite provideror find out what programs they might be eligible for,they can turn to our respite network. The Oklahoma modelhas flexible funding, so the State can find the mostcost-effective way to deliver services through vouchersand allow caregivers control over the resources.

Our idea around recipients and beneficiaries ofservices, being able to look at what dollars areavailable and how those dollars should be spent, has beenabsolutely 100 percent successful.

The efficacy of allowing families to be a part of howthe dollars are going to be spent makes far more sense,and really our program has proved that we aretrustworthy. We know the value of a dollar.

If I had to place my children in out-of-home care, itwould have cost the State millions. We know respiteallows caregivers to keep their children at home, and Rayhas addressed that. It reduces the stress and risk ofabuse and neglect. Respite is really important tomarriages as well.

Similar Lifespan programs have been mentioned here,the ones in Oregon, Nebraska, and Wisconsin. I wouldlike to take the liberty, on behalf of caregiversnationwide, to applaud the administration's support forrespite. Respite funds that would be available under theNew Freedom Initiative are especially critical now.

Many Medicaid waivers, as I have said, in other Stateprograms are eliminating or cutting back. The NewFreedom Initiative respite demonstrations are verycomplementary to respite systems that would beestablished by the Lifespan Respite Care Act.

These would address my concerns that I would haveabout the issues and the confusion and the fragmentationof services that we often get. I know that has beenmentioned earlier today.

The way we have run our respite program, we haveprovided an opportunity for all those agents thatcontributed to the cause of risk to work together so thatfamilies, whatever age group they are in, are entitled tothose dollars, however few they may be, towarddetermining how they want to spend them and their respitevouchers.

I am concerned about the demands of families andcaregivers who would not be served under the New FreedomInitiative because they

are not Medicaid-eligible, and asa result may not be able to afford respite.

Even when families have resources to pay, frequentlyfinding quality respite providers who meet theirpreferences, who are safe, and who are acceptable to thefamilies may not be accessible.

While the New Freedom Initiative respitedemonstrations are an important and absolutely necessarypiece of the puzzle, the Lifespan Respite Carelegislation is the glue that holds the puzzle piecestogether.

I applaud the Senate for passing the Lifespan RespiteCare Act. This legislation will allow States to providethe infrastructure for coordinating and maximizing therespite resources and filling in the gaps.

The Lifespan Respite Care Act provides a way to savemoney, recruit and train providers, and make it easierfor families to find quality respite, regardless of theirMedicaid status, their disability, or age.

I urge you to support the President's proposed NewFreedom Initiative respite demonstrations. At the sametime, it is my belief that these benefits will not befully realized without the enactment of the LifespanRespite Care Act.

I would just ask you to consider the millions offamilies who continue and who are dedicated to care fortheir family members across the country and remember thatoccasionally they are going to need that naturalseparation that typical families get when their kids gospend the night with a friend, or have the friend spendthe night with them.

Help us to be able to gain a little light at the endof the tunnel. Help us to maintain our respite. Thankyou so much for allowing me to participate today.

The CHAIRMAN. Thank you, Ms. Moss.

[The prepared statement of Ms. Moss appears in theappendix.]

The CHAIRMAN. Now, Ms. Findley?

STATEMENT OF DI FINDLEY, EXECUTIVE DIRECTOR, IOWACAREGIVERS ASSOCIATION, DES MOINES, IOWA

Ms. FINDLEY. Chairman Grassley, members of thecommittee, thank you for this opportunity. My name is DiFindley and I am the executive director of the IowaCaregivers Association, founded in 1992 as one of thefirst independent State-wide direct-care workerassociations in the country.

Our mission is to enhance the quality of care throughdedication to those direct care workers. One barrier toaccess to Medicaid home- and community-based services, asidentified in the New Freedom Initiative, is the shortageof workers.

In fact, it is probably one of the most compellingproblems that we face. While most care in the country isstill delivered by family members, when the family can nolonger handle that 24-hour around the clock care and mayseek outside assistance with a home care agency provider,or, as a last resort, place someone in a nursing home,and in other instances with the expansion of home-andcommunity-based services and with a more equitabledistribution of resources between institutional-basedcare and home- and community-based services that wouldallow for more

personal assistance, the elderly andpersons with disabilities can remain in their homesindefinitely, it is the family caregivers, the home careaides, the personal assistants who make remaining in thehome possible.

Access to, or expansion of, home- and community-basedservices is impossible without access to a stable,direct-care workforce. We know that there are at leasttwo aspects to the shortage. One, is just sheerdemographics, the huge aging population that is beforeus.

While the aspect of just not enough people tends toget the greatest attention from policymakers and themedia, we have focused our attention on the second aspectof the shortage, that which occurs when workers tend toleave the field at very alarming rates.

Some direct-care workers enter the field of directcare as a stepping stone to become a licensed nurse or aphysician. But, contrary to what a lot of people think,this is a career choice for many people.

Others enter the field, but leave within the first3 months of employment because physical, mental andemotional demands of the work was far more than they hadexpected.

In 1998, we conducted a survey to determine whydirect care workers leave the field. There were nosurprises in the findings, because we have debated theseissues for decades. But for the first time, at least inour State, the survey findings actually represented thevoices of those who were doing the leaving.

They cited the top four reasons for leaving as: shortstaffing, poor wages and benefits, a lack of respect, anda lack of opportunities for advancement within the fieldof direct care.

So, strategies to improve access to Medicaid home-and community-based services must include strategies toimprove access to a good workforce. We are pleased tosee the $2.9 million in additional funding proposed inthe New Freedom Initiative in the 2005 budget.

However, given the magnitude of the problem, itwarrants a higher level of funding and a longer termcommitment. It is pretty simple, really. Withoutdirect-care workers and caregivers, people's needs aregoing to go unmet.

Seniors and persons with disabilities and otherconsumers are being promised this huge continuum of care,from services in the home to end-of-life care. However,we do not have a continuum of caregivers and workers thatis consistent with all of those different levels of careand services that we are offering and promising.

I would echo what several people have already saidtoday. We have a very fragmented system when it comes todirect care workers as well. If we want a stable pool ofdirect care workers, it requires an investment and itjust makes more sense to invest in the people and theworkers rather than continuing to spend millions andmillions of dollars in the cost of worker turnover, whichis just a futile strategy.

Direct care workers need health care coverage. Theydeserve a wage that is reflective of the important workthat they do. With the push for home- and community-based services, I know it is being driven by consumerchoice, and that is good. But I also know it is beingdriven by cost containment. We want to make sure thatthe cost savings are not at the expense of the direct-care workers and lower wages.

Some States have begun to address these workforceissues by starting direct-care worker associations. Infact, some of them have begun with the Real ChoiceSystems Change grants. But States need the resources tocreate and maintain these great efforts.

Recently, thanks to research that has been done byDr. Robin Stone here at the Institute for the Future ofAging Services, and State Dawson with the Para-Professional Health Care Institute, and many, manyothers, the Robert Wood Johnson Foundation and theAtlantic Philanthropies earmarked $15 million to developthe Better Jobs, Better Care grant program to be usedspecifically for the recruitment and retention of directcare workers.

This recognition by these private foundations isreally a big deal and a tremendous boost to the direct-care worker movement and the overall effort, because inthe past there have been funding streams, both public andprivate, for recruiting and retaining primary physicians,licensed nurses, and other health professionals, but thedirect-care workers have not even been on the radarscreen.

As the Federal Government places a higher priority ondirect care worker issues, we hope to see more privatefoundations begin to fund these types of initiatives,too.

So, in closing, I would say we are very pleased thatdirect-care worker issues are beginning to get theattention that they deserve, but we still have a long wayto go. We would urge you to increase the amount offunding for the direct-care worker recruitment andretention portion of the New Freedom Initiative and makea long-term commitment to those who dedicate their livesto the long-term care and support of others. Thank you.[Applause].

The CHAIRMAN. Thank you.

[The prepared statement of Ms. Findley appears in theappendix.]

The CHAIRMAN. Before I ask questions, I would liketo suggest—and I should have suggested this to the otherpanel, too, but I think they are with the executivebranch so they know how this works—even members thatwere here, but particularly because of members who werenot able to come here, you may get questions in writing.In 2 weeks, if you could have those answered, we wouldappreciate it.

I would ask that the staff of the committees wouldinform their members that, maybe in 48 hours, have yourquestions submitted so that they will be timely, and thenwe would submit those to you. If any of you would haveany problems with the process of answering those, thestaff of the Finance Committee would try to be as helpfulas they can in that response.

But, other than that, it would not be any differentthan your responding as you would to me or to othermembers orally. Then probably there will not be othermembers coming back, because this is the day that we havea Republican and Democrat caucuses, and that will bestarting very shortly. So, I will probably be the onlyone asking questions now.

I am going to start with Ray. Ramona, if you want toanswer, that is all right as well, whatever is the case.Also, if you feel that it is easier to respond inwriting, I will submit the questions for answer inwriting.

You mentioned the drawbacks of living in aninstitution and the freedoms that living in the communitycan afford, or have afforded

you as an individual,including more privacy and more independence.

Could you explain if there is such a thing as atypical day in your life, and explain a little bit aboutthat and expand upon the ways that living in thecommunity has enhanced your quality of life?

Mr. GERKE. What is a typical day? That is a goodquestion. I do not even know what a typical day is. AllI can say is, my typical day, there are certain thingsthat have to be done, like getting me out of bed, gettingme out the door so I can go to work. I have an aide thatcomes to work for a couple of hours to help me there, ifI need assistance with a meal, and stuff. Then thatnight, they would come and help me get back to bed.

But the rest of the time, I do all kinds of things,the advocacy stuff. The work that I do for the otherpeople that I support has a large priority.

The CHAIRMAN. It would be difficult for me to givean answer for you, but probably what you said in a day,is difficult to describe a typical day because you do allsorts of things, I think you just said.

Mr. GERKE. Right.

The CHAIRMAN. So, it is all sorts of things thatare obviously your quality of life, I assume.

Mr. GERKE. Right.

The CHAIRMAN. A follow-up question. This is inregard to drawing upon two aspects of your life, theinstitutional part and then the life that you have now.

How did your experiences in an institution affectyour outlook towards life, other individuals, and yourperspective on community-based living?

Mr. GERKE. More of not trusting, being suspiciousof people in the community. That is the only way I cansay that.

The CHAIRMAN. Do you want to help?

Ms. EDMISTON. I know he always is worried thateverything is going to go all right. I know some of theother caregivers, if anybody is a little bit late, he ison the phone. "Where are you? I need help to get out ofbed. I need help. I have got a meeting I have got toget to," or whatever it is. In his day, once he is outthe door, he may go to the office. He has an accessiblevan that he is able to drive himself.

Other times, he may have to travel to a meeting forOlmstead or wherever, and that may be some distance andhe may need someone to come along to drive because it istoo far for him and he would be fatigued.

But I see him do all kinds of these varied things,helping other people. He even goes and gets involvedwith charity fundraisers for clients that live in aninstitution. So, he does a wide variety of things andyou just never know what he is going to need.

The CHAIRMAN. One of the first things he said, as Idetected—and correct me if I am wrong—is he said whenhe was in community-based living he could trust people.Is that what he said?

Ms. EDMISTON. At first he did not, but now he hasgotten to the point where he is familiar with a lot ofus, especially me.

The CHAIRMAN. But from his testimony that he gavebefore the question, in the institutional setting, he didnot feel he could trust people.

Ms. EDMISTON. Right.
Mr. GERKE. Right.
Ms. EDMISTON. There was no trust.
The CHAIRMAN. And there was a slow learningprocess, but now he feels he can trust people.
Ms. EDMISTON. Yes.
The CHAIRMAN. All right.
Bruce, you mentioned in your testimony that one ofthe reasons for changing the Medicaid program is becausethe individuals involved in the program have the desireto move from the nursing home to the community.
What are the characteristics of these individualswanting to move into the community, and if they share acommon characteristic—and I am not saying they should,but if they do—what would that be?
Mr. DARLING. I think the common characteristic theyhave is they are Americans and they want their freedom.Beyond that, we have assisted so many different people.One gentleman, a young African-American man who had beeninjured, used a ventilator. He was the first person inour community to move into the community who used aventilator, which was a big deal.
Anthony said, "Now that I am out, you have to help myfriend Phyllis." It turned out that Phyllis was a 50-year old woman who had lived in the suburbs, a nice,white lady who was actually married and had two daughtersat home, and she could not be there because she could notget the assistance in her home to be there.
We assisted another woman named Betty. She was anolder woman whose son was willing to have her live withhim. They had a whole plan. But she needed a ventilatoras well. She lived down-State, close to New York City inthe nursing facility, in the special facility, as it was,but her home was several hundred miles away in UpstateNew York in a small town.
She could not leave because they said the ventilatorwas theirs, and she could not get assessed for acommunity ventilator until she was up in the communitywhere she lived. So, she faced an insurmountable barrierthat she could not get authorized for services.
So what we see, is a pattern of people who want toget out, but we do not have the systems in place. Theyare so complicated and there are so many hurdles you haveto jump through in order to get community services, thatpeople are just stuck in those nursing facilities.
So I guess that is another commonality, is that thereare a bunch of people who are stuck in a system that doesnot understand or assist them in getting their needs met.
Just to give you another example. I was working witha woman down in New York City who had a friend who had abrain injury, and she started to call around, looking forservices to help her friend move out of a nursingfacility. I gave her some phone numbers, to start.
Two days later, she called me back and she said, Ihave made over 40 phone calls to people all over theState trying to track down what has to be done to help myfriend go home. This is the system that was set up forpersons with brain injury. That is ridiculous.

What we are looking for is to level the playing fieldand let these people, who represent all of America, goback home so that they can make a real choice and returnto their home. And Senator Grassley, we are reallylooking to you to help us do that. [Applause].

The CHAIRMAN. Thank you.

Ms. Moss, although you say that providing constantcare for family members with disabilities is not heroic,I happen to believe that all family caregivers should becommended for the love and dedication that they showtheir families. [Applause].

Ms. MOSS. Thank you.

The CHAIRMAN. As you said, however, this dedicationand care does not come without some health consequencesto the caregiver. In fact, years ago when I was chairmanof the Aging Committee, I held a hearing on caregivers.

One of the things that I learned from that hearingwas, when family members decide to be caregivers, theymight not really understand what they are getting into.Then they end up having health problems just because theyare being caregivers and they do not realize that, andpretty soon they have problems that they would nototherwise have.

Anyway, could you elaborate for me on health problemsthat caregivers face, and what ways respite care couldhelp individuals avoid these health risks associated withtheir care giving?

Ms. MOSS. All right. First, I want to give you anillustration from our own family. My father-in-lawdeveloped Parkinson's Alzheimer's disease, and my mother-in-law was his primary caregiver. She fell.

After going through a protracted time with my father-in-law, he had lost his ability to know day and night.He had time lapse issues. So, she was really up so manyhours with him and became so fatigued, she fell. She isnow sometimes at home and sometimes in more congregatecare because of our abilities to care for her.

She has a spinal cord injury. She has a permanentinjury. She became someone who required care while inthe process of being the primary caregiver, so it put anextra stress on our family.

Very common kinds of caregiver issues are jointdisorders. You have third cervical disks, you have fifthlumbar disks. I mean, these are so common. When we sitaround visiting, as families do, we will talk about, oh,yes, well, I have got that neck problem. Oh, yes. Well,so and so had to have a fusion. Well, such and such isgoing to have to have a hip replacement. Then there areother kinds of issues you get into.

Sleep disturbances is probably one of the mostcommon. My son has a lot of seizures in his sleep. Soif I have an issue where I have not had a lot of sleep,for one reason or another, it is not like I can take asleeping pill and just say, all right, I am going to getcaught up. It never happens that way.

Along with sleep disturbances, you get a lot of otherthings. Falls, burns, twists, sprains, all those kindsof things are so common, and they are the things that youget treated for by your family physician or you go to theemergency room for. But collectively, the numbers, thedollar numbers for ancillary injuries, are huge, inaddition to the carpal tunnel and the more permanentkinds of things that happen.

Then not ever getting fully rested, if you mis-carefor your son or your daughter or supervise their care foryour family member,

whether it is your son, yourdaughter, or your parent, and you become ill with apretty common kind of cold or something like that andyour rest is impaired enough, then your recuperativepowers and your immune system really gets tagged.

I also want to talk about living with theanticipation of not being able to care for them, orgetting hurt or getting sick, and all that "saving yourleave." You do not take off when you really need to.

Eventually, and certainly it would be true of anyonemy age, your adrenals just get depleted. I have theyips. I know there are people who probably think I havedifferent kinds of disabilities than my children.

My startle reflex is highly accentuated. I jump, Iturn, all these kinds of things. It is because I havejust stayed on guard for so long. It is no fun to think,I must be on guard indefinitely.

The CHAIRMAN. Thank you very much.

Nw, Ms. Findley, in your written testimony youdescribe demands placed upon direct-care workers in Iowa,as well as nationwide. In the needs assessment survey ofyour association, and I believe that was conducted in1998 and 1999, you found that short staffing is the topreason caregivers leave the profession. Over the last5 years or so, how has this problem been better orworse?

Ms. FINDLEY. I think the problem is still outthere. We survey our membership on a regular basis. Wehave about 1,500 direct-care worker members. At the timethe survey was completed, some of the CNAs—and keep inmind, because of our funding stream, most of our surveyshave targeted nursing home workers or ones in aninstitutional care setting.

What they reported at that time is that some of themwere caring for as many as 30 and 40 clients orresidents, which is just not humanly possible.

I do think, however, that there are some changes,really positive things going on in Iowa with the BetterJobs, Better Care project and a few other efforts inchanging the workplace culture in the institutionalsetting and looking at more reasonable staffing demands.

The CHAIRMAN. Then a follow-up is, your ideas fromyour background of things that can be done to improvedirect-care provisions.

Ms. FINDLEY. Oh, gosh. Where do I start? It justseems like the issues are so complex. I think one of themost fundamental things is that our society, for so long,has under-valued the elderly and persons withdisabilities, and as a result we tend to under-value thecaregivers and the workers who assist them. So, I thinkwe have a long way to go in trying to change the socialvalue and how we view direct-care workers and theimportant role that they play.

In addition to that, I think the issues are socomplex. We have been working for about 10, 11 years totry to promote professionalism within the field of directcare. Again, it is also integrated. I mean, it issocial value, it is education and training standards, itis respect, it is opportunities for advancement, it isall of those things. All of those are tied to wages andbenefits.

So, I think when we address these issues we have todo it in a very comprehensive manner. It is not justwages, it is not just lack of respect. All of thosethings are very integrated and we need to work harder attrying to take a comprehensive approach to that.

I would also say, with the push for home- andcommunity-based services and the use of personalattendants, we need to do more to foster goodrelationships between the family caregivers, the personalattendants, personal assistants, and those home careaides and other direct-care workers.

The CHAIRMAN. I thank you all very much for yourtestimony.

The hearing is adjourned.

[Whereupon, at 12:34 p.m., the hearing was concluded.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

PREPARED STATEMENT OF HON. HILLARY RODHAM CLINTON

Mr. Chairman and Members of the Committee,

Thank you for the opportunity to testify today in support of the efforts to assure that Americans with disabilities or chronic illnesses have improved access to care in the least restrictive settings. Access to respite services for individuals, including Medicaid-enrolled children and adults, is crucial to those efforts, but we currently need better infrastructure and more funding to make those services more widely available. That is why I am urging support of the equally critical and complementary Lifespan Respite Care Act of 2003 (S. 538, HR 1083).

The Lifespan Respite Care Act of 2003 was passed unanimously by the Senate on April 11, 2003. I sponsored the bill with Senator John W. Warner (VA), Senator John Breaux (LA), Senator Olympia J. Snowe (ME) and Senator Barbara A. Mikulski (MD). This Act would provide $90 million in grants for states and local bodies to increase the availability of respite care in their regions, and to help families care for their dearest ones as they see best.

As a nation, we rely on family caregivers. Although care-giving is certainly personally rewarding, it can also result in substantial emotional and physical strain and financial hardship. Many caregivers are exhausted and become sick themselves. Many give up jobs to care for loved ones, putting their own financial security in jeopardy.

One in five million Americans cares for a family member or friend who has a chronic illness, disability or is unable to care for themselves. Four million Americans with mental retardation or a developmental disability rely on family members for care and supervision. In addition, an estimated 18 million children have chronic physical, developmental, behavioral, or

emotional conditions that demand caregiver monitoring, management, supervision, and/or treatment beyond that required of children generally. If services provided by family caregivers were replaced by paid services it would cost over $250 billion annually.

Ideally, these caregivers remain in their home, permitting care recipients to live less restricted, more independent lives. As we know, for the disabled and the elderly, remaining at home, surrounded by friends and family in familiar surroundings, is the best option as clinically proven to be the most positive of reinforcements. Therefore, what is clear is that families need assistance in being able to choose that option without having to fully bear financial, emotional, and physical hardship.

Caregivers suffer from increased depression, fatigue and or poor health. Few services address these issues. This legislation provides care-givers a break from daily care-giving responsibilities, for a few hours or a few days through home visits or at an on-site respite care-facility. The burden on these caregivers is too heavy to be calculated here. However, the much needed funding would allow women and men to continue caring for their loved ones as desired.

For the over 3 million family caregivers in New York, the problem is simple: there are never enough hours in the day. The emotional, physical and financial toll that caregiving exacts is extraordinary. But sadly, current respite care programs are unable to provide relief to all overtaxed caregivers who need a helping hand.

The NFI Respite demos will begin to address the respite needs for the Medicaid eligible population, but they don't go far enough. States can also restrict the demonstrations to a small geographic area of the state or to a single disability category. Consideration of legislation to implement these demos should go hand in hand with passage of the Lifespan Respite Care Act, which provides a better infrastructure that will make the investment of Medicaid dollars more effective, which is important especially in this time of tight budgets.

With modest funds, the Lifespan Respite Care Act will allow states to put a respite system in place – not just a solitary service for a few. The bill would allow states to coordinate the disparate respite funding streams and make best use of them. Current programs reach only a small proportion of those in need

because of restrictive eligibility criteria and limited funding. Shortages of respite providers exist in every state. And even when families can afford their own respite resources, finding quality, reliable respite can be difficult if not impossible.

The Lifespan Respite approach will allow states to identify existing respite resources, pool and share providers, funds, training resources and administrative capacities, and identify and fill gaps in services. The Lifespan Respite Care Act will allow states to ensure that new targeted respite services and funding streams, such as those proposed by the Administration, are meeting the need. The Lifespan Respite Care Act provides the umbrella that will improve efficiency, save money, and make quality respite available and accessible to families and caregivers, regardless of their Medicaid status, disability, or age. Without this infrastructural component, high quality respite service providers may not be readily available to Medicaid beneficiaries, even if some reimbursement is made available through the demonstration.

The proposed NFI respite demos could provide benefits to some very needy families and caregivers, and infusion of funds for critically needed respite services, training and evaluation is vitally necessary. However, to fully realize the reality of home and community based services, a system must be in place to support the nation's caregivers, regardless of their current eligibility for government programs. The Lifespan Respite Care Act will help accomplish that. Thank you for this opportunity to testify today.

Joint Statement by Senator Charles Schumer and Senator Hillary Rodham Clinton

Finance Committee Hearing

"Strategies to Improve Access to Medicaid Home and Community Based Services"

April 7, 2004

On behalf of myself and Senator Clinton, I would like to thank Senators Grassley and Baucus for calling this hearing to discuss much-needed strategies to improve access of Medicaid patients to home and community based services. We would also like to thank Senator Harkin for being responsive to the needs of the Medicaid population by introducing the two important pieces of legislation that we have both co-sponsored, S. 971 (MiCASSA) and S. 1394 (The Money Follows the Person Act).

The Medicaid system currently encourages states to provide services to the disabled in an institutional setting rather than in an individual's home or community. We need to change the funding structure so that we can allow seniors and people with disabilities to live at home rather than in nursing homes and other facilities, which will reduce expenses and allow patients greater independence.

MiCASSA, the Medicaid Community Based Attendant Services and Supports Act, eliminates the funding preference for institutional care by making community care mandatory for states. Although institutional care is already mandatory, community care is currently discretionary, which makes it an easy target for budget cuts in this time of rapidly escalating deficits for states. MiCASSA will change the way decisions are made, allowing patients to be treated in the most appropriate settings as determined by them and their health care providers.

The second bill, the Money Follows the Person Act of 2003, would establish a demonstration project to ease the transition of patients from institutions to the home by providing federal funding for the first year of community-based services a patient enrolled in Medicaid would receive after leaving an institutional facility. These two bills working together will make great strides toward truly providing patients with a choice between living at home and living in a facility.

It is time to place an appropriate emphasis on community and home care in order to allow seniors and the disabled the option of living in their homes. We sincerely hope that the Senate will recognize the necessity for and diverse interest in these two pieces of legislation. Under the leadership of Senator Harkin, we believe that we can make significant steps toward increasing the quality of life for elderly and disabled Americans.

End the Institutional Bias: No More Stolen Lives!
MiCASSA, Money Follows the Individual and More!

Testimony of the ADAPT Community
Presented by Bruce E. Darling

Good Morning. My name is Bruce Darling, and today I am testifying on behalf of the ADAPT Community and the many thousands of people with disabilities who want to have a REAL CHOICE so that they may live fulfilling and productive lives in the community.

I am the Executive Director of the Center for Disability Rights (CDR), an Independent Living Center based in Rochester, New York which provides community-based services that support people with disabilities in the community and advocates on disability issues. About four years ago, CDR began to formally transition people out of nursing homes. Since that time, our Center has helped over 100 people return to community living.

Over the last few years, I have also trained literally hundreds of people from 37 different states and the Territory of Guam on how to assist people with disabilities to return to community living from institutional settings. As I have traveled throughout the country, I have heard the same stories from people who had years of their lives stolen by a system which supports institutions over individual rights.

- People who were separated from their families,
- People who lost their homes,
- People who lost their freedom and thought their lives had ended.

People with disabilities and our allies are fighting the institutional bias, but conviction, training, and hard work are simply not enough. We need YOU to take action and establish a national Community First policy! You have the power to end the institutional bias and assure that there are no more stolen lives.

PROBLEM STATEMENT AND ITS IMPACT ON REAL PEOPLE

Our long-term care system has remained essentially unchanged since its creation nearly 40 years ago. No one would have guessed that today this system would warehouse over 1.4 million Americans in nursing facilities and 110,572 in ICFs, or Intermediate Care Facilities for the Mentally Retarded.[1]

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[1] Lakin, K.C. and Prouty, R. (2003). Medicaid Home and Community-Based Services: The First 20 Years. *Policy Research Brief.* University of Minnesota: Minneapolis, Institute on Community Integration, *14*(3). Obtained from http://ici.umn.edu/products/prb/143/

The system was built on a medical model. At the time of its creation, individuals with disabilities were considered patients who needed to be cared for. Over the years, the medical model has added costs, requiring medical staff to do tasks which could be done by an unlicensed attendant either through delegation or assignment of a health professional. In this system, health-related tasks are often done by a nurse, who charges Medicaid over $100, rather than an attendant who is billed at only $15.

The medical model fostered a system where services were made available based on diagnosis, creating fragmentation and service gaps. I worked with a woman named Lisa Cyphers. She wanted to be at home rather than a nursing home. To go home she needed support services that were provided under the state's Traumatic Brain Injury waiver, but because she had Multiple Sclerosis she was not eligible for them. Even though she had the same exact functional needs, she wasn't eligible for the services to get her home.

Over the years long term care services have become even more fragmented. Attempts at modernizing the system, including the development of new programs and a multitude of Medicaid Waiver programs, have created a disjointed mish-mash of services, which vary from state to state, and even county to county. States may have a dozen different waivers and a complicated array of services that even the most skilled social worker couldn't navigate.

Our spending in long term care clearly illustrates the institutional bias. According to 2002 Medstat data, 70% of the $82.13 billion that is spent on long term care services goes to institutional services, while only 30% funds community services and supports.[2]

The institutional bias is demonstrated on a personal level as well.

Medicaid rules allow individuals who are in nursing facilities (or deemed eligible for a nursing facility and receive services through a Medicaid Waiver) to retain income up to 300% of the Supplemental Security Income (SSI) federal benefit rate, nearly $1,700 per month for a single person. By comparison in most states, individuals who need personal care or home health care are only allowed to retain one third of that amount.

If an individual's spouse is institutionalized in a nursing home, federal rules allow them to keep at least some of their income and resources without totally impoverishing themselves. The same is not true for community-based services. As an example, we worked with Phyllis Patnode. As a 50-year-old woman, Phyllis was forced to leave her husband and home and go into a nursing home because her husband worked and she didn't want to financially devastate him and her daughters.

A fundamental problem is that Medicaid funding for long term care services is securely tied to the institutions. States must provide institutional services, like nursing home care, while community-based services are completely optional. To provide alternatives to nursing homes or ICF-MR facilities, states must apply for a Medicaid Waiver, which

[2] www.medstat.com

means that the federal government is agreeing, on a case-by-case basis, to waive certain Medicaid requirements in order for that state to provide home and community based services. There are often no waiting lists for nursing homes. However, when states apply for a Medicaid Waiver, the federal government authorizes a certain number of "slots", which results in waiting lists for Home and Community Based Medicaid Waiver Services.

Because institutional services are mandatory, states cannot cut their funding. We are in tough fiscal times. States have no choice but to cut community based services. Even states that want to provide less expensive community-based alternatives are prevented from doing so by a federal policy that mandates institutional care.

In addition to all of this, there is one very important reason we must change this system. It isn't what people want.

According to the data from the Centers for Medicare and Medicaid Services, nearly 19% of individuals in nursing homes have expressed an interest in returning to the community.[3] This information was collected by the nursing homes themselves. From our experience, the number of people who want to live in the community is actually much higher. We have the data that shows this. According to Barriers to Independence, a study conducted by Access Living and the Center for Urban Research and Learning at Loyola University in Chicago, 64.5% of the nursing home residents that were surveyed expressed that they would prefer to live somewhere else if the opportunity were available.[4]

PERSONAL IMPACT: REAL VOICES

Last year, as part of our Stolen Lives Campaign, ADAPT began documenting the names and stories of people from nursing homes and institutions.

These stories document the voices of people institutionalized as children...

... like **Leonard Roscoe**, from **Georgia**. Leonard was put in the institution in 1972 after living in hospital the first 3 years of his life. Leonard has Osteogenesis Imperfecta (brittle bones). He was institutionalized for 35 years before he got out.

... like **Patrick King** from **Austin, Texas**. When Patrick was eight he got hit on the head in a schoolyard accident resulting in multiple disabilities. He ended up in a Texas State Mental Health Hospital and stayed there for over a decade because he had what was

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[3]MDS Active Resident Information Report: December 31, 2003, from http://www.cms.hhs.gov/states/mdsreports/res3.asp?var=Q1a&date=5.

[4] Barriers to Independence: A study of housing and personal assistance issues for people with disabilities residing in nursing homes. Access Living and the Center for Urban Research and Learning, Loyola University Chicago, June 21, 2000.

described as "bizarre behaviors". Nobody believed Patrick could live in the community and he lost over a decade of his life because of this neglect.

These stories document the voices of people who lost their freedom during the prime of their lives…

… like **June Adams** from **Denver, Colorado**. June had two little boys when she had her stroke. She was put in a nursing home, where she was held captive for 17 years while her children grew up without her.

These stories document the voices of older persons who were forced to leave their homes…

… like **Betty Cranston** from **Lake Katrine, New York**. When Betty's COPD worsened and she needed a ventilator, she was forced into a specialized nursing facility hundreds of miles away from her son, home, and small town. Even though she did much of her own personal care at the facility and her son wanted his mother to return home to live with him, she was forced to stay there because she couldn't get approved for community services – or a portable ventilator.

I have included the individual stories we received at the end of this testimony. Their words are compelling. Their voices rise up and ask for just one thing: freedom.

SOLUTIONS: REAL CHOICES

It is clear that we need a new model.
No longer should community based services be the exception to the institutional rule.

Community based services must become as easy to access as institutional services.

To accomplish this, the tie between the institution and funding must be cut. Individuals must have real, meaningful and effective choices in what services they receive, where they receive services, and who provides those services.

Our nation must pass legislation which reforms the long term care system and incorporates the following principles:

- Attendant services must be available in the community, 24 hours per day, seven days per week;
- Eligibility must be based on functional need, not on diagnosis, age, or funding stream;
- Incentives are offered to encourage states to allow assignment or delegation of care tasks previously restricted to only doctors and nurses;
- Consumer control must be maximized at every step of the process, including flexible payment and management systems; and
- Attendants must earn a livable wage and benefits.

Immediate Actions

This shift will take time, but there are immediate steps you can take to end the institutional bias.

First, you must pass **Money Follows the Individual** legislation.

Under this legislation, the Federal government will fund community-based services for the first year for individuals who transition out of institutions! This legislation would provide a critical incentive to the states in providing Real Choices in long term care. This will encourage states to build their capacity to more effectively transition people back into the community.

Senator Harkin introduced the Money Follows the Person Act of 2003 (S.1394) on July 11th. Shortly after that, on July 25th, the White House distributed its own draft legislation: the New Freedom Initiative Medicaid Demonstration Act of 2003. We understand that you, Senator Grassley, are considering introducing legislation based on the administration's proposal. This more comprehensive legislation would authorize a Money Follows the Individual Demonstration program and support other initiatives to promote community-based services. Thousands of people with disabilities in nursing homes and other institutions will benefit if you fund these initiatives and give states the incentive to move people into the community. This first step, though not the complete answer to ending the institutional bias, will lay the foundation for the more comprehensive changes to the Medicaid system that must occur if nursing homes and other institutions are to become the alternative rather than the entitlement.

Whether you pass S. 1394 or the administration's proposal, it is imperative that you take action now. This legislation must be passed during this session. The CMS data I spoke about earlier shows that at least 267,000 people with disabilities want to return to the community NOW!

267,000 people are telling the nursing homes that they want to go home;
267,000 people are asking you to help them go home; and
On behalf of those 267,000 people, I am pleading with you not to make them wait one more day!

There are other steps you could take to address the institutional bias. You could create an Enhanced Federal Medicaid Matching Rate for home and community based services. By paying a larger percentage of the cost of home and community based services, you will create a strong and on-going incentive for states to promote community living.

Such a step would help the states address their budget difficulties during these difficult times and promote community living options. It would also send a clear message that our nation values the freedom of all of its citizens, including those with disabilities.

A Lasting Solution

While demonstration programs and enhanced Medicaid matches would promote community living, they still leave much work to be done. The ultimate solution to ending the institutional bias which has stolen the lives of so many thousands of seniors and people with disabilities is clear.

Pass MiCASSA!

The Medicaid Community Attendant Services and Supports Act (S. 971) gives people Real Choice in long-term care. MiCASSA provides individuals eligible for Nursing Facility Services or ICFs with the opportunity to choose Community-Based Attendant Services and Supports.

Rather than be forced into institutional placement, people would get assistance in their own homes. Such assistance would include the basic activities of daily life that most people take for granted like meal preparation, eating, toileting, bathing, grooming, shopping, managing finances, and participating in the community. MiCASSA addresses the need for assistance with health-related functions.

MiCASSA implements other necessary reforms. It would:

- provide assistance in the home and community, such as at school, work, or religious activities;
- include systems for securing back-up attendants;
- offer options for consumer control of services;
- address the inequity in financial eligibility between nursing facilities and community based services; and
- support those minor but essential expenses needed by people returning to the community, such as security deposits for housing, bedding, and kitchen supplies.

Because the money is following the individual, MiCASSA is not a new, unfunded mandate. We pay for this assistance already. MiCASSA makes the existing mandate more responsive to consumers. People who are already eligible for services will have a Real Choice.

Every major national disability organization supports MiCASSA. In fact, 92 national organizations are MiCASSA supporters. An additional 255 state or regional organizations also support the bill, as well as 306 local groups. I have included the full list at the end of my testimony. As you look through the list, you will notice that ADAPT is working with children's advocates and senior advocates. Supporting organizations represent people with all types of disabilities: people with cognitive disabilities, people with sensory disabilities, people with mental health labels and/or people with physical disabilities.

We are asking that you take action now!

Today, we would not be here had it not been for the heroic efforts of hundreds and hundreds of ADAPT members who have put their bodies on the line year after year.

On behalf of these people, I would like to thank you for this hearing.

But on their behalf, I must point out that we need more than hearings.

We need action.

Take the steps I have outlined today and pass these important pieces of legislation to FREE OUR PEOPLE!

For an institution free America,
Bruce E. Darling

ATTACHMENT 1: Organizations Supporting MiCASSA

National Organizations Supporting MiCASSA

1 ABLED! Publications: ABLED Woman Magazine
2 Ad Hoc Committee on Healthcare Reform and Disability
3 ADA Watch
4 ADAPT
5 American Association of People with Disabilities, AAPD
6 American Association on Mental Retardation
7 American Geriatrics Society
8 American Rehabilitation Counseling Association
9 Americans with Disabilities Vote
10 The Arc
11 Association for Persons in Supported Employment, APSE
12 Association Programs for Rural Independent Living, APRIL
13 Association for Protection of the Elderly
14 The Autism National Committee
15 Bazelon Center for Mental Health Law
16 Brain Injury Association
17 The Bridge
18 Center for Housing and New Community Economics, CHANCE
19 Center for Self Determination
20 Center on Human Policy
21 Christopher Reeve Paralysis Foundation
22 Concrete Change
23 Consortium of Developmental Disabilities Councils
24 Consumer Research and Advocacy
25 Democratic National Committee
26 DIMENET
27 The Disability Grapevine
28 The Disability News Service, Inc.
29 Disability Rights Action Coalition for Housing
30 The Disability Rights Center
31 Disability Rights Education and Defense Fund, DREDF
32 Disabled People's Direct Action Network of Great Britain
33 Disabled Queers In Action, DQIA
34 Eastlake Derry and Associates
35 Families USA
36 Family Voices
37 Gerstmann Syndrome Support Network
38 GnarlyBone News/Gnarly Bones Productions
39 Gray Panthers
40 HalfthePlanet.com
41 HUMAN

Independent Living Research Utilization, ILRU
Institute for Disability Access
Institute on Disability Culture
International Ventilator Users Network/Post-Polio Health International
Justice for All
Mainstream Magazine
The Mouth
National Association of the Advancement of Colored People, NAACP
National Association for Home Care
National Association of Area Agencies on Aging
National Association of the Deaf
National Association of Developmental Disabilities Councils
National Association of Protection and Advocacy Services, NAPAS
National Association for Rights Protection and Advocacy
National Association of State Head Injury Administrators
National Catholic Office for Persons with Disabilities
National Center for Latinas with Disabilities
National Citizens Coalition for Nursing Home Reform
National Coalition of the Chemically Injured
National Coalition on Self-Determination
National Council on the Aging
National Council on Independent Living
The National Disability Party
National Family Caregivers
National Home of Your Own Alliance
National Organization for Women, NOW
National Organization on Disability
National Rehabilitation Association
National Spinal Cord Injury Association
New Mobility
Not Dead Yet
Oglala Sioux Nation
On A Roll Talk Radio
Paralyzed Veterans of America, PVA
The Ragged Edge
Research and Training Center on Independent Living at the Unversity of Kansas
The Rural Institute, University of Montana
Self Advocates Becoming Empowered, SABE
Senior Support Network
Service Employees International Union, SEIU
Shepherd Center
Socialist Party USA
Southern Disability Law Center
TASH
United Cerebral Palsy

87 United Spinal Association
88 Universal Health Care Action Network, UHCAN!
89 US Conference of Mayors
90 Very Special Arts
91 World Association of Persons with Disabilities, WAPD
92 World Institute on Disability, WID

State/Regional Organizations Supporting MiCASSA

1 Access to Independence and Mobility, New York
2 ADA Consortium, Utah
3 Advocacy Center, Louisiana
4 Advocacy Incorporated, Texas
5 Advocates for Texans with Brain Injuries, Texas
6 Alaska Division of Vocational Rehabilitation
7 Alaska Governor's Committee on Employment and Rehabilitation of Peopl with Disabilities
8 Alaska Transition Initiative
9 Alaska State Independent Living Council
10 Alpha-One, Maine
11 Alzheimer Society of Washington
12 The Arc of Arkansas
13 The Arc of Iowa
14 The ARC of Maryland
15 ARC of Mihigan
16 ARC of Washington State
17 ARC of Wisconsin
18 Arizona Governor's Council on Developmental Disabilities
19 Arizona Governor's State Rehabilitation Advisory Council
20 Arizona Governor's Statewide Independent Living Council
21 Arkansas Independent Living Council
22 Arkansas Support Network
23 Assistive Technologies of Alaska
24 Association of Colorado Independent Living Centers
25 Association for Independent Living of Utah
26 Atlanta Alliance on Developmental Disabilities, Georgia
27 Aurora Residential Alternatives, Wisconsin
28 Autism Society of Michigan
29 Brain Injury Association of Texas
30 Brain Injury Association of Wisconsin
31 California Alliance for Inclusive Communities
32 California Coalition of United Cerebral Palsy Associations
33 Califmia Disability Alliance
34 California State Independent Living Council
35 Campaign for Better Health Care, Illinois
36 Central New York Self Advocacy Grassroots Regional Organizing Program

37 Chemical Sensitivity Disorders Association, Maryland, Virginia, Delaware, DC, and Pennsylvania
38 CLASS CTD, Columbus Kansas
39 Client Assistance Program of Wisconsin
40 Coalition for Citizens with Disabilities, Mississippi
41 Coalition of Citizens with Disabilities in Illinois
42 Coalition of Montanans Concerned with Disabilities
43 Coalition of Texans with Disabilities
44 Coalition on Disabilities Education (C.O.D.E.) Georgia
45 Colorado Cross-Disability Coalition Colorado Democrats
46 Colorado Developmental Disabilities Planning Council
47 Colorado Governor's Council for People with Disabilities
48 Colorado Nurses' Association
49 Colorado State Independent Living Council
50 Commonwealth Coalition for Community, Virginia
51 Comprehensive Advocacy, Idaho
52 Connecticut Coalition of Citizens with Disabilities
53 Connecticut Council on Developmental Disabilities
54 Connecticut Legal Rights Project
55 Connecticut Statewide Independent Living Council
56 Council for Disability Rights, Illinois
57 Delaware Maryland Paralyzed Veterans Association
58 Delaware Statewide Independent Living Council
59 Demanding Equal Access for All (D.E.A.F.) Georgia
60 Disabilities Law Project, Pennsylvania
61 Disability Law Center, Massachusetts
62 Disability Law Center, Utah
63 Disability Law Center of Alaska
64 Disability Policy Consortium, Texas
65 Disability Resource Association, Missouri
66 disAbility Resources of Southwest Washington
67 Disability Rights, Hawaii
68 Disability Services of the Southwest, Texas
69 Dykes, Disabilities and Stuff Quarterly
70 Easter Seals Delaware & Maryland's Eastern Shore
71 Environmental Illness Association of Hawaii
72 Equip for Equality, Illinois
73 Families Helping Families, Louisiana
74 Federation of Families for Children's Mental Health, Georgia
75 Florida Independent Living Council
76 Florida Spinal Cord Injury Research Center
77 Georgia Advocacy Office
78 Georgia Developmental Disabilities Council
79 Georgia State Independent Living Council
80 Governor's Commission on Disability in New Hampshire
81 Governor's Committee on Concerns of the Handicapped, New Mexico

82 Governor's Committee on Disabilities Issues and Employment, Washington
83 Governor's Council on Disabilities and Special Education, Alaska
84 Georgia Parent Support Network
85 Granite State Independent Living Foundation, New Hampshire
86 Great Lakes ADA, Illinois, Indiana, Michigan, Minnesota, Ohio & Wisconsin
87 Hawaii Statewide Independent Living Council
88 The Howell Group, Michigan
89 Idaho State Independent Living Council
90 Illinois Network of Centers for Independent Living
91 Illinois Rehabilitation Council
92 Illinois State Council of Senior Citizens
93 Illinois Valley Center for Independent Living
94 Iowa Creative Employment Options
95 Iowa Human Rights Commission - Division of Persons with Disabilities
96 Iowa Statewide Independent Living Council
97 Iowans with Disabilities Exercising Advocacy Skills
98 Indiana Institute on Disability and Community
99 Institute on Disability, New Hampshire
100 Irene Ward and Associates, Ohio
101 Jay Nolan Community Services, California
102 Kansas Association of Centers for Independent Living
103 Kansas Association of the Deaf
104 Kansas Commission on Disability Concerns
105 Kansas Council on Developmental Disabilities
106 Kansas Disability Rights Action Coalition for Housing
107 Kansas Nurses Association
108 Kansas State Independent Living Council
109 Kansas State Chapter WAPD
110 Kansas TASH
111 Kentucky Developmental Disabilities Council
112 Kentucky Statewide Independent Living Council
113 League of Human Dignity, Nebreska/Iowa
114 Legislative Coalition for People with Disabilities
115 Let's Get Together, Georgia
116 LIFTT, Billings Montana
117 Lupus Foundation of Colorado
118 Maine Disabilities Coalition
119 Maryland Association of Community Services
120 Maryland Developmental Disabilities Council
121 Maryland Disabilities Forum
122 Maryland Statewide Independent Living Council
123 Massachusetts Arc
124 Massachusetts Office on Disability
125 Massachusetts Statewide Independent Living Council
126 Massachusetts Statewide Personal Assistance Coalition

127 Mental Health Association in Texas
128 Mental Patients Liberation Alliance of New York State
129 Michigan Association of Centers for Independent Living
130 Michigan Developmental Disabilities Council
131 Michigan Disability Rights Center
132 Michigan Protection and Advocacy Service
133 Minnesota Association of Centers for Independent Living
134 Minnesota Governor's Council on Developmental Disability
135 Minnesota State Independent Living Council
136 Missouri Governor's Council on Disability
137 Missouri Head Injury Advisory Council
138 Missouri Planning Council for Developmental Disabilities
139 Missouri Statewide Independent Living Council
140 Monday Morning Project - New Jersey
141 Montana Advocacy Program
142 Montana Independent Living Project
143 National Association of Social Workers, Texas Chapter
144 National Multiple Sclerosis Society - Oklahoma Chapter
145 National Multiple Sclerosis Society - Wisconsin Chapter
146 Nebraska Advocacy Services
147 New England Health Care Employees Union - District 1199
148 New Jersey Developmental Disabilities Council
149 New Jersey MiCASSA Advocacy Coalition
150 New Jersey Statewide Independent Living Council
151 New Hampshire Developmental Disabilities Council
152 New Hampshire Statewide Independent Living Council
153 New Mexico Developmental Disabilities Planning Council
154 New Mexico Legislative Health and Human Services Committee
155 New Mexico State Agency on Aging
156 New Mexico Statewide Independent Living Council
157 New York State Developmental Disabilities Planning Council
158 New York State Independent Living Council, Inc.
159 New York State Institute on Disability
160 NHHomeless@egroups.com, New Hampshire
161 North Carolina Statewide Independent Living Council
162 The Oaks Group, California
163 Office of Handicapped Concerns, Oklahoma
164 Ohio Association of Centers for Independent Living
165 Ohio Developmental Disabilities Council
166 Ohio Disability Action Coalition
167 Ohio Personal Assistance for Independent Living, OPAIL
168 Ohio Personal Assistance Services Coalition
169 Ohio Statewide Independent Living Council
170 Oklahoma Conference of Churches Impact Committee
171 Oklahoma Parent Network
172 Oklahoma Statewide Independent Living Council

173 Oklahomans for Independent Living
174 Oklahomans for Reasonable Health Care
175 Older Adult Services Providers Consortium, Wisconsin
176 Options IRCIL, Minnesota and North Dakota
177 Oregon Developmental Disabilities Coalition
178 Oregon Disabilities Commission
179 Oregon State Independent Living Council
180 Osteogenesis Imperfecta Council of Georgia
181 Out in the Valley, Oklahoma
182 Paralyzed Veterans Association of Florida
183 Paralyzed Veterans of America, PVA, Delaware - Maryland Chapter
184 Paralyzed Veterans of America, PVA, Zia Chapter, New Mexico
185 Parents Education Project of Wisconsin
186 Parents, Let's Unite for Kids, PLUK, Montana
187 PEAK Parent Center, Colorado
188 Pennsylvania Action Coalition for Disability Rights in Housing, PAC
189 Pennsylvania Association of Area Agencies on Aging
190 Pennsylvania Coalition of Citizens with Disabilities, PCCD
191 Pennsylvania Council of the Blind
192 Pennsylvania Council on Independent Living
193 Pennsylvania Developmental Disabilities Council
194 Pennsylvania Statewide Independent Living Council
195 People First of California
196 People First of Georgia
197 People First of Wisconsin
198 Project PAS-Port for Change of Washington
199 Rammler & Wood, LLP, Connecticut
200 Rehabilitation for Wisconsin
201 Roosevelt Warm Springs Institute for Rehabilitation
202 Self-Advocacy Association of New York State
203 Self-Advocacy Network of Michigan
204 South Carolina Independent Living Council
205 South Carolina State Chapter WAPD
206 South Dakota Coalition of Citizens with Disabilities
207 Speaking for Ourselves, Colorado
208 Speaking for Ourselves, Pennsylvania
209 Special Education Associates, SEA, Missouri
210 State Council for Persons with Developmental Disabilities, Delaware
211 State Independent Living Council of New Hampshire
212 State Independent Living Council of Wisconsin
213 State Rehabilitation Planning and Advisory Council of Wisconsin
214 Statewide Independent Living Council of Illinois
215 Tennessee Association for Disability Rights
216 Tennessee Developmental Disabilities Council
217 Tennessee Disability Coalition
218 Tennessee Network for Community Economic Development

219 Texas Advocates
220 Texas Advocates Supporting Kids with Disabilities
221 Texas Association of Centers for Independent Living
222 Texas Civil Rights Project
223 Texas Health and Human Services Commission
224 Texas Mental Health Consumers
225 Texas Nurses Association
226 Texas Paralyzed Veterans of America
227 Texas Planning Council for Developmental Disabilities
228 Texas Rehabilitation Commission
229 Texas State Independent Living Council
230 Texas State Chapter WAPD
231 United Cerebral Palsy of Pennsylvania
232 United Cerebral Palsy of Texas
233 United Cerebral Palsy of Wisconsin
234 University Affiliated Program, University of Texas
235 University of Delaware Disabilities Studies Program
236 Utah State Democratic Committee
237 Utah Statewide Independent Living Council
238 Vermont Center for Independent Living
239 Vermont Coalition for Disability Rights
240 Virginia Association of Persons in Supported Employment
241 Virginia Statewide Independent Living Council
242 Virginia TASH
243 Washington Coalition of Citizens with Disabilities
244 Washington Protection and Advocacy System
245 Washington State Independent Living Council
246 West Virginia Statewide Independent Living Council
247 Wisconsin Coalition for Advocacy
248 Wisconsin Coalition of Independent Living Centers
249 Wisconsin Council on Developmental Disabilities
250 Wisconsin Council on Physical Disabilities
251 Wisconsin Governor's Committee for People with Disabilities
252 Wisconsin Nurses Association
253 Wisconsin Rehabilitation Association
254 Wisconsin State Independent Living Council
255 Wyoming Statewide Independent Living Council

Local Organizations Supporting MiCASSA

1 504 Democratic Club, New York New York
2 ABIL, A Bridge to Independent Living, Phoenix Arizona
3 The Ability Center of Greater Toledo
4 Abilities In Motion, Reading Pennsylvania
5 Ability Resources, Tulsa Oklahoma
6 ABLE - CIL, Odessa Texas

Absolute Care Enterprise Inc., New Orleans Louisiana
Access II Independent Living Center, Gallatin Missouri
Access Center for Independent Living, Dayton Ohio
Access Center for Independent Living, Gainesville Georgia
Access Living, Chicago Illinois
Access Resorts, Hilton Head South Carolina
Access to the Arts, Louisville Kentucky
Access to Independence, Madision Wisconsin
Access to Independence of Courtland County, Cortland New York
Accessible Construction, Cary Illinois
Action for a Better Community, Rochester New York
Active Re-Entry, Price Utah
Advocating Change Together, St Paul Minnesota
Aging & Disability Coalition of Metro Kansas City, Independence Missouri
Alameda County Developmental Disabilities Planning and Advisory Council, Oakland California
Alliance for the Disabled in Action, Edison New Jersey
American Legion - Post 400, Topeka Kansas
Americans Demanding Access of NY State, Binghamton New York
Ann Arbor Center for Independent Living, Michigan
Anthracite Region Center for Independent Living, Hazleton Pennsylvania
Arc Cobb, Cobb County Georgia
The ARC of Detroit
The Arc of Lincoln/Lancaster County, Lincoln Nebraska
ARC of Milwaukee, Wisconsin
Area Agency on Aging, Cameron, Elk and McKean Counties, Pennsylvania
Area Agency on Aging, Price Utah
Area Agency on Aging Office of Human Services, Ridgeway Pennsylvania
ARISE Child and Family Services, Syracuse New York
Arkansas Support Network, Bentonville Arkansas
Association for Community Advocacy
Atlantis Community, Denver Colorado
Aurora Community Services, Menamonie Wisconsin
Austin Resource Center for Independent Living, Austin Texas
Austin Mayor's Committee for People with Disabilities, Austin Texas
Bainbridge Advocacy Individual Network, Bainbridge Georgia
Baltimoreans Against disAbility Discrimination, B.A.d.D., Baltimore Maryland
Birmingham Independent Living Center, Alabama
Blue Panthers
Blue Ridge Independent Living Center, Roanoke Virginia
Blue Water Center for Independent Living, Port Huron Michigan
Bootheel Area Independent Living Services, BAILS, Kennett Missouri
Boston Center for Independent Living, Massachusetts
Brain Injury Family Assistance Center, Atlanta Georgia
Brain Injury Services, Fairfax Virginia

51 Brazoria County Center for Independent Living, Angleton Texas
52 Bronx Independent Living Services, Bronx New York
53 Brooklyn Center for Independence, Brooklyn New York
54 Bucks County Area Agency on Aging, Pennsylvania
55 Buffalo River Services, Waynesboro Tennessee
56 Calvert County Commission for Individuals with Disabilities, Maryland
57 Camden City Independent Living Center, Camden New Jersey
58 Cape Organization for the Rights of the Disabled, CORD, Hyannis Massachusetts
59 Capital District Center for Independence, Albany and Schenectady New York
60 C.C.E., Chicago Illinois
61 Center for Advocates for the Rights and Interests of the Elderly, CARIE, Philadelphia Penn.
62 Center for Disability Rights, Rochester New York
63 Center for Independence, Grand Junction Colorado
64 Center for Independence of the Disabled, Belmont California
65 Center for Independent Living for Western Wisconsin, Menomonie Wisconsin
66 Center for Independent Living of Broward, Tamarac Florida
67 Center for Independent Living of Central Pennsylvania, Camp Hill Pennsylvania
68 Center for Independent Living of Mid-Michigan, Midland
69 Center for Independent Living of Middle Tennessee, Nashville
70 Center for Independent Living of North Central Pennsylvania, Williamsport Pennsylvania
71 Center for Independent Living of Northeastern Minnesota, Hibbing Minnesota
72 Center for Independent Living Options, Cincinnati Ohio
73 Center for Independent Living of South Central Pennsylvania, Altoona Pennaylvania
74 Center for Independent Living of South Jersey, Westville, New Jersey
75 Center for Independent Living of Southwest Kansas, Garden City Kansas
76 Center for Independent Living of South Valley, Visalia California
77 Center for Living and Working, Inc., Worcester Massachusetts
78 Center for People with Disabilities, Boulder Colorado
79 Central Texas Coalition on Aging and Developmental Disabilities, Central Texas
80 Central Texas Rehabilitation Association, Central Texas
81 Citizens for Independence and Access, York Pennsylvania
82 City of Chicago
83 Coalition for Independence, Kansas City Kansas
84 Coastal Community Advocates, Aberdeen Washices for Independence, Erie Pennsylvania
85 Community Service Options, Chicago Illinois
86 Concerned Citizens with Disabilities, Logan Utah

87 Connections for Independent Living, Greeley Colorado
88 Consumer Connection, Philadelphia Pennsylvania
89 CORD, Spokane Washington
90 Council for Disability Rigcson Arizona
91 Disability Action Center - NW Inc., Moscow Idaho
92 Disability Center for Independent Living, Denver Colorado
93 Disability Connections, Middle Georgia Center for Independent Living,
94 Macon Georgia
95 The Disability Institute, Hopkins Minnesota
96 disAbility LINK, Decatur Georgia
97 Disabilities Network of Eastern Connecticut, North Franklyn
98 Disabilities Network of NYC, New York New York
99 The Disability Network, Flint Michigan
100 Disability Resource Agency for Independent Living, Modesto, Stockton and Sonona California
101 Disability Resource Center, North Charleston South Carolina
102 Disability Resource Center, Knoxville Tennessee
103 Disability Resource Center of Fairfield County, Stratford Connecticut
104 disAbility Resource Center, Everett Washington
105 disAbility Resource Center of the Rappahannock Area, Fredricksburg Virginia
106 Disability Rights Enforcement, Education, Services; San Rafael California
107 Disabled Citizens Alliance for Independence, Virburnum Missouri
108 Disabled in Action, DIA, of Greater Syracuse New York
109 Disabled in Action, DIA, of Metro New York
110 Disabled in Action, DIA, of Philadelphia Pennsylvania
111 Disabled Resource Services, Fort Collins & Loveland Colorado
112 Disabled Rights Action Center, Salt Lake City Utah
113 The Disabled Womyn's Education Project, Madison Wisconsin
114 East Bay Innovations, Oakland California
115 East Tennessee Technology Access Center, Knoxville Tennessee
116 Easter Seals South Eastern Wisconsin, Milwaukee
117 Employment Resources, Madison Wisconsin
118 Endependence Center, Norfolk Virginia
119 Environmental Illness Association of Hawaii, Waikiki
120 Evert Conner Rights and Resources Center for Independent Living, Iowa City IA
121 Everybody Counts, Merrillville Indiana
122 Families Helping Families, Monroe Louisiana
123 Family Empowerment Council, Inc., Middletown New York
124 Finger Lakes Independence Center, Ithaca New York
125 The Freedom Center, Frederick Maryland
126 Freedom Center for Independent Living, Middletown Delaware
127 Freedom Valley Disability Center, Newton Square Pennsylvania
128 Gaston Residential Services, Inc, Gastonia North Carolina
129 GMSA Management Group, Austin Texas

130 Grandmothers, Aunts, Mothers, Sisters and Supports, Witchita Kansas
131 Great Lakes PAS PAC, Detroit Michigan
132 Greater Austin Texas Paralyzed Veterans Association, Austin Texas
133 Greater Boston Arc, Boston Massachusetts
134 Greater Rochester Spina Bifida Association, Hilton New York
135 Hamilton County Early Intervention Collaborative, Cincinnati Ohio
136 Head Injury Support Group, Hays Kansas
137 Headlines: Brain Injury Support Group, Rockford Illinois
138 Health and Medicine Policy Research Group, Chicago Illinois
139 Houston Area Women's Center, Texas
140 Houston Center for Independent Living, Texas
141 Humbolt Community Access and Resources, Eureka California
142 Huntington West Virginia Grassroots Advocacy Project
143 Hutchinson Resource Center for Independent Living, Kansas
144 Illinois Iowa Center for Independent Living, Rock Island Illinois
145 IMPACT, Alton Illinois
146 Inclusion Daily Express, Spangle Washington
147 The Inclusion Network, Cincinnati, Ohio
148 Independence Inc. Lawrence Kansas
149 Independence Inc Center for Independent Living, Minot North Dakota
150 Independence First, Milwaukee Wisconsin
151 Independence Now, Riverdale Maryland
152 Independence Unlimited, Rocky Hill Connecticut
153 Independent Lifestyles, St Cloud Minnesota
154 Independent Living Center of North Central Ohio, Mansfield Ohio
155 Independent Living Center of North Shore & Cape Ann, Salem Massachusetts
156 Independent Living Resource, Fairfield California
157 Independent Living Resource Center, Albuquerque New Mexico
158 Independent Living Resource Center, Jefferson City Missouri
159 Independent Living Resource Center, San Francisco California
160 Independent Living Resources, Portland Oregon
161 Independent Living Resources, Roswell New Mexico
162 Independent Resources, Inc., Wilmington, Delaware
163 Indianapolis Resource Center for Independent Living, Indiana
164 Innovative Solutions Inc., Louisville Kentucky
165 Interfaith Specialty Services, Philadelphia Pennsylvania
166 Iowans with Disabilities Exercising Advocacy Skills, Iowa City Iowa
167 JAM Specialists, Inc. Cape Cod Massachusetts
168 Jefferson County Association for Retarded Citizens, Mapaville Missouri
169 Justice For All Social Services, New York New York
170 Kalamazoo Handicappers United, Michigan
171 Kenai Peninsula Independent Living Center, Homer Alaska
172 Lakretz Creative Support Services, Copiague New York
173 Law Offices of Mark Partin, Middlefield Connecticut
174 Lawrence County Comm on Disability, New Castle Pennsylvania

175 League for the Blind and Disabled, Fort Wayne Indiana
176 League of Women Voters of Rochester Metro Area, Rochester New York
177 LEAP Center for Independent Living, Lorain County Ohio
178 Lehigh Valley Center for Independent Living, Allentown Pennsylvania
179 Leon Advocacy and Resource Center, Tallahassee Florida
180 Liberty Resources, Inc. Philadelphia Pennsylvania
181 LIFE, Inc. Pocatello Idaho
182 LIFE, Inc. Savannah Georgia
183 LIFE Center for Independent Living, Bloomington Illinois
184 Life and Independence for Today, St. Mary's Pennsylvania
185 LINK Inc., Hays Kansas
186 Living Independence for Everyone of Central Mississippi
187 Living Independence for Everyone of North Mississippi
188 Living Independence for Everyone of South Mississippi
189 Living Independently for Everyone, Farmington Missouri
190 Living Independently for Today and Tomorrow, LIFTT, Billings Montana
191 Long Island Advocacy Center, New Hyde Park New York
192 Lorain County Coalition of Citizens with Disabilities, Lorain County Ohio
193 Lupus Foundation of Philadelphia Pennsylvania
194 Mainstream Supported Living Services, Soquel California
195 Marin Center for Independent Living, San Rafael California
196 Massena Independent Living Center, Massena New York
197 MCIL Resources for Independent Living, Baltimore Maryland
198 Memphis Center for Independent Living, Tennessee
199 Mental Health Association of Rochester & Monroe County, Rochester New York
200 Mental Health Association of Southern Tier, Binghamton New York
201 Metro Justice of Rochester, Rochester New York
202 Metro Seniors in Action, Chicago Illinois
203 Metropolitan Center for Independent Living, St. Paul Minnesota
204 Metrowest Independent Living Center, Framingham Massachusetts
205 Midland Empire Resources for Independent Living, MERIL, St. Joseph Missouri
206 Mid-Ohio Board for an Independent Living Environment, MOBILE, Columbus
207 Montana Independent Living Project, Helena Montana
208 Montgomery County Commission on People with Disabilities, Rockville Maryland
209 Mountain State Centers for Independent Living, Huntington West Virginia
210 Mountain Valley Regional Center, Stockton, Modesto and San Andreas California
211 Multnomah County Disability Services Advisory Council, Portland Oregon
212 Mycare Home Medical Supplies, Niles Illinois
213 National Multiple Sclerosis Society Greater Delaware Valley Chapter
214 New Horizons Independent Living Center, Monroe Louisiana
215 Niagara Frontier Center for Independent Living, Niagara Falls New York

216 North Country Center for Independence, Plattsburgh New York
217 North Country Independent Living, Ashland and Superior Wisconsin
218 North East Pennsylvania Center for Independent Living, Scranton Pennsylvania
219 North Shore Arc, Massachusetts
220 Northeast Independent Living Program, Lawrence Massachusetts
221 Northern Regional Center for Independent Living, Watertown New York
222 Northern West Virginia Center for Independent Living, Morgantown West Virginia
223 Northwestern Independent Living Center for Independent Living, Rock Falls
224 Illinois
225 Office for Persons with Disabilities, Bridgeport Connecticut
226 Options Center for Independent Living, Bourbannais Illinois
227 Options for Independence, Logan Utah
228 Options for Independent Living, Green Bay Wisconsin
229 Panhandle Independent Living Center, Amarillo Texas
230 Parents as Case Managers, Houston Texas
231 Pathways for the Future, Sylva North Carolina
232 Paraquad, Inc. St. Louis Missouri
233 Partnership for Choice, Pittsburgh Pennsylvania
234 People of Livonia Addressing Issues of Diversity, PLAID, Livonia Michigan
235 Personal Assistance Services Program, Mellville New Jersey
236 P-FLAG, Rochester New York
237 Pierce County Department of Human Services, Ellsworth Wisconsin
238 Placer Independence Resource Services, Auburn California
239 Planning for Elders in the Central City, San Francisco California
240 Professional Home Health Services, Hays Kansas
241 Progress Center for Independent Living, Forest Park Illinois
242 Progressive Center for Independent Living, Ewing New Jersey
243 Progressive Independence, Norman Oklahoma
244 Public Interest Law Office of Rochester, New York
245 Queens Independent Living Center, New York
246 RAMP Center for Independent Living, Rockford Illinois
247 Ranch Community Services, Menomonee Wisconsin
248 REACH Resource Centers on Independent Living, Dallas, Ft Worth & Denton TX
249 Red Rock Center for Independence, St. George Utah
250 Resource Center for Accessible Living, Kingston New York
251 Resouce Center for Independent Living, Osage New York
252 Resouce Center for Independent Living, Utica New York
253 Resouces for Independence, Cumberland Maryland
254 Resources for Independent Living, Baton Rouge Louisiana
255 Resources for Independent Living, New Orleans Louisiana
256 Resources for Independent Living, Sacramento California

257 Restructuring for Inclusive School Environments, Memphis Tennessee
258 Rights for Equality and Dignity of the Disabled, Worcester Massachusetts
259 Rochester Center for Independent Living, Rochester New York
260 Rochester Chapter of the National Spinal Cord Injury Association, New York
261 Rockland City Commission on Human Rights, New City New York
262 Rocky Mountain MS Center King Adult Day Enrichment Program, Denver Colorado
263 Rolling Start, San Bernadino, California
264 Ron Mace Center for Disability Community Development, Raleigh North Carolina
265 Rural Advocates for Independent Living, RAIL, Kirksville Missouri
266 San Antonio Independent Living Services, San Antonio Texas
267 San Juan Center for Independence, Aztec New Mexico
268 Saratoga County Options for Independent Living, Saratoga Springs New York
269 Savannah-Chatham County Fair Housing Council, Savannah Georgia
270 Self Help for Hard of Hearing People, Western Kansas Group, Hays Kansas
271 SETLIFE, Beaumont Texas
272 Services for Independent Living, Cleveland Ohio
273 Silicon Valley Independent Living Center, Gilroy California
274 Society for Equal Access, Dover Ohio
275 So-Lo Center for Independent Living, Vallejo California
276 Sources, Fayetteville Arkansas
277 South Central Iowa Center for Independent Living, Oskaloosa Iowa
278 South East Kansas Independent Living, Parson
279 Southern Indiana Center for Independent Living, Bedford Indiana
280 Southern Maryland Center for L.I.F.E.
281 Southern Maryland Independent Living Inc. Mechanicsville Maryland
282 Southern Minnesota Independent Living Enterprises & Services, Mankato, Truman, New Ulm
283 Southern Tier Independence Center, Binghamton New York
284 Southwest Center for Independence, Durango Colorado
285 Southwest Louisiana Independence Center, Lake Charles Louisiana
286 Southwestern Center for Independent Living, Marshall Minnesota
287 Southwestern Independent Living Center, Jamestown New York
288 Soyland Access to Independent Living, Decatur Illinois
289 Spa Area Independent Living Services, Hot Springs Arkansas
290 Spinal Cord Injury Outreach Network, Largo Florida
291 Springfield Center for Independent Living, Springfield Illinois
292 St. Clare Management, Milwaukee Wisconsin
293 St. Francis Catholic Worker Community, Columbia Missouri
294 St. Louis Civil Rights Enforcement Commission, St. Louis Missouri
295 Staten Island Center for Independent Living, Staten Island New York
296 Staten Island Independent Living Association, Staten Island New York

297 Stavros Independent Living Cety Center for Independent Living, Rolla Missouri
298 Tri-County Independent Living Center, Akron Ohio
299 Tri-County Patriots for Independent Living, TRIPIL, Washington Pennsylvania
300 United Cerebral Palsy of Central California, Fresno California
301 United Cerebral Palsy of G, Missouri
302 West Coast Florida Multiple Chemical Sensitivities & Chemical Injury
303 Support Group, Bradenton
304 Westchester Disabled on the Move, Yonkers New York
305 Western Alliance, Asheville North Carolina
306 Western Kansas Association on Concerns of the Disabled, Hays KS

ATTACHMENT 2: ADAPT's Principles for Reforming Long Term Care

ADAPT believes the following principles should be incorporated as minimum standards in any national attendant services program passed by Congress and attendant programs run by the states:

1. Maximum control of the consumer to select, manage and control their attendant services.
2. Attendant services must be community-based, in other words non-institutional.
3. Eligibility based on functional need not medical diagnosis, disability and/or age.
4. Services must be available in-home and other locations.
5. Attendant services must be available 24 hours a day, 7 days a week.
6. Back up and emergency attendant services must be available.
7. Program must allow for co-pay and cost sharing for people with higher incomes.
8. Delivery of service must include vouchers, direct cash payment, individual provider model, as well as consumer directed agency model.
9. Health related tasks can be delegated to or done by unlicensed personal attendants.
10. Voluntary training should be available for consumers.
11. Attendants should receive a livable wage and benefits.
12. Attendant services should be based on an agreed upon individual service plan.

ATTACHMENT 3: Consumer Direction in Long Term Care

ADAPT Definition of Consumer Direction

As it relates to program design for attendant services, consumer direction means the right of the consumer to select, manage and dismiss an attendant.

The consumer has this right regardless of who serves as the employer of record, and whether or not that individual needs assistance directing his or her services.

This includes but not limited to delivery systems that use:

- Vouchers
- Direct cash
- Fiscal intermediaries
- Agencies that allow choice (Agencies with Choice)

Components of Agency-Delivered Consumer Directed Services

1. Maximum control by the consumer to select, manage and dismiss the attendant, regardless of who is the employer of record.
2. Flexibility of services. After number of hours are assessed, the consumer has the responsibility to determine when and how these services are delivered.
3. Services must be community-based, in other words non-institutional.
4. Services are available based on functional and health related needs, regardless of disability and/or age.
5. Services are as non medical as possible and allow for unlicensed people to perform health related tasks through delegation or assignment.
6. Agency can provide a pool of attendants for the consumer to select.
7. System has a back up and emergency requirement that is designed by the consumer and/or the agenc.
8. Services are provided where the consumer needs them (including home, work, school, church or other locations).
9. Services must be available 24 hours a day, 7 days a week.
10. The agency can be the fiscal agent for employment responsibilities, or these responsibilities can be done by the consumer.
11. Voluntary training is available on attendant management and employment responsibilities.
12. Program must allow for co-pay\cost sharing for people with higher incomes.

ATTACHMENT 4: Summary of MiCASSA

MiCASSA provides direct services to the Consumer:

1) MiCASSA provides community-based attendant services and supports including assistance with:
   • activities of daily living (eating, toileting, grooming, dressing, bathing, transferring),
   • instrumental activities of daily living (meal planning and preparation, managing finances, shopping, household chores, communications, participating in the community),
   • health-related functions.
2) MiCASSA includes hands-on assistance, supervision and/or cueing, as well as skills development to learn, keep and enhance skills to accomplish such activities more independently
3) MiCASSA provides community-based attendant services and supports that are:
   - based on functional need, rather than diagnosis or age,
   - provided in home or community settings - school, work, recreation or religious facility,
   - selected, managed and controlled by the consumer of the services,
   - supplemented with backup and emergency attendant services,
   - furnished according to a service plan agreed to by the consumer including voluntary training on selecting, managing and dismissing attendants
4) MiCASSA requires services and supports be provided in the most integrated setting appropriate to the needs of the individual.
5) MiCASSA provides for quality assurance programs which promote consumer control and satisfaction.
6) MiCASSA includes a maintenance of effort requirement so that states cannot diminish more enriched programs already being provided.

MiCASSA offers flexible management, delivery and payment options:

7) MiCASSA allows consumers to choose among various service delivery models including vouchers, direct cash payments, fiscal agents and agency providers. All of these models are required to be consumer controlled.
8) For consumers who are not able to direct their own care independently, MiCASSA allows an "individual's representative" to be authorized by the consumer to assist in managing these services and supports. A representative might be a friend, family member, guardian, or advocate.
9) MiCASSA allows health-related functions or tasks to be assigned to, delegated to, or performed by unlicensed personal attendants in accordance with state laws.
10) MiCASSA also covers individual transition costs from a nursing facility or ICF-MR to a home setting, for example: rent and utility deposits, bedding, basic kitchen supplies and other necessities required for the transition.
11) MiCASSA serves individuals with incomes above the current institutional income limitation if a state chooses to waive this limitation to enhance the potential for employment.

MiCASSA provides financial incentives for states:

12) MiCASSA allows an enhanced Federal match (up to 90% Federal funding) for individuals whose costs exceed 150% of average nursing home costs.
13) Between 2003 and 2007, after which the services become permanent, MiCASSA provides enhanced matches (additional 10% for each category) for states which:
    - begin planning activities for changing their long term care systems, and/or
    - include Community-based Attendant Services and Supports in their Medicaid State Plan.

MiCASSA encourages systems change:

14) MiCASSA provides funding for grants for Systems Change Initiatives to help the states transition from current institutionally dominated service systems to systems more focused on community based services and supports, guided by a Consumer Task Force.
15) MiCASSA calls for national five to ten year demonstration project in five states to enhance coordination of services for non-elderly individuals dually eligible for Medicaid and Medicare.

ATTACHMENT 5: Effectiveness of Rider 37
The Texas Money Follows the Person Policy

While we have not seen Money Follows the Person implemented on a national level, several states have been effective in establishing the policies and infrastructure needed to allow the money to follow their citizens into community living. The efforts in Texas to develop a money follows the person policy led the Texas legislature to pass a budget rider, Rider 37. In a review of Texas's Rider 37 conducted by the Independent Living Research Utilization (ILRU), the ILRU found that:

"There was unanimous agreement among interview participants and the study team that Rider 37 and its implementation were successful for a number of reasons. Five of the major reasons include:

1. Movement of 2,022 people. The greatest success is the fact that 2,022 people of all ages, including some with significant support needs, moved out of nursing facilities from September 1, 2001 through August 31, 2003. As a result, these individuals have much greater opportunities for choice, independence, and community life.

2. Increased awareness. The implementation of Rider 37 has raised awareness within the legislature and among people with disabilities and their families about the possibilities of community living.

3. Learning experience. The collective experience of implementing the transitions from nursing facilities--by people with disabilities, family members, advocates, DHS staff, relocation specialists, and others--promoted the realization that "it really can be done," and generated a deeper understanding about the types and amount of work required to make it happen.

4. Increased collaboration. Efforts to implement Rider 37 promoted new or increased collaboration among various stakeholders, who felt that the collaboration, alone, represented one of the major successes of Rider 37.

5. Cost savings. Participants in the study assumed that Rider 37 resulted in a considerable cost savings. DHS has reported that in State Fiscal Year 2002, the Community Based Alternative (CBA) Waiver served an average of 443 people per month who entered the program via Rider 37. During this time, Texas spent an average of $1188.70 per month for these individuals, compared to an average monthly nursing facility cost per person of $2373.66. In Fiscal Year 2003, Texas served an average of 1513 CBA individuals per month who entered the program using Rider 37 at an average monthly cost of $1256.721, compared to a monthly average Nursing Facility cost of $2375.49."

ATTACHMENT 6: MDS Data on Discharge Potential

MDS Active Resident Information Report: December 31, 2003			
Q1a: Discharge Potential and Overall Status			
Resident Expresses/Indicates Preference to Return to the Community			
State	**No**	**Yes**	**State Total**
Alabama	85.90%	14.10%	22,991
Alaska	74.10%	25.90%	607
Arizona	74.60%	25.40%	12,342
Arkansas	84.30%	15.70%	17,937
California	78.20%	21.80%	103,291
Colorado	79.00%	21.00%	15,806
Connecticut	80.40%	19.60%	27,352
Delaware	79.40%	20.60%	3,821
District of Columbia	82.90%	17.10%	2,747
Florida	76.60%	23.40%	69,943
Georgia	86.00%	14.00%	35,327
Hawaii	85.40%	14.60%	3,682
Idaho	75.00%	25.00%	4,570
Illinois	80.60%	19.40%	77,228
Indiana	82.70%	17.30%	39,659
Iowa	82.80%	17.20%	26,835
Kansas	83.40%	16.60%	20,381
Kentucky	83.20%	16.80%	22,088
Louisiana	89.50%	10.50%	28,087
Maine	79.10%	20.90%	6,698
Maryland	77.90%	22.10%	24,664
Massachusetts	82.10%	17.90%	44,393
Michigan	76.90%	23.10%	41,062
Minnesota	80.80%	19.20%	34,515
Mississippi	90.00%	10.00%	15,598
Missouri	80.10%	19.90%	37,301
Montana	78.60%	21.40%	5,565
Nebraska	81.40%	18.60%	13,057
Nevada	78.00%	22.00%	4,091
New Hampshire	84.20%	15.80%	6,957
New Jersey	80.90%	19.10%	43,190
New Mexico	77.30%	22.70%	6,265
New York	81.80%	18.20%	111,244
North Carolina	82.10%	17.90%	37,451
North Dakota	85.70%	14.30%	6,028
Ohio	78.30%	21.70%	76,541
Oklahoma	84.40%	15.60%	20,684
Oregon	73.30%	26.70%	8,165
Pennsylvania	83.60%	16.40%	77,846
Puerto Rico	44.40%	55.60%	169

Rhode Island	83.20%	16.80%	8,345
South Carolina	83.20%	16.80%	15,981
South Dakota	84.90%	15.10%	6,652
Tennessee	81.00%	19.00%	32,697
Texas	84.50%	15.50%	88,072
U.S. Virgin Islands	70.00%	*	30
Utah	70.00%	30.00%	5,187
Vermont	79.30%	20.70%	3,208
Virginia	78.90%	21.10%	27,444
Washington	74.70%	25.30%	19,410
West Virginia	78.60%	21.40%	10,129
Wisconsin	80.10%	19.90%	35,134
Wyoming	78.00%	22.00%	2,415
NATIONAL TOTAL	81.10%	18.90%	1,410,882

ATTACHMENT 7: Long Term Care Spending by State
Comparison of Institutional and Community Spending

2002 Long Term Care Expenditures by State

	Institutional	%age	Community	Percentage
AL	$753,386,069	77.00%	$225,195,368	23.00%
AK	$87,224,259	43.90%	$111,593,160	56.10%
AZ	$18,767,801	84.00%	$3,573,553	16.00%
AR	$526,198,840	74.70%	$177,904,393	25.30%
CA	$3,406,273,915	64.40%	$1,886,784,547	35.60%
CO	$410,738,443	48.60%	$435,189,857	51.40%
CT	$1,239,787,432	65.40%	$654,910,254	34.60%
DE	$155,632,375	73.00%	$57,640,633	27.00%
DC	$260,487,903	92.40%	$21,365,476	7.60%
FL	$2,186,242,530	74.30%	$755,303,767	25.70%
GA	$946,351,188	74.50%	$323,535,029	25.50%
HI	$177,993,887	73.30%	$64,848,069	26.70%
ID	$177,427,142	64.00%	$99,739,643	36.00%
IL	$2,235,201,332	81.80%	$497,310,644	18.20%
IN	$1,211,606,096	83.70%	$235,584,539	16.30%
IA	$913,059,994	80.90%	$215,312,623	19.10%
KS	$582,425,417	61.00%	$372,021,441	39.00%
KY	$713,041,753	71.60%	$283,188,173	28.40%
LA	$1,686,790,945	90.20%	$184,271,878	9.80%
ME	$246,482,636	56.20%	$192,331,124	43.80%
MD	$816,510,398	71.20%	$330,382,992	28.80%
MA	$1,617,650,360	64.80%	$878,485,328	35.20%
MI	$1,809,960,555	75.70%	$579,520,543	24.30%
MN	$1,101,344,752	51.10%	$1,054,761,777	48.90%
MS	$626,760,332	87.40%	$90,719,371	12.60%
MO	$1,425,612,251	72.90%	$528,821,781	27.10%
MT	$155,403,321	62.70%	$92,535,111	37.30%
NE	$439,202,235	69.60%	$191,556,715	30.40%
NV	$137,823,149	73.40%	$49,870,146	26.60%
NH	$304,374,773	65.40%	$160,759,154	34.60%
NJ	$2,758,913,933	80.10%	$683,492,314	19.90%
NM	$187,765,214	38.20%	$303,558,884	61.80%
NY	$9,077,231,956	62.80%	$5,367,977,066	37.20%
NC	$1,306,504,101	60.60%	$847,721,805	39.40%
ND	$229,159,313	80.60%	$55,236,925	19.40%
OH	$3,431,656,290	83.50%	$677,658,057	16.50%
OK	$562,306,180	63.80%	$319,465,385	36.20%
OR	$207,993,750	27.10%	$560,712,555	72.90%
PA	$4,502,350,838	81.20%	$1,039,509,121	18.80%
RI	$269,302,754	59.30%	$184,484,158	40.70%
SC	$565,146,822	65.40%	$299,228,043	34.60%
SD	$190,167,009	73.20%	$69,487,425	26.80%

TN	$1,197,393,742	84.40%	$220,869,173	15.60%
TX	$2,582,158,096	70.40%	$1,083,152,546	29.60%
UT	$150,602,607	58.20%	$108,312,811	41.80%
VT	$93,814,492	44.20%	$118,341,454	55.80%
VA	$914,526,111	73.10%	$335,704,635	26.90%
WA	$839,356,363	52.70%	$753,493,288	47.30%
WV	$358,783,151	62.10%	$219,017,679	37.90%
WI	$1,544,148,990	70.40%	$649,175,975	29.60%
WY	$65,901,189	49.20%	$68,026,194	50.80%
Total	$57,404,944,984	69.90%	$24,719,642,582	30.10%

ATTACHMENT 7: Long Term Care Spending by State
Comparison of Institutional and Community Spending

June Adams
Denver, Colorado
17 years

I had two little boys when I had a stroke. My husband became my guardian and put me in a nursing home, where I was held captive for 17 years as my children grew up. I was able to get rid of the guardianship and move into my own apartment where I can live.

Judy Anderson
Denver, Colorado
7 years

It was terrible, and they took advantage of me. It is more peaceful in my home.

Nancy Anderson
Denver, Colorado
10 years

I was in the military at age 21. I developed a brain tumor. They put me in a nursing home for 10 years. I sued the nursing home for abuse. I won and bought my own house. I have been free for the last 28 years.

Adren Ward Ange
Norfolk, Viginia

I'm fed up with all the shit at the Transitional Care Hospital where I live. They never let me go out by myself. Can't have loud music. Can't have no privacy. Notice the word "transitional." Under Medicaid's defintion, if you look up the word "transitional", it must say "ten years" or more because I've been here for 14 years and am on the DD Waiver Medicaid wait list until Moby Dick was a minnow. I'd rather be sitting on the beach, watching the beautiful people. I'd rather be living in my own apartment, going fishing, and working.

Anthony

Intro:Anthony

This is a third person account of a man who has repeatedly refused and spat upon the current service options offered to him. His story epitomizes the struggle we have with the concept of personal freedom and choice. Anthony is not a man who many would call honorable. His teasing and joking belies the fact that his circumstances are largely of his own making and he does not accept the consequences of his actions with adult logic. Rather, he flies into a rage, and threatens to "run you over" as he flings hurtful words at the bearer of unfair news. He has little self-control and no interest in developing any. People prefer not to be around him, if only from a sanitation level.

Yet, how we treat Anthony defines who we are. We have an uncomfortable kinship with this man who acts before thinking, who can only see the next moment instead of the larger picture. We don't understand how someone who complains about not being able to take more than one shower a week would choose to live in Pioneer Park, where he may not have a shower for months.

Kay Fox from SLCAP first met Anthony while part of a community effort to secure SSI for homeless and disabled individuals. Since that time, according to Kay, Anthony was in a car accident, which made him a wheelchair user. As Anthony grows weaker from AIDS related problems, his anger isn't so dramatic.

He is happy to see people, but then verbal harassment begins. We can do better. We can treat people with more respect and common courtesy than he was treated. We can be better. Perhaps we can begin by providing services for individuals, not institutions. Why couldn't Anthony have someone help him with personal needs such as personal hygiene and taking medication where he is?

Anthony's quality of life would be better for it. Anthony's search for respect may have been broader had he been able to take a simple shower on his terms. If he were cleaner, more people may have interacted with him. He may have even discovered that respect is a two way street.

Not all news is bleak – the Utah Department of health staff are aware that there are people in nursing homes or on the street who have behavior problems the state doesn't have resources to address. They are applying for funding to study how best to assist this population.

Anthony's Story:
Anthony Wadell has burned more bridges than most people have occasion to build, according to Sheryl Dobson, CHAMP worker. In the two years she has worked with Anthony, virtually every nursing home in the Valley has offered Anthony shelter that he has eventually walked away from. After Anthony has left against medical advice, the nursing homes rarely want him back.

He violates rules at shelters, or at the hotels that offer temporary shelter to people on the street. He is not on good terms with the food pantries, and the Utah AIDS Foundation can only allow him minimal services.

"Anthony is verbally abusive to just about everyone. He has trashed and destroyed furniture and other property in most of the p0laces he has stayed," said Dobson.

The staff and volunteers involved with the "Our Homes, Not Nursing Homes" project at the Disabled Rights Action Committee (DRAC) echoes Dobson's assessment.

"Not many organizations will offer services to Anthony anymore. His behavior jeopardizes their relationship with other service providers and makes it harder to get services for other people." A DRAC volunteer explains.

Dobson, however, recognizes both Anthony's vulnerability and strength. "If he were anyone else, Anthony would have been dead a long time ago, " said Dobson. "I like Anthony, and he likes me because I am straight with him. While he plays up his delusions to others; he and I have real conversations and I find him to be a very personable man."

"The man is incredibly resilient," agreed Jerry Costley, supervisor of the Our Homes, Not Nursing Homes project, "and people seem to respect this trait."

Indeed, in the past, some agencies have gone out of their way to accommodate Anthony because they see this strength of will. Repeatedly over the years, a multi-discipline team consisting of representatives from different organizations has worked with Anthony to provide a service plan to meet his needs, only to have Anthony sabotage the plan. But, can we just turn away?

"Everyone needs somewhere they can go, someplace where they are not stopped at the front door. Ironically, DRAC and CHAMP can do this because as advocacy organizations, we have no services to provide. We don't have living spaces that can be trashed, counselors with egos to bruise or food to complain about," said Dobson.

DRAC works on long-term goals for equal access, while advocacy is invaluable to the disability community, when your clothes are deteriorating under layers of filth, the last time you ate was the day before last and you are battling AIDS related pneumonia, political advocacy on your behalf seems a little too abstract.

Looking through the case files at DRAC, Lori Brock realized that DRAC also spends a lot of time trying to repair burned bridges between service providers and Anthony.

"People at DRAC take the time to listen and because we do not provide expensive services that may be trashed and mutilated, we are able to listen without bias, I realized."

Sometimes advocating for Anthony means getting him not to reject the few services being offered.

"It is so ironic to be part of an organization that tries so hard to find community options for people in nursing homes to actually encourage someone to stay in a nursing home!" Brock laughs ash she remembers how DRAC members tried to find Anthony temporary housing in a nursing home so he could be out of the cold and confusion during the Olympics.

At first, DRAC's willingness to look at nursing homes as an even a temporary option seems to go against the philosophy of the Our Homes Not Nursing Homes Project, but as Costley explains, "Although we believe vehemently in necessity of providing services to people in community settings rather than in isolated and segregated settings like nursing homes; we also believe that people need to be informed of all the current options available."

Anthony, however, doesn't wait for any options. When the restrictions and regulations of a shelter or nursing home program anger and frustrate him; he leaves.

When the weather is warm Anthony's home is Pioneer Part. "He knows where he can get the things he needs and wants," said Crock, who first met Anthony when he grudgingly accepted nursing home services during the Olympics.

"He has people who will provide him with his favorite soda, other people who replace his clothes periodically and still other people who will replace a stolen sleeping bag from time to time. Every time I see him, he looks thinner and sicker than the last time I saw him," said Brock.

"The Our Homes, Not Nursing Homes Project at DRAC is all about people making their own choices and having power over their own lives. Anthony is actually a teacher. He teaches us that people's choices may not be the ones we want or wish for them but their own choices make them uniquely who they are. Whether Anthony is sheltered from the cold in a nursing home or homeless in Pioneer Park, he is in charge. And he wouldn't want it any other way," said Costley.

Jeff Arrison
Corning, New York

His "way of life" was progressing. Jeff Arrison was born September 24, 1959. H went through high school, land was preparing for college when he had a single car accident in 1980. This resulted in him becoming a quadriplegic. From age 20 onward Jeff would pretty much be in Medicaid institutions.

He had been planning the arrest of his life of completing his education, a job, marriage, and children. Medicaid institutionalization would end this plan. Although he made over one dozen serious attempts he never was able to "break free" from Medicaid's grip. Even

when his counselor said to him "we will get you out of that nursing home", he remained there.

Jeff did know for positive that he was capable of managing an apartment because for a while he had an apartment of his own from 1981-1984. Due to the fact that Social Security and Medicaid and the state of Massachusetts did not live up to their word about available community services, he returned to institutionalization and was never able to 'escape" again.

Right now Jeff is institutionalized in Founder's Pavilion Nursing Home, a very inappropriate place for him, but the only place available in his hometown of Corning, N. Y. He "rots" there with little hope of returning to society.

His day begins at approximately 10:30 (he says any nursing home is pleasant when you are asleep, so he tries to sleep as much as possible.) After getting morning "hygiene" he exists by having lunch (he worked in kitchens before his accident so he knows what kitchens are capable of, this kitchen doesn't even try). Adequate nutrition is maintained by "junk food". After lunch he gets through the afternoon by watching boring television, napping, etc. Keeping him appropriately entertained would be impossible if it were not for his relations pooling their efforts and purchasing him a computer to keep him busy (when he asked the state to help him finance the computer they said "No"). Then another meal of inadequate dinner is served. Followed by doing the days business (like correspondence) and more television. This is followed by his evening 'hygiene" at approximately 10:30. Then at approximately 1:30 A.M. he goes back to sleep.

He has had to endure such things as broken and dislocated bones, inadequate doctors care, physical "forcing," unpleasant social care, medications that is prescribed or requested being often more than one-hour late without immediate correction. After many years of non action about "problems" he has come to the conclusion that Medicaid institutions "just don't care."

Michael Barczak
Jackson, Mississippi
5 ½ years

For several months during the mid seventies there was some talk about me leaving my parents home. After some lengthy discussions I thought the talk had subsided. One day I was sitting eating lunch and to my complete surprise this strange woman walked into the house. My mother proceeded to tell her that I could no longer live with them because of illness in the family. I knew my parents had been ill but I had no idea things were that bad.

This strange woman began looking for a place for me to live. I told her about a care home that I had heard about. She contacted them and they had a bed open so I moved in

with them. I didn't know anything about the system. It was a hard time for me. I pretty much went along with whatever the powers that be told to me. To my knowledge there wasn't any handbook and if there was I didn't have access to it. Things went reasonably well for the first three or four months, but when my father stopped making regular visits things changed considerably. In general, the staff started to treat me like a five year old and this was unacceptable to me as a young man in my mid-thirties. The staff had very little understanding that as a person with Cerebral Palsy it often takes long to complete tasks and they began to complain.

I received an eviction notice and my search for a new home began again. A social worker that was put in charge of my case didn't like me because I would often speak my mind. I've always been a natural problem solver and I often had my own connections and would attempt to solve my own problems. This was an alien concept that someone could actually advocate for themselves and control their own destiny after a short unsuccessful search the social worker and the owner of my current home recommended that I be placed in a nursing home.

Being in a nursing home was a completely different experience. The atmosphere was dark and filled with hopelessness. I tried to make friends with the other residents but when the mindset of your potential friends dwells on dying it is a hard thing to accomplish. Most of the real relationships I had were with the staff members. One of the only positive activities that helped me to maintain my sanity was that I was able to go town a couple of times a month. After four and a half years of that there was an annual state inspection at the facility I was housed in conducted by the health department. To my complete surprise they told me I couldn't stay there any longer because I did too many things for myself. This was my beginning in the Independent Living Movement. In the beginning my shocked. Parents tried to block my becoming independent. They even went as far as to threaten legal action against the nursing home. In the end they couldn't stop my drive to become independent.

The caseworker I had told everyone at that time I wouldn't make it on my own. Well my friends that statement was made some fourteen years ago and I'm still living independently in my own apartment. Independent Living is a challenge, a series of problem solving steps that with some work can be done. My message is that people with disabilities need to be prepared for Independent Living as early as possible. Much earlier than myself the earlier people get started the more opportunity they will have to meet their goals.

Paula Barton
Rochester, New York

My name is Paula Barton. I am a 28 year old, disabled female. After going to emergency with chest pain, I was sent to a nursing home. They told me I could not return to my apartment because I could not get any Nurses Aide service to get me in and out of bed. I was there for four months.

During my stay in the nursing home, the experience was not good. Here are some of the reasons why. The hospital was not geared for a young person. I could not move freely and I had to be signed out by a person who was not in a nursing home. I had no independence.

I did have one good experience. The social worker was a young woman. She understood what I was going through. She started a month after I arrived there. Together we found an agency that would give me aide service. I am now home after 4 months. I have 20 hours of aide service and I'm doing very, very well.

Barrie Berliner
Gloversville, New York
1 Year

I, Barrie Berliner, was in a nursing home because I fell off a balcony and the nursing home was not a place for me to spend the rest of my life. With financial supports funded by the Department of Health, I moved into a house with a few housemates where the care is great. I have my own room with my own things, help to cook my own meals and I have all my workout equipment in the living room and it is basically my own home.

At the nursing home, I had room assigned to me and there were elderly people there and it was very regimented. Being a spontaneous person, I couldn't go out with my friends. It was very strict, there were strict rules and I hated it there. I felt almost dead. It was because of the Physical Therapy at Lexington, I can walk by myself and before, I couldn't walk by myself, I couldn't transfer. I needed a lot of help. Now I need no help. I am so independent. I couldn't even take a shower before. Now, I can take a shower by myself and I can take a shower everyday. Lexington Center has done wonders for me. They've done so much. There is personal help. Instead of being fed, they taught me how to feed myself, which in the long run, made me feel great. Nobody wants to be fed for the rest of their life. Independence is great.

I am a true testimony of what not living in a nursing home can do for you. Do they want to be waited on or do they want a free independent life? A choice of freedom. This is America.

I am also available as a public speaker to support this, because I have such strong feelings toward this.

Joe Bonomo
Rochester, New York

Christmas time is always one of my favorite times of the year. It's when people spend time with their families, friends and loved ones. It is also the time I'm reminded of how wonderful my life is; it's when I became a free man.

I was born with a disability, Osteogenesis Imperfecta (OI), brittle bone disease. Shortly after I was born, I was imprisoned at the Newark State School, where I was incorrectly diagnosed with being mentally retarded as well as having OI.

This institution was hardly a school at all; it was a horrible place, a place where I was mentally, physically and sexually abused for fifteen years of my life. I was never offered anything that would resemble a class in Mathematics, English or Reading. Instead, everything I learned I picked up from watching television. Staff would sedate me with drugs and then I would be forced to sit in a room covered in urine and feces by the other unattended people who were imprisoned with me and left to watch television.

When I was fifteen I was reevaluated. The institution's doctor was shocked to learn that I could tell time. He realized that in fact I was not mentally retarded I was incorrectly diagnosed. He befriended me and encouraged me to enter the Helen Hayes Rehab Hospital.

It was at the Rehab Hospital that I was able to take classes and start to assemble something which reflected a "normal" life. In two years I was able to complete all the required course work for grades 1 through 8. It was here that I realized that my life was nothing like I wanted it to be.

At the age of eighteen I was forced to leave Helen Hayes Rehab Hospital because I was too old to receive services there. I was then transferred to Monroe Community Hospital. I was in an institution once again and one thing remained the same - I still felt like a prisoner. I was again put on drugs, sedated and attended by nurses and doctors that didn't seem to care about me or anyone else there.

After four months of intolerable living conditions I decided that I wanted to be *needed.* I wanted to be *free*. Through the help of a staff member, whose daughter I befriended in the hospital, we escaped late on Christmas Eve, 1977.

I moved into my first apartment with my friend with whom I escaped. We supported ourselves by using the money that was to be spent on us in the institution. When we informed the state that we had moved, no one checked to see where we moved, they just changed the address on our checks. **I was free!**

Over the next few years, I attended Jefferson High School, graduated, moved into my own apartment, and with the help and guidance of a counselor at VESID, I enrolled in BOCES and learned the skills needed to work in electronics.
In 1982 I was offered a job with Kodak and met my wife Debbie who has Cerebral Palsy. Today, we live in a home we own and everyday we continue the fight to keep our freedom. In February of 2002, I suffered three strokes which diminished my physical

abilities, but not my intelligence or desire for freedom. Several doctors said I should go back to the nursing homes, but I refused. With the help of my family, friends and aides paid for through Medicaid's personal care option, I returned home from the hospital just before Christmas of 2002. Almost exactly 25 years after first escaping to freedom I had again fought for and won my freedom.

According to Minimum Data Set numbers, collected by New York's Department of Health, nearly 20,000 of New York's nursing home residents would rather live in the community. Though the only crime they have committed is having a disability, these people are prisoners. Every time I hear about someone imprisoned in a nursing home I feel nothing but pity for him or her because I have lived that life, and I know how much better life is in the community. I can't fathom anyone wanting to live in a nursing home or any institution.

In the November 23rd New York Times magazine, Harriet Johnson wrote "In the gulag (institutions) you have no power. The gulag swallows your money, separates you from your friends, makes you fearful, robs you of your capacity to say-or even know-what you want." I couldn't agree with this more. More recently, the New York times reported that according to NYSDOH, the percentage of nursing home residents who are under the age of 65 is climbing! Now, 12.5 % of nursing home residents are under the age of 65.

There are options that could help these many young people and seniors with disabilities live in the community like me. In Congress right now, there is a bill, the Medicaid Community-based Attendant Services And Supports Act of 2003, also known as MiCASSA. MiCASSA would shift the bias of funding away from nursing homes and into community support services. Money that is spent on institutions would be redirected to individuals and allow them to make the choice to live their lives in their own homes. MiCASSA would help people escape from nursing homes and institution and give them the choice, the freedom, to live just like the rest of us.

So this Christmas, I will celebrate with my family, friends, and loved ones, not only a holiday, but the anniversary of my freedom. I can truly say that it's a wonderful life. With MiCASSA, many thousands of New Yorkers will have this same opportunity.

Marie Brawn
Eastern, Kentucky
20 Years

I was born in Eastern Kentucky in 1953. I have Cerebral Palsy. It affects my limbs and speech. I was institutionalized from age 2 until 27. I will tell you of things that happened to me during this time. I was drugged so I wouldn't talk about what I heard or saw. I saw physical abuse. People were being hit. I went to school wearing dirty clothes. I had to wait a long time for help to the bathroom. I had very little privacy, even when talking on the phone or to my priest.

Some of the aides would make fun of me.

Things are now changed for me. I have been out for 23 years because my second husband got me out after a big fight. He died in 1994 from a heart attack. Then with the assistance of personal attendants, I learned to live on my own. I have a part time job working for the Salvation Army collecting money. I have a pet cat named Shadow. As a child in an institution, I could never have a pet.

I hope that Congress will pass MICASSA. I know a lot of people in institutions who Want and need to get out. It would cost the government less to keep us in the community. I am glad to be out and to have more freedom. I can be my own boss.

Kurt Breslaw
Boulder, Colorado
15 Years

You don't live in a nursing home; you only exist in a nursing home. I love living in my own house. I get better care in my own home then I ever did in the nursing home.

Brian
Utah

Introduction: Brian
If Brian's family had received community support services such as respite care and home health assistance, it is possible that Brian never would have gone to a nursing home. Furthermore, since Brian was already deeply rooted in his family and community, it is more than likely that with only a little instruction on the need for structure Brian would have gone on to be a very productive and influential person within that microcosm of society. As it was, Brian spent years of his life waiting for the next meal, the possibility of a recreational activity, or bedtime.

Brian watches as others were able to access specific waivers to get the funding they needed to move out of the nursing homes. Brian followed suit but was continually frustrated in his efforts to move out into the community, because he didn't meet the specific requirements of the existing waivers.

Finally out of the nursing home and receiving services from Flexcare (a pilot program that accesses funding for people who don't fit into any of the waiver programs) Brian has moved into an assisted living program. He reports that he is happier and more energetic. He is also looking for volunteer opportunities that will let him contribute to the community.

Brian's Story

I want to tell my story because I want others to know how frustrating it is to want to be a part of the community when you live in a segregated setting such as a nursing home.

When I was nine years old I was diagnosed with an inoperative brain tumor and while it didn't kill me, both the tumor and the exploratory surgery I underwent at that time caused some brain damage. My father died when I was ten and it was a difficult time for my family. One of my early experiences living in a nursing home happened when my brother and his wife could not longer take care of me. My legs were swollen and so big that I couldn't move around.

That first night, I felt totally devastated because I couldn't live with my family anymore. I felt useless like there wasn't anything I could do for them and I felt like it was my fault. Instead of being with my family all the time and being part of its on going story, when I was in the nursing home I saw most of my family only on occasion. This made me very lonely.

This first experience happened over twenty years and it was really the only option for me and my family at the time. Now we could have thought about community services such as personal assistance and respite care—provided we could access the funding for these services. The availability of services could have allowed me to participate in family and community life and get the care I needed at the same time. (And these services would have cost much less than living in a nursing home.)

I've been out in the community living on my own several times but I always had to go back because without the services I needed to help me maintain a structure, I tended to gain a lock of weight and my skin would break down. That meant that I couldn't move around very much, which would cause my skin to break down even more. Every time I went back to the nursing home, I tasted failure. It was like I had my chance but now I was back to square one. I blamed myself. I didn't want to be in the nursing home but I couldn't get the specific services I needed to be successful on my own. Now I realize that services (similar to what I now receive in the assisted living program that I now participate in) including: cooking instruction, personal assistance, accessible housing and transportation, would have opened so many doors. I could have found (and gone to) work—even volunteer work would have kept me interested and connected to the community. I could have also been more involved with my church. I could have given more to the community. So often I felt like all I could do was take but with the right services, I could have given more.

Now I want to help make sure services like: scheduling and planning assistance, transportation, physical therapy, and diet and medication reminders are not only available to me but to the younger people who want to both live in and give to the community.

The nursing home alleviated the problems that my family and friends had taking care of me. But in the nursing home, I very often didn't have control over what I did or when I did it. I had to schedule a shower and was lucky if I could have one three times a week. Now, in the assisted living program, I take my own showers everyday if I want to. In the

nursing home, I had a limited choice in what I ate. In assisted living, I have my own refrigerator and microwave in my room, so if I don't like what they are serving, then I can have my own food. I guess the most important thing that is happening now that I'm not in a nursing home is the availability of natural opportunities I have developed and practice more skills on my own. In the nursing home, there is an encouraged and forced dependence.

A typical day in the nursing home began when I woke up at 6:00 am. I got ready for the day and went downstairs to the dining room. There were usually two, sometimes three others down there and we would play cards until breakfast time. We waiting, breakfast would come, and we would have our breakfast.

After breakfast, I went to my room. That was about 9:00 am. A lot of the time I sat and watched TV. I waited to see if there would be an activity to go to. Sometimes the staff would run bingo or something. If that was the case, I would go the activity, and then come back and sit around.

At 10:30 am, there would be a coffee break, but I don't drink coffee, so I would have hot chocolate. Sometimes immediately following the coffee break, there would be another activity, which I usually went to. Then it was time for lunch. I would go down to lunch early to play cards again. We ate lunch and I went upstairs and I just sat around because there wouldn't be anything to do. Sometimes I took a nap. Around mid-afternoon, they might have some kind of activity.

Once in a while, they would have some kind of entertainment after dinner but not very often. After dinner, we just went to out rooms and waited until it was time to go to bed.

People normally have at least one roommate in a nursing home. Sharing a room with someone was intrusive because of a lot of things. I had to take into consideration things like having the TV on, or the radio, or the light on. Even how late I stayed up or when I went to bed depended on a shared understanding with my roommate. I had many arguments with my roommate because I might not agree with him on something. It's worse if you have separate TV's because one is watching one and one watching another. I had to keep my TV loud enough to hear it and quiet enough for my roommate. To top it off, my roommate was in the bathroom constantly! I had to watch and take advantage of the times he would vacate the throne in order to relieve myself!

I did meet a dear friend in the nursing home and I missed seeing her everyday. I think the world of her. The main reason I think so highly of her is that she is one who will stand her own ground for herself. She will say what she feels and ever since I have met her I have really, really looked up to her for that. I didn't used to be that way. My mother even likes her. My friend always tells me to make sure that I tell my mother I love her. This friend has and will always have a very, very special spot in my heart. My relationship with her is one of the very few positive things about my experience the nursing home where I lived.

Now that I am in an assisted living place I feel happier now because the environment feels happier to me. Family members who come to visit say they notice a difference. They all say, "This is so much better than the nursing home." There is more energy in the air and more of an assumption that you will find things to do, even though there are not as many planned activities. The staff assumes that you have interests and hobbies of your won that you will pursue.

My room feels more like an apartment. It is my own room. I don't share it with anyone, unless I invite someone to be there. I have my own shower, refrigerator, microwave and I could have a pet if I wanted to.

I think almost everyone would want to live as independently as possible but the funding is not set up make it easy to get services in the community. In order to get the money that was used to pay the nursing home to pay for the assisted living place I am in now, I needed to fit into a category so I could qualify for a waiver that would channel my funding. The trouble was that I didn't fit. The Personal Assistance Waiver requires that you have the loss of function in at least two legs needed to perform daily living activities. With me, sometimes this is true but sometimes it's not. (Sometimes I walk quite well but a lot of the time I really can't.) The Traumatic Brain Injury Waiver requires that the brain injury be traumatic and caused by some sort of accident. My brain injury wasn't caused by a traumatic event so I don't qualify for the TBI Waiver. I do get funding from Flexcare, a pilot program that helps people who are hard to fit into other waiver programs transfer funds from nursing homes to community based services. But there are so many people who could live successfully in the community and do it a lot cheaper than they would in a nursing home and not enough programs like Flexcare to help transfer the funds. Right now, people are entitled to nursing home care and not community services. This is what needs to change. It needs to change because not only is it cheaper to provide services in the community, but it lets people be part of the community, but it lets people be part of the community. I not only receive services in the community, but it lets people be part of the community. I not only receive services in the community but I shop, attend church and I am thinking about volunteering for a youth organizatrion. And this makes me a contributor as well as a consumer. And isn't
That what the community needs.

James Burke
Erie, Pennsylvania
1 Year

I was brain injured in 1993 and then spent the worst year of my entire life at Anchor Inane in Erie Pa. From May of 96 to May of 97. I witnessed and had atrocities done to myself by staff. Now I thankfully live on my own. How short is a short summary because I have a lot to say. The owner Sherry hill has a lot of friends in high places and my three page complaint sent throughout law offices and state agencies went unanswered.

Donna Caudill

Thank heaven I didn't have to stay too long in a Nursing home. It was a big waiting game. If they didn't come on time when you called, they didn't mind fussing at you when you had an accident. If it was treatment day, in my case, the treatment was to keep down the odor when they did not come in time to take me to the bathroom.

I thought I'd better myself by going to a state institution, developmental disability home. However, I didn't. The things they showed me and promised me were a joke. They said I'd receive occupational and physical therapy. I didn't. Thank God I'm out and in my own home.

Thanks to supported living, I'm out on my own. I can tell people what I want them to do for me. I can go out every day if I choose.

Would you please support MICASSA so other people can do what I am already doing.

Maureen Charley
Gallup, New Mexico
9 Years

Maureen Charley moved off the Navajo Reservation into a group home in Gallup in 1985. She lived in the group home until it closed in 1994. She then moved into her own Apartment.

The past 10 years she has been working at The Thunderbird jewelry Supply Store in Gallup. She lives with her boyfriend and her baby boy.

Barbara Coppens
Cherry Hill, New Jersey
15 years

I lived at Vineland State School for 15 years. I went there when I was five years old. When I was a teenager they let me go to public high school so I got my high school diploma. When I was 20 years old I was moved to a group home. I knew that I wanted to live in my own place. I have a real job, learn new things, and can be on my own. So I learned everything at the group home. I found a job as a janitor on my own, and then moved into my first apartment with my friend Josephine.

Josephine and I just moved into a brand new apartment. I am no longer a client. I travel all over the state by public transit working for self-advocacy. I have a state job helping people with developmental disabilities understand their health insurance rights. I keep busy serving on boards, committees. Life changed for the better the day I walked out of

the institution. I had a dream. I am living my dream come true. I like to tell people to have a dream and believe in your self, matter what.

Kit Cromwell
Ann Arbor, MI

I was in a nursing home for seven months. I was treated with extreme cruelty. I was told, more than once, that I would have to choose between lunch or dinner, they didn't have time to feed me both. They rarely washed me. I was sexually abused by the physical therapist. One night my ventilator came loose and the respiratory therapist stood there with her arms crossed in front of her and asked "So, do you want me to hook you back up?" By the time I was transferred to a hospital , I was like a wild animal. They had to sedate me. I had become so accustomed to fighting for any scrap I got. I was treated with valium for quite a while.

While nursing homes instill powerlessness living independently germinates empowerment. Living on your own and having the freedom to hire and fire is liberating. Now, is my life always easy-no. There are tremendous challenges in living on my own. But I wouldn't give up on it for anything.

It's been ten years since my stay in the nursing home and I have come a long way. Family Independent Agency pays for my care attendants now. I work as a disability advocate for the Center for Independent Living and the Alliance for the Mentally, Ill. I have good friends, a handsome and supportive finance and three cats! I am a happy and productive member of society.

We need supportive independent living options-not nursing homes!

Robert Cutler
Arlington, Massachusetts

I am going to say enough with institutions. There is not one illness or deformity which should be given as an excuse to be discarded away from society.

I, Robert Cutler, am 46 years old. I am autistic. My life has been hell because nobody truly understands autism. I live a life hunting to survive. I enjoy the opportunity to choose who helps me. This was not always the case.

I lived for five years at the Fernald State School. I call it in the Fernald Penitentiary. I felt like a criminal the first day I was in Fernald. My crime was no one really understood autism, allergies and sadness in my heart.

Fernald was worse than prison. The food was garbage. My daily life was military like. I lost the right to be human when I entered Fernald. It was a horrible experience. I was beaten.

Suicide was a thought I had while in Fernald. I was asked to act like a seal, being fed food to do nonsense jobs because I was different. If I was good, I was given food. If I was bad, I was restrained. I was beaten, locked in dark rooms. Not because I was bad but because no one took the time to understand me. The screams through my stay were screams for freedom. A staff person loved to beat and hurt me almost every night and no one hear my screams. I hated this but I had no voice.

They tried to destroy my will but I hung onto my sanity. But I still have nightmares and they are even worse than the flashbacks. I live a life hunting to survive. A survivor is a person who even though he was physically and mentally beaten, refused to give up the hope that someday I would be free. Yes, I am a survivor.

I want to type about the freedoms I now have but didn't have at Fernald. I have the right to vote. I have the right to walk when I want to, not when they want me to. I can choose to have a sick day, a vacation wherever I want to go. I don't need staff staring at me while I use the bathroom.

I feel there needs to be more money vested in people who suffer from PTSD because of being sent to institutions because they were different and society wanted not to help us but to hide us.

Why do states take away our rights to determine our life's pathways when they put us away in institutions instead of homes? I think this is wrong! We need services in the public eye, instead of hiding us away from society.

Too long have many suffered away from the community. No amount of money can recreate a community on institutional grounds. I find it offensive when I hear of MIA/POW flags at institutions. Don't they realize that those people in institutions are held captive and can't roam communities like American citizens do. Is our nation creating institutions to discard us as waste, garbage, or is this country willing to admit they made a mistake?

Freedom will prevail.

Dan
Logan, Utah

Introduction:
"When I first met Dan in the spring of 2000" said Kay Fox "it was at a living wage coalition meeting. I mentioned a new project that Salt Lake Community Action Program and DRAC were co-sponsoring to assist nursing home occupants to live in the community. I couldn't have been more surprised when after the meeting Dan said he had

lived in a nursing home, but had escaped. What first stood out as I listened to his story of survival was that no one ever talked to Dan about any services and options to live in the community. As a result, when he left the nursing home he had open wounds in his side. Dan risked infection and death by leaving. Later when I talked to my colleague, Jerry Costley, about the risk Dan took when he left the nursing home against doctor's advice, Jerry said that Dan exemplifies "how life in an institution can be so restrictive and degrading that the only alternative he had was his van." He had no money, no home, but in his flight from the oppression and segregation he experienced, Dan found dignity and self respect."

Dan has been one of the Our Homes project's most active volunteers. As a peer advocate, Dan is a role model of independent living. If a nursing home occupant complains about the amount of paperwork necessary to apply for housing subsidies, utility assistance, food stamps and housing applications, Dan can laugh and explain that its better than living in a van. In addition to the Our Homes project, Dan has volunteered to work for change in Medicaid policies and funds.

He has participated in protests and marches, press conferences, policy meetings and at the Utah Legislature on issues that impact health and quality of life. He works to assure that others at risk of or who are in nursing homes are told of their rights and the resources available. For those of us who Dan volunteers with, this self-described "troublemaker's" mischievous smile makes a hard issue more fun.

Dan's Story:
I was born in Logan, Utah and graduated from Utah State University in 1972. After graduation, I migrated to northern California where I started a custodial service business. In 1996, I moved to Wyoming. On the way, I visited my sister in Salt Lake City. I became ill while there and my sister took me to the emergency room. I had bleeding ulcers and went into a coma from the loss of blood. The doctors performed a radical surgery, removing one third of my stomach and four inches of intestines and bowel.

Amazingly, after the surgery, I felt fine. But because I had no insurance, they tried to rush my recovery and gave me solid food before I should have been eating it. I had massive hemorrhaging. My kidneys and liver were also failing. I became delirious and I thought I was being kidnapped and tortured. I was sent to the University of Utah Trauma Center and from there to a nursing home.

I stayed at the nursing home for a year. At first, I was very weak. I curled in a fetal position and slept and slept. They thought I was going to die but I slowly gained strength and decided to live. I became more and more aware of what was going on in the nursing home.

The treatment at that nursing home was dehumanizing. Nursing home administrators wanted everyone to be docile. They frowned upon individuality. People were herded

like cattle. They didn't treat my needs or wishes seriously. When I asked for information, I was branded a troublemaker. So, I accepted that role.

There was a lot of theft in the nursing home. A contributing factor of this theft may have been that the people who worked there were at the bottom of the labor market and not paid enough. People who value their jobs would not steal. When I reported theft from my closet, I asked for a lock. I was told that to get a lock I had to submit a work order and go through the procedure. I did. Still, I did not get the lock. This was part of the established communication pattern: I asked, they said go through the proper channels, I would, they ignored me.

Diet restrictions likewise were ignored. Diet was very important for me because of my medical history, surgery and the liver damage. I was not supposed to eat those things they served. But, everyone was fed the same thing. I talked to the nutritionist and administrators. They would not make changes. Fortunately, I had some money, so I started to go out and eat nutritious meals. But that made me a troublemaker and I could not afford to go out and eat every time.

As soon as I could, I started walking. There was no rehabilitation for me at the facility. Because I had hepatitis C, they said that I was dangerous and they could not provide rehabilitation. I used to be athletic when I was young, so I knew what I should do. I did my rehabilitation myself.

Medication was another problem. I talked with my doctor at the University Hospital and he told me not to take some of the medication that they wanted me to take at the nursing home. So, troublemaker that I am, I didn't take them. They put on my record that I was non-compliant.

One of those medications was a depression medicine. I watched what happened to other people who took the medication. Every morning, they'd go down and stand in a line to take medication. By the time breakfast was over, the drug kicked in. It took their spirit away and they became automatons. Everyone was depressed there. In that situation, being depressed was normal.

Life is an expression of identify. You need to express your individuality, make independent choices about your life, be creative. If you take that away, you might as well be dead. I watched people come in the nursing home fine. But they deteriorated rapidly. In three months, they didn't know who they were. They were dead in a year. Being treated like a none-person will erode you.

Another thing that infuriated me was that they were making a profit on the residents. Once, a guy's feet became purple. So two aides and I tried to get socks to protect his feet. We worked hard but it took two weeks to get a pair of socks. It was a for-profit agency. It made me angry that the owner made a profit and could not afford a pair of socks immediately for a patient.

I saw feces on the floor one night. In the morning the feces were still there. They left it all night. The nursing home makes money, but cannot afford to have a night cleaner. An attendant was joking that he had to put on rubber boots to come to work. I said that I hoped they lived long enough land got sick enough to experience this. Residents were injured because the staff was not trained well enough to assist them. I don't think those incidents were ever reported.

Residents had to stand in line for everything. We had to stand in line to get permission to go for a walk. By the time we got it, we were tired and our time was up anyway. So I left and went for a walk. I needed to go out and see flowers, go to the park, and meditate. I was trying to live. Of course, I got a non-compliance recorded for that.

At first, the staff chased me when I went across the street to get a cup of coffee. Eventually they gave up and marked me as non-compliant. They tried to force me into the role of docile patient, but I wasn't playing.

While I was there, the nursing home got a new CDO. Her goal was to have 100% occupancy rate, and tighter control of the residents. By that time, I had a refrigerator in my room for my special diet. She took the privilege away from me. I already felt that my self-respect was deteriorating by staying in the nursing home. And I knew that with the new management, it would only get worse.

"I won't let you kill me" I told them. I had my van, so I put in as much as I could carry. An aide even helped me load things. They understood that they could not stop me. They made me sign a paper and I left.

I had no place to live, so I lived in the van. It was hard. But it made me stronger, more able. At that time, I still had a hole in the side of my body and it was draining. But I could not take more dehumanization and de-self-actualization in that nursing home. I studied herbs and took care of myself.

After awhile, I got involved in the National Health Insurance Campaign and Living Wage Campaign. I met members of the Disabled Rights Action Committee and I got involved with their activities too. I purchased a property in Northern California and left Salt Lake. I dreamed of living with nature, independently, growing my own vegetables. But I also realized that I wanted to do more with my life than just live in a beautiful place. So I came back.

Since I got back, things have been working better. I got a place here that is better than I ever dreamed I'd find. It's close to Salt Lake. I can even have animals. I have a goat and chickens. I have the best of both worlds, living in a city and the country.

I believe that people were born to fulfill the purpose of universe, becoming who we are. I feel more and more that my life has purpose and meaning. My involvement with DRAC is a part of the process of becoming. I am living a far more rewarding and fulfilling life.

I am happy the way things are for me right now. I will never stop working to reform this system.

Adelaide Daskam
Elizabeth, New York
5 Years

When I was a teenager I was taken from my family and put in Totowa State School for Girls, now called North Jersey Developmental Center. I have three brothers and two sisters and my mother was sick. They said I was retarded so they put me away. I was badly treated, beat up by the staff, and other girls. They accused and punished me for things I didn't do. I was there for five years.

I say that getting out and living in the community is 100% good. I have made friends. I am happy to be free. I learned to be independent. I got to take care of my mom when she was sick and dying. Last year I went to my family reunion. It was great. I became a self-advocate to help others. I help other people get out of institutions. I tell them they will do new things, make new friends and have more control over their lives out where it is free. I am happy. I have my apartment. I have my job. I have my cat. I have my boyfriend.

If I could talk to President Bush I would say to him~ "Free my brothers and sisters."

Sheila Dean
Denver, Colorado
2 Years

I was 28 years old in a nursing home, and had a seven year old son. I got out when I was 30, and I wouldn't trade my freedom for anything!

Darrin Decker
Murfreesboro, Tennessee
4 Years

My name is Darrin Decker. I live in a nursing home to get the services I require because I cannot get the services that I need outside of the nursing home. I need these services because I have had cerebral palsy since birth. I have to have help to ear and bathe and toilet. I am around older people all day long. And it is not much of a life for a 36 year old man. And to get out of this nursing home they want me to be declared mentally retarded. I am not mentally retarded. There is only money for in home services for certain types of disabilities in the State of Tennessee. I lived at home until I was 32 years old. I lived with different family members and they cared for me. I felt like a burden on my family because they were having to do everything for me. So I wound up in the

nursing home. It was my only option. I have been there four years and it is really hard to be in that type of situation. I hope to one day very soon to be able to get out of a nursing home and have a normal life. I would like to work, be able to come and go as I want to, and have a real life.

Jay Dickens
Gallup, New Mexico
43 Years

Jay Dickens lived in Gallup with his family until he was court ordered into a state institution for the mentally retarded at the age of 11. He lived in two different state institutions for a total of 29 years. Then moved back to Gallup and into group homes for the next 14 years. For the past 9 years Jay has lived in a two-bedroom apartment he shares with a roommate. He pays for his own living expenses. Jay has been employed in the community for the past four years.

When jay was moved back to Gallup his contact with his mother was limited as she was living in a nursing home and had Alzheimer's. Three years ago Jay attended the funeral of his mother, and was reunited with his mother's best friend and her adult daughter who is the same age as Jay. Jay remembered them and was thrilled to see them. The daughter was Jay's playmate during the first 11 years of his life. He had lost contact with them because of being institutionalized. Jay is now supported in maintaining close contact with them.

Jay had been conditioned to be compliant as a result of being institutionalized for so many years. It has taken him years to break free to where he can now make his own choices and he can say "no" to staff, land have his wishes respected.

Jay likes making his own decisions, and living and working like anyone else in the Gallup community.

Ella Dil
Gallup, New Mexico
33 Years

I went to Los Lunas institution, then to Ft. Stanton institution, then to Santa Rosa group home, then to the MASH group home in Gallup.

I never came home for Christmas or Thanksgiving. I was sad and very scared living in these places. I wanted to be with my family growing up, not in institutions.

I have had my own apartment for years. I live by myself. I pay my own rent and pay for my food, and everything else I want. I work at Subway. I have worked there for many

years. Now, I visit with my family on Christmas, Thanksgiving and when I want to on weekends.

Paul Dorenkamp
Chesterfield, Missouri
2 ½ Years

I have been living with MS for over ten years. I'm unable to walk and care for myself. When my care became too burdensome for my wife to care for me, I was placed in this nursing home. Since I arrived at this place, I've been sexually and physically abused. My needs and wants are ignored and neglected on a daily basis. I want to go home and live with my family. I want to watch my children grow up, because of the current Medicaid policies. I'm trapped and imprisoned in this nursing home.

PLEASE support the MICASSA legislation that will reform the long-term care system so no other person has to be unnecessarily institutionalized and have to go through what I am going through now and I can go home to be with my family.

Curtis Dudley
Macon, Georgia
4 Years

Since being out of the nursing home my health has improved. I was ill most of the time I was in the nursing home. I went to the nursing home after I had become ill and was not able to take care of myself at the time. I lost everything as a result. I feel I am taking better care of myself since moving out of the nursing home.

Mikel Elmore
Washington, D.C.
5 Years

In December 2001 at age 47, Mikel Elmore was released from a nursing home in Washington, DC where he had lived for 5 years following a hit and run accident that left him paralyzed and in need of wheelchair accessible housing and Medicaid attendant care services. H now lives with his wife in an accessible public housing apartment close to the wharf where he goes fishing every day. He currently attends a computer instruction course and intends to become a technician.

Mikel is an active member of Capital Area ADAPT and he was a named plaintiff in Young et al v. District of Columbia Housing Authority (DCHA), a class action lawsuit seeking compliance with Section 504 of the 1973 Rehabilitation Act. The case resulted in a federal court order requiring the renovation or construction of 565 fully wheelchair accessible public housing units, among other mandates.

Todd Emmoms
Mapleshade, NJ

Hi! I'm Todd Leroy Emmons. When I was thirteen years old I went to live in New Lisbon, NJ When I was fifteen years old I went to Edward R. Johnstone Training and Research Center. I helped take care of the blind boys. I left Johnstone on June 16, 1976. Johnstone closed for good in 1991.

Since I have been living in the community I got my high school diploma. I am very active in my church, Special Olympics, self advocacy, and I have a good job at the mall.

Thank you very much for listening to me.

Michael Engro
Philadelphia, PA
6 Years

They took my independence. Now I have a life, eat what I want, when I want. I have privacy.

Vircy Evans
Jacksonville, Florida
21 years

Perhaps you will help me get this idea across to the multiple numbers of disabled folks that do not have to have total nursing care. I was one. I only needed "custodial" care for a few years eventually becoming well enough that I did not need to cost Medicaid the unnecessary" expense of a nursing home. Tell me why should the taxpayer's have to pay for ME to live in a nursing home when it would be cheaper living independently? I was thirty-eight when I became partially and permanently disabled. I had to go live in a Nursing Home because I had no where else to go. I lost my job because I had to use a wheelchair and I could not afford to hire someone to just stay with me. Can you imagine having to take orders from the people that YOU use to give orders to? Can you imagine having to share your little space with a roommate when you have been used to doing your own thing in your own space. For twenty-one years, I cost "taxpayer's such as yourself the burden of paying for my upkeep", in a nursing home. This cost Medicaid from $350.00 to $400.00 a day in addition to my SSDI of $865.00. Now, all I pay is $235.00 plus my groceries and medicines.

Sybil Feldman
Boston, Massachusetts

"I live on my own, I go out on my own, I go anywhere I want, and I live dangerously."

My name is Sybil Feldman and I am writing this to speak out about support services in the community for persons who are developmentally disabled and physically disabled.

I was born with Cerebral Palsy (CP) on October 1st, 1940 in the Boston Lying Inn Hospital, Boston, MA. I had one sister who was four years older, and lived with my parents in Malden, MA. When I was one year old at the time of the famous Coconut Grove fire in Boston. I was very sick and had a high fever of 105 which worsened my CP. At this time my parents were unable to find a doctor to care for me because of this unfortunate dire disaster. Because of this I think my CP became more severe. I have had muscle spasms since. Although they call these spasms "seizures" they are not technically not seizures because I do not black out.

At the age of five and a half I had an operation on the heel cords of both feet to help me walk better. It was successful. But I also recall a conversation between my specialist and my parents. The reason I remember this is because the specialist advised my parents to put me away and for get about me. As a result of this, I went to Pine Harbor, Rhode Island and attended Miss Gilmore's School until I was nine. I learned to dress myself and walk better there.

I returned home for a year and a half and enrolled in the Industrial School now known as the Cotting School which was in Boston (now in Lexington). There I received a first grade education at age 10. By this time, 1950, I attended the Kennedy School; after staying for afive years I received the equivalent of a third grade education.

I had tried to get into the Canton State School but I couldn't pass the test. On March 30, 1955 I was admitted to the Walter E. Fernald State School in Massachusetts. I was fifteen and a half. Some of my experiences at this school were:

When experiencing muscle spasms they immediately tied me to my bed.
They would also leave me on the floor tied up for hours.

There were a lot of nurses that I didn't like because they'd yell at me, and tell the doctor that I was "putting on" a spasm when I was not. I can only remember one doctor believing me.

Also because of being tied and not believed, I often developed bruises all over my body. During this period my mother and father died.

On August 22, 1969 I was moved to a better and newer building at this school. Although the staff were not better I was encouraged to become more independent yet. I received no formal schooling whatsoever during my years at this school. I remained at the third grad level; and almost all of this I lost.

After living at the Fernald State School for 21 years, 4 months, and two weeks I went to a community residence named Stott House located in Needham Mass. It was now July of 1976, and I was 36 years old. It was avery big move after living all that time at the state school. They did not have my records. I had a series of long spasms and after two weeks they had to bring me back to Fernard. But this was only for two weeks and then I returned to Stott House.

I had independence at Stott House for six years, but they were for the most part not nice to me. They did not always know what they were doing. However despite this I was able to move to bigger and better things.

Although my father was never able to see me out on my own, I think he would have liked to. On May 18, 1982 I began the transitional living program through the Boston Center for Independent Living (BCIL). I moved into my own apartment, in Brookline; my very first.

Now I am going back for my GED after living through the (BCIL) for fourteen years on my own. During this time I have worked in various places: I have volunteered at the Brigham and Womens hospital transporting lab work and paper work from one department to another. I was trained in 1989 as an "Access Monitor" to access accessibility in public buildings. I have worked at a workshop in Lynn for Independent Living, and was paid $9/hr, but it was for "doing nothing". This lasted six months. The last time I had a paying job was in 1990.

I want to learn to read instead with the help of a volunteer, but I have been waiting for a volunteer since I moved here. I am not waiting around. Over these years I developed my own motto "I live on my own, I go out on my own, I go anywhere I want, and I live dangerously."

In 1990 I was at the State House in a protest demonstration. I met Bill Henny who invited me to go on a Civil Disobedience protest in Baltimore for the rights of disabled people and those in nursing homes. So I joined ADAPT (American Disabled People for Attendant programs Today). We want disabled people in nursing homes to be able to get out and live independently like anybody else. This was my first action of civil disobedience.
The second one I went to was in Orlando, Florida. I took my electric wheelchair. During this action I was arrested for trespassing. Next to the Disabled Persons Commission we shut down the street so that no one could drive a car through. Our point was to say disabled people can be independent without being in nursing homes; we want care at home, not in nursing homes at all. There were 75 of us arrested; blind, in wheelchairs, with canes, and walkers. The police did not know what to do with us. I spent two nights in jail. This meant that I did not get my medicine. The police had to call my doctor. Every time I laid down I had spasms. They let us go and I was fined but the organization ADAPT paid and also my cousin helped. CORD (Cape Organization for the Rights of the Disabled) pays half my transportation.

I have been to Washington DC three times to Civil Disobedience actions. I was arrested once there and dealt with similarly. I have been to Chicago once; Las Vegas once; and Atlanta after the Olympics. In November last year (96) I joined 30 other ADAPT members and met with House Speaker newt Gingrich. Because of the pressure we put on him, he pledged in writing "to pass a bill which will create choices so people with disabilities can get attendant services instead of being forced into nursing home care." This June I am going back to Washington, DC.

I have paid for my independence with my life and every ounce of my strength, and I am determined to not lose any freedoms I have gained.

Robert Fesel
Robbinsville, New Jersey
11 years

I am a man with Cerebral Palsy. In my life I have lived in a boarding home, a developmental center, and three group homes. I have been restrained, starved, burnt with cigarettes, and abandoned for dead.

I use a wheelchair and I communicate via an electronic language board called a Liberator. Technology has changed my life. I now live in a condominium and work with preschoolers. I work as a volunteer to help other people move out of developmental centers.

I have my freedom.

I ask you if one of your daughters had a disability would you put her in an institution. PLEASE, PLEASE help us get people out of institutions and help get institutions out of our great nation.

Carolyn Finnell
Denver, Colorado
5 years

It was hard getting out, but I knew that the older I was, it would be. I never regretted getting out. It has been over 27 years.

Barney Franklin
Idaho

"It was suggested...that I write to you regarding my experiences with a forced nursing home confinement, the type of Personal Care Services (PCS)

(in my situation, this involved a Personal Care Attendant (PCA), which is usually a Certified Nurse's Aide (CNA)), not of my chosen, and Medicaid ineligibility. Perhaps they will shed a favorable light toward your accepting the recommendations as presented in the "Report of: The Governor's Medicaid Reform Advisory Council -- December 1996." Perhaps, also, it will manifest a better understanding of the constant struggle my wife, Edna, and I have in retaining and maintaining our independence and self-assertiveness, our strive and drive for self-integrity and dignity, and our life-long fight for the right of self-worth and self-decision-making -- these are some of the inherent qualities which constitute the well-deserved but little recognized and seldom-bestowed Red Badge of Courage worn so proudly by the far too few of the mainstream disabled!

"Edna and I will be celebrating our 27th wedding anniversary on June 27th. We both have cerebral palsy of the worst type: athetosis. Our ages are that of young seniors, but our minds and hearts are that of the young and the bold. The only source of income we have is my disability pension from Civil Service, not SSI as many people think -- I had worked as a computer programmer/analyst in the Federal Government for seven years (1970 - 1977).

And to add to our pride, we are buying, with no government assistance, a house in which we had resided since 1979 at the address shown in the letterhead above.

"(Athetosis: The most puzzling of all cerebral palsied conditions – AND the most prone for many, both professionals and the lay alike, to wrongfully associate with mental retardation!

"Range of Disability: The most varied imaginable, from the triflest of quiver to the tremblest of quake a human body can involuntarily emit – AND the most apt for the haughty to voluntarily interdict!)

"My disability is far greater than that of Edna's. I am wheelchaired; she is quite ambulatory. My speech is heavily slurred and slow but intelligible when attentively listen to; hers, although impaired, is quite understandable in most instances. My manual dexterity only allows me limited use of my left hand, e.g., holding a pencil to enable me to keystroke the computer keyboard; she is able to drive our golf cart around town, grocery shop, and provides and cares for both herself and me with the best homelife for which I can ask. Despite my apparent physical limitations, however, I am able and mobile enough to go through a day or so alone should Edna finds it necessary to be out of the house for that long. She would arrange certain items to make it easier for me to manage myself. And at present, I have arranged with a local private PCA provider for a CNA to come once a month for about an hour (at $15 per plus transportation, that's all I can afford) to tend to my needs which are very difficult, if not impossible, for Edna to handle.

"The current amount of my monthly income ($1,079 gross) makes me ineligible for the Medicaid program; yet, it is not really and nearly enough to pay for the type of products and/or services from which we would benefit. This puts us "in between the cracks," a

somewhat comfortable and uncomfortable predicament to be in. We are covered by standard Blue Cross under the Federal Employees Health Benefit plan, of which I pay $108 a month. I find this more or less adequate, for it pays much of our medical bills. It does not provide coverage for a PCA/CNA, however.

"In late summer of 1994, Edna had to go into the hospital for an operation. However, I started asking around two or three months before this about getting a PCA/CNA to come in to help me just in case she becomes incapacitated or something of that sort, unaware then of what was to happened. I wanted to set up a support system for myself. (A premonition or foresight!?) I tried several agencies serving the disabled and the elderly for assistance, but they couldn't or wouldn't offer any. They just gave me the all-too-common bureaucratic mumbo jumbo. When I did found out a few days before hand that she was going in, I really worked frantically trying to arrange something until she was home, up and going again. Still, I didn't get anything positive. Three basic excuses stood out as to why I was virtually denied help: 1/ Boise would be the place to live if I wanted the services requested; 2/ the surprise and dismay that I wasn't receiving SSI and subsequently was not under the Medicaid program; and 3/ the ever popular "It takes time" cliché -- they still do!

"On the day she went into the hospital and was operated on, I was told by someone from an agency on aging here that help was on the way for me. With a slight sigh of relief, I got a friend to take me to see Edna. She was just coming out of the anesthesia when I got there. I stayed a couple hours, then came back home with the assurance that the prognosis on her condition would be positive. Then my rights to decide for and do myself were suspended for the next two or three weeks.

"Around 3 o'clock that same day the senior citizens van pulled up into our driveway. The driver came to the door and asked for person from the agency on aging. Puzzled at first, I told him that she wasn't here yet. After saying that, she came by. She then came in and told me how sorry she was that she was unable to find someone to help me, that there were concerns about me being home alone, that the house might burn down and, because of this, arrangements had been made for me to stay at a local nursing home until Edna was released from the hospital, hence the reason for the van. So, very reluctantly, I went upon the stipulation that I come home when Edna does; and that a PCA/CNA come for about an hour a day, primarily to get me out of bed in the morning and to help me back in at night until she's back on her feet again.

"(The argument here was that I had agreed with this woman's line of logic. However, since I was not given a choice of alternatives, my contention is that I had been forced into the nursing home out of ignorance to my civil rights.)

"This was on a Tuesday. Edna came home that Friday while I was going bananas trying to secure my freedom. The social worker at the nursing home first told me on that same day that the woman at the agency on aging was looking around for a PCA/CNA for me. But on the following Monday she said that she, the social worker herself, had assumed that responsibility.

Exhausted and tired from lack of sleep due the sickness of the man with whom I shared the room, disgusted and disgruntled with having my humanity retarded, agonized and aggravated by being unnecessarily separated from my wife, and issuing a threat of legal action should I be constrained another day, I finally came home that Thursday, 10 days after being incarcerated.

"(I was told that my stay at the nursing home had been paid out of a Medicaid emergency fund.)

"The kind of outside help I really needed when I got home was basically for someone to help me to get in and out of bed. (If I had a ceiling-to-floor grab pole beside our bed, I could do it myself, thus eliminating the need for this kind of help. This was one of the items I told an agency serving the disabled about several months prior, but nothing was done.) So arrangements were made by the nursing home with a local church to have a volunteer to come in, starting that Thursday night, to help me the way I had requested it. A man came at my designated time of 10pm and 8am, help me the way I wanted, and then left. This continued until a CNA was selected and started coming Monday morning.

"When she did, she first got me up and then tried to transform our home into a nursing home environment, as she was from one of the other local nursing homes. Her schedule was from 9 to 11 in the morning and 7 to 8 at night -- this peeved me and Edna very much, as we don't go to bed that early. And to make matters worse, much of her time was spent in idleness because I refused to do some of the things she had on her nursing home agenda. It was disrupting our lifestyle. Something had to be and ultimately was done.

"(The money for the CNA was obtained through a grant from one of Idaho's largest utility suppliers, I was informed by the woman from the agency on aging. The amount was enough to cover five weeks of service, seven days a week, three hours a day. However, it was not used and was returned due to the following.)

"The woman from the agency on aging came by that Tuesday evening to see how things were going. I told her about my dislike of the 7 to 8pm time slot for going to bed. Since the CNA was already present, a compromise bedtime was more or less agreed upon: between 8 and 9pm. However, I kept insisting and pressing for the grab pole aforementioned herewith and of which she knew about, to be placed in the bedroom. It paid off because she, to my surprise, the woman came again Thursday evening with a friend of hers to install such a pole they bought and brought along. I then practiced getting in and out of my wheelchair onto the bed and back until I felt comfortable with it.

"As for the CNA, she came Friday but not Saturday nor Sunday. If it wasn't for the grab pole, it would have been extremely difficult for Edna to help me to get in and out of bed, for as she was well on the way to recuperating from her operation, she was still quite weak yet. So, when she, the CNA, arrived Monday morning, we asked her what happened. She said another CAN was to have taken her place that weekend, but offer no reason for the no-show. Then, with Edna's approval, I terminated her position here.

"I had taken a lot of heat for doing this. I have been accused of not understanding, not appreciating the kind of help people have given me under the handicap of limited resources. And, in a mega-subtle manner, I'm being told by some ,that the amount of freedom and rights a disabled person has is proportionate to the degree of his/her abilities. Many of my peers even with far less physical limitations than mine have experienced this type of imposed criteria for "mainstream acceptance." But the fact remains, I did not get the assistance I requested in establishing a support system for myself in case something should happened to my wife. And because of my ineligibility for Medicaid at a critical time, I was committed to the cold confounds of a nursing home instead of continuing to enjoy the comforts of my own home with a PCA of my choice and direction while Edna was in the hospital.

"Several times since that horrible happening, a few people from local and state health agencies, including Health & Welfare, tried to get me eligible for Medicaid but couldn't because the amount of my monthly income is slightly above the maximum limitation of that program. The only way, which I could become eligible would be under the Miller Trust. But because of its two main requirements, I cannot in good conscience participate in it:
1. The relinquishing of everything above $863 of my income a month to a trust fund; and
2. and the requirement that I have a CNA for a minimum of 16 hours per week. First and foremost, my income is direct deposited into a joint checking account under my name and that of my wife's. It is to remain under our sole control. And, I do not need a CNA for 16 hours a week. If a minimum is required, I would put it two to four hours per month barring any emergencies. That's the maximum number of hours I would like to have for the PCA/CNA who presently comes, but I can't afford it.

"It is my sincere and utmost hope that this letter be given serious consideration when weighed with the Medicaid reforms as discuss in the Governor's Report. Also, clear and precise thoughts must be given to any alleviation or waiver of regulations, which would have beneficial effects on the disabled's goal of independence with respect and honor. Thank you for your patience, courtesy and understanding..."

And this is an excerpt from an email, which I sent the executive director of the State Independent Living Council.

"...That was the second time I was incarcerated in a nursing home, the first being Christmas Eve 1990. Edna was forced to join me a few days later. It then was used as a totally miscalculated ploy by CO-AD (Idaho's P&A system for the disabled), particularly by then executive director B....M....., to get us PCS and Medicaid, something we didn't want nor need at the time. We were threatened by him that if we try to leave the nursing home sooner than the "required month's stay" in order to quality for these services, he would have us judged as "mentally incompetent" to make us stay. Along with this, nobody from the outside would help us because "...the state knows what it's doing..." And so, we had to, in the absence of due process, stay until our release late January of '91.

"Why were we committed? It was by the strict temperance and irrationality of a so-called friend of ours who was able to convinced a doctor, a social worker and God knows who else that our house was a fire trap and that our lives were in danger. All I did was to asked her to get Edna a Christmas present for me. Instead, she walked into our house, saw that we celebrating the holidays in our own way and decided to take over. Quite literally, I was shackled and gagged in such a way that no matter what I had said or did, we were, according to M.... of CO-AD, "...under house arrest by the state for being cerebral palsied!"

"All in all, it was the most dehumanized experience we have ever had. A short time after coming back home, we were informed by Health & Welfare that our "application" for PCS and Medicaid was denied because of the amount of my income. (Some people still don't understand that.) And even though most people wouldn't denied that we had a pretty solid legal case against those who had anything to do with our imprisonment, I think B.... S...., State Rep. from Nampa, summed it up best the prejudicial ignorance of those who are empowered to help in these types of situations, including himself: "I understand what you're saying, but who else will?" This was in reference to my speech impairment. Are there any defense mechanisms here to prevent these shinanigans from happening?..."

(I have tried and tried to seek legal council here in Idaho regarding the first incarceration but to no avail, including the Idaho Chapter of the ACLU. They claimed that since my case didn't involved the First Amendment. How can that be when we were prohibited from speaking in our defense. Since the statutes of limitation have long expired for this type of case, we can't do anything about the criminality and, the cruelity, both physically and psychologically, my wife and I were force to endured. My question then is, isn't there a national defense fund setup to defray the legal costs of those disables who are entrapped in similar situations?)

I sincerely hope I can be of help to the cause of ADAPT in whatever capacity and capability of which I am able to fulfill.

Eddie Lee Freeman
Milledgeville, Georgia

Since I have been out of the nursing home, I have been able to purchase a new electric wheelchair. Have a ramp built to meet my needs. When I was in the nursing home I was not able to spend a lot of time with my family because the nursing home had restrictions on how long I was able to stay away from the nursing home. I was also not able to purchase a wheelchair to meet my needs while I was in the nursing home but was able to do so since being out of the nursing home. I am able to spend more time with my family and do the things I want to do without restrictions.

Marlene Fulton
Hammonton, New Jersey

21 years

I lived at three institutions, When North Princeton Developmental Center closed in 1998 I moved into an apartment but I didn't like living alone so now I share a home with two housemates. It was hard adjusting to the community. I went through a lot of changes. They had misdiagnosed me in the institutions. I got help learning how to cook and houseclean when I moved into the house with Robert and Chris. Now I cook for all of us. Right now I am learning how to manage my own medication. I have a lot of medicine to take. I do volunteer work. I have made friends and I go to church, which is something I couldn't do in the institutions. I have freedom. I can go where I please. In an institution they keep you locked up.

The institution was not good for me. There were mean people there. You feel like a prisoner.

I say to President Bush – "No one should have to live in an institution. Everyone deserves a chance to live in the community. All the institutions should be closed."

Roberta Gallant
New Hampshire

My name is Roberta and I am a 51 year old "child left behind." The state-and-federal education service-delivery systems ought to be reformed soon. They contain gaps. For example, many other adult citizens and I lack some basic math, reading, and writing skills. While they and I were children living at the Laconia State School and Training Center (the residential placement), New Hampshire deprived them and me of opportunities to receive proper elementary-and-secondary grade school academic services. The Laconia State School and Training Center itself also never offered private tutoring which we needed.

On April 12, 1978, residents' parents filed a class action lawsuit against the Laconia State School and Training Center and the state of New Hampshire to correct problems at Laconia State School. However, the settlement left no entitlement-funding resources available for us uneducated and undereducated adults to finish school as full-time students.

New Hampshire still owes those people and me appropriate math, reading, and writing education because the state stole it from us. A few other persons and I had to hire personal tutors to recoup some of that missing instruction. This cost Lakes Region Community Services Council and Community Bridges too much money and has been unfair.

The New Hampshire **House Bill 914** and the **public Law 94-142** are guilty about age discrimination! **RSA 186-C:7** of the Special Education Laws for New Hampshire and part B of the Individuals with Disabilities Education Act protect children's educational

rights but do not apply to people currently age 21 and over. Regarding age, every citizen should now be entitled to an elementary-and-secondary grade school education. The state-and-federal legislatures must remove the age restrictions from **House Bill 914** and **Public Law 94-142**, allowing everyone the opportunity to earn a diploma or its equivalency. By eliminating such ridiculous restrictions, we will finally be able to obtain the education the state initially denied us during our childhoods spent at the former Laconia State School and Training Center. Therefore, elementary-and-secondary grade school instructions are very important to adults - not only children. I encourage the state-and-federal representatives and senators to expand **House Bill 914** and **Public 94-142** to adults, so that they have the same educational rights, as children with and without disabilities do so today.

Gary
Utah

Gary's life underwent a dramatic change after a drug overdose that resulted in a traumatic brain injury. As a young man he was involved in an armed robbery for which he was convicted and sent to a prison for 18 months. He was a promising boxer, but illicit drug use halted his career. The brain injury has affected Gary's mobility (he now uses a wheelchair to get around), his coordination, speech and his short-term memory. Other changes are less tangible. Gary has a lot of time to thin. He has undergone a religious conversion to Islam, has deliberately and purposefully chosen role models to emulate, and has nurtured a fire within him that longs to spark and ignite other spirits. Gary feels he must help young people learn from his life and wants to share his story at every opportunity.

Gary is #28 on a static Traumatic Brain Injury Waiver. He's been #28 for three years. Because of his particular difficulties, especially his problems with short-term memory, Gary needs a more supervised and structured place in the community. Right now, while Gary is tucked away in a nursing home, both Gary and the community are suffering form his exclusion in its daily life.

Gary lives in a kind of twilight zone between two states. Nevada funds a private nursing home in Utah. Out of sight, out of mind: Nevada officials don't visit the nursing home to review his case, Utah officials never see Gary's name on any of their lists as they survey the nursing homes. Is Gary getting adequate services? Has anyone considered whether he can live in the community? Does he even have the federally mandated discharge plan? No one knows because Gary doesn't quite exist as a Nevada resident and he doesn't quite exist as a Utah Resident. It seems a sad commentary on this society that Gary was sentenced and served 18 months in jail for armed robbery and 10 years in a nursing home for having a brain injury.

Gary's Story:
I like women, the Utah Jazz and talking with kids. I have two kids of my own. A boy about 22 years old and a girl about 18 years old. I didn't really get a chance to tell them

when they were younger how good life is and how terrible it would be to mess up their lives with drugs. Fortunately, their Mamas did that for me. My kids are really good kids and they are doing well. I'm proud of them. But I need to tell other kids. If I could, I would tell them to stay away from drugs, that drugs, will take everything away from you. I would also tell them to learn all they can.

I was doing real good as a boxer until drugs messed my world up. I was boxing in Las Vegas and doing drugs. I thought I was having a good time. Now, when I look back at that time, I can't imagine what I thought was good about it. I was young and didn't know what I was doing.

One day I used drugs with a friend, and the next thing I knew I woke up in a hospital. I don't know how long I was unconscious or how long I was in the hospital. The doctors told me that the drugs went to my brain. I could not walk, so I was discharged to a nursing home in Vegas.

Nevada was OK. People there treated you like a friend. The nursing home there had professional physical therapists. They worked with me. One day, Nevada's Medicaid sent met to a nursing home in Salt Lake City. They sent many of us here. It was not my choice.

I've liked in the nursing home in Salt Lake City for 10 years. In many ways it is worse than a prison. They treat you like a number, not a person. Nevada's physical therapists were good. They were real physical therapists. Here, in the nursing home I am in, they don't have real therapists. They have people there who have that job title but they don't know what to do. I am not getting muscle exercises at all.

It's really like a prison. The staff should be helping us to find housing in the community. But they don't because we are their paychecks. It's just a job for them, so they don't care. And they don't stay very long. We had three different administrators in two years. But, they make us stay.

In the nursing home, they control my life. I can't go to bed when I want to. They decide when I go to bed. I can't have food in my room. Once, I wanted to go out but they didn't let me go out. They said that it was my punishment because I had bad behavior that day but they didn't explain what I had done.

Once, I invited Governor Leavitt to visit our nursing home. He should know what it is like to live in here.

The only good thing that happens is having visitors from organizations like the Disabled Rights Action Committee (DRAC). I joked with my first visitor from DRAC, "Are you my parole officer? They told me about getting out of the nursing home. Another visitor from DRAC, who uses a wheelchair like I do and also has severe cerebral palsy, so she

can't do a lot of the things that I can, has shown me there's another life. She showed me her apartment and explained the modifications and services she gets so she can live there.

The people from DRAC look after you. They show me there is life outside. I know my life is more than a nursing home. Now I want to be going out and doing different things. That gives me hope. They also show me respect, so I can trust them. The nursing home staff treats me like a number. But if other people outside care about you, the nursing home staff begins to show you some respect. They know that if they treat you wrong somebody will stick up for you.

In the nursing home, I also learned that no one will respect you if you don't respect yourself. We need some people who work here because they love what they do. I pray sometimes, not so much about me, but for people like the people at DRAC or the nursing home staff who are decent people, that they'll be rewarded in real life for what they do and who they are.

I know someone who lived in the nursing home with me who got out. So I know it can be done. With the support of his family and hard work, he got out and now he has his own place. That was a good lesson for me. Thing can be better. I want to get out of here and be a good lesson for someone else in the nursing home. I want to prove not only to other people but also to myself that I'm not a loser.

The trouble is when you get out of the nursing home you need funding to get the services you need in the community. There are programs and waivers that let the nursing home funding go with you when you leave. That way you can pay for the help you need. I am #28 on The Traumatic Brain Injury Waiver at this time. I have been #28 for years. I'm tired of being a number. I'm a person, not a number.

When I get out of the nursing home, I want to go back to school to get a GED. The nursing home gives me no chance to get an education. It is understaffed. I have no change to study in there. You need to get education to learn right from wrong.

When I get out of the nursing home. I'll get my life together. I want to be a good father. My boy did not have me while he was growing up. My ex-wife did a great job. My young man is in college becoming an architect. My ex-wife did good by my boy. I can't say nothing bad about my ex-wife. Allah blessed me. She went the whole nine yards. She told my sister that she always cares about me. My girl calls me too. She is becoming a receptionist. Family is important.

I want to be a counselor. I want to work with kids and teach them about drugs, gangs, and safe sex. I want to teach them if you do the right thing, you don't have to worry. I want to teach them that education is important.

When I am out of the nursing home, I will see the People of Islam on a regular basis. Malcolm X opened lots of doors. He taught that you have to respect women like queens. He taught that just praying gets you nowhere. You need to put action in your prayer. If

you want to get out of the nursing home, you need action. I learned in the nursing home that I have no one to rely on but Allah. Allah blessed me when I met people like those at DRAC.

I pray 5 times a day – in the morning, afternoon, evening, late at night, land before going to bed. I can keep on because Allah gave me the strength to carry on.

There's so much more I'd like to say. But there's even more that I want to do. I need to put my thought into action. I hope my story can make life better for someone else.

Nathaniel Gates
Rochester, New York
3 years

My name is Nathaniel Gates and I have Multiple Sclerosis. In 1999 while living independently, in Rochester, New York, I found out I needed spinal surgery. After my operation, I was sent to Monroe Community Hospital for rehabilitation. Following my rehab, I waited to return home. I was then told I could not live on my own because I couldn't walk. They told me I was unable to get aides to take care of me through a traditional Home Health Care Agency. For this reason I ended up staying at Monroe Community Hospital for the next 3 years. Living at the hospital was a big disappointment. It was very depressing and I felt the whole world was passing me by.

The Center for Disability Rights has helped me to get an apartment. I have hired my own aides and live independently. I'm happier now and I'm own boss again. It's like being on top of the world.

Ray Gerke
Perry, Iowa
6 years

It was scary and didn't know what to expect from the other individuals that were residing there and the staff.

However, I learned quickly that the way to service there was to lie, cheat, steal. Be destructive so that I could get the attention of the staff.

After leaving that living enviroment it took me several years to change the inappropriate behaviors that I learned there. I mostly learned this by myself with some support from friends.

I am presently and have been working for (32) thirty-two years-the past (27) twenty seven of these years with my present employer.

Karen Greeban
Austin, Texas
12 years

I am disabled, I have cerebral palsy. I lived in a nursing home for 12 years, but now have been living in my own home, with attendant services, for 10 years.

I would never go back. I sympathize with the parents or kinfolks but on the other hand they don't look at it that it could be better for their loved one, and they could still be taken care of in the community. My parents were against me moving out of the nursing home, because they felt like that I was better off where I was. They said that I could not make it, that I would be right back where I was in a couple weeks, and here I am going on 11 years on my own. They said, "you can't feed yourself, go to the bathroom, go grocery shopping." I realize I can't do these things, but with attendant care I am making it like anybody else in the community. So I feel like the parents should wake up and realize it can be better. We just have to give it a chance.

When you're in a State School or other institution it's hell because your life is not your own. You are under constant supervision. I don't care how old or young you are they treat you like you don't have a lick of sense. They speak for you. You don't get no respect. You got to go to bed when they say go to bed. You got to eat when they say eat -- or you go hungry. If you get hungry after supper and you want a snack, they say "sorry kitchen's closed." Then you got to go hungry until the next morning. An older person may not eat at all and then after a while they get hungry. Sometimes they do go around after the last meal and offer you juice or a cookie but some people need more than that.

People that have to eat pureed food, I've seen their food that looked like water, it was ice cold. And when the state people would come and you would tell them about the food, they would always take up for the dietitian and say that's the way its supposed to be. Or they would make it better as long as they stayed. Then they go and the nursing home would get a high rating. And then they would go right back to the way it was before.

People laying in their own urine. You would go down the hall and you would see the bed patients half covered. You go up to them and feel on their leg or arm and they would be cold and wet and you would go and tell a nurse they need to be changed and they would say it's not time to change them yet. They changed on the two hour shift so they might not go back for hours to change that person. To me that's a hell hole.

At night you would hear people screaming harder, crying from pain. I know they can't give an overdose of medication, but they would be so ugly to that person, let them holler all night long with pain. They would close the door so they would not hear the noise, but being in an institution you can still hear the noise.

In a person who normally don't need medication, if you would get upset about something the first thing they would do is throw a damn valium down your throat so you would be

quiet. What it all boils down to is they just don't give a damn about a person's personal life. They just want the money that's all they care about.

Every time all they talk about is people being let go from jobs if [State] Schools are closed. Like at the [legislative] hearings they were talking about a lot of people loosing jobs. It's funny when people are talking about rights the first thing that comes up is the employees, which I know is very important. Everybody needs a job.

This would eliminate jobs but on the other hand they could work in the same field only they would be working in the community instead of the warehouse (that's what I call an institution – a warehouse). If we would get enough money in the community people could get paid the same amount as they would in an institution. If we get people out in the community then we could give them more quality care, because you would be working for only one or two people and you could give them more quality care than you could give them in an institution.

I agree that some people won't be able to live all by themselves but people who can't live on their own, I think they have the right to live in community as anyone else.

That stuff about people being too disabled -- just because you are disabled don't mean you have to be hospitalized for the rest of your life! You're not sick, your body just don't perform like you'd like it to. And me and a lot of my friends, have proved that already. We can live on our own.

Now that I'm living on my own I can do what I want and don't have to answer to anybody. I can come and go as I please and I have control over my life. (If

I make a mistake so what? I like making mistakes. You learn from them.) I feel like a person not like a number or a puppy dog. In an institution somebody pats you on the head and says, "oh you poor thing you're in here and we got control over you life." They may not say it in so many words but you can feel what they're thinking. I have a better feeling about myself because I'm making it on my own. I use attendant services and it's not always easy, but at the same time you have control of who you want and who you don't want.

Like everything else you have to give and take, but that's everywhere; that's part of life.

To sum it all up, all institutions should be closed so we can get on with more productive and happier lives. They say it's cheaper to live in an institution ... that's not so. There are costs besides dollars. It's not dollars its people's lives."

Arthur Gutierrez
Gallup, New Mexico
8 years

I am Arthur Gutierrez.

I lived with my family when I was a child. When I was 10 years old I was taken to Los Lunas (Institution). I was scared, crying. They let me out when I was 18. I went back to live with my mother and father in Gallup. I moved out on my own when I was 22.

I'm handicapped. My brothers and sisters don't want much to do with me.

I live on my own, pay my own rent and bills, get my food, everything on my own.

Robert Habas
Savannah, Georgia
9 years

Nine years of my life were wasted or at least not lived to their fullest or happiest because of my being forced to live in a nursing home. The care, staff, and attitudes, there were terrible. This home taught me a lot about bad side of the human spirit as the people caring for our elderly and the disabled were in many ways abusive. For example, employees were drinking and smoking drugs on a regular basis. Another rather horrid story involved two staff member stealing a gold tooth from one of the resident who had died in his room. In many ways abuse was pervasive and hard to describe, but it certainly was constant.

Since I left this home where I was constantly told I CAN'T or WON'T be able to live on my own, or do anything, I completed my college education. I purchased an accessible van, which I drive daily. I also work for an Independent Living Center. My health, life and my general well-being is 1000% better (yes, that is one thousand percent better).

I support the MiCASSA legislation that will reform the long-term care system so no other person has to be unnecessarily institutionalized and have to go through what I went through.

Bobby Hartwell
Denver, Colorado
26 years

I was put in a nursing home when I was one year old. Wade Blank got me out when I was 27 years old. I have lived in my own apartment for the last 26 years.

John Hays
Parsons, Kansas

Let me introduce myself. I am John Hays. I was just a little kid when I was first sent to an institution. I was so young, I don't remember what year it was or how long I was

stuck there. I was in several different institutions, Osawatomie State Hospital, KNI in Topeka and Parson State Hospital.

I finally got an opportunity to live in the community about 10 years ago. I have had lots of good and bad times. It is not always an easy world to live in, but I'm making it. I have gone without any formal supports for over 3 years. I know that I will ace many more challenges, but I will gladly face them, rather than ever spend another day in an institution.

Katy Hoffman
Denver, Colorado

I felt bad. I didn't want to be there. I cried all the time. I feel independent beong on my own.

Rick James
Denver, Colorado
5 years

It was fucking hell, and it is better in my own home.

Patrice Jetter
Montclair, New Jersey

Sometimes the staff would steal our personal property; especially clothes and shoes. My brand new outfit my Mom bought me for Easter and some brand new underwear (still had the tags on) were stolen by staff members.

The staff member who stole not only wore it to work the next day, but helped me look for it when it turned up missing.

She denied stealing it, despite it had my name in the collar.

I told my family not to bring me anymore brand new clothes. From that day on, I wore all "County clothes" to deter stealing. It didn't hurt as much if they stole the donated clothes as much as the clothes my family paid for.

Another one of my most memorable moments was when I finally got a holiday pass to go home for Christmas. I was so happy because I hadn't been home for almost a year.

One of the staff deliberately started a fight with me so I couldn't go home. (This happened quite regular, especially with the patients who get upset easily-like me).

He came in the TV room and began shouting profanities and the usual, "Go ahead, hit me!... I want you to". I got up to leave the TV room and he hit me from behind.

Four other staff members immediately jumped on me so fast I couldn't react. The head nurse was told that I started the fight, and she believed the staff, not me.

I was put in seclusion and lost my holiday pass.

Not only did the staff find the whole thing amusing, the same staff member who started the altercation ended up being my one-on-one on Christmas Day.

To this day I will never understand why the staff would find this sot of thing as a form of entertainment, staff sympathizers are either fired or reassigned to other hospitals, or why staff members continue to defend each other when you can have as many as 10 or more witnesses to on incident and will outright deny seeing anything,

Today I am living independently in the community with supports. I work as a school crossing guard in Montclair, NJ and in the fabric department at the Rag shop in West Orange. I also volunteer with special education students and active member of DIAL Inc. for Independent Living. Even though now I'm out of the institution, I still have fear of being sent back there sometimes and still have occasional nightmares.

I worry about some of my friends who are still there and wonder if they're okay, or still alive, or still being mistreated.

One of my good friends died as a result of an alleged beating by staff (they told his family he fell). He had black and blue marks all over his body that indicated to his family he took a beating, but nobody is speaking for him.

I need to go to Washington to testify because I don't want anyone else to suffer the way me and my friends have. That could be your home tomorrow.

I must do this—for myself and for my friends who cannot speak for themselves. Maybe I can have some closure and try to save some of my friends as well. Thank you for this opportunity.

Charles Jurek
San Antonio, Texas

My name is Charles Jurek. I am sixty-four years old. I have cerebral palsy. I spent thirty-five years of my life in the State School because no one could understand my speech and no one believed in me. For the last ten years I have been living with two roommates in my own apartment. I work at Burger King, I volunteer in the community, and I spend weekends with my adopted family.

Janet Kelly
Oneonta, New York
11 ½ years and counting

Hello, my name is Janet Kelly. On 8/3/91, I was involved in a motor vehicle accident in which I was hit by a drunk driver; rendering me a quadrapalegic at C4/5. After rehab at Rusk Institute NYC, I was told by the social worker that I never ever could be alone, and had to be in a nursing home. I was 38 years old, my children were age 10 and 12.

My children went to live with their Father, I had been their sole caregiver under joint custody agreement in my divorce 2 months prior. Life with a new stepmother, and separation from me (their natural mother) was a great source of trauma for both the children and me. I was reduced from being a fully involved parent in my community to a "visitor", as in jail. What was my crime? I felt like I was dropped down a well with no one to hear my cries! No one should have to be treated like that. Ever.

What I missed: birthdays, school events, my children's daily lives, religious celebrations, graduations. To date I have missed half my children's lives and important milestones. I was, and still am, segregated from my children and community. I still am in a nursing home.

What I got in a nursing home: being treated like a permanent patient, loss of privacy/dignity, homesickness, depression, having people die at my bedside time and time again (semi-private rooms), a feeling of homelessness. Despair at being locked in while everyone else seemed to be enjoying a normal life.

This year, 2003, I will be 50. I feel like the way I'll get out is in a hearse. If I can earn a B.S. in Psychology from the nearby State University, why can't I live outside nursing home walls? I am told again and again that I need "care", can't be alone, can't get nurse's aides help or the hours I require. My family says this, the nursing home says this.

This is my story. This is how it is, and I want someone to listen to me. If I could, I'd testify before congress to make my story heard so others won't suffer like I still do.

Joanne Kenworthy
Philadelphia, Pennsylvania
14 years

My independence was stolen from me and I had to live by the rules. They took all of my money and only gave me $30. a month and you had to buy clothes with this money. The people that take care of you call you every name in the book and you can't prove that they did. You don't get any respect and you are nothing but a vegetable.

Bernard King
Mapleshade, New Jersey
20 years

In 1963 I was put away at the New Lisbon State School for Boys. My mother didn't want to send me there but I had Cerebral Palsy and a lot of brothers and sisters and she didn't have a choice. But she came to visit me almost every Sunday. I saw a lot of abuse, sexual and physical. The staff used to get the stronger boys to beat up on the weaker ones. It happened to me. If you didn't do what they said there were consequences.

When I got out I lived in a group home but now I live in my own apartment. I wish my mother could see me. I make my own decisions and the support staff is better than in the institution. I work, I like to play botchy, and I am very active in the self-advocacy movement in New Jersey. I go back to institutions including the State School (now New Lisbon Developmental Center), to help people get out. I wish someone could have helped me when I was getting out. That's why I do it. I will do it as long as I am needed.

I want to tell President Bush that all people with disabilities need to be in the outside world. No one really knows how institutions really are, only the people who live there. If a person needs help it can come to the person in the community.

Jim King
Boulder, Colorado
1 year

People should not have to put up with that shit.

John Kover
Barrington, New Jersey
40 years

I was 16 years old when I was sent with my mother to love at the Village for Epileptics near Princeton. My mother and I had seizures and my father was told to put us there. She and I lived in different parts of the village but we would meet at the bridge near the barn (my job was to milk the cows) almost every day and I saw her at dances, on visitor's days, and the such. My mother got a job as a live-in maid with one of the staff and I didn't see much of her. Then she died.

I left in the late 1970's. I can't remember exactly when. My dream was to get my high school diploma, get a good job and see America. I did all those things and then some. I retired from my job as a janitor when I became 84 years old. I have seen the Pacific Ocean, traveled to Florida, Rhode Island, Virginia, just to name a few and have been to Washington, D.C. several times to testify on behalf of people with disabilities. I'll be going to Washington, D.C. in May for MiCASSA.

I want to tell President Bush to sign a law to close all Institutions. That's my dream now.

John Lagamarsino
Macon, Georgia
3 years

I have been to Disability Connections and have been able to ride the local paratransit system since getting out of the nursing home. I feel that I am able to do whatever I choose to do with my life since moving out of the nursing home.

Herb Larkins
Philadelphia, Pennsylvania
5 years

I was robbed of my freedom to come and go as I pleased. They took away my dreams and independence and what I was capable of doing. I was robbed of my privacy and my ability to have company when I wanted it. They took away my right to speak up for myself and to speak my mind.

Roger Manuelito
Gallup, New Mexico
21 years

I am Roger Manuelito. I am Navajo.

I was born in my family's Hogan in Naschitti (New Mexico). I lived on the Navajo reservation. I lived with my mother, father, brothers and sisters. I helped with herding sheep. I was 8 years old when I was taken away from my family, my home. They put me in institutions. I was in lots of institutions, they moved me around a lot

I was scared and missing my family. It felt like being in prison. I wanted to go back home to my family. I cried a lot.

I got out, finally, in 1981 and moved to a group home in Gallup, New Mexico.

After a few more years, I got a real job. I got my own apartment. I have lived by myself in my own apartment for several years. I pay my own rent and other bills. My sister visits me at my apartment. I visit my sisters and brothers at their homes when I want to.

I work at the McKinley County Humane Society and the Cedars Hill Animal Clinic. I've been working there for 9 years. I just got another job with Pep Boys. I quit the Humane

Society. I still work at Cedars Hills Animal Clinic. I make extra money at the mall. At night time I go to several stores and take out their trash and they pay me money.

I don't want any more institutions. I get scared if I think I might be sent back. I helped start People First of Gallup last year. I go to Albuquerque to help with People First of New Mexico. It is new. I go to Sante Fe on Freedom Day to talk to people who make the laws. I go to conferences and learn about self-advocacy. I speak up for myself and others.

Frank McColm
Denver, Colorado
43 years

My father put me in the home when I was 14 years old. I was in for 43 years. Wade Blank helped me move out 23 years ago.

Veronica McSherry
Worchester, MA
5 years

My life was theirs.

Being in a nursing home was very controlling/suffocating. Having little freedom and rights. Also there was a limit on time spent out. Days were fine but taking to many nights out would result in loss of residency or your personal belongings being moved to another room with things missing. The residents could get violent ex. One time while in my wheelchair I was tipped over backwards. The staff could be careless as well being understaffed they moved to fast and I ended up on the floor, and the time for Mother Nature doesn't come when they do.

My life on my own has given me full rights and my dignity as a human being – My Freedom – as Americans should have – No Matter the Person or Disability. It took courage to get here some 20 years now. I had to fight for my right and freedom – Literally – having been arrested and I continue to be as active as possible still. It's who we are inside. Today I am able to have my own apartment, go where I chose, stay out as late as I want and Mother Nature Knows. Hello My Name is Veronica McSherry

Josephine Messina
Cherry Hill, New Jersey
15 years

When I was a very little girl I was put in Vineland State School because my mother was sick and they said I was retarded. When I was 12 years old I went home to live with my

mother and I went to public school. But my mother was too sick to take care of me so I was sent to Edward R. Johnstone Research and Training Center when I was 14 years old. I lived there for five years. Then they put me in a boarding home. They beat me there so I ran away. When they found me they sent me to a group home. It was the best place I had ever lived. I was glad to be there. I met my best friend Barbara there. I learned how to take care of myself, how to keep house, cook, shop. It was the first time I had freedom.

Barbara and I have been roommates for years. We just moved into a new apartment. I have a job. Barbara and I have been very active in self-advocacy. We like to travel. We went to the TASH conference in Boston in December. We are helping to start a NJ TASH.

People should not live in institutions. People should have a choice where they want to live. Anybody with a disability can live out in the community if they get the help they need. Listen to us.

Marjorie
Utah

Introduction:
Marjorie doesn't quite remember how long she has been living in the nursing home; one day creeps into the next. An immediate Care Facility for people with Mental Retardation (CF-MR) would likely have been a more appropriate placement for her than a nursing home.

If Marjorie had been placed in an ICF-MR, she would have been out of the facility and living in the community under the Portability Waiver three years ago. Now due to bureaucratic mishaps, this option is not available at the present time. The nursing home cites her diagnosis of mental retardation as the most significant barrier that is preventing her from achieving her dream of living in her own apartment. The state has also determined that she qualifies for developmental disability funding for persons with mental retardation and related disabilities; she is just 71 on the waiting list. Marjorie falls through the cracks with other funding possibilities. For example, she doesn't qualify for the Personal Assistance Waiver because she needs help hiring and firing her attendants.

She has also been a casualty of medical professionals who not only have little understanding of the community services available but because they are paid by the nursing home industry, have a vested interest in keeping people in the nursing homes. If it weren't for such a medical professional who denied her access to community services "for her own protection," Marjorie would be receiving community services now through the Utah Flexcare program.

Finally, because of the institutional bias in funding, community services are often unable to accommodate all the people who need services. There are also individual needs that

can't currently be met by our community services. If people were entitled to needed services instead of a bed in a nursing home, perhaps Marjorie would not be faced with the potentially terrible choice of moving into the community and leaving her husband or staying in the nursing home with her husband because there are not adequate community services for him. Marjorie's story was written before her recent marriage.

Marjorie's Story:
I have cerebral palsy. I was living in Ala Chapell condominium. The man up above me turned his bathtub on and forgot to turn it off and water leaked down through the ceiling in the kitchen and on the carpet. As a result, I was moved into a nursing home and nobody told me why.

In my room at the nursing home, the space between my bed and my roommate's dresser is narrow that it is hard to use my motorized wheelchair. It is too difficult to back out or turn around. The telephone cord gets tangled when I move the over-bed table for me to go in or out.

When my boyfriend and I want to get together and talk, there is no place to go and be alone. We both want to move out of the facility and get married. To get out of the nursing home and have some happiness. I believe we have the right to some happiness.

I'm really getting tired of all the things I have to deal with such as: Nursing home people bossing me around; the other patients telling me what to do; always being asked if I want to go to an activity but when I say no they try to coax me into going. I like bingo and when someone comes to play the accordion or sing but other stuff I don't like. I've got my own life to live.

I don't understand why I can't live in an apartment instead of a nursing home. First, the staff at the nursing home told me I couldn't live in my own place because I liked to sleep during the day. Well, life here is boring. Why do I want to stay awake during the day, when I can get together with my friends in the evening after they get off of work? Then the staff told me I couldn't leave because I couldn't manage my medications. So I learned how, and the doctor still wouldn't let me leave. Then they told me I would not be able to manage my attendants. I can do that. I could tell them what I needed them to do when they came over. I would want help checking their backgrounds and things before I hired them and I don't like to fire people. But, I can tell them what to do.

I'm also worried because my boyfriend and I want to get married but he is going to have a much harder time getting out of the nursing home than I will. The nursing home will let us share a room after we are married but it will be so crowded that it won't be much of a home.

Now they tell me that I might be able to leave the nursing home without my husband. They say he can come visit me anytime but that he has to live in the nursing home. Would you want to start a life together like that?

Floyd Nelson
Gallup, New Mexico
16 years

I lived in institutions and group homes. I didn't like it. I had lots of problems living in institutions. Staff told me what to do.

I live on my own now, in my own apartment. I do what I want to do. No one tells me what to do now.

Preston Nelson
Gallup, New Mexico
16 years

I am Preston Nelson. I grew up on the Navajo Reservation. When I was a kid I was sent off to live in an institution. When I got out of there I had to live in group homes. I did not like living there. I was told what to do. I couldn't go out in Gallup without a staff saying I could.

Today I live on my own. I do what I want to do now. I don't have to ask permission.

I live alone in my apartment. I pay the rent, gas and cable and phone bills with my money. I work at Pizza Hut. I worked at a truck stop before Pizza Hut. I'm happy being my own boss.

Greg Nix
Boulder, Colorado
5 years

No hope, no privacy, no self accomplishments. Feel like I'm not living, just existing. At least one congressman or senator ought to visit one nursing home in their state and do the math to determine how much it costs for a person to live in the community versus how much it would be to live in a nursing home. In here, you are a number, and you feel like a number. They say they can provide anything you need, but that's not so. There is good and bad living in a nursing home or living outside. Outside the nursing home you have freedom and I will take the bad things about living outside the nursing home any day to have that. Give me 20% of what they give the nursing home and I can live outside the nursing home like a king.

Lahoma Osment

Denver, Colorado
11 years

I was 24 years old when they first got me (the state). I ran away 'cause they didn't take care of me.

Lisa Owen
Augusta, Georgia
2 years, 4 months

It was boring, you had no life, people told you what time to go to bed, what time to get up. You couldn't go outside the facility at all for recreational activity. It was no life and I Had to use the Protection and Advocacy office (Georgia Advocacy Office) to help me get out. Now I'm in charge of my life and house. I'm going to be going to work and be successfully employed. Soon I hope to be in my apartment and not just the personal care home. I can do anything I want to.

Edward Palermo
Robbinsville, New Kersey
19 years

I was sent to live at Edward R. Johnstone Training and Research Center because I use a wheelchair and I am blind. My mother didn't know what it was like in an institution. When the state announced they were going to close Johnstone I wrote to the governor and told him to keep it open because I didn't know what it was going to be like to live and on the outside and I was scared. So were my friends. My mother had died and a lot of the staff told us scary things about the community. But they closed Johnstone and now I am glad.

In the institution you couldn't say how you felt about things, you had to do what you were told, you couldn't speak up. I had friends who were handcuffed and locked up for doing those things in the institution.

Now I live in my own condo with my housemate. I have good support people to help me. I work at a copy center and I travel. I love to travel and visit new places. I make my own decisions, I vote, I worship. In 2001 I testified in Washington DC at the New Freedom Initiative Hearings and this past January I testified at our State House against restraints and aversive treatment for institutionalized children and adults. I would never put a member of my family in an institution. I will never go back.

Gerald Pemberton
Universal City, TX

A few years ago, a man died in a car wreck. He grew up a Christian, but somewhere along the way he fell down. The best thing in his life was that slap on the head that God used as a wake up call.

I spent five months in a coma, and then another year in the VA hospital. When I first woke up my world was just a spot on the ceiling. I couldn't speak nor walk and my short term memory was gone. Over the next year, they taught me to speak again. I spent the next few years in and out of hospitals and nursing homes for a total of eight years.

One day while I was in my wheelchair, I met a lady who worked as a relocation specialist for an agency which assists people to transition from nursing homes to the community. The agency's name is MOVE which is located in Salado, Texas. I spoke with her about me moving out of the nursing home into my own place, but I wanted to live near my family in San Antonio. She contacted an agency called the San Antonio Independent Living Services (SAILS). SAILS worked in conjunction with the Department of Human Services to assist me in making my dream come true. With everything in place, and a lot of hard work on everyone's part on December 9, 2002, I was driven to the bus station and started my life in my own apartment in San Antonio.

To assist me with my personal needs, I have a provider who comes in about 20 hours a week. She is a vital part of my success, she assists me with such things as washing my clothes, cooking my meals and other tasks that most people take for granted. I pretty much do things on my own. I have two sisters and their husbands, and one brother and his wife who live in this area who also are a big help.

What prompted me to write this article was one day I was sitting out front, smiling and waving at the cars passing by and I realized that in all my life this is the best I've ever felt about myself and my life.

Before the wreck, I was married and had my own business. I lost everything, and now I have regained my spirit and life. What a wonderful thing.

Francis "Tubby" Peyrouse
Denver, Colorado
35 years

They treated me bad, and I had five televisions stolen from me. I was really happy when Wade got me out. I'm more happy in the community.

Samuel Ray Price
Gallup, New Mexico
20 years

I lived with my Grandparents when I was a child. I lived in Smith Lake, on the Navajo Reservation.

I was taken away from my family and put in a group home. I lived in two group homes.

I was treated like an animal. They (the staff) bossed me around. Always telling me what to do. If I didn't do it I punished, I was told O couldn't go places with everyone else. They (the staff) got pissed off at me.

Three years ago I got out. They didn't want me to go. I wanted out and to be in Gallup. I live in my own apartment now. I pay for my own bills. Nobody tells me what to do. I can do it on my own.

I am President of People First of Gallup. I can go anywhere I want to.

That's it.

Peter
Utah

Introduction
Peter's experience with the nursing home industry is in one way unusual and in another poignantly illustrated that even a "good" nursing home is still a segregated, warehouse environment and not a place where many people would choose to call home. Peter's first experience in a nursing home is painfully familiar to most people who have spent time in one of these institutions. The second experience shows what happens when the staff recognizes a resident as a person.

Peter's Story:
I went into my first nursing home about twenty-five years ago. As a young man of twenty with psychiatric problems, I didn't have the skills to live on my own. I had problems with my family and more problems managing all the medications I was taking for my psychiatric disorder. Without a job, I took to hanging and loitering around the county building. Finally, a social worker told me to go to a nursing home. Back then there were no group homes or home care services. No one came to your door to help you out. There were no one to tell you about independent living. If you couldn't take care of yourself, you went to a nursing home.

Growing up with a dad who was an engineer, we traveled around the country. We lived in many places. When I was a kid, I was identified as having a learning disability. At the beginning of 6th grade, I was diagnosed with ADHD and was put on lots of medications. In the 7th grade I was hospitalized for the first time and by the 8th grade I had numerous hospitalizations. These hospitalizations continued through high school and contributed to my lack of independent living skills. These hospitalizations disrupted an already stressful and dysfunctional family life.

Living in the nursing home was a bad experience. The nursing home staff told me when to get up, when to go to the bathroom, when to eat, when to take a nap, and when to go to bed. There was very little independence. There was a strong smell of urine. It was not a place to live. You don't have a life there.

Another very frustrating thing was that one aide would tell me one thing, another aide would tell me something else and the nursing supervisor would overrule everything. I never knew what to do.

I was accused of starting fires and all kinds of things. I don't know how this could be true because I couldn't really function physically. I was on so many medications that I was in bed all the time. I was never in trouble with the law and I don't think I would ever do such a thing.

One morning in November 1979, I went to see people at the Mental Health Department and was told that I could not go back to the nursing home. At the time, they didn't explain why; but later, I found out that the nursing home did not have Medicaid's prior approval. I slept on the floor of the Rescue Mission that night.

Not only was I kicked out of the nursing home, but I was also kicked off of SSI, main source of income. In order to survive, I joined the Navy. Boot camp was very hard and many people couldn't cut it. But I wanted to succeed. I graduated from boot camp but I was later discharged because I couldn't meet the physical requirements.

After getting out of the Navy, I got an apartment and got a job as an orderly in a nursing home in Salt Lake. But I had to quit because the job pressure was too much. I went to Mental Health and I got medicine and they helped me apply for welfare, medical assistance and food stamps.

I traveled around on freight trains in Colorado and Idaho. The Mental Health Department in Colorado got me a bed at the Salvation Army and I also spent some time in a group home.

One day I called my sister from Denver. I was sleeping on a floor in front of a bank on newspapers at that time. She sent me a bus ticket to come back to Salt Lake.

Back home, my social worker once again told me to "take advantage of the system" and check into a nursing home to get my weight stabilized and help once again with mental health issues. I was not eating right and had lost a great deal of weight. The social worker referred me to a nursing home. As it happens, I knew a nurse who was a coordinator in the nursing home. As it happens, I knew a nurse who was a coordinator in the nursing home since I was fourteen and this nursing home treated me like a person.

As part of my treatment plan, I had to attend Mental Health group sessions and day programs, which was fine with me. The nursing home staff made sure that I went to

Mental Health. While I was there, I joined a group – a kind of a social club. This club provided me with several work and social experiences.

When I got my weight stabilized, I left the nursing home. This was a good nursing home. I visit nursing homes now, so I know that a good nursing home is one in a million. This nursing home does not exist anymore because it was sold to a different company. And even though this nursing home was a good nursing home, it doesn't begin to compare to living independently in the community.

I am also able to make real contributions to the community. One project that I am particularly proud of being part of is an apartment project for people who need mental health services. When I saw a need for this kind of housing, I contacted an administrator at Mental Health and together, we started an apartment project managed by Mental Health. I was there in the project for thirteen years.

A few years ago, I was diagnosed with manic depression. I had been misdiagnosed and had been taking the wrong medications until then. Now with the right medications, I'm doing fine. I have continued with day treatment. I met my current girlfriend five years ago. Our biggest focus is on taking care of ourselves and each other. If I have problems with driving, she drives. When she gets tired, I drive. We share. When we clean our apartment, she cleans one room and I clean another room. Then we sit down and take a break.

We're also members of the Disabled Rights Action Committee (DRAC). We are very proud to be members. I belong to other organizations and advocacy groups. But there's no advocacy group like DRAC. I am just sold on DRAC. We get things done rather than sitting back and waiting for the change of government to happen. Sometimes things move fast, sometimes slow.

But at least we have an organization of disabled people. It is not run by social workers. It is run by us, people with disabilities. When we mess up, we mess up. But we usually correct the mess very quickly.

Nancy Qual
Austin, Minnesota

My name is Nancy Qual. I was born in Thief River Falls, Minnesota to wonderful, wonderful parents, Alice and Bob. I started out in grade school in special education. I went on to middle school before it burned down, they had to add on. I spent one extra year at Ellis School in Austin. Then I was institutionalized at Fairbault State Hospital. I have come a long way when I was discharged. I am real happy about that. I encourage everybody to do the same. It is a wonderful things. Don't give up, keep going! After I was discharged from the State Hospital I lived in Cedar Valley residence. From there I got my own apartment and started working at Cedar Valley residence. From there I got my own apartment and started working at Cedar Valley Rehab workshop. I now am on

community based with Cedar Valley Services doing janitorial work. I would like to earn myself a competitive job in the future. In the late 80's my dad opened up an Arc for everybody's benefit. What a wonderful dad. I would like all counties to get Arc's and People First groups started.

Katie Ranck
Minneapolis, Minnesota

My name is Katie Ranck. I was in a wheelchair in the past and as I got older I went into alcoholism and drugs. I landed in a state regional hospital and I went through a treatment program. I was told that if I had passed away there, I would have been buried as a number. I am now a member of ACT, and I'm on the Board. I am one that does not want to see a number on a persons grave; whether or not they have a disability they should all be treated as human beings and buried with dignity.

I would like to see the communities and all races be treated with respect. There should be no discrimination in this world. We have a voice in this community, all of us, and every voice should be heard. Together we work as a team and team works towards success.

James Riddle
Cheyenne, Wyoming
30 years

They put me in Lander State Training School 1961-1976. I worked my butt off. After all that work I did up Lander and her now I am at a retirement home. This home better that Lander State Bug House. I took care of kids and helped people at kitchen up Lander. But don't have to do that here.

There was hard floors like in kitchen. Is not good for my feet. In '67 I walked to work when it was 29 below. I am a tough guy! When first went in Lander, I worked 7 day week. Bug House that what I call it.

In '75 I went home. I said, "Now! No more Lander. You know what? Lander State School, it is no good!"

They used say dumb guy Jim don't got any sense. I have my own mind. I have. I can tell they think I have not.

1976-2001 I was at Magic City, Cheyenne Wyoming. I lived in group homes. I moved into an apartment July 1989. 10 years lived by myself. No roommates. Nobody there to bug me. I went to bed when I wanted to and got up 5:30 in the morning. They had TV up Lander but not my own TV, When I had my apartment, I bought my own TV.

More than 3 years ago I was on my deathbed. Heart trouble. I moved into old folks home. This better than group home. I need be with other people. If I was in a group home, they would have to make too many changes. I am better off here. I don't have much choice. 2001-2002 I was People First of Cheyenne President. I am Past President now. I still go every month. My friend takes me. Nursing home won't take me in their van since meeting is on Sunday afternoon. They use to but say can't anymore.

I am 67 years and holding. 1961 I went to Lander. If I could talk I could right all things. If I could talk I just about have Lander closed. I could tell George Bush about Lander. Don't think I wouldn't tell Bush. If I could talk.

Willie Robinson
Memphis, Tennesee
5 years

Everything here (on my own) is perfect, well, not technically perfect, but such a vast improvement it seems perfect.

Linda Romanelli
Midland, Michigan

During March 2002 I went into the nursing home for rehabilitation due to a complicated hip replacement. I was allowed only 10% body weight on my leg, and also had a brace that fit around my waist and down my leg to help keep it stable. During my stay there I received insufficient physical therapy from the rehab staff or from the nursing home staff. I got so frustrated and discouraged that I decided I was leaving. That is when they showed an interest in helping me after I told them I was leaving in a few days. Then they couldn't do enough. I did what therapy that I could do on my own so that the doctor would approve my release. I had not walked in two years and was given a faulty wheelchair that had no brakes and the left leg didn't lock, when I complained about it! I was punished by having the wheelchair taken away. I talked to A supervisor and she agreed that I could use the wheel chair to go to the dining room and then use my walker to walk back, the few times a nurse or an aide would walk with me. There were times I had to walk by myself, from my room to the dining room was approximately 2 hallways long. Too long to walk alone. At bedtime when it came to getting me up or down I had to remind these people how to handle my leg so to keep them from doing harm. At one point
I was given the wrong medicine and if I hadn't noticed I would have taken something that could have done considerable harm to me, the nurse laughed it off and said it happens. The depression I and the others suffered is heartbreaking, depression is a terrible thing. I pray no one who reads this has to go through it.

Leonard Roscoe
Atlanta, Georgia

25 years

I was put in the institution in 1972 after living in hospital my first 3 years. I have Osteogenesis Imperfecta (brittle bones). It was assumed I would be retarded. My mother was tricked by the state into institutionalizing me. I was here 35 years. I had unnecessary Pneumonias and breaks from the environment. Now that I'm out I have a life. I come and go like everyone else.

Dorothy Ruffin
Philadelphia, Pennsylvania
3 years

When I was in the Philadelphia Nursing Home they use to get me up at dark time they said because I was easy to do so they were getting me out the way for the next shift.

Bonnie Schuller
Vineland, New Jersey
38 years

There are seven developmental centers still open in New Jersey. In my lifetime I have lived in five of those seven institutions. I was institutionalized when I was 2 years old. My mother couldn't take care of me and they said I was retarded. I was sexually abused when I was a little girl in the developmental center. I know they abuse and kill people in institutions and the food is terrible. I have been put in straight jackets and tied down. While I was in North Jersey Developmental Center I found out about self-advocacy. Steve Gold and Tim Cook came and helped me and some other women get out and move into a group home but they sent me back because I had behaviors.

I finally got out of Vineland Developmental Center in 1999. I now live in a supervised apartment. I have my privacy, I can watch TV when I want, and buy my own food. I am a member of a group of self-advocated that help other people get out of institutions. Self-advocacy helped me to understand that I have rights and I want to help other people living in institutions understand that they have rights!

Dorothy Shatzky
Cortland, New York
5 years

What I Miss about Life by Being in a Nursing Home…

Having a place where I'd have room to keep things that I have had in the past like pictures and personal things. I miss my personal privacy, particularly having to share a

room with somebody else. Not being able to go out as often as I'd like is something else I miss.

What I Want to do Outside a Nursing Home…

I prefer to have my own choice of food, not having a huge meal at lunchtime and a small one at dinner and I'd like some diet food and real eggs instead of egg products. I'd also be able to have my own schedule for doing things instead of having to depend on the schedule established by the nursing home.

Irma Shirley
Gallup, New Mexico
35 years

I am Irma Shirley. I live in my own apartment and pay the rent and bills. As a child I was taken from my home to live in an institution. For 35 years I lived in institutions and group homes.

I have worked the past several years at day care centers for little children. I am paid just like everyone else. I am happy where I live and work. I am looking for a house to rent where I can have my own dog. I make my own choices for my life.

John Sime
Minnetonka, Minnesota

My name is John Sime. I have worked in Faribault, Owatonna, and Cambridge. I have done janitor work, cashier work, restaurant work. I have received awards for helping people in wheelchairs, choir singing. Our father was an alcoholic. I went to the workshop today to learn how it affects our family, friends and jobs. It has a big effect on all! I think my two sisters, even though they are both married now, have taught me to respect other people and get along with everybody. That has changed my life completely. Right now I am involved with an empowerment group on Tuesday nights. It is an interesting class. I'm learning different things that I didn't know. I've been in self-advocacy help empowerment group for about four years, I've had three or four instructors, they have been a big help. I work in the community Monday and Tuesday at Maple Grover, Minnesota at a packaging plant. We do a lot of sorting for many different companies. Wednesday and Thursday I work at Opportunity Partners at Minnetonka, Minnesota, which we do all different kinds of work. I'm trying to get along with all the instructors in class. I'm trying to meet new friends each day. On Friday, they have a senior option class, which we go to different places. My new instructor is Beth, she has also been a big help to me and the rest of the group. We all like her!

Bobby Simpson

Denver, Colorado
11 years

It was terrible and the food was awful and I was treated bad. I am glad I have my own home.

Paul Smith
Minneapolis, Minnesota
13 years

My name is Paul Smith. One of the things I had a time with is at the State Hospital. With all the assaults. I was at the State Hospital down in St. Peter. One time I got upset and one other person didn't know what the reason I was getting upset. I tapped him on the shoulder and he ended up flipping me on the floor which was damaging to both of my knees. That kind of thing would happen a lot. I lived there for 13 years. Now I live in a Mains'l home. I live alone and basically do everything on my own. It's a big direct turnaround when you move out of the State Hospital and into the community. You have to start dealing with reality and that's a hard thing to learn. I do not have a job now, but would like to have one. I would like to do anything that would bring me money.

Genell Stopp

I moved to a nursing home a few months before my 19th birthday. My mother could no longer take care of me. I have a form of Muscular Dystrophy that is not as progressive as some although I have never walked. At the time of my stay in the nursing home, I only needed help getting on and off the commode, bathing, and getting in and out of bed. I was able otherwise to care for myself. This cost the state $1700 per month for a 12 by 12 room. This room I shared with 80 and 90 year old people. And I might add, 3 unbalanced meals and no snacks.

When I moved to my own apartment, it cost $ 800 per month for the state to assist me. I graduated from the University of Tulsa. I worked full time as an Independent Living Councilor, bought my own home and raised my niece.

Now due to the progression of my MD, I use a ventilator part-time and Oxygen full time. I still live in my own home.

Pam Stover
Rochester, New York
2 years

My doctor sent me to a nursing home because the Home Health Aide Service assigned to me refused to cook the food that I requested. Instead, they only gave me sandwiches.

They told me that they were not allowed to cook for me. As a result, my health deteriorated. I was bleeding internally, and eventually, vomited 4 basins of blood. I was in the hospital for ten days. Then I was sent home briefly, and then I was admitted to a nursing home. My stay in the nursing home was dismal. The aides in hospital refused to dress me in the clothes I requested. They would ignore me and dress me in any manner they chose. I had to wear dirty, wrinkled, mismatched clothes. My family and friends would take me out on trips within the community. They would call the front desk before the came to pick me up to ask that I be dressed appropriately before they arrived. The staff would make a nasty face but they would comply to avoid a confrontation from my loved ones. I observed that residents who had their haircut by the hospital staff lacked style. They all looked like they had a bowl put over their head before cutting their hair. I chose not to have my hair cut. The recreation program was lacking in many ways. There were not a variety of activities available for the patient. Everything was focused on the older generation. There weren't any options for the younger adults. The weekends were very dreary. There were no activities at all.

My medical care was not up to par. I developed a very bad infection in my chest. Fortunately, my new caseworker from the Center for Disability Rights came to get me and took me to a doctor before it was too late. The nursing home was completely oblivious to the fact that I had an infection. I had complained about pain in my chest and was told, "You'll get over it." Fortunately my new case manager from CDR and concerned staff members, worked hard to get me released from this negligent environment.

My main goal is to help free others from facilities that do not provide quality care and are not concerned with the well being of their patients. My wish is that others may enjoy a free, content life that I am grateful to have.

Ross Sweat
Seminole, Texas
3 ½ years

My name is Ross Sweat, and I live in Seminole, Texas. I did not respond to the first request I saw for this information because my time in nursing homes was so long ago, and, while it was miserable, it was neither a wasted nor a useless experience for me. I was paralyzed in 1965, was in a hospital for almost a year, and then spent about 3 and 1/2 years in 6 different nursing homes in several Texas cities. I left nursing homes in late 1970 when I met and married a stubborn young lady who is still my wife and partner. After college, I became a Rehabilitation Counselor in New Mexico.
During my career there I was also an area supervisor and, for four years, the state director of the NM Division of Vocational Rehabilitation. I took disability retirement from NMDVR in1992 because of health issues. I returned to my hometown and now teach psychology and sociology (part time) at a small college. I also serve on the Texas SILC and Rehabilitation Council.

Doreen Talk
Gallup, New Mexico
15 years

I am Doreen Talk. I am Navajo. I speak and read English and speak Navajo.

When I was a child I was put in an Institution in North Dakota but my family lived in New Mexico. I think I was in this Institution from age 4 to 11. I did get out and went back home. Then I went to Special Education classes in high school. Then I was again put in an institution, where I did not want to go. A few years later I was moved into a Group Home. I did not like living in any of these institutions.

Now, I live in my own apartment and pay my own bills. I got my own apartment when I started working. I live by myself. I have a job a Wal-Mart. I have been working at Wal-Mart for eight years. I have friends all over town. People know me everywhere I go. I am angry about living in institutions and group homes all those years. I am happy now, I like living on my own and I like my job.

Tammy
Salt Lake City, Utah

Introduction:
"Tammy is a freedom fighter," said Kay Fox, a community organizer at the Salt Lake Community Action Program. "The first weekend we met at a national action in DC, Tammy protested at then HUD Secretary Andrew Cuomo's house and the next day demonstrated by jumping out of her wheelchair and crawling to the Executive Office Building to encourage the Clinton Administration to end institutional bias. At ht end of the day she was bruised and needed stitches. I ran to her to see if she was OK. "This was the best day of my life, Tammy said about the solidarity experienced after these activities. I knew she was in a real leader. It was no surprise that DRAC hired Tammy. She's a real leader."

Tammy's story illustrates that even the toughest "freedom fighters" can come perilously close to total defeat when confronted by the lunacy of our institutionally biased system. A system whose first resort is a nursing home for a teenager who is aging out of the foster care system. A system that won't provide a young adult with a disability the resources they need in the community; they must either wait years, and in Tammy's case literally die waiting, or give up all that they hold dear—career, schooling, friends, apartment and personal possessions to enter a nursing home. Only after entering the nursing home with funding will be made available for community life. Only after giving up everything will you be given an opportunity to try and reclaim and rebuild the broken pieces of your life. Fortunately for Tammy, she had a strong group of friends who found this situation intolerable and would not accept it. Sadly, not everyone is so fortunate.

Tammy's Story:
Nineteen years old and a college freshman: I remember the day in November of 1997 that forever changed my life. Abby, my social worker, and a representative from Adult Protection Services appeared in the doorway of my class. I excused myself from the classroom as my professor continued to fantasize being the lead reporter during the death of Princess Diana. I was led in silence to the library, where a private room had been reserved for the occasion. Had I known what was about to happen, I would've took a sudden interest in the Princess Diana phenomenon and a new appreciation for my professor's every word.

They said they would escort met to my home to gather my things and to stay at the community hospital for a day or two until we found a nursing home that I "could live with". No amount of crying, begging, or pleading changed their minds. They did, however, agree to let me finish off the day at school to say goodbye to my friends. How kind of them!

Alas!-I was too quick for them! The next day I moved into my friend's apartment. This was only a temporary solution-John was a 21-year-old student from Brazil and had to go home in December for Winter Break. It, however, gave me almost one-and-a-half months of freedom and enabled me to finish the semester with my friends. I was lucky to have the friends that I did. John lived on the third floor of his apartment. Because a lot of my friends were in Student Government, every evening we would leave my wheelchair in their office, John would carry me to his car, then up the three flights of stairs to his apartment, where he and other friends did all of my care. I try not to think of the burden that was placed on my friend during this time-I am OK accepting help, but I believe I should be able to hire paid attendants for this and not expect services from my friends. And then on December 19.1997, the inevitable came.

No one should spend Christmas in a nursing home. I had never let my disability stand in my way- ever. Why was I being imprisoned all of a sudden? For the most part, I had believed in God all of my life, and not once had I felt any bitterness towards Him regarding my disability, I could not truly and completely control my own life. At nineteen, disability became a crime from which there was no parole. Everyone around me was three or four times my age – many had been captive for several years. Had I suddenly set foot into reality?

I have always been a fighter. Fighting to get out "till the end or spending the next several decades in a nursing home wishing I were dead wasn't much of a choice. I was probably no older than 5 when I adopted the concept of "Survival of the Fittest" and I have had plenty of opportunity to develop it.

To make a long story short, I got out. I ran away for days at a time, I broke other rules—in short, I was a "behavioral problem" and a "liability risk" that they finally didn't want to deal with. I got my own apartment, attendant care, went back to college, a job, got engaged, broke off my engagement in the name of independence, moved by myself to

another state, organized a local disability rights group, adopted two cats, and the list goes on...

...All to be jeopardized by moving to Utah.

In May of 2001, ADAPT – a national grassroots disability rights organization – gathered in Washington DC to push for legislation for community attendant services and supports (MICASSA). Kay Fox, long-time organizer and strategist of ADAPT Utah, approached me about the opportunity to serve as an AmeriCorps *VISTA Member in the Disabled Rights Action Committee's (DRAC) Our Homes Not Nursing Homes Project. To be honest, I was less than thrilled about the location and leaving my friends, school and the wonderful Big Sky Country. However, my goal in life has been to get a job/career and eventually become financially self-sufficient. The Project represented my deepest passion – what I would like to do for the rest of my life, or until the threat to personal freedom is gone.

As a VISTA Member, I would receive a small living stipend, an education award at the completion of my first and second year and non-competitive eligibility status for appointments to U.S. government executive branch agencies for a short period. My service would pay off all of my outstanding Student Loans and I would be able to pay off any other debts I had acquired. If truth be known, even more enticing was the opportunity to learn under Barbara Toomer – one of the greatest disability rights activists in the nation.

Before I knew it, I was relocating to Salt lake City, Utah. While I was not ignorant to the work ahead of me in setting up all of the bureaucratic webbing that follows me wherever I go, I had not expected the Utah "booby-trap"!

I soon learned that Utah State Medicaid provides only sixty hours of in-home attendant services per month – broken down that is fourteen hours per week or two hours per day - a mere one-third what I was receiving in Montana. I don't know of one non-disabled person who can get out of bed in the morning, bathe/shower, dress, groom, prepare and eat breakfast, clean up get ready for work, later prepare and eat lunch, clean up, prepare and eat dinner, clean up, and finally get ready for bed – not to mention using the restroom throughout the day – all in two hours. There was no way I could survive on two hours of services a day. It would have only taken a couple of days for me to be in serious danger!

I applied for the Physical Disability Waiver – the only program in Utah that would enable me to receive the services and supports I need to live in the community. It was this waiver or institutionalization. Upon applying, I was informed that because I was not in a nursing home at the time, I be #25 on the waiting list, that people had been on for more than seven years. Basically, by being refused services because I started out in the community, I was being forced into a nursing home by the same program that funds people with disabilities transition from nursing homes into the community. It was even suggested that I go into a nursing home so that the waiver would provide me with services and supports upon return into the community.

Fortunately, Montana Medicaid funded my attendant care for the first month I was in Utah. I cannot begin to describe the fear and devastation I felt as the month passed. Then twenty-three years old, I had hoped for a 'land of opportunity', as should anyone moving to a new state for a job.

Fortunately, the people of ADAPT, Utah and DRAC were not about to take this ironic twist lying down. They mobilized, made calls, wrote letters and eventually descended en-masse on the Governor's office with the pointed message that it was unacceptable and most likely illegal that I be forced into a nursing home just to reapply for funds to move out. The Governor's representatives basically agreed, but countered that it would be unfair for me to get services before the then twenty-four who were ahead of me on the "waiting list." My friends at DRAC were not persuaded by this argument, though they agreed with the fairness issue. Finally, by some miracle the state officials agreed to fund all twenty-four persons on the waiting list ahead of me.

Never doubt the power of a committed group of friends who are willing to go to the mat for you and who have the law on their side. I narrowly avoided nursing home care, and in doing so helped twenty-four other people get needed services. However, my heart still goes out to those who don't have no choice but to accept the intolerable offer of the entitled nursing home stay.

Life is good now—I am working in two meaningful VISTA placements. I have a wonderful apartment with an extra room for an attendant. I have a cat. I have friends, I have a little income and I have a life—a life that I could not have in the nursing home. Believe me, I speak from experience.

Trish
Utah

Introduction: Trish's triumph over a system that ties services to a place instead of the person serves a beacon of light for those still struggling to be free. Cerebral palsy, clinical depression, asthma and a host of other medical problems make it difficult, if not impossible for Trish to live in the community without services. The personal Assistance Waiver For People with Disabilities makes it possible for Trish to get the services she needs to live independently in the community for a fraction of what it cost Trish to receive the same services in a nursing home. As a VISTA Volunteer for the Disabled Rights Action Committee, Trish help others make the transition from nursing home to independent living in the community. She is active in her church and takes civic duties very seriously.

Trish's Story: I write this in hopes of giving John Q. Public a bit of insight into what it is like to live in a nursing home.

I spent a year of my life transferring between three nursing homes, hoping to find a place that I could call "home". To my dismay, I found nothing of the sort. All of the facilities were sterile in their environments. Each had overworked and underpaid staff. There was no personal attention. You slept and lived in a 10-foot-by-10-foot space, and ate in overcrowded dining rooms. The décor left much to be desired, and you could count on a monotonous, predictable routine. I've heard it likened to being in jail and believe me, the analogy fits.

I am not an elderly person. I am less than 40 years of age. The most important things I lost in the nursing home were my dignity and freedom. I felt as trapped as a caged animal with very little to say regarding anything that directly affected me. Your dignity suffers greatly when someone has to dress you, bathe you, put you to bed and dispense your medication on schedule.

I waited anxiously for a phone call or visit from my friends, my only connection to the outside world. To take a ride in a car with no particular destination in mind was a reason to celebrate. To do menial tasks such as a part-time job, or helping with the facility laundry was something I looked forward to because I had something to do that was productive.

Finally came the chance to live in the community once again. A group here in Salt Lake City called the Disabled Rights Action Committee (DRAC) launched a program called Our Homes Not Nursing Homes. The project was the result of the Supreme Court decision that said that a person should live in "the most integrated setting." For me, that was definitely not a nursing home. In late 2000, I moved into my own apartment. I now have the freedom to choose what I do and when to do it. My dignity is restored as a productive citizen of this community. I supervise every aspect of my life and don't have to answer to anyone but myself when it comes to making decisions affecting my life.

There were hurdles placed in front of me in my transition to the community, but it has been worth it, and I was able to overcome all of these hurdles with help from my friends. I was permitted $45 a month to provide all my personal needs while living in the skilled nursing facility. That left me nothing to save toward paying rent or buying household supplies, etc. Thanks to many people at DRAC, and the fact that I had some things in storage, everything I needed was patched together in a short time.

My little apartment is not Taj Mahal, but it is mine. From inside these four walls, I pay my bills and live my life as I choose from day-to-day. I treasure my freedom more each day, and have learned to appreciate the little things in life, even those things that can be a big hassle. If one can find blessings in having occupied a nursing home, then so be it. For me, there is no such thing..
life to live..

Gilbert Yazzie
Gallup, New Mexico

27 years

I am Gilbert Yazzie.

I lived with my family. The state sent me to live in an institution. I went all over the place, from one institution to another. It was a terrible thing.

I work at Pizza Hut. I have worked there for 10 years. I live in my own apartment, Sunset Hills Apartment #105. It's a great place to live. I go home to visit my family every year at Christmas and Thanksgiving. I go where I want, when I want. I have my own checking account and no one can sign my checks but me.

Ken Thomas
Philadelphia, Pennsylvania
10 years

In there, I lost my freedom; I lost my enjoyment of life. I was unable to meet people. The people in the institution were mean to me and told me what to do and when to do it. They took away my wheelchair, which was my only way to get around. Mostly, they took my heart away because they were evil to me.

Lou Ann Thompson
Florence, Kentucky
21 years

I was first put in a private mental hospital where I was for 3-1/2 years. I was forced to take shock treatment. When I got out I was in and out of the local hospital Psych Ward then they gave my dad a choice of putting me in the state mental hospital or a nursing home my dad choose the nursing where I was for the next fourteen years. I got sick physically and had to go to the hospital, the administrator wanted me revaluated before finished it after I got back to the nursing home. I spent another several years in the nursing home but they were working to get me out

June 8, 1991 I moved out of the Nursing Home. I moved into transition where they taught me how to live on my own. I lived there one year. July 1992 I moved into my own apartment. I was working 3 days a week and going to TRP 2 days a week. I got myself involved in the state. I was on the ATAK/MI Board, P&A Council, Department Mental Consumer Advisory Council. I am on the Statewide Independent Living Council, I have served on the Supported Living Council. The Governor appointed me to a task force on law, violet crimes and serious mental which I was the only consumer. I have given workshops at the State Consumer Conferences and National Conferences.

Thru my advocacy I have helped get several consumers out of nursing homes.

I have also received the Abilities Award in 1994 that is a state award given out every year. I was employee of the year in 1993 and I was consumer of the year in 1994 for Northern Kentucky Comp Care.

Duc Van Le
Denver, Colorado
12 years

I was 22 when I came to the United States. Five years later, I was institutionalized. After 12 years, I was able to get out, and have lived in my own apartment for the last 15 years.

Rick Viator
Denver, Colorado
3 years

It was living hell and I had kids and had to get out. I love being in my own home. I had to move out of the state of Louisiana to get out.

Maria Valenzuela
Rochester, New York
25 years... the first time.

My father didn't like me, and so, when I was five years old, he put me in an institution. I worked for the next 25 years to get out. I didn't want to stay there all of my life.

As I grew up, I went to school in the institution, regular school and a cooking school. I had to do chores to prove I could leave. I ended up taking care of other patients and cleaned the whole place.

Finally, when I was 19 years old, they let me go. I got my own apartment and went to work.

Seven more months...

Maria Valenzuela a 66-year-old woman with complex medical issues through out her life. Maria was extremely determined to stay in her own home not a nursing home. Maria was placed in a state institution at the age of 5 and remained there for the next 25 years; her childhood and life was stolen from her. It was only after the state institution went on strike, did they even begin to think that Maria deserved and was capable of being on her own. During the strike there were only two people on the 25-bed unit to care for the patients left behind: Maria and the staff doctor. Maria did all the personal care and knew the entire routine including the medication of each resident. Shortly after, Maria was released and swore she would never go back! Maria always reminded us of her anniversary to freedom; each year -- that was over years ago!

Maria's health became more complex and fragile over time with numerous health issues. Once again, Maria's freedom was being threatened. Maria was hospitalized from a fall.

Maria refused to go to a nursing home and remained in the hospital for seven months. The hospital attempted to obtain a guardianship over Maria. The Center for Disability Rights began assisting Maria in order to avoid a nursing home. This would be done by coordinating community supports which would enable her to go home where she wanted to be.

Maria's long-time friend became her health care proxy and was a tremendous community advocate for Maria by suggesting proactive measures to ensure her continued safety and happiness. The entire organization assisted in Maria's 24-7 care needs. On June 12, 2003, with everyone's diligent efforts and with Maria's will power, she won her case. The judge terminated the temporary guardianship. Maria went HOME! Local providers stated that they were extremely pleased with Maria's exceptional care and Maria was so very proud of this great accomplishment. She was free once more!

Sadly now, Maria has since passed away, but thing is for sure, Maria was determined to be back in her own home, living life her way – FREE no one could tell her anything different!

Patty Winkel
Denver, Colorado
10 years

My dad left me out on the street. I was homeless. They put me in a group home where I stayed for 10 years. I have been free in my own apartment for the last 16 years.

Carol Young
Gloversville, New York
1 year

I am writing to tell you some of the benefits of living in the community as opposed to living in a nursing home. First a little background information about myself.
I am a traumatic brain injury and stroke survivor. I was 42 years old with a teen-age daughter graduating with college credits in engineering from high school. I had a great job working with Easter Seals as an Occupational Therapy Assistant. I worked with children and their families. Then I found myself in a nursing home in another state. Luckily in New York, they have TBI programs to bring people out of state, back to New York, in an effort to save Medicaid dollars. The program does work, not to mention how happy I am to be my family was to have me closer to them even if it was in another nursing home. I was told it was only temporary, until the local program for traumatic brain injured people have a room for me in a local home. I'd have a new home with a garden, my own room, and my own staff to assist with needed help. They are there to

help to become more independent so that one day I will be able to get a real job instead of working in a sheltered environment, and get my life back to normal.

The biggest difference between living in a nursing home and living in the community, is freedom. Freedom is being able to go where you want, when you want, and the ability to make your own choices.

Questions from Senator Max Baucus for Bruce Darling
April 7, 2004

Question 1 from Senator Max Baucus
Mr. Darling, you are a long-time and passionate advocate for the rights of disabled people, and for their ability to choose where and how they want to live their lives. What, from your experience, makes transition from institutions into the community the most successful for the individual involved? Which services are the most important, and which are the hardest to access?

Answer:
We have found that people need support to make the transition. Please don't get the wrong impression. I am not saying that this is due to some deficit that people in institutions all have in common. The problem is the complexity of the system. Unfortunately, community-based services can be complicated to access. It can take a knowledgeable and skillful advocate to assist someone. People need support in navigating the complex long term care system in order to get the services they need.

I have some very close friends whose personal story shows why this support is so important. Joe Bonomo has Osteogenesis Imperfecta, or brittle bones. Even though as a child he was institutionalized, he got out of the institution because of a compassionate doctor, got a real job, married Debbie (the true love of his life), and they bought a home. A couple of years ago, he had a series of serious strokes. He was paralyzed and lost the ability to speak and swallow. The hospital staff broke both his legs and one of his arms. They initially wanted to just "let him go." Debbie fought for him and he began to stabilize.

Soon the hospital began to insist that he needed to go to a nursing home because there would be no way he could manage in the community. Advocates worked with Debbie and Joe to develop a plan that would get him home. After ten months he finally did get to go home, but it would not have happened without a knowledgeable advocate on their side.

The details of returning to the community are overwhelming... not highly technical, but overwhelming none-the-less. Finding the community support services, assuring that the housing will work, making sure the financial benefits are in place take work. That is why I really have supported the Real Choice Nursing Facility Transition grants. They have funded people to go into facilities and help get people out. The problem with those is that they are time limited and there has been no planning and there is no system to assure that these projects with their trained staff will continue past the initial grant period.

Personal assistance services are the most important service and often the most difficult to access. One of the access problems we have found is the disparity of services from state to state across the nation. Even within New York State, an individual may qualify for wildly different amounts of services depending on the county in which they are applying

for the service. And in some counties, the individual may have no community-based options at all.

In order to improve access to these and other vital services, we need a uniform, national program of community-based services and supports. Until it is equally easy to access community-based care as institutional services, our people with disabilities will not be full partners in the American dream. That is why we need to pass MiCASSA!

Question 2 from Senator Max Baucus
Based on your experience and given the widespread existence of Medicaid home and community-based waivers, why is MiCASSA needed?

Answer:
We need MiCASSA because institutions are still the entitlement and community-based services are just the alternative. The Medicaid long-term care system is inherently biased towards institutions because states must apply for waivers. Individuals must then apply to the state in order to qualify for these community-based alternatives. MiCASSA would level the playing field.

We need MiCASSA because there is huge disparity depending on where you live. One state (or even county) may offer services that are completely different from the services in another jurisdiction. Some people simply cannot move because the disparity in services is so wide. Other have no choice but to move. In fact we have developed our own "underground railroad" to free people from institutions in Tennessee by moving them to Colorado! No American should be forced to move across the country in order to have the basic freedoms enjoyed by most other Americans. MiCASS would assure that there is at least a basic level of service across the country.

MiCASSA is needed because there are such giant gaps in the existing systems that entire communities fall through, not just isolated individuals. Even in states with some waivers for community-based services, the waivers often focus on select disability groups or ages, leaving people of other disability groups or ages without any community-based options. MiCASSA would assure that every American has access to a basic level of service irregardless of their age or type of disability.

Question 3 from Senator Max Baucus
In your view, what are some short-term, medium-term and long-term steps that can be undertaken to reform the long-term care system?

Answer:
Community based services must become as easy to access as institutional services. Individuals must have real, meaningful and effective choices in what services they receive, where they receive services, and who provides those services.

There are immediate steps we could take. First, you must pass **Money Follows the Individual** legislation.

With this important legislation, the Federal government will fund community-based services for the first year for individuals who transition out of institutions! It would be a critical incentive to the states to begin providing Real Choices in long term care. It would encourage states to build their capacity to more effectively transition people back into the community.

An intermediate step you could take to address the institutional bias would be to create an Enhanced Federal Medicaid Matching Rate for home and community based services. By paying a larger percentage of the cost of home and community based services, you will create a strong and on-going incentive for states to promote community living. This step would help the states address their budget difficulties during these difficult times and promote community living options.

The lasting solution, however, is pass MiCASSA! This legislation would finally level the playing field and give people a Real Choice in long-term care by providing individuals eligible for Nursing Facility Services or ICFs with the opportunity to choose Community-Based Attendant Services and Supports.

MiCASSA would:

- provide assistance in the home and community, such as at school, work, or religious activities;
- include systems for securing back-up attendants;
- offer options for consumer control of services;
- address the inequity in financial eligibility between nursing facilities and community based services; and
- support those minor but essential expenses needed by people returning to the community, such as security deposits for housing, bedding, and kitchen supplies.

Question 4 from Senator Max Baucus
I recall from your testimony that you said that 19% of current nursing home residents would prefer to return to the community. How can we know or assess which of those residents actually could return to the community and receive the supports they needed outside of a nursing home?

Answer:
They have already told you the answer. In Rochester, New York where my Center has been working to transition people back into the community, we helped two people with very significant disabilities move back into the community. After we helped them move out, their social worker called to say we had transitioned the two "highest care" people out of their facility and no one should be in there who didn't want to be there.

Based on my experience, I believe that no one needs to be in a nursing home who doesn't want to be there. There is no service provided by a nursing home that could not be

provided at home if we were determined to reform our long-term care system. In that way, anyone could return to community living with adequate supports.

Not everyone will want to return home immediately, but the CMS data could be very helpful in identifying those who have already expressed a desire to return home. It is my understanding that there has been some discussion within CMS as to how to organize the data and make it useable for organizations that would assist individuals in transitioning out, without violating the individual's confidentiality rights. We support these efforts.

There is also discussion regarding revising the data gathering process. Instead of filing the information while a real person languishes in a facility and wants to go home, CMS set up a system to facilitate automatic referrals for any individual who wants to get out. When the Minimum Data Set (MDS) information I mentioned is gathered, any individual indicating that they want to return to the community would automatically be put in touch with an Independent Living Center, Area Agency for the Aging, Real Choice Systems Change grantee, or other organization that would work to educate the individual about their choices and connect him/her with community-based services.

In terms of assessing to determine who can go home, while I believe that everyone can and should be able to go home with the right services, I recognize that our system does not currently provide the right services for everyone. During the initial implementation of MiCASSA, states and organizations could focus on building the infrastructure to do transition and support more people with community-based options. We have found that by working hard to identify HOW to get people out of facilities we have developed a greater understanding of how our system needs to change to make transition a realistic goal for everyone who wants it.

The MDS data gathered by the nursing homes could be used to identify people. Again, making this data more useable and interactive would be a giant step forward for the people waiting to get out of nursing homes.

Question 5 from Senator Max Baucus
In your view, how can we best ensure that individuals will receive quality long-term care services in the community?

Answer:
The most effective quality assurance programs I have seen are those which feature consistent and meaningful input and feedback from the people receiving services through any given waiver. Any new community-based programs should involve people with disabilities in the development of the program as well as the ongoing monitoring and determination of program quality and success.

From my experience in New York State, the policy makers have tried to limit or exclude us from the process of assessing our state's systems. Even though CMS required that the state involve community members in the Real Choice Systems Change process, our involvement has only been extremely limited at best. Had our state worked with us, like

Colorado for example, I know we would be further ahead in our state. You see, as consumers of the services, we have first hand knowledge of how the systems work. Because we fight to return people to the community, we know better than any state bureaucrat what it takes to provide quality community based services. There are other things which would help assure that people get quality community based services.

A clear and easy to use grievance procedure is also critical to ensure consumer control, and therefore quality, of services in community-based settings. When an individual is able to make complaints against individuals or against the system, and when these complaints are promptly address and acted upon adequately, the individual is further empowered and better able to manage their own care through the community-based program. The grievance procedure can also contain mechanisms for reporting abuse or neglect and a means to be sure that these reports are acted upon swiftly with appropriate resolution.

Another means of assuring high quality of care through community-based programs is ensuring a variety of management systems that promote consumer control. The more control people have over their services and their lives the higher the quality and the greater their satisfaction. Not every individual is able to manage 100% of his/her services. For these individuals, there should be options to distribute unmanageable tasks to a family member, designee, or agency to manage the facet of service, such as scheduling or discipline of attendants. At the same time, the individual would maintain control over the facets such as selection or training of attendants.

Providing an individual with consistent access to unbiased licensed physicians and nurses would also be a key component for the success of some individuals. Currently, individuals may avoid contact with institutional services, such as hospitals, because they are afraid that these institutionally biased physicians will attempt to force them into a nursing facility, where they will be "safe". This fear is unfortunate, but not unwarranted. By ending the institutional bias, we would also end the fear that many in our community experience when visiting a physician. With this, people would be able to make their physician an active partner in ensuring that the care provided through a community-based program was meeting all of his/her health needs.

MiCASSA has a variety of systemic quality assurance measures. Under MiCASSA, states are required to develop quality assurance programs that set down guidelines for operating Community-based Attendant Services and Supports, and provide grievance and appeals procedures for consumers, as well as procedures for reporting abuse and neglect. These programs must maximize consumer independence and direction of services, measure consumer satisfaction through surveys and consumer monitoring. States must make results of the quality assurance program public as well as providing an on-going process of review.

Question 6 from Senator Max Baucus
Given your experience in transitioning people, what impact has institutionalization had on their lives? What impact has returning to the community had?

Answer:
For our people, escape from an institution makes all the difference in the world. In my original written testimony, I included the stories of many people who have spent part of their lives in an institution against their will. I recommend you review these stories to hear the effects of institutions as experienced by the people who survived.

In my experience, I have had friends and colleagues tell me about the time they spent in an institution. I've had friends who were beaten, neglected and sexually assaulted while in nursing homes, group homes and developmental centers. Our center serves several individuals who lived in Willowbrook, the state school for children with developmental disabilities which was called a "snake-pit" by Bobby Kennedy and later exposed by Geraldo Rivera for horrendous abuse and neglect. While Willowbrook received massive attention and infamy for its abuses, there were dozens of "Willowbrooks" in every state. The abuses suffered at Willowbrook continue, though not as widespread and better monitored.

Even in the "good institutions" our people were not happy. If you do not have even the basic freedoms, you don't enjoy living in one of the "good" nursing homes, the "clean" developmental center or the "friendly" group home. We have seen many people, deprived of choice, become passive drones, drained of their humanity.

Freedom for our people, means everything. Upon returning to the community, we have seen our people become entirely renewed people, so unlike the person we met in the nursing home. Alfred was one of these people.

When we first met Alfred, a 30 year old quadriplegic who had been injured when he was assaulted, he spent most of his days asleep, or nearly so, in his wheelchair. His head was slumped down, often covered by a hooded sweatshirt. When Alfred traveled with us to meet the Department of Health officials who could change his situation, he was barely able to stay awake and spent most of the meeting leaning heavily on the table. He never looked up. At first we were frustrated but then we realized how hopeless Alfred thought his situation was.

But the meeting was fruitful. Because he had confronted the Department of Health, Alfred was soon assessed and approved for community-based services, the accessible apartment with his name on it was held until his services were ready.

Alfred returned home, despite the serious pressure sore he got while in the nursing home. Once home, with his own aides, Alfred's sore began to heal. Alfred began to participate in the community. Alfred's head was up, he was bright and alert. Alfred now works part-time and sees his family and young daughters several days each week. He has a great smile. He's a different person. He's alive again.

Question 7 from Senator Max Baucus
You said that you train people on nursing facility transition. What barriers do people encounter when moving from institutions to the community?

Answer:
The barriers we have faced when trying to transition a person back the community are varied.

There are physical barriers. There simply is not enough affordable, accessible, integrated housing. What accessible housing exists has long waiting lists. People have difficulty obtaining needed home modifications or have difficulty obtaining appropriate Durable Medical Equipment.

The lack of services may be another barrier. The shortage of attendants to perform the duties needed for someone to live safely at home keeps people in institutions. Often this is due to the low wages for such work. Insufficient hours of assistance also keep people in institutions. Sometimes the person is unable to find the financial resources for start-up costs (i.e. furniture, cookware, rent deposit, bed, etc.) to return to the community.

Sometimes it is just the discharge planner's lack of knowledge about community resources which prevents people from staying in or returning to the community. They may not know about community based services, advocacy agencies and financial benefits.

Attitudes are also a significant barrier. Physicians may refusal to support an individual's right to live at home simply because they don't know any better. We have found that a physician's general attitude toward disability is a far better predictor of their recommendations than the level or type of disability a person may have. We have had doctors support transitions for people with very complex needs while other doctors refuse to support patients with relatively minor issues.

People also assume that people with disabilities are "safe" in a facility. However, everyone we have helped return to the community felt far safer in their own home. As one young woman pointed out, "In my own home I can LOCK my door. I don't worry at night about what may happen to me because I am behind a locked door. I am safe at home."

Question 8 from Senator Max Baucus
You testified that, as a general matter, community-based services are less expensive that services provided in nursing homes. What data do you have to support your testimony?

Answer:
Medicaid Waivers, the primary source of data on long-term community-based care services, are by Federal definition cost neutral. At the very least, these community-based services do not cost more than institutional services. And while these waivers are

different than MiCASSA, they are a good source of data regarding the savings that can be realized with community-based services.

I am from New York so I will use our state as an example. Our Traumatic Brain Injury waiver is aggregately budgeted. This means that money saved serving less expensive individuals can be used to fund the community-based care of more expensive individuals. Even with this type of budget, and despite the fact the traumatic brain injury can be one of the most needs intensive disabilities, New York State Department of Health reports a savings of more than $1,600 per person per month with the TBI Waiver.

I simply must point out that because community-based services are cheaper and they are what people want, I can not understand why we haven't made them the norm.

Questions from Senator Jim Bunning for Bruce Darling
April 7, 2004

Question 1 from Senator Jim Bunning
Receiving community-based care is not an option for everyone. What type of factors should be considered when determining if home-based care or institutional care is best for a particular individual?

Answer:
The biggest single factor should be what they want. Not type or level of disability. Not age. Not race or background. Not involvement of family.

We have successfully transitioned people with all types of disabilities. People of all ages... young, old and in between. We have worked with people who have a variety of disabilities, some very complex or medically frail. We have taken each situation and identified its unique strengths and then built on those strengths to overcome many issues.

From my experience, I believe that with significant reform of the existing long-term care system, institutionalization would almost never be necessary. While, as you stated in your question, "community-based care is not an option for everyone", I believe you should add the word "currently" to your statement.

Community-based care is not currently an option for everyone because we have a Medicaid long-term care system that is biased towards institutional placement. In order to get any community-based care, people often have to qualify for a waiver. Existing Medicaid waivers leave significant gaps, large enough for whole communities to fall through. The answer is to change the system – fill the gaps – rather than decide which people and which populations we give up on and allow them to be forced into institutions.

There are people we have not been able to transition... YET. But it isn't a problem because of something in them. In one case it was a backward state policy that said if they got the very same disability just 154 days sooner, they could get the services they need to go home. In other cases, if they just had a slightly different diagnosis, we could get the services. As a cross-disability organization we are in a unique position to make these observations. As a consumer organization we see the commonalities far more quickly than professionals who see the world through blinders of diagnoses.

With MiCASSA, institutional placement would be a choice for the individual and his/her family, not a determination made by professionals. With MiCASSA and Money Follows the Person, the economy of long-term care would be driven by the desires of the consumers, not by the long established bias of funding tied to facilities.

Questions from Chairman Charles Grassley for Bruce Darling
April 7, 2004

Question 1 from Chairman Charles Grassley
As you know, the Medicaid HCBS waiver program is a necessary and critical component in helping to create the diverse range of options in states' Medicaid long-term care programs. You may also know that the success of this program or others like those that you have described depend on Medicaid's ability to ensure high quality of care to beneficiaries. What do you think are the best ways to guarantee quality of care in the home and community-based setting?

Answer:
Consumer control and a policy which makes community living a Real Choice is the best way to guarantee quality of care in the home and community-based setting.

Consumer control means that people can take control of their lives. They can choose who comes into their homes and who touches their bodies. Even if they can do everything associated with managing their own services, some basic level of control makes a huge difference. It has been when this control has been taken over by a system – either in an institution or the community – that there a problems with "quality".

Really, let's take a look at the quality measures of facilities.
What percentage of people have pressure sores?
What percentage of people have moderate to severe pain?
What percentage of people are physically restrained?
What percent of people are more depressed or anxious?
What percent of residents have a urinary tract infection?

Are these really measures of quality?

We would never accept such standards for other services. Could you imagine asking a store owner "What is the acceptable percentage of people coming to your business who experience pain?" Could you imagine being told that you should select a yard service based on the percentage of times it injures its clients? This would never be acceptable. But these are the measures we use for institutional "care."

From my perspective, people with disabilities in the community are actually safer. When we got Dennis out of the nursing home, he was angry. He complained, "Look at what they did to my feet!" He hadn't had skin beak-downs until he was forced into the nursing home. Since he's been out, he hasn't had them again.

One of the most significant things you could do to assure quality of services is to make community living the same entitlement as the institutions. It may be hard for you all to understand, but the most likely reason people get taken advantage of is that they would do almost anything to avoid going to an institution. Right now, because getting services in the community is a special privilege for a limited number of people, those people are

less likely to make complaints. They know that complaining could result in services being withdrawn and then they will be forced into an institution and lose everything... their home, their family and their freedom.

Think about it. An older woman makes a mistake with her money and gives some to an unscrupulous person. Is she likely to call her family and ask for help? No! Her FIRST inclination is to hide the problem because she doesn't want to be "put away."

I know that people we work with get quality services because they feel empowered to complain. They know they are safe because we fight to keep each other out and not let others "put us away." By making community living the norm, everyone would be empowered to complain. By providing real consumer control, people would be empowered to act.

Questions from Senator John Kerry for Bruce Darling
April 7, 2004

Question 1 from Senator John Kerry
What can be done to connect people that are interested in using a Money Follows the Person policy with the services that can be used to help them return to the community?

Answer:
The federal government is not current utilizing the Minimum Data Set (MDS) Assessment to its fullest potential. By a mandate from the federal government, nursing homes must complete a MDS Assessment for each resident that is currently in the nursing home. The current purpose of this tool is to assess each resident's functional capabilities. In addition, this tool could be used in order to develop discharge plans and connect people with community-based services.

Among other indicators, the current MDS Assessment questions whether a resident "expresses/indicates preference to return to the community". The information from the MDS Assessment is then compiled into a report that is shared with the state and the Centers for Medicare and Medicaid Services. For example, in the December 31, 2003 MDS Active Resident Information Report, nearly 267,000 active nursing home residents reported that they want to return to the community.

Although the MDS Assessment questions a person's desire to return to the community, there is currently no link between that desire and the actual community based services that are needed to return to the community. The Federal government is simply TRACKING the unjust incarceration of people who want to be free. We are not USING this information.

People who express an interest in community living should be referred to an organization which could help them, like an Independent Living Center or Area Agency on Aging. In states with Real Choice grants, these people could be referred to the grantees.

Questions related to perceived barriers and needed community-based services could be added to the MDS so that it could be used as a discharge planning tool, in addition to its current use. If the MDS were used to facilitate discharge, CMS could also require that nursing homes have community based organizations, such as Independent Living Centers and Area Agencies on Aging, complete this section of the assessment, rather than having the facilities do it themselves. After all these facilities would have an inherent conflict of interest in maintaining their occupancy rate.

Question 2 from Senator John Kerry
We have given out Real Choice Systems Change Grants to promote this change. Why do we need additional legislation?

Answer:

Real Choice Systems Change Grants have been a great resource that many cash-strapped states have used to promote community living. Although these grants have been a welcome source of funding, they do not provide lasting systems to get/keep people out of institutions. We must go further.

We must create a uniform system where home and community based services are just as much as an entitlement as nursing homes. While Real Choice Systems Change Grants have helped some people with disabilities remain in or return to the community, many more people with disabilities have not benefited at all from these grants because either their state did not receive funding or their state did receive funding but decided to use it to benefit only people with a specific disability or in a specific geographic area.

We need serious, lasting long term care reform that will give people a Real Choice in where they want to receive their long term care services, regardless of their disability type or geographic location. That is why we need important legislation like Money Follows the Person and MiCASSA.

Question 3 from Senator John Kerry
Why do you think we need an enhance FMAP for community based services? Explain how that will make a difference.

Answer:
Creating an Enhanced Federal Medicaid Matching Rate for home and community based services could be an immediate step that Congress could take to address the institutional bias until we can pass MiCASSA. An enhanced FMAP would create an incentive for states to promote community living. Given the budget difficulties that many states are currently having, having the federal government pay a larger percentage for home and community services would help alleviate some of these fiscal woes, while at the same time promote community living options.

Congress has recognized the need to provide relief to the states. By offering relief in this manner, you not only meet the needs of the states but also help FREE OUR PEOPLE!

Question 4 from Senator John Kerry
Other than ADAPT, what organizations are supporting MiCASSA?

Answer:
Every major national disability organization supports MiCASSA. If you can think of a major national disability organization, I assure you they support MiCASSA. In all, 92 national organizations are MiCASSA supporters. This issue affects everyone and other national non-disability groups also support MiCASSA, including the Gray Panthers, NAACP, National Council on the Aging, National Organization for Women, Service Employees International Union, and US Conference of Mayors. An additional 255 state or regional organizations also support the bill, as well as 306 local groups. And this number continues to grow.

Question 5 from Senator John Kerry
What are your thoughts about reforming the long term care system in general?

Answer:
Reform of the long-term care system must put Community First! People must be given a Real Choice in what services they receive, where they receive services, and who provides those services. For too long, the long-term care system has focused on the needs and desires of the providers instead of the individual. This provider-focused system has forced thousands of people with disabilities to leave their homes and enter into unwarranted institutional placement. Countless lives have been stolen by the current system. Therefore, reform must create real choices that result in home and community based services becoming the norm, instead of the exception to the rule.

Reform of the long term care system must incorporate the following principles:

- Attendant services must be available in the community, 24 hours per day, seven days per week;
- Eligibility must be based on functional need, not on diagnosis, age, or funding stream;
- Incentives are offered to encourage states to allow assignment or delegation of care tasks previously restricted to only doctors and nurses;
- Consumer control must be maximized at every step of the process, including flexible payment and management systems; and
- Attendants must earn a livable wage and benefits.

Question 6 from Senator John Kerry
How will MiCASSA address the needs of people with cognitive disabilities?

Answer:
MiCASSA will provide community-based services and supports for any individual who is (1) eligible for medical assistance under the State plan, (2) is assessed as being eligible to receive services in a nursing facility or intermediate care facility for the mentally retarded and (3) chooses to receive such services and supports in the community. This means that the services and supports available through MiCASSA will be available for individuals with all types of disabilities, including those with cognitive disabilities.

In fact, MiCASSA will greatly benefit people with cognitive disabilities. There are some individuals with cognitive disabilities who cannot, due to their disability, independently manage their attendant services. MiCASSA allows for a person to designate a representative that can assist them with managing their attendant services. The representative could be a friend, parent, family member, guardian, advocate or other authorized person. By allowing for assistance with attendant management, individuals with cognitive disabilities will be able to obtain the personal assistance services that are necessary for them to remain in the community.

Furthermore, MiCASSA specifically allows for the provision of cueing and supervision so that individuals with cognitive disabilities can live in the most integrated setting. This

is extremely important for individuals with cognitive disabilities who are able to perform some of their own activities of daily living, instrumental activities of daily living and health-related functions, but need direction on how to perform these activities. Currently some states, such as New York, do not allow cueing or supervision, which forces individuals with cognitive disabilities into unwanted institutional placement. MiCASSA will level the playing field for individuals with cognitive disabilities, just as it will for individuals with other types of disabilities.

Question 7 from Senator John Kerry
What have been the experiences of states that already have a Money Follows the Person policy?

Answer:
While we have not seen Money Follows the Person implemented on a national level, several states have been effective in establishing the policies and infrastructure needed to allow the money to follow their citizens into community living. The efforts in Texas to develop a money follows the person policy led the Texas legislature to pass a budget rider, Rider 37. In a review of Texas's Rider 37 conducted by the Independent Living Research Utilization (ILRU), the ILRU found that "There was unanimous agreement among interview participants and the study team that Rider 37 and its implementation were successful for a number of reasons.

Five of the major reasons include:

1. Movement of 2,022 people. The greatest success is the fact that 2,022 people of all ages, including some with significant support needs, moved out of nursing facilities from September 1, 2001 through August 31, 2003. As a result, these individuals have much greater opportunities for choice, independence, and community life.

2. Increased awareness. The implementation of Rider 37 has raised awareness within the legislature and among people with disabilities and their families about the possibilities of community living.

3. Learning experience. The collective experience of implementing the transitions from nursing facilities – by people with disabilities, family members, advocates, DHS staff, relocation specialists, and others – promoted the realization that "it really can be done," and generated a deeper understanding about the types and amount of work required to make it happen.

4. Increased collaboration. Efforts to implement Rider 37 promoted new or increased collaboration among various stakeholders, who felt that the collaboration, alone, represented one of the major successes of Rider 37.

5. Cost savings. Participants in the study assumed that Rider 37 resulted in a considerable cost savings. DHS has reported that in State Fiscal Year 2002, the Community Based Alternative (CBA) Waiver served an average of 443 people per month who entered the

program via Rider 37. During this time, Texas spent an average of $1188.70 per month for these individuals, compared to an average monthly nursing facility cost per person of $2373.66. In Fiscal Year 2003, Texas served an average of 1513 CBA individuals per month who entered the program using Rider 37 at an average monthly cost of $1256.721, compared to a monthly average Nursing Facility cost of $2375.49.

Question 8 from Senator John Kerry
What place will there be for nurses or other medical professionals in a reformed long term care system that values real choice?

Answer:
The current medical model system has been in operation for nearly 40 years. This system has stolen the lives of thousands of individuals with disabilities by forcing them into nursing homes or other institutions. Given the strong institutional bias of the current system, many people with disabilities actually distrust medical professionals and avoid getting care because they are afraid that their doctor will send them to a nursing home.

This system needs to be changed. In a reformed long term care system that values real choice, the medical professional will be viewed as a partner. Consumers that utilize long-term care services will work with their medical professional, as their partner, to decide which services are best for them.

But more importantly, medical professionals will be freer to focus on MEDICAL issues rather than support needs. Doctors didn't go to medical school to be gatekeepers of personal assistance. Their job is to help people get well. Demedicalizing long term care will actually allow people to get better medical care, have more control over their own support services and reduce the overall cost of those services.

Although MiCASSA specifically allows health related tasks to be delegated or assigned by licensed health-care professionals to be performed by an attendant, medical professionals will still have an important role in this system. MiCASSA is all about real choice. Thus, the consumer can still choose to have a nurse perform health related functions if desired.

Questions from Senator Jay Rockefeller for Bruce Darling
April 7, 2004

Question 1 from Senator Jay Rockefeller
Over the years, several lawsuits have been filed in different states concerning the way in which Medicaid services are offered to those with mental and physical disabilities. Many of these lawsuits have involved waiting lists and claims that a state has failed to provide Medicaid home and community-based waiver services within "reasonable promptness" to eligible persons. In my home state of West Virginia, a lawsuit was filed in 1999 that dealt with this important issue. Ultimately, the parties in Benjamin H. et. Al. v. Ohl reached a settlement requiring the state to 1) develop a plan to eliminate waiting lists; 2) establish reasonable promptness time frames for waivers; 3) provide choices in selecting institutional or home-based care; and 4) implement policies to inform persons of eligibility.

Given that similar lawsuits continue to be filed across the country, what do you think can be done legislatively to improve access to home and community based services for Medicaid beneficiaries with disabilities? Do you think giving states the option to provide home and community-based services without a waiver would improve access?

Answer:
Passing MiCASSA would definitely improve access to home and community based services for Medicaid beneficiaries with disabilities. MiCASSA would provide equal access to community based services and supports. Under MiCASSA, all states that accept federal Medicaid dollars will provide these community based services and supports under their State Medicaid Plans.

With Medicaid Waivers, there are often times waiting lists for services because there are a limited number of "slots". With MiCASSA, the money will follow the person and not the facility. Therefore, individuals with disabilities will have greater access to the services and supports that are needed for them to remain in the community.

Question 2 from Senator Jay Rockefeller
What are your thoughts on how we can improve the quality of home and community based services?

Answer:
Quality of home and community based services must be ensured so that individuals with disabilities can remain successfully in the community. However, current standards are based on a medical model where the consumer has little or no control over the services they receive. In the current system, the consumer is viewed as the "patient", and, as such, must be cared for and protected. Thus, quality is measured solely by certain health indicators and not by consumer satisfaction.

While health indicators are a strong measurement of quality, consumer satisfaction is equally important. New standards for quality, that incorporate the principles of real choice and consumer control, must be established. In addition, we must move away from a "one size fits all" policy. Standards for quality must acknowledge that there is a "dignity of risk", and that consumers have the right to make decisions for themselves.

MiCASSA addresses this concern. In order to ensure the quality of home and community based services, MiCASSA stipulates that states must establish quality assurance programs that maximize consumer independence and consumer control. Such quality assurance programs must provide for an appeals and grievance process; external monitoring; meaningful input from consumers and the use of consumer satisfaction surveys; an ongoing public process for the development, implementation and review of the quality assurance program; and sanctions for providers that violate the terms for the provision of community based services and supports.

In addition, MiCASSA includes mandates for the federal government to ensure the quality of home and community based services. The Department of Health and Human Services must conduct period evaluations; may conduct targeted investigations upon receipt of an allegation of neglect, abuse or exploitation; and develop guidelines for states to use in developing sanctions.

Statement of Democratic Leader Tom Daschle
Senate Finance Committee hearing on
Strategies to Improve Access to Medicaid Home and Community-based Services
April 7, 2004

Ten million children and adults in the United States need access to long-term services and supports. The majority of these individuals would prefer to receive these services in their homes or in community settings rather than in institutions. They should have that choice.

No individual should be forced into an institution for services that can be delivered effectively and efficiently in his or her home or local community. But right now, the Medicaid program has an institutional bias. Medicaid spends 70 percent of its funding for these services on long-term care in institutions. All too often, decisions relating to the provision of services are dictated not by what individuals want and need, but by funding rules that create exactly the wrong incentives.

In 1999, the Supreme Court, in the *Olmstead* decision, held that if individuals with disabilities can be and want to be cared for in a home, they should get their care in such a setting. The court held that, "unjustified institutional isolation of persons with disabilities is a form of discrimination," that violates the Americans with Disabilities Act. Now, five years after that decision and nearly 14 years after the Americans with Disabilities Act, we still do not guarantee home or community-based care for individuals with disabilities. It's our job to change that.

Though the Administration has taken early steps to address these issues, and I applaud them. Still, these steps are only short-term, interim solutions, and I am concerned they do not go far enough. Furthermore, I am very troubled by the Administration's proposed budget, which would cut more than $11 billion from Medicaid over the next five years. I'm also troubled by the Administration's continued push – over the objections of many of us and many of our states' governors – for block grants that would undermine critical programs.

Americans with disabilities should be able to take advantage of the opportunities other Americans take for granted – to take a walk when they want to, to choose what they want to eat and when they want to go to bed, to visit family and friends, and to be an active part of their communities.

I am pleased that the Finance Committee is considering these issues and hopeful that, with insightful input from today's witnesses, we can do something meaningful to ensure that people with disabilities have the variety of choices they deserve for their care.

Strategies to Improve Access to Medicaid
Home and Community Based Services

Introduction

Chairman Grassley and Members of the committee: Good morning.

My name is Di Findley and I'm the executive director of the Iowa CareGivers Association, founded in 1992 as one of the first independent statewide direct care worker associations in the country. Those we serve are Certified Nurse Aides (CNAs), Home Care Aides (HCAs), Patient Care Technicians (PCTs), and Personal Assistants. In other words, we serve those who deliver some of the most basic and fundamental care and supportive services to people of all ages and in settings that range from the home of a consumer to a nursing home or hospice.

Some of our 1500 members are family caregivers, providers, policy makers, and others who consider themselves direct care worker advocates.

Our mission is to enhance the quality of care through dedication to the direct care worker and other caregivers.

Access to Medicaid Home and Community Based Services

One of the most compelling problems we face today is the inability to meet the growing demand for care and supportive services due to a shortage of workers.

This is something identified in the New Freedom Initiative and the funding for the Systems Change grants have helped states make strides in the recruitment and retention of direct care workers.

While most care and supportive services in this country are still delivered by family members, there often comes a time when the family can no longer handle the 36-hour day or round the clock care and must seek outside assistance. They may seek assistance from a home care provider or as a last resort place a loved one in an assisted living, nursing home, or some other care setting.

In other instances, with the expansion of home and community based services and the right supports and personal assistance the elderly, persons with disabilities and others with special needs can remain in their home indefinitely.

When outside assistance is sought, it is the direct care workers...the nurse aides, home care aides, and personal assistants who make remaining in the home possible by assisting with meals, bathing, dressing, ambulating, and toileting, and in many cases companionship.

Access to or an expansion of home and community based services is impossible without access to a stable direct care workforce.

Lack of Workforce is Barrier to Access

There is clearly documented evidence that supports the Direct Care Worker shortage and the challenges before us in meeting the growing demand for services.

We know that there are at least two aspects to the shortage:
1- Demographics: In Iowa an estimated 800,000 Iowans will reach retirement age over the next few years and at least 40% of those individuals will require some form of long term care. And this aspect of the shortage is certainly not unique to Iowa.

Olmstead Decision: With the expansion of home and community based services to meet the personal assistance and support needs for persons with disabilities, there becomes an increasing demand for this workforce.

While this aspect of "not enough people" seems to get the greatest attention from policy makers, the media and others...we have focused our attention on the 2nd aspect.

2- The shortage that occurs when workers tend to leave the field at alarming rates.

Some direct care workers enter the field of direct care as a stepping stone to becoming a licensed nurse, doctor, or social worker. And contrary to general belief...many choose this as a life long career.

Others enter the field and become disillusioned early on and leave within the first three months of employment because the physical, mental, and emotional demands of the work are more than they can bear.

In 1998/99 we conducted a statewide CNA Needs Assessment Survey to determine why Direct Care Workers tend to leave the field. Those who responded were CNAs working in nursing facilities, HCAs, and some hospital aides. There were no surprises in the findings, but for the first time in our state...the survey actually represented the voices of those who were leaving the field. They cited the top four reasons for leaving as:

1- Short-staffing
2- Poor wages and benefits
3- Lack of respect by supervisors, clients or residents, and the general public
Our society is guilty of placing a low value on the elderly and persons with disabilities and as a result places a low value on those who provide care or supportive services to them.
4- Lack of educational and advancement opportunities within the field of direct care.
Contrary to what some believe, direct care is a career choice for many. Not every Direct Care Worker is interested in becoming a registered nurse or physician. What we need are more opportunities for advancement within the field of direct care. Unfortunately, in our society, Direct Care Workers who have been in the field for 20, 30, or even 40 years are still viewed as "entry level workers".

In our opinion, it makes more sense to invest in doing more to keep workers by addressing these needs rather than continuing to waste money on the high costs associated with worker turnover.

Strategies to Improve Access

Strategies to improve access to Medicaid Home and Community Based Services must include strategies to improve access to a good workforce.

We are pleased to see $2.9 million proposed in the New Freedom Initiative 2005 budget. However, given the magnitude of the problem it warrants a higher level of funding. Some of the funded strategies under the New Freedom Initiative have 5 year commitments as opposed to only one year for the direct care worker recruitment and retention funding. Dedicated funding with a continued commitment for efforts to ensure a quality direct care workforce is desperately needed in this country.

Seniors and persons with disabilities and other consumers are being promised a vast "continuum of care/supportive services". However, we do not have a continuum of caregivers that is consistent with all of the different levels of service or care that are being promised. Every time another level of care or service is added, it is done without giving much consideration to the affects on other systems such as the workforce. When a new service or care delivery system is created, an entirely new set of rules and regulations are created with little consideration given to the existing rules and regulations which results in a very fragmented system which does an injustice to the workers, providers, and consumers.

If we want to recruit and retain direct care workers, it does not take rocket science. We simply need to respond to their needs and concerns as the Direct Care Workers have defined them.

- Direct Care Workers need health care coverage.
  The Iowa Commission on the Status of Women in cooperation with the Iowa CareGivers Association conducted a Direct Care Worker Wage and Benefit survey in 2001 to gather baseline data. We learned that over 77% of those surveyed said that their employers "offered" health care coverage but 41% said they could not afford the coverage offered. It is tragic that some of those on the front lines of care in our country do not have health care coverage for themselves and their families.
- Direct Care Workers deserve a wage that is reflective of the important work that they do. The push for home and community based services is being driven by consumer choice. It is also being driven by cost containment. The cost savings should not come at the expense of the direct care workers in lower wages.
- Direct Care Workers seek opportunities for advancement within the field of direct care. The current educational and training standards are fragmented and lack streamlined standards. The current system is a barrier to Direct Care Worker recruitment and retention and is often a burden to the worker.
- Short staffing whether in institutional care, a home care agency or other setting is a serious problem. Sadly, these heavy workloads drive many long time direct care workers from the field causing us to lose the stability of that veteran workforce.

To simply continue to recruit workers without attempts to fix what needs to be fixed to keep workers longer is a futile strategy.

There is currently a movement in this country to create Direct Care Worker associations. The Associations become a vehicle for the Direct Care Workers' voices to be heard. Through the Associations Direct Care Workers have the opportunity to take more responsibility for their profession and to become a part of the solution rather than always being viewed as the problem. In some states the Real Choice grants are being used to create direct care worker or personal assistant associations.

Aside from our association in Iowa, Maine, North Carolina, Pennsylvania, Vermont, Arizona, and Virginia, Florida, Connecticut, and other states have begun Direct Care Worker Associations.

But states need the resources to create and maintain these efforts and the infrastructure to recruit and retain direct care workers.

Recently, for the first time, two major private foundations (The Robert Wood Johnson Foundation and The Atlantic Philanthropies) earmarked $15 million dollars to develop the Better Jobs Better Care grant program. What is exciting is that the program is earmarked for the recruitment and retention of Direct Care Workers. It is a big deal and a tremendous boost to the Direct Care Worker movement and the overall effort because in the past there have been funding streams for the recruitment and retention of physicians, licensed nurses and other health care professionals, but the Direct Care Worker wasn't even on the map.

Closing

We are pleased that direct care workforce issues are beginning to receive the attention they deserve but we have a long way to go.

We urge you to place a high priority on the workforce issues as we all work together to seek ways to improve or expand access to home and community based services. Access to any level of care or supportive services is not possible without access to a quality workforce. It makes more sense to invest in ways to keep workers rather than wasting money on the high costs associated with worker turnover.

So often organizations like ours, are doing a lot of good work on extremely limited resources to address needs in our communities. We are often forced to make a program that is already working sound innovative in order to meet the criteria for a funding stream rather than the funding stream meeting the need.

States need the resources to create and maintain the infrastructure to recruit and retain direct care workers, and to create greater partnerships and understanding between consumers, personal assistants and other direct care workers, and family caregivers in order to meet the growing demand for care and services.

Thank you.

Strategies to Improve Access to Medicaid
Home and Community Based Services
Hearing before US Senate Finance Committee
April 7, 2004

Dear Senator Grassley,
Thank you for your questions and the opportunity to provide additional written testimony in follow up to the April 7, 2004 hearing before the US Senate Finance Committee on Strategies to Improve Access to Medicaid Home and Community Based Services.

We greatly appreciate the consideration that you continue to give these important issues and your ongoing support of quality care and quality jobs.

Questions submitted by Senator Charles Grassley, Chairman, US Senate Finance Committee:

Question #1: *As we have learned today, the New Freedom Initiative proposes funding for a demonstration project that addresses the shortage of community direct care workers. What kinds of grants and evaluations do you think would be most helpful to Iowa's caregivers?*

Response: Iowa is joined by states throughout the country that are faced with an inability to meet the growing demand for Direct Care Workers in various long term care settings. Iowa and other states are at various stages in their plans and efforts to address these compelling problems.

From our perspective, we cannot begin to meet these demands until our federal and state policy makers place a priority on the direct care workforce aspect of any long term care delivery system by creating a dedicated funding stream for the specific purposes of recruitment and retention of Direct Care Workers in all settings (home care, nursing homes, or within the community as personal assistants or private duty caregivers).

While grants and evaluations at the state level are badly needed, there must be a simultaneous effort at the federal level to work with states in assessing ways that federal policy, aside from funding, can be updated. Much of the federal regulations related to Direct Care Workers is outdated and out of sync with the

current climate and actually impede efforts to streamline programs and services, stifles creativity and innovation, and in many cases does a disservice to Direct Care Workers.

The following are recommendations for grants and evaluations at both the state and federal levels. I can't speak for other states, but based upon my experience in working with other states, I can say with some degree of certainty that they would also benefit from such opportunities:

State Level

- Support for the creation and maintenance of independent direct care worker associations that give Direct Care Workers opportunities to take more responsibility for their own profession (paraprofession) and become part of the solution in ensuring a stable and qualified direct care workforce
- Initiatives that foster greater understanding and partnership between Direct Care Workers (Certified Nursing Assistants, Home Care Aides, Patient Care Technicians), Personal Assistants or Private Duty Workers, and family caregivers
- Direct Care Worker empowerment programs
- Direct Care Worker recruitment and retention initiatives at both the micro (workplace) and macro (profession/community/association) levels
- Incentive programs for providers who maintain higher staff retention and staffing levels
- Consumer education on how to hire, train, and supervise workers
- Development of English as a Second Language (ESL) and other programs and infrastructure to meet the needs of immigrant workers and their employers. With tight state budgets many ESL and other such programs have been cut at a time when the number of immigrant workers is increasing
- Development of programs designed to "defragment" state/federal systems that govern and regulate education and other standards related to direct care workers in order to better serve the workers, providers, and consumers
    - Development of state entities/commissions/boards to give oversight to licensing/certification/credentialing of Direct Care Workers
    - Streamline or expand purpose of state Direct Care Worker (Nurse Aide) Registries to maintain more accurate and reliable data, and to better serve the needs of workers, providers, and consumers

- Systems designed to maintain an accurate assessment of the supply and demand of Direct Care Workers so states can better determine their ability to meet existing and future care/support service needs given the changing economic, demographic and political climates

Federal Level

- Creation of a federal commission or task force to review federal standards related to the education, continuing education, and certification/licensure of Nurse Aides and other Direct Care Workers, and the variations in state Nurse Aide (DCW) Registries in the country. Direct Care Workers should serve on such a commission or their input should be sought.
- Establish a test site to determine the feasibility of replacing the existing federal requirement for Certified Nurse Aides to work within a 24 month period of time in order to maintain their certification with a continuing education requirement that is linked to their certification. We requested a waiver from CMS to do so was denied.
- National Return on Investment study. Some information is available that references the costs associated with worker turnover, but the figures range from $500 to $4000 per year per person. A major national study could provide valuable information to policy makers and key stakeholders about whether the investment in workers is a better utilization of resources than the costs associated with high worker turnover.

Follow Up Question #2: *In your testimony, you also mention that the magnitude of the direct care worker shortage warrants a higher level of funding. What would you recommend to elevate the profession over the longer term?*

Response: In order to maintain a quality and stable long term care workforce within all settings, workers must be able to work in a supportive environment, earn a decent wage and benefits, and have opportunities for education and advancement within the field of direct care. When creating policy for Improved Access to Medicaid Home and Community Based Services, I would reiterate that Direct Care Workers belong to a very large community of caregivers who wear various titles and provide care and services to people of all ages and in all care settings. They exist within a system that is extremely fragmented and inconsistent with any continuum of care and service that is being promised to consumers. Policies should serve long term care workers across the spectrum.

A dedicated funding stream for Direct Care Worker Recruitment and Retention demonstration projects and the maintenance of existing successful programs are critical. The real answer, however, is a permanent promise, real commitment and

an investment by policy makers to place a higher value on Direct Care Workers at all levels of care and not use them as a means for cost containment through lower wages and benefits in any proposed system change or redesign.

Level of Funding:
We are pleased to see money within the New Freedom Initiative designated for the recruitment and retention of Direct Care Workers. However, given the magnitude of the problems states are facing in finding and keeping Direct Care Workers, the $2.9 million, is a gross underestimation of the seriousness of the issues, and is indicative of how the role of Direct Care Workers and those they serve are undervalued.

Given the levels of funding earmarked for other initiatives within the New Freedom Initiative, the following request is more reflective of the need:

- $1.5 to 2 million per state (depending upon population) for Direct Care Worker Recruitment and Retention Initiatives over 5 years
- $25-50 million to support federal initiatives over 5 years

We ask that you consider five year commitments to these initiatives which would be consistent with the other funding opportunities within the New Freedom Initiative.

Thank you so much for your questions and the opportunity to submit additional written testimony for the permanent record. And thank you for your ongoing commitment to Iowans and our great state.

Respectfully submitted by
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4/28/04

Strategies to Improve Access to Medicaid
Home and Community Based Services
Hearing before US Senate Finance Committee
April 7, 2004

Dear Senator Bunning,

Thank you for your question and the opportunity to provide additional written testimony in follow up to the April 7, 2004 hearing before the US Senate Finance Committee on Strategies to Improve Access to Medicaid Home and Community Based Services.

We greatly appreciate the consideration that you are giving these important issues.

Question submitted by Senator Jim Bunning:
Question #1: *Receiving community-based care is not an option for everyone. What type of factors should be considered when determining if home-based care or institutional care is best for a particular individual?*

Response: I am in agreement with your statement that home and community based care is not an appropriate option for everyone. The concern you raise about the appropriateness of care/support is shared by advocates, consumers, providers, workers, and others. The determination of an appropriate level of care and type of care setting is based on a multitude of factors. These include a thorough assessment of the individual's health status, family and community support mechanisms that are available to the individual to ensure safety, and the availability of providers who are able to provide quality care at the frequency and duration required by the individual.

The quality of care and services are only as good as those who are providing the care and services regardless the care setting (home and community based or institutional). That is the very reason that Direct Care Worker issues demand a higher priority.

Pre-screening to determine the appropriate level of care is a start, but within that system the consumer should have choice. However, pre-admission screening for appropriate placement or level of care is pointless without the resources to make home and community based services/care possible. A pre-screening

assessment may find that a consumer can and chooses to remain at home with the assistance of a Home Care Aide, but if the Home Care Aide is not there, the pre-screening assessment process is a waste of time and resources. Unfortunately, the push for home and community based care and service is coming at a time when Home Care Aide and other such programs are being cut due to tight state budgets.

With the growing momentum around home and community based services and consumer directed care consumers and the public must not be misled into believing that "consumer directed care" is synonymous with "staying in one's home". AARP and other consumer surveys of the elderly and persons with disabilities report that most want to remain in their homes.

However, care should be taken to not send the message that remaining at home is the only option. Not all consumers are equipped to manage their own care or to be the employer to a personal assistant. In fact, consumers who are taking on the responsibility of their own care should be provided some training/education on how to be a good supervisor or employer. Otherwise, Direct Care Workers will be driven from the field for the same reasons they leave some institutional care settings (lack of respect, poor pay and benefits, etc.). In addition, family caregivers should not be coerced or be made to feel guilty for not keeping a loved one at home when they know it is beyond their mental and physical capabilities.

In some instances a husband may want to move into a care facility to live with his wife; in another instance the spouse may refuse placement of a spouse whose care needs are beyond his capabilities and are not being met because he doesn't want to pay for institutional care; or abusive families may keep a parent, grandparent, or spouse at home under the worst conditions for money.

Cash and counseling and other "money with the consumer" and consumer directed care models should only be presented as one option for some people. It is not the answer for everyone.

Poor care and abuse can occur within any service delivery model or system. Policy makers and all key stakeholders must ensure that there is a balance between consumer choice, protection, and accountability. Ideally, consumers should receive the appropriate level of services and care within the setting that they choose (providing their mental capacity enables them to make those decisions) and regardless the care setting. Consideration must also be given to how quickly one's condition or service/care needs can change. Appropriate oversight is needed to protect consumers and their right to choose, but also to

protect against abuse of both the consumer and the worker and safeguards should be put into place to prevent abuses of public payment systems.

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Strategies to Improve Access to Medicaid
Home and Community Based Services
Hearing before US Senate Finance Committee
April 7, 2004

Dear Senator Lincoln,

Thank you for your letter that clearly identifies many of the barriers to recruiting and retaining Home Care/Health Aides. It's true that direct care workers are grossly undervalued by society, underpaid, and un or underinsured.

I appreciate the opportunity to provide additional written testimony in follow up to the April 7, 2004 hearing before the US Senate Finance Committee on Strategies to Improve Access to Medicaid Home and Community Based Services.

Thanks for the consideration that you are giving these important issues and for your comments during the hearing.

Questions submitted by Senator Blanche Lincoln:

Question #1: *Does your experience provide a different picture—hopefully an improving one—or any recommendations to improve these situations?*

Response: Needs assessment surveys of direct care workers in Iowa have revealed:

- Lack of health care coverage is a barrier to recruiting and retaining workers
- 74% of those surveyed said their employers (health care providers) offered health care coverage
- 43% of those individuals said they could not afford the health care coverage offered by their employer

One of the objectives of the recent Better Jobs Better Care grant awarded to Iowa, with the Iowa CareGivers Association serving as the lead agency, is to conduct a feasibility study to determine what we can do to ensure that direct care workers have health care coverage given Iowa's political and economic climate.

The issue of health care coverage is a serious dilemma for both the worker and the provider (employer). **An unwritten incentive exists to keep direct care worker wages low enough to make them eligible for state insurance programs.**

Some insurance companies will not insure home care agencies due to the high utilization. The high utilization is the result of 1- high risk workers who experience a high incidence of injury on the job and 2- workers who lack consistent and preventive health care that results in postponement of health care until it is of a more emergent and costly nature.

Some nursing facilities have completely dropped their employee health care benefits for the direct care staff. In one instance the CNA had worked for the corporation for 9 years and she was suddenly without health care coverage for herself and family. Another CNA working for the same corporation was left without health care coverage and had to file bankruptcy because her husband had to have an emergency surgery that left them with $30,000 in medical bills.

The suggestion to include direct care workers in the state's employee health plan has not been popular because they fear that the enrollment of direct care workers into their pool would drive up their rates.

Health care providers such as nursing home trade associations have tried to provide group health insurance plans through the association, but because they represent businesses rather than individuals, there are laws that prohibit the formation of such pools. Our association, however, could form a pool for direct care workers. There would no doubt be risks to our small association, too. The feasibility study that we will conduct as part of the Better Jobs Better Care program will determine the feasibility. Most studies indicate that groups of direct care workers alone would be cost prohibitive.

Another irony that exists is that at least in Iowa the need for Home and Community Based services continues to rise, but the funding for the Home Care Aide program has not seen an increase since 1994.

The instability of the Home Care/Health Aide employment status can also be the result of the volatility of the client population. The average client age is 84. They are elderly and frail and are often in and out of the hospitals, skilled nursing and other care settings. Those changes in a client's condition have a dramatic impact on the worker's hours. On a more positive note, some workers prefer the more flexible part-time hours.

Reliable transportation for Home Care Aides is also a significant barrier to recruiting and retaining workers, particularly in rural Iowa.

Lasting change will never occur until society and policy makers place a higher value on caregivers and caregiving.

While we support consumer choice, we do have concerns about the implications that programs like cash and counseling will have on the workforce and we urge policy makers to consider these very complex issues and ensure that cost savings are not at the expense of personal assistants or direct care workers. And we must use caution to not diminish the work that has been done by many over the past several years to promote professionalism within the field of direct care by enhancing educational standards, and opportunities for advancement within the field of direct care that we believe will ultimately drive wages up.

State and federal regulations and funding streams do little to create an infrastructure conducive to the recruitment and retention of direct care workers. In fact, we tend to reduce standards in times of worker shortages when it is the bare minimum standards that often drive career direct care workers from the field. States and the federal government with input from workers, consumers, and providers need to be able to create an infrastructure for a continuum of direct care workers/caregivers that is consistent with the many different levels of care. What I've witnessed over the past few years in Iowa is that our efforts to invent vast array of levels of care to meet consumer need and to streamline those systems and services has resulted in even greater fragmentation when it comes to the direct care workers

Direct care workers are now being heard through surveys, leadership/mentor trainings, and representation on boards and committees. Researchers have finally figured out that if they want to address direct care worker issues that they need to survey and listen to the workers rather than their employers. There is currently a direct care worker movement in this country with several states starting direct care worker associations. These associations can be very effective in bringing about needed change, but they need the resources to maintain those efforts.

In Iowa over 30 attended our first direct care worker leadership training this month. Those individuals are now eligible to serve on the Iowa CareGivers Association Direct Care Worker Advisory Council. It is another way that their voices can be heard. They will advise the Iowa CareGivers Association and the Better Jobs Better Care program Coalition so that we know we remain true to our purpose and address the issues that are important to DCWs. In August the advisory council will meet for the first time to plan their first day on the hill to take place during the 2005 Iowa legislative session.

We also offer direct care workers continuing education and networking opportunities through a statewide direct care worker convention, sponsor an annual public awareness campaign, and conduct direct care worker mentor training that is now being modified for the home care setting. We know that we are touching the lives of many direct care workers in Iowa. A formal support network and an affiliation independent of industry ownership have been long overdue.

So in answer to your original question: You paint a bleak but accurate picture of the issues that Home Care/Health Aides and their employers face. These complex issues demand a comprehensive approach to addressing them.

Senator Lincoln, we are making progress or these issues or they would not be on the radar screen of the Senate Finance Committee. We thank you, Chairman Grassley, Senator Harkin, and the members of the committee for that!

Respectfully submitted by
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Statement of Senator Bill Frist
"Strategies to Improve Access to Medicaid Home and Community Based Services"
Senate Committee on Finance
April 7, 2004

I want to thank Chairman Grassley for calling this hearing today on strategies to improve home and community based services for the 54 million individuals with disabilities. Not only will the discussion today focus on the important steps that have been taken in the President's New Freedom Initiative to fully integrate individuals with disabilities into the community, but it will also seek additional strategies to address the issue. I welcome the testimony from the witnesses on our three panels.

I want to recognize the impressive efforts of the Administration in promoting full access to community life for individuals with disabilities. Following the *Olmstead* decision by the Supreme Court which affirmed the right of disabled individuals to live in the community wherever possible, President Bush issued an Executive Order to swiftly implement this decision. The President's leadership on this issue produced the New Freedom Initiative which addresses not only community based living, but promoted assistive technology, disability education and integration into the workforce.

Integration of disabled individuals into the community is an important goal we should all work toward. With the aid of assistive technologies, the ability to telework, and the increased quality of in-home assistive care, individuals with disabilities are enjoying a higher quality of life and have become highly-productive members of our society. I look forward to this discussion to further efforts to increase community based alternatives for individuals with disabilities.

"Strategies to Improve Access to Medicaid Home and Community Based Services."



Wednesday, April 7, 2004 at 10:00 a.m.

215 Dirksen Senate Office Building

Ray Gerke - Member
Iowa Olmstead Real Choices Consumer Task Force
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My name is Raymond (Ray) Gerke. I live in Perry, Iowa.

Thank you for allowing me to speak to you today. I am honored to be here to share my story with you in order to help you understand the importance of supporting home and community based services.

I received a diagnosis of cerebral palsy when I was an infant. At that time, my parents were given the choice – take me home and raise me like any other child, or place me in an institution. They chose to take me home.

My early years were filled with family vacations, road trips with my Dad in his truck, and games, rivalry and love between me and my siblings and cousins. When I was eight, my parents were told that I needed more intense therapy services than what I could get in my home community. They were told the best thing they could do for me would be to place me in a facility where I could get physical, occupational and speech therapy.

So, all of a sudden, I found myself in a town two hours from my home – alone without understanding why. I was totally unprepared for this strange setting. Instead of my family and friends, I found myself sharing my life with 97 other individuals with disabilities. Some of those strangers became my friends, but no one could replace what I left at home.

Because I did not understand, I cried for those first two days, and then many days off and on for the two years I lived there full-time. After those first two years, I returned to my home during the school year, and spent summers back in the facility.

It took three years to learn the system – to know what to expect and be able to handle things without those childhood tears. For example, I learned independence. We were not allowed visitors as they might upset us. I learned not to trust people. In a congregate setting, the young kids gets teased and bullied by the more experienced. Kids take things from each other, and worse, if adults see something they like, those things also often come up missing.

In that same setting, my experience included having to go along with demands of an authority figure who had power to make my life miserable – even when that authority figure's demands included misusing my body to meet his personal desires.

I got all the intense therapy I needed – but at what cost?

When the professionals decided that the therapy had gone as far as it could, I returned to my family home. That experience – though over four decades ago – has had lasting impact on my life and my perspectives.

Today I live with my wife, who also has Cerebral Palsy, in a home we own. I work full-time. I drive myself to work and wherever else I need to go. I have many, many friends,

some who have a disability, some who do not. I live a full life – a life that I direct myself with supports.

I also carry with me each and every day the burden of knowing that the threat of institutionalization is as real for me today as it ever has been. If I lost the funding sources that provide me the ability to maintain my life as it is, my salary could not cover the costs of having staff to assist me with getting ready for work, preparing my meals, or getting me into bed at night.

Without that support, I'd have few options but to return to a setting much like the facility I knew those early years. I would then no longer be directing a few select personal assistants to assist me with the choices I make on how I like to live, and I would also no longer have the independence I know today. My life would lack privacy. When I lose choice, independence and privacy, I also lose my dignity and I lose my freedom.

In order for me to maintain my life in the community, and to provide other people of all ages who live with disabilities today the same opportunity, I ask you to:

- Eliminate the institutional bias in Medicaid by requiring states to include community based personal assistance services in their Medicaid plans. Individuals who qualify for Medicaid should automatically be eligible for community services—not just services delivered in institutional settings as in current law.
- Provide financial incentives for states to help individuals transition from institutions to community settings. Because community settings are typically less costly, this benefits not only the individual but also the federal and state treasuries.
- Assist states in developing and implementing a strategy to "re-balance" their long term care systems so that there are more cost-effective choices between institutional and community options.
- Provide financial support and create incentives for states to develop quality community-based supports and services, including support to help states find ways to recruit, train, and retain direct support workers.
- Offer respect to the people whose lives are affected by disability policy decisions by not just listening to them, but by having them be a part of the decision-making itself.

Today, I am an active advocate for all people with disabilities. I serve on many boards and committees, two of which strongly apply to this topic:

- I am a member of Iowa's Olmstead Real Choice Consumer Task Force. We are working to effectively implement the Olmstead decision in Iowa. This includes advocating for the policies I just stated as well as working with the Iowa Department of Human Services to take advantage of CMS's new progressive policy of self-direction, which promotes community living and affords individuals more choice and control over the services they receive.

- I also serve as the co-president (self advocate representative) for the National Coalition on Self-Determination, Inc. – the only national coalition that has both parents and consumers working together on issues.

The work of both of these groups focuses on "real choices" –

- The freedom to live the way you want – to self-direct your life
- To be able to purchase the services you need to support you in your life
- To live a life with dignity
- To have the freedom to make new friends and participate in your community, and
- To support your right to vote

Again, I urge you to pass legislation that will incorporate the policies I have mentioned today that help people like me have all the right resources exist in the community for me to participate fully as an American citizen. Your decisions are important to the lives of many, many people who like me, live under a threat that should not be present.

Thank you very much for your time and attention to improving access to Medicaid Home and Community Based Services.

Finance Committee Hearing
Responses to Questions for the Record
By Ray Gerke

Questions from Chairman Charles Grassley to Ray Gerke:

1. *Mr. Gerke, in your testimony you refer to the term "institutional bias" and propose that Congress should work to eliminate this bias from the Medicaid program. Could you please define the term "institutional bias" and provide suggestions on what steps Congress could take to eliminate this bias from the Medicaid program?*

   I would define institutional bias by pointing out that the largest percentage of money goes to ICFMR's and nursing home facilities while community services get a smaller proportion of the money available. There is no choice. Individuals should be able to make a choice as to where they want to live. The fact is though, there is never a doubt that care would be available in an institutional setting... the same option should be as accessible for someone wanting to live in the community.

   I would suggest steps to eliminate the bias include reversing those amounts; support community placement opportunities at the same level as facilities. That money should be provided in a way that gives the individual a choice to purchase services elsewhere if they want.

2. *I'm pleased to hear that you are serving on Iowa's Olmstead Real Choice Consumer Task Force. As you know, the task force received a grant from the Centers for Medicare and Medicaid Services (CMS) and aims to remove institutional bias, prevent institutionalization, and provide choices to Iowans with disabilities about where they will live and what services they will use. What is the Olmstead Task Forced doing to increase access to Home and Community Based Services? Has the task force made recommendations that will impact the Iowa Medicaid program?*

   The task force has made recommendations; for example, with the Iowa MH/MR/DD/BI system redesign, the task force made recommendations and the design team did listen and implement many of those. From my perspective, the task force has not specifically increased the access to the waiver program. A large portion of the focus has been on increasing awareness levels. I would, quite honestly, like to see the task force accomplish more than it has.

Questions from Senator Jim Bunning to Ray Gerke:

1. *When did you live in an institution? How long were you there?*

   I lived in the facility for two years (1958 to 1960) year-round, and four years in the summers that followed (1960 – 1064).

2. *How do institutions today compare to the one you were committed to years ago? What has changed?*

   Speaking specifically from my own knowledge of the facility I stayed in and one of the state institutions which I am most familiar with, I would say the direct care staff today is better trained and prepared. The facility I resided in was in a college town so staff had a wide range of abilities. A second difference today is that when I was living in the facility, I had no idea that I had any rights. Today, at least in one Iowa institution, residents are made aware of their rights and the responsibilities that go with those rights.

Questions from Senator Jim Bunning to Panel III:

3. *Receiving community –based care is not an option for everyone. What type of factors should be considered when determining if home-based care of institutional care is best for a particular individual?*

   First, with all due respect, I must admit that I disagree with your beginning statement of fact. I believe that services can be provided in the community no matter what level of care is required. There are models available in pockets around the country that can show it can and does happen. Each individual should be allowed the choice to access services whether they be in a congregate setting such as an institution or the community. Community services should be as accessible and have as high of level of care in order to offer all individuals the ability to stay in the community of their choice.

[SUBMITTED BY SENATOR GRAHAM]

United States Senate

WASHINGTON, DC 20510

January 30, 2004

The Honorable Charles Grassley, Chairman
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Max Baucus
Senate Finance Committee
254 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Grassley and Senator Baucus:

We are very troubled to learn that the Bush Administration's newly-revealed cost estimate of the *Medicare Prescription Drug, Improvement, and Modernization Act of 2003* is $534 billion over the period 2004 to 2013. This is an enormous increase from the $395 billion estimate presented to Congress just two months ago. If the Administration possessed this analysis prior to final congressional action, its failure to share these figures would be both misleading and inexcusable.

Accordingly, we are requesting that you hold hearings to examine when the Bush Administration reached its conclusions and whether these estimates were concealed or withheld from senators and members of Congress. We are confident that you share our concern regarding this enormous cost overrun. The Administration had a clear obligation to share its cost estimates, if they were completed, with all senators to better inform us in voting on the conference report.

We also ask you to examine the basis for the Administration's numbers. We are particularly concerned about the extent to which the inflated estimate is a result of further overpayments and giveaways to HMOs. Moreover, we have also just learned that, by the Administration's own estimates, the price of the new law will continue to skyrocket. If the budget window is shifted just one year to the period 2005 to 2014, the cost balloons to $621 billion. Surely, in the face of these estimates, we must address the new law's failure to meaningfully reduce the cost of prescription drugs and the consequent increase in drug company profits.

For these reasons, we believe it is critical that, in addition to investigating the timing of the release of these numbers, you also hold hearings to examine the underlying assumptions and basis for the Administration's estimates. As members of the Senate Finance Committee, we would welcome the opportunity to participate fully in such hearings.

United States Senator

United States Senator

United States Senator

United States Senate

WASHINGTON, DC 20510

March 26, 2004

The Honorable Charles Grassley, Chairman
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, DC 201510

The Honorable Max Baucus
Senate Finance Committee
254 Dirksen Senate Office Building
Washington, DC 20150

Dear Chairman Grassley and Senator Baucus:

We write to respectfully request that the Senate Finance Committee convene an oversight hearing regarding the Administration's cost estimate of the *Medicare Modernization and Improvement Act (MMA)* and the circumstances surrounding the failure to release this analysis to Congress.

You may recall some of us wrote to you on January 30 requesting a hearing based on the Administration's then newly-revealed cost estimate of the *Medicare Prescription Drug, Improvement, and Modernization Act of 2003*. The need for that hearing has grown greater over the past two weeks.

Recent news accounts indicate that Mr. Rick Foster, the Chief Actuary of the Medicare program, was ordered by the former Administrator of the Centers for Medicare and Medicaid Services, Mr. Thomas Scully, to withhold critical actuarial data from Congress, and that failure to abide by this order may result in his termination. If this information is accurate, the procedure followed was contrary to past practices, and, moreover, appears to directly violate the Balanced Budget Act of 1997 which confirmed the independence of the Chief Actuary.

Most troubling is that the Chief Actuary had information that would have been valuable to us – both Republicans and Democrats – in our deliberations long before we took our votes on the conferenced version of the legislation. The White House first indicated that their experts estimated the bill's cost at $534 billion in January 2004 – after the President signed the bill. In Finance Committee and Budget Committee hearing testimony in February 2004, however, Secretary Thompson said that the actuaries had estimated the higher cost in December 2003. Mr. Foster's statements contradict both of the above time lines. Mr. Foster has indicated that he had provided relevant cost estimates directly to the White House as early as the summer of 2003.

The New York Times reported on March 14 that Mr. Foster estimated a drug benefit similar to the Senate-passed measure could cost significantly over $500 billion as early as mid-June. According to the New York Times article, "Mr. Foster said he prepared "dozens and dozens of analyses and estimates" of the cost of the legislation last year. "All our estimates showed that the cost of the drug benefit, through 2013, would be in the range of $500 billion to $600 billion," he said. The cost estimates were all provided to Mr. Scully, and some were also sent to the White House, the Office of Management and Budget and top officials at the Department of Health and Human Services, Mr. Foster said. For example, he said, "some cost estimates were sent directly

to Doug Badger," the White House official who coordinates health policy for the administration."

Many members of the Senate voted for the legislation in part because they believed the bill would cost no more than the $400 billion limit provided for in the budget resolution. While some members of the Senate advocated for legislation that was significantly more costly than $400 billion, the MMA legislation was the bill that was voted upon. If Congress was deceived as to the true cost of this bill, the Finance Committee should investigate this deception, and the relevant circumstances surrounding these actions in order to prevent any such reoccurrence.

Specifically, we believe that a Finance Committee oversight hearing should include testimony from Secretary Thompson, Mr. Scully, Mr. Foster, and Mr. Badger. We are particularly interested in answers to the following questions:

- When did Mr. Foster first project that Medicare program's cost would be greater than the $400 billion limit set by Congress? When did the Office of Management and Budget first learn of a potentially higher estimate from the Office of the Actuary (OACT)? When did the President first learn of a potentially higher OACT estimate? Witnesses should provide the dates on which anyone within the Office of the Actuary, within CMS and/or within the Department provided information and estimates of the cost of the Medicare legislation to anyone in the White House or the Office of Management and Budget.

- What communications have taken place between Mr. Foster and Mr. Badger, Mr. Scully and others concerning analyses and estimates of the cost of the Medicare bill over the past 15 months, and when did they take place? Similarly, witnesses should testify to communications between Mr. Scully and others in the Administration.

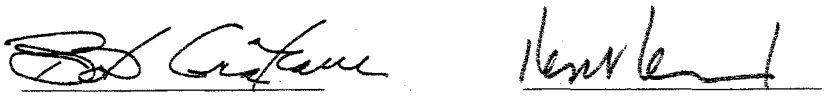
- What actions, if any, were taken by the Department of Health and Human Services, the Office of Management and Budget and/or the White House to prevent the timely and accurate reporting of information known to the Chief Actuary on the subject of the cost of the Medicare bill?

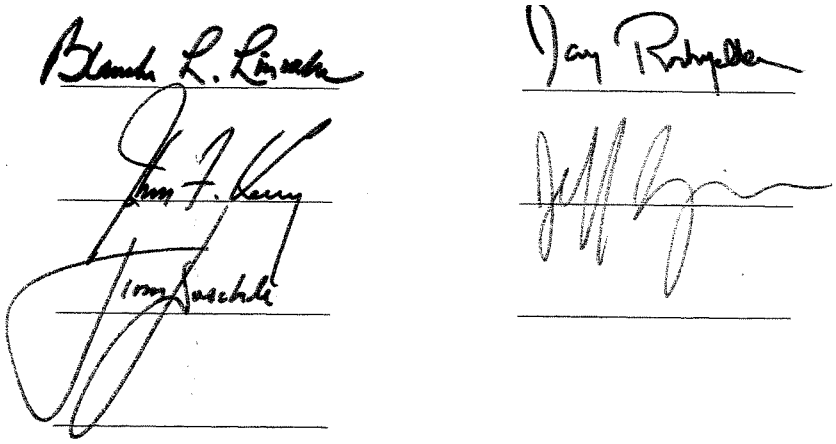
- Was Mr. Foster told or in any way pressured to withhold information from Congress? Was his job in jeopardy at any time?

Additionally, it would be most helpful if Administration witnesses would provide copies of all analyses and estimates of the cost of the prescription drug legislation prepared by the Office of the Actuary during 2003.

Thank you for your consideration of this request.

Sincerely,





U.S. SENATE COMMITTEE ON
Finance
SENATOR CHUCK GRASSLEY, OF IOWA - CHAIRMAN
http://finance.senate.gov

Opening Statement of Sen. Chuck Grassley
Hearing, "Strategies to Improve Access to Medicaid Home and Community-Based Services"
Wednesday, April 7, 2004

Good morning. This hearing will come to order. Let me start by extending a special thanks to the witnesses for their participation in today's important hearing. And, I'd like to give special thanks to those who traveled long distances to be here today, including two Iowans -- Diane Findley and Ray Gerke. The purpose of today's hearing is to review proposals to improve access to Medicaid Home and Community Based Services. One of these proposals is the President's New Freedom Initiative. Another is the Medicaid Community-Based Attendant Services and Supports Act of 2003, also known as the MiCASSA bill. We will hear about aspects of both of these proposals today.

The President first announced the New Freedom Initiative over two years ago. Since that time, government agencies have been busily working together to find new ways to improve services we refer to as "home and community based services." Today, we'll take a close look at the various programs laid out in the initiative. One demonstration would allow individuals who choose to live at home or in the community to make decisions about not only where they are going to live but also how their care is delivered. This is known as "Money follows the Person."

Another concept in the initiative would allow individuals who rely on family caretakers the chance to receive respite care. The respite demonstration recognizes that individuals who receive care and their caretakers occasionally need to step away from their respective roles. A third demonstration would test a proposal to offer community-based services to children residing in psychiatric residential treatment facilities. Finally, we will discuss the importance of providing additional supports to those who choose the career of a direct care worker. Like nurses, direct care workers are becoming a scarce resource.

Each of today's witnesses brings a unique background to the issue. The collection of their individual experiences and perspectives will help us better understand the home- and community based service system. For instance, the community-based services demonstration for children receiving care in psychiatric residential treatment facilities draws attention to an issue that I continue to defend. Current law does not allow states to offer Medicaid home- and community-based services as an alternative to inpatient psychiatric care. Susan, a single mother from Harlan, Iowa, described her frustration trying to keep her family together. Her son, Colton, has been diagnosed with bi-polar disorder and depression and is developmentally delayed. One of his biggest fears is having to leave his mom. Susan feels she is willing and able to care for him at home if she gets the supports

and services at her community level. The lack of covered home- and community-based supports means that some parents face the impossible decision of relinquishing custody of a child to a state institution so their child can get necessary, live-saving services.

A provision in the Family Opportunity Act, which is legislation I sponsored for the past three Congresses, recognizes the hardship that families face in caring for a child with a mental health illness. Under my bill, families will no longer have to give up their child. These families deserve understanding and compassionate public policy that addresses the special needs of caring for a child with mental illness.

As we consider recommendations regarding the direction of future policy-making, it's important to keep in mind the legislative history in this area. Like Medicare, the Medicaid program was first enacted in 1965. Our nation's service delivery system was vastly different at that time than it is today. Thanks to the dedicated advocacy of consumers and their family members, our long-term care system has seen major improvements over the years. That's not to say that our work is finished. Far from it. Unfortunately, the demand for home- and community-based services exceeds current capacity. States, providers, and many others have made great strides in building capacity in consumer demand, but many challenges remain. It's also important to note that not all consumers want to be cared for in their homes. For instance, nearly one million frail elderly citizens are currently cared for in a nursing home.

The elderly and people with disabilities and their families deserve a choice. They should have the ability to choose whether they prefer to live in the community or in a facility. Home- and community-based services consist of a vast array of services. The system is complicated whether you are on the inside or the outside. Consumers of the system are the best judge of how well a system is working. I welcome their input and suggestions on how to shape current or new policies. The overarching goal of our hearing today is to further understand the kinds of successful, cost-effective and consumer-friendly systems of providing home- and community-based services to Medicaid beneficiaries.

PREPARED STATEMENT OF HON. TOM HARKIN

I want to begin by thanking the Chairman and the Ranking Member for holding this hearing. Senator Smith and Senator Specter joined me in requesting this hearing, and I am very grateful to the committee for taking up this important issue. We are very fortunate to have the leadership of my friends from Iowa and Montana on this important committee and I thank them for their work on behalf of older Americans, people with disabilities, and those with low incomes. I'd also like to recognize Senators Specter and Smith for their ongoing leadership on the issue before the committee today: how do we give older Americans and people with disabilities greater choices by expanding access to community based services.

When we passed the Americans with Disabilities Act almost 14 years ago, we said that our nation's great goals regarding individuals with disabilities were to ensure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals. And when we passed ADA, I was under no illusions. I knew then that Medicaid was going to be the next challenge, because some of the Medicaid rules prevent us from reaching all of these goals. It is hard to be full participants and economically self-sufficient if your only choice is to live in a nursing home or institution.

Since 1990, I have been working to correct the institutional bias in our Medicaid program. And I am hopeful that this hearing is the beginning of a quick legislative process to finally address this serious problem. According to the Congressional Research Service, national data indicates that we are spending 70 percent of our Medicaid long-term care dollars on institutional and nursing home care, and only 30 percent on community-based services. The Chairman will be interested to know that in Iowa, the latest figures are even worse: 81 percent of our state's Medicaid funds are going to institutional and nursing home care, and only 19 percent is paying for services in the community.

This is wrong – and it's time to rebalance the system. That's why I have introduced two bills that would make a tremendous difference. I hope the committee will look carefully at these bills and move quickly to mark up legislation and move it to the floor.

The first bill is called MICASSA for short. That stands for the Medicaid Community Based Attendant Services and Supports Act. MICASSA has a simple aim. It would level the playing field by requiring states to cover community services under their Medicaid programs. Right now, states are required to provide nursing home care, but there is no similar

requirement for community attendant services and supports. Why should this be? MICASSA would change that, and it's high time.

The second bill, the Money Follows the Person Act, also has a simple aim. It says: Provide resources so people with disabilities and older Americans can make their own choice among service options. The Money Follows the Person Act would provide 100 percent federal funding for the first year of community-based services for people who move out of a nursing home or institution. After that first year, the individual would remain in the community, and states would receive their regular Medicaid match for their services. States would be allowed to expand their waiver programs, offer new waivers, or add community based services to their Medicaid plans. The Money Follows the Person Act would provide $350 million a year for a total of $1.75 billion over 5 years. And that would be a major contribution to expanding community services.

It is important to note that these two bills are bipartisan initiatives, as was the ADA and other major civil rights legislation for individuals with disabilities. Senator Specter has joined me in co-sponsoring both of these bills. Senator Smith is the lead Republican co-sponsor of the Money Follows the Person bill.

In addition, the Money Follows the Person program is a critical piece of the President's New Freedom Initiative. We have support from President Bush and from both sides of the aisle for moving forward to expand access to community based services. That's why I am so hopeful that we can move forward quickly to put an end to needless institutionalization.

Let me give you just one example of how these two bills can transform the lives and living conditions of people with disabilities. I was in Iowa just a few weeks ago to talk about these initiatives. And I had the privilege to be on a panel with a young man named Joel Justin. Joel is a 36-year-old man who experienced a brain injury. He is currently forced to live in a nursing facility in Waterloo -- more than two hours away from his family and friends -- because there is no funding to support him in his own community. He spends most of his time watching TV, but he would prefer to be working at a job. He also wants to live in his own apartment because he is tired of the restrictions in the facility. He says that he wants – and I quote -- "freedom to do whatever I want and to come and go as I please."

The Independent Living Centers, and Protection and Advocacy in Iowa, tell me that there are many other people in similar situations. And I know that Iowa is not unique in this respect. We need to change federal law

so that Joel and thousands like him can realize their hopes and dreams, and become fully participating, economically self-sufficient citizens.

This is the right thing to do, but it is also the smart thing to do. States can save money by giving individuals greater choices. For example, when Secretary Tommy Thompson was governor of Wisconsin, the state implemented a Community Options Program to expand access to community based services. In a 2001 report to the legislature, the Department of Health and Family Services noted that, using the most conservative estimate, the total public spending of individuals served in the community was $64 million *less* than if they had resided in nursing homes for the same length of time.

While we can put a dollar figure on cost savings, there is a much greater cost at stake here – the cost in lost opportunities and lost dreams. When we passed the ADA, Congress created a vision of opportunity, equality, and independence. Current Medicaid policy is preventing that vision from being a reality for millions of older Americans and people with disabilities. They have waited 14 years since the passage of ADA for this injustice to end, and they should not have to wait any longer.

I thank the committee for the opportunity to be here today. I know that you will be hearing from many wonderful witnesses, including two

remarkable Iowans – Ray Gerke and Di Findley. I've had the opportunity to read their testimony in advance, and if all 100 Senators could hear what they have to say, I think we'd have legislation passed within weeks.

Again, I want to thank the Chair and Ranking member for inviting me to testify. I stand ready to help in any way I can to move this process forward and get legislation passed and signed into law.

Statement of Senator John F. Kerry
Finance Committee Hearing
"Strategies to Improve Access to Medicaid Home and Community Based Services"
April 7, 2004



Last September, at the conclusion of ADAPT's "Free Our People" march, I joined Senator Harkin and many other of my colleagues in calling for Congressional hearings on the MiCASSA bill and for this landmark legislation to be enacted without further delay. I appreciate the willingness of Chairman Grassley and Ranking Member Baucus to conduct such an important hearing and believe this is a crucial first step in bringing us closer to ending the institutional bias that exists in Medicaid today.

But let's stop fooling ourselves. We don't need a hearing to discuss strategies for improving home and community based services under Medicaid. We know what works. We know what needs to be done. What we must do is to summon the political will to make it happen. People with disabilities are rightfully tired of the excuses they hear out of Washington and in State Houses across the country on why, for one reason or another, they must wait for justice to be delivered. Justice delayed is justice denied. No wonder people in wheelchairs are chaining themselves to fences and taking to the streets. If the tables were turned, we would be doing the same.

This is America. No one should be imprisoned in a nursing home or denied the help they need to eat, bathe, dress and live in their communities. We must right this wrong by making the policy changes necessary to fund people and their needs, not just programs and their rules.

Let me start by saying that I am one of the biggest supporters you'll ever meet for strengthening and protecting the Medicaid program. I strongly oppose the Bush Administration's proposal to block grant it to the states. Medicaid's entitlement should never be threatened. I am deeply concerned about the growing trend among states using Medicaid as a source for service cutbacks and eligibility restrictions to balance budget deficits. States are already woefully in non-compliance with the *Olmstead* decision, in part, due to the fiscal stresses many of their budgets are experiencing in this troubled economy. Fiscal relief for states – in the form of higher Medicaid reimbursements – should be a consideration during this federal budget cycle. Without additional relief, optional Medicaid programs and benefits for people with disabilities are sure to be threatened – from implementation of the Ticket to Work and Work Incentive Improvement Act, to growing waiting lists that result from reduced slots under current home and community based waiver programs. But such funding should only be offered in exchange for assurances that Medicaid coverage will be preserved or expanded – not used as a slush fund for tax cuts or to cover other state funding shortfalls. Keeping Medicaid strong should remain a top priority for this Committee.

But for all of Medicaid's strengths, there is one inherent weakness in the way the program is structured – and that is the cruel choice that many people with disabilities must make to receive any assistance at all: leave your home, your family, your friends, and your community to live in an institution, or be denied care. What kind of a choice is that? It's un-American. We must stand for freedom, independence, and real choices for people with disabilities and it starts with assuring equal access to community living services to people with disabilities of all ages nationwide.

The ADA stands for the proposition that people with disabilities have the right to be a part of the American community rather than to live their lives separate and apart from it. For these reasons, I am a proud original cosponsor of MiCASSA and the Money Follows the Person Act. Passage of both of these bills is vital to ending the institutional bias that makes it impossible for millions of Americans to exercise the most basic of human liberties: freedom, choices, and independence. These are the birthright of every American. Our nation's long-term care policies and programs must promote rather than undermine these cherished values.

The time has come and gone for us to get serious about making these needed changes to improve the lives of people with disabilities. I look forward to working with you, Chairman Grassley, and members of the Committee, to move as quickly as possible from just talking about the problem to actually implementing the solutions. In the 1960's, Martin Luther King answered those who claimed that we must go slow to right the great and seemingly insoluble injustices of his day in a book entitled, *"Why We Can't Wait."* Today, we will witness living proof of why we can't wait to right these grave and seemingly insoluble injustices of our own day and time.

Testimony of Jan Moss
Family Caregiver
Oklahoma City, Oklahoma
Senate Finance Committee Hearing
"Strategies to Improve Access to Medicaid Home and Community Based Services"
April 7, 2004

Mr. Chairman and Members of the Committee,

Thank you so much for the opportunity to testify today. I especially want to thank Sen. Grassley and Sen. Baucus for the invitation and Sen. Nickles for his long-serving leadership in representing the state of Oklahoma in the U.S. Senate.

My name is Jan Moss. I am a family caregiver and have been providing supervision and care to both my children (now adults) with developmental disabilities, and my husband's parent(s) for a total exceeding 36 years. I am a widow now, and continue to have the same caregiving responsibilities that were shared when my husband was living.

I am here to support the President's proposals for respite demonstration programs for both Medicaid enrolled adults and children as outlined in the proposed New Freedom Initiatives Medicaid Demonstrations Act. Given the serious funding shortfall for respite in most states, any new resources for respite would be a godsend. But I am also here to tell you about Oklahoma's Lifespan Respite Care Program – the "Oklahoma Respite Resource Network" -- that has helped thousands of families not eligible for Medicaid, but in dire need of respite. I want to begin by thanking you and the entire Senate for its leadership in passing the Lifespan Respite Care Act which would help strengthen Oklahoma's efforts and make Lifespan Respite systems available in more states.

When my children were young, I did not even know I needed respite. There were no respite projects or information explaining the need and support that respite provides. In recent years, I have made use of respite services and know the difference it has made in my life and in the well-being of my family. I am grateful and appreciative of this opportunity to share my personal experience to promote and explain the value and necessity of respite.

My husband and I divided our entire lives into "*pieces*" of care. Frequently, our time for each other was the missing "*piece*". We reserved our paid leave for hospital "vacations." We prioritized our employment according to who had the best benefits. The unusual care needs of our children affected every decision in our marriage and family life.

Except for the birth of my son, I went 18 years without taking a full day's rest due to illness or injury. No wonder I have blocks of time for which I have little or no memory. Those years I call my "automized-suspension." I was suspended in a fatigue fugue that allowed only for basic routine and automated behavior. I remember waking on our divan or in one of the kid's rooms, but did not remember going to sleep there. I remember the year of Jennifer's tendon transfer, the year of Jason's heart surgery, eye surgery, hernia surgery, oral surgeries; the many heart caths, EEG's EKG's, ultrasounds, major uncontrolled seizures, or minor uncontrolled seizures, but I do not remember the birthday parties and anniversaries. Family pictures capture me at those events. I can prove I was there, but how sad, how tragic not to recall the benchmarks of my family.

Caregiver fatigue related directly to the spinal cord injury of my husband's mother. She fell about 4 years into caring for my father-in-law who developed Parkinson's, then Alzheimer's disease. Ten years later, in addition to caring for my two adult children who still live at home, I now share a portion of my mother in-law's care with my husband's sisters.

The most difficult experience for me personally was the sudden death of my husband and care mate. On Fathers Day of 2000, he dropped dead from an undiagnosed heart problem. Now I see how important those missing pieces might have been to his health. Frightening me now is the loss of his income and my ability to maintain my health and responsibilities. It may seem heroic to you, but it is better to live for the sake of our family members who need care than to suffer and die for them. For who then will care, who then will supervise and manage the quality of care?

Respite, a brief separation from care giving, is natural. It is developmental in typical families. Constant care with no reprise for the spirit or rest for bodies is not heroic; it's dangerous and costly in fatigue related injuries and illnesses: falls, cuts, burns, not to mention prolonged stress that can lead to abuse and neglect, pharmacological mismanagement in missed dosages, over dosages, under dosages. I myself suffer from typical caregiver health issues, serious dental and joint disorders and the companion auto-immune issues associated with prolonged stress/tension.

When my daughter Jennifer turned 19, she became eligible for a "Home and Community Based Medicaid Waiver" and respite was one of the services offered. However, recent state budget cutbacks forced Oklahoma families to reduce or give up respite to lower the cost of their plans of care. If I want to continue to receive respite, I am going to have to give up other important services and supports and find a provider myself.

Oklahoma's Lifespan Respite Program

Thank goodness we have Oklahoma's Lifespan Respite Program, known as the Oklahoma Respite Resource Network, which could help me find new respite providers. The Network is a collaboration of 34 partners including three public agencies (DHS, Health Department and Mental Health), caregivers, advocacy agencies, private foundations and providers. This network has redirected almost $1.8 million in public and private funds to respite care in Oklahoma and is able to serve families across age and disability categories.

The network was built on family support principles. Our system was built on the belief that caregivers are the experts and should be in control of the resources. Caregivers are given vouchers to purchase respite care from anyone they choose and negotiate the rate of pay. This can be another family member, friend, next door neighbor, day care center, home health agency, or a private provider. A survey completed in August of 2003 for the Oklahoma Respite Resource Network showed that 85% of the caregivers chose a respite provider from within their own natural support system.

If families need help in finding a respite provider, or finding out what programs they might be eligible for, they can turn to the Oklahoma Respite Resource Network. If a family desires training for a respite provider of their choosing, the state will provide that as well. The Oklahoma model has flexible funding, so the state can find the most cost effective way to deliver services, and allow caregivers control over resources.

This program currently serves approximately 2200 caregivers. For the past 3 ½ years the average cost for the respite vouchers has been between $5.62 and $5.87 per hour, compared with $12.80 to $26.50 per hour if the caregiver had chosen a provider from a private/public agency. This program has proven that caregivers are much more cost efficient with the resources.

Many policy makers think that when a caregiver or family needs support, that it will cost tens of thousands of dollars. We have shown that respite is a cost effective way to meet the needs of caregivers. In Oklahoma, caregivers are eligible for $400 in vouchers every three months. In our survey, 47.7% of the caregivers said this amount was adequate to meet their needs; 52% said they could use more, but added that they needed

just another $100. This means that $1600-$2000 per year would meet the needs of 97.7% of the caregivers in Oklahoma.

We know respite allows caregivers to keep their loved ones at home longer, reduces stress, improves the stress levels in a home, reduces the risk of abuse and neglect and improves the quality of life of the caregiver and the care receiver. In the survey conducted by the Oklahoma Respite Resource Network, 88% of caregivers agreed that respite allowed their loved one to remain at home, 98% of caregivers stated that respite made them a better caregiver, 98% of caregivers said respite increased their ability to provide a less stressful environment, and 79.5% of caregivers said respite contributed to the stability of their marriage.

Benefits of New Freedom Initiative Respite Demos

On behalf of caregivers nationwide, I applaud the Administration's recognition that respite is central to the concept of home and community-based services. The New Freedom Initiatives Medicaid Demonstration Act respite demonstration proposal, which represents a small, but absolutely necessary infusion of funds for respite for the Medicaid population, may demonstrate that respite is a benefit worth providing under Medicaid. This is especially critical now when many existing state Medicaid waivers are eliminating or cutting back on the respite benefit because of serious state budgetary constraints.

With a focus on evaluating the effectiveness of respite in promoting home and community based services, the NFI provisions would also strengthen and add credence to respite findings from evaluations already underway by such national organizations as the ARCH National Respite Network and Resource Center that are demonstrating how effective respite is in keeping families together, strengthening marriages, and avoiding or delaying more costly out-of-home placements.

Lifespan Respite Care Act (S. 538, HR 1083) Complements NFI Respite Demonstrations

I also applaud the Senate for passing the Lifespan Respite Care Act (S. 538). This bill has been endorsed by the Lifespan Respite Task Force, a diverse coaltion of over 180 national, state and local organizations. The NFI respite demonstration funds are critically needed and are fully complementary to respite systems that would be established by the Lifespan Respite Care Act. The NFI demos alone, however, will not address the respite care needs of millions of family caregivers who are not Medicaid eligible or currently not eligible for any government program. Under the proposed NFI respite demos, in addition to limiting eligibility to only those enrolled in Medicaid, states can limit respite to a specific geographic area of the state, to a limited number of individuals, or to specific disability or chronic condition.

Millions of these families and caregivers who would not be eligible under NFI sustain extraordinary expenses and sometimes even job loss due to the disability or chronic condition of their loved ones. As a result, many cannot afford respite. Even when family resources are available to pay for respite, finding quality respite that meets a family's needs and preferences, and is appropriate, safe, culturally acceptable, or geographically accessible may be impossible.

NFI respite demos are an important piece of the puzzle. If that piece is missing, the picture is not complete. But the Lifespan Respite Care legislation is the glue that holds the picture together.

The Lifespan Respite Care Act would allow states to provide the infrastructure for coordinating and maximizing use of all existing respite resources. Existing categorical federally or state funded respite programs often have limited reach because of restrictive eligibility criteria, limited funding, and long waiting lists. Other federal or state programs

may have the potential to fund respite, but often don't because of limited resources and competing demands. As a result, families often do not know where to turn to find or pay for respite resources.

Under the lifespan approach, states can identify and coordinate existing respite resources, pool and share providers, funds, training resources and administrative capacities, and identify and fill gaps in services. The Lifespan Respite Care Act provides a way to improve efficiency, save money, and make quality respite available and more accessible to families and caregivers, regardless of their Medicaid status, disability, or age.

Lifespan respite programs also exist in Oregon, Nebraska and Wisconsin. With flexible funding and requirements, each program has been adapted to meet their individual state needs, but the defining characteristic of each is the statewide, coordinated approach to ensure respite services for those in need. Many of the lifespan respite programs have established community-based networks that rely on the development of local partnerships to build and ensure respite capacity. These local partnerships include family caregivers, providers, state and federally funded programs, area agencies on aging, non-profit organizations, health services, schools, local business, faith communities and volunteers.

These networks are the central point of contact for families and caregivers seeking respite and related support regardless of age, income, race, ethnicity, special need or situation. Respite stipends may be limited by income eligibility, but are generally more generous than existing programs. Providing a single point of contact for families to access respite information and services is crucial to assisting families in helping themselves.

Services typically offered by Lifespan Respite Programs are providing public awareness information to the community and building diverse respite partnerships, recruitment and training of paid and volunteer respite providers, connecting and matching families with respite payment resources and providers, coordinating respite related training for providers and caregivers, identifying gaps in services and creating respite resources by building on existing services.

State Medicaid Programs Work Cooperatively with State Lifespan Respite Programs

Precedent has already been set by these State Lifespan Respite Programs for cooperative working and funding arrangements with State Medicaid agencies. In Nebraska, the regional Lifespan Respite Network Coordinators recruit providers for Medicaid, as well as for the Lifespan Respite Program. The Coordinators meet with staff from HHS, DD, Early Intervention Program, etc. on a monthly basis in order to determine need. Respite providers are recruited and trained to fill the gaps, and provider lists are shared.

Oregon was the recent recipient of a CMS demonstration grant for respite care for children with disabilities this fiscal year. The state will be doing a feasibility study to look at how Oregon's Lifespan Respite system could be the structure for implementation of that effort. Secondly, local community Lifespan respite registries share providers. Local coordinators also share training resources and criminal background checks. The Medicaid Home and Community Based Waivers that pay for respite in the state have Medicaid case managers coordinate with local Lifespan Respite Network coordinators.

I urge you to support the President's proposed NFI respite demos, which would provide benefits to some very needy families and caregivers, and infuse funds for critically needed respite services, training and evaluation. At the same time, it is my belief that these benefits would not be fully realized without enactment of the Lifespan Respite Care Act as well. I urge you to work with the House colleagues to move the Act forward. Thank you for this opportunity.

Strategies to Improve Access to Medicaid Home and Community-Based Services

Response of Jan Moss, Family Caregiver, Oklahoma City, Oklahoma to a question from the Honorable Senator Jim Bunning, Senate Finance Committee

Question for the Record: "Receiving community-based care is not an option for everyone. What type of factors should be considered when determining if home-based care or institutional care is best for a particular individual?'

Response: Decisions regarding choices between home-based care or facility-based care for a particular individual are best made by the individuals themselves and their families.

Factor 1) Family caregiver fear and exhaustion determine and even may force decisions for out-of-home placement. Families are forced to choose institutional/congregate care when their fiscal, physical, and mental resources are depleted, no one is helping, and they are exhausted and worried, seeing no light at the end of the tunnel. *The caregiver fears that they must make "arrangements" which will continue in the event something prevents them from giving care.* Frequently the only choice is a nursing facility, not because care cannot be provided at home, but because of the *fear* it cannot be provided at home. Fear is a *bully* in the daily lives of family caregivers. Fear is the insidious hideous voice that endlessly repeats; "How are you going to do this the rest to your life? What if you get sick? What if your car breaks down? What if you loose your job? What if you don't ever get a full-nights sleep? What if the cost of meds or diapers or equipment goes up?" When services and supports are directed to the family and individual needing care and help to answer those questions is provided and fear put aside, then a determination should be made by the family.

The ARCH National Resource Center on Respite and Crisis Care reports respite helps families avoid more costly care in out-of-home placements. Hospitalizations, institutionalization, nursing home, and foster care placements have been shown to decline with statistical significance when respite or crisis care is the intervention.

Factor 2)Funding is always a main determinate of where care is provided. Funding should be directed to where the individual needing care wishes to be served. *It is not a choice if services will only be paid for and available in an institutional/congregate setting.* Choices and options for making the determination for home-based care or institutional care should be based on real services obtainable and accessible in **either setting**.

According to the testimony of Dennis Smith , Director of the Centers for Medicaid and Medicare before this committee, 71% of Medicaid funds for long-term supports for seniors and person's with disabilities were spent for institutional services. Carol Novak, National Council on Disability, testified before this committee, "The institutional bias of the Title XIX (Medicaid) program, in which home and community based waiver-funded services and personal care are optional and while nursing facility services are required, and financial eligibility rules for institutional residents are more generous than those for people living in their own homes, greatly compounds the problem."

Factor 3) Flexibility for directing dollars and supports also is a key factor. If we direct the kind of support and resources to families and individuals that we do for institutional/congregate care, the ***best care will emerge***!

Factor 4) The **fallacy** in out of home/institutional placement is that it also provides respite for the family and other informal caregivers. Families who have been forced to place their members

requiring care in institutional/congregate settings report that what eventually occurs is that they are *still* providing care. They face the disadvantage of not having quality control. New issues emerge regarding visiting hours, regulations, medical neglect, depression management, detachment issues, staff arguments -- the list is endless. The only change has been the physical location of problems. The locos of control for solving the problems has been exacerbated. The stress and worry remains.

I'll conclude by stating ***Respite*** is central to prevention and treatment of caregiver preservation. Facility-based care should be a point on the continuum of long term care and one of the choices individuals could make, but the current funding, eligibility requirements, and lack of caregiver supports, such as respite, make it the point from which there is little rescue.

Thank you for the opportunity to respond to your question.

Sincerely, Jan Moss

Strategies to Improve Access to Medicaid Home and Community-Based Services

Response of Jan Moss, Family Caregiver, Oklahoma City, Oklahoma, to question from Chairman, Senate Finance Committee, The Honorable Charles Grassley

Question for the Record: "Could you explain to the committee what a typical day is like in the life of Jan Moss? What time do you rise in the morning, what are your daily duties, and what time do you finally go to bed?"

Response:

There are rarely typical days, but there are days that have fewer interruptions than others. A good day begins when Jason has not had a seizure during the night and I don't have to change his bed and bathe him. It's a good day when I don't have to call the neurologist and adjust any of his three medications. It is a good day when I can sleep until my alarm goes off and have not been awakened, startled and scared by a noise that could possibly be Jason having a seizure. That kind of a good day begins about 6:30 AM.

Before I leave for work everyday there are the "have-to-do's and need-to-do's" that must be completed: Do any of the 9 prescriptions need to be refilled and picked up? Which case managers (DDSD, DHS, SSA, Medicaid) must be contacted? How much money do the kids need today. I have to check their calendars for activities, arrange schedules of direct care staff who assist them, and stop by to assist my ailing mother-in-law. I check the front door to see if the puff paint is still there so Jennifer will have a prompt to help her turn her key in the right direction when she returns from work. Some days, I must come home because she can't get in the house. I must call the taxi and make sure they have the correct time and orders for Jennifer to get to and from her work. It's a good day when Jennifer's taxi arrives on time to take her to work. It's a bad day when it doesn't arrive at all and I have to come home from work and take her myself. I lay out the breakfast foods and prepare Jason's evening meds in a baggie and put it with his wallet. It's a bad day when he has lost his wallet again and I have to replace his ID, SSA card, Medicaid card and Medicare card. Replacement of those items is very costly in time and energy. Forms must be completed, calls and contacts made, usually time lost from work.

On a good day I can go to work after execution of the *have-to-tasks*. Bad days are when it rains, or snows, or ices, or tornado warnings blurt and direct care staff can't come. Then I have to miss work or take Jason with me. It's a good day when I can stay at work all day and complete my duties and responsibilities to my employer. It's a bad day when I am called from a meeting by the police because the children have set off the burglar alarm again.

Like other families, everyday there is cleaning to be done, laundry, ironing, shopping, and evening meals to prepare. But I must also assist my adult children with trimming nails, shaving of faces, armpits, and legs. Jennifer can only use one arm, Jason doesn't like the electric razor on his face. A good day would be no arguments, head banging, anxiety behaviors or crying. A good day would be when the check books all

balance before 2 AM and I can get to bed by midnight. A good night's sleep is usually 4 to 6 hours uninterrupted.

Everyday Considerations:

- ✓ Jennifer cannot change a light bulb. She only has use of one arm and she has a drooling problem.
- ✓ Jennifer must use the relay system for all her phone calls. This requires more time to both place and answer phone calls.
- ✓ Jennifer can read and write but she cannot spell very well and is frequently misunderstood at work and this necessitates her employer calling me frequently to interpret.
- ✓ Jennifer can read and write well enough to enter magazine sweepstakes, or order things for which she cannot pay. I never know when I will have to intercede. (If I were Disney or the Franklin Mint I'd automatically discard Jennifer's orders).
- ✓ Jennifer by nature of her developmental delays is in perpetual pubescence, prone to dramatics and emotional outbreaks. I expect at least one a day.
- ✓ Jason will not use or answer the phone, he has phone fear. (You won't find it on the DSM scale but it's real inconvenient just the same). This seems odd because he talks incessantly, known as hyper verbosity. He follows me from room to room with "scanning comments, one moment on dinner, the next on electromagnetic fields, or oscillation or the properties of condensation, (like a radio on perpetual scan). Frequently I ask him to talk to the boy in the mirror, so I can collect my dwindling focus.
- ✓ Jason's seizures are of main concern all day and all night -- he has every kind. I worry about his bathing, falling down stairs, riding escalators, etc..

All these tasks were divided according to time and expertise when my husband was living. Now I fear I am wearing out all my friends and family. Dale's mother is currently in rehab from blood clots in her legs and we do not know what the future holds for her health. The kids and I visit her and my husband's sisters and I monitor her care closely. We have had to move her already because of lack of medical attention to an open wound.

Tonight I will stay up late to change and reseal the flapper valve on the toilet. I can do it. I don't want to have to take time off from work and wait for a plumber.

I graciously thank you for the opportunity to share, somewhat embarrassingly, my typical day. What is most compelling, I think, is that this routine has gone on for more than 36 years and will be my retirement routine also.

I adore my children. They are who they are. They do not need fixing, they cannot be fixed, but they do need supports. What I ask is that I am able to look at the opportunity for respite. I am not alone. Recent data from the National Family Caregivers Association conservatively estimate the number of the nation's caregivers at 25 million. An estimated one third of adults between 20 and 75 are providing some kind of informal care to an ill or disabled family member. Survey after survey of family caregivers has shown respite to be the most requested family support service and yet it remains in critically short supply.

By 2020, you and I will be part of the 40 million who may and probably will need assistance with daily living.

Sincerely provided by Jan Moss

NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

TESTIMONY OF CAROL NOVAK, MEMBER
NATIONAL COUNCIL ON DISABILITY

before the U.S. Senate Committee on Finance
"Strategies to Improve Access to Medicaid Home and Community Based Services"

Washington, DC
April 7, 2004

Good day distinguished members of the Senate Finance Committee. My name is Carol Novak. I am a Board Member on the National Council on Disability (NCD). I am also the parent of a remarkable young man who is currently trying to create his own vision for independence and community living.

Thank you for inviting NCD to be here today. NCD is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. It is composed of 15 members appointed by the President and confirmed by the U.S. Senate. NCD is charged by Congress with monitoring federal statutes and programs pertaining to people with disabilities, and assessing the effectiveness of those programs in meeting the needs of people with disabilities. As part of its mission, NCD provides a voice in the Federal Government and to Congress for all people with disabilities in the development of policies and delivery of programs that affect their lives.

As our nation's population ages, the costs and alternatives for community living, long-term care, and support services have become a subject of growing attention and concern. For many people with disabilities, including people living in institutions because of the lack of community-based or in-home alternatives and those at risk of entering institutional care settings against their will, the issues take on pressing personal significance.

Fortunately, there are some initiatives that have garnered attention and momentum in our nation that can correct this nationwide problem. The first is MiCASSA; the second is *Olmstead*; the third is Money Follows the Person. Together, these three initiatives represent a community imperative and a vision for promoting the independence of people with disabilities in all walks and circumstances of American life. These initiatives and this vision are part and parcel of the New Freedom Initiative, and are rightfully at the heart of today's Senate hearing.

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The New Freedom Initiative and Community Living

On June 18, 2001, President George W. Bush, pursuant to his New Freedom Initiative, issued Executive Order No. 13217, committing the Administration to implement the integration mandate of the ADA as interpreted in *Olmstead*. The Executive Order required federal agencies to promote community living for persons with disabilities by providing coordinated technical assistance to states, identifying specific barriers in federal law, regulation, policy and practice that impede community participation, and enforcing the rights of persons with disabilities. As a result of that Executive Order, federal agencies evaluated their own programs to identify barriers, and issued their final reports on March 25, 2002.

All together, these federal agencies' reports acknowledged the many barriers to community integration of persons with disabilities, including the institutional bias of the Medicaid program, unaffordable and inaccessible housing, a critical shortage of personal assistants and direct support professionals, and the unavailability of supported employment, and the need for early treatment and adequate mental health services for youth with disabilities. A majority of the proposed agency actions consisted of technical assistance, training, research, demonstration, policy review, public awareness campaigns, outreach, enforcement of existing regulations, information dissemination, convening of advisory committees and interagency coordination and collaboration.

Notwithstanding the early intentions and efforts of the NFI, and Executive Order 13217, the nature and scope of the problems facing millions of Americans with disabilities is daunting. Correcting these problems requires our best efforts and concerted attention.

A Community Imperative

The extent of unnecessary institutionalization of people with disabilities in the United States is shameful. There are too many hundreds of thousands of people with disabilities who, because of the bias of the current Medicaid system, are destined to spend their lives in nursing homes or institutions against their wishes.

If people who have economic needs require assistance, the default given to them through Medicaid is a nursing home or an institutional placement. It should be the other way around. The person first should be given the opportunity to live in the community. States should be obliged to provide assistance and supports in the community, and only if there is no other alternative to community based living, would states then consider nursing home or institutional placement. This is essentially one way to effectively reverse the Medicaid institutional bias that dominates too many lives in America today. People are most productive and have the highest quality of life in an integrated community with friends and family members nearby.

MiCASSA, introduced but not yet enacted in the last several sessions of Congress, and supported overwhelmingly by the disability rights movement, is important because it would end the institutional bias of Title XIX of the Social Security Act by allowing people eligible for services from nursing facilities or intermediate care facilities for people with intellectual disabilities the

election to receive community-based attendant services and support. Services covered by MiCASSA would include assistance with activities of daily living, including personal care, household chores, shopping, managing finances, using the telephone, participating in community activities, supervision, and teaching community living skills. MiCASSA would require services that are provided in the most integrated setting appropriate to the needs of the individual;

- based on functional need, rather than diagnosis or age;
- in home or community settings, including school, work, recreation, or religious settings;
- selected, managed, and controlled by the consumer of the services;
- supplemented with backup and emergency attendant services;
- furnished according to a service plan agreed to by the consumer; and
- accompanied by voluntary training on selecting, managing, and dismissing attendants.

MiCASSA would allow consumers to choose among various consumer-controlled service delivery models, including vouchers, direct cash payments, fiscal agents, and agency providers.

Olmstead

The Supreme Court's 1999 *Olmstead* decision has become a powerful impetus for a national effort to increase community-based alternatives and eliminate unjustified and restrictive institutional placements.

In September 2003 NCD published *Olmstead: Reclaiming Institutionalized Lives*, located on our web site (at http://www.ncd.gov/newsroom/publications/reclaimabridged.html). NCD's 2003 report on the status of *Olmstead* implementation indicates that, overall, progress to varying degrees has occurred in the implementation of the *Olmstead* decision. In this study, NCD heard from representatives of all disability groups who agreed that lack of affordable and accessible housing is the single biggest barrier to community integration in the United States. People with disabilities whose incomes depend on government benefits need housing subsidies or shared housing to live in the community.

Unfortunately, because of systemic barriers, people with disabilities tend not to receive their fair share of the approximately $7 billion in federal housing subsidy programs, and the various Section 8 housing subsidy programs targeted to persons with disabilities are funded at a relatively modest amount ($271 million in 2001) in comparison. An additional barrier is the lack of meaningful collaboration between human services agencies and housing agencies. High unemployment rates for persons with significant disabilities (typically, 60 to 90 percent) maintain dependence on public benefits.

The institutional bias of the Title XIX (Medicaid) program, in which home and community based waiver-funded services and personal care are optional while nursing facility services are required, and financial eligibility rules for institutional residents are more generous than those for people living in their own homes, greatly compounds the problem. Title XIX waivers have significantly expanded available funding for home and community based services, but have not

leveled the playing field; because state governments do not recognize home and community based waiver services as entitlements, waiting lists for waiver services are long in most states.

The unavailability of Title XIX reimbursement for services to adults below the age of 65 in institutions for mental diseases poses a significant barrier to the use of home and community based waivers to fund community mental health services.

And, from other research (National Academy of Sciences, Institute of Medicine's 1998 report on the "Quality of Long-term Care"), we know that one of the most important and frequently reported barriers to the expansion of Medicaid waiver services is the shortage of direct care workers, particularly those working in the home. States with large rural populations faced particularly imposing challenges. State officials identified these shortages as being related to the growing competition in the labor market and the low state Medicaid reimbursement rates for Home and Community Based Service providers. Low wages and benefits severely limit the availability of personal assistants and other direct support professionals. In turn, low wages are the result of low reimbursement rates for community services. Lack of quality health care and dependable transportation are also significant barriers.

Although the experiences of states and stakeholders in implementing *Olmstead* vary widely, NCD's study documents some key overarching findings, including:

- Plans do not consistently provide for opportunities for living in the most integrated setting as people with disabilities define "the most integrated setting."
- The majority of states have not planned to identify or provide community placement to all institutionalized persons who do not oppose community placement.
- Few plans identify systemic barriers to community placement or state action steps to remove them and few plans contain timelines and targets for community placement.
- State budgets often do not reflect *Olmstead* planning goals.

However, given the many areas where progress has not yet been achieved and in recognition of the relatively brief time since the decision was rendered and governmental initiatives were undertaken, it is clear that further efforts are necessary to increase public awareness of *Olmstead.* It is also necessary to provide education and clarification regarding the applications and implications of the decision to relevant entities, and provide resources necessary to both encourage and to ensure effective adherence to the spirit and intent of *Olmstead.*

Children and Mental Health

Consistent with both the New Freedom Initiative's commitment to *Olmstead* implementation, and the findings contained in the President's New Freedom Commission on Mental Health report

of 2003, NCD found that far too many children with emotional disturbance cannot get the mental health care they need. (See, http://www.ncd.gov/newsroom/publications/mentalhealth.html). As a result they often end up in foster care or juvenile justice, and are too often consigned to institutional settings where they are further cut off from support systems.

The lack of home- and community-based services has negative consequences. The lack accounts for unnecessary hospitalization of children and youth with emotional disturbance. It also contributes to readmission. For lack of services that might ease the transition from hospital to home, including respite services for their families, these children cycle back and forth between hospital and the community without ever achieving stability. In turn, unnecessary hospitalization usurps the limited resources of state mental health budgets, thus obstructing the provision of services that might have prevented institutionalization and perpetuating an unproductive cycle.

The failure to identify (and treat) emotional disturbances is also associated with the growing problem of teen suicides and/or suicide attempts. If properly implemented, Medicaid's Early Periodic Screening Diagnosis and Treatment program should assist parents of youth with emotional disturbance and school personnel in identifying their disabilities, providing the appropriate treatment, and preventing suicide and unnecessary institutionalization.

If all aspects of the system—from assessment to treatment—took into account the long-term needs of children, rather than episodic or crisis occurrence, children's needs would be described in terms of their underlying issues and in the context of their family and living situation instead of mere documentation of short-term behavior or services available. For some children, the system must be prepared to make a commitment to serve the child for their entire childhood, with easy entry and re-entry into the system.

Money Follows the Person Rebalancing Demonstration

The Administration wants to build on the federal-state partnership to assure Medicaid-eligible individuals with disabilities are served in the most appropriate setting according to their own needs and preferences. There is a tremendous opportunity to serve people who meet nursing facility levels of care in their own homes or other community residential settings without increasing costs.

Many states have engaged in activities and developed programs that serve persons in the most appropriate community setting rather than in an institution. These programs and activities, developed under existing authority, have included diversion programs to maintain people in the community, transition programs to actively move individuals from institutional settings to alternative community placements, and program models in which the 'money follows the person' to assure stability of community living.

In an effort to enhance the federal-state partnership, in early 2003 the Administration announced a five-year program, the "Money Follows the Person" Rebalancing Demonstration, which was designed to begin in FY 2004 to enable people with disabilities to move from institutions to the

community. The program was expected to provide 100 percent federal funding for home and community based waiver services for a person leaving an institution for one year, after which the state would agree to continue to provide services for the person at the regular Medicaid matching rate. In 2003, the Administration was seeking $350 million to fund the program in 2004, with $1.75 in proposed funding over a five-year period. Unfortunately, the Administration's 2005 budget request calls for significantly reduced spending for the Money Follows the Person Demonstration—from $1.75 billion to $500 million over five years.

Real Lives for Real People: Seeing the Big Picture

In our efforts to empower Americans with disabilities of all ages to live lives with choice, opportunity, and dignity, we face real challenges. Some challenges are of our own making.

The first challenge involves the coordination of funding and services. Disability programs and policies are so fragmented between Administrative Agencies and Legislative Committees that it is difficult to achieve the combination of Personal Assistance Services + Affordable, Accessible Housing + Affordable, Accessible Transportation + Livable Communities: any combination of which are often essential to a quality life in the community for people with disabilities.

The second challenge involves the shortage of quality direct service and/or support providers. Establishing eligibility for personal assistance services is only one part of the picture. Hiring and keeping capable, trustworthy personal assistants will continue to be difficult until competitive wages and health insurance benefits are offered. Establishing personal assistance as a respected career through competitive pay, benefits and training will attract the caliber of employees needed.

In our attempt to empower Americans with disabilities we also face major opposition to change. Some of the opposition is of our own making; some of it is not.

The first type of opposition to change comes from special interests. Those who profit from the existing Medicaid long term care structure, such as nursing home owners, state and federal bureaucracies, and employees' unions, want to maintain the institutional status quo. They are powerful and cannot be ignored. In order to achieve real change, these special interests' concerns must be acknowledged and their opportunities in a new system that empowers and supports people in living the life of their choice must be made clear to them. As long as America's public policies continue to fund programs instead of individuals, services and supports will be provided in a manner that benefits those who control the money rather than the individuals we intend to serve and support.

The second type of opposition to change comes from redundant, inefficient bureaucracies. The separate administrative structures for each of the States' Medicaid Home and Community Based waivers and for institutional Long-Term Services and Supports absorb an excessive amount of funding that would be better spent on direct services. The parallel bureaucracies also make it challenging and confusing for beneficiaries and their families to transition from one model of

Medicaid long term service to another. For example, transitioning my father-in-law from a nursing home to an Assisted Living Facility meant that his first Medicaid number was cancelled and he was issued a new Medicaid number. However, his essential medication could not be billed to the new number for several days, yet the nursing home had to turn in all of the medication he had not yet taken because it was billed to the nursing home Medicaid number.

In our efforts to empower Americans with disabilities, we need to recognize and act on those opportunities for change that could enhance peoples' lives.

Currently, people who rely on Medicaid Home and Community Based waiver services do not have the freedom to move from one state to another because there is no portability from one state's Medicaid program to another. If people do take the risk of moving to another state, they lose all Personal Assistance Services and have no idea how long they will have to wait for services in another state. They also have to contend with the disparity of Home and Community Based waiver services among states because each state designs its own waivers with different target populations and service menus.

The notion of transforming Medicaid Long Term Care into a coordinated program administered by a single agency that is responsible for all models of long term services and supports, including Personal Assistance Services, could give people the freedom to move from one state to another, eliminate the disparity in services between states and the difficulty in transitioning from one model of Medicaid Long Term Care to another, reduce the number of bureaucracies, and make it easier to establish Personal Assistance Services as a viable career. It could also make coordination with housing and transportation entities easier to achieve. You may want to consider this strategy.

Often Home and Community Based waivers do not provide enough hours of personal assistance services for individuals to realistically and safely live on their own in the community. Innovative utilization of resources and service options must be employed in order for people to have adequate hours of service to make community life feasible.

Finally, personal assistance services need to be available to adults with disabilities in the workplace if meaningful employment for disabled adults is to become a reality.

In our efforts to empower Americans with disabilities, we need to take advantage of options for cost-effectiveness. These options include: private long-term care insurance; support for family caregivers; and, utilizing natural supports in the community.

Most of the people in Medicaid nursing home beds today acquired their disability as a consequence of aging. Despite being productive throughout most of their lives, their assets were quickly exhausted and they became eligible for Medicaid. Encouraging younger Americans who are not disabled to buy private long term care insurance by implementing a tax credit for the premium will ultimately save Medicaid billions of long term care dollars that can be allocated to provide personal assistance services for people with disabilities who cannot buy private long-

term care insurance. Having private long-term care insurance also gives beneficiaries choice of and control over services.

Family caregivers provide millions of hours of unpaid care each year. Without their participation, the long-term services and supports system would crumble. Many states provide inadequate or no respite services to relieve family caregivers. This eventually leads to caregiver 'burnout' and institutionalization of the person with a disability. By supplementing the efforts of family caregivers, costly institutionalization can be avoided and impairment of caregivers' health can be prevented.

When vulnerable people live in the community, they have the opportunity to avail themselves of 'natural supports' in the form of family, friends, neighbors, faith-based organizations, etc. These natural supports complement paid supports and enrich the lives of both the disabled individual and the people involved with them.

Ongoing and Relevant NCD Policy Work

NCD is currently evaluating a range of promising community-based and consumer-oriented service and support reforms and initiatives. We believe that the results of our current policy research will also be of value to this Committee in the months ahead. NCD's current work includes: (a) an evaluation of federal and state initiatives in the area of consumer-directed reform through Medicaid and Medicare; (b) Livable Communities for people with disabilities and people who are elderly; and c) Long-Term Services and Supports refinancing and systems reform.

Through this policy work, NCD will continue to provide objective advice to policymakers, public and private agencies, consumers, researchers and others to refine the knowledge we have, identify new information about what works, and help policymakers build capacity within our communities and our nation to meet these challenges.

Conclusion

America needs to develop delivery systems, service capacity and financing streams that provide an increasing number of people with disabilities with choices about how to live their lives and receive the services and supports they need in community based settings. We need to pay particular attention to supportive services and housing issues, which determine whether individuals can maintain the autonomy and independence they desire. Our nation will be much more prosperous when it makes real the right of people with disabilities to live in the most integrated setting.

Thank you for inviting the National Council on Disability to this critically important hearing today.

Strategies to Improve Access to Medicaid Home- and Community-Based Services
Senate Questions and National Council on Disability Responses for the Record

From Chairman Grassley:

1. *The National Council on Disability was established about 25 years ago in 1978. In between now and then, the disability community has won two significant victories: the passage of the Americans with Disabilities Act in 1990, and the Supreme Court's Olmstead decision in 1999. Would you comment on the changing role of the National Council on Disability over time?*

Since the National Council on Disability (NCD) was established on November 6, 1978, there have been a number of critical victories, to which NCD has directly contributed that include, but are not limited to, the following:

- Passage of Public Law 97-35, the Social Security Act, Section 2176 of P.L. 97-35 established section 1915(c)} of the Act which established the Medicaid Home- and Community-Based Services (HCBS) Waiver program;
- Passage of Public Law 97-248, the 1982 Tax Equity and Fiscal Responsibility Act which permitted states to cover home care services for certain children with disabilities under Medicaid (Katie Beckett waiver);
- Passage of Public Law 99-506, the Rehabilitation Act Amendments of 1986 which broadened the purposes of the Act which required consumer control of Boards in Centers for Independent Living, and required states to establish State Independent Living Councils;
- Passage of Public Law 101-336, the Americans with Disabilities Act (ADA) which created a national mandate for the elimination of discrimination against individuals with disabilities in employment, public services, and public accommodation and services operated by private entities;
- Passage of the Public Law 104-204, the Mental Health Parity Act of 1996 which prohibited certain insurance companies from lifetime cap differences between mental health and medical treatment allowances;
- Passage of Public Law 106-170, the Ticket to Work and Work Incentives Improvement Act of 1999 which was established to provide SSI and SSDI beneficiaries with a ticket for vocational rehabilitation services, employment services and other support services from an employment network of their choice; and
- The 1999 Supreme Court *Olmstead* decision which interpreted Title II of the ADA as a mandate for public entities to provide services to persons with disabilities in the most integrated setting appropriate to their circumstances.

Paralleling what has occurred in our nation with the emergence of the disability rights and independent living movements, over the past 25 years, NCD has fulfilled its statutory mandate to be a voice within the Federal Government for policies, programs, practices, and procedures that

- guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and
- empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Over the past 25 years, NCD has been intrinsically involved in achieving progress for people with disabilities and consistently fulfilled its unique role as the only federal agency charged with addressing, analyzing, and making recommendation on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, functional ability, veteran status, or other individual circumstance.

Notwithstanding the many great victories listed above, as well as the wealth of information and advice NCD has provided to the Federal Government since 1978, NCD firmly believes that much more work needs to be done to ensure that people with disabilities are able to live real lives. Based on its reports (http://www.ncd.gov/newsroom/publications/2004/publications.htm), NCD continues its work to ensure that:

- existing laws are enforced;
- outreach and awareness campaigns are launched to educate the public about the human and societal benefits of achieving independence for people with disabilities and the important role that civil rights and community-based supports play in promoting independence;
- incentives for the inclusion of people with disabilities in all aspects of society are further developed and implemented;
- principles of universal design are applied in creating more livable communities for people with disabilities;
- systems, services, and supports for people with disabilities are further developed as a part of the mainstream of community life; and
- accurate data about people with disabilities are regularly collected, analyzed, reported, and used to strengthen laws and programs on behalf of all Americans.

Follow-up:
Would you describe if and how the health care delivery system is changing to accommodate individuals with disabilities in response to these victories (ADA and Olmstead)?

Under the ADA, it is generally believed that there is better physical access to health facilities in the United States. The *Olmstead* decision, however, was not about the health care delivery system, per se. In 1999, the United States Supreme Court held in *Olmstead v. L.C.*, 527 U.S. 581 that, under the Americans with Disabilities Act (ADA), undue institutionalization qualifies as discrimination by reason of disability and that a person with a mental disability is "qualified" for community living when the state's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities. The plaintiffs in *Olmstead* were the 'victims' of the same type of institutional medical/health care bias in the Medicaid system that the Senate Finance Committee is trying to address by virtue of its April 7, 2004 hearing. It is not the "health care delivery system" that lies at the heart of this hearing, but rather, it is the long-term services and supports system that promotes community integration, independence, and individual choice that is changing and in need of more improvement such as that proposed by MiCASSA and the Money Follows the Individual Rebalancing Demonstration.

2. *In your written testimony, you mention that the need for viable alternatives to institutional care requires serious attention and concern due at least in part to the aging of the nation's population. What policies described in the New Freedom Initiative and elsewhere will help ensure that the availability of community-based or in-home services meets the demand into the near future?*

The costs of providing long-term services and supports for both the growing population of senior citizens (many of whom will be people with disabilities) and persons with disabilities under the age of 65 will continue to grow rapidly. Demographics alone, including the projected doubling between 1980 and 2030 of the number of Americans over 65, make this inevitable, even without regard to changes in per capita costs. Few people would choose institutional care over their own homes and neighborhoods, if allowed to make that choice with dignity, autonomy and comfort. A February 2002 HHS study revealed that as many as 90 percent of the nation's nursing homes may face staff shortages that compromise adequate resident care. For all these reasons, the variety of initiatives summarized under the *Olmstead* rubric can be said to carry with them the destiny of a generation.

Creation of a paradigm to meet these new needs and fulfillment of the *Olmstead* promise on behalf of institutionalized or at-risk Americans with disabilities (seniors and younger persons alike) presents structural, resource allocation, public-private partnership, coordination and federalism issues of unprecedented and sometimes baffling complexity. NCD has repeatedly praised the commitment of the Bush Administration through the NFI to the values of ADA, as embodied in the Supreme Court's 1999 *Olmstead v. L.C.* decision. As indicated by President Bush's 2001 Executive Order and the subsequent coordinated planning, the Administration recognizes that new levels of interagency cooperation and high-level oversight will be necessary for the success of *Olmstead* in ensuring that Americans with disabilities can live (as they have already long been legally entitled to learn and to work) in the most integrated settings possible. New concerns have arisen over the sustainability of progress, as the *Olmstead* initiative confronts major new challenges while still endeavoring to surmount the old ones.

Federal Coordination

As the initial participation of nine major federal agencies in the comprehensive planning process under the President's June 2001 community-based living executive order attests, few policy initiatives involve so many agencies and programs as *Olmstead.* In order to marshal the community resources necessary for the success of *Olmstead* (that is, to enable people to leave institutions and to prevent at-risk citizens from entering them), the resources, procedures and priorities of over a dozen traditionally separate and self-referencing service systems, funding streams and statutory jurisdictions must be coordinated. At a minimum these include, at the federal level, Medicaid (both regular and waiver programs), transportation, housing, assistive technology, attendant services, food and nutrition programs, Older Americans Act, Social Security Administration (SSA), community development block grants, independent living and veterans benefits, along with private insurance and pensions and state and local programs with their rules and discretionary interpretations of federal provisions. Even the tax system is implicated in the success of *Olmstead,* insofar as the costs of many categories of home care and assisted living services do not qualify for deductibility, whereas equivalent costs, if encompassed

in the fees charged by nursing homes, can lower the middle class family's or individual's tax obligation.

The nature of the coordination required to make *Olmstead* and the NFI work may well exceed the administrative and planning resources currently available for the purpose. Recent experience in other spheres of policy has demonstrated the enormous difficulty of, and the entrenched institutional and jurisdictional barriers to, achieving seamless, coordinated interagency action, based on shared goals, methods, information resources, timeframes and standards of accountability, among divergent federal agencies, each with its own budget, institutional culture and chain of command. The key problem remains that no one agency is capable of making or carrying out plans in ways and according to timeframes that fully anticipate and reflect the related plans and activities of all the other key participants.

Until or unless coordinating structures such as the Interagency Committee on Community Living (ICCL) can be constituted with the resources and authority to accomplish or compel coordinated planning, the best planning efforts of any one agency may be all too easily negated by the varying priorities or differing time horizons of another, or even of another entity within the same department or under the same management.

These coordination problems also emerge in the budgeting process. *Olmstead* implementation is not a budget line or cost center in its own right. Thus, when the budgets for the various programs, statutory responsibilities and functions making up the work of each agency are determined, impact on *Olmstead* is hardly the key variable determining whether or how much programs will be cut. While one agency may develop its budget recommendations and requests to the OMB and Congress with *Olmstead* in mind, others may not.

As a result, NCD recommends that the Federal Government begin developing cross-agency program scoring methods and unified budgeting models that will link the relevant activities and budget requests of various agencies so as to allow the impact of budget proposals on multi-agency policy initiatives such as *Olmstead* to be tracked and reported and to allow effective budgeting for multi-agency initiatives. In connection with coordination, NCD commends the administration for two major NFI-related initiatives during 2002: establishment within HHS of the Office of Disability and creation of two new Independence Plus waiver programs within Medicaid. The Office of Disability should contribute considerably to coordination within HHS and the agencies it supervises and may develop linkages with similar coordinating offices in other departments that will add further coherence to the federal effort. The new waiver programs reflect important early steps toward infusing consumer-directed community-based services by giving states more flexibility to direct funds in accordance with beneficiary choices.

But as encouraging and innovative as these measures are, they may in the end serve as much to highlight the seemingly intractable problems of coordination as they do to resolve them. For in the absence of interconnected and timely actions by other departments, the effects of what any one agency does in the *Olmstead* context may be considerably diminished. It does little good, for example, to give an individual the option to use Medicaid waiver funds to provide home-based services rather than going to a nursing home (to allow for the money to follow the person) if no accessible housing is available in the community that can meet the individual's needs, or if no accessible or affordable transportation is available between the accessible housing and other locations in the community where the individual needs or wishes to go. Without transportation, the isolation of one's own home can all too easily become as crushing as that of an institution.

Additional Federal Initiatives – Public-Private Partnerships

Any full-fledged effort to make the promise of *Olmstead* and Title II of ADA a reality depends upon both private sector and public resources. So far as the resources of individuals and families are concerned, we have already noted that, even for people of sufficiently modest means to qualify for Medicaid (particularly where spend-down is used), tax laws may play a role in influencing key personal and life choices. Along similar lines, for people of all income levels, another key variable is availability and affordability of private long-term care insurance that does not force policyholders into nursing homes.

In the current discussion of health-care reform, access to insurance is a major issue. Although the tax code has already been used to enhance the ability of self-employed persons to pay for health insurance, what has been missing from the discussion are suggestions for ways that tax policy and other forms of positive leverage could likewise be used to increase the supply and quality of private long term care insurance that would help defray the costs of staying in one's own home. Various models of coverage, including partnerships between insurance and Medicaid, already exist, but other models that specifically emphasize the meeting of in-home and community-based care costs, rather than devoting their resources primarily to nursing homes, are needed.

So long as coverage tips the scales in favor of nursing homes by providing vastly smaller and patently inadequate benefits for home- and community-based services and by defining covered services in ways that further the bias in favor of institutional care, no viable private-sector participation in solving this problem is likely. NCD recommends that Congress should hold hearings and invite recommendations on coverage packages, including seller and purchaser incentives, that would help to meet the existing and foreseeable needs for greatly expanded private-sector participation in the financing of home- and community-based services and care.

State Initiatives

The coordination issues encountered in implementing *Olmstead* in the federal sector are mirrored at the state level and, indeed, depend in large measure on what the states do. Although some states have done very well (embracing *Olmstead* out of commitment and/or pragmatism), anecdotal evidence suggests that other states have followed a path of reluctance and resistance, perhaps going through the motions of planning but in the end putting few if any significant mechanisms into place. Whatever the explanation for the variation in states' responses, the fact that more than half the states have not moved effectively to implement *Olmstead*, more than three years after it was decided, raises troubling questions regarding both state capacity and federal commitment.

The prospect in many states of huge cuts in Medicaid to help close budget deficits adds further obstacles to *Olmstead* implementation and NFI success and further urgency to getting started. Waiver programs, proportionally perhaps even more than regular Medicaid, are likely to be affected by these cuts. While painful Medicaid cuts are inevitable, HHS and CMS should find means (within the scope of their regulatory and oversight authority) to identify the kinds of cuts least destructive to burgeoning *Olmstead* initiatives and should do everything possible to encourage states not to make these kinds of cuts. CMS should also provide additional technical assistance to states on what Title II of ADA requires and share exemplary state plans that have thus far been developed and put into effect.

More broadly, NCD recommends (See, http://www.ncd.gov/newsroom/publications/2003/reclaimabridged.htm) that the Administration conduct and publish a comprehensive audit of all state-based *Olmstead* implementation activities, designed to describe what has worked, to identify states that have been successful or are trying as well as those that have not been successful, and to make certain that citizens and voters are as fully informed as possible about the values at stake in the responsiveness or unresponsiveness of their state officials and leaders. Anecdotal information about state responses to *Olmstead* suggests that neither partisan affiliation nor position of the state government on the ideological spectrum is a predictor of states' responses. Only when we know what has worked, why some states have embraced *Olmstead* and others not and why some have met with noticeably more success than others can we hope to engender the galvanized response so desperately needed if the transition and deinstitutionalization that *Olmstead* betokens can reach critical mass across our nation.

3. *In your testimony, you describe the challenges inherent to the current system. For example, services that are essential to a quality of life in the community – affordable housing and accessible transportation – are often fragmented between Federal agencies. As home- and community-based services become more readily available, what can be done to improve coordination and promote independence for individuals with disabilities?*

There are both short-term and long-term strategies to be considered to improve coordination and promote independence for individuals with disabilities. Some of the short-term strategies for consideration are listed above as NCD's response to question #2 from Chairman Grassley. The short-term strategies include: (a) (re)constituting relevant Federal interagency initiatives such as the ICCL with sufficient resources and the authority to accomplish or compel coordinated planning and implementation; (b) doing everything possible to encourage states not to make budget cuts that would negatively affect their *Olmstead* initiatives; and (c) CMS providing additional technical assistance to states on ADA Title II requirements, and sharing exemplary state *Olmstead* plans.

One long-term strategy idea that NCD currently is reviewing internally involves the concept of an Agency on Disability. Such a entity might be charged with administering the combination of long term support services, accessible housing, accessible transportation, employment supports, and assistive technology that people with disabilities need in order to live, work, and participate successfully in their communities.

An Agency on Disability might enable a more cost effective use of taxpayers' money by eliminating redundant bureaucracies, cost-shifting, and compartmentalized budgets. The following is an example of how compartmentalized budgets are not cost effective: A person with quadriplegia is at high risk for pressure sores from sitting in the same position all day. A wheelchair with a seat that can be tilted to different positions during the day can greatly reduce this risk. However, most State Medicaid DME (durable medical equipment) Department budgets cap the cost of a wheelchair at well below the cost of one with the tilt seat – despite the fact that the cost of such a wheelchair is substantially less than the cost of hospitalization and treatment for a pressure sore. This happens because the DME budget is separated from the acute care budget, so the benefit to the overall Medicaid program budget is ignored and overall costs to Medicaid escalate.

In addition, the separate funding streams and administrative bureaucracies for each Medicaid home- and community-based waiver, Intermediate Care Facilities, Assisted Living Facilities, and nursing homes make it extremely difficult for an individual to transition from one model of long term services and supports to another. Cost-shifting among various disability programs also occurs frequently, causing delays in service provision that can be life-threatening to consumers and result in greater costs to taxpayers because when an individual's heath care needs are not addressed in a timely way, health often deteriorates.

Creating an Agency on Disability that views the whole individual and oversees a comprehensive budget for long-term services and supports, acute care services, housing, transportation, employment, and assistive technology might result in more productive lives for people with disabilities and more cost-effective use of tax dollars. An additional benefit could be that under a comprehensive Agency on Disability, collecting and analyzing this essential data might be more effectively and affordably accomplished.

We intend to continue our consideration of this type of long-term strategy, as well as others, during the remainder of the fiscal year and will keep you apprised of our further thoughts and any recommendations on this issue.

From Senator Bunning:

1. *There is a concern about the lack of access to quality medical, dental and other health services for people with mental retardation and developmental disabilities. Would you support using federal funding for the development of MR/DD clinics that deliver specialized care to the MR/DD population while also training future health care professionals?*

Respectfully, Americans with disabilities in general are not able to access quality medical, dental and other health services in this nation. It is not just people with mental retardation and/or developmental disabilities who need access to better health care, it is all people with disabilities.

The United States has among the finest and most advanced health care in the world, but the systems for delivering that care to many of our citizens are under severe strain and, in some sectors, in crisis. The problems are no mystery, even if their solutions are elusive. These problems include shortages of adequate primary care (particularly in inner-city and rural areas); overuse of hospital emergency rooms in the face of a decline in the number of such facilities; rising insurance premiums in the private sector that preclude individuals from purchasing or employers from providing coverage; declining incomes and growing dissatisfaction among doctors; escalating scarcity of physicians willing to treat Medicaid or Medicare beneficiaries; opting out by managed care organizations from coverage in various areas and of various subgroups of the population; narrowing definitions of what is covered and increasing co-payments and deductibles (resulting in larger out-of-pocket costs to the fully insured); medical personnel who receive inadequate and insufficient training regarding disabilities; crushing prescription drug costs; and, most recently, sharp cutbacks in state Medicaid programs, among others.

By some estimates there are nearly four million adults and children with severe disabilities who are uninsured (e.g., Jack Meyer and Pamela Zeller, Profiles of Disability: Employment and

Health Coverage, Economic and Social Research Institute for the Kaiser Commission on Medicaid and the Uninsured, September 1999). Accordingly, NCD believes that all Americans with disabilities need access to quality medical, dental and other health services, including people with mental retardation and/or developmental disabilities.

No one is satisfied with the current system, yet no one can bring forward anything approaching consensus recommendations for reform. Recognizing that in matters of accessibility, availability, affordability and adequacy of health care, persons with disabilities are the proverbial canary in the mineshaft, NCD has followed and contributed to the evolution of health-care policy for more than a decade. NCD is currently evaluating a range of promising community-based and consumer-oriented service and support reforms and initiatives. We believe that the results of our current policy research will also be of value to this Committee in the months ahead. NCD's current work includes: (a) an evaluation of federal and state initiatives in the area of consumer-directed reform through Medicaid and Medicare; (b) Livable Communities for people with disabilities and people who are elderly; and (c) Long-Term Services and Supports refinancing and systems reform.

2. *There has been some concern about implementing new and expensive programs while some people are currently on waiting lists for services. Do you have any thoughts on addressing issues of the waiting lists?*

Waiting lists are a direct function of the institutional bias of the Medicaid system and the very services authorized by Congress under Title XIX of the Social Security Act. If this bias were removed, and if long-term services and supports were instead mandated by Congress rather than maintaining the institutional bias, waiting lists would be less of a challenge. In that vein, while there may be an initial investment or outlay to change the bias away from institutional placement towards community placement, the ultimate goal is to provide consumer choice and direction in using the same federal dollars. The *Olmstead* Supreme Court decision requires that waiting lists move at a reasonable pace. Finally, greater numbers of young people should be encouraged to purchase long-term care insurance through the private sector.

3. *Receiving community-based care is not an option for everyone. What type of factors should be considered when determining if home-based care or institutional care is best for a particular individual?*

The classical view of the medical model is that a person with a disability has problems are caused by the fact of his or her disability, and whether or not the disability can be alleviated by the medical profession. This model implies then that the person with a disability must always trust members of the medical profession to make the right decisions for him or her, including choices regarding institutional versus community placement. It is NCD's view that the changing role of an individual with a disability in American society today involves greater responsibility, more empowerment, and choice. Individual choice is the key to the Senator's question.

The main thrust of the Americans with Disabilities Act and the Supreme Court's *Olmstead* decision is that people with disabilities have the same rights as other citizens to freedom, equality, equal protection under the law, and control over their own lives. These rights must be honored if people who have disabilities are to be fully included as valued citizens in the relationships and opportunities of community life.

As part of its research for NCD's 2003 report entitled *Olmstead: Reclaiming Institutionalized Lives,* we included interviews with informants with disabilities and their advocates. We asked what the person considered "the most integrated setting" for persons with disabilities. Almost without exception, the interviewees responded by naming the qualities that make home living meaningful and satisfying to the individual. Only two respondents named a type of program, such as a supported living arrangement or a two-person home. Response patterns were similar across all categories of disability.

The most common response was that the most integrated setting is "a place where the person exercises choice and control," including choice of service providers: "What people themselves want! ... Self-determination is essential. People decide for themselves what they want and need." A variation on this response was, "Whatever the person considers most integrated." The second most common response was, "A home of one's own shared with persons whom one has chosen to live with," or where one lives alone. The third most common response emphasized that home living for persons with disabilities should be like home living for other community members. Integration is "living in the community with everyone else like everyone else." Several respondents defined community integration as the result of participation in community activities or of the assumption by persons with disabilities of leadership roles in the community. And finally, one respondent defined community integration as affording opportunities for privacy, unlike an institution.

Similarly, when interviewees were asked what people with disabilities need to live in the most integrated setting, they responded, almost universally, not by listing formal services but by identifying ordinary human needs. Again, response patterns were similar across all disability groups. The most common response was that support depends on the person, must be defined by and tailored to the individual, and may change over time. The second most common response was that people need friendships, emotional support, and networks of friends, family, and mentors. Education, participation in community activities, and transportation were mentioned by a number of respondents.

Every person NCD interviewed who was affiliated with a disability organization stated that the organization had a position on the right to live in the community. Organizational positions on community living varied little from one disability group to another. Some stated that the right to live in the community is "absolute," and others that closure of institutions is their organization's highest priority. The following were other common positions:

- Everyone has the right to live in the community with support.
- People should live independently, not in a nursing home.
- We support the right to choose.
- We support self-determination.
- We support inclusive communities.

While at one time in America services and supports was generally only available in nursing homes and in private residences (for people with disabilities) with the help of informal family

caregivers, there is now a continuum of care of options, including assisted living, adult day services and home health care. In addition to selecting the most integrated setting possible, when determining if home-based care or institutional care is best for a particular individual, the type of factors that should be considered includes, but is not limited to, the following:

- the individual's needs and preferences;
- the availability of formal and informal support services;
- whether the individual qualifies for public assistance, has long-term services and supports insurance, and, other income-related issues;
- how individuals and their families will be involved in decisions about the delivery of services and supports services;
- that home care services should supplement, not supplant family care giving;
- that increased access to respite services and training for family caregivers is needed to sustain their efforts and ensure that people receive care in the least restrictive setting possible;
- that people of all income levels should have access to necessary and appropriate services and supports with a sliding scale contribution.

If people who have economic needs require assistance, the default given to them through Medicaid is a nursing home or an institutional placement. It should be the other way around. The person first should be given the opportunity to live in the community. States should be obliged to provide assistance and supports in the community and then, only if there is no other alternative to community-based living, would states consider nursing home or institutional placement. This is essentially one way to effectively reverse the Medicaid institutional bias that dominates too many lives in America today. People are most productive and have the highest quality of life in an integrated community with friends and family members nearby.

From Senator Baucus:

1. *In your view, how can we strengthen and bolster the Medicaid program to help states fully implement the Olmstead decision in the short and long term?*

In NCD's 2003 report *Olmstead: Reclaiming Institutionalized Lives*, we asked the persons with disabilities whom we interviewed, "What policies could the states enact that would help people who do not need to be institutionalized live in the community?" The responses strongly and consistently favored self-determination and consumer-directed models of service. The respondents showed an awareness of how federal housing programs need to change to foster community integration, as well as the obvious changes that need to occur in the Title XIX program. Many people from all disability groups urged the passage of MiCASSA. Our respondents also advocated better information and training for people with disabilities and support and funding for self-advocacy. The responses include the following:

- Fund self-advocacy and add self-advocacy organizations to the "Big 3" [Administration on Developmental Disabilities] programs [the University Affiliated Programs, the Protection and Advocacy systems, and the Developmental Disabilities Planning Councils]
- Get rid of red tape; change Medical Assistance (MA) rules and guidelines

- Pass MiCASSA
- Make self-determination federal law
- Set aside Section 8 vouchers for people who are ready to leave nursing homes
- Tie a rent subsidy program to persons leaving institutions
- Shift Section 811, which traditionally has been a project-based funding source, to individual vouchers
- Assist people to live in homes with support staff
- Stop putting money into institutions and instead put it into housing.
- Provide essential therapies and communication
- Change professional and bureaucratic attitudes
- Provide more direct information sessions for people with disabilities to learn their rights
- Train people in institutions to learn how to live in the community; have "buddy systems"
- Provide more home-based programs
- Provide vouchers for homeownership
- Provide peer support
- Have flexible emergency response systems
- Provide vouchers for homeownership
- Provide better salaries for personal assistance providers
- Eliminate programs' institutional bias
- Provide more supported-living apartments
- Have better pay for front-line staff
- Have mandatory training for staff to overcome the outdated attitude that "I'm here to take care of you"
- Have more flexibility with waivers
- Provide equitable support for people with disabilities entering the workforce
- Allow people to earn higher wages without influencing benefits
- Give money to people and allow them to use it for support from family and friends, not agencies
- Provide education to communities that it is okay to be different

Our respondents' emphasis on flexible funding and on self-determination, choice, and control over how service dollars are spent are reflected in service models based on self-determination, consumer direction, and direct control of service dollars. These models are not necessarily new- the Centers for Independent Living (CILs) and the mental health consumer/survivors' self-help movement have been providing consumer-controlled services for the past two decades. Indeed, most of these service models are strongly supported by scientific studies of their outcomes for consumers.

In addition, the following are some of the many examples suggested by NCD's *Olmstead* report of promising practices in the design, delivery, and financing of community services that are consistent with the *Olmstead* decision.

- Good practice in *Olmstead* planning. Indiana's recent plan assigns each recommendation to one of three categories: (1) those that should be implemented quickly and with little or no fiscal impact or regulatory requirements; (2) those that should be implemented quickly but have a fiscal impact or require regulatory changes; and (3) those that are more complex, costly, or difficult and will require more time to develop and implement. Indiana's plan should serve as a model for other states. Nevada's *Olmstead* plan is commendable for its candid analysis of the state's compliance with *Olmstead.*
- Overcoming incentives to unnecessary institutionalization. Methods include Maine's use of pre-admission screening by an independent agency prior to nursing facility placement,

Minnesota's legislation encouraging nursing facility operators to take beds out of service, and Washington's system for tracking reduction targets for nursing facility placements.

- Identification and transition of people with disabilities from institutions. Disability rights advocates are doing the work of identifying people in nursing facilities who could move to more integrated settings in Colorado and Kansas.
- Use of trusts and fine funds to finance transition costs and start-up of community services. A creative and under appreciated set of strategies for financing transition costs, providing "bridge funding," and funding new community services involves the creation of trusts and fine funds dedicated to the needs of people with disabilities. North Carolina, Oregon, and Washington have used the proceeds from the sale of state facilities to establish trusts to generate funds for people with disabilities.
- Housing strategies. Commendably, and in large part because of the influence of the technical assistance provided by HHS's Office of Civil Rights (OCR), the more recently developed plans tend to reflect the input of housing agencies. Provisions for requiring universal design in new units that state housing agencies fund or finance; ensuring that all existing publicly financed housing has completed Section 504/ADA self-evaluations; conducting utilization reviews to ensure that targeted Section 8 programs are fully used; and including home modifications and home repair in the services provided under home- and community-based waivers and independent living programs are examples of housing-related recommendations in state *Olmstead* plans.
- Single point of entry systems. Single point of entry structures have the potential to reduce unnecessary institutionalization by providing easier access to a wider array of community services. Single point of entry systems that separate assessment and service brokerage from service provision are also responsive to findings of the Centers for Medicare and Medicaid Services (CMS) in a number of states that Medicaid beneficiaries' right to choose among qualified providers was violated.
- Beyond institutional closure: Increasing community integration. Developmental disabilities services in Vermont and New Hampshire show that "the most integrated setting" is more than placement in a residence outside an institution; rather, it is a continuous process of increasing community inclusion. These states' service systems have progressed far beyond institutional closure and are eliminating group homes in favor of living in a companion home or a home of one's own and working at a real job with support.
- Self-determination. Self-determination and consumer-directed service models have been so broadly tested and practiced that they have emerged as fundamental principles in human services.

The *Olmstead* decision has become a powerful impetus for a national effort to increase community-based alternatives and eliminate unjustified institutional placements. We must continue to empower *Olmstead* stakeholders in their efforts to redesign the state service systems to enhance choice, independence, self-determination, and community integration. Ultimately, there may be a need to carve out a Long-Term Care Title in the Act.

TESTIMONY OF
DENNIS SMITH
DIRECTOR OF THE CENTER FOR MEDICAID
AND STATE OPERATIONS
ON
THE NEW FREEDOM INITIATIVE
BEFORE THE
SENATE FINANCE COMMITTEE
APRIL 7, 2004

Chairman Grassley, Senator Baucus, distinguished Committee members, thank you for inviting me to discuss the Medicaid legislative proposal under the New Freedom Initiative. The New Freedom Initiative is President Bush's plan to ensure that individuals with disabilities have the opportunity to live independently in their communities. As part of the initiative, the President asked relevant Federal agencies, including agencies within HHS, to evaluate their policies, programs, statutes, and regulations to determine whether they should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities, so they may live with the respect and dignity independent living brings. While New Freedom is a government-wide initiative, I will focus specifically on the Medicaid provisions that require statutory changes in order to implement it.

Medicaid Spending on Home and Community-Based Waivers

Medicaid is a vital resource of financial support for community living. More than 800,000 individuals are served through home- and community-based waivers. State and Federal expenditures have increased from $13.9 billion in FY 2001 to an estimated $20.7 billion in FY 2004.

Between 2001 and 2004, a total of $68.7 billion will be spent under home- and community-based waivers. More money has been spent in those four years than was spent during the previous eight years ($56.6 billion). Over the same period, care expenditures for state plan service grew, from $5.25 billion to $7.95 billion, a 51 percent increase.

New Freedom Initiative in the FY 2005 Budget

CMS remains committed to identifying and eliminating obstacles faced by those with disabilities. To further enhance the opportunities for people to live meaningful lives in the community, the President included support for the New Freedom Initiative in his FY 2005 budget proposal. The budget authorizes approximately $428 million in FY 2005 and approximately $2.2 billion over 5 years to improve community services, help transition people out of institutions, and support Americans in the community through a variety of initiatives.

Money Follows the Individual

Our message is simple and clear. We believe individuals and families make better decisions for themselves than the current institutional-based, provider-driven systems. In 2001, 71 percent of Medicaid funds for long-term support for seniors and people with disabilities were spent on institutional services. While states are making efforts to develop infrastructures designed to support community-based services, progress in reducing dependence on institutional care has been difficult to achieve due to the fiscal challenges states are facing. The Money Follows the Individual Rebalancing Initiative is a $1.75 billion, five-year demonstration program to help Americans with disabilities transition from nursing homes or other institutions to community living. The initiative will help states achieve a more equitable balance between the proportion of total Medicaid spending on institutional services and the proportion of funds used for community-based support in their state plans and waivers. The initiative also will help States design flexible financing systems for long-term supports that allow funds to move with the individual to the most appropriate and preferred setting as the individual's needs and preferences change.

To assist individuals who move voluntarily from a Medicaid-certified institution to the community, the initiative will pay for one year the full cost of home and community-based services for each individual moved from institutional care to a package of home and community-based services. At a minimum, the package of services must be equivalent to the services that a state could provide under a Medicaid waiver. After the

demonstration year, the state would agree to continue such care at the regular Medicaid matching rate and agree to maintain a balance between institutional and community-based services in their long-term care systems. States will be required to develop a multi-year plan that includes specific action steps to redesign funding arrangements to implement the principles of money follows the person and reduce reliance on institutional forms of Medicaid service. The plan also must identify steps to increase the infrastructure for community services and improve the ability of individuals to live and participate in their communities.

The President's commitment to the New Freedom Initiative budget proposal has not changed. The President's FY 2005 budget proposes the authorization of $1.75 billion over five years for the Money Follows the Individual Rebalancing Demonstration. While we recognize that the Budget in Brief that was published on the web shows budget outlays of $0 in FY 2005 and $500 million over 5 years we should not confuse proposed budget authority with estimated outlays.

While CMS will award a total of $350 million a year in grants for each year of the initiative (FY 2006- FY 2009), we anticipate that States will likely spend their awards slowly over the course of their 5-year project periods. As a result of this assumption, CMS estimated smaller initial outlays to States.

The outlay estimate also takes into account our assumption that CMS will need time to develop a solicitation, review proposals, and award the demonstration grants. Awards are likely to be made close to the end of the fiscal year, and as a practical matter given the timing of awards, states will likely begin to draw down funds at the beginning of FY 2006.

LIFE Accounts

The President's budget proposes the Living with Independence, Freedom, and Equality (LIFE) Account Savings Program as the next improvement in the home- and community-based system. LIFE Accounts will be personal savings accounts owned and directed by

the individual. At no cost to the federal government, LIFE Accounts will remove barriers to independence, community living, and participation in the labor force for Medicaid-eligible individuals with disabilities by giving them the opportunity to build savings for purchases that will increase their independence and productivity while also maintaining their vital health coverage and standard of living.

Currently, individuals who live in states with a CMS Independence Plus waiver are permitted to direct their own long-term supports in order to delay institutional or other high-cost placement outside their community. In states with such programs, individuals may direct and control their own supports within the bounds of an individualized budget established in agreement with the relevant state agency. States that have programs built on this concept encourage high-value, cost-effective decision-making. Independence Plus waivers have built on the very successful "Cash and Counseling" waiver.

Under the President's proposal, individuals who self-direct all of their Medicaid, community-based, long term supports will have the opportunity to place up to 50% of the savings from their self-directed Medicaid community-based service budget into LIFE Account at the end of the year. Earnings from employment and limited contributions from others may be used in the LIFE Accounts to align the amount in the fund with the level of need.

To prevent the assets in a LIFE Account from jeopardizing an individual's ability to qualify for other forms of assistance, income and resources in the accounts will not be considered when making a determination for a state's Medicaid program or any federal assistance program. LIFE Account income and assets will not be considered in establishing benefit levels under those programs for either the account holder or for any members of the account holder's immediate family.

New Freedom Demonstrations

The President's FY 2005 budget proposal also includes a number of other investments in the New Freedom Initiative. Three innovative demonstrations will enhance the ability of

individuals with disabilities to live and fully participate in the community. These demonstrations support:

- Respite services to caregivers of adults with disabilities
- Respite services to caregivers of children with severe disabilities
- Home- and community-based services for children residing in psychiatric residential treatment facilities.

With $18 million proposed for FY2005 (and $327 million over five-years), these demonstrations will test the provision of respite for caregivers of adults as a Medicaid service, the provision of respite for caregivers of children with substantial disabilities as a Medicaid service, and the provision of family- and community-based programs for children with psychiatric disabilities as an alternative to psychiatric residential treatment facilities.

Other proposals in the President's FY 2005 budget are designed to provide flexibility to families and States.

- *Spousal Exemption* – Under current law, if an individual is Medicaid eligible and that individual's spouse participates in the section 1619(b) program – a Supplemental Security Income work incentive program, the spouse's earnings could cause the individual to lose his or her Medicaid. The President's budget proposes to protect the Medicaid coverage of an individual married to a disabled individual participating in 1619(b).
- *Presumptive Eligibility* – To reduce the prevalence of individuals entering nursing facilities from hospitals due to the length of time required to determine Medicaid eligibility for home and community-based services, the President has proposed to offer States the option of providing those individuals who need Medicaid home- and community-based care with services for up to 90 days while Medicaid eligibility is being determined. Under this proposal, the Federal government will pay its share of the first 90 days of community services whether or not the individual is ultimately deemed Medicaid-eligible.

- *Direct Service Community Workforce Demonstration* – Proposes $3 million in discretionary funds to continue a demonstration to increase recruitment and retention of direct care service workers including an emphasis on the provision of a health care benefit for the workers.
- *Real Choice System Change Grants* – Proposes $40 million in discretionary funds to continue assistance to States in developing systems that support community-based care alternatives for people of all ages with disabilities.

Existing CMS Initiatives

The President's FY 2005 budget proposal builds upon a number of accomplishments that have been achieved since the President signed an Executive Order on June 18, 2001, directing Federal agencies to "tear down the barriers" to community living for individuals with disabilities. This order called for a government-wide framework to provide the elderly and people with disabilities with the support system necessary to choose where they want to live and to participate fully in community life. CMS has been working diligently on the initiative to eliminate the obstacles facing people with disabilities who want to live and work in their communities.

Real Choice System Change Grants

Since 2001, CMS has awarded approximately $158 million (FY 2001-2003) in grants to help states and others develop programs that allow people with disabilities or long-term illnesses to live meaningful, productive lives in the community. These grants are intended to foster the systemic changes necessary to allow those with disabilities to access quality services from their choice of providers in accordance with their living preferences and priorities. For example, a number of states, including Maine and Pennsylvania, received grants for "Money Follows the Person" research and demonstration programs in FY 2003. These particular grants helped States to determine what infrastructure and policy changes would be required to rebalance their long-term support systems and to implement the principles of money follows the person. Also in FY 2003, CMS funded feasibility study grants in areas that are included in the President's

FY 2005 budget, including respite for adults, children, and alternatives to community-based treatment for children.

Independence Plus Initiative

In 2002, CMS launched the Independence Plus Initiative to afford Medicaid participants increased choice and control that results in greater access to community living. The Independence Plus Initiative expedites the ability of states to request waiver or demonstration projects that give individuals and their families greater control over their own services and supports.

Currently there are five Independence Plus Programs, including four 1915(c) waivers (New Hampshire, Louisiana, South Carolina and North Carolina), and one 1115 Demonstration (Florida). The Independence Plus programs allow participants to design a package of individualized supports, identify and attain personal goals, and supervise and pay their caregivers.

Florida's Independence Plus Program, funded through CMS' 1115 demonstration authority, was recently recognized with a grant from the Social Security Administration to expand the impact of the program. The new collaborative program, named the Florida Freedom Initiative, will waive certain SSI rules to test whether the combination of Medicaid and Social Security waivers will foster greater self-sufficiency among the SSI and CMS beneficiaries who participate in the demonstration.

Additionally in FY 2003, CMS awarded 12 grants to states under the Real Choice Systems Change grant opportunity to help states design self-directed waiver and demonstration programs. These "Independence Plus" grantees are: Connecticut, Colorado, Florida, Georgia, Idaho, Louisiana, Massachusetts, Maine, Michigan, Missouri, Montana, and Ohio.

CMS Action Plan for Quality

CMS has taken a multi-faceted approach to addressing quality of care issues in home and community-based services. Earlier this year, Secretary Thompson submitted to Senators Grassley and Breaux an updated report on *CMS's Action Plan for Quality in HCBS*. The *Action Plan* provides a status report on the quality initiatives that CMS has undertaken in Medicaid home and community-based services. I am pleased to inform the Committee that the majority of the actions (16 of the 18 promised actions) to which we committed have been completed. We have made substantial progress on the other two. One example of our success in this area was the development of the *Quality Framework*, a guide to provide states with a uniform national format to describe the key components of their quality assurance and quality improvement programs. We intend the *Quality Framework* to serve as a common frame of reference. CMS also has worked with a variety of key stakeholders, subject matter experts, and consumers to complete a national inventory of state quality assurance and improvement strategies and provide technical assistance to states to assist them in redesigning their quality management systems.

Additional Accomplishments

CMS has made progress on a number of other fronts through the New Freedom Initiative. This year, CMS awarded a total of $15.7 million in grants to 28 States and the District of Columbia to help people with disabilities keep and find work without endangering their health benefits as part of the Ticket to Work and Work Incentives Improvement Act.

CMS also funded approximately $6 million in grants to improve the recruitment, training, support, and retention of direct service workers in FY 2003. For FY 2004, CMS plans to fund additional grants to States and others at the same level of support.

Recognizing the importance of providing information to and receiving input from key stakeholders, CMS holds Open Door Forum teleconferences on the New Freedom Initiative to discuss possible reforms that could remove barriers to community living and participation of those with disabilities. Last year, 2,519 people participated in 9 forums.

Conclusion

Chairman Grassley, Senator Baucus, and members of the Committee, thank you again for the opportunity to speak to you today about the New Freedom Initiative, a nationwide effort to remove barriers to independent, community living for people of all ages with disabilities and long-term illnesses. The President is committed to helping people with disabilities exercise more control over all aspects of their lives, including the supports they receive and where they live. This commitment is critical to helping people with disabilities achieve the freedom and independence they deserve. The New Freedom Initiative represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, and live with the dignity and respect that comes with full participation in community life. Thank you again for this opportunity, and I look forward to answering any questions you might have.

RESPONSES TO QUESTIONS FROM SENATOR GRASSLEY

Question 1: One of the policies that you mentioned in relation to the "Money Follows the Person" demonstration would allow for one year of 100 percent Federal match, often referred to as FMAP. This proposed policy seems to counter the Medicaid Federal-State partnership. In Medicaid, a balance is struck between the available contribution of the States and the Federal government's requirement to match those dollars. If the State does not want to contribute funds and receives Medicaid payment, what incentives does the State have to limit costs? Further, what do you anticipate States will do with the State share of these costs? Will States simply save money or will they make one-time investments to support the individual to live in the community?

Answer: The intent of the "Money Follows the Person" (MFP) program is to provide States with some short-term savings to achieve a long-term rebalancing of Medicaid delivery of long-term care services and support. Under the MFP proposal, the Federal government would pay for a package of home and community-based services for eligible individuals, furnished for a 12-month period following discharge from an institutional facility. States are unlikely to excessively use Federal funds for three reasons. First, since qualified expenditures for this package of services are only those that a State currently provides under its State Plan, or sections 1915(c), 1115, 1915(d), or 1929 programs, a State would not be able to claim unexpected expenses under the demonstration. Second, participating States would still be expected to meet the cost-effectiveness requirements of section 1915(c)(2)(D) of the Social Security Act. Third, participating States must commit to continuing to sustain their effort in provision of services for each participating individual beginning on the first day of the 13th month following their discharge from the institutional setting and continuing while the individual remains eligible for Medicaid. Participating States will only receive regular Medicaid match rate for that continuation of services.

Question 2: How will the Federal government ensure that its investment in community-based living will continue beyond the first year when 100 percent FMAP is offered? What steps are you taking to ensure that in years when State budgets are tight that these home and community-based services will not be cut from the State's Medicaid program?

Answer: Under the "Money Follows the Person" (MFP) proposal, the Federal government would pay for a package of home community-based services for eligible *individuals,* furnished for a 12-month period following discharge from an institutional facility. The package of home and community-based services would be for eligible individuals who are discharged from an institutional facility, not a State's entire Medicaid population. In their proposals, States must commit to continue to fund a package of home and community-based services for each individual served in the demonstration. As this requires legislation, we look forward to working with you to build in appropriate protections. However, the proposal is designed to provide some short-term savings for States just as the enhanced match in other Medicaid provisions serves as incentive to achieve long-term objectives.

The MFP builds on the success we have seen in the programs provided through existing Home and Community-Based Service (HCBS) waivers in several States. In these programs, States have the flexibility to meet the specific long-term care needs of defined groups of people, but States are required by section 1915(c)(2)(A) of the Social Security Act to ensure the health and welfare of the individuals served. States fulfill this requirement by providing services pursuant to a plan of care that is required in section 1915(c)(1) of the Social Security Act. The plan of care must be a comprehensive documentation of the total needs of the waiver participant. While States have the flexibility to reduce a participant's waiver package, States must ensure the health and welfare of waiver participants and must make sure that they receive all the services necessary (as defined and approved in the waiver) as long as the participant continues to be served in the waiver. If the HCBS waiver package of services does not meet the person's needs, participants maintain the ability to receive care in an institutional setting.

We believe States will want to maintain HCBS waiver services even in times of tight budgets because of the benefits to HCBS participants. Individuals who receive long-term care services and supports in the community have increased satisfaction, lower incidence of care neglect, lower incidence of adverse effects and health problems, and lower unmet needs. Individuals and their families have higher levels of satisfaction with overall care and quality of life.

Question 3: You may remember the letter that Senator Breaux and I sent the Department of Health and Human Services last July regarding the importance of quality following the release of the GAO report, "Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should be Strengthened." This report identi-

fied many systemic failures on the part of the Department of Health and Human Services (HHS) in assuring quality of care in its waiver programs. Failure to provide necessary services, weakness in plans of care, and inadequate case management are just a few of the concerns outlined by GAO. Secretary Thompson has assured us that numerous steps have been taken by HHS to ensure quality outcomes. Can you tell me specifically what the Administration has done to promote quality in the home and community-based setting?

Answer: CMS has made significant progress in improving HCBS services. Earlier this year, Secretary Thompson submitted to Senators Grassley and Breaux an updated report on CMS's Action Plan for Quality in HCBS. The Action Plan provides a status report on the quality initiatives that CMS has undertaken in Medicaid home and community-based services. We are pleased that the majority of the actions (16 of the 18 promised actions) to which we committed have been completed and we have made substantial progress on the other two.

On February 29, 2004, CMS released the final version of the Quality Framework and the Quality Inventory Report. Both of these documents reflect our collaboration with the National Association of State Medicaid Directors, the National Association of State Units on Aging and the National Association of State Directors of Developmental Disability Services. The Quality Framework emphasizes the importance of building quality into the design of the HCBS program and developing a quality management program that assures on-going discovery, remediation and improvement in services.

The Quality Inventory Report provided information about the significant efforts States have made to develop systems of self-monitoring. The National Quality Inventory Survey succeeded in providing critical information on HCBS waiver Quality Assurance/Quality Improvement systems. Based on this knowledge, we issued Interim Procedural Guidance to CMS Regional Offices to re-focus the waiver review on States' oversight activities. The guidance establishes several fundamental principles upon which CMS's approach to quality is built. These are:

1. States have first-line responsibility for assuring waiver quality and improving it;
2. CMS oversight of waiver quality is:
- Continuous;
- Involves on-going dialogue with the States to identify opportunities for quality improvement and collaboration on a course of action; and
- Involves technical assistance, either directly from CMS or in collaboration with CMS' National Quality Contractor.

The guidance will continue to evolve as CMS moves to implement changes in the waiver application process and annual waiver report process, both of which will provide additional information about States' HCBS quality assurance and improvement.

Question 4: I see the New Freedom Initiative as an opportunity to continue to promote the importance of quality of care. What new policies in this initiative will further the goal of providing quality care to Medicaid beneficiaries in the home and community-based setting?

Answer: Increased access and individual choice is fundamental to quality home and community-based services. Through the New Freedom Initiative, CMS is committed to working with States to enhance their ability to develop financing systems that support individual choice, provide responsive services and supports, and develop comprehensive systems to assure quality of life and services. President Bush announced the New Freedom Initiative in February 2001 and expanded the initiative through Executive Order 13217 on June 18, 2001. The New Freedom Initiative is a plan to ensure persons with disabilities who are able and choose to do so to have the opportunity to live in the community in order to reach their full potential as outlined by the Supreme Court's *Olmstead* decision. The FY 2005 President's budget includes several policies that build on the New Freedom Initiative and promote work incentives and long-term care options for people with disabilities. To further enhance the opportunities for people to live meaningful lives in the community, the budget authorizes approximately $428 million in FY 2005 and approximately $2.2 billion over 5 years to improve community services, help transition people out of institutions, and support Americans in the community through a variety of initiatives. Items in the President's FY 2005 Budget that support the New Freedom Initiative include:

Money Follows the Individual Rebalancing Demonstration: This proposal creates a five-year demonstration that finances services for individuals who transition from institutions to the community. Federal grant funds would pay for the home and community-based waiver services of an individual for a year at an enhanced Federal match rate of 100 percent. As a condition of receiving the enhanced match, the par-

ticipating State would agree to provide care at the regular Medicaid matching rate after the first year and to reduce institutional long-term care spending.

Living with Independence, Freedom, and Equality (LIFE) Accounts: Individuals who are Medicaid eligible and self-direct all of their own community-based long-term care support services will be eligible to establish a LIFE Account. A LIFE Account will allow these individual to accumulate savings and still retain eligibility for Medicaid and Security Income (SSI). Under current law, beneficiaries are discouraged from accumulating savings because it could jeopardize their eligibility for Medicaid and SSI.

Spousal Exemption: States would be given the option to continue Medicaid eligibility for the spouse of a disabled individual who returns to work. States may already continue to allow Medicaid eligibility for the disabled worker under current law despite the income increase. Under current law, individuals with disabilities might be discouraged from returning to work because income they earn could jeopardize their spouse's Medicaid eligibility. This proposal would extend to spouses the same Medicaid coverage protection offered to workers with disabilities.

Presumptive Eligibility for Home and Community Based Care Services: Establishes a State option of allowing Medicaid presumptive eligibility for institutionally qualified individuals who are discharged from hospitals into the community.

Systems Change Grants: The Budget proposes $40 million to continue the Real Choice Systems Change grants to provide financial assistance for States to develop systems that support community-based care alternatives for persons with disabilities who require an institutional level of care. The Real Choice Systems Change grants are being funded out of CMS's Research, Demonstration, and Evaluation budget.

New Freedom Demonstrations: The President's budget also includes a number of other investments in the New Freedom Initiative. Three innovative demonstrations will enhance the ability of individuals with disabilities to live and fully participate in the community. These demonstrations support respite for caregivers of adults with disabilities; respite services to caregivers of children with severe disabilities; and home and community-based services for children residing in psychiatric residential treatment facilities.

Question 5: As you may know, I strongly support proposals to strengthen and elevate the direct care worker profession. Late last year, I was able to secure pledges from the nursing home community to direct a total of $4 billion over 10 years to direct, hands-on care for residents. The New Freedom Initiative contains a demonstration that addresses shortages of community direct care workers, and allocates $2.9 million in 2005. What kinds of activities are you planning to support under this demonstration?

Answer: CMS will make grants to States and others to develop recruitment and retention strategies for workers who provide direct services to Medicaid eligible individuals. This program will offer an opportunity to explore ways to improve incentives for people to become direct care professionals, with a focus on health care coverage for the workers, in hope of building a workforce that can meet the needs of present and future Medicaid participants.

Question 6: Given that the shortage of direct care workers is likely to continue into the near future, would you consider supporting a longer-term solution?

Answer: Yes. CMS is willing to partner with other Federal agencies, States, consumers, and other stakeholders to address the direct service workforce shortage and work towards a long-term solution.

RESPONSES TO QUESTIONS FROM SENATOR BAUCUS

Question 1: The Administration has proposed to permit States to require beneficiaries participating in the Money Follows the Person Initiative to self-direct their own services, but has relied exclusively on the use of individual budgets as the only model for self-direction.

- What do you see as the role of other models of self-direction that States have successfully used (other than the Cash and Counseling and Independence Plus models) in which beneficiaries are permitted to self-direct their services without using an individual budget?
- If an individual wanted to have greater control over scheduling of the hours of personal attendant services, would the Money Follows the Person Initiative provide this individual any opportunities to self-direct without having to take on all of the responsibilities associated with self-direction under the Independence Plus model?

- Finally, if a State could make self-direction a prerequisite for an individual to leave a nursing home under a Money Follows the Person grant, how could you consider self-direction to be truly "optional" for that individual?

Answer: CMS supports innovations in self-directed service delivery, and recognizes that there are many models that provide opportunities for self-direction in Medicaid services. The "Money Follows the Person" proposal does not require participating States to use individualized budgets, but does require that States provide participants with an individualized package of services from what the State is currently able to provide under its State Plan, or sections 1915(c), 1115, 1915(d), or 1929 programs. States, in the applications for this demonstration, will be required to address what opportunities for self-direction will be provided to participants.

Question 2: The "Money Follows the Person" proposal indicates that States must continue to provide home and community-based services for each individual participating in the demonstration for as long as the individual remains eligible for Medicaid.

- For how long after the demonstration would CMS enforce this requirement?
- Will home and community-based services be considered an entitlement to any beneficiary who participates in the demonstration?
- What would happen if, after the completion of the demonstration, a State decided to restrict the package of benefits available to persons receiving services in the community?
- After the demonstration, how would CMS prevent States from restricting Medicaid eligibility for "optional" beneficiaries so that a State could more easily comply with this requirement?

Answer: States must commit to continuing to sustain their effort in provisions of services for each participating individual beginning on the 13th month following their discharge from the institutional setting and continuing while the individual remains eligible for Medicaid. States have considerable control over HCBS waiver services today in terms of restricting the number of people enrolled, defining what services will be available and the amount of services to be provided. The proposal does not change any of those dynamics, it merely serves as an incentive to help individuals return to their homes or communities. While the objective is to assist States in rebalancing their long-term care delivery systems, we certainly would not want to prevent an individual from returning to a facility if their level of care or preference changed.

Question 3: What could leftover LIFE Accounts be used for?

Answer: "LIFE Account" programs will operate in connection with a State's home and community-based services program—a program providing home and community-based services operating under a State Plan, or sections 1915(c), 1115, 1915(d), or 1929 program. To be eligible for a LIFE Account, individuals must have an approved self-directed service budget that is part of the qualified home and community-based service program. If the individual expends fewer resources than what was in his/her budget, up to 50 percent of the leftover budgeted amount can be credited to the LIFE account. Credits and other contributions to the account could be used for services and supplies that promote or maintain the participant's independence, productivity, and participation in the community, such as the purchase of equipment, environmental modifications, and supports; educational assistance and supports; employment or vocational training and supports; and expenses associated with any subsequent transitioning of the participant from an institution to the community. An Individual will continue to have the opportunity to make disbursements from the LIFE Account even if they no longer participate in a qualified home and community-based service program.

Question 4: How would CMS ensure that the existence of a LIFE Account does not substitute for providing adequate funding for anticipated needs through the individual budget?

Answer: States will continue to establish individual Medicaid community-based supports budgets based on accurate assessments of participant needs. LIFE Accounts are intended to be a separate account from an individuals' Medicaid, community-based, long-term supports budget, and CMS will enforce these two programs to assure that LIFE Accounts do not reduce Medicaid community-based supports budgets. Assets in a LIFE Account will not be considered in determining Medicaid eligibility or allocating an individual's annual Medicaid community-based supports budget. States that use self-directed budgets have mechanisms in place to review and adjust the self-directed budgets in response to a variety of changes in circumstances.

Question 5: If a person decided to forego services in order to save money in a LIFE Account, how could CMS ensure that the reduced spending/reduced service use was not considered in setting that person's budget in the following year? I understand that "savings" would not be taken into account in setting budgets, but can you as-

sure me that past service use under a capped budget would not be taken into account?

Answer: CMS ensures that States with individual budgets have adequate safeguards to make sure that they are calculated fairly. The individual budget is an amount of money determined to be the equivalent of the cost of specified services that would otherwise be included in an individual's plan of care, but it does not constitute the entire plan of care. The individual budget provides the beneficiary with the additional flexibility to move funds between services, and allows the beneficiary a greater degree of authority over the planning, design and delivery of services than would be possible under more traditional arrangements. States must have procedures to ensure that the use of an individual budget does not prevent the beneficiary from gaining access to needed services provided under its HCBS waiver to ensure health and welfare.

States with LIFE Account programs will have monitoring processes in place to assure that individuals do not unnecessarily limit their services and adversely impact their health and welfare. Any assets that are built up in a LIFE Account will not be considered when allocating an annual Medicaid community-based supports budget.

Question 6: Would there be a maximum amount that could be saved in a LIFE Account?

Answer: No. Although there is no cap on the amount that can be accumulated, we anticipate that individuals will use this account to save for equipment and supports that would increase their independence, productivity, education, community services, and housing rather than to simply build assets.

Question 7: How would savings in the LIFE Accounts be treated for tax purposes?

Answer: Income and earnings in the account, except for deposits from unexpended resources in the individual's approved Medicaid budget for self-directed services, will be treated as income to the participant for purposes of applying laws relating to taxation of income.

Question 8: What impact would the existence of a LIFE Account have on eligibility for SSI or SSDI? Have you consulted with the Social Security Administration to ensure that this initiative does not create unforeseen conflicts for Social Security recipients?

Answer: Assets in a LIFE Account will be excluded from consideration in determining and re-determining eligibility for and amount of benefit level of SSI or SSDI. CMS has consulted with SSA on design issues of the LIFE Accounts and at this time we have not identified any conflicts for SSI or SSDI recipients.

Question 9: Why are you proposing to limit participation in the LIFE Accounts to persons who direct "all" long-term care services? How would you define "all long-term care services?"

Answer: To participate in the LIFE Account savings program, individuals must be participating in a qualified home and community-based services program—a program providing home and community-based services operating under a State Plan, or under a section 1915(c), 1115, 1915(d), or 1929 program—and the individual must have an approved plan and approved budget for self-directed services in connection with such participation and not receive other medical assistance for home and community-based services under the qualified program. Individuals who are currently self-directing these supports budgets have demonstrated a clear interest and capacity to manage their own care, and the LIFE Account program is most appropriate for these individuals. Non-institutional LTC services include personal care, certain home health services and home and community-based services. States are providing 70 types of services under HCBS. Some of the most used are respite, home modifications, personal care, personal transportation, emergency response systems and homemaker services.

Question 10: What if new expensive technologies became available or if prices went up after a budget cap was already set? Could budgets be adjusted during that year to account for changed circumstances in the supply/availability of services, as opposed to changed circumstances in that individual's health or support network? Is there a requirement that States be willing to reconsider budgets under any particular set of circumstances?

Answer: States that use self-directed budgets determine the length of their self-directed budget periods, which might be quarterly, semi-annually, or annually. In addition, these States have mechanisms in place to review and adjust the self-directed budgets in response to a variety of changes in circumstances.

Question 11: Regarding the New Freedom Initiative/Independence Plus self-directed care models and proposals, could any durable medical equipment expenses be covered under the capped grant to individuals under any existing Independence

Plus waivers or under any of the New Freedom Initiative's consumer direction proposals? What about assistive technologies such as a voice recognition organizer?

Answer: States have the option to determine what services and supports to include in their individual budget programs. This could include durable medical equipment and assistive technologies if the State determines to include them.

Question 12: Do all States have adequate infrastructure to provide the intensive counseling that was integral to the Success of the Cash and Counseling demonstrations?

Answer: Under the Independence Plus program requirements, a State must provide self-directed supports and services which will adequately assist participants in planning, securing, budgeting and managing the services identified in their individual budgets. The extent to which participants use the supports and services will vary with their abilities and preferences. States may design these supports and services in a variety of ways, including: 1) combining them with existing services, 2) creating a new service category to include all or some of the activities, or 3) identifying them as an administrative function. With this flexibility, all States are expected to be able to provide as much or as little counseling as a participant may need.

Question 13: If a beneficiary participating in a self-direction program believes that his/her individual budget is set at inadequate levels, what recourse is available to him/her? What standards has CMS established for evaluating a claim of inadequate financing?

Answer: States must meet certain requirements to establish an Independence Plus program, including standards for evaluating individual budgets. With respect to the Individual Budget process, the following is a list of participant protections:

1. Participants must have the flexibility to move money within the approved budget service categories.
2. The program must allow for open disclosure of the methodology used to calculate the individual budget.
3. Participants must be informed of the procedures to follow to request an adjustment to the individual budget.
4. The program must have procedures to re-evaluate the plan of care/person-centered plan if the individual budget is over or under-expended.
5. The program must have a prompt mechanism for adjusting the funding level/total budget if the participant's needs or situation changes.
6. The program must describe the State's methodology for calculating individual budgets, using actual or reliable service utilization and cost information.
7. The resources available to participants must use a consistent methodology.
8. The methodology must be applied consistently to each participant.
9. Review and monitoring of the individual budget must occur according to a specified method and frequency which is known to the participant.

Participants in Independence Plus programs must have the ability to flexibly manage their individual budgets so that their resources are spent in a way that preserves their needed and desired services. This provides participants with a lot of control, but CMS recognizes that participants are not always accustomed to having that control. CMS, therefore, requires the provision of "self-directed supports and services" that help participants understand and implement their rights, roles and responsibilities. Accordingly, States are required to provide Independence Plus participants with assistance in effectively managing their self-directed services. The self-directed supports and services include regular fiscal review, counseling and education to participants who may not be effectively managing their funds. Each program has to build in a budget review methodology and inform the participants of that process.

The Independence Plus 1915(c) waivers are designed to meet the needs of particular populations (*i.e.,* developmentally disabled, elderly, physically disabled) and prevent institutionalization. Under sections 1915(c)(2)(A), States must assure the necessary safeguards have been taken to protect the health and welfare of individuals provided services under the waiver. Each beneficiary must have a written plan of care required under section 1915(c)(1). An individual's budget is a monetary estimate based on this plan of care. Because the plan of care drives the individual budget, it must be sufficient to pay for supports and services to prevent institutionalization. If participants feel their individual budget is inadequate, participants can have a new needs assessment to review the budget and adjust it accordingly. Then, if still unsatisfied, the participant could file a grievance and if desired, use the services of the independent advocate or advocacy organization to file that grievance or complaint. Like other Medicaid recipients, waiver participants have the same right to a fair hearing and appeals process when their claim for assistance is denied or not acted upon promptly.

Question 14: Do you believe that the methods for calculating the individual budgets under the Independence Plus demonstrations have been fair? Are there appropriate safeguards in the Independence Plus demonstration to ensure that individual budgets are adequate and fair? Why?

Answer: Yes. The Independence Plus demonstrations contain adequate safeguards to make sure that individual budgets are calculated fairly. In these demonstrations, an individual budget refers to the monetary value of services and supports under the control and direction of the beneficiary. Independence Plus features plans of care that include individual budgets. However, the individual budget, an amount of money determined to be the equivalent of the cost of specified services that would otherwise be included in the plan of care, does not constitute the entire plan of care. The individual budget provides the beneficiary with the additional flexibility to move funds between services, and allows the beneficiary a greater degree of authority over the planning, design and delivery of services than would be possible under more traditional arrangements. States must have procedures to ensure that the use of an individual budget does not prevent the beneficiary from gaining access to all needed services to ensure health and welfare.

Specific State-level safeguards are required in Independence Plus programs to assure that individual budgets are adequate and fair. Within both the section 1915(c) programs and the section 1115 demonstrations, States must have the following mechanisms included in their program design, specifically with regard to the individual budget, in order to have their Independence Plus programs approved:

- A mechanism for prompt adjustment of the funding level/total budget if the person's needs or situation changes;
- A budget based on actual or reliable service utilization and cost information;
- A budget developed using a consistent methodology to calculate the resources available to each participant;
- A methodology that is consistently applied to each participant;
- Assurances that the budget is reviewed according to a specified method and frequency;
- Assurances that expenditures are monitored on a regular basis;
- A mechanism that provides participants with the opportunity to move money within the approved budget service categories; and
- A description of the methodology used to calculate the individual budgets that is open to public inspection.

Further, Independence Plus participants are required to receive assistance to help them effectively manage their self-directed services. Such assistance includes, but is not limited to, supports brokerage services, financial management services, and independent advocacy services. In terms of the recourse afforded to participants if they feel their individual budget is inadequate, if needed, a participant can work in collaboration with her/his supports broker for a new needs assessment to review the budget and adjust it accordingly. Then, if still unsatisfied, the participant could file a grievance and if desired, use the services of the independent advocate or advocacy organization to file that grievance or complaint. Like other Medicaid recipients, waiver participants have the same right to a fair hearing and appeals process when their claim for assistance is denied or not acted upon promptly.

In addition, with respect to the Individual Budget process, the following is a list of participant protections:

1. Participants must have the flexibility to move money within the approved budget service categories.
2. The program must allow for open disclosure of the methodology used to calculate the individual budget.
3. Participants must be informed of the procedures to follow to request an adjustment to the individual budget.
4. The program must have procedures to re-evaluate the plan of care/person-centered plan if the individual budget is over or under-expended.
5. The program must have a prompt mechanism for adjusting the funding level/total budget if the participant's needs or situation changes.
6. The program must describe the State's methodology for calculating individual budgets, using actual or reliable service utilization and cost information.
7. The resources available to participants must use a consistent methodology.
8. The methodology must be applied consistently to each participant.
9. Review and monitoring of the individual budget must occur according to a specified method and frequency which is known to the participant.

Question 15: In your testimony you indicated that families of children with disabilities often like the flexibility that an individual budget might offer them in directing the long-term care services of their minor son or daughter. To what extent does a parent's acceptance of a capped individual budget amount limit or otherwise

affect their child's entitlement to receive all medically necessary services—including long-term care services—under EPSDT?

Answer: Under EPSDT, a State is required to provide medically necessary services to a child. Participating in a home and community-based waiver or directing these services does not change the EPSDT requirement.

Question 16: It is my understanding from numerous news reports that CMS is or has recently been negotiating with New Hampshire, Florida, California, and several other States regarding Section 1115 waiver applications or concept papers that, if approved and implemented, would impose a global cap in Federal spending on either a State's entire Medicaid program or a substantial portion of the State's Medicaid program. I would appreciate an update on any such negotiations, including information about where the public can learn more about the proposals being discussed. Among other things, please inform the Committee which States CMS is negotiating with over waiver proposals that would impose any kind of enforceable cap (other than a per capita cap) on Federal matching payments; what the status of the negotiations are; and what CMS intends to do to ensure that there is meaningful public participation in the waiver development and negotiation process.

Answer: All States under 1115 waivers operate under a budget cap that is enforceable. Whether designed as a per capita cap, aggregate cap, or global cap, the Federal government limits its fiscal liability to an amount no greater than what it would have spent without a waiver. If spending is projected to exceed the 1115 cap, the State may choose to end the waiver or cover the costs above the cap. The cap is enforced by the Federal government recovering funds that exceed the limit.

CMS has received calls from a few States, including California, Florida, Montana, Kentucky and Tennessee, to discuss broad conceptual changes to their programs, but we have not received any specific proposals. Public participation is one of the elements we use in evaluating a waiver application, and we have strongly encouraged States to engage in a broad public participation process. We believe States considering reform are incorporating such participation.

Question 17: As you know, the so-called Medicaid IMD exclusion prohibits Federal matching funds for services provided to residents in facilities with 16 or more beds serving adults with mental illnesses ages 18 to 64. Over the past decade, CMS has approved waivers of the IMD exclusion for a number of States. Some of these waivers have been a part of larger efforts to promote access to community-based services and acute care in inpatient settings. However, in recent months CMS has been denying waivers of this IMD exclusion, including applications by States to extend existing waivers. Has CMS put in place a policy of denying all waivers of the IMD exclusion? If so, could you explain the rationale for the new policy? And if not, could you explain whether CMS has developed new criteria for approving waivers of the IMD exclusion and describe what they are?

Answer: Section 1905(a)(27) of the Social Security Act excludes Federal financial participation (PPP) for services provided to Medicaid beneficiaries aged 22–64 when residing in an institution for mental diseases (IMD). Examples of these facilities include State mental hospitals, private psychiatric hospitals, and residential substance abuse treatment facilities.

Under the demonstration authority in §1115 of the Social Security Act, CMS permitted FFP for IMD expenditures for beneficiaries' aged 22–64 in eight States. Beginning with Tennessee in 2002, the IMD waiver authority has been phased out because such waivers were creating financial imbalances among the States. As a matter of equity, more waivers would be sought by States to a point of rendering the statutory exclusion meaningless. We have also begun the phase-out of the IMD authority in Rhode Island, Oregon, Delaware, and Vermont. When the remaining States (Arizona, Hawaii, and Massachusetts) request to have their §1115 authority extended, we intend to phase it out for them at that time.

RESPONSES TO QUESTIONS FROM SENATOR SMITH

Question 1: The Shortage of Health Care Providers—How Best to Address the Need: Currently, there is a shortage in the health care field for nurses and home health care providers. I believe to adequately implement the President's Initiative it is imperative that there is sufficient supply of skilled staff to provide quality, long-term care. What do you think Congress and the Administration can do to address the need for a quality, stable workforce? Do you think this initiative helps to address this workforce shortage?

Answer: CMS's Demonstration to Improve the Direct Service Community Workforce is an excellent opportunity to explore ways to improve incentives for people to become direct care professionals in hope of building a workforce that can meet the needs of present and future Medicaid recipients. CMS awarded five Direct Serv-

ice Community Workforce demonstration grants in FY 2003, and another five in FY 2004. The 10 grantees will test a variety of interventions to recruit and retain direct service workers. Six grantees will offer some forms of health insurance product such as employer-sponsored, State-subsidized health insurance, or health reimbursement accounts. Four of the grantees will focus on ways to enhance professional competencies or refine recruitment methods by developing interventions such as training or mentorship programs, professional assistance associations, web-based registries, and targeted recruitment programs.

There are two evaluation components to this Demonstration. First, each grantee will conduct a site-specific evaluation of its interventions. Second, CMS plans to conduct a national evaluation of the demonstration grantees to answer key questions around recruitment and retention that inspired this CMS demonstration project, such as:

- What kinds of interventions had the greatest impact on the direct service workforce?
- What other effects did the interventions have on the direct care system (*e.g.,* increased consumer satisfaction, increased employee satisfaction, increased interest in the caregiving profession.

In 2003, CMS granted $1.4 million to the following entities to offer health insurance to direct service workers during the three-year demonstration:

- State of Maine, Governor's Office of Health Policy and Finance;
- New Mexico Department of Health; and
- Pathways for the Future, Inc., a private corporation in North Carolina.

Grants of $680,000 each will go to the following grantees to develop educational materials, training of service workers, mentorship programs and other activities:

- Volunteers of America, Inc. to pilot training programs in the greater New Orleans area; and
- University of Delaware.

In 2004, CMS granted $1.4 million to the following entities to offer health insurance to direct service workers during the three-year demonstration:

- Virginia Department of Medical Assistance Services;
- Home Care Quality Authority, an agency of State government in Washington State; and
- Bridges, Inc., a non-profit service agency in Indiana.

Grants of $680,000 each will go to the following grantees to develop educational materials, training of service workers, mentorship programs and other activities:

- Arkansas Department of Human Services; and
- Seven Counties Services, Inc., a service provider in Kentucky.

Question 2: Implementing the President's Initiative—Ensuring Adequate Choices: As you know, the needs of the elderly and individuals with disabilities are extremely diverse. Some are able to work and live independently, while others require a great deal of assistance in their everyday lives. In providing services based on an individual's particular needs and choices, how do you envision implementing such a proposal? That is, how best can we ensure that these Americans will have the optimal choice of where to live that best fits their unique needs? In part, I believe this will require helping people make informed choices. Do you foresee individuals having professional assistance in making decisions about where they live?

Answer: Medicaid beneficiaries are indeed a diverse group, and CMS recognizes that community-based care models do not work for all individuals in need of long-term care services. The Aging and Disability Resource Center Grant Program, a cooperative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS), was developed to assist States in their efforts to create a single, coordinated system of information and access for all persons seeking long-term support to minimize confusion, enhance individual choice, and support informed decision-making. In FY 2003, HHS announced the award of 12 grants totaling $9.26 million to support State efforts to develop Aging and Disability Resource Centers. In FY 2004, Secretary Thompson announced the funding of 12 additional State Resource Center grants totaling nearly $9 million.

Through the New Freedom Initiative, CMS is committed to ensuring that home and community-based services and supports offered through home and community-based service programs develop comprehensive systems to assure quality of life and services. The Independence Plus programs offer assistance that includes, but is not limited to, supports brokerage services, financial management services, and independent advocacy services, and many waiver programs operated by States provide case management services to help beneficiaries make informed choices. In total, these services, in combination with the Aging and Disability Resource Centers, will help and assist beneficiaries in tapping into community resources, building relationships, exploring choices, supervising staff, and understanding budgets. CMS will

continue to work with States, consumers, and other stakeholders to utilize effective strategies to provide the tools necessary for beneficiaries to be able to make informed decisions.

RESPONSES TO QUESTIONS FROM SENATOR BUNNING

Question 1: There is a concern about the lack of access to quality medical, dental, and other health services for people with mental retardation and developmental disabilities. Would you support using Federal funding for the development of MR/DD clinics that deliver specialized care to the MR/DD population while also training future health care professionals?

Answer: The President's FY 2005 Budget does not include any specific proposals on this idea. We note that Federal funding is currently available for the training of future health care professionals through the Maternal and Child Health Block Grant (Title V of the Social Security Act). Currently, Title V funding also supports 36 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs in 29 States that provide long-term, graduate-level interdisciplinary training to health professionals. The program focuses on health conditions of mental retardation, neurodegenerative and acquired neurological disorders and multiple handicaps. All LEND Programs operate within a university system and most have collaborative arrangements with local university hospitals, children's hospitals, and/or health care centers. We do see a future in which staff in ICF/MRs act as a potential resource for individuals in the community seeking care from highly specialized professionals. ICF/MRs often serve as appropriate settings for training health care professionals.

Question 2: There has been some concern about implementing new and expensive programs while some people are currently on waiting lists for services. Do you have any thoughts on addressing the issue of the waiting lists?

Answer: CMS takes a multi-pronged approach to assisting States to best meet the needs of their Medicaid participants. Although some waiver programs have waiting lists, others do not. Through technical assistance, grants, waivers, and demonstrations, CMS works with States to build their infrastructure and capacity to provide home and community-based services and address waiting list issues, as well as develop new innovations in service delivery. We certainly believe the President's MFP proposal is a step forward in reducing waiting lists.

Question 3: Receiving community-based care is not an option for everyone. What type of factors should be considered when determining if home-based care or institutional care is best for a particular individual?

Answer: CMS recognizes that community-based care models do not work for all individuals in need of long-term care services. Where to seek services is a very personal decision for individuals and families. Our goal is to expand the choices available to them.

States have the flexibility to design programs to meet specific needs of defined populations. However, any participant in an HCBS waiver must meet an institutional level of care (either hospital, nursing or ICF/MR). States can design programs that meet the needs of persons with intense medical/support needs or for those who require minimal assistance to remain in the community.

For those persons served in an HCBS waiver program, States are required to ensure their health and welfare. In keeping with this requirement, services are provided in an HCBS waiver to participants pursuant to a plan of care. The plan of care must be a comprehensive documentation of the total needs of the waiver participant. While States may modify a participant's waiver package, States must still ensure the health and welfare of waiver participants—*i.e.,* making sure that they receive all the services necessary (as defined and approved in the waiver) as long as they continue to be served in the waiver. If the HCBS waiver package is lacking and the person's needs cannot be met through the waiver program, participants maintain the ability to receive institutional care.

RESPONSES TO QUESTIONS FROM SENATOR ROCKEFELLER

Question 1: Senator Baucus and I recently introduced S. 2222, the Medicaid and CHIP Safety Net Preservation Act. This important legislation will ensure that Section 1115 of the Social Security Act (the so-called "1115 waiver" authority) cannot erode core objectives of Medicaid and CHIP that Congress has enacted into law. One provision of our legislation prohibits the elimination of the individual entitlement to Medicaid. The individual entitlement to Medicaid protects access to all covered benefits and services. We believe that any attempt to undermine this individual entitlement is a violation of the Federal-State guarantee of Medicaid benefits to those who are eligible. Yet, HHS has approved numerous 1115 waivers that impose global

caps and eliminate or limit the guarantee of Medicaid for eligible individuals. A prime example of this is the Florida Independence Plus Program, which I understand has a global cap. According to a December 2003 Kaiser report, when a person is given an individual budget, it is difficult to enforce that person's right to the Medicaid entitlement. How can we be sure that the Money Follows the Individual Initiative won't morph into one of these Independence Plus waivers and limit the guarantee of Medicaid for eligible individuals? Or is that this Administration's objective?

Answer: With respect to Florida's Independence Plus program, I want to correct the impression that it is funded through a global cap. The program is funded through CMS' 1115 demonstration authority and uses a per-member per-month methodology for demonstration participants.

With regards to the Money Follows the Person demonstration, the objective is to provide individuals with an opportunity to receive services in a community-based setting rather than an institution. There is no global cap or mandate that an individual budget be used. Rather, under the MFP demonstration, the Federal government would pay for a package of home community-based services for eligible individuals, furnished for a 12-month period following discharge from an institutional facility.

Under current law, the total amount a State will spend on Medicaid services, including waiver services, cannot exceed the cost of providing services in an institutional setting. Waiver programs are required to be cost-effective, that is, the total cost cannot be greater than the cost of providing those services in an institutional setting. MFP does not change the underlying HCBS construction. It is an incentive for States to provide greater access to them for people currently in institutions.

Question 2: The specifics on the "LIFE" accounts are minimally outlined in the FY 2005 budget. Can you provide me with more details about this proposal? How will it impact beneficiaries?

Answer: Beneficiaries will be able to save money without losing their eligibility for Medicaid and Social Security benefits. These accounts would give individuals an opportunity to build savings for the future. They will remove barriers to saving for services and supplies that promote or maintain the participant's independence, productivity, and participation in the community, such as the purchase of equipment, environmental modifications, and supports; educational assistance and supports; employment or vocational training and supports; and expenses associated with any subsequent transitioning of the participant from an institution to the community. Individuals will continue to have the opportunity to make disbursements from their LIFE Account even if they no longer participate in a qualified home and community-based service program.

Question 3: How many people do you estimate would benefit from this proposal?

Answer: Because of the requirement that individuals must direct all of their Medicaid, community-based, long-term supports, we anticipate that no more than 20 percent of Independence Plus participants would be eligible to establish LIFE Accounts. Currently, approximately 30,400 individuals in seven States are self-directing at least some their services under Independence Plus, and an additional 4,450 self-direct some of their services under Cash and Counseling programs. As a result, we estimate that approximately 6,970 individuals would be eligible to establish a LIFE Account at this time.

Question 4: Would family members be able to contribute without jeopardizing an individual's eligibility for benefits?

Answer: Yes. Contributions to LIFE Accounts by parents, grandparents, siblings, spouses, adult children, and/or employer of the account holder may not exceed the annual gift exclusion under Federal tax law. The annual gift exclusion is currently $11,000 a year. States may establish lower contribution limits when establishing their LIFE Account programs.

Question 5: If a person is participating in this program, would his/her individual entitlement to Medicaid be protected?

Answer: Yes. Medicaid participants are entitled to medically necessary services under their State Plan. The LIFE Account savings program is proposed to enable Medicaid-eligible individuals to build savings while retaining their Medicaid eligibility.

Question 6: Have you worked out implementation details with the Social Security Administration?

Answer: CMS has consulted with SSA on a variety of design issues of the LIFE Accounts, and we believe there would be no conflict.

Question 7: Medicaid can have different disregards for income, but Supplemental Security Income (SSI) cannot. There is a $2,000 limit on assets. Will this proposal compromise an individual's SSI benefits?

Answer: No. Funds in a LIFE Account are excluded from consideration in determining and re-determining eligibility for and amount of Medicaid and SSI or SSDI benefits for the participating individual and their families.

Question 8: I am particularly concerned about the availability of home and community-based services in rural States like West Virginia. As you are aware, rural States tend to have a significant shortage of health care personnel. As part of the New Freedom Initiative, you have proposed a demonstration project to address the shortages of direct care workers. Will demonstration grants for direct care workers be available in rural States like West Virginia?

Answer: Yes, grantees under the Demonstration to Improve the Direct Service Community Workforce are selected through a competitive process by which applications are reviewed and scored by a panel of experts based upon the merits of the proposals. CMS relies heavily on the results of the panel reviews when making decisions on which applicants should be funded. CMS received over 100 proposals to our FY 2003 grant solicitation. Out of the many meritorious applications we were able to award 5 grants with the available funding (DE, ME, NC, NM and VA). In FY 2004, CMS awarded $1.4 million each to the Virginia Department of Medical Assistance Services, the Home Care Quality Authority, a Washington State agency, and Bridges, Inc., a non-profit service agency in Indiana. Each of these grantees will be offering health insurance to direct service workers during the three-year demonstration. Grants of $680,000 each will go to the Arkansas Department of Human Services and Seven Counties Services, Inc., a service provider in Kentucky, for developing educational materials, training of service workers, mentorship programs and other activities.

Question 9: I understand that CMS is negotiating with at least six States (including New Hampshire, Florida, and California) to develop 1115 waivers that would change the financing structure of the Federal-State partnership to include global caps. Specifically, these waivers would impose a global cap on either a State's entire Medicaid program or a substantial portion thereof. I am very concerned about this, because such caps would have a detrimental effect on the States' ability to provide critical health and long-term care services to its most vulnerable citizens. What is the status of those negotiations and what is CMS' intent regarding public involvement in this process?

Answer: CMS has received calls from a few States, including California, Florida, Montana, Kentucky and Tennessee, to discuss broad conceptual changes to their programs, but we have not received any specific proposals.

Question 10: A number of the States represented on this Committee have not yet recovered from what the National Governors Association has called the worst State fiscal crisis since World War II. Last year, over the vehement objections of the Administration, Congress enacted fiscal relief for the States in the form of a 2.95 percentage point increase in the Federal matching rate. This fiscal relief was crucial to the ability of a number of States to avoid making drastic cuts in Medicaid eligibility, benefits, and provider payments. Unfortunately, this fiscal relief ends on June 30, and many State economies are still not out of the woods. And the Administration's budget for the fiscal year starting October 1 does not propose to extend this fiscal relief. Unless we act in the next two months, States will face a loss of $10 billion in Federal resources on July 1. If the States with economies that are not yet fully rehabilitated are faced with the choice of cutting home and community-based waiver slots, reducing payments to nursing homes, or raising taxes to make up for the loss of the enhanced FMAP, what exactly do you believe will happen? Do you honestly believe States will expand home and community-based services?

Answer: We understand the fiscal challenges facing States in meeting the needs of their Medicaid beneficiaries, and we believe long-term restructuring of the Medicaid program is needed. I believe States will continue to expand HCBS because that is in part what they are doing as they try to keep pace with the people they serve.

Question 11: Mr. Smith, as I understand your budget, it includes a cut of $9.6 billion over 5 years, or $23.5 billion over 10 years, to the Medicaid program. The proposal as outlined on page 65 of the Budget in Brief notes,

"The FY 2005 President's Budget proposes to further improve the fiscal integrity of Medicaid by curbing IGTs that are in place solely to undermine the statutorily determined Federal matching rate. The Budget proposes to cap Medicaid payments to individual State and local government providers at the cost of providing services to Medicaid beneficiaries and restrict the use of certain intergovernmental transfers."

This language is very vague. This is no specific proposal and it is unclear how West Virginia will be affected by it. If there are instances of fraud, we in Congress stand ready to work with the Administration to address the matter as we have in

the past. But, I would like to understand exactly what you are proposing. So, my questions on this issue are as follows:

- What exactly is your proposal, and how would West Virginia be affected?
- Is your proposal based simply on a cut of some portion of your estimate of total Upper Payment Limit (UPL) spending? How much total UPL spending is there—excluding the transition period funds? How much of that is going to hospitals? How much of that is going to nursing homes? How much of that stays with each respective provider?
- What is the total dollar value of illegal intergovernmental transfers (IGTs) today?
- What is the dollar value of all legal intergovernmental transfers (IGTs) today?
- Which intergovernmental transfers (IGTs) that are allowed now would be allowed to continue under your proposal, and what is the dollar value of those IGTs?
- Does this proposal represent eliminating the existing phase-out of the 2000 law and immediately taking that money away from States?

Question 12: What exactly is your proposal, and how would West Virginia be affected?

Answer: At this time, I do not know specifically how West Virginia would be affected because I do not know whether the State engages in the practices to be prohibited. The President's FY 2005 budget proposes to build on past efforts to improve Federal oversight of Medicaid and ensure that Federal taxpayer dollars for Medicaid are going to their intended purpose. The Administration proposes to further improve the integrity of the Medicaid matching rate system through steps to curb funding arrangements that are in place solely to avoid the legally determined State financing. To be clear, CMS considers IGTs that meet the protections of the Medicaid statute as permissible sources of State funding of Medicaid costs, protections which are meant to allow units of local governments, including government health care providers, to share in the cost of the State Medicaid program.

In this regard, we are developing a proposal under which the Federal government, when matching a claimed State expenditure for a service provided by a government provider, will only provide matching payments on the basis of the State's true net expenditure. For a simple illustration, assume that a State with a 50/50 match rate submits a claim for $100 for a service provided by a government provider. If the government provider is required to return 5 percent of the claim to the State as an IGT, we believe the net expenditure is only $95, so the Federal match should be only $47.50 instead of $50. As noted previously, the Department's Office of Inspector General recommended this approach as part of its September 2001 final report. Specifically, the OIG recommended that CMS "Require that the return of Medicaid payments by a county or local government to the State be declared a refund of those payments and thus be used to offset the FFP generated by the original payment."

The total amount of savings from each State, including West Virginia, would depend on the degree to which they make claims for Federal matching funds associated with certain Medicaid payments that health care providers are not ultimately allowed to retain. Specifically, each State will be affected by the total amount of Medicaid payments State and/or local governments require the health care provider to forgo and/or return.

The estimates for the program integrity proposal were developed by the Office of the Actuary for the President's Budget for Fiscal Year 2005. It is intended to restrict certain State payments from being matched by Federal Medicaid funding. The estimates were developed by examining reimbursements to government providers and IGTs between State and local governments.

Question 13: Is your proposal based simply on a cut of some portion of your estimate of total Upper Payment Limit (UPL) spending? How much total UPL spending is there—excluding the transition period funds? How much of that is going to hospitals? How much of that is going to nursing homes? How much of that stays with each respective provider?

Answer: Regarding the reimbursements to government providers, it is expected that this proposal would limit some enhanced payments unaffected by previous rules on upper payment limits (UPL), excluding transitional UPL payments. Based on the Office of the Inspector General's Review of Medicaid Enhanced Payments to Local Public Providers and the Use of Intergovernmental Transfers (September, 2001), it was estimated that Medicaid would save one-third of the unaffected enhanced payments. This would result in savings of $2.0 billion from 2005 to 2009 and $4.7 billion from 2005 to 2014.

Question 14: What is the total dollar value of illegal intergovernmental transfers (IGTs) today? What is the dollar value of all legal intergovernmental transfers (IGTs) today?

Answer: Regarding the IGTs, the estimates are based on a review of State Medicaid financing by the Center for Medicaid and State Operations and the CMS regional offices. This review of 2002 Medicaid spending showed that 25 States had a total of $5.7 billion of potential recycled funds from disproportionate share hospital (DSH) payments and UPL payments. It is important to note that many other States likely have recycled funds, and thus the actual amount is higher than $5.7 billion; however, this data is unavailable at this time. The amount of recycled funds was projected forward using the growth rates of Medicaid services from the President's budget. From that amount, transitional UPL payments and the savings from the cost-based reimbursement requirement were subtracted. The States reviewed by the Office of the Inspector General in its report had 50 to 100 percent of enhanced payments returned to them from providers during the audit period. As payment systems and conditions vary from State to State, it is difficult to generalize about how much each State retains from these enhanced payments. Conservatively, it was estimated that 25 percent of these transfers would be disallowed under this proposal. This would result in savings of $7.7 billion from 2005 to 2009 and $18.8 billion from 2005 to 2014.

The total savings of this proposal are estimated to be $9.6 billion from 2005 to 2009 and $23.5 billion from 2005 to 2014. It is likely that a more extensive review of each State's IGTs and financing will impact these estimates.

Some may suggest that the action taken on UPL has addressed the IGT concerns. Experience shows this is not the case. Since we began our in-depth review of SPAs that deal with Medicaid reimbursement last summer, 82 have been approved, 4 have been disapproved and 5 have been withdrawn entirely by States. States temporarily withdrew 39 SPAs as a result of our requests for additional information. Another 153 SPAs are under review at CMS.

However, States not engaged in these practices will not be affected by this proposal. Moreover, the proposal would not impact current law permitting the phase-out of UPL transition amounts.

Question 15: Which intergovernmental transfers (IGTs) that are allowed now would be allowed to continue under your proposal and what is the dollar value of those IGTs?

Answer: There appears to be a great deal of confusion about the term "intergovernmental transfer." IGTs that meet the conditions set out in the Medicaid statute are a permissible source of State funding of Medicaid costs. The statutory provision governing IGTs is an exception to the otherwise very restrictive requirements governing the use of provider-related donations and taxes. The IGT provision was meant to continue to allow units of local government, including government health care providers, to share in the costs of the State Medicaid program. In order for a health care provider to transfer funds that are protected under the Act, the health care provider must be a unit of State or local government. Therefore, in order for a governmental health care provider to make a protected transfer, it must have access to State or local revenues either by having a direct taxing authority or be able to access funding as an integral part of a governmental unit with taxing authority.

Question 16: Does this proposal represent eliminating the existing phase-out of the 2000 law and immediately taking that money away from States?

Answer: No, we assume those phase-outs would be protected.

Question 17: The Administration's FY 2005 budget includes a proposal for Long-Term Care Partnerships and estimates that this proposal will be cost-neutral. What type of consumer protections would be implemented for individuals purchasing these policies?

Answer: Partnership policies would be sold under regulations issued and enforced by individual States.

Question 18: What type of model is your proposal based on: total-asset protection or dollar-for-dollar?

Answer: The legislative proposal does not specify which of these models States would use. States would be free to use either model or a hybrid model that combines both, as in Indiana.

Question 19: Would there be a ceiling on the amount of assets that individuals would be allowed to protect?

Answer: The legislative proposal does not specify a limit on the amount that can be protected.

Question 20: How many years of long-term care insurance would insurance companies be required to provide?

Answer: The legislative proposal does not specify a minimum or a maximum duration of coverage. Individual States would be responsible for establishing these limits.

Question 21: What would happen if a person purchased a long-term care insurance policy in one State and then moved to another State? I know that Indiana and

Connecticut have a portability arrangement, but how would you address portability in other States?

Answer: The legislative proposal does not specify how States should resolve the asset protection portability issue. Participating States would be free to work out agreements similar to that of Indiana and Connecticut.

Question 22: Would Medicaid estate recovery be optional in all States or just in States with a Long-Term Care Partnership?

Answer: Federal law requires all States to conduct estate recovery, and the existing Partnership States are no exception. Existing partnership States recover from the estates of partnership participants, however, their "protected assets" are considered unavailable for recovery. Assets in excess of their "protected assets" are available for recovery.

If the law passes, States implementing new partnership programs would also be required to conduct estate recovery, however, they would be allowed to define "estate" for purposes of recovery, as do all non-partnership States.

RESPONSES TO QUESTIONS FROM SENATOR LINCOLN

Question 1: My understanding is that individuals who chose LIFE Accounts are ineligible for any other long-term, social services, or community-based care, but are still entitled to receive health care services. How does that relate to the Medicare home health benefit, in which supportive services (which could also be referred to as "social services") are included as part of the benefit?

Answer: LIFE Accounts is a program that would be associated with Medicaid services, and would have no relationship to the Medicare home health benefit. A LIFE Account is a private account that belongs to an individual who has chosen to direct his or her Medicaid community-based services. The LIFE Account savings program does not affect eligibility for any Medicare services and supports.

To participate in the LIFE Account savings program, individuals must self-direct their Medicaid community-based supports budget for all their "Medicaid, community-based, long-term supports." Individuals who are Medicaid-eligible and also Medicare-eligible and receive supports under the Medicare home health benefit are not precluded from establishing a LIFE Account.

Question 2: The Medicare hospice benefit includes respite care. Does the LIFE account preclude this social service?

Answer: The LIFE Account savings program is designed for individuals who are Medicaid-eligible and does not have any impact on Medicare benefits, including the Medicare hospice benefit.

Question 3: States must approve State Medicaid plans; they could argue that a variety of services designated under the LIFE Account program are in fact under the purview of home health for those individuals receiving home health care, resulting in limitation of supportive services for that beneficiary due to unrealistic expectations of an already overburdened home health system.

Answer: LIFE Accounts is a savings program that is separate from an individual's Medicaid benefits that allow those who self-direct their Medicaid services to save money while not risking their eligibility. They are intended to enable Medicaid eligible individuals to save for the future and increase their resources while maintaining eligibility for Medicaid services. These accounts are for individuals who are participating in a qualified home and community-based services program—a program providing home and community-based services operating under a State Plan, or under a section 1915(c), 1115, 1915(d), or 1929 program—and the individual must have an approved plan and approved budget for self-directed services in connection with such participation. LIFE Accounts are intended to be a separate account from an individuals' Medicaid, community-based, long-term supports budget, and CMS will enforce these two programs to assure that LIFE Accounts do not reduce Medicaid community-based supports budgets. LIFE Accounts are intended to be a separate account from an individuals' Medicaid, community-based, long-term supports budget, and CMS will enforce these two programs to assure that LIFE Accounts do not reduce Medicaid community-based supports budgets.

Question 4: Home health agencies already often end up being the de facto overseer of services provided by personal care aides or other privately-hired assistants in the home setting; they are often called on to teach or demonstrate procedures. How will this time and money and liability concern be addressed?

Answer: Individuals who self-direct a Medicaid community-based supports budget purchase their supportive services from a variety of sources. Service sources (including home care agencies) can be reasonably expected to build in their administrative expenses into the fees they charge for their services.

COMMUNICATIONS

STATEMENT OF THE ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

The Association of University Centers on Disabilities (AUCD) is pleased to submit written testimony on policies that promote community-based services and supports to Chairman Grassley and the other distinguished Members of the Senate Finance Committee.

AUCD is the national organization representing 61 University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD. For over 30 years, UCEDDs, have been instrumental in providing research; post-secondary education and community training; advocacy; and the provision of high quality, community-based services and supports for people with disabilities. The mission of the UCEDDs, authorized by the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402), is similar to the mission President Bush set forth in his 2001 executive order on the *Olmstead* decision: to work toward a shared vision of a nation in which all Americans, including those with disabilities, participate fully in their communities. Self-determination, independence, productivity, and community inclusion are key components of this vision.

AUCD applauds the Senate and the Administration (through its New Freedom Initiatives) for seeking improvements in long term services and supports for people with disabilities. AUCD has long advocated for such improvements because people with disabilities do not have adequate quality services and supports in the community to meet their needs. Individuals continue to languish on interminable waiting lists for services; receive inadequate or poor quality services; are forced to impoverish themselves in order to get services; or are forced to live in more costly institutions away from family, friends, and community life. Medicaid spending continues to be heavily weighted to supporting individuals in institutions rather than in community-based settings.

AUCD believes that national policy must be reformed to meet the unmet needs of people with disabilities in the community. The 1999 U.S. Supreme Court decision, *Olmstead v. L.C. and E.W.* has provided more impetus for states to re-design their systems to improve their capacity for serving individuals in their own homes or communities. The Federal government must support states to comply with this important decision.

AUCD strongly supports pending proposals in Congress that would help to begin to rebalance and expand the long term care system and to provide quality supports and services in the community. These include the following:

- Medicaid Community-Based Attendant Services and Supports Act of 2003 (MiCASSA, S. 971/H.R. 2032)
- Money Follows the Person Act of 2003 (S. 1394);
- New Freedom Initiative (NFI) Medicaid Demonstrations Act (transmitted from the Administration but not yet introduced)

MiCASSA

MiCASSA would help to eliminate the institutional bias in Medicaid by requiring states to include community based personal assistance services in their Medicaid plans. This would allow individuals who qualify for nursing home services through Medicaid to have the choice to use those dollars for community based services and supports.

The Money Follows the Person Act and the New Freedom Initiatives (NFI) Medicaid Demonstrations Act

The Money Follows the Person Act and the NFI Medicaid Demonstrations Act would provide demonstration grants to states to help individuals transition from institutions to community settings and would provide financial incentives for states to rebalance their long term care systems and to provide more cost-effective choices between institutional and community options.

The New Freedom Initiatives Medicaid Demonstrations Act would also provide demonstration grants for states to develop quality community-based supports and services, such as respite care for caregivers of children and adults with disabilities, to help families support their loved ones at home. At a time when federal and state fiscal resources are so limited, relatively minimal investments in respite care help family caregivers to continue to provide this care at home and in the community. Without respite and other family supports, many are forced to stay at home with family members and experience enormous stress, loss of employment, financial burdens, and marital difficulties. Some families are forced to place their family members in more costly institutional or foster care placements. The NFI proposal would provide a small, but necessary infusion of funds for respite for the Medicaid eligible population. In addition to this proposal, AUCD urges Congress to support separate pending legislation, the Lifespan Respite Care Act (H.R. 1083/S. 538) that would help to provide the infrastructure for coordinating and maximizing these new resources along with existing respite resources.

The NFI proposal would also address the direct care workforce crisis by providing $3 million in FY 2005 for state projects designed to identify and test methods to address shortages of community service direct care workers. AUCD also commends the Administration's Centers for Medicare and Medicaid (CMS) for its work in promoting self-direction/increased consumer control over resources (e.g. the cash and counseling models now underway in several states that allow consumers to pay for personal assistance provided by individuals not affiliated with traditional provider agencies). These innovations are another way of addressing workforce shortages while embracing the right consumer values.

However, AUCD feels that the amount of dollars available and duration of the grants (one year) within the NFI legislative proposal are not enough to address the severe crisis our nation is facing in this area. According to the U.S. Bureau of Labor Statistics, by 2010 more than 780,000 additional aides must be found to fill long-term care direct-staff positions. We do not have a thoughtful national policy designed to support a quality direct care workforce system. Instead, our funding system is fragmented and our workforce is poorly paid, insufficiently trained, undervalued, and inadequately supported. Long term care jobs are physically and emotionally challenging, and workers poorly compensated, so it is not surprising that communities experience such high rates of vacancies and turnovers. The NFI proposal is a good first step solving this crisis; however, AUCD recommends that much more funding be dedicated to this effort and that a comprehensive system of long term direct support be developed. The Citizens for Long Term Care group has developed several good recommendations for national solutions to this crisis.[1]

[1] Citizens for Long Term Care. Long-Term Care Financing and the Long-Term Care Workforce Crisis: Causes and Solutions. Washington, D.C. 2002.

Finally, while AUCD is pleased that the Administration and the Congress is paying close attention to the issue of the institutional bias in Medicaid, it is also important to note that the value of these initiatives would be overwhelmed by the losses in services and eligibility caused by the Medicaid allotments or block grants that have been recently proposed. Removing the entitlement to Medicaid for children and adults with disabilities and their families and capping funding will give states unlimited discretion to limit access to health and long-term services and supports that these individuals need. For people with disabilities, "safety net" programs like Medicaid have life-altering implications. Instead, Congress should consider extending the temporary increase in the Federal matching rate (FMAP) that is set to expire in June to help preserve the national investment in Medicaid. When the economy struggles, the federal government has a vital role in preventing a worsening crisis.

AUCD believes that the 108th Congress should take immediate steps to eliminate the institutional bias in Medicaid and to provide more community- and family-based services and supports to individuals with disabilities. Congress should work in a bipartisan basis to develop and pass legislation that incorporates the policies in MiCASSA, the Money Follows the Person Act and the New Freedom Initiatives Medicaid Demonstration Act.

AUCD also hopes that Congress will continue to seek ways to address other significant barriers to community living for people with disabilities. These barriers include a lack of comprehensive, quality, affordable health care; a shortage of affordable, accessible housing; a dearth of accessible public transportation; a shortage of well-trained interdisciplinary professionals in the area of disabilities; and limited technology and other supports to achieve meaningful employment.

Again, AUCD applauds your commitment to improving access to Medicaid home and community based services and supports and looks forward to working with you to pass legislation in this Congress to achieve that goal.

April 6, 2004

Dear Senators,

I am writing to urge you to vote for ending the institutional bias. To include M.CASSA (S.971) and Money Follows the Person (S.1394) in this legislation. I cannot attend the hearing April 7, 2004 but I wish to show my support of this legislation.

It has been my experience that institutions take away the dignity of the individual in need. My loved ones who have had to go to institutions have been fearful and anxious. The institutions have been understaffed and the staff that have been there

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are overworked. They become hardened to the needs of the people and rush through their services. Anything that can be done to allow people in need of care to remain in their homes with loved ones must be done. I support the "end to the institutional bias" and urge you to pass this legislation (S. 971 and S. 1394). These people in need of care should have the choice to stay in their homes and receive their care without an extreme cost to them.

Thank you for your consideration in this matter.

Sincerely,
Kathleen Beaver

© HMK. COS.

B Kathleen Beaver
3049 Old State Rd
Gaylord, MI 49735-9037

Senate Finance Committee
Money Follows the Individual and Other New Freedom
Initiative Programs Hearing
April 7th 10 a.m. 215 Dirksen Senate Office Building

Testimony by:

Mark J. Boatman
501 19th Street NE
Jamestown, ND 58401

My name is Mark J. Boatman and I live in Jamestown North Dakota. I am 28 years old and have Duchenne Muscular Dystropy.

I lived independently in my own apartment from 1994 to 2002. I received personal care services provided through a waiver from the North Dakota Human Services Department. This provided me assistance in my activities of daily living (i.e. dressing, bathing, cooking, cleaning etc.).

In January 2003, I had a tracheostomy and had to go on a ventilator due to respiratory failure. After leaving the hospital, my only choice was to go into a nursing home. I am currently wanting to have my medical care provided in the least restrictive environment (i.e. the community). For me to live in the community, I would need 24 hour care. The main barrier is the lack of Medicaid funding for Home and Community Based Services.

There is an institutional bias in the Medicaid system. If the money would follow the person into the community, it would be more feasible for people like myself to leave an institutional environment. For too many years, people with disabilities have not been given a choice where they can live and receive their services. The current Medicaid system must change in order to eliminate discrimination among those living in institutions.

I urge this committee to seriously consider the importance of legislation that would allow Medicaid funding to follow the person! This fundamental change will promote equality for all disabled who want a choice other than an institution. Thank you.

Mark J Boatman

There are important changes that must be made for my son to have an appropriate place to live AND to live a real adult life. There are troublesome institutional biases primarily in funding that restrict, eliminate and prevent the establishment of alternative living situations that may offer positive and supportive housing in the least restrictive settings for adults with dependent care needs. There are available and existing government programs and funding sources that support eldercare housing concerns, or support minor children with disabilities and housing concerns, but none provide healthy options and practical settings for dependent adults with disabilities. The reality is that this population of adults is growing and there are growing frustrations with lack of available, practical, and appropriate housing. As medical care progresses and saves lives, yet individuals acquire life-changing disabilities, there is ample evidence that the needs of this adult population must count as a priority in financial planning and humanitarian supports that involve the US government from the federal level down through the states and counties and communities.

For my son, a young man with disabilities, he requires assistance and supervision to enable him to live the normal life of any adult in the United States. I am his mother, legal guardian, legal conservator, and Representative Payee for his Social Security funds. As my son's advocate, I must speak out in testimony to be documented in the Finance hearing of the Senate today, April 7, 2004, regarding MiCASSA (S.971, H.R. 2032) and Money Follows the Person Act (MFPA, S.1394). Any progress that can be achieved to move funding from the nursing homes and agencies into community services so that he can be served in our community without waiting for legislative changes is a matter of urgent concern to his health, safety and happiness. What sense is there to our present government funding of $30,000 and $60,000 and more per year for many of these adults but ONLY with the requirement that they live in a nursing home or residential facility that contracts with the state or counties?

If this adult with disabilities can be better served in their own home, there is NO money available to them or their guardians to fund their shelter, maintenance and personal care assistants that may be needed. All funding or no funding is a poor and tragic choice for these adults! This limits many people to life in inappropriate and restrictive agency facilities. In addition, the frustrations of not having financial support to seek and create better placements rub salt into this disgraceful situation. How can appropriate supported-living settings be developed if there is an institutional bias in funding? How can adults in dependent care hope for a future and transition to a better life? For testimony that enlightens these issues, the following information is submitted from details of how this affects my son and I.

For this record, I am B. Jefferson Bolender, 1721 Muscatine Avenue, #1, Iowa City, IA 52240 and my son is Drew T. Bolender, using the same address. We are residents of the State of Iowa. My son receives Social Security funds, Medicare, and Medicaid to assist with his maintenance and support services.

THREE IMPORTANT GOALS are urgently needed to remove institutional bias from the Medicaid long term care program.

1. MiCASSA (S.971, H.R. 2032)
2. Money Follows the Person Act (MFPA, S.1394)
3. Move funding from nursing homes into community services so more people can be served in the community without having to wait for legislative changes

These are the barriers to having my son served in an appropriate environment, in the least restrictive setting. Without change, my son is forced to live in a nursing home-like facility restricting visitation

and paralyzing his social security funds to reimburse that facility with only $65 a month left for his own personal expenses. While he is not retarded, and a young adult, he must live with all severely retarded and handicapped residents. The supervision, routines, leisure activities, and staff support is limited to the scope of what works to the agency convenience to serve the usual residents. The agency is required to meet standards that most skilled care nursing facilities must meet. This type of a facility is the only one in the entire county where he lives. Their funding concerns, bureaucratic requirements, and the securing, training, and retaining of staff significantly restrict the agency ability to meet my son's needs in appropriate ways. These priorities for my son's current agency are by no means specific to this agency: they are endemic difficulties for residential facilities of all types.

The facility limits personal possessions to that which one would be able to have in a hospital room. Banned are his games, puzzles, toys, craft supplies, framed family photos, most books, magazines, and computer. His room looks exactly like many hospital rooms, with a roommate and a curtain to divide the two. Few personal possessions may be kept. There is little or no freedom to decorate or individualize his bedroom as any adult would wish to do. Although he is a sports fan, he is not allowed to put up posters. He does not get to use washcloths anymore: the room has a motel-like sink unit with paper towels and soap dispenser. He has no dresser for clothing: there is a small built-in wall unit with a tiny closet shared with his roommate. Since there are few electrical outlets, he cannot have small appliances or electrical appliances that would need to have an extension cord, power strip or surge-protector. This accounts for the inability to have his personal computer while he lives there. Because he is temporarily living there until a "permanent" placement can be found, my son has been deprived of hobby and personal activities he enjoys. Now how is a person with Attention Deficit Disorder expected to occupy himself? Even if he did not have ADD, any normal adult would be most distressed to live in this place.

My son can only leave the place to visit or his family or friends about two days a month. This is a requirement from the state that agencies follow or they will not receive funding. If he takes a vacation to see his brother in Arizona he would only have a 20 days left per year to visit me on weekends, even though I am only 30 miles away. Say he came to visit me for Thanksgiving and Christmas - this now leaves only 1 day or so a month he can come see me. How could this be supportive to mental health? This restriction on his "free time" off work is one that is very sad.

His morning medications total 11 pills, but the agency will only give medications two times a day. Instead of having taking part of these pills at wake-up and the rest with breakfast to lessen the wallop, he must now take the hit all at once because it is convenient for the agency. Here's another fact: he must not leave the facility after work from 3:00 to 5:00pm because that is the rule. If he needs to do some shopping or banking, it therefore cannot be on a work day and this limits him from all activity conducted in a business that has a 9 to 5 work day. He can make or receive calls for only 10 minutes at a time because all 15 residents and staff have only one phone. Having access to the Internet? Not possible there. These are just the tip of the prison-like changes he and his family are now forced to accept in order for him to have supported living funding.

What is the "institutional bias" in funding? This is addressed in MiCASSA (S.971, H.R. 2032). There is only one facility for care in this county that receives government funding. State and county funding will only be given to agencies like the one that he is in. There are no alternative care settings or supports in his community. If he lives in my home or in an apartment in my community, he and I, his guardian/conservator/payee and mother, will receive NO funding to help pay for his food, shelter, maintenance, and staff as needed. Even though he could live and work in my community, I would not be able to pay for a place for him to live or staff to cover supervision when I am not available. If he lived in my home, I would not be able to work. I would have no relief: no money to pay for someone to

come in to cover care if I were ill or out for a night. No money to fund even temporary supervision and support for my son should I be unable to continue to provide for him.

What is "Money Follows the Person"? This is a change addressed in this hearing for Money Follows the Person Act (MFPA, S.1394). I live a one in Iowa, but we'd like eventually to move to another state to live near my oldest son and his family. If we move to Arizona from Iowa, he will receive no funding at all for 3 months until he can then apply for Medicaid and Medicare in that state. Then, he would have an evaluation there to see IF Arizona would pay for his care and medications. IF accepted, he would then go on a waiting list to receive funding through Medicare and Medicaid. And, that state's funding may not pay for many living expenses, medications, and medical treatment required, for it varies substantially from state to state. Arizona notoriously pays little. He could be on a waiting list for years, with no money towards medical treatment and medication until he is accepted. At $700 per month in medications alone, he is effectively barred by severe financial loss from making a move that makes sense for his future care when I am no longer able to be his advocate and guardian.

My son is only 24. He is not retarded. His abilities and interests are that of most young adults. He has a severe seizure disorder and thus needs supervision by staff who can assist in times he would need transport to an ER. He has severe ADD and poor impulse control, with very poor short-term memory. He cannot be expected to remember to give himself his meds appropriately on schedule, and to prepare himself daily for work, or even go to bed at a reasonable time. He needs assistance in preparing food, doing laundry, housecleaning and the routines of dressing and needs of hygiene. A great deal of his needs for support are not because he is retarded or physically-incapable: his short term memory for following directions is preventing him from being more independent. His disabilities lie in that realm of "non-visible". To most people he would appear to be a normal 14-year-old. It often comes up that if had even MORE disabilities he would be qualified for more waivers and funding sources. What an irony. He cannot live in American society by conforming to regular norms behaving and functioning as "normal" adults do, yet he doesn't have even greater challenges that would then make his available living situations more "appropriate". He does not fit in either way and should not be punished for his disabilities, disbarred from progress to a better life by the "dis-incentives" imposed by agency rules, state rules, federal rules and funding restrictions. He is not alone nor an unusual example of such an adult with dependent care needs.

What a terrible choice or dilemma: live in a more independent setting or choose the "prison" or "nursing home". At 24, condemned to that type of facility for the rest of his life? Dating? I don't think so in the facility. Recreational and leisure activities? Only as provided by the facility, with the disabled population and no mixing with "normals". Work? Only where the facility has contracts. Income? Controlled by the facility. Ability to save money to make a transition to another place to live? Limited to $65 a month if he saves ALL of his "personal needs allowance". How can this be "America" with life, liberty and the pursuit of happiness? He is condemned by bureaucracy and funding to living where the government will pay. And there are no alternatives allowed by present government restrictions, nor alternative settings that can apply to receive essential funding to make other options available to people like him.

In many areas, there are very few if any agencies that provide dependent living care. In the state of Iowa, for example, many counties have only ONE agency that provides supported living environments, if any at all. In such a climate where the need for placements is increasing, the few agencies there are run their programs with little or no oversight and competition. Without alternatives, monopolies and agency fiefdoms develop and since they are the "only game in town" one must "like it or lump it" as to the routines and rules imposed by such agencies. An adult with disabilities must adapt to the agency as a "good" client!

Definition of a "good" client:

One who signs away all financial control to the agency and easily adapts to the routines and policies convenient to the agency. Preferably there are no "troublesome" guardians who are family members,

and certainly no conservators who ask questions. Advocacy for the resident is at the convenience of the agency or typically for the benefit of the agency, not the client. A good client goes along with all agency rules and routines and easily conform to them.

Definition of a "bad" client:

A client who is not retarded and wishes to live in the least restrictive setting possible. One who wishes to maintain or develop relationships outside of the agency setting. One who has strong advocates who help them to achieve more independence than the agency is comfortable with. Those who require an agency to "be out of their comfort zone".

It is really a matter of life for those involved. Adults with dependent care needs, whether eldercare or disability care, are STILL in "institutions" though now called agencies and facilities: that "institutional bias". Please hear, consider, and investigate our testimony for this hearing.

Respectfully Submitted,
B. Jefferson Bolender

B. Jeff Bo
4/7/04

BOSTON CENTER FOR *INDEPENDENT* LIVING

April 14, 2004

Senate Committee on Finance
Attn. Editorial and Document Section
Room SD-203
Dirkson Senate Office Building
Washington, DC 20510-6200

To whom it may concern:

Please accept the enclosed testimony in regards to the April 7, 2004 hearing titled "Strategies to Improve Access to Medicaid Home and Community Based Services" from members of the Boston Center for Independent Living (BCIL) South End Action Group.

As a group we encourage the Senate Committee on Finance to support Senate Bill 971, the Medicaid Community Services and Attendant Services Act (MiCASSA). Many members of this group use Massachusetts Medicaid funded Personal Care Attendant (PCA) program. The group hopes that the federal government will mandate the continuation of this program as part of Massachusetts' Medicaid program, and that all people with disabilities in all states (who are eligible for Medicaid) will have the option to receive care in their own homes.

Thank you for your attention to our comments.

Sincerely,

Helen M. Hendrickson
Community Organizer

95 Berkeley Street . Suite 206 . Boston, MA 02116 . http://www.bostoncil.org
617.338.6665 TEL . 617.338.6661 FAX . 866.338.8085 TOLL FREE . 617.338.6662 TTY

United Way

Typewritten versions of testimony from the Boston Center for Independent Living's South End Action Group

In Support of the Medicaid Community Services and Attendant Services Act (MiCASSA) (S. 971)
Hearing Title: "Strategies to Improve Access to Mediaid Home and Community Based Services"
Hearing Date: April 7, 2004 at 10:00 am

Submitted by: Maggie Waltower (617) 298-6961
24 Mattapan Street, Mattapan, MA 02126

PCA is very good help with my daughter, Lorraine Waltower, to be herself in life. We need more PCA for disable people, and help them to get around and be good care for my daughter and some one you can depend only.

Submitted by: Peter Wong
210 Stuert Street, Apartment #130, Boston, MA 02116

I have been a PCA user for over 20 years. It helps me to be Independent. I can set my own hours. I am proof that PCAs work. My PCAs stay with me a long time. I never have to hire new PCAs. If I lived in a nursing home it wouldn't be the same.

Submitted by: Billie Tyler (617) 266-1175
334 Massachusetts Ave, Boston, MA 02115

Where as I am a AKA there are a lot of things I can't do. My PCA is a God-send. Without her sometimes I think my life and living conditions would change for the worst.

Submitted by: Kathryn Ehrhardt Mathews (617) 266-9389
361 Massachusetts Ave #B2, Boston, MA 02115

Due to circumstances beyond my control I was discriminated in getting a homemaker here in Massachusetts. I had an injury that I needed time to heal, recuperate and become independent. I found a registered nurse who offered a course of homemakers, home health aides, respite workers and prolicture workers.

I feel it is vital for anyone who has had an injury without/with hospitalized stay and during the healing process, get some assistance with personal hygiene, laundry, cooking, cleaning. Sometimes family member's can not always be impartial due to the closeness and it becomes an emotional problem instead of helping one become independent and respect the independence of the individual without hard feelings. Also be careful of who one selects to be the PCA. There have been reports of verbal abuse, thefts and not keeping appointments.

TESTIMONY FOR U.S. SENATE FINANCE COMMITTEE

In Support of the Medicaid Community Services and Attendant Services Act (MiCASSA) (S. 971)

Hearing Title: "Strategies to Improve Access to Medicaid Home and Community Based Services"
Hearing Date: April 7, 2004, at 10:00 a.m.

Submitted by Maggie Wallower Phone # 617-298-1961
Address 24 Mattapan St City Mattapan State MA

Please Note My Experience and Views as you Consider Senate Bill 971

P.C.A is Very Good help With my daughter Lorraine Wallower to be her self in life, we need more P.C.A For disable People, and help them to get around and be good Care For my daughter and Some one you Can depend only.

Signed Maggie Wallower Date 4-6-04

TESTIMONY FOR U.S. SENATE FINANCE COMMITTEE

In Support of the Medicaid Community Services and Attendant Services Act (MiCASSA) (S. 971)

Hearing Title: "Strategies to Improve Access to Medicaid Home and Community Based Services"
Hearing Date: April 7, 2004, at 10:00 a.m.

Submitted by PETER WONG Phone # _____

Address 210 STUART ST, APT #30 City BOSTON State MA

Please Note My Experience and Views as you Consider Senate Bill 971

I HAVE BEEN A PCA USER FOR OVER 20 YEARS. IT HELPS ME BE INDEPENDENT. I CAN SET MY OWN HOURS. I AM PROOF THAT PCAs WORK. MY PCA. STAY WITH ME A LONG TIME. I NEVER HAVE TO HIRE NEW PCAs. IF I LIVED IN A NURSING HOME IT WOULDN'T BE THE SAME.

Signed Peter Wong Date 4-6-04

TESTIMONY FOR U.S. SENATE FINANCE COMMITTEE

In Support of the Medicaid Community Services and Attendant Services Act (MiCASSA) (S. 971)

Hearing Title: "Strategies to Improve Access to Medicaid Home and Community Based Services"
Hearing Date: April 7, 2004, at 10:00 a.m.

Submitted by Lillie Syler Phone # 617-364-1175
Address 334 Mass Ave City Boston State MA 02115

Please Note My Experience and Views as you Consider Senate Bill 971

Where as I am a AKA, there are a lot of things I can't do. My PCA is a God send. Without her sometimes I think my life and living conditions would change for the worst

Signed Lillie Syler Date April 6 2004

TESTIMONY FOR U.S. SENATE FINANCE COMMITTEE

In Support of the Medicaid Community Services and Attendant Services Act (MiCASSA) (S. 971)

Hearing Title: "Strategies to Improve Access to Medicaid Home and Community Based Services"
Hearing Date: April 7, 2004, at 10:00 a.m.

Submitted by Kathryn Ehrhardt Mathews Phone # 617-266-9389

Address 361 Mass. Ave #B2 City Boston State Ma 02115

Please Note My Experience and Views as you Consider Senate Bill 971

Due to circumstances beyond my control I was discriminated in getting a homemaker here in Massachusetts. I had an injury that I needed time to heal, recuperate and become independent. I found a registered nurse who offered a course for homemakers, home health aids, respite workers and practical nurses.

I feel it is vital for anyone who has had an injury without/with hospitalized stay and during the healing process, get some assistance with personal hygiene, laundry, cooking, cleaning. Sometimes family members can not always be important due to the closeness and it becomes an emotional problem instead of helping one become independent and respect the independence of the individual without hard feelings. Also be careful of who one selects as the PCA. There have been reports of verbal abuse, thefts and not keeping appts.

Signed Kathryn Ehrhardt Mathews Date 4.6.04

BOSTON CENTER FOR *INDEPENDENT* LIVING

April 16, 2004

Senate Committee on Finance
Attn. Editorial and Document Section
Room SD-203
Dirkson Senate Office Building
Washington, DC 20510-6200

To whom it may concern:

Please accept the enclosed testimony in regards to the April 7, 2004 hearing titled "Strategies to Improve Access to Medicaid Home and Community Based Services" from one member of the Boston Center for Independent Living (BCIL) Jamaica Plain Action Group.

Please note that the testimony of Ms. Higgins, enclosed, raises issues that are close to the hearts of many members of BCIL's JP Action Group. Many members of this group use Massachusetts Medicaid funded Personal Care Attendant (PCA) program and, as a group, we encourage the Senate Committee on Finance to support Senate Bill 971, the Medicaid Community Services and Attendant Services Act (MiCASSA). The group hopes that the federal government will mandate community based services so that all people in all states will have the option to receive care in their own homes.

Thank you for your attention to our comments.

Sincerely,

Helen M. Hendrickson
Community Organizer

95 Berkeley Street . Suite 206 . Boston, MA 02116 . http://www.bostoncil.org
617.338.6665 TEL . 617.338.6661 FAX . 866.338.8085 TOLL FREE . 617.338.6662 TTY

United Way

April 16, 2004

Senate Committee on Finance
Attn. Editorial and Document Section
Room SD-203
Dirkson Senate Office Building
Washington, DC 20510-6200

Re: Hearing titled "Strategies to Improve Access to Mediaid Home and Community Based Services" held April 7, 2004 at 10:00 am

To whom it may concern:

I am writing to show my strong support for Senate Bill #971. It is highly necessary that this country adopt a national attendant care program using the standards already in place in the state of Massachusetts. In 1987 I moved to Boston from Delaware in order to take advantage of the many programs for people with disabilities that were present in this state at that time. I know that it is increasing difficult to maintain these programs given the interests of the current administration, which I am hoping will change with the next presidential and gubernatorial election.

Since moving to Massachusetts with the assistance of my personal care attendants (PCA) I have been able to work and maintain an active life. However, because the PCA program is not nationalized, I am unable to use the assistance of similar services when visiting family members, including my aging father, in Delaware or my mother in Maine. Currently, when I visit my parents in these states I must depend on them to provide my care, use visiting nurse services which are limited and medically based, or hire outside help at my own expense. I realize that if there was a national attendant care program it might be slightly different than what is provided in Massachusetts, however, its establishment would make it easier for people with disabilities to travel and live throughout the country.

The current consumer-based PCA program which we fight to maintain in Massachusetts would be an excellent prototype for a national program provided that it retain the strict standards that now exist.

Having PCA services that allow me and others with disabilities to maintain our home-based lifestyle is an extremely important human and civil right. Before last year's massive budget cuts I worked as a peer counselor for many people with differing disabilities and on their behalf as well as mine, I advocate the passage of this bill. Thank you for supporting Bill #971.

Sincerely,
Cynthia L. Higgins
90 South St. Apt. 707
Jamaica Plain, MA 02130
cindytasha2@earthlink.net

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.



Name: Tameka Caleb

Address: 1239 Belmont Ave., Apt. 9

City: Philadelphia State: PA Zip: 19131

Age: 25 Phone: 215-477-4274

Type of institution:

Nursing Home X
State Institution/Developmental Disability
State Mental Hospital
Group Home
Rehabilitation Facility

How long institutionalized? 2 years

Please attach a short summary of your time in the nursing home or other institution and how your life has changed now that you are out.

I can now have a boyfriend and friends. In the institution, I lost my friends.

ADAPT—FREE OUR PEOPLE!

MEMORANDUM

To: Senate Committee on Finance

From: Jennifer Hill Buehrer
1200 E. Clark Rd.
Ypsilanti, Michigan 48198

Date: April 2, 2004

Re: Testimony on MiCASSA (S. 971) and Money Follows the Person (S.1394)

To the members of the Senate Committee on Finance, thank you for the opportunity to give testimony on two extremely important bills, S. 971, known as MiCASSA, and S. 1394, entitled Money Follows the Person.

I am strongly in favor of passage of both these bills, and I hope that you will vote to have them approved and sent to the Senate floor for a vote. They are long overdue, and we have been waiting years for these bills to go to a vote. It is time for us to end the institutional bias in federal Medicaid AND Medicare policy. Had we done this several years ago, my grandfather could have spent the last months of his life in his home of 40 years, rather than in a nursing home. But because Medicaid would only pay for institutional care, and not the assistance he needed in his own home, he was forced to exist in a nursing facility, where he was neglected, and eventually died from aspiration pneumonia, as none of the staff in the nursing facility was paying enough attention to him to realize that he was having trouble swallowing.

I have worked for years with adults with disabilities, and I have seen the horrors of institutional life. Whether it is neglect, apathy, or outright abuse, it all exists in the institutional facilities. And because the general public believes that these places are adequately monitored, most people do not pay attention to what is really going on there.

I hope that you will recognize the importance of supporting people with disabilities to be an equally valued part of our communities. To do this, we must provide support for individuals to *live* in the community, *work* in the community, and *play* in the community. Please vote to support S. 971 and S. 1394, and end the institutional bias that has been the driving force in our federal policies for far too long.

Thank you for taking the time to read and consider my testimony on this matter.

I, J.C.Colsey, as an individual and a proud member of ADAPT request that my written testimony be entered into the Record for the Hearing on April 7, 2004 by the Senate Finance Committee. Both the MiCASSA Bill (S. 971) and the Money Follows the Person Bill (S.1394) simply makes good sense and enactment of the above bills will put an end to the institutional bias in Medicaid long term care!

Why do I care so much about S.971 & S.1394. I care because it is the right thing to do. An individual should have their own "choice" in their own lifestyle.

Existing in a nursing home or institution of any kind a person is granted no options. It is a proven *FACT* that Living in familiar surroundings a person is happier, healthier and better off in so many ways. That is what the passage of the above legislation will do at less cost to everyone concerned.

I cannot fathom why this is so difficult to understand. Please make MiCASSA & the Money Follows the Person a

***Reality and not just Rhetoric*!**

J.C.Colsey



Senate Committee on Finance
Attn. Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Bldg.
Washington, DC 20510-6200

4-7-04 Strategies to Improve Access to Medicaid Home and Community Based Services

WHY I WANT MiCASSA PASSED

My name is Johnny Crescendo and I have just emigrated from the UK to the USA with my American wife and child.

It is unbelievable that the richest country in the world has a system that supports people being put in Nursing homes against their will.
It is astonishing that Politicians support the mandate that States must have institutions whilst the freedom of living in your own home is an option or a luxury.
It is disturbing that a country that aspires to be a world leader on freedom incarcerates disabled people in Nursing homes.
I have been coming to the US for the past 14 years and was in Washington when MiCASSA was first introduced. I have been into institutions and seen for myself the abuse and the degradation that is taking place.
It is time for this to stop and for politicians to enact MiCASSA.
Every day you wait every time you put this at the back of your mind is another day of the systematic and legalized abuse of your citizens including the wounded soldiers returning from the present operation in Iraq.
A system which keeps people dependent all their lives is more expensive in every way for the country than a system which encourages independence and autonomy. You can't go to work from a Nursing home.
A politician who ducks this issue is a danger to the community they represent. This is not a disability issue, anyone can become disabled and will if they live long enough and we need to transform the structures

so that all Americans have the right to a family life.
So if you don't believe in Freedom, if you don't believe in family values, if you believe that disabled people shouldn't be born if you believe that its ok that disabled people are abused DO NOTHING.
But if you believe in freedom and equality for all Americans.....
PASS MiCASSA NOW.

Johnny Crescendo
Apt B1- 160
800 Cottman Ave
Philadelphia
PA.
19111

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Calvin Cress
55 years old.

Philadelphia, PA

Spent 5 years in three different nursing homes.

I had a stroke and no where else to go. I know people who have killed themselves rather than go back into a nursing home. I knew an 80 year old lady in the nursing home and we sat together every day. I hadn't seen her then for three weeks and I found out she had died. No one had told me. This really hit me hard. I really cared about her. He called the Ombudsman about things happening in the nursing home and she told me about LIBERT RESOURCES. It took a few months to get out of the nursing home and I have been out since November 2003. While in the nursing home, I had a diamond ring stolen from me. I am learning how to deal with the community again and learning how to socialize with others.

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Ruben Cruz
30 years old.

4632 Spruce Street
Philadelphia, PA 191

Spent 12 years in St. Edmonds

My family did not know better about choices in the community and put me in the institution. It took three years to get out. Someone I knew from my church there is something much better than living in an institution. I have got more freedom, independence and can go around ion my power wheelchair by myself. I was hit in the institution and didn't get showers. I would never go back there. I am with ADAPT and that opens more doors.

ARTHUR G. DEMPSEY

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April 4, 2004

To: Senate Committee on Finance
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Dirksen Senate Office Bldg.
Washington, DC 20510-6200

Money follows the Individual...April 7, 2004

To whom it may concern:

My Sister and I live under the threat of being placed in a Nursing Home! I am disabled and have been, ever since developing Muscular Dystrophy at age of 13, back in 1957. My life has been a struggle, as you can imagine it would be with a progressively debilitating disease, but the quality of life has been quite good until now...!

Now... my Sister, also disabled by muscular dystrophy, and I are involved in a long standing fight to remain in our OWN home since the passing of our Mother and sole caregiver in 2001! A situation, not uncommon for the physically or mentally disabled that outlive their caregivers. We are two, mentally alert, functioning adults that are quite capable of managing our existence, but due to the Institutional bias in the long-term health care field, we face the horrendous aspect of being placed in a nursing facility against our will!

Why is this so? Because those of us with nothing more than Medicare / Medicaid as insurance are denied an OPTION! An option on CHOICE... how the funds that are set aside for OUR long term care are disbursed! Most of us have paid into Social Security during our working years, my Sister and I included, yet when it comes down to selecting how best to utilize those funds we're denied any input!

Under current law, the recipient of OUR funds are the Institutionalized Care providers, in other words, the Nursing Home Industry!

Because that is how, Title XIX of the Social Security Act, was originally written! The powerful lobby that represents the Institutional Care providers has held sway

over this franchise since it's inception, protecting it as one would protect their child!

A great many of you may be unaware that there are, at this very moment, many disabled Individuals shut away in nursing homes that just shouldn't be there! The nursing home has become the, "HUMAN WAREHOUSE", of our modern society!

Result! What started out with, the best of intentions, for those in our society, that are most vulnerable has become a,"LIVING HELL", for many! The "for profit" businesses that operate most of these homes are more cognizant of the "bottom line" than they are of the "health line". Understaffing is commonplace, infectious diseases run rampant, governmental inspections have degenerated into a industry-wide joke! This industry has operated so long under these conditions, that only now are you beginning to read of the horrors that abound in these "Warehouses"! Under increasing public pressure the media has uncovered a myriad of abuses that are nationwide in scope! Now, on top of all this, consider the loss of one's independence and you can see why my Sister and I have chosen to remain in our home for as long as we possibly can while bringing our dilemma and the dilemma of many to your attention!

There needs to be reform! We don't want to live in a nursing home, we want to live just where we are, in our home. The funds are there, but we cannot avail ourselves of them!

OUR DECISION

Together, we're remaining in our own home, paying what expenses we can and putting on credit those we can't, all in the express purpose of trying to make a life here! One where we'll be able to get up on a regular basis, allowing me a life as free as possible... away from the ventilator. Where we'll be able to pursue our activities at our convenience, in surroundings that we're accustomed too and easily negotiable. But most importantly to continue to enjoy what we had before... INDEPENDENCE!

What we are striving to do, is quite unique! Two disabled adults requiring care 24/7 living in their own home and utilizing only Medicare and Medicaid insurance! Presently, there's no such alternative available to the severely disabled... we are just shuffled into one of these human warehouses!

In the beginning, when I first started petitioning the various State officials about helping us to remain in our home, as opposed to a nursing home, I was advised that there were no such programs! But, at the same time, the individual that advised me as to that situation also encouraged me to continue and write... you never know what might happen!

WHAT WE'VE ACCOMPLISHED

I was enrolled in an innovative Florida program called, Consumer Directed Care Plus. Consumer-Directed Care Plus is an innovative program where you the Consumer decide how best to meet their care needs. Within their budget, the participant, or their Representative decides how to purchase and supervise things like personal care, homemaking, and respite.

Basically this exceptional program is a scaled down version of what MiCASSA can accomplish on the National level.

My Sister and I have carried on a letter writing campaign and contacted every State official concerning our plight since May 2001.

The St. Petersburg Times published a letter that I wrote to their editor! I have included it on my website, along with a "feature article" compiled by The Tampa Tribune.

The website URL is: http://www.saveartman.com

What we require now is your prompt action to correct a wrong done to the disabled community for so many years by passing MiCASSA (S. 971), and Money follows Individual (S. 1394)!

Sincerely,

Arthur G. Dempsey
Arlene F. Dempsey

Disabled Rights Action Committee

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Senate Committee on Finance
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April 16 2004

Hearing Date: April 7, 2004
Topic: "Money Follows the Person"

Honorable Senators:

Frequently, when we talk about the ultimate impact of far-reaching government policies we speak in terms of probabilities about which reasonable leaders, researchers, experts and lay people may disagree. Will current levels of industrial pollution lead to disastrous global warming? Are tax cuts the best way to stimulate the economy? Which tax cuts are most likely to benefit varying groups of individuals?

Today, as an organization of individuals with disabilities, we would like to speak of verities regarding which there can be no disagreement among reasonable people. Our Medicaid system has a clear institutional bias. Persons who need assistance in meeting their day-to-day needs can be guaranteed service by moving into a nursing home—it is an entitlement. Persons who need assistance, but wish to maintain the personal freedom, integration and dignity of living in their own homes, communities and neighborhoods must negotiate a complex array of waivers, each with their own idiosyncratic eligibility criteria. At the end of this maze there is often an interminable waiting list—community living is, after all, optional, while nursing homes are an entitlement.

Life in a nursing home invariably entails a loss of freedom and dignity at best. At worst, those who reside in nursing homes face the horrors of abuse, neglect, deteriorating health, depression and untimely deaths. Nursing homes "care" for large groups of individuals with a bare minimum of underpaid and under trained staff—this keeps profits at an optimal level. Of necessity, they must have standard times to eat, standard menus, standard shower times, standard activities and standard shopping places. Gone are the individual freedoms and personal rituals that we in the community take for granted, but which are at the very core of much of our happiness. Deciding when to get up, whether to shower or eat first. Deciding what to eat for breakfast. Deciding who we will share our bedroom with. If help in intimate details of life are needed, deciding who will provide that help.

A review of the rules of one typical nursing home revealed the following: Everyone must be up at 6 AM, weekdays and weekends or miss breakfast. One or two offerings are

provided for each meal—if you don't like what is being served, you will go hungry. You are not allowed to "loiter" in the front part of the building while waiting for friends and family who never come to this depressing environment. You may not chew gum in most parts of your "home." You will be bathed on Mondays, Wednesdays and Fridays. There are no exceptions, no matter what happens. If you feel you are being abused you must complain to nursing home management, who hopefully will follow the law and contact the authorities, who in turn are woefully overworked and may not consider your abuse to be sufficiently significant to warrant an investigation. The nursing home may take action, but it is not likely they will want to lose one of their most precious resources—staff who are willing to work for minimum wage.

We have lived in nursing homes. We have helped others get out. We have rebelled against these conditions and have been punished. We have been drugged. We have had our wheelchairs removed so that we lost that last shred of freedom and dignity—our mobility. We have been the subject of screaming taunts and insults. Our friends have been subjected to physical and sexual assaults. Some of us have risked death rather than remain cut off from society in these deplorable conditions. We have felt terror and hopelessness and we now say no more! No more for us—we will not return and no more for our brothers and sisters who languish as we once did.

In fighting these injustices and for passage of MiCASSA we have marched through drenching rain and howling wind. We have braved subzero temperatures and scorching heat. We have chained ourselves to public buildings and we have been arrested. Formal incarceration on our nation's penal system, even death hold less terror for us than slipping back into what has aptly been called the "institutional gulag."

We are testifying on behalf of MiCASSA (S91) and money follows the person (S1394). With these bills, a free-market economy would be introduced to balance the tyrannical monopoly that the nursing home industry has heretofore enjoyed. If, as nursing homes claim, they are the safest, most comfortable, most humane place to reside, the industry has nothing to fear from the competition of free choice. With these bills, those of us who need assistance would not have to enter a nursing home and those who currently reside in nursing homes would be free to leave. The government would be required to offer those of us who qualify for nursing homes up to an equivalent amount of funding (in the aggregate) with which we could hire our own staff. With no profit involved, we offer our attendants a living wage and hire quality, caring people. We are the employers, the boss. We schedule our attendants when we need them. If our attendants attempt to abuse us in any way, we fire them, and with our living wage, hire replacements—no need to wait on an investigation that may never take place. We will never hear someone tell us that our humiliation, our hurt isn't sufficient to rate as abuse.

With our attendants we will live in our own apartments and homes. We will live with friends, family, and roommates of our own choosing, among neighbors of our choosing. Many more of us will work at jobs that provide us further dignity and economic independence. We will contribute to our communities in countless ways. Our lives will not be wasted. We will choose what to eat, where to eat, when to go to bed and when to

get up. We will choose where to shop, how and where we will recreate. We will choose what to wear. We will decide how often we will bathe and who will assist us. We will decide what level of assistance we want. We will choose where and from whom we receive our medical care. We will have lives worth living.

There will be risks. Some attendants may not be reliable. We may be stranded, without needed help. We will get sick. We will get hurt. But we will cope. We will carry cell phones. We will call upon friends and family. Remember, we have braved hurricanes in pursuit of these bills. We have risked death and arrest. No risk involved with attendant care can compare to the terror of even one day of so-called life in a nursing home. It is our life. It is our risk to take. Dignity entails risk. The government is not our mother or father and we are not children.

These bills make economic sense. They have been tried, in various forms, in many states, always with the same result. In the aggregate, community services are less expensive than nursing home services. These bills make humanitarian sense. Lives will be fuller and more productive.

Some have argued that the government saves money when it offers an expensive service that no one wants. It is true that many have lived lives of desperation, have died rather than accept the help that is only offered within the walls of a nursing home. However, no society that balances its budget by forcing its elderly and citizens with disabilities to choose between incarceration and death has any claim to morality.

These bills may be rightly claimed by persons of all political stripes. We may talk of a level playing field, market-driven economies and individual enterprise. We may talk of individual dignity and freedom. We may talk of civil rights and Supreme Court decisions. We may talk of people earning their own way and contributing to their societies. We may talk of moral imperatives—of inherent right and wrong. It matters not from where we start in our exploration of these issues, the conclusion will always be the same. Passing MiCASSA and the Money Follows the Person Act is the right thing to do. Nothing less, no other alternative will do. Our freedom, our dignity, our lives are non-negotiable.

We have worked hard to help others leave hellish nursing homes. In the course of so doing we have asked these individuals to write their stories. It is the Utah "Stolen Lives." We ask that it be included with our testimony into the public record. We recognize there is a page limit on individual testimony. Please consider each story for what it is—the individual testimony of those who have been there.

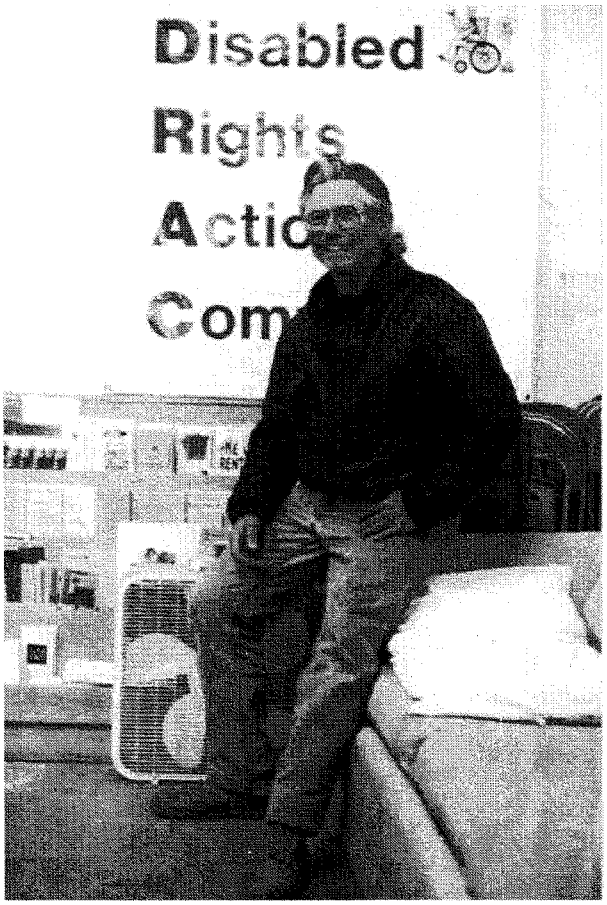
One story was not complete at the time of our book's publication and we suspect that much more remains to be written. In closing we would like to share Tammy's story. Tammy requires assistance for virtually all activities of daily living—eating, drinking, bathing, getting dressed, toileting, going to bed… When her state's foster care system failed her she was placed in a nursing home. She eloquently tells of having her wheelchair removed for days at a time in order to improve her "attitude." She speaks of the daily humiliations that we have already addressed. She tells of the joy when she was

finally able to leave the nursing home with the assistance of dedicated activists and progressive state-sponsored community services.

She relates the terror of moving to Utah to accept an employment offer only to be told that Utah would only offer nursing home care. Again, a group of dedicated activists fought for community services. Without their organized action she would still be living in the nursing home, waiting to come to the top of a never-ending list. The nursing home professionals—prognosticators talked of the risks Tammy was taking. They predicted her certain doom in the rough and tumble world that we all take for granted. Tammy ignored the naysayers, got an apartment, hired her attendants, worked full time, married and is now expecting her first child. Her miracle—no other word is adequate, was not a cure for her condition—that was not what she wanted. It was a cure for our society's disability. A societal blindness, born of ignorance and prejudice, which has allowed us as a society to build institutions that lock people away for the "crime" of having a disability. It is a cure we can and must extend to countless more. It is the only cure for which we seek. Please cure the prejudices, the policies, the shortsightedness that has imprisoned so many of us for far too long. Pass MiCASSA. Pass the Money Follows the Person Act. Free our people.

Jerry Costley. Executive Director
Disabled Rights Action Committee
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Stolen Lives



"I didn't belong in a nursing home."

Our Homes
Not Nursing Homes

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Introduction

In a free market system, the most important item in deciding endorsement of any product, be it commodity or ideology, is the bottom line. In Utah, basic care in nursing home for a year costs about $30,000. Personal care and support in a community setting is much less. This alone should be enough to sway decision makers to spend tax dollars toward the concept of community living with the necessary supports and funding needed to assure success.

We need to raise higher concerns: Is basic freedom, accessibility, and self-determination just for certain people? Can the government deny or put off the responsibility to assure freedoms for people with disabilities? Do we want to live in a society that isolates a huge cluster of people - a cluster, by the way, that we may join at any time.

The following stories illustrate the struggles of men and women who are attempting to find their place in a truly interdependent society - a society that recognizes its need for their gifts and its responsibility to include and support them as equal members and partners. These stories also demonstrate the sense of isolation and frustration people with disabilities feel when they are segregated in large nursing facilities by government entities who manage their care but do not provide them with a valued place in society.

Legislation that removes preferential funding for nursing homes and allows everyone who qualifies for services in them the choice of spending this funding on community services is needed. On the federal level the Medicaid in Community Attendant Services and Support Act (MiCASSA) will accomplish this. On a state level, a continuing commitment to eliminate the institutional bias in Medicaid for Utahns with disabilities is essential.

Acknowledgements

We are grateful to the following individuals and organizations who so graciously donated their time and expertise towards the success of this endeavor.

The Community Writing Center is the Salt Lake Community College Writing Program's Outreach project. The services to all adults who live in the Salt Lake area include: writing classes, group writing mentoring, individual writing assistance and writing workshops. The Community Writing Center offered their writing expertise and their volunteers who acted as scribes and mentors for the people telling their stories.

The Disabled Rights Action Committee (DRAC) is a grassroots organization for people with disabilities. Affiliated with ADAPT, a national advocacy organization for people with disabilities, DRAC has worked to implement The Americans With Disabilities Act (ADA) in Utah. DRAC has been instrumental in changing transportation policies, enforcing the Federal Fair Housing Act, and supporting the US Supreme Court decision, called Olmstead, that affirms the rights of people with disabilities to live in the community rather than in nursing homes or other institutions. Thanks to the many DRAC members who served as peer mentors and volunteers in the Our Homes Not Nursing Homes project.

AmeriCorp/VISTA members Lori Brock and Tammy Miner perform meaningful and constructive volunteer services at DRAC, where they work on the My Homes Not Nursing Homes project. Utah Issues sponsored the VISTA project.

Salt Lake Community Action Program (SLCAP) has been working to alleviate the paradox of poverty in our affluent society. Since 1965, SLCAP has been supportive of both the independent living movement and access to Medicaid services for the disability community. In 2000, after the Olmstead decision, SLCAP staff wrote grants and supervised the Our Homes Not Nursing Homes project of DRAC.

The following members of the South Valley Community Boys and Girls clubs are responsible for the portraits: Jacob Dunn, Devon Frenchwood, Angelicka Ruesga, Teresa Ruesga, Morgan Slusser, Marisa Cox, Juan Salazar, Julian Moore, Victor Sida, Vincente Rodriguez, Emmanuel Rodriguez, Jesus Silva, Danny Rochester, Lalo Soriam David Merino, Cynthia Conteras, Lucia Curiel, and Goya Gregoria.

Fred Hayes, Salt Lake City Weekly for his photo of Tammy Miner and Ravell Call, Deseret News, for his photo of Trish Smith.

Finally, this project would not have been possible without generous funding from the Public Welfare Foundation.

Why is there an institutional bias in Medicaid for People with Disabilities?

Medicaid is the major funder of long-term care services and supports for low-income Utahns with disabilities. In 1965, when Medicaid was first enacted, it only provided funds to institutions—in our case nursing homes. People with disabilities and their allies across the United States have been advocating for decades for resources and services to live independently. As a result, a wider array of services are available in the community. However, in Utah more Medicaid funding goes to institutions than to community based services. Partially this problem results from politicians reluctance to challenge funding of historically entrenched privately-owned businesses like nursing homes.

The other aspect of the problem is Medicaid's historic institutional bias. In Utah, if a person with a disability qualifies for the nursing home level of care, they automatically qualify to receive care that day at the nursing home.

In Utah, to provide community services the State has had to apply to the Federal government for "waiver" programs or demonstration projects. Waiver programs are so-named because they allow Medicaid moneys that at one time could only be spent on nursing home care to be used for community services, while "waiving" some of the more onerous institutional rules and regulations. Unfortunately, even with a waiver in place, a person with a disability can get nursing home care today, but faces daunting bureaucracies and waiting lists of up to a decade for similar community based services. Nursing homes are an entitlement, community living a rare privilege. It's no wonder that people who are leaving the hospital end up in nursing homes. When that happens the person loses their subsidized housing, furniture, food stamps, and their SSI (except $45.00). Soon, leaving the nursing home becomes economically impossible. None of us want to die in a nursing home.

Does the ADA address the Medicaid institutional bias for People with Disabilities?

There is some good news. In 1999, in its key decision, *Olmstead v L.C.*,[1] the United States Supreme Court made "two evident judgments" underlying the recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination:

> First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life....Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social

[1] 527 US 581 (1999)

> contacts, work option, economic independence, educational advancement and cultural enrichment. [2]

In Utah, Barbara Toomer of DRAC and ADAPT/Utah said "When I read Olmstead, I felt like I was reading *Brown v Board of Education."*

Olmstead was issued on June 22nd and by July 16th, DRAC and SLCAP met and I sent a letter to the Medicaid Director to start meeting to make Olmstead real in Utah."

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[2] at 600-601

Our Homes Not Nursing Homes Project

The Disabled Rights Action Committee (DRAC) and Salt Lake Community Action Program (SLCAP) share a philosophy that the experts on a given issue are the people personally impacted by the issue. In this context, people who have or are currently living in nursing homes are the experts regarding living in and getting out of nursing homes. Their expertise is a cornerstone of every aspect of planning and implementing the Our Homes project.

Part of the project involves working to identify barriers and gaps in services and addressing these policy problems. This is not an intellectual pursuit. Each individual who we've worked with realizes their choice to move to the community has identifiable barriers. If there are barriers they don't recognize up front, they soon learn about them through experience. Another aspect of the project involves role models, both VISTA Members and peer volunteer mentors with disabilities, many of whom have lived in nursing homes themselves, who are now successfully living in their own homes. The VISTA members and peer mentors pair up to visit individuals at nursing homes each week. These visits are to assist the individual in applying for Medicaid waivers, rental applications, subsidized housing applications, replacing identification papers, accessing transportation, food stamps, social security card replacements, picking Health Maintenance Organizations (HMO'S), finding doctors, self medication services, and hiring attendants to name just a few activities.

For example, the first person we assisted to live in the community turned out to be typical of both the models of paperwork and conflicting rules, as well as of the circumstances that landed him in his dilemma. BJ was a twenty something employee at a local business firm when he was hit by a drunk driver, which left him first in a coma, and later in a nursing home with a traumatic brain injury (TBI). Ironically, although Medicaid provides for a TBI waiver, the more self-sufficient the person is, the lower they "score" on the waiver waiting list. First, the Our Homes team worked with BJ to secure a spot on the then (April 2000) new pilot project, Flexcare. Then we assisted him in finding housing, transition costs, furniture, and other necessities. Today, BJ lives in his own apartment. BJ has said of his nursing home stay "It was hell for me. I felt like I was locked up." Now, BJ has beat doctor's predictions by walking again, he is in a work retraining program so he can resume his career and most importantly, he has his pet cat.

Both the strength and weakness of the Our Homes project is that the staff and volunteers don't "own" or control any resources. The Nursing Home occupants trust us because we have no power to deny or supply services—because we are not part of the system and have no need to defend the indefensible. However, watching people go without is painful.

The Our Homes project is grateful to the good people who took the time to tell their stories. At a meeting with Steve Jardine of the Governor's Budget and Planning Office, Gary Brown said "If you and the Governor would only come and spend one night with

me at the nursing home, your would understand." Gary's invitation reminds us all to ask how long would WE want to live in the most restricted setting?



Tammy's Story

"Tammy is a freedom fighter," said Kay Fox, a community organizer at the Salt Lake Community Action Program. "The first weekend we met at a national action in DC, Tammy protested at then HUD Secretary Andrew Cuomo's house and the next day demonstrated by jumping out of her wheelchair and crawling to the Executive Office Building to encourage the Clinton Administration to end institutional bias. At the end of the day she was bruised and needed stitches. I ran to her to see if she was OK. 'This was the best day of my life, Tammy said about the solidarity experienced after these activities. I knew she was a real leader. It was no surprise that DRAC hired Tammy. She's a real leader."

Tammy's story illustrates that even the toughest "freedom fighters" can come perilously close to total defeat when confronted by the lunacy of our institutionally biased system.



A system whose first resort is a nursing home for a teenager who is aging out of the foster care system. A system that won't provide a young adult with a disability the resources they need in the community; they must either wait years, and in Tammy's case literally die waiting, or give up all that they hold dear—career, schooling, friends, apartment and personal possessions to enter a nursing home. Only after entering the nursing home will funding will be made available for community life. Only after giving up everything will you be given an opportunity to try and reclaim and rebuild the broken pieces of your life. Fortunately for Tammy, she had a strong group of friends who found this situation intolerable and would not accept it. Sadly, not everyone is so fortunate.

Nineteen years old and a college freshman: I remember the day in November of 1997 that forever changed my life. Abby, my social worker, and a representative from Adult Protection Services appeared in the doorway of my class. I excused myself from the classroom as my professor continued to fantasize being the lead reporter during the death of Princess Diana. I was led in silence to the library, where a private room had been reserved for the occasion.

Had I known what was about to happen, I would've took a sudden interest in the Princess Diana phenomenon and a new appreciation for my professor's every word.

They said they would escort me to my home to gather my things and to stay at the community hospital for a day or two until we found a nursing home that I "could live with". No amount of crying, begging, or pleading changed their minds. They did, however, agree to let me finish off the day at school to say goodbye to my friends. How kind of them!

Alas! – I was too quick for them! The next day I moved into my friend's apartment. This was only a temporary solution – John was a 21-year-old student from Brazil and had to go home in December for Winter Break. It, however, gave me almost one-and-a-half months of freedom and enabled me to finish the semester with my friends. I was lucky to have the friends that I did. John lived on the third floor of his apartment. Because a lot of my friends were in Student Government, every evening we would leave my wheelchair in their office, John would carry me to his car, then up the three flights of stairs to his apartment, where he and other friends did all of my care. I try not to think of the burden that was placed on my friend during this time—I am OK accepting help, but I believe I should be able to hire paid attendants for this and not expect services from my friends. And then on December 19, 1997, the inevitable came.

No one should spend Christmas in a nursing home. I had never let my disability stand in my way – ever. Why was I being imprisoned all of the sudden? For the most part, I had believed in God all of my life, and not once had I felt any bitterness towards Him regarding my disability. For the first time in my life, I realized that because I had a disability, I could not truly and completely control my own life. At nineteen, disability became a crime from which there was no parole. Everyone around me was three or four times my age – many had been captive for several years. Had I suddenly set foot into reality?

I have always been a fighter. Fighting to get out 'til the end or spending the next several decades in a nursing home wishing I were dead wasn't much of a choice. I was probably no older than 5 when I adopted the concept of 'Survival of the Fittest' and I have had plenty of opportunity to develop it.

To make a long story short, I got out. I ran away for days at a time, I broke other rules—in short, I was a "behavioral problem" and a "liability risk" that they finally didn't want to deal with. I got my own apartment, attendant care, went back to college, a job, got engaged, broke off my engagement in the name of independence, moved by myself to another state, organized a local disability rights group, adopted two cats, and the list goes on...

...All to be jeopardized by moving to Utah.

In May of 2001, ADAPT – a national grassroots disability rights organization – gathered in Washington DC to push for legislation for community attendant services and supports

(MiCASSA). Kay Fox, long-time organizer and strategist of ADAPT Utah, approached me about the opportunity to serve as an AmeriCorps*VISTA Member in the Disabled Rights Action Committee's (DRAC) Our Homes Not Nursing Homes Project. To be honest, I was less than thrilled about the location and leaving my friends, school and the wonderful Big Sky Country. However, my goal in life has been to get a job/career and eventually become financially self-sufficient. The Project represented my deepest passion – what I would like to do for the rest of my life, or until the threat to personal freedom is gone.

As a VISTA Member, I would receive a small living stipend, an education award at the completion of my first and second year and non-competitive eligibility status for appointments to U.S. government executive branch agencies for a short period. My service would pay off all of my outstanding Student Loans and I would be able to pay off any other debts I had acquired. If truth be known, even more enticing was the opportunity to learn under Barbara Toomer -- one of the greatest disability rights activists in the nation.

Before I knew it, I was relocating to Salt Lake City, Utah. While I was not ignorant to the work ahead of me in setting up all of the bureaucratic webbing that follows me wherever I go, I had not expected the Utah "booby-trap"!

I soon learned that Utah State Medicaid provides only sixty hours of in-home attendant services per month – broken down that is fourteen hours per week or two hours per day – a mere one-third what I was receiving in Montana. I don't know of one non-disabled person who can get out of bed in the morning, bathe/shower, dress, groom, prepare and eat breakfast, clean up, get ready for work, later prepare and eat lunch, clean up, prepare and eat dinner, clean up, and finally, get ready for bed – not to mention using the restroom throughout the day – all in two hours. There was no way I could survive on two hours of services a day. It would have only taken a couple of days for me to be in serious danger!

I applied for the Physical Disability Waiver – the only program in Utah that would enable me to receive the services and supports I need to live in the community. It was this waiver or institutionalization. Upon applying, I was informed that because I was not in a nursing home at that time, I be #25 on the waiting list, that people had been on for more than seven years. Basically, by being refused services because I started out in the community, I was being forced into a nursing home by the same program that funds people with disabilities transition from nursing homes into the community. It was even suggested that I go into a nursing home so that the waiver would provide me with services and supports upon return into the community.

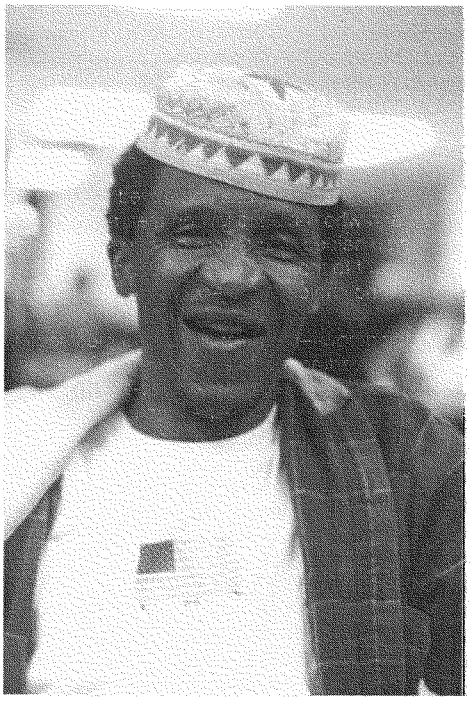
Fortunately, Montana Medicaid funded my attendant care for the first month I was in Utah. I cannot begin to describe the fear and devastation I felt as the month passed. Then twenty-three years old, I had hoped for a 'land of opportunity', as should anyone moving to a new state for a job.

Fortunately, the people of ADAPT Utah and DRAC were not about to take this ironic twist lying down. They mobilized, made calls, wrote letters and eventually descended en-masse on the Governor's office with the pointed message that it was unacceptable and most likely illegal that I be forced into a nursing home just to reapply for funds to move out. The Governor's representatives basically agreed, but countered that it would be unfair for me to get services before the then twenty-four who were ahead of me on the "waiting-list." My friends at DRAC were not persuaded by this argument, though they agreed with the fairness issue. Finally, by some miracle the state officials agreed to fund all twenty-four persons on the waiting list ahead of me.

Never doubt the power of a committed group of friends who are willing to go to the mat for you and who have the law on their side. I narrowly avoided nursing home care, and in doing so helped twenty-four other people get needed services. However, my heart still goes out to those who don't have committed, knowledgeable friends and family, who have no choice but to accept the intolerable offer of the entitled nursing home stay.

Life is good now—I am working in two meaningful VISTA placements. I have a wonderful apartment with an extra room for an attendant. I have a cat, I have friends, I have a little income and I have a life—a life that I could not have in the nursing home. Believe me, I speak from experience.

Gary



Gary's life underwent a dramatic change after a drug overdose that resulted in a traumatic brain injury. As a young man he was involved in an armed robbery for which he was convicted and sent to prison for 18 months. He was a promising boxer but illicit drug use halted his career. The brain injury has affected Gary's mobility (he now uses a wheelchair to get around), his coordination, speech and his short-term memory. Other changes are less tangible. Gary has a lot of time to think. He has undergone a religious conversion to Islam, has deliberately and purposefully chosen role models to emulate, and has nurtured a fire within him that longs to spark and ignite other spirits. Gary feels he must help young people learn from his life and wants to share his story at every opportunity.

Gary is #28 on a static Traumatic Brain Injury Waiver. He's been #28 for three years. Because of his particular difficulties, especially his problems with short-term memory, Gary needs a more supervised and structured place in the community. Right now, while Gary is tucked away in a nursing home, both Gary and the community are suffering from his exclusion in its daily life.

Gary lives in a kind of twilight zone between two states. Nevada funds a private nursing home in Utah. Out of sight, out of mind: Nevada officials don't visit the nursing home to review his case, Utah officials never see Gary's name on any of their lists as they survey the nursing homes. Is Gary getting adequate services? Has anyone considered whether he can live in the community? Does he even have the federally mandated discharge plan? No one knows because Gary doesn't quite exist as a Nevada resident and he doesn't quite exist as a Utah Resident. It seems a sad commentary on this society that Gary was sentenced and served 18 months in jail for armed robbery and 10 years in a nursing home for having a brain injury.

Gary's Story

I like women, the Utah Jazz and talking with kids. I have two kids of my own. A boy about 22 years old and a girl about 18 years old. I didn't really get chance to tell them when they were younger how good life is and how terrible it would be to mess up their lives with drugs. Fortunately, their Mamas did that for me. My kids are really good kids and they are doing well. I'm proud of them. But I need to tell other kids. If I could, I would to tell them to stay away from drugs, that drugs will take everything away from you. I would also tell them to learn all they can.

I was doing real good as a boxer until drugs messed my world up. I was boxing in Las Vegas and doing drugs. I thought I was having a good time. Now, when I look back at that time, I can't imagine what I thought was good about it. I was young and I didn't know what I was doing.

One day I used drugs with a friend, and the next thing I knew I woke up in a hospital. I don't know how long I was unconscious or how long I was in the hospital. The doctors told me that the drugs went to my brain. I could not walk, so I was discharged to a nursing home in Vegas.

Nevada was OK. People there treated you like a friend. The nursing home there had professional physical therapists. They worked with me. One day, Nevada's Medicaid sent me to a nursing home in Salt Lake City. They sent many of us here. It was not my choice.

I've lived in the nursing home in Salt Lake City for 10 years. In many ways it is worse than a prison. They treat you like a number, not a person. Nevada's physical therapists were good. They were real physical therapists. Here, in the nursing home I am in, they don't have real therapists. They have people with who have that job title but they don't know what to do. I am not getting muscle exercises at all.

It's really like a prison. The staff should be helping us to find housing in the community. But they don't because we are their paychecks. It's just a job for them, so they don't care. And they don't stay very long. We had three different administrators in two years. But, they make us stay.

In the nursing home, they control my life. I can't go to bed when I want to. They decide when I go to bed. I can't have food in my room. Once, I wanted to go out but they didn't let me go out. They said that it was my punishment because I had bad behavior that day but they didn't explain what I had done.

Once, I invited Governor Leavitt to visit our nursing home. He should know what is like to live in here.

The only good thing that happens is having visitors from organizations like the Disabled Rights Action Committee (DRAC). I joked with my first visitor from DRAC, "Are you my parole officer?" They told me about getting out of the nursing home. Another visitor from DRAC, who uses a wheelchair like I do and also has severe cerebral palsy, so she can't do a lot of the things that I can, has shown me there's another life. She showed me her apartment and explained the modifications and services she gets so she can live there.

The people from DRAC look after you. They show me there is life outside. I know my life is more than a nursing home. Now I want to be going out and doing different things. That gives me hope. They also show me respect, so I can trust them. The nursing home staff treats me like a number. But if other people outside care about you, the nursing home staff begins show you some respect. They know that if they treat you wrong somebody will stick up for you.

In the nursing home, I also learned that no one will respect you if you don't respect yourself. We need people who work here because they love what they do. I pray sometimes, not so much about me, but for people like the people at DRAC or the nursing home staff who are decent people, that they'll be rewarded in real life for what they do and who they are.

I know someone who lived in the nursing home with me who got out. So I know it can be done. With the support of his family and hard work, he got out and now he has his own place. That was a good lesson for me. Things can be better. I want to get out of here and be a good lesson for someone else in the nursing home. I want to prove not only to other people but also to myself that I'm not a loser.

The trouble is when you get out of the nursing home you need funding to get the services you need in the community. There are programs and waivers that let the nursing home funding go with you when you leave. That way you can pay for the help you need. I am #28 on the Traumatic Brain Injury Waiver at this time. I have been #28 for years. I'm tired of being a number. I'm a person, not a number.

When I get out of the nursing home, I want to go back to school to get a GED. The nursing home gives me no chance to get an education. It is understaffed. I have no chance to study in there. You need to get education to learn right from wrong.

When I get out of the nursing home, I'll get my life together. I want to be a good father. My boy did not have me while he was growing up. My ex-wife did a great job. My young man is in college becoming an architect. My ex-wife did good by my boy. I can't say nothing bad about my ex-wife. Allah blessed me. She went the whole nine yards. She told my sister that she always cares about me. My girl calls me too. She is becoming a receptionist. Family is important.

I want to be a counselor. I want to work with kids and teach them about drugs, gangs, and safe sex. I want to teach them if you do right things, you don't have to worry. I want to teach them that education is important.

When I am out of the nursing home, I will see the People of Islam on a regular basis. Malcolm X opened lots of doors. He taught that you have to respect women like queens. He taught that just praying gets you nowhere. You need to put action in your prayer. If you want to get out of the nursing home, you need action. I learned in the nursing home that I have no one to rely on but Allah. Allah blessed me when I met people like those at DRAC.

I pray 5 times a day – in the morning, afternoon, evening, late at night, and before going to bed. I can keep on because Allah gave me strength to carry on

There's so much more I'd like to say. But there's even more that I want to do. I need to put my thought into action. I hope my story can make life better for someone else.

Dan

"When I first met Dan in the spring of 2000" said Kay Fox "it was at a living wage coalition meeting. I mentioned a new project that Salt Lake Community Action Program and DRAC were co-sponsoring to assist nursing home occupants to live in the community. I couldn't have been more surprised when after the meeting Dan said he had lived in a nursing home, but had escaped. What first stood out as I listened to his story of survival was that no one ever talked to Dan about any services and options to live in the community. As a result, when he left the nursing home he had open wounds in his side. Dan risked infection and death by leaving. Later when I talked to my colleague, Jerry Costley, about the risk Dan took when he left the nursing home against doctor's advice, Jerry said that Dan exemplifies 'how life in an institution can be so restrictive and degrading that the only alternative he had was his van'. He had no money, no home, but in his flight from the oppression and segregation he experienced, Dan found dignity and self respect."

Dan has been one of the Our Homes project's most active volunteers. As a peer advocate, Dan is a role model of independent living. If a nursing home occupant complains about the amount of paperwork necessary to apply for housing subsidies, utility assistance, food stamps and housing applications, Dan can laugh and explain that its better than living in a van. In addition to the Our Homes project, Dan has volunteered to work for change in Medicaid policies and funds.

He has participated in protests and marches, press conferences, policy meetings and at the Utah Legislature on issues that impact health and quality of life. He works to assure that others at risk of or who are in nursing homes are told of their rights and the resources available. For those of us who Dan volunteers with, this self-described "troublemaker's" mischievous smile makes a hard issue more fun.

Dan's Story

I was born in Logan, Utah and graduated from Utah State University in 1972. After graduation, I migrated to northern California where I started a custodial service business. In 1996, I moved to Wyoming. On the way, I visited my sister in Salt Lake City. I became ill while there and my sister took me to the emergency room. I had bleeding ulcers and went into a coma from the loss of blood. The doctors performed a radical surgery, removing one third of my stomach and four inches of intestines and bowel.

Amazingly, after the surgery, I felt fine. But because I had no insurance, they tried to rush my recovery and gave me solid food before I should have been eating it. I had massive hemorrhaging. My kidneys and liver were also failing. I became delirious and I thought I was being kidnapped and tortured. I was sent to the University of Utah Trauma Center and from there to a nursing home.



I stayed at the nursing home for a year. At first, I was very weak. I curled in a fetal position and slept and slept. They thought I was going to die but I slowly gained strength and decided to live. I became more and more aware of what was going on in the nursing home.

The treatment at that nursing home was dehumanizing. Nursing home administrators wanted everyone to be docile. They frowned upon individuality. People were herded like cattle. They didn't treat my needs or wishes seriously. When I asked for information, I was branded a troublemaker. So, I accepted that role.

There was a lot of theft in the nursing home. A contributing factor of this theft may have been that the people who worked there were at the bottom of the labor market and not paid enough. People who value their jobs would not steal. When I reported theft from my closet, I asked for a lock. I was told that to get a lock I had to submit a work order and go through the procedure. I did. Still, I did not get the lock. This was part of the established communication pattern: I asked, they said go through the proper channels, I would, they ignored me.

Diet restrictions likewise were ignored. Diet was very important for me because of my medical history, surgery and the liver damage. I was not supposed to eat those things they served. But, everyone was fed the same thing. I talked to the nutritionist and administrators. They would not make changes. Fortunately, I had some money, so I started to go out and eat nutritious meals. But that made me a troublemaker and I could not afford to go out and eat every time.

As soon as I could, I started walking. There was no rehabilitation for me at the facility. Because I had hepatitis C, they said that I was dangerous and they could not provide rehabilitation. I used to be athletic when I was young, so I knew what I should do. I did my rehabilitation myself.

Medication was another problem. I talked with my doctor at the University hospital and he told me not to take some of the medication that they wanted me to take at the

nursing home. So, troublemaker that I am, I didn't take them. They put on my record that I was non-compliant.

One of those medications was a depression medicine. I watched what happened to other people who took the medication. Every morning, they'd go down and stand in a line to take medication. By the time breakfast was over, the drug kicked in. It took their spirit away and they became automatons. Everyone was depressed there. In that situation, being depressed was normal.

Life is an expression of identity. You need to express your individuality, make independent choices about you life, be creative. If you take that away, you might as well be dead. I watched people come in the nursing home fine. But they deteriorated rapidly. In three months, they didn't know who they were. They were dead in a year. Being treated like a non-person will erode you.

Another thing that infuriated me was that they were making a profit on the residents. Once, a guy's feet became purple. So two aides and I tried to get socks to protect his feet. We worked hard but it took two weeks to get a pair of socks. It was a for-profit agency. It made me angry that the owner made a profit and could not afford a pair of socks immediately for a patient.

I saw feces on the floor one night. In the morning the feces were still there. They left it all night. The nursing home makes money, but cannot afford to have a night cleaner. An attendant was joking that he had to put on rubber boots to come to work. I said that I hoped they lived long enough and got sick enough to experience this. Residents were injured because the staff was not trained well enough to assist them. I don't think those incidents were ever reported.

Residents had to stand in line for everything. We had to stand in line to get permission to go for a walk. By the time we got it, we were tired and our time was up anyway. So I left and went for a walk. I needed to go out and see flowers, go to park, and meditate. I was trying to live. Of course, I got a non-compliance recorded for that.

At first, the staff chased me when I went across the street to get a cup of coffee. Eventually they gave up and marked me as non-compliant. They tried to force me into the role of docile patient, but I wasn't playing.

While I was there, the nursing home got a new CEO. Her goal was to have 100% occupancy rate, and tighter control of the residents. By that time, I had a refrigerator in my room for my special diet. She took the privilege away from me. I already felt that my self-respect was deteriorating by staying in the nursing home. And I knew that with the new management, it would only get worse.

"I won't let you kill me" I told them. I had my van, so I put in as much as I could carry. An aide even helped me load things. They understood that they could not stop me. They made me sign a paper and I left.

I had no place to live, so I lived in the van. It was hard. But it made me stronger, more able. At that time, I still had a hole in the side of my body and it was draining. But I could not take more dehumanization and de-self-actualization in that nursing home. I studied herbs and took care of myself.

After awhile, I got involved in the National Health Insurance Campaign and Living Wage Campaign. I met members of the Disabled Rights Action Committee and I got involved with their activities too. I purchased a property in Northern California and left Salt Lake. I dreamed of living with nature, independently, growing my own vegetables. But I also realized that I wanted to do more with my life than just live in a beautiful place. So I came back.

Since I got back, things have been working better. I got a place here that is better than I ever dreamed I'd find. It's close to Salt Lake. I can even have animals. I have a goat and chickens. I have the best of both worlds, living in a city and the country.

I believe that people were born to fulfill the purpose of universe, becoming who we are. I feel more and more that my life has purpose and meaning. My involvement with DRAC is a part of the process of becoming. I am living a far more rewarding and fulfilling life. I am happy the way things are for me right now. I will never stop working to reform this system.

Peter

Peter's experience with the nursing home industry is in one way unusual and in another poignantly illustrates that even a "good" nursing home is still a segregated, warehouse environment and not a place where many people would choose to call home. Peter's first experience in a nursing home is painfully familiar to most people who have spent time in one of these institutions. The second experience shows what happens when the staff recognizes a resident as a person.

Peter's Story

I went into my first nursing home about twenty-five years ago. As a young man of twenty with psychiatric problems, I didn't have the skills to live on my own. I had problems with my family and more problems managing all the medications I was taking for my psychiatric disorder. Without a job, I took to hanging and loitering around the county building. Finally, a social worker told me to go to a nursing home. Back then there were no group homes or home care services. No one came to your door to help you out. There were no one to tell you about independent living. If you couldn't take care of yourself, you went to a nursing home.

Growing up with a dad who was an engineer, we traveled around the country. We lived in many places. When I was a kid, I was identified as having a learning disability. At the beginning of 6th grade, I was diagnosed with ADHD and was put on lots of medications. In the 7th grade I was hospitalized for the first time and by the 8th grade I had numerous hospitalizations. These hospitalizations continued through high school and contributed to my lack of independent living skills. These hospitalizations disrupted an already stressful and dysfunctional family life.

Living in the nursing home was a bad experience. The nursing home staff told me when to get up, when to go to the bathroom, when to eat, when to take a nap, and when to go to bed. There was very little independence. There was a strong smell of urine. It was not a place to live. You don't have a life there.

Another very frustrating thing was that one aide would tell me one thing, another aide would tell me something else and the nursing supervisor would overrule everything. I never knew what to do.

I was accused of starting fires and all kinds of things. I don't know how this could be true because I couldn't really function physically. I was on so many medications that I was in bed all the time. I was never in trouble with the law and I don't think I would ever do such a thing.

One morning in November 1979, I went to see people at the Mental Health Department and was told that I could not go back to the nursing home. At the time, they didn't explain why; but later, I found out that the nursing home did not have Medicaid's prior approval. I slept on the floor of the Rescue Mission that night.

Not only was I kicked out of the nursing home, but I was also kicked off of SSI, my main source of income. In order to survive, I joined the Navy. Boot camp was very hard and many people couldn't cut it. But I wanted to succeed. I graduated from boot camp but I was later discharged because I couldn't meet the physical requirements.

After getting out of the Navy, I got an apartment and got a job as an orderly in a nursing home in Salt Lake. But I had to quit because the job pressure was too much. I went to Mental Health and I got medicine and they helped me apply for welfare, medical assistance and food stamps.

I traveled around on freight trains in Colorado and Idaho. The Mental Health Department in Colorado got me a bed at the Salvation Army and I also spent some time in a group home.

One day I called my sister from Denver. I was sleeping on a floor in front of a bank on newspapers at that time. She sent me a bus ticket to come back to Salt Lake.

Back home, my social worker once again told me to "take advantage of the system" and check into a nursing home to get my weight stabilized and help once again with mental health issues. I was not eating right and had lost a great deal of weight. The social worker referred me to a nursing home. As it happens, I knew a nurse who was a coordinator in the nursing home since I was fourteen and this nursing home treated me like a person.

As part of my treatment plan, I had to attend Mental Health group sessions and day programs, which was fine with me. The nursing home staff made sure that I went to Mental Health. While I was there, I joined a group – a kind of a social club. This club provided me with several work and social experiences.

When I got my weight stabilized, I left the nursing home. This was a good nursing home. I visit nursing homes now, so I know that a good nursing home is one in million. This nursing home does not exist anymore because it was sold to a different company. And even though this nursing home was a good nursing home, it doesn't begin to compare to living independently in the community.

I am also able to make real contributions to the community. One project that I am particularly proud of being part of is an apartment project for people who need mental health services. When I saw a need for this kind of housing, I contacted an administrator at Mental Health and together, we started an apartment project managed by Mental Health. I was there in the project for thirteen years.

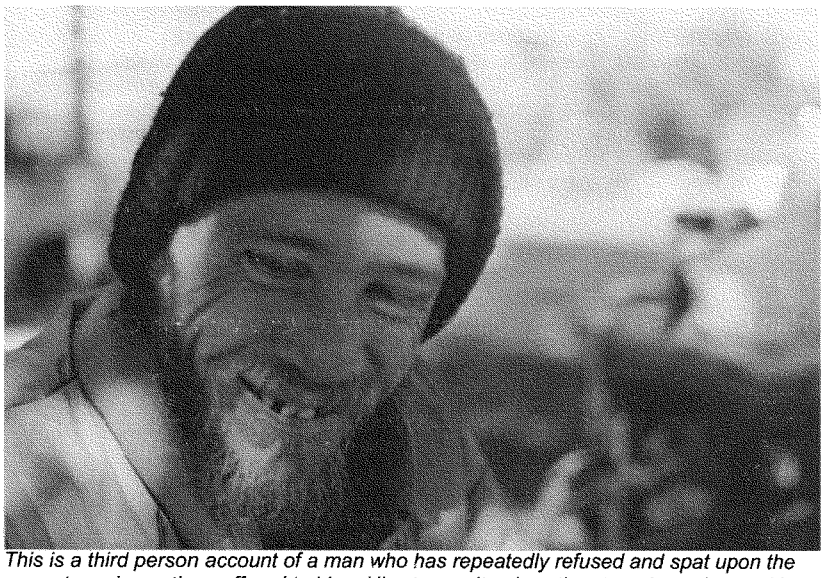
A few years ago, I was diagnosed with manic depression. I had been misdiagnosed and had been taking the wrong medications until then. Now with the right medications, I'm doing fine. I have continued with day treatment. I met my current girlfriend five years ago. Our biggest focus is on taking care of ourselves and each other. If I have

problems with driving, she drives. When she gets tired, I drive. We share. When we clean our apartment, she cleans one room and I clean another room. Then we sit down and take a break.

We're also members of the Disabled Rights Action Committee (DRAC). We are very proud to be members. I belong to other organizations and advocacy groups. But there's no advocacy group like DRAC. I am just sold on DRAC. We get things done rather than sitting back and waiting for the change of government to happen. Sometimes things move fast, sometimes slow. But at least we have an organization of disabled people. It is not run by social workers. It is run by us, people with disabilities. When we mess up, we mess up. But we usually correct the mess very quickly.



Anthony



This is a third person account of a man who has repeatedly refused and spat upon the current service options offered to him. His story epitomizes the struggle we have with the concept of personal freedom and choice. Anthony is not a man who many would call honorable. His teasing and joking belies the fact that his circumstances are largely of his own making and he does not accept the consequences of his actions with adult logic. Rather, he flies into a rage, and threatens to "run you over" as he flings hurtful words at the bearer of unfair news. He has little self-control and no interest in developing any. People prefer not to be around him, if only from a sanitation level.

Yet, how we treat Anthony defines who we are. We have an uncomfortable kinship with this man who acts before thinking, who can only see the next moment instead of the larger picture. We don't understand how someone who complains about not being able to take more than one shower a week would choose to live in Pioneer Park, where he may not have a shower for months.

Kay Fox from SLCAP first met Anthony while part of a community effort to secure SSI for homeless and disabled individuals. Since that time, according to Kay, Anthony was in a car accident, which made him a wheelchair user. As Anthony grows weaker from AIDS related problems, his anger isn't so dramatic.

He is happy to see people, but then verbal harassment begins. We can do better. We can treat people with more respect and common courtesy than he was treated. We can be better. Perhaps we can begin by providing services for individuals, not institutions. Why couldn't Anthony have someone help him with personal needs such as personal hygiene and taking medication where he is?

Anthony's quality of life would be better for it. Anthony's search for respect may have been broader had he been able to take a simple shower on his terms. If he were cleaner, more people may have interacted with him. He may have even discovered that respect is a two way street.

Not all news is bleak – the Utah Department of Health staff are aware that there are people in nursing homes or on the street who have behavior problems the state doesn't have resources to address. They are applying for funding to study how best to assist this population.

Man Challenges Advocacy Organizations to Live with His Choices

Anthony Wadell has burned more bridges than most people have occasion to build, according to Sheryl Dobson, CHAMP worker. In the two years she has worked with Anthony, virtually every nursing home in the Valley has offered Anthony shelter that he has eventually walked away from. After Anthony has left against medical advice, the nursing homes rarely want him back.

He violates rules at shelters, or at the hotels that offer temporary shelter to people on the street. He is not on good terms with the food pantries, and the Utah AIDS Foundation can only allow him minimal services.

"Anthony is verbally abusive to just about everyone. He has trashed and destroyed furniture and other property in most of the places he has stayed," said Dobson.

The staff and volunteers involved with the "Our Homes, Not Nursing Homes" project at the Disabled Rights Action Committee (DRAC) echoes Dobson's assessment.

"Not many organizations will offer services to Anthony anymore. His behavior jeopardizes their relationship with other service providers and makes it harder to get services for other people," a DRAC volunteer explains.

Dobson, however, recognizes both Anthony's vulnerability and strength. "If he were anyone else, Anthony would have been dead a long time ago," said Dobson. " I like Anthony, and he likes me because I am straight with him. While he plays up his delusions to others; he and I have real conversations and I find him to be a very personable man."

"The man is incredibly resilient," agreed Jerry Costley, supervisor of the Our Homes, Not Nursing Homes project, "and people seem to respect this trait."

Indeed, in the past, some agencies have gone out of their way to accommodate Anthony because they see this strength of will. Repeatedly over the years, a multi-discipline team consisting of representatives from different organizations has worked with Anthony to provide a service plan to meet his needs, only to have Anthony sabotage the plan. But, can we just turn away?

"Everyone needs somewhere they can go, someplace where they are not stopped at the front door. Ironically, DRAC and CHAMP can do this because as advocacy organizations, we have no services to provide. We don't have living spaces that can be trashed, counselors with egos to bruise or food to complain about," said Dobson.

DRAC works on long-term goals for equal access, while advocacy is invaluable to the disability community, when your clothes are deteriorating under layers of filth, the last time you ate was the day before last and you are battling AIDS related pneumonia, political advocacy on your behalf seems a little too abstract.

Looking through the case files at DRAC, Lori Brock realized that DRAC also spends a lot of time trying to repair burned bridges between service providers and Anthony.

"People at DRAC take the time to listen and because we do not provide expensive services that may be trashed and mutilated, we are able to listen without bias, I realized."

Sometimes advocating for Anthony means getting him not to reject the few services being offered.

"It is so ironic to be part of an organization that tries so hard to find community options for people in nursing homes to actually encourage someone to stay in a nursing home!" Brock laughs as she remembers how DRAC members tried to find Anthony temporary housing in a nursing home so he could be out of the cold and confusion during the Olympics.

At first, DRAC's willingness to look at nursing homes as an even a temporary option seems to go against the philosophy of the Our Homes Not Nursing Homes Project, but as Costley explains, "Although we believe vehemently in necessity of providing services to people in community settings rather than in isolated and segregated settings like nursing homes; we also believe that people need to be informed of all the current options available."

Anthony, however, doesn't wait for any options. When the restrictions and regulations of a shelter or nursing home program anger and frustrate him; he leaves.

/hen the weather is warm, nthony's home is Pioneer Park. ⊣e knows where he can get the ıings he needs and wants," said rock, who first met Anthony when e grudgingly accepted nursing ɔme services during the ılympics.

⊣e has people who will provide im with his favorite soda, other eople who replace his clothes eriodically and still other people 'ho will replace a stolen sleeping ag from time to time. Every time I ee him, He looks thinner and icker than the last I saw him," aid Brock.

The Our Homes, Not Nursing lomes Project at DRAC is all bout people making their own hoices and having power over ıeir own lives. Anthony is ctually a teacher. He teaches us ıat people's choices may not be ıe ones we want or wish for them ut their own choices make them niquely who they are. Whether ,nthony is sheltered from the cold ı a nursing home or homeless in 'ioneer Park, he is in charge. And e wouldn't want it any other way," aid Costley.



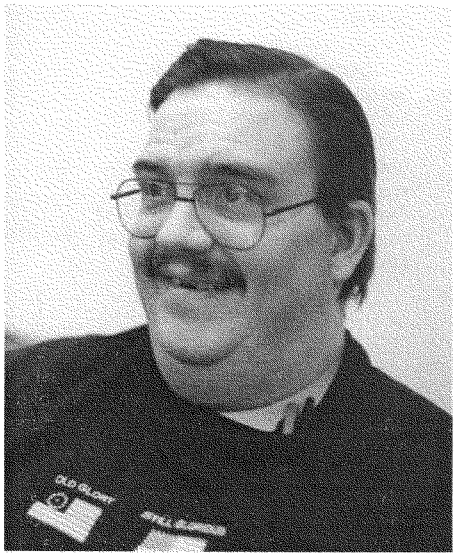
Brian

If Brian's family had received community support services such as respite care and home health assistance, it is possible that Brian never would have gone to a nursing home. Furthermore, since Brian was already deeply rooted in his family and community, it is more than likely that with only a little instruction on the need for structure Brian would have gone on to be a very productive and influential person within that microcosm of society. As it was, Brian spent years of his life waiting for the next meal, the possibility of a recreational activity, or bedtime.

Brian watched as others were able to access specific waivers to get the funding they needed to move out of the nursing homes. Brian followed suit but was continually frustrated in his efforts to move out into the community, because he didn't meet the specific requirements of the existing waivers.

Finally out of the nursing home and receiving services from Flexcare (a pilot program that accesses funding for people who don't fit into any of the waiver programs) Brian has moved into an assisted living program. He reports that he is happier and more energetic. He is also looking for volunteer opportunities that will let him contribute to the community.

Brian's Story



I want to tell my story because I want others to know how frustrating it is to want to be a part of the community when you live in a segregated setting such as a nursing home.

When I was nine years old I was diagnosed with an inoperative brain tumor and while it didn't kill me, both the tumor and the exploratory surgery I underwent at that time caused some brain damage. My father died when I was ten and it was a difficult time for my family. One of my early experiences living in a nursing home happened when my brother and his wife could no longer take care of me. My legs were swollen and so big that I couldn't move around.

That first night, I felt totally devastated because I couldn't live with my family anymore. I felt useless like there wasn't anything I could do for them and I felt like

it was my fault. Instead of being with my family all the time and being part of its on-going story, when I was in the nursing home I saw most of my family only on occasion. This made me very lonely.

This first experience happened over twenty years and it was really the only option for me and my family at the time. Now we could have thought about community services such as personal assistance and respite care—provided we could access the funding for these services. The availability these of services could have allowed me to participate in family and community life and get the care I needed at the same time. (And these services would have cost much less than living in a nursing home.)

I've been out in the community living on my own several times but I always had to go back because without the services I needed to help me maintain a structure, I tended to gain a lot of weight and my skin would break down. That meant that I couldn't move around very much, which would cause my skin to break down even more. Every time I went back to the nursing home, I tasted failure. It was like I had my chance but now I was back to square one. I blamed myself. I didn't want to be in the nursing home but I couldn't get the specific services I needed to be successful on my own. Now I realize that services (similar to what I now receive in the assisted living program that I now participate in) including: cooking instruction, personal assistance, accessible housing and transportation, would have opened so many doors. I could have found (and gone to) work—even volunteer work would have kept me interested and connected to the community. I could have also been more involved with my church. I could have given more to the community. So often I felt like all I could do was take but with the right services, I could have given more.

Now I want to help make sure services like: scheduling and planning assistance, transportation, physical therapy, and diet and medication reminders are not only available to me but to the younger people who want to both live in and give to the community.

The nursing home alleviated the problems that my family and friends had taking care of me. But In the nursing home, I very often didn't have control over what I did or when I did it. I had to schedule a shower and was lucky if I could have one three times a week. Now, in the assisted living program, I take my own showers everyday if I want to. In the nursing home, I had a limited choice in what I ate. In assisted living, I have my own refrigerator and microwave in my room, so if I don't like what they are serving, then I can have my own food. I guess the most important thing that is happening now that I'm not in a nursing home is the availability of natural opportunities I have develop and practice more skills on my own. In the nursing home, there is an encouraged and forced dependence.

A typical day in the nursing home began when I woke up at 6:00 am. I got ready for the day and went downstairs to the dining room. There were usually two, sometimes three others down there and we would play cards until breakfast time. We waited, breakfast would come, and we would have our breakfast.

After breakfast, I went to my room. That was about 9:00am. A lot of the time I sat and watched TV. I waited to see if there would be an activity to go to. Sometimes the staff would run bingo or something. If that was the case, I would go to the activity, and then come back and sit around.

At 10:30 am, there would be a coffee break, but I don't drink coffee, so I would have hot chocolate. Sometimes immediately following the coffee break, there would be another activity, which I usually went to. Then it was time for lunch. I would go down to lunch early to play cards again. We ate lunch and I went upstairs and I just sat around because there wouldn't be anything to do. Sometimes I took a nap. Around mid-afternoon, they might have some kind of activity.

Once in a while, they would have some kind of entertainment after dinner but not very often. After dinner, we just went to our rooms and waited until it was time to go to bed.

People normally have at least one roommate in a nursing home. Sharing a room with someone was intrusive because of a lot of things. I had to take into consideration things like having the TV on, or the radio, or the light on. Even how late I stayed up or when I when I went to bed depended on a shared understanding with my roommate. I had many arguments with my roommate because I might not agree with him on something. It's worse if you have separate TVs because one is watching one and one is watching another. I had to keep my TV loud enough to hear it and quiet enough for my roommate. To top it off, my roommate was in the bathroom constantly! I had to watch and take advantage of the times he would vacate the throne in order to relieve myself!

I did meet a dear friend in the nursing home and I miss seeing her everyday. I think the world of her. The main reason I think so highly of her is that she is one who will stand her own ground for herself. She will say what she feels and ever since I have met her I have really, really looked up to her for that. I didn't used to be that way. My mother even likes her. My friend always tells me to make sure that I tell my mother I love her. This friend has and will always have a very, very special spot in my heart. My relationship with her is one of the very few positive things about my experience the nursing home where I lived.

Now that I am in an assisted living place I feel happier now because the environment feels happier to me. Family members who come to visit say they notice a difference. They all say, "This is so much better than the nursing home." There is more energy in the air and more of an assumption that you will find things to do, even though there are not as many planned activities. The staff assumes that you have interests and hobbies of your own that you will pursue.

My room feels more like an apartment. It is my own room. I don't share it with anyone, unless I invite someone to be there. I have my own shower, refrigerator, microwave and I could have a pet if I wanted to.

I think almost everyone would want to live as independently as possible but the funding is not set up make it easy to get services in the community. In order to get the money that was used to pay the nursing home to pay for the assisted living place I am in now, I needed to fit into a category so I could qualify for a waiver that would channel my funding. The trouble was that I didn't fit. The Personal Assistance Waiver requires that you have the loss of function in at least two legs needed to perform daily living activities. With me, sometimes this is true but sometimes it's not. (Sometimes I walk quite well but a lot of the time I really can't.) The Traumatic Brain Injury Waiver requires that the brain injury be traumatic and caused by some sort of accident. My brain injury wasn't caused by a traumatic event so I don't qualify for the TBI Waiver. I do get funding from Flexcare, a pilot program that helps people who are hard to fit into other waiver programs transfer funds from nursing homes to community based services. But there are so many people who could live successfully in the community and do it a lot cheaper than they would in a nursing home and not enough programs like Flexcare to help transfer the funds. Right now, people are entitled to nursing home care and not community services. This is what needs to change. It needs to change because not only is it cheaper to provide services in the community, but it lets people be part of the community. I not only receive services in the community but I shop, attend church and I am thinking about volunteering for a youth organization. And this makes me a contributor as well as a consumer. And isn't that what the community needs?

Marjorie

Marjorie doesn't quite remember how long she has been living in the nursing home; one day creeps into the next. An Intermediate Care Facility for people with Mental Retardation (ICF-MR) would likely have been a more appropriate placement for her than a nursing home.

If Marjorie had been placed in an ICF-MR, she would have been out of the facility and living in the community under the Portability Waiver three years ago. Now due to bureaucratic mishaps, this option is not available at the present time. The nursing home cites her diagnosis of mental retardation as the most significant barrier that is preventing her from achieving her dream of living in her own apartment. The state has also determined that she qualifies for developmental disability funding for persons with mental retardation and related disabilities; she is just 71 on the waiting list. Curiously, the state has also determined that Marjorie doesn't qualify for placement in an ICF-MR—a determination that could allow her to bypass this waiting list. Marjorie falls through the cracks with other funding possibilities. For example, she doesn't qualify for the Personal Assistance Waiver because she needs help hiring and firing her attendants.

She has also been a casualty of medical professionals who not only have little understanding of the community services available but because they are paid by the nursing home industry, have a vested interest in keeping people in the nursing homes. If it weren't for such a medical professional who denied her access to community services "for her own protection," Marjorie would be receiving community services now through the Utah Flexcare program.

Finally, because of the institutional bias in funding, community services are often unable to accommodate all the people who need services. There are also individual needs that can't currently be met by our community services. If people were entitled to needed services instead of a bed in a nursing home, perhaps Marjorie would not be faced with the potentially terrible choice of moving into the community and leaving her husband or staying in the nursing home with her husband because there are not adequate community services for him. Marjorie's story was written before her recent marriage.

Marjorie's Story

I have cerebral palsy. I was living in Ala Chapell condominium. The man up above me turned his bathtub on and forgot to turn it off and water leaked down through the ceiling in the kitchen and on the carpet. As a result, I was moved into a nursing home and nobody told me why.

In my room at the nursing home, the space between my bed and my roommate's dresser is so narrow that it is hard to use my motorized wheelchair. It is too difficult to

back out or turn around. The telephone cord gets tangled when I move the over-bed table for me to go in or out.

When my boyfriend and I want to get together and talk, there is no place to go and be alone. We both want to move out of the facility and get married. To get out of the nursing home and have some happiness. I believe we have the right to some happiness.

I'm really getting tired of all the things I have to deal with such as:
Nursing home people bossing me around; other patients telling me what to do; always being asked if I want to go to an activity but when I say no they try to coax me into going. I like bingo and when someone comes to play the accordion or sing but other stuff I don't like. I've got my own life to live.



I don't understand why I can't live in an apartment instead of a nursing home. First, the staff at the nursing home told me I couldn't live in my own place because I liked to sleep during the day. Well, life here is boring. Why do I want to stay awake during the day, when I can get together with my friends in evening after they get off work? Then the staff told me I couldn't leave because I couldn't manage my medications. So I learned how, and the doctor still wouldn't let me leave. Then they told me I would not be able to manage my attendants. I can do that. I could tell them what I needed them to do when they came over. I would want help checking their backgrounds and things before I hired them and I don't like to fire people. But, I can tell them what to do.

I'm also worried because my boyfriend and I want to get married but he is going to have a much harder time getting out of the nursing home than I will. The nursing home will let us share a room after we are married but it will be so crowded that it won't be much of a home.

Now they tell me that I might be able to leave the nursing home without my husband. They say he can come visit me anytime but that he has to live in the nursing home. Would you want to start a life together like that?

Trish

Trish's triumph over a system that tied services to a place instead of the person serves a beacon of light for those still struggling to be free. Cerebral palsy, clinical depression, asthma and a host of other medical problems make it difficult, if not impossible for Trish to live in the community without services. The Personal Assistance Waiver For People with Disabilities makes it possible for Trish to get the services she needs to live independently in the community for a fraction of what it cost Trish to receive the same services in the nursing home. As a VISTA Volunteer for the Disabled Rights Action Committee, Trish helped others make the transition from nursing home to independent living in the community. She is active in her church and takes civic duties very seriously



Trish's Story

I write this in hopes of giving John Q. Public a bit of insight into what it is like to live in a nursing home.

I spent a year of my life transferring between three nursing homes, hoping to find a place that I could call "home". To my dismay, I found nothing of the sort. All of the facilities were sterile in their environments. Each had overworked and underpaid staff. There was no personal attention. You slept and lived in a 10-foot-by-10-foot space, and ate in overcrowded dining rooms. The décor left much to be desired, and you could count on a monotonous, predictable routine. I've heard it likened to being in jail and believe me, the analogy fits.

I am not an elderly person. I am less than 40 years of age. The most important things I lost in the nursing home were my dignity and freedom. I felt as trapped as a caged animal

with very little to say regarding anything that directly affected me. Your dignity suffers greatly when someone has to dress you, bathe you, put you to bed and dispense your medication on schedule.

I waited anxiously for a phone call or visit from my friends, my only connection to the outside world. To take a ride in a car with no particular destination in mind was a reason to celebrate. To do menial tasks such as a part-time job, or helping with the facility laundry was something I looked forward to because I had something to do that was productive.

Finally came the chance to live in the community once again. A group here in Salt Lake City called the Disabled Rights Action Committee (DRAC) launched a program called Our Homes Not Nursing Homes. The project was the result of the Supreme Court decision that said that a person should live in "the most integrated setting." For me, that was definitely not a nursing home. In late 2000, I moved into my own apartment. I now have the freedom to choose what I do and when to do it. My dignity is restored as a productive citizen of this community. I supervise every aspect of my life and don't have to answer to anyone but myself when it comes to making decisions affecting my life.

There were hurdles placed in front of me in my transition to the community, but it has been worth it, and I was able to overcome all of these hurdles with help from my friends. I was permitted $45 a month to provide all my personal needs while living in the skilled nursing facility. That left me nothing to save toward paying rent or buying household supplies, etc. Thanks to many people at DRAC, and the fact that I had some things in storage, everything I needed was patched together in a short time.

My little apartment is not the Taj Mahal, but it is mine. From inside these four walls, I pay my bills and live my life as I choose from day-to-day. I treasure my freedom more each day, and have learned to appreciate the little things in life, even those things that can be a big hassle. If one can find blessings in having occupied a nursing home, then so be it. For me, there is no such thing.



"I didn't belong in a nursing home."

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STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.



Name: Michael Engro

Address: 2600 Belmont Ave., Apt. 205

City: Philadelphia State: PA Zip: 19131

Age: 41 Phone: 215-473-1825

Type of institution:

Nursing Home X
State Institution/Developmental Disability
State Mental Hospital
Group Home
Rehabilitation Facility

How long institutionalized? 6 years

Please attach a short summary of your time in the nursing home or other institution and how your life has changed now that you are out.

They took my independence. Now I have a life, eat what I want, when I want. I have privacy.

ADAPT—FREE OUR PEOPLE!

To: The Senate Finance Committee

From: Kurt Fedewa
221 N. West Street
Portland, MI 48875
February 6, 2004

Re: Senate Bill 971, "MiCassa," and Senate Bill 1394, "Money Follows the Person."

I would like to offer testimony to you about an issue that is important to many people who have disabilities.

Many people who have disabilities are living in nursing homes and in other institutions. The Medicaid program provides funding to these institutions, to pay for the housing of these people. Unfortunately, a nursing home, or any other type of institution, is not necessarily the best place to treat these people. Many of these people would rather live in their own homes, as members of the community. This living arrangement would afford them the opportunity to live a life that is as "normal" as possible. These people would indeed be able, in fact, to live in such manner, if the law would allow the use of Medicaid funding for such living arrangements. The freedom to live in one's own home, rather than in an institution, greatly enhances the quality of life for those of us who have disabilities. This freedom is very important to us, and this freedom may even allow us to be employed in the community, to thus become contributing members of society.

I am a person with a disability, and I was almost sent to an institution sixteen years ago. Fortunately for me, I was instead allowed to live in my own home. Because I was allowed to remain in the community, I have been able to improve my health in a substantial way—enough so, in fact, to be able to hold a part-time job and to be a contributing member of society. Had I been institutionalized, I may not have had this opportunity. I am now an asset to my community.

I ask you to support Senate Bill 971 and Senate Bill 1394. Passage of these bills would help many citizens with disabilities to use Medicaid funds in such manner that would allow them to live independently—that is, outside of institutions. It has been demonstrated that use of funds for independent living, costs no more, and often less, than the old way of housing people in institutions. Institutions rob people of their lives. I feel that citizens of this country, who have disabilities, should have a right to choose where they are to live.

Thank you for your consideration of my testimony.

Yours truly,

Kurt Fedewa

Kurt Fedewa

Senate Committee on Finance
Attn. Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Bldg.
Washington, DC 20510-6200

"Strategies to Improve Access to Medicaid Home and Community Based Services"

Barbara Forgione
20 Community Manor Drive #1
Rochester, NY 14623

I write to you in the role of a concerned Certified Social Worker of New York State. I have been in the field of Human Services approximately 25 years and have mainly dedicated my efforts in working with people physical and/or emotional disabilities. It remains vital to me professionally and personally that the people with disabilities are given a life that incorporates freedom of choice, independence and dignity. I will continue to strive for the personal, legal constitutional and civil rights of those having disabilities for the rest of my life. It has not only been a career choice of mine but remains an ongoing focus. Any opportunity I have to educate the government, politicians and or the general public about the need to end institutional bias by allowing community integration as opposed to be forced into a nursing home or similar institutional setting I will do.

I believe that facts have power when it comes to advocating for those with disabilities. Government always looks for proof, so I here it is... My years as a professional has involved doing extensive therapy/ counseling with clients dealing with trauma resulting from physical, psychological and sexual abuse that they experienced first-hand from their so- called care givers in institutional settings They all had no choice in regard to their living arrangements. Abuse ran the continuum of verbal attacks to repeated rape and near death. Many of my clients have been abused on a daily basis for years, at various institutional settings. Whether the person had been institutionalized recently or had been as a child and is now a Senior Citizen, the fact is abuse is REAL and its devastating constant affects remain. This fact is not over dramatized or should ever be thought of as a myth. I have treated people having diagnoses such as: Post Traumatic Stress Disorder, Depression, Anxiety, Adjustment Disorder, Substance Abuse and more. It is not uncommon for people to be on strong psychiatric medication, not able to work or function on a daily basis. Affects of abuse may be "less" on some days but the feelings never go away.

Clients have told me over and over, " I have been to hell already, I am out but I still live the nightmare everyday with my eyes open...my daily hell still continues, I just don't live there anymore." It does not matter the disability, age or how long they have had freedom. The reality is that these diagnoses are due to abuse that could have been avoided. This problem would largely decrease if people were given freedom of choice. I believe that the decision made by government to institutionalize people, leaves decision-makers responsible for such deplorable treatment. As a Democratic society how can Officials stand by and watch this abuse continue? How can government continue to not

see the benefits of freedom of choice I am not talking about doing what is nice, I am talking about giving quality of life to all, by ending institutionalization and in many instances saving lives.

The choice is simple, and you have the power to make sure that ALL citizens are given quality of life, WITHOUT HESITATION – PASS MiCASSA Now! None of us know when disability or illness occurs. Decisions you make today will determine if abuse continues and in many cases if more lives will be saved. People are living to die and dying to live! End institutional bias NOW! Knowing you have power to make positive change, do what must be done and end institutional bias and put proper and adequate supports in place. Knowing what you must do I respectfully request that you PASS MiCASSA NOW!

Sincerely,

Barb Forgione

Senate Committee on Finance
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"Strategies to Improve Access to Medicaid Home and Community Based Services"

Chris Hilderbrant
96 AA Clintwood Court
Rochester, NY 14620

Honorable Committee Members:

For half of my life, I have been a person with a disability. For the past five years of my life, I have been an active and vocal advocate for myself and all other people with disabilities. In my professional role, I am the Director of Advocacy at the Center for Disability Rights in Rochester, New York. I am also a Community Organizer for the Rochester chapter of ADAPT and I am an active member of the Rochester chapter of the National Spinal Cord Injury Association. I am the father of a beautiful eight month old girl. I frequently speak to college classes and other organizations regarding the struggle for civil rights for people with disabilities.

In all of my roles, and in all of my days, I remember one thing – I am one of the lucky ones. I broke my neck at age 14. I fractured the sixth cervical vertebrae, thrusting it and the fifth and seventh vertebrae into my spinal cord when a shallow water drive went too deep. After years of intermittent physical therapy and personal rehabilitation efforts, I am able to use a sporty lightweight wheelchair and can even stand up for good periods of time. I have some of my sensation as well, though few muscle groups work in any significant way.

I am a lucky one because I broke my neck at 14. I am a lucky one because I had a strong family willing and able to support me at home. My family was able to make several significant modifications to our home in order for me to access the home, bathroom and my bedroom. Also, because I was an honor student at age 14, my family was able to use my potential employability to leverage funding from New York's Vocational Rehabilitation program, Vocational and Educational Services for Individuals with Disabilities (VESID).

Since I have grown up, graduated college, and found a career, I have met many people, very much like myself, but no so lucky.

I have worked with many individuals with disabilities, some like mine, some unlike, who have survived terrible hardships in their lives. Many of them were forced into nursing homes when they needed simple personal care, but were not able to receive the needed care at home. Our counties, our states and our nation are biased toward forcing people

into nursing facilities and Intermediate Care Facilities for the Mentally Retarded (ICF-MR). These people do not need and do not want to be forced into an institution.

I have seen young men and women with spinal cord injuries just like mine, living in nursing homes. We have forced these people into these places because our country is unwilling to provide for sometimes very simple care in the community. Many of the people we have helped escape had been forced into the institutions because they needed just a few hours of support each day. Only when our center and the threat of legal action got involved did the county and state take these people and their wishes seriously.

I have seen older people forced to stay in nursing homes to get basic needs met. With family members working full-time, or more than full-time, families cannot be expected to take care of their elderly members. There is, however, no reason that we cannot provide supports and services to these seniors and their families in order to enable the person to stay at home throughout the aging process. If we are willing to pay for the care, often much more expensive, in an institution, it is absolutely immoral that we would not make care at least as readily available in the community.

In New York State, we have a patchwork of programs that sometimes helps people with certain kinds of disabilities live in the community. And sometimes it fails. And many times, if you don't have the right kind of disability, you are not even eligible to try the patchwork. We call this the "disability lottery" – pull the right ticket and maybe you'll do well. But for the one winning ticket, there are many thousands of losing tickets. And this is in New York, the so called "Cadillac" of Medicaid.

In other states, there is little or no hope of escape from institutions. People, young and old, are forced into institutions, never to return to their homes. This must end not with a few pilot projects or demonstration grants, but with vast systemic change to end the institutional bias. It is time to pass MiCASSA.

The Medicaid Community-Based Attendant Services and Supports Act (S. 971) gives people Real Choice in long-term care. MiCASSA provides individuals eligible for Nursing Facility Services or ICFs with the opportunity to choose Community-Based Attendant Services and Supports.

Rather than be forced into institutional placement, people would get assistance in their own homes. Such assistance would include the basic activities of daily life that most people take for granted like meal preparation, eating, toileting, bathing, grooming, shopping, managing finances, and participating in the community. MiCASSA addresses the need for assistance with health-related functions.

MiCASSA implements other necessary reforms. It would:

- provide assistance in the home and community, such as at school, work, or religious activities;
- include systems for securing back-up attendants;
- offer options for consumer control of services;

- address the inequity in financial eligibility between nursing facilities and community based services; and
- support those minor but essential expenses needed by people returning to the community, such as security deposits for housing, bedding, and kitchen supplies.

Because the money is following the individual, MiCASSA is not a new, unfunded mandate. We pay for this assistance already. MiCASSA makes the existing mandate more responsive to consumers. People who are already eligible for services will have a Real Choice.

Every major national disability organization supports MiCASSA. In fact, 92 national organizations are MiCASSA supporters. An additional 255 state or regional organizations also support the bill, as well as 306 local groups.

I appreciate your consideration of this matter and my testimony. The lives of many people with disabilities have already been stolen by institutions, please help us make sure that no more lives are stolen. The answer to our problem is clear, and the power to move forward rests within the Senate Finance Committee.

Free Our People – Pass MiCASSA now!

Sincerely,

Chris Hilderbrant

Good morning and thank you to the Senate Finance Committee and to Senator Charles Grassley, Committee Chairperson.. I am Claude Holcomb, from Connecticut. I reside at 2 Park Place, Apartment 4-F Hartford, Connecticut.

Medicaid Community-Based Attendant Services and Supports Act, will allow people with disabilities and the elderly to have a choice to live where they want to and not have to go into an institution just because they have no one to help them perform the activities of daily living, like getting out of bed, bathing, etc. I was institutionalized for 14 long years from the time I was 7 years old. I saw people dying when I was a little boy. If this Committee thinks about that for just a minute and remember that you are a kid and because you are institutionalized, your family may miss the experience of seeing you grow up, you will realize how cruel this is. I got out in 1980. I had to fight to get out because with my severe disability the institution thought I could not live by myself because of my speech disability. Once I got out, I lived by myself for fourteen years until I met my girlfriend, with whom I have lived for eight years. I get my attendant care through the Medicaid program and a small State of Connecticut grant program. If I was still living in an institution, it would cost much more to keep me in an institution than in the community.

I had someone whom I loved go into an institution. My mother, she got Amyotrophic Lateral Sclerosis *or* Lou Gehrig's Disease in her 50's . If this country had Medicaid Community-Based Attendant Services and Supports Act, I would have been able to live at home with my family. I would not have had to watch my mother live in a hell hole like I was living in. In the institution, they took away her dignity . One day I went to see my mother and she was not in her room, so I waited a few minutes. I heard a little voice, I looked in her bathroom and she had been on the toilet a good hour before I got there. I went to find the aides to help her . They told me she had to wait because they were busy. We waited for 30 minutes and they still had not come. We waited some more. That was the last time she went on the toilet. If this country had Medicaid Community Based Attendant Services and Supports Act, these types of things would not occur.

The Constitution says this country is free for all people to live in. If that is true why does the nursing homes industry have a medical model to put people with disabilities and the elderly into institutions. The disability community is not trying to change the country but we want a choice where we live in the community.

I want to have a choice for all my Brothers, Sisters and the elderly.

We are passionate about getting this bill passed because much of the population in institutions does not need or want to be locked away in institutions so that society will not see them. This country needs to change the way people with disabilities and the elderly get care if they need it to live in the community.

Please help S. 971 and H. R. 2032 get through in your Congress ! Thanks! I will take questions if someone has some.

Senate Committee on Finance
Hearing Held on April 7th, 2004
Ending the Institutional Bias
Attn: Editorial and Document Section
Room SD-203
Dirksen Senate Office Building
Washington, DC 20510

My name is Cassie James-Holdsworth and I have been involved with Independent Living and the transitioning of disabled people from nursing homes since 1988. Many of my friends with disabilities died in nursing homes from neglect and isolation.

One of my friends who died in a nursing home was Bev Welsh. She dreamed of a day when she would be worthy of community life.

Once Bev tried to run away from the nursing home (Inglis House) and they withheld her drugs. As a result, her breathing became labored and, of course, she returned scared and defeated.

As years went by, she grew tired. She was never happy in the home. Staff constantly told her she would never make it out here.

Still with all her fears, she finally thought maybe it was time to move into the community with assistance from Liberty Resources, Inc.

Bev stopped coming to Liberty so I went by to visit her and she said she was having really bad headaches. The staff claimed she was just trying to get attention.

Bev died of a blood clot in her brain. I could tell countless stories about people who have not made it out of the nursing home to freedom in the community.

Instead, Bev to me represents the many people who have had their lives stolen. She was my first friend in a nursing home and she is the one who started my commitment to changing the system so that disabled people could all live in the community and have control and choice over their lives.

I have been a warrior in ADAPT for many years now and I think it is terrible that in a country like America, disabled people are still sentenced to nursing homes for life.

You politicians know better. There has been enough research and cost findings. It is time to implement the system changes needed to stop this inhumane treatment to countless numbers of disabled people.

How can you sleep at night when you know this is wrong? Disabled people who have lived in nursing homes have told their stories to you. Pass "MiCASSA" now, along with "Money Follows the Person".

Prove that you value every American. Stop the talk and take action to end this shameful violation of our civil rights.

TESTIMONY TO THE SENATE FINANCE COMMITTEE APRIL 7, 2004 HEARING ON ENDING THE INSTITUTIONAL BIAS IN LONG TERM SERVICES AND SUPPORTS

SUBMITTED IN WRITING
BY THE
INSTITUTE FOR DISABILITY ACCESS (IDA)

Thank you for the opportunity for to submit written testimony on the issue of ending the institutional bias in long-term service and support programs.

The Institute for Disability Access (IDA) is a national, not for profit organization that does research, education and training on issues that affect the rights and services of people with disabilities throughout the United States. IDA was established in 1992 and is based in Austin, Texas.

Outline of Testimony

I. Statement of Issues
II. Data
III. Legislative Solutions
    A. Short Term
    B. Long Term
IV. Administrative Remedies
V. Issue Areas
    A. Most Integrated Setting
    B. Consumer Direction
    C. Nurse/Physician Delegation/Assignment
    D. Worker/Personnel Issues

STATEMENT OF ISSUES

The number of people with mental and/or physical disabilities and older Americans needing ongoing support services is growing at a rapid rate. The aging of the American population is well documented. The baby boomers are moving into old age. With age comes the higher chance of acquiring some type of physical and/or mental disability. What is not as obvious and is not as well documented is the growing number of children and young adults who also need similar ongoing support services. These numbers are growing due to the advancements in medical technology, rehabilitation techniques and new life saving drugs.
The overwhelming numbers of people with disabilities, old and young, want long-term service and support services in their own homes and communities. The crux of the problem is that these support services currently are provided:

- **Mostly in institutionalized setting,**
- **In an overly medical way that is frequently unnecessary and costly,**
- **Only when people "spend down" to poverty and get on Medicaid.**

The current long term service and support system was originally developed in 1965 when the Medicare and Medicaid programs were created. These funding streams were originally designed and continue to have an institutional bias

that favors nursing homes and other institutions over home and community services.
Medicare funds mostly acute care services but not ongoing support services after the acute episode. Medicare Home Health, though community based, was conceived as short-term assistance after a hospital stay but was never designed to provide ongoing long term services and supports for chronic conditions.
Medicaid, the state run federally matched program for low-income people, created an entitlement to nursing home services that states had to provide to all eligible low-income people if the state was to receive any Medicaid funds. Home and community services were then, and remain now, optional services that states may choose to provide. This has resulted in Medicaid becoming the largest funder of institutional long-term service and support programs.

The states are experiencing dramatic budget crises and Medicaid services are a large part of the issue. Because of this institutional bias, States are forced to make dramatic cuts in community services.

People with disabilities, older Americans families, providers, bureaucrats, professionals and politicians all dislike the current system. Reform has defied a political solution. Everyone knows most people want home and community services to be the first priority; however, Congress has not acted to make the public's desire a reality.

DATA

Below are two charts that tell part of the story about the institutional funding bias and the folks in nursing homes today who have expressed an interest in returning to the community.

62% of our long-term care funding comes from public funding. Over $82 billion (1/3rd of all Medicaid funding) is spent on long-term care programs. 70% of this ($57.4 billion) is spent on institutional services, leaving only 30% ($24.7 billion) for ALL home and community services. (See Chart 1)

Chart 2 tells the story that almost 19% of those in nursing homes today want out. This statistic, in all likelihood, is actually low because the question is asked – and data collected -- by a nursing home staff person. But even with these conservative numbers, over 250,000 residents of nursing homes currently want to return home with community services rather than stay in the nursing home. This is a strong argument against the institutional bias and for a money follows the individual program, and for a Real Choice/Community First national policy!

P.4, Senate Finance Committee, IDA Testimony: Ending the Institutional Bias, Money Follows the Person, MiCASSA and more…

CHART 1

MEDICAID LONG TERM CARE DATA – 2002

(September 2001 through September 2002)

Total Medicaid	***$243.50 billion***	
Total Long Term Care	***82.13 billion***	
	LTC - 33.7% of Medicaid	
##########		
Nursing Homes	***$ 46.53 billion***	
ICF-MR (public)	***6.47 billion***	
ICF-MR (private)	***4.41 billion***	
Total Institutional	***57.41 billion***	***70%***
Personal Care	***$ 5.55 billion***	
HCBS Waivers	***16.41 billion***	
Home Health	***2.76 billion***	
Total Community	***$ 24.72 billion***	***30%***

##########

HCBS WAIVER BREAKDOWN 2002 BY CATEGORY

Total HCBS Waivers	***$ 16.31 billion (adjusted figures)***	***approximate***
MR/DD	***$ 12.03 billion***	***73.8%***
Aged/Disabled	***3.08 billion***	***18.9%***
Physical Disability	***395.25 million***	***2.4%***
Aged	***515.83 million***	***3.2%***
Tech Dependent	***88.82 million***	***.5%***
Brain Injury	***104.73 million***	***.6%***
AIDS/ARC	***66.17 million***	***.4%***
Mental Illness	***32.36 million***	***.2%***

Numbers are taken from a report by MEDSTAT (www.medstat.com) The MEDSTAT Group Inc. – (617)492-9300

MEDSTAT data taken from CMS 64 reports submitted by the states

CHART 2

CMS's December 31, 2003 Minimum Data Set (MDS) Numbers for Question Q1a

Question Q1a - Discharge Potential and Overall Status
Resident Expresses/Indicates Preference to Return to the Community

The way to use the chart below:

Take the State Total number and multiply by the percent that answered Yes -
This will get you the number of people in nursing homes in your state that want to get out of nursing homes and return to the community.

Example:

State: Texas
State Total: 88,072
Percent that answered Yes: 15.5%
Want to Return to the Community: 13,651 people (88,072 X 15.5%)

The number of people who answer yes on the MDS can be the priority population for your State's Olmstead efforts.

The ADAPT Community
www.adapt.org

http://www.cms.hhs.gov/states/mdsreports/res3.asp?var=Q1a&date=5

Centers for Medicare & Medicaid Services
MDS Active Resident Information Report: December 31, 2003
Q1a: Discharge Potential and Overall Status
Resident Expresses/Indicates Preference to Return to the Community

To view a description of the report table contents, click here.

State	No	Yes	State Total
Alabama	85.9%	14.1%	22,991
Alaska	74.1%	25.9%	607
Arizona	74.6%	25.4%	12,342
Arkansas	84.3%	15.7%	17,937
California	78.2%	21.8%	103,291
Colorado	79.0%	21.0%	15,806
Connecticut	80.4%	19.6%	27,352
Delaware	79.4%	20.6%	3,821
District of Columbia	82.9%	17.1%	2,747
Florida	76.6%	23.4%	69,943
Georgia	86.0%	14.0%	35,327
Hawaii	85.4%	14.6%	3,682
Idaho	75.0%	25.0%	4,570
Illinois	80.6%	19.4%	77,228
Indiana	82.7%	17.3%	39,659
Iowa	82.8%	17.2%	26,835
Kansas	83.4%	16.6%	20,381
Kentucky	83.2%	16.8%	22,088
Louisiana	89.5%	10.5%	28,087
Maine	79.1%	20.9%	6,698
Maryland	77.9%	22.1%	24,664
Massachusetts	82.1%	17.9%	44,393
Michigan	76.9%	23.1%	41,062
Minnesota	80.8%	19.2%	34,515
Mississippi	90.0%	10.0%	15,598

Missouri	80.1%	19.9%	37,301
Montana	78.6%	21.4%	5,565
Nebraska	81.4%	18.6%	13,057
Nevada	78.0%	22.0%	4,091
New Hampshire	84.2%	15.8%	6,957
New Jersey	80.9%	19.1%	43,190
New Mexico	77.3%	22.7%	6,265
New York	81.8%	18.2%	111,244
North Carolina	82.1%	17.9%	37,451
North Dakota	85.7%	14.3%	6,028
Ohio	78.3%	21.7%	76,541
Oklahoma	84.4%	15.6%	20,684
Oregon	73.3%	26.7%	8,165
Pennsylvania	83.6%	16.4%	77,846
Puerto Rico	44.4%	55.6%	169
Rhode Island	83.2%	16.8%	8,345
South Carolina	83.2%	16.8%	15,981
South Dakota	84.9%	15.1%	6,652
Tennessee	81.0%	19.0%	32,697
Texas	84.5%	15.5%	88,072
U.S. Virgin Islands	70.0%	*	30
Utah	70.0%	30.0%	5,187
Vermont	79.3%	20.7%	3,208
Virginia	78.9%	21.1%	27,444
Washington	74.7%	25.3%	19,410
West Virginia	78.6%	21.4%	10,129
Wisconsin	80.1%	19.9%	35,134
Wyoming	78.0%	22.0%	2,415
NATIONAL TOTAL	81.1%	18.9%	1,410,882

LEGISLATIVE SOLUTONS

Short Term Solutions

The Administration has proposed draft language for a bill known as the "New Freedom Initiative Medicaid Demonstration Act". This includes a section on Money Follows the Individual: in this concept, any individual who chooses to leave the nursing home or other institution could have the funds being spent on their institutional services moved to cover the cost of their services in the community. Senator Harkin has introduced S. 1394 which is a stand alone Money Follows the Individual bill. IDA strongly supports Money Following the Person and demonstration programs to encourage states to follow such a policy. IDA believes one or both of these bills must be passed this session.

Another action Congress can take, as an incentive for states to choose home and community services, would be to increase the FMAP by 5%-10% when a state chooses home and community services. This would leave the nursing home entitlement as is, but give states an economic incentive to choose home and community services.

Long Term Solutions

MiCASSA, the Medicaid Community Attendant Services and Supports Act, S 971, would allow real choice, money follow the person and enhance consumer direction. Simply, if you are eligible for a nursing home or ICF-MR facility you can choose instead to have a community service titled "Community Attendant Services and Supports". You could select to have this service delivered through the traditional agency model, fiscal intermediary, or voucher system. MiCASSA would assure that no one goes into a nursing home or other institution because of lack of options, and it would assure greater consumer control of services. It assures REAL CHOICE.

The bigger fix would be to reform the entire system and separate out health care funding from long term services and supports. This requires developing a social model of long term services and supports that is coordinated but not linked to the acute/health system . This reform would include in one system those with physical and/or mental disabilities, older Americans and children with disabilities with low/middle/high incomes who need Activities of Daily Living (ADL) and/or Independent Activities of Daily Living (IADL) assistance, as well as cognitive supports.

This bigger fix would require developing a "Long Term Services and Supports, LTSS, Fund" that would include the current dollars in the

Medicare/Medicaid used for long term services and supports, as well as a new funding source to meet the growing needs of the US population.

IDA is opposed to any block grant proposals that would arbitrarily cap dollars and force reduction in services and numbers of people on programs.

ADMINISTRATIVE REMEDIES

The Center for Medicaid and Medicare Services, CMS, could do many things to end the institutional bias through changes in rules and policies to enhances community services. These include:

- Put consumer direction in ALL community programs
- Relax any requirements for the person to be homebound or unnecessary medical requirements
- Ease restrictions on how states can use Minimum Data Set, MDS, data
- Add a requirement that federally authorized entities such as Centers for Independent Living and Area Agencies on Aging be involved when a nursing home resident in chooses to live in the community.
- Require a "most integrated setting" question as part of the process of getting into a nursing home or other institution
- Create incentives for discharge planners at hospitals and rehabilitation facilities to promote community placements.

Congress should work with CMS to encourage administrative fixes.

ISSUE AREAS

A. Most Integrated Setting/Olmstead

States still have not adequately complied with the Supreme Court's 1996 Olmstead decision which said that unnecessary institutionalization of people with disabilities is discrimination. Congress should put language in the US Dept. of Health and Human Services, HHS, budget bill directing HHS to monitor and ensure states are getting and keeping folks out of nursing homes and other institutions. Dept of Justice and HHS/Office of Civil Rights, OCR, should be directed to assure no civil rights abuses are taking place by folks not getting/staying out of nursing homes and other institutions.

B. Consumer Direction

A consumer directed philosophy should permeate any and all Congressional legislation. This is not an agency - consumer directed dichotomy; in other words agency provided services can be consumer directed as well as voucher

type services. We would be happy to provide more information on this if asked.

ADAPT Definition of Consumer Direction

As it relates to program design for attendant services, consumer direction means the right of the consumer to select, manage and dismiss an attendant.

The consumer has this right regardless of who serves as the employer of record, and whether or not that individual needs assistance directing his or her services.

This includes but not limited to delivery systems that use:

Vouchers
Direct cash
Fiscal intermediaries
Agencies that allow choice (Agencies with Choice)
Concept included in MiCASSA S. 971 and HR. 2032)

C. Nurse/Physician Delegation/Assignment

One of the most costly aspects of community programs is the over medicalization of services. IDA is for quality of services, but we know quality can be accomplished without unnecessary medical involvement. Delegation/ Assignment of tasks is working in states across the country. Though Congress may not be able to address the issue directly, you could make recommendations and develop incentives for states to work with advocates to provide "quality services" without unnecessary medical intrusion.

D. Worker/Personnel Issues

The shortage of well paid home care workers is reaching epidemic proportions. Some of it is the low wages and no benefits of the occupation. Congress needs to develop incentives to bring together consumers, family members, providers, attendants, administrators and union representatives to develop recommendations on how to enhance the pool of workers available to do home care services.

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April 8, 2004

Senate Committee on Finance
Attention: Editorial and Document Section
Rm SD-203
Dirksen Senate Office Bldg
Washington DC 20510-6200

RE: "Money Follows the Person"
Hearing of April 7, 2004

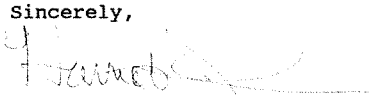
Dear Senator Grassley and Honorable members:

Please accept this letter as my brief testimony in support of S. 971 (MiCassa) and S. 1394 (Money Follows the Person). For a detailed exposition of my reasoning and personal connection, I enclose a copy of "The Disability Gulag," an article I wrote for The New York Times Magazine, published on November 23, 2003.

I am thrilled that your Committee took the important step of holding hearings on this issue. I am also thrilled that so many people with disabilities, families, and supporters appeared in person to speak for me. I would have loved to have been there too and appreciate this opportunity to express my support.

I urge you to give this legislation a favorable report and to work for its passage this session.

Sincerely,



Harriet McBryde Johnson

Enclosure (as stated)

CC (w/enc):

Senator Ernest F Hollings
Senator Lindsay Graham
The Hon Henry Brown
The Hon James Clyburn
Senator Tom Harkin



As the author fiercely resists the world of state-sponsored institutionalization, she argues that for herself and others with severe disabilities, having needs shouldn't mean losing all freedom.

The Disability Gulag

By Harriet McBryde Johnson

"My father died when I was 2, and I lost my mother when I was 5." Throughout my childhood, that's what Grandmother says. She's a fine storyteller with rare gifts for gross delicacy and folksy pomposity, but she doesn't give the details, and we don't ask. To me, it's enough knowing that she's an orphan, like Heidi — like Tarzan even! What else is worth knowing?

Eventually our cousins tell us. When Grandmother was 5, her mother didn't die. She was placed in an asylum. There she lived until Grandmother was in her 20's. There she died.

The news seems to answer some questions about Grandmother. Why does an independent thinker set such store on conventional behavior? Why did she marry a ridiculously steady Presbyterian?

I think it's fear. Fear that one day something will go wrong and she, too, will be taken from her family, snatched from the place she has made in the world, robbed of her carefully constructed self and locked up for life.

I know that fear. I share it.

Grandmother lost her mother in the early 1900's to what was considered progressive policy. To protect society from the insane, feebleminded and physically defective, states invested enormous public capital in institutions, often scattered in remote areas. Into



Institutionalized because of their disabilities:
a fate the author has managed to keep at bay . . . so far.
Photograph by Eugene Richards

this state-created disability gulag people disappeared, one by one.

Today, more than 1.7 million mothers and fathers, daughters and sons, are lost in America's disability gulag. Today's gulag characterizes isolation and control as care and protection, and the disappearances are often called voluntary placements. However, you don't vanish because that's what you want or need. You vanish because that's what the state offers. You make your choice from an array of one.

But now the gulag faces a challenge from people who know the fear firsthand.

It's 1978. Just out of college, I'm working for a local disability rights organization. I'm riding, and also in my small way powering, a new wave, a shift from care and protection to rights and equality for people with disabilities. Part of my job is to give technical assistance on the new Section 504 regulations, which ban disability discrimination where the federal dollar goes. This gig has me squirmy. I'm consulting with Coastal Center, a state institution housing people with developmental disabilities — primarily cognitive impairments and some severe physical disabilities — about 20 miles from my home in Charleston, S.C.

My paycheck won't support a lift-equipped van, so I go by car. I am transferred to my portable wheelchair and rolled into a room full of functionaries. How to establish an authoritative presence? I'm young and small and disabled and female. I seem to get away with the female part, but the rest is tough.

Still, once I get going I start to think I can talk circles around the very best functionaries. In no time, it's almost noon. We're breaking up.

The moment has come. "I have some old school friends in Cottage D-4," I say. "Could I possibly have lunch with them?"

There's some surprised hemming and hawing, but, yes, certainly, if I like. An administrative assistant is tasked to push me there.

The "cottage" is a big rectangle in cement blocks and brick veneer. One side houses boys — adult "boys" — and the other is for "girls."

My pusher leaves me in the central day room, parked against a wall. It seems both chaotic and lifeless. High on a wall, a TV blares, watched by no one. Ambulatory residents move across the floor with no apparent purpose. Along the walls, wheelchair people are lined up, obviously stuck where they're placed — where we're placed, I should say, because I, too, am parked against a wall, unable to move — like knickknacks on a shelf.

Six of these knickknacks are my old friends. Their eyes are happy to see me. Their bodies are beyond happy: wild, out of control. Cerebral palsy does that. I make myself grin.

My pal Thomas is a cool customer. He looks straight at me, then cuts a rueful look at the others spazzing out. I can't hear his soft voice over all the racket, but I know he's offering formal words of welcome.

Then we're moved en masse. Plates are put in front of us, with measured food in bite-size pieces. I'd like butter and salt, water instead of milk, but this isn't a restaurant. Thomas is parked beside me, and we chat about old times at our special crip school. We talk politics, as we did as kids.

Some staff members sit and feed residents. Others come and go. They talk loudly to one another, and we tune them out. Then a woman's voice penetrates my skull, reaches my brain. "Is this the new girl from Whitten Center?"

I'm aware that the state's oldest institution is trying to reduce crowding. I look around for the new girl from Whitten Center.

She asks again, "Is this the new girl from Whitten Center?"

I realize that she means me.

I know it's irrational, but I want to scream. I can't, because they don't like screaming here, and in this panic I don't know what to do if I can't scream.

My friends, amused, grimace and writhe. Please don't start laughing, I want to say. Don't go all spazzy!

"Is this the new girl from Whitten Center?"

Thomas answers. "She's our friend. She's from outside." He has come to my defense!

The loudmouthed staff members don't hear. "Who is this girl?"

"She's from outside."

"Did you say from outside?"

Thomas coughs. "Look at her hair."

The aide studies the shiny braid that falls to my knees. She remarks on my pretty dress and my real gold bangle bracelet. Obviously from outside. Speaking to me now, she asks simple questions. I manage to explain how I know these people, where I live, what I do. The staff members are amazed that someone with such high care needs went to college, has a job, lives outside. All agree that I'm high-functioning, mentally.

Time to go home, but first I have to use the bathroom. Why did I sip that coffee in the conference room? Oh, well. At least this place has beds and bedpans and aides who handle them regularly. I ask for help.

Aides scurry about to improvise a screen. "I'm sorry there's no privacy; we're just not set up for visitors to use bedpans."

What about residents? Is privacy only for visitors with gold bracelets?

I can't ask; I'm begging a favor. In front of my friends, I can't demand special treatment. If they routinely show their nakedness and what falls into their bedpans, then I will, too. Despite my degree and job and long hair, I'm still one of them. I'm a crip. A bedpan crip. And for a bedpan crip in this place, private urination is not something we have a right to expect. I say it's O.K.

It's a two-person job the way they do it. My way is quicker and easier, but they get their instructions from their bosses, not from the people they help. They try to hide me with sheets.

That evening, I tell my family the funny story about how I was mistaken for the new girl from Whitten Center and how Thomas and my long hair saved me from life in prison. I don't tell them it wasn't funny when it happened. I don't tell how the fear felt.

IT COMES FROM a different experience, but I'm convinced that my fear is the same fear Grandmother knew. Because of a neuromuscular disease, I have never walked, dressed, bathed or done much of anything on my own. Therefore, I am categorized as needing special treatment and care.

To Grandmother, that meant extra concern, special pleasure when things went well, tangible help at times. Most summers, she kept me at her house for a week or so with my cousin Mary Neil. The widow of a prosperous small-town pharmacy owner, Grandmother let us roam the town with whichever teenager she had hired to help. Anyone could do the job, because I explained everything step by step; Mary Neil learned the drill, too. Free of hands-on duties, Grandmother entertained herself and us with her inexhaustible store of memorized poetry, quoted inappropriately. Squeezing into an old-fashioned girdle, she would say, "What strange Providence hath shaped our ends?" or "Oh, that this too too solid flesh would melt." Coping with my special needs wasn't all that onerous.

To the larger world, my needs had serious implications. I couldn't go to school or to camp with my brothers and sister. I was exiled to "special" places. As my peer group entered adolescence, the gulag swallowed about half of my classmates. Four went in 1969. They "graduated" into an institution after a ceremony with caps and gowns and tears. Others, including Thomas, just didn't come back after summer vacation. My friends' parents, asking the state for help, were persuaded to place them where they would get the specialized care they supposedly needed.

In fact, until they disappeared, my friends got their care from people with no formal training. The main difference between them and me was economic. My family could afford hired help. Thus insulated, they didn't go to the state, and the state didn't tell them it puts people like me away.

Hariett McBryde Johnson last wrote for the magazine about her exchanges with Peter Singer.

The gulag swallows
your money, separates you from your friends, makes you fearful, robs you of your capacity to say – or even know – what you want.

I knew my family wasn't like F.D.R.'s or Helen Keller's; they didn't have the means to set me up for life. I was more like one of my girlfriends, who had lived with nice parents in a nice house with a nice hired lady to take her to the park to meet me and my lady — until something went wrong and she disappeared into Coastal Center. Whenever my parents scrambled to pay for something unexpected, a part of me saw my freedom hanging in the balance. I learned early that privilege doesn't always last.

The nondisabled world sees powerlessness as the natural product of dependence and dependence as the natural product of our needs. However, for nondisabled people, needs are met routinely without restricting your freedom. In the gulag, you have no power. The gulag swallows your money, separates you from your friends, makes you fearful, robs you of your capacity to say — or even know — what you want.

The day I visited Coastal Center, I was beginning an interesting career and should have felt that the world was all before me. Instead, worries nagged me. What if there isn't enough money? What if family can't take care of me?

Back then, my best hope was to die young. My disability would progress until I needed a ventilator. Then, near the end of my life, I figured, I'd slide into my slot in the gulag.

All it takes to teach me how wrong I have been is about 45 seconds in the company of a man named Ed Roberts. It's 1979. He's speaking in Arlington, Va.

In the small world of disability rights, he is a star with a famous story. He is paralyzed from the neck down as a result of childhood polio. In his youth, he was denied services by California's Department of Rehabilitation for being too disabled to work. A decade and a half later, he became head of the department. In between, he fought his way into the University of California at Berkeley and, with other severely disabled activists, helped set in motion the disability rights movement, which is now challenging the gulag's right to exist. It is pushing for a shift away from public financing for institutionalization and to public financing for personal assistance, controlled by us. The government should pay for the help we need, and it should not force us to give up our freedom as the quid pro quo.

Never was a big star more frail. Physically, his power chair overwhelms him. And there's more. He gets each breath from a machine; his speech follows the rhythms of the ventilator whoosh. With each whoosh, he is changing my worldview.

It's not what he has done. Not what he is saying. Not who he is. It's his presence. Whoosh. His bad-boy delight in truth-telling. Whoosh. His hellcat gusto for proving the world wrong. Whoosh.

He is decrepit and tough and amazingly funny. He is a big state agency head unlike any the world has ever seen.

In less than a minute, Ed shows me that I have been wrong about people with vents, just as the nondisabled world has been wrong about me. Whoosh.

A life like his can turn a life like mine upside down. Whoosh. And lives like ours can turn the world upside down — or maybe set it right side up. Whoosh.

IT'S 1984. I'M living in Columbia, S.C., 100 miles from my family, taking advantage of new possibilities. Until the Section 504 regulations, disability discrimination by universities was routine and unapologetic. Now, at the University of South Carolina law school, I am one of six wheelchair users. Five of us use power chairs; without someone's help, we can't get out of bed. As schoolmates strut in power suits, we whir around with book bags hanging from our push handles and make bottlenecks at the elevators. I think of us as a counterculture that challenges the get-ahead Me Decade. Most people, when they think about us, operate under the delusion that we're inspirations.

Between classes, I catch up with Dave, a classmate who is quadriplegic as a result of spinal cord injury. There's a good movie at the student union tonight. Let's go. O.K., and a burger before. Fine. A plan.

Nearly. First we repair to adjoining pay phones to reschedule our afternoons. Each of us grabs a passing student to dial. Busy signal. Try this number. No answer. Try that first number again. Hey, can you do 4 instead of 5? Then another call. No answer. Try this one.

My student dialer has to run. Another takes his place.

Hey, I'm going out. Can we do 10 instead of 9? Do you know where so-and-so is? Hi. Can you unpack my books at 3?

Between us, it takes about a dozen calls.

"Dave," I say, "this is some crazy way to live, ain't it?"

He gives his diffident C-student shrug. "Yeah. When I was injured, I didn't want to live this way. They said I'd adjust, but I wanted to die. Well, you know, the guy I was then, he got what he wanted. He died. I'm a different guy now."

It's a complicated life, to schedule in advance each bathroom trip, each bath, each bedtime, each laying out of our food and big law books, each getting in and out of our chairs. But it can be done. We're doing it. We can do what we want. No need to get anyone's permission. No need to have it documented in any nursing plan or logged onto any chart. No one can tell us no.

We can meet for a burger and a movie if we want.

EVERY SO OFTEN, there are efforts to try something different for young disabled people. When Dave and I were in law school, the university got one dormitory licensed as a care facility. Medically, I qualified for placement there, and the promise of around-the-clock aides sounded appealing when I had never lived away from home. Financially, I was too rich for Medicaid and way too poor for the self-pay rate. Dave had Medicaid, but his life had already taught him the value of freedom. The students in the on-campus nursing home helped me learn the same lesson. Even with a good staff and decent conditions, they were robbed of basic choices. The staff members were controlled by the facility, not by the students who lived there.

I relied mainly on resources available to any student. Because of Section 504, I had access to student housing, transportation and cafeteria

'I want the legal right to say who comes in my bedroom and who sees me naked – same as you do, Senator!'

service. A small grant from a disability agency, a student loan, work study, summer earnings and a Strom Thurmond Scholarship, of all things, covered the usual costs of law school, plus three and a half hours of help per day from student workers I selected. Sometimes I kicked in a bit extra on the rent to get an especially helpful roommate. It's true that I depended on the kindness of strangers and friends and sometimes wondered how I would hold it together. But always there was some lucky break.

Sometimes the break was a check from Grandmother with a note, "Be prepared a strict account to give." Or, "Squander in riotous living." Either way, she showed that she still rejoiced in my success and also worried about me.

By this time, she also worried about her own place on the edge of the gulag. As age brought disabilities, she got my cousin Mary Neil to move in. Grandmother had enough money to see her through, but not if it had to purchase lots of long-term care. The state's only solution was to make her poor and then foot the big bill for lockup in a nursing home.

The nursing home is the gulag's face for people like Dave, me and Grandmother. That is where the imperatives of Medicaid financing drive us, sometimes facilitated by hospital discharge planners, "continuum of care" contracts or social-service workers whose job is to "protect vulnerable adults." Pushed by other financing mechanisms, people with cognitive disabilities land in "state schools," and the psychiatrically uncured and chronic are Ping-Ponged in and out of hospitals or mired in board-and-care homes. For all these groups, the disability rights critique identified a common structure that needlessly steals away liberty as the price of care.

In 1984, the general thinking couldn't go beyond nicer, smaller, "homier" institutions. With my experience as a high-maintenance, low-budget crip surviving outside the gulag, I offered myself in local meetings, hearings and informal discussions as an independent living poster girl. I explained that certain states, like New York, Massachusetts, Colorado and California, offer in-home services.

But, people said, South Carolina is a conservative state.

I talked up the need for comprehensive civil rights legislation. Extend Section 504's principles to all levels of government and the private sector.

It'll never happen, people said. The civil rights era has passed.

We got civil rights legislation — the Americans With Disabilities Act — in 1990. It's a fluke, people said. It won't be enforced.

In 1995, the United States Court of Appeals for the Third Circuit ruled that the A.D.A. bans segregation. Needless isolation of people with disabilities in institutions is segregation. That's a liberal circuit, people said. The Supreme Court will reverse.

In 1999, the Supreme Court, in Olmstead v. L.C., affirmed that needless institutional confinement violates the A.D.A. Fine, but it's just words on paper, people said. The financing still drives us into institutions.

That's very true. But the movement has been treating Olmstead rights as if they're real, using the court's legitimacy to demand a wide variety of programs, like in-home care, on-call and backup help, phone monitoring, noninstitutional housing options, independent-living-skills training and assistive technology. We're also going after red tape, legal restrictions and the mind-set that says that if you need help, you need professional supervision.

It's the spring of 2002. I'm testifying before a subcommittee of the South Carolina State Senate. Beside me is my friend Kermit.

Kermit calls me his big sister in disability. In fact, he's downright massive and a generation older than I am, but I'm his senior because he became a quad two years after I was born into disability.

The black battery box on his chair sports two stickers. The shocking pink one is from Mouth, a radical disability magazine. It says, "Too sexy for a nursing home." "It's true, you know," Kermit often explains. "I did seven years inside. In so long, I felt weird when someone took me out, like I didn't belong. But I was too sexy to stay. I took up with one of the aides and married my way to freedom." That marriage ended years ago, and Kermit no longer has family help, but he will never go back. His other sticker, plain white, says, "Yes 977." He had them printed today. They're about the bill we're here for.

Senate Bill 977 would amend state law to exclude "self-directed attendant services" from the legal definition of nursing. Current law presumes that all hands-on physical care, for pay, is the practice of nursing and must be provided by or supervised by licensed personnel. The nursing profession has jurisdiction over our bodies and decides when to delegate authority. Those who handle us are supposed to get their instructions from a written nursing plan, not from us.

The law hasn't been enforced against self-pay crips like Kermit and me, but federal law requires Medicaid and Medicare to abide by the state nursing law. That means that their beneficiaries must accept whatever comes from a licensed agency. Agencies typically can't cover Christmas morning, late nights out or many bathroom trips spread out over the day. Because the easiest place to get nursing is in a nursing facility, this law becomes another path into the gulag.

Kermit and I know what works. Through informal networks, we find people to do what we need. Because we are the ones doing the delegating, we are free. Kermit used his freedom for a civil service career; today he uses $20,000 per year of his retirement savings to pay for that freedom, about half of South Carolina's Medicaid nursing home rate. With family backup, I get by with the irregular income of a solo law practice, stashing money in good years to cover bad ones. Our bill would legalize the way we live. It would also remove a legal barrier so that we can agitate for South Carolina Medicaid to finance self-directed services and make real choices possible.

The subcommittee is bothered about safety. The administrator for the Board of Nursing argues that complications like pressure sores and infections can be fatal. Nursing supervision is needed, she says, to recognize the danger signs.

I wish Kermit were testifying. He has been self-directing very complicated stuff, and he endures, more than 40 years after his accident. He also has a great physical persona. His stillness communicates rock-solid strength. His whiteness — a result of avoiding Columbia's killing sun — is not so much pale as gleaming. But he doesn't like public speaking. He is happiest finding people in nursing homes with dreams of freedom, helping them make the break. It's underground railroad work, and I'm ashamed to say it's not for me. I

still panic when I go into those places. Let me talk to the functionaries.

So I explain our reality to the senators. We learn to recognize our danger signs. We care about our own safety. We can decide when to consult a professional, as nondisabled people do.

And, incidentally — bad things have been known to happen even when a nursing plan is in place.

Inevitably, the senators look for a middle ground. What if we allow self-direction for "routine" procedures like bathing and dressing, but retain nursing control over "nonroutine" procedures like vent care and catheters?

Kermit's craggy face falls. They're talking about fixing the law for me, but not for him — or for Ed Roberts, who lived on a ventilator, or future me.

I have been advised to sidestep the gory stuff, but here we go. "Senator, if you need a urinary catheter inserted every time you need to go, say three to six times per day, that becomes a routine procedure — for you."

I sit so low, I can see, under their table, all of the senators crossing their legs. I have their attention.

They question me about procedures involving tubes, needles, rubber-gloved fingers, orifices natural and man-made. I won't flinch. Never mind that Grandmother would consider all of this indelicate. "We know how to do them. And all these procedures are commonly done by unpaid family members. That's entirely legal, and the nurses don't mind. The nursing law isn't about safety and professional qualifications. It's about who can get paid."

One senator is a fundamentalist-Christian Republican, the kind who says that the anti-sodomy laws should be strengthened and enforced. "Ms. Johnson, you've explained why this bill won't put people at greater risk, but I don't understand why you care enough to travel from Charleston to push for it.

"Two reasons, Senator. One is, changing the law will free up resources to meet needs that aren't being met now. With this change, we can push third-party payers like Medicaid to fund more options, make the money go further. Home care in the aggregate costs less than locking people up.

"The other is simpler. I want the legal right to say who comes in my bedroom and who sees me naked — same as you do, Senator!"

Redness rises from the senator's tie and washes up his face. Once we have him blushing, the others fall in line. The favorable vote is unanimous.

We roll outside. My teal minivan is parked near Kermit's "Freedom Van" — a white vehicle with controls he can operate with his limp fingers in metal splints.

Kermit stops. "You done good, girlie."

No one but Kermit gets to call me girlie. I sometimes call him Mount Rushmore.

OUR BILL BECAME law on July 1, 2002, in time for Independence Day. Self-pay people won the right to control our bodies, but getting public financiers to allow the same flexibility is a continuing struggle.

Ultimately, saving ourselves from the gulag will take more than redefinition. It also takes money for in-home services. But in a sense, we're spending the money now — $20,000 to $100,000 per person per year, depending on the state — for institutional lockup, the most expensive and least efficient service alternative.

For decades, our movement has been pushing federal legislation, currently known as MiCassa, the Medicaid Community Assistance Services and Supports Act, to correct the institutional bias in public financing, especially Medicaid, the gulag's big engine. We ask, Why does Medicaid law require every state to finance the gulag but make in-home services optional? Why must states ask Washington for a special "waiver" for comprehensive in-home services? Why not make lockup the exception? "Our homes, not nursing homes." It's a powerful rallying cry within the movement. In the larger world, it's mostly unheard, poorly understood. We are still conceptualized as bundles of needs occupying institutional beds, a drain upon society.

We know better. Integrated into communities, we ride the city bus or our own cars instead of medical transportation. We enjoy friends instead of recreational therapy. We get our food from supermarkets instead of dietitians. We go to work instead of to day programs. Our needs become less "special" and more like the ordinary needs that are routinely met in society. In freedom, we can do our bit to meet the needs of others. We might prove too valuable to be put away.

While the movement has been collectively trying to change the world, individuals continue to live and die.

My law-school friend Dave fell into the gulag in the end. A series of events — a career setback, some acute medical problems, perhaps creeping disappointment — made him sign into a nursing home. He vanished without telling his friends he was going and died within the year. My little brother Kermit remains free and is using his freedom well.

Ed Roberts died in 1995, free, keyed up about digital organizing among other things. For one, he was planning to get back to Hawaii to swim with whales: a shark sighting had thwarted his previous attempt. He did manage to float with dolphins in Florida. His respirator fell into the ocean, but he always traveled with two.

Most of my friends from Coastal Center are now placed in small group homes. Although they have bedrooms with doors they can close, they work in "special" programs, and they still can't select their own assistants or decide where they live or with whom. After more than 30 years in the system, they probably can't imagine living any other way, but in a way they never had a choice. "Placed" remains the operative word.

Thomas lives in his own apartment and works as a courier in a hospital. Through a waiver program, South Carolina Medicaid pays an agency to get him in and out of bed each day. To cover frequent no-shows, he paid an on-call aide out of pocket for a while, but he couldn't afford to continue. He would like to use Medicaid funds to pay his own people, but state rules haven't yet been changed to allow that. He has taken advantage of programs that have slowly evolved and says he hopes to stay free long enough to have genuine control of his life.

Grandmother died in 1985 and avoided the gulag, thanks to Mary Neil. She inherited the house and lives with her family in the rural community where our family would otherwise be extinct.

When Grandmother died, I thought she might leave me some money — for riotous living or a strict account to give. She didn't, but I wasn't disappointed. She left me the silver spoons that belonged to her mother. Sometimes I wonder if my great-grandmother missed her spoons when she was locked up. More often I wonder how Grandmother felt when she held her lost mother's spoons and turned them over in her mouth and let her tongue mold itself to their shape.

I use those spoons daily. Their flat handles are easy to grasp. Their deep bowls hold as much yogurt as I can swallow. For me, that smooth silver represents the treasure of living free. Riding in the van I bought, in a hand-me-down power chair I got from Kermit, I hold my freedom precious. I can no longer braid my own hair, but I remain free to keep it long, and I do. My gold bracelet was mangled in a fall a while back, but I still wear it for good luck. I still need all the luck I can get.

I have prospered and know a world I once could not imagine. I sometimes dare to dream that the gulag will be gone in a generation or two. But meanwhile, the lost languish in the gulag. Those who die there are replaced by new arrivals. Powerful interests, both capital and labor, profit from our confinement and fight to keep things as they are. At this writing, MiCassa is stalled in committee. Again. Institutional financing remains nondiscretionary under Medicaid.

It is still possible — indeed, probable — that before I die I will become separated from my silver spoons and my gold bracelet and I'll have to get my hair cut for the convenience of the people who staff whatever facility I am placed in.

Even now, I live on the edge of the disability gulag. ■

TESTIMC NY FOR SENATE FINANCE COMMITTEE FOR 4-7-04 HEARING ON INSTITUTIONAL BIAS IN I 0ONG-TERM CARE, S 971(MiCASSA) and S 1394 (MONEY FOLLOWS THE PERSON)

My name i s Sharon Joseph. I am 53 and have had multiple sclerosis (a debilitating nerve/brain disorder) since 1973 My doctor told me 31 years ago I was 21 then), that when I could no longer care for myself, I would hav : to go to a nursing home. Even then, I knew nursing (old age) homes were not an option to my idea of "liv ing" during any part of my life!

Currently, nstitutional care is an entitlement. Home & Community-Based Services are not. Choice is what it's a l about! HCBS needs to be an entitlement as well.

With some one to assist me with activities of daily living (ADLs), I can remain in my own home, be a contributir g part of the community, pay taxes, interact with my friends and neighbors and live freely with the opport nities of life, liberty and the pursuit of happiness!

This institu tional bias in our great country's long-term care must be balanced with a-living-independently option. It s more humane and dignified, a definitively more cost-effective alternative to being locked away for no mec ical reason, but just because I may no longer be able to bathe myself, drive or walk. Personally and for ma ıy of my friends, family and fellow Americans:

I'D RA1 HER BE DEAD THAN TO GO TO A NURSING HOME

PASS MiC ASSA (S 971) NOW!! End the bias and inequities in long-term health issues!

Thank you for your time,

Sharon R Joseph
2041 SW Westwood Drive
Topeka, K 3 66604-3272
785-233-4 372 Work
ksadaptsj@ cox.net

April 7, 2C 04

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Name: Stephanie Kapitanovich

Address: 6850 W. Oxford Street, G103
City: Philadelphia State: PA
Zip: 19151



Age: 47 Phone: 215-878-7463

Type of institution:

Nursing Home X
State Institution/Developmental Disability
State Mental Hospital
Rehabilitation Facility
How long institutionalized? 18 years

Please attach a short summary of your time in the nursing home or other institution and how your life has changed now that you are out.

They took away my freedom of speech. I had to sign in and out all the time. My family only visited every other weekend when I was a kid. I had to go to bed when they said and get up when they said. No choice of what to eat except for one day a week. A time to go out and a time to be back. I felt like I was in jail.

ADAPT—FREE OUR PEOPLE!

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

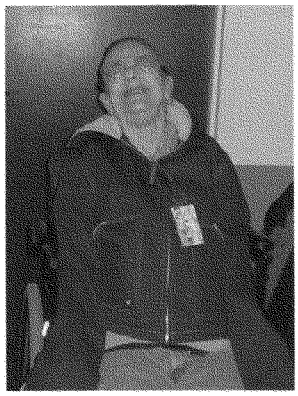
SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Name: Joanne Kenworthy

Address: 3002 Mario Lanza Blvd.

City: Philadelphia State: PA Zip: 19153

Age: 64 Phone: 215-863-0675



Type of institution:

Nursing Home X
State Institution/Developmental Disability
State Mental Hospital
Group Home
Rehabilitation Facility

How long institutionalized? 14 years

Please attach a short summary of your time in the nursing home or other institution and how your life has changed now that you are out.

My independence was stolen from me and I had to live by their rules. They took all of my money and only gave me $30. a month and you had to buy clothes with this money. The people that take care of you call you every name in the book and you can't prove that they did. You don't get any respect and you are nothing but a vegetable.

ADAPT—FREE OUR PEOPLE!

Jaclyn Michelle Kratzer
Ms. Wheelchair PA 2003
306 Bordic Road
Reading, PA 19606
610-914-1491

Money Follows the Person
April 7, 2004

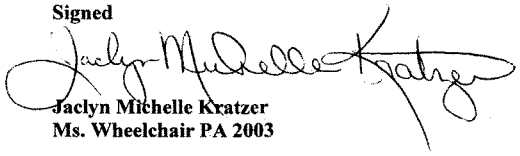
I was born in 1973 when mainstreaming a child was new and services for people were just beginning. However, it was still socially acceptable for parents to "place" their "disabled" child into an institution to spare their family disgrace or incovenience. I was lucky. My family decided to "keep" me. That decision did come with a price. I spent many days in tears with an emotionally abusive father threatening to put me a way the first chance he got – especially if my mother would pass. After all, who would blame him? Children and adults who have disabilities are often seen as burdens to their family and to society.

My entire life was spent proving to others that I was capable and competent to live independently. Each day I lived with the knowledge of a lesson my brother taught me when I was four years of age. He said, "We won't live forever to take care of you, so learn to take care of yourself". I have spent 30 years doing just that. It is a struggle for me as it is for the 54 million Americans with disabilities. We need help to be interdependent in this society.

Home health services help keep people with disabilities from being warehoused in institutions. We need these services to continue. Allowing nursing homes the bulk of the money is giving the government permission to victimize their citizens. It sends the message that we are disposable. If you had a disability, would it be ok to throw you away? Would you have thrown President Roosevelt away? Of course not. If we allow more money to go to these institutions that is indeed what will happen.

Let a citizen choose. Choose where they want to live, not be warehoused. Let this money follow them. It is their right! Money Follows the Person and MiCASSA are the laws we need to survive. Without them my father's threat becomes a reality and the hopes and dreams of millions will die when we are locked away and forgotten. You hold the key to freedom. Vote for MiCASSA!

Signed



Jaclyn Michelle Kratzer
Ms. Wheelchair PA 2003

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Name: Herb Larkins

Address: 5031 Race Street, Apt. 206

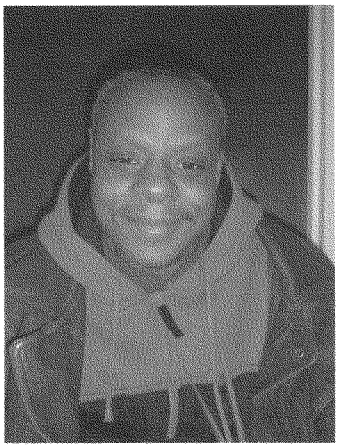
City: Philadelphia State: PA Zip: 19139

Age: 38 Phone: 215-471-3562

Type of institution:

Nursing Home X
State Institution/Developmental Disability
State Mental Hospital
Group Home
Rehabilitation Facility

How long institutionalized? 5 years



Please attach a short summary of your time in the nursing home or other institution and how your life has changed now that you are out.

I was robbed of my freedom to come and go as I pleased. They took away my dreams and independence and what I was capable of doing. I was robbed of my privacy and my ability to have company when I wanted it. They took away my right to speak up for myself and to speak my mind.

ADAPT—FREE OUR PEOPLE!

Statement by Dr. Karen Orloff Kaplan,
President and CEO of Last Acts Partnership
Senate Finance Committee Hearing
April 7, 2004
On
"Strategies to Improve Access to Medicaid Home and Community Based Services"

Mr. Chairman and Members of the Committee:

I am pleased to submit this statement on behalf of *Last Acts Partnership,* a national, not-for-profit organization dedicated to improving care and caring near the end of life. Through our efforts to inform healthcare professionals, advocate policy change, and empower private citizens with information and opportunities for action, we are raising expectations for quality end-of-life care and championing fundamental change in the way that care is delivered.

Among the issues high on the agenda of *Last Acts Partnership* is support for family caregivers. I commend the Committee for focusing your attention on the needs of this vitally important group of people – the more than 25 million family caregivers who play an unsung but indispensable role, providing an annual $257 billion worth of unpaid supportive services for their family members or other loved ones. This amount is comparable to total Medicare spending in 2002 and substantially more than total federal spending for Medicaid in the same year. Without this cadre of loving, dedicated and uncompensated caregivers, the quality of life for chronically ill, disabled and terminally ill individuals would decline dramatically, institutional care would be overwhelmed, and the cost of alternative care- if there were sufficient numbers of paid caregivers available - would be unsustainable.

Last Acts Partnership is dedicated to seeing that all Americans have access to the highest quality care in the last chapter of their lives, and that their families and loved ones have support during the caregiving process all the way through bereavement. For terminally ill patients, having a family member or loved one directly involved in their care is a key factor in the level of satisfaction and peace they find as death approaches. Giving supportive services to family caregivers is critical to maintaining their health, their spirit, and their ability to successfully grieve and go on with their own lives when their caregiving days have ended.

Whether caring for a loved one who is terminally ill or someone with a chronic illness or disability, family caregivers face overwhelming and unrelenting daily stresses: physical, emotional and financial. They are frequently isolated, untrained and at risk for developing their own health problems especially depression, anxiety, insomnia and injuries. Studies have consistently shown that caregivers, primarily women, also jeopardize their financial stability by reducing work hours or leaving jobs, which is often accompanied by loss of health insurance and credits toward Social Security benefits leaving older women with fewer resources to care for themselves.

Respite care is one critically important service that has been shown to improve the lives of family caregivers and their care receivers. These invaluable services allow family caregivers a brief time - from a few hours to a few days - to care for themselves, to refresh and renew their spirits, to sleep, or to spend quality time with a spouse or child. Whether respite

care allows the caregiver to spend a weekend at a wedding celebration, an hour getting a haircut, or even a trip to the grocery store without worrying about leaving their loved one unattended, this occasional relief has many positive benefits. The one being cared for also benefits from respite care because these brief interludes help sustain family stability, avoid out-of-home placements and reduce the likelihood of abuse and neglect.

Unfortunately, respite care services are in short supply for all age groups and income levels. That is why *Last Acts Partnership* and its predecessor organization, *Partnership for Caring*, have supported the Lifespan Respite Care Act since it was introduced in 2002. We strongly believe respite care must be more accessible, affordable, and of the highest quality. I applaud the Senate's passage of this bill and your efforts to expand respite services through the Medicaid Demonstration Act. But demonstrations alone will be insufficient. There are already wonderful programs at the local and state levels, some supported by Medicaid funds, and numerous studies that show the benefits of respite care. What is lacking is sufficient resources to expand services, recruit and train respite care workers and do outreach to consumers.

The legislation before you would provide additional resources to expand respite care services to some Medicaid beneficiaries, which is certainly a welcome step. To reach the goal of making respite care available to all who need it will require many more steps as well, starting with enacting the Lifespan Respite Care Act.

We are all indebted to family caregivers. They are an essential part of our country's health and long-term care systems. Providing respite care services is one way to support them. We urge you to do so.

KUSF 90.3FM

"Disability and Senior News Report"
Sundays, Live: 12:30 p.m.

April 1, 2004

To: U.S. Senate Committee on Finance
Att: Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Building
Washington, D.C. 20510-6200

Hearing Date: April 7, 2004

Topic: MiCASSA (S. 971) and Money Follows the Person (S. 1394)

Comments from:
Maggie Dee-Dowling
426 W. 11th Street
Pittsburg, CA 94565-2424
Tel: 925-427-1219
E-mail: maggiedee@earthlink.net

Thank you for the opportunity to express my views on "Money Follows the Person" to be heard on, April 17, 2004 and put into the Hearing Records.

I am a 63-year old woman with multiple disabilities. I experience freedom each day as I awaken. Prompting my home-care attendant, she and I work in unison to begin a new day.

Cindy Wallace, my personal assistant, was born in Korea, married a service man and has two grown children. Encouraging Cindy, as a friend, she studied in adult school to gain enough knowledge to pass her citizenship tests and became a United States citizen; Cindy voted in her first election this year. We have worked together and been friends since 1990.

As a result of home care, through our state's In-Home Supportive Services, I receive 283 hours of home care. I participate in a second home care program called In-Home Operations. Through that program I receive 165 hours, a total of 448 hours a month. These two programs provide me independence in the community of my choice.

This year I resigned from my volunteer post as executive director of "Share-a-Helping Hand, Inc.", a tiny 501(c)(3). I held this post for 17 years. During this same time period, I was a self-employed newspaper columnist-"stringer" for our local newspaper, writing two weekly columns.

Since 1988, I have been a radio show host of "Disability and Senior News Report", two years ago I began producing and co-hosting the radio show on San Francisco's award winning station KUSF, 90.3 FM heard around the world live and archived on www.station504. In 2003, I was hired by the University of California, School of Behavioral Sciences, as a researcher.

I have worn with pride the mantle of "advocate" for my community. I am a member of ADAPT and stand with my fellow members on the premise that every man, woman and child should be given the same equal rights to live in

the community of their choice without the fear of being institutionalized; or if institutionalized, given the choice to move into the community of their choice with community-based services offering a new found sense of hope and freedom to each deinstitutionalized person regardless of age or ability.

I offer these comments with a deep sense of commitment and hope that today will be the beginning of something so powerful that your Committee and the rest of Congress will look back a decade from now knowing that your Committee's work on "Money Follows the Person" efforts changed not only the lives of those who wish to remain in their homes, but also those who have been languishing in nursing facilities wanting to experience freedom as other Americans.

Each year more services are threatened by state budgets. This year is particularly frightening in California. I, along with many others stand to lose our freedom, some their very lives as a result of the proposed cut backs in the community-based services which keeps our personal assistants in our lives ensuring that freedom.

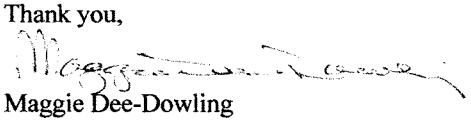
Instead of people being freed from restrictive nursing home settings, many of us currently experiencing freedom face institutionalization: this, in direct disregard of the U.S. Supreme Court decision, "Olmstead vs. L.C," which requires that each person's ability should be individually assessed and offered the least restrictive setting in the community of their choice.

One of my fellow advocates took his own life last month when he studied the State Budget proposed cuts. If the Budget cuts go through as proposed he knew that he could no longer remain "independent". He wrote about a year ago that he would rather be dead than live out his life in a nursing home. He was in his late 40's. So, for some of us, while the choice is still ours, some people will decide as Ron; his last decision. We grieve his loss. For me it made me even more committed to the tasks at hand.

Page 4-4, U.S. Sen. Comm. on Fin., April 7/04, MiCASSA (S. 971) and Money Follows the Person (S. 1394), Comments: M. Dee-Dowling

Freedom is sweet! Freedom is challenging! Freedom is the American way, isn't it? Please continue to support "Money Follows the Person" and know that you are offering millions of people the freedom to choose life over warehousing, the latter being an economic nightmare.

Thank you,



Maggie Dee-Dowling

Lifespan Respite Care

A PROGRAM OF SPOKES UNLIMITED

April 9, 2004

Senate Committee on Finance
Attn. Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Bldg.
Washington, DC 20510-6200

Hearing Date April 7, 2004

This is a letter of support to the Lifespan Respite Care Act.

First as a Mother and Grandmother of children with special needs I can tell you how important it is to have a Respite Program. Everyone is entitled to a break and for the majority of us Respite is that break.

Second as the Coordinator of the Klamath County Lifespan Respite Care Program I urge you to approve the Lifespan Respite Act, it's the most affordable service we can offer our Families to date.

Thanks so much for taking the time to read this letter of support.

Sincerely,

Teresa Selig-Hardt

Teresa Selig-Hardt
Lifespan Respite Care Program
415 Main Street
Klamath Falls, OR 97601

United Way

415 Main Street
Klamath Falls, OR 97601
541-850-5200 (V/TTY)
541-885-2469 (FAX)

Senate Committee on Finance
Attn. Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Bldg.
Washington, DC 20510-6200

"Strategies to Improve Access to Medicaid Home and Community Based Services"

April 7, 2004, at 10:00 a.m. in 215 Dirksen Senate Office Building

My name is John Lorence, Jr. I live in Carmichaels, Pa. I am a person with a disability who is and always have been "nursing home eligible", but I have successfully avoided residency in one of those facilities.

I am 49 years old and have dealt with the functional effects of Muscular Dystrophy all of my life. I have been employed all of my adult life. Ten years ago, I became an employer. Two years ago, I purchased my own home. Ten months ago I married for the first time.

At any time during my 49 years, I could have made a phone call and ordered the government to pay in excess of $50,000 per year to give me a bed in a nursing facility for the rest of my life. There would have been no questions asked!

I have been able to avoid being incarcerated in a nursing facility for having a disability because I have always had a good family network and a good network of friends. But I was never able to consider moving out on my own or consider married life until I received an adequate (but not appropriate) amount of attendant care under Pennsylvania's Attendant Care Program.

Without the fact that Pennsylvania gave partial attention to advocates who made the case that community-based care is cheaper that institution care, I faced the prospect of an aging family, a changing network of friends, and inevitably, inadequate attendant care to live independently. As it stands now, at least in Pennsylvania, I can remain a viable member of my community, an employer to primarily single moms who became my attendants, a tax payer, and a loving husband.

That is, however, not the case nationwide. Without Federal leadership and support and passage of bills like S971 and S1394, people will have to choose states to live in, like Pennsylvania in order to remain free. This will often mean choosing state of residence over family and community. This sounds mysteriously like the underground railroad of the 18th and 19th century.

I was one of the hundreds on the Rayburn Building lawn on June 23, 1997 when HR2020, the original S971, was put into the form in which it was introduced the next day.

FROM :TRIPLE_SERVICES FAX NO. :724-223-5119 Apr. 06 2004 03:40PM P2

That was 7 years ago.

Time is running out. I would like to see the passage of S971 and S1394 in this Congressional session!

John Lorence, Jr.
213 East South Street
Carmichaels, PA 15320
724-966-2233

FROM :TRIPIL_SERVICES FAX NO. :724-223-5119 Apr. 06 2004 03:40PM P3

To: Senate Finance Committee
Attn. Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Building
Washington DC 20410-6200

From: Aileen Martin
36788 NYS Route 12E
Clayton, New York 13624

Date: April 7, 2004

Title: Strategies to Improve Access to Medicaid Home and Community Based Services

Thank you for this opportunity to provide testimony on Money Follows the Individual Demonstration and the component of the New Freedom Initiative known as MiCASSA, the Medicaid Community Attendant Supports and Services Act. This legislation will mean significant improvements in the lives of many people with disabilities. The availability of community attendant services will make it possible for people with significant disabilities to become a part of our community in Jefferson County, New York. I know many people with significant disabilities who are practically trapped in their homes and even more in institutions who are eager to share their gifts with their neighbors but cannot because of the problem accessing attendant services in the community.

It is high time we caught up with the reality of life in America today. There is fantastic potential for the Money Follows the Individual demonstration to really change how attendant services are delivered in our society. I have never understood why a government such as ours, which values our family units as a basis for our society and economy would pay a corporation to take care of our family members who are aging or have disabilities when the same recompense is not offered to their own families to provide these same services. It is awful that our government would provide funding to rip apart families, the very basis of our society and economy with this policy.

When I have had these conversations with elected officials and the directors of the institutions where people with disabilities and seniors are place, they have told me about family members who come to them begging them to take this person off their hands. I know these stories well. I know these people well. These are not cold-hearted, uncaring folk. They are people who have been beaten down by this policy of institutional "care". They are unsupported by our government and our society in their efforts to date. These families have not received financial assistance in their efforts to maintain their families in their home communities.

Instead of thanking these folks for helping to maintain their family, the building blocks of our society, we punish them by forcing them to make the decision to institutionalize their family member. We insult these families by paying total strangers, with no commitment

to the person with the disability other than a paycheck from some institutional corporation to provide food, medicine, bathing and a bed.

I have worked with people with disabilities to help people with disabilities to get out of institutions and resume a life of full and active participation in the community. I have fought with people with disabilities against the investment in new institutional facilities. I have faced down those institutional providers who will bold-facedly tell you the same stories about how families don't want their disabled family members any more. I tell you you are not getting the whole story.

In one town meeting opposing the building of a new institution, one of my friends with significant developmental disabilities testified about his life as a child in a "residential school" and how he was never schooled. He spoke about how when he asked to go to school because he wanted to learn, the people who ran this "residential school" told him that he would never learn any more than he already knows. This person lives in Watertown, NY in his own apartment and holds down a job because he went to school when he "aged out" of the institution. He shared how difficult the healing process has been with his parents because while he now can see they didn't have a choice, he grew up feeling betrayed.

I helped an adult woman with Multiple Sclerosis leave a local institution. Her children would not help her because they were afraid that they might lose their own home if she needed to return to a nursing home. The institution would not approve her living out on her own because they got paid as long as there was someone in the bed. This was a woman with significant personal care needs including eating, bathing, mobility, almost every imaginable activity required some level of assistance. Her determination to live independently and make friends with neighbors who actually were active in the community was insurmountable. She managed to leave with help from an independent living center who helped her find private care. She lived on her own for years until her death. Why would our government pay to keep this proud, accomplished woman imprisoned against her will just because she had a disability that required for her to have personal care attendants? Why should she be kept in an institution when she should be a welcomed, active member of our community?

I know that families want to remain together and I know the utter exhaustion of providing on-going care with no outside assistance, the fear of losing hard earned property and the freedom they carry. It isn't hard to research the profit margins of the providers. Please let's not injure and insult any more. Let's move on. Let's change the system so that real choice is provided and new freedoms are experienced as people with disabilities become full participants in community life. The payback will be there for all of us in the forms of stronger communities with enriched diversity and enriched quality of life.

Thank you again for this opportunity to provide testimony.

Aileen Martin

Aileen Martin

Nancy Maynard
1201 S. Courthouse Rd.
#126
Arlington, VA 22204

April 2, 2004

Senate Finance Committee
Senate Dirkson Office Building
Room 219
Washington DC 20510
Fax: 202/224-0554

Dear Sir or Madam:

I am asking the Committee to vote in favor of MiCASSA (Medicaid Community Attendant Services and Supports Act). What MiCASSA means is that everyday citizens can remain independent and live in their own homes. These citizens happen to be disabled and may have special needs which can be met by an attendant or nurse. At present people are being forced into nursing homes, merely because of their inability to pay for exorbitantly expensive attendant care. People lose their independence, their property, their pets and their quality of life, merely because of a legislative oversight.

Take a poll of your friends, family and acquaintances - you may find that many are disabled in one way or another. People who accept Medicaid are still entitled to quality of life. You can make a difference by speaking up on behalf of your constituents. There are at least a dozen disabled people that I know of living in various units of my regular apartment building near Washington, D.C. who will benefit from the passage of this bill.

This bill needs to be passed. Take note that there are many disabled veterans returning everyday from Iraq who might qualify for the services provided by this bill. Would you deny these heroes basic services and quality of life? Would you condemn people who merely want to live a normal life - and can with a little assistance - to the confines of a nursing home?

We can do better for our citizens and we should. Please add my letter to the public record.

Sincerely,

Nancy L Maynard

Nancy Maynard

Testimony of Mr. Michael Oxford, President
National Council on Independent Living
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Arlington, VA 22201
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ncil@ncil.org

United State Senate
Committee on Finance
Hearing on
"Strategies to Improve Access to Medicaid Home and Community Based Services"
April 7, 2004

Mr. Chairman and members of the Senate Finance Committee, thank you for the opportunity to provide testimony related to the April 7, 2004 hearing on "Strategies to Improve Access to Medicaid Home and Community Based Services."

Introduction – The bias against people with disabilities, a bias that results in a long term care policy of locking people away from society in segregated institutions must end. The only barrier to swift elimination of this travesty is political will. This nation has the knowledge and the resources to do so. The existence of this knowledge, resources, and public policy in a few states, lends both a good example to be followed by the entire country, as well as highlighting the need for national legislative intervention. Historically, gross variations in basic liberties, and citizenship status, have produced federal laws which equalized the quality of citizenship and liberty in all states of the nation.

In terms of long term care policy, instead of "liberty and justice for all", the situation is liberty and justice for some depending on your age or the type and severity of your condition and the budget cycle of the state you happen to live in. It is shameful that people with disabilities who need long term services and supports have more freedom in Colorado than in Tennessee. The happenstance of where you live should not determine your very ability to enjoy your home and community, yet this is absolutely the case in America today.

The following testimony will acquaint you with the National Council on Independent Living, our membership, and activities and commitment to ending the institutional bias over the last twenty years. The National Council on Independent Living (NCIL) calls on Congress to contact us, use us, and count on us to help with the immediate dissolution of the institutional bias in the United States of America. When Congress provides the leadership by passing "Money Follows the Person" and "MiCASSA", NCIL and its members will continue to be there to provide the day-to-day, person-by-person work of helping people leave institutions and fully access, and integrate into their communities of choice across America.

A History of Leadership – The National Council on Independent Living (NCIL) is the oldest, cross disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL's membership includes over 300 organizations representing thousands of individuals including: Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

NCIL was established four years after the 1978 amendments to the Rehabilitation Act of 1973. The 1978 amendments added statutory language and funding for the formation of Centers for Independent Living. The Executive Directors of the newly federally funded CILs met regularly with Rehabilitation Services Administration (RSA) to discuss issues related to the development and expansion of CILs nationwide. Believing that the views of CIL consumers and people with disabilities, as a whole, were not being heard by the federal bureaucracy, the Administration, or the Congress, the CIL executive directors worked to organized and establish the National Council on Independent Living – an organization governed by people with disabilities advocating for the development and expansion of a nationwide network of centers for independent living. **For more about NCIL, its mission, issues and events, please go to www.ncil.org.**

Opposing the Institutional Bias through Services and Advocacy – There is a strong historical linkage between NCIL and the struggle for people with disabilities to live in their own homes and communities and not in institutions. In fact, the definition of a CIL found in federal law (Rehabilitation Act of 1973, as amended) is that a CIL must be non-residential (not located in an institution or long-term care facility) but, rather must be in the community at large. Part of the life story of the first President of NCIL, Max Starkloff, includes his fight to move himself out of a nursing facility and back into the community where he developed a housing project for himself and others with disabilities. This was a rare victory at this time in history (early 1970s), but it sets a clear and shining example for all of us still today of the depth of passion people with disabilities feel regarding the desire to be free and independent if they so choose. NCIL still carries this passion into the future through its mission, activities and particularly, by its strong advocacy efforts for "Money Follows the Person" and "MiCASSA" (S. 971).

NCIL's CIL members remain at the forefront of the de-institutional movement. According to a recent State Data Book on Long Term Care Program and Market Characteristics, the average cost of nursing home services across the US is over $35,000/person/year. A 1999 report from the National Conference of State Legislatures found that the average cost for community-based services is $14,902/person/year. In 2000 alone, as a result of centers for independent living, almost 1,500 people were able to leave nursing homes and 19,000 were able to remain in our communities. This saved taxpayers over $410 million in just one year while expanding the liberty interests of thousands of people with disabilities and their families and friends.

Related services are helpful or even necessary for people with disabilities whether they qualify for long term care services or not. CILs lead the way with over 54,000 individuals receiving peer counseling services; 36,600 people receiving assistance finding housing; 36,000 receiving assistance with transportation services; over 59,800 individuals receiving independent living skills training and 85,500 people acquiring personal assistance services with referral and application assistance from CILs.

This kind of effort is regarded as a necessary core service for CILs across the country. In 1998, NCIL successfully advocated for adding deinstitutionalization as a service to be included on the federal performance reporting instrument that CILs must submit in order to receive federal funds from the Rehabilitation Services Administration of the US Dept. of Education ("704 Report"). Additionally, many State Plans for Independent Living (SPIL) which promote activities of CILs have included ending institutional bias to their covered activities.

Current Leadership Role of NCIL – More recently, at the request of NCIL, deinstitutionalization language has been added as a fifth (5th) core service to the Senate's bill reauthorizing the Rehabilitation Act of 1973 as amended. No other organization has made this kind of commitment to this core independent living issue – to ask to be required to provide direct assistance to people with all kinds of disabilities with any and all aspects of leaving an institution - from personal

assistance to housing to counseling and service coordination. In the end, after laws are passed, programs are implemented and budgets are approved, someone has to provide a comprehensive and endlessly individualized array of services to assist people with leaving and staying out of institutions. As a matter of philosophical, historical and legal commitment, elimination of the institutional bias remains a primary and expanding role of NCIL and our CIL and SILC members.

NCIL has provided 13 national training presentations on ending the institutional bias and home and community services since 2000. Additionally, NCIL in conjunction with the Independent Living Research Utilization project of the Baylor University in Houston has trained participants ranging from attorneys, to state officials and aging and independent living advocates on these topics through national teleconference trainings through a project called the "IL NET". These training activities have continued to provide cutting edge, hands-on information in a "how-to" style to thousands of advocates and service providers from across the country since 1995. The commitment to end the institutional bias must include a well trained cadre of advocates, counselors and agency officials to carry out this important work; work that is not just a concept or a funding stream, but rather is a veritable life commitment to liberty of the thousands of CIL staff who carry out this important work on a daily basis; many of whom have the unfortunate, personal experience of existing in institutions as well as the liberating experience of leaving an institution for home, community and employment. CILs employ thousands of people with every kind of disability. Many of these employees have direct experience with the institutional bias and because of this experience, a fundamental commitment to ending it.

Leading the Way through Membership Activities – CILs are required by law and committed by philosophy to serve people with all and any type of disability regardless of age. In the past ten years, because of these legal and philosophical commitments, many have become providers of personal assistance services which are controlled and managed by the individual with the disability. In fact, the concept of having in-home, personal assistance services controlled and managed by the person with a disability was first promulgated and practiced by one of the founders of the independent living movement and founder of the first CIL in Berkley, California, Ed Roberts. This concept, now well known as "consumer control" of services, is promoted by NCIL's CIL and SILC membership nationwide. Allowing this option of consumer control within the provision of Medicaid Waiver attendant services is now becoming widespread. CILs were the first type of Medicaid Waiver provider to push for and put into practice consumer control within these programs that are so important to the independent living and very liberty of thousands of people with disabilities of all ages today.

This direct involvement of CILs with the Medicaid personal attendant service programs has caused a major paradigm shift in the nature of these programs nationwide. This involvement has caused the federal and state agencies who oversee the programs to fundamentally change the way the program recipients, people with disabilities, are viewed. Recipients and independent living advocates are now much more involved in the planning, start-up and delivery of the services provided, including direct control and management of the day-to-day services. This increased involvement in all aspects of the program has strengthened the services and improved the quality of outcomes of the program, including employment of the recipients and others with disabilities. Now, more than ever, people who use personal attendant services are working and remaining at work. The rise in employment of people who receive home and community services, especially consumer controlled services. This, compared to the stark unemployment of people residing in institutions must be noted, emphasized, and nurtured in our nation's long term care policies.

The leadership provided by CILs in the provision of, and advocacy for, consumer controlled personal attendant services has given NCIL a wealth of direct experience and observations to

share. These experiences and observations range from the wondrous and appealing to the woeful and appalling:

> The local CIL in Topeka, Kansas recently assisted Charmaine a young woman of 38 years with moving from a nursing facility. She has her own apartment close to friends and family and has learned to ride the public transit system. She has hired and manages her own attendant and is very happy volunteering with the CIL. She is now seeking employment through the local vocational rehabilitation agency.
>
> Lorraine, on the other hand, has a different and appalling story to tell. She is elderly, 72 years old. Four years ago, she had a routine hip replacement done. The surgery went well and she was discharged from the hospital to a nursing facility for a 90 day planned brief stay for additional rehabilitative therapy. Lorraine owned her own home, ran her own business and had much loved family pets all waiting for her at home. Four years later, she has lost her pets and her business. Her house is in terrible shape because it has been closed for so long. Lorraine's "planned brief stay", as happens so many times, turned into an unplanned permanent stay because the nursing home wouldn't let her leave and she wasn't given information about home and community alternatives. The local CIL is helping her leave, getting her house made habitable again and assisting her with litigation for the harm she has suffered from being unnecessarily institutionalized against her wishes for so many years.

This kind of situation, all too common, must come to an end! Only passage of "Money Follows the Person" and "MiCASSA" will fix the broken system that creates this kind of problem to begin with. Expertise has allowed NCIL members to produce basic materials useful on day-to-day basis which we have shared and have been replicated around the country. The experience, the knowledge and the tools are available and NCIL is committed to sharing them. The laws need to be changed so they can be put to effective use!

How do we identify people who want to leave an institution for home and community? How do we get information and assistance to those who may have an interest? The federal government, CMS, collects information from people who nursing facility operators feel have a potential for discharge back to the community. This information, collected annually, is contained in a document called the Multiple Data Set (MDS) and is readily available and would be fairly easy to use as a good place to start. According to this information, which we feel under-represents the need, over 19% of the people currently residing in nursing facilities have potential for discharge back into their homes and communities. Over 263,000 people are being unnecessarily segregated and isolated in nursing facilities.

Besides this basic information, our experience has taught us that a very effective method of finding and assisting people who want to leave the institution and go back home, is to have knowledgeable, empathetic staff and volunteers, peers with disabilities wherever possible, go in to the facilities and talk with residents one-on-one and in small groups about programs, services, assistance and options. This builds rapport and trust. Over time, family, if any, can be met and the resident can venture out into the community, check things out, ride the bus, and look for housing and so on. This is the peer-to-peer independent living model that many CILs use to good effect.

(See *Appendix A* for examples of one of many planning tools designed by a CIL that is used to provide information and assistance to people who are interested in leaving and institution for home and community)

Rationale for Congressional Action / Time for a Change – With the passage of the Americans with Disabilities Act (ADA), people with disabilities have been legally defined as a "discrete and insular" minority class of people who have suffered historical segregation and second class status in all areas of life including denial of employment, housing, transport and education and, further, unnecessary segregation into institutions away from community and family life. The "Helen L. v Didario" and perhaps better recognized, "Olmstead" decisions clarified the law to mean that forcing unnecessary institutionalization upon a person with a disability is illegal and a violation of civil rights defined in the ADA. In spite of the now 14 year old ADA, and in spite of various court interpretations such as "Helen L." and "Olmstead", and in spite of progress in terms of funding shifts and numbers served in the community, the institutional bias is still alive and well today in America. The very topic of this hearing recognizes this unfortunate reality.

The history in this country of finally and comprehensively addressing bias, segregation and second class status in citizenship is instructive in telling us what needs to be done in eliminating this bias, called "institutional", but really is a bias against people with significant disabilities of all ages. In fact, instead of a hearing on "institutional bias", it would be clearer to call this a hearing on bias against people with disabilities who need long term services and supports, because this is the root problem and the true bias.

When women demanded the right to vote and own property and to have equality under the law, opponents said they were too hysterical and emotional, too weak in mind and limb, couldn't make sound judgments, would cost extra money through excessive use of sick and maternity leave, cause extra bathrooms to be built, would really be happier in the home raising kids, and so on. State by state the status of women varied until finally the federal government stepped in mandating equal status under the law and societal bias began changing (is still changing) after federal legal requirements were put into place.

When African-Americans suffered the complete form of bias and oppression, of slavery, the federal government stepped in and later, when racial and ethnic bias and segregation continued in its awful and manifest forms that varied from state to state, the federal government stepped in mandating equal status under the law and societal bias began (and still is) changing after federal legal requirements were put into place.

The same is true today for institutional bias and the same remedy is needed. Because after all, what is institutional bias, but disability bias? The fact is, that society is still too uncomfortable, even frightened with disability and the aging process – better for everyone out of sight, out of mind. Once the legal requirements to allow people to choose to receive services in the setting of their choice are put into place, the societal bias will begin to change and improve albeit slowly and imperfectly just like history has shown every other group. Reform of the system is necessary to foster the change that will truly eliminate bias. "Money Follows the Person" and "MiCASSA" are necessary steps along the way toward complete reform.

We must begin to end the disability bias by eliminating the institutional bias. Simply put, we have to stop locking people away from home, friends and family just because they are disabled. Ending this bias will make a better and richer society because history has shown that ending bias and segregation against people, any and all people, is good for us all.

Reform of the long term care system is a clearly needed antidote to a system that expresses the poison of bias against people through institutional segregation of those that society is uncomfortable with having around. A federal "money follows the person" option is a solid, fairly easy step that should be taken immediately in this Congress. However necessary, this step is not sufficient to tackle and remove a centuries old system of seclusion and segregation. States must

be directed to allow people who so desire, to leave institutions and go back home to their community of choice. Fundamental reform such as MiCASSA, or something similar, is still needed and soon, to begin the process of truly eradicating the deep seated bias that exists. Passage of MiCASSA must follow swiftly on the heels of "Money Follows...".

Whether through Waivers, Medicaid state plan services, state and local services, or federal and state "money follows..." programs, people must be allowed to exercise their own liberty interests. There is funding available through Medicaid, through grant and demonstration projects, through soon to come (hopefully!) money follows projects and through already existing long term care budgets so that no one should be institutionalized against their wishes. Given all the research and publications, given available technical assistance and Real Choice grants there is enough information and guidance available so that there is no excuse for failure to at least act on this premise:

It is immoral and against the law to institutionalize people against their wishes any longer.

Besides enacting "Money Follows the Person", at a minimum, states must be prohibited from forced segregation through institutions. This could be done by writing regulations that implement the Olmstead and Helen L decisions for the Medicaid program and by passing MiCASSA. This would, in fact, be a funded mandate.

End the bias against people with disabilities of which institutional segregation is a symptom so NCIL can do its job even better!

Thank you for attending to these remarks. NCIL appreciates the opportunity.

Appendix A

TILRC Move-Out / Freedom Plan Narrative

All move-outs will include a completed Move-Out/Freedom Plan to assure necessary supports, supplies and advocacy have been explored. A Move-Out Plan will be utilized by all staff involved with any aspect of assisting someone with leaving a facility. Plans will be used for consumers moving out of the following situations:

- Nursing Home
- Intermediate Care Facility for People with Development Disabilities
- Intermediate Care Facility for People with Mental Disabilities
- Group Living Environments (Group homes, adult care homes)
- Assisted Living Facilities
- State Hospitals
- Out-of-state Consumers

A Move-Out Plan may be utilized with people in the following situations, if necessary, for successful coordination of our advocacy assistance:

- Homeless Shelters
- Battered Women's Shelter Houses
- Drug and Alcohol Rehab/Detox Programs
- Individuals moving out on their own for the first time
- Homeless

This plan will assure we have offered advocacy and service/support options and will allow for identifying possible Olmstead violations.

Remember: We are one center, with a unified goal to assist people with living free, in their own home. The advocacy team leader will assure that all aspects of this move out/freedom plan are utilized toward this goal. Every move-out will include at least 2 advocates who represent various skill areas. Ongoing coordination and great communication must happen, to prevent any misunderstanding of the various specific supports/advocacy our center offers. Examples:

an Independent Living Advocate should not make promises to a consumer that "we" will find them a nice2 bedroom house with a fenced yard (they live on $500 a month SSI and do not have a Section 8 Voucher) since this is most likely not going to happen. Remember: All IL Advocates will need to rely on their co-workers' specific knowledge.

Promises made without having the knowledge necessary to offer them hurt our consumers and cause delays in the move-out process.

- TILRC staff are not case managers or social workers. We do not make promises about anything. We offer advocacy and peer support to explore available options and create opportunities for independent living. The goals are achieved by the consumer, through learning the skills or obtaining desired services/supports they choose.

Once great communication and coordination are established, we work with the consumer on development of his or her goals and what he or she wants. This is typically done through development of the Independent Living Plan (ILP).

Remember: Development of an ILP will require coordination between all team members. There are many things that must happen simultaneously to assist with a successful move-out. The items below must all be done prior to actual move-out day.

IL Advocates complete intake/paperwork, such as;

- ❖ Rights and Responsibilities
- ❖ Develop Independent Living Plan (ILP)
  - S pecify for each goal who, what, where and how, and establish time frames for achieving goals.
- ❖ Release of Information, and all other paperwork
- ❖ Obtain emergency contact/support person information
- ❖ HCBS Screening/Waiting List/Money Follows Referral

HCBS, Medicaid, Medicare, Self Pay – You should know if the person is on HCBS, Medicaid, Medicare or private pay. This is important to be able to explore possible options for obtaining necessary medical/adaptive equipment or assistive devices or identify possible advocacy action on securing other benefits, such as food stamps, LIEAP, and assuring that essential services are in place. For example, if a person receives attendant care but is private pay, it may indicate that he or she could pay for certain assistive items.

Medical/Adaptive Equipment/Assistive Devices – Adaptive equipment and assistive devices include medical and non-medical equipment such as accessible phones, wheelchairs, shower chairs, lifts, canes, hospital beds, holding devices, ramps, oxygen, and whatever. Medicaid programs may be able to pay for some things, and Medicare may be able to pay for some things, however It is critical that needed adaptive/medical/assistive devices be in place at time of move-out if it impacts the person's being able to live a safe quality life.

Remember: Adaptive/medical/assistive devices should be secured prior to date of move-out with assured availability on the day of move-out! If the basic necessary equipment/devices are not in place, the move-out may have to be postponed until these items are obtained. Communicate the need with the team members and leader.

Medical Care

The consumer moving from a primary care facility such as a nursing home, intensive care facility for people with mental or developmental disabilities, and other congregate settings will most likely have to obtain a primary care physician. Most facilities have their own doctors that only serve the residents of that facility. The consumer may need advocacy on locating a doctor who accepts new patients or Medicaid patients.

Remember: A primary Care Physician must be obtained by date of move-out.

Prescription Medications – Many consumers will have several medicines. The nursing home/facility will not (as a general rule) send medications with the consumer when they move out. Most facilities buy bulk medications and do not have an individual prescription system. The consumer must have written prescriptions for their medication(s) upon moving out of the facility. He or she must have his or her medicine in place before moving. This is very important as this could affect health, welfare, or life.

Remember: Advocates must assist consumers with assuring that all medications are ready to be filled and are obtained at move-out time.

Housing – If the consumer has identified obtaining accessible, affordable housing as a goal, the application process must start at initial intake. Locating accessible, affordable housing of choice may take at minimum 45 days to several months for low income subsidized housing programs. The consumer will need a Kansas ID, Social Security Card, Income Verification, 2 Character Reference Letters, and list of past 5 years place of residency. This is the minimum information required for most subsidized (low income) housing. There are privately owned subsidized housing programs and public housing authorities, also. It is critical that housing applications get turned in very early if the consumer is low income and wants subsidized housing.

Remember: Get signed releases for all housing providers.

If the consumer has enough income to rent in the general market from a private landlord and does not want low income housing, it may not take as long to obtain a unit. Applications must still be completed and it could take 5-30 days to be offered a unit. Most private, non-subsidized housing will not require income verification to establish eligibility, but will often want documentation that the person has an income which will cover the rent amount. This is an important time in the landlord/tenant relationship as many fair housing/civil rights violations occur at this juncture. It is crucial that the advocate have a basic understanding of landlord/tenant and fair housing laws. Many private apartment complexes require an application fee (generally non-refundable, this fee may be in the 25-75 dollar range. A security deposit will be required either to hold the unit or at move-in day. This will typically be $100-up).

Remember: Provide information/materials on Landlord Tenant Laws and Fair Housing.

Utilities/Phone/Cable – Once an affordable accessible home is secured, all utilities must be turned on. Some subsidized units include all utilities (not phone or cable) as well as some private apartments with all bills paid. If the unit rent includes utility costs, the consumer need only secure a phone (if desired) and any other service, like cable or satellite TV. Some units may include water and trash pick up, thus only requiring electric/gas and phone and cable.

Remember: Most consumers moving out of an institution will not have account credit that can be relied on in lieu of having to pay a cash deposit. So in most cases, the person will have to have a water/trash, electric/gas and phone deposit. These may range from $50.00 and up. Some utility companies may allow the person to break up the deposit in several month payments (KPL and phone). The advocate should explore these options with the consumer. The consumer may request budgeting/bill payment skills to be able to make an informed choice about these options.

Banking/Automated Bill Payment/Direct Deposit – For set bills like rent or cable, the consumer may want to consider automatic bill payment service. Several banks offer this service, for a fee. This may assist a consumer with avoiding having a payee or conservator. Advocates should provide information to the consumer so he or she can make an informed choice on these opportunities.

The consumer moving from the nursing home will need to have their SSI/SSDI checks send directly to them at move out time.

Remember: A person in a nursing home only has access to $30 a month to live on; the rest of the check goes to the nursing home. It is critical that SSA be notified as soon as possible when a move-out date is scheduled. If SSA is notified before the 15th of the month (in most cases) the next month's check will be able to come directly to the consumer. He or she can have the check deposited directly into an account or mailed to a new address or if there is a payee or guardian, it

will be sent to them. Explore options with the consumer so that he or she can make informed choices about banking and money issues.

Transportation – Consumers may need to explore transportation options available in the area they will move to. Information on lift-accessible transit, fixed route, cabs and others need to be explored. Most lift equipped door-to-door transit service requires that eligibility be established. Advocates should provide applications/information in establishing eligibility and information/route schedules for fixed route and other transportation options, at initial intake. Medicaid may at times pay for medically related trips. Inform the consumer of this option so he or she may make informed choices about transportation options. Some consumers may express a desire to learn to drive. We can assist with locating options for adaptive driving training and studying for the test.

Household Items/Furniture – Often a person moving out of a facility will need all basic household items: pots, pans, towels, beds, small appliances, and lamps. TILRC accepts donations of these items. If a consumer indicates this area of need, the advocate should explore natural supports/resources to obtain these items, check to see if we have any desired items in our warehouse, and explore low-cost options for obtaining these items. Some options would be thrift stores, other agencies, garage sales, checking the paper, dollar stores and such.

Remember: This need may trigger budgeting/money issues.

STATEMENT OF THE NATIONAL MENTAL HEALTH ASSOCIATION

[SUBMITTED BY MICHAEL M. FAENZA, MSSW]

Today's Senate Finance Committee hearing on strategies to improve access to Medicaid home and communitybased services presents a valuable opportunity to highlight the crisis in community-based care for individuals with mental illness. We commend Senators Grassley and Baucus for holding a forum to address these important issues.

Improving access to community-based services for people with mental illness is a central goal of the National Mental Health Association (NMHA), the nation's oldest and largest advocacy organization addressing all aspects of mental health and mental illness. With more than 340 affiliates nationwide, NMHA works to improve the mental health of all Americans, especially the 54 million people with mental disorders, through advocacy, education, research, and service. NMHA was actually founded in 1909 by a former psychiatric patient, Clifford W. Beers, largely in response to the horrible abuse that he witnessed and was subjected to during his own stays in public and private institutions. The founding of our organization was one of the major events that started a reform movement to improve the conditions of individuals in mental institutions and the availability of communitybased services.

However, our mental health service delivery system is "in shambles," according to the President's New Freedom Commission on Mental Health. In fact, the Commission stated in its recent report that "the nation must replace unnecessary institutional care with efficient, effective community services that people can count on." New Freedom Commission on Mental health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA–03–3832. Rockville, MD: 2003 (available at *www.mentalhealthcommission.gov*), p.4. To achieve the reforms envisioned in the Commission's report, Congress must make mental health a real priority by committing substantial new resources and strengthening coordination among state and federal agencies to improve access to community-based mental health services.

MEDICAID AND MENTAL HEALTH CARE

As the single largest source of financing for mental health care in this country, Medicaid plays a crucial role as a safety net for millions of Americans with mental illnesses. However, fiscal constraints facing most states and certain Medicaid policies have blocked many of those who need assistance from receiving care. As states continue to struggle with large budget shortfalls for next year, federal assistance through the Medicaid program to improve access to more integrated, community-based care for individuals with mental illness is desperately needed.

Today, millions of people with mental illness fall through the cracks of our health care system largely because community-based care is not accessible or available to them. As a result, many people with serious mental illnesses wind up homeless or incarcerated in jails and prisons. Studies have shown that an estimated one-third of individuals who are homeless and hundreds of thousands of those in our jails and prisons have serious mental illnesses. In some areas, prisons and jails have become the de facto mental institutions of our time, inhumanely warehousing people with mental illnesses.

As the U.S. Supreme Court held in *Olmstead v. L.C.*, for which the plaintiffs were two women with mental illness and mental retardation, the Americans with Disabilities Act requires states to provide services in the most integrated settings possible. Beyond just keeping people confined in institutions unnecessarily, leaving people homeless or locking them up in jails also clearly goes against the spirit, if not the letter, of this decision.

The state of children's mental health services, particularly community-based services, is just as bleak, if not worse than that for adults. Many children are placed in institutional settings—sometimes far from their families—even though they could be more effectively and efficiently treated in the community while remaining at home. While the lack of Medicaid coverage for adults between the ages of 21 and 64 in institutions for mental diseases (IMDs) serves as a disincentive for keeping adults with mental illness unnecessarily institutionalized, this disincentive is less effective with regard to children since states may opt to receive Medicaid funding for covering institutional care of children under 21 in psychiatric facilities. Moreover, funding for communitybased services for children through public programs or private insurance is extremely limited.

CHILDREN'S MENTAL HEALTH NEEDS GO UNMET

The inaccessibility of children's mental health services forces thousands of parents to relinquish custody of children with mental disorders to the state each year so that these youngsters will become eligible for Medicaid and gain access to services through the child welfare system. Treatment of serious mental disorders is very expensive and private insurance tends to run out long before these children have received the care they need, but they often are not eligible for Medicaid because their parents' incomes are too high. Desperate to secure needed treatment, these parents have no other viable options. Another tragic indicator of the tremendous dearth of adequate mental health care for children is the finding, cited by the President's New Freedom Commission on Mental Health, that 80 percent of children coming into the juvenile justice system have mental illnesses.

In fact, the General Accounting Office found that in 2001, 12,700 children in 19 states and 30 counties were placed in child welfare and juvenile justice systems solely to access mental health services. This shocking finding actually grossly understates the magnitude of the problem since most states did not respond to the GAO's survey. A number of states have passed laws prohibiting custody relinquishment, but the pressures are still there while adequate services and supports are not. Thus, parents continue to make the heart-wrenching choice to forego custody of their children with the desperate hope that they will be better off somehow.

Behind the statistics, the stories of these families are heart-breaking. With no other illness is access to treatment made conditional on the removal of a child from the custody of his or her parents. These children feel abandoned and unwanted, and their parents are devastated. Although these parents often have nowhere else to turn in cases where a child has become a danger to him or herself or others, the act of removing these children from their homes makes the path to recovery from mental illness much steeper. We have heard from parents all over the nation who have relinquished or nearly relinquished custody of their children. They consistently state that if they could access the community-based services available to foster care families, they could have kept these children at home. These parents need to be able to access more community-based services and a critical first step would be to make children in psychiatric residential treatment centers (RTCs) eligible for services through Medicaid home and communitybased care waivers.

AVENUES FOR PROVIDING NEEDED HOME AND COMMUNITY-BASED SERVICES

Over the last decade, psychiatric residential treatment centers have become the primary providers of institutional care for children with serious emotional disturbances. Despite the fact that many RTCs are very structured settings that closely resemble psychiatric hospitals, CMS has refused to recognize them as hospitals and thus they do not qualify as institutions against which states may measure home and community-based care waiver costs. As a result, states have been unable to use the home and community-based care waiver authority to provide community-based alternatives for children in RTCs except in a very few cases.

Authorizing states to use home- and community-based care waivers for children in RTCs would enable states to offer children with mental disorders real community-based alternatives to institutional care. The Family Opportunity Act (S. 622/ H.R. 1811), tirelessly championed by Senators Grassley and Kennedy and Representative Pete Sessions, would make this change in Medicaid law. We will continue to work with the sponsors to ensure that this legislation is enacted in the near future. And, we appreciate the support the President has shown for this proposal by including a similar provision in the set of New Freedom Initiative demonstration projects proposed in his FY 2005 budget.

Besides this very important provision, the Family Opportunity Act would also give more families the flexibility they need to access mental health services for their children by enabling those with incomes up to 250 percent of poverty to buy into the Medicaid program. To prevent the tragedy of custody relinquishment, in addition to making more community-based services available, families of children with mental disorders must be able to obtain Medicaid coverage for these children so that they can access these services.

Medicaid is a critical lifeline for millions of individuals with mental illness, but unfortunately it has been stretched very thin by the recent financial difficulties faced by the states and resulting cuts in Medicaid coverage. Although states continue to face extraordinary budget shortfalls, the fiscal relief Congress provided last year is set to expire at the end of June. This relief lessened the extent to which states have cut services for people with mental illnesses who rely on Medicaid.

One of the most important steps Congress should take to improve or at least preserve existing community-based care is to **extend state Medicaid relief legisla-**

tion and reiect the cut to Medicaid included in the House budget resolution.

Another important step Congress should take to **improve access to services for adults with mental illness is to consolidate the different options states must choose to provide comprehensive mental health services into one option under Medicaid**. Currently, coverage for community-based mental health care is spread across more than six optional Medicaid service categories which presents a significant barrier preventing states from providing the comprehensive, coordinated services that many Medicaid beneficiaries with mental health disorders need. To finance many of these services, states must piece together multiple options which results in a confusing patchwork of programs and fragmentation of services. The Medicaid statute should be amended to allow states the option of providing a full continuum of mental health care with one change to their Medicaid program. This change would lessen the fragmentation in mental health service delivery that the President's New Freedom Commission on Mental Health highlighted as one of the main barriers preventing people from accessing needed mental health care.

Consumer-run services can play a critical role in the process of recovery from mental illness and research has shown these services to be highly effective. The President's New Freedom Commission recommended these services as important sources of community-based care.

> "Consumers who work as providers help expand the range and availability of services that professionals offer. Studies show that consumer-run services and consumer-providers can broaden access to peer support, engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis. Because of their experiences, consumer-providers bring different attitudes, motivations, insights, and behavioral qualities to the treatment encounter." Commission Report, p. 37.

Approximately eleven states purport to cover peer-support services in their Medicaid state plans, but in most cases these services are not actually available. Georgia has a model program for credentialing consumer or "peer" support providers for reimbursement under Medicaid. We urge the Finance Committee to **take up legislation to give states an explicit option to follow Georgia's lead and establish procedures for credentialing consumer-run services for coverage through their Medicaid programs**.

Finally, in light of the large numbers of individuals with mental illness who are held in jails and prisons, Congress should **require states to suspend, instead of terminate, Medicaid eligibility of those who are incarcerated**. Although Medicaid does not cover health services provided in jails or prisons, while incarcerated, a beneficiary's eligibility for Medicaid does not necessarily terminate. Medicaid eligibility for these individuals is generally tied to SSI eligibility that is only suspended, not terminated, as long as a person is incarcerated for less than 12 months. When SSI benefits are suspended due to incarceration, states have the option to, and generally do, terminate an inmate's Medicaid eligibility, but federal law does not require this and these individuals may remain on the Medicaid rolls even though services they receive while in jail are not covered. Unfortunately, most states terminate Medicaid eligibility automatically anytime someone is incarcerated, even though this is not required. As a result, when individuals with mental illness leave jail they are often unable to access the care they need to stay healthy in their communities and are at risk of cycling back into mental institutions or jail. These individuals need to be able to access Medicaid coverage, to which they are entitled, as soon as they leave jail or prison, and the most effective way to ensure that is to call on the states to simply suspend Medicaid coverage, rather than terminating it, while these individuals are incarcerated.

We urge Senators Grassley and Baucus and the entire Finance Committee to build upon today's hearing by swiftly approving legislation that incorporates these proposals to improve access to community-based mental health services.

April 1, 2004

Dear Committee Members,

I'm blind and crippled and brain injured. And a lifelong Republican.

Fortunately I acquired millions before the trauma of assault.

If I hadn't that good fortune, I might have been institutionalized. Being cooped up is never preferable to enjoying the larger freedoms of choice.

In the community, a loving support group may be assembled. In the institution, low wage workers, usually unable to speak proper English much less educated enough for pleasant discourse is the norm. What most people so afflicted do to sustain life is accept SSI, which asks Americans to live--pay rent, buy food, clothes, books, magazines, newspapers, movies, medical deductibles, phone, gas and electricity, plan for retirement, buy cards and gifts for loved ones, attend social or political or entertainment events, all of existence on $541/month, less than 17.50 per day, less than what you pay to park your car for an hour.

The money that would be spent on institutionalize folks in many cases would be better spent in the community. With that money should come some leadership at the local level, reflecting your national leadership, that demonstrates care and concern and tolerance of others and a recognition of a duty to honor special needs of the bunch of us who do not fit into one standard deviation of productive capacity and ability.

It does pain me that the vast majority of the disabled community are Democrats without giving weight to the good things that Republicans have endeavored to do to protect the marginalized. We seem to be typecast, us saying, 'Please, please, feed us, clothe us , shelter us, protect us from disease and criminals because we cannot provide for ourselves....' and the Republicans saying, 'It costs too much, I'm sorry, life's not fair, wish I could help you, but no, not now, maybe later.....' Certainly the money follows and Mi Casa are issues that can generate consensus between Democrats and Republicans.

I hope Mr. Grassley and Mr. Baucus, both from states where common sense is more prevalent than on our Coasts, can make life better for the disabled.

Start by arranging consensus among the bottom 3 Senators on each side.

Sincerely,

Dirk Neyhart
1400 Hearst Avenue
Berkeley, CA 94702
510-644-1405

Money Follows Person

Testimony of Fred Earl Pinson, Jr.
To the U.S. Senate Finance Committee
Regarding S. 971 and S. 1394
April 7, 2004

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I request that you pass S-971 and S-1394 to make it easier for states to comply with the U.S. Supreme Court's order in the Olmstead case.

For the past 5 years, many – if not most – states have been in violation of an order from the U.S. Supreme Court in a civil rights matter. In the Spring of 1999, the Court issued its ruling in the Olmstead case and said – in part – that if a state provides home-based care to some of its citizens with disabilities and requires others to be institutionalized to receive similar services, such a state is discriminating on the basis of disability and is in violation of the Americans with Disabilities Act, a law signed by President George H. W. Bush in 1990.

When Alabama tried to prevent Black Americans from attending its university in the1960s, President Lyndon Johnson federalized the units of the Alabama National Guard that Alabama Governor George Wallace had ordered to keep the black students out of the university. In the 1860s, several states defied Federal authority and even laid siege to Fort Sumter resulting in the Civil War. These historical events show the importance of states being made to follow Federal law. Also, think about the chaos that would result if a state decided to prevent Federal taxes from being collected within its borders. Failure to enforce one Federal law puts all Federal laws – especially Federal civil rights laws – in jeopardy.

Today you are considering two bills that will, if passed and signed by President George W. Bush, make it much easier for states to comply with the Olmstead decision. S. 971 provides Federal money to cover most of any extra costs incurred by a state's Medicaid program when a person leaves a long-term care institution for a community-based care setting. S. 1394 requires that the same state money that would be spent to maintain a person in a long-term care institution go with that person if he/she chooses a community-based care arrangement.

Let me clarify the term, "extra costs" as it applies to community-based care verses institutional care. When most Medicaid consumers leave long-term care institutions, Medicaid saves a significant sum; however, certain consumers' community-based care costs more than Medicaid would pay to keep these few consumers institutionalized. It is these "extra costs" that most states sight as justification for keeping people in long-term care institutions in continued violation of the Americans with Disabilities Act and the Supreme Court's ruling in the Olmstead case.

I urge you to vote to approve both of these bills with the strongest possible recommendation that they be passed by the full Senate.

Senators, which of you can guarantee that you will not get a disability or have a close relative who will not get a disability? If you will not pass these two pieces of legislation for the approximately two million Americans who need them now, pass them for yourself and for your son, daughter, wife, husband, father, mother, grandchild, or friend who will need the services these bills will create. If you fail to pass these two bills, know that you or someone you love may need these services. Are you prepared to explain your vote on these bills to that person you care about when that person has to enter a nursing home less than two years after he/she graduated from high school as I had to do? If you are not prepared to explain a negative vote to a family member or close friend, why should you explain such a vote to your constituents?

My Personal Story

I was born in 1961 and diagnosed as having cerebral palsy soon afterward. The doctor who diagnosed me urged my mother to institutionalize me then because he said that I would probably die before age 30 and that if I could learn to talk at all, my vocabulary would be limited to around six words. Fortunately, my parents ignored this early advice and raised me as the oldest of four children. In the 1976-77 school year, I began taking classes with non-disabled students. I was the first student who could not read or write in the normal way to attempt this in Gwinnett County. In this same school year, I became the first student with a disability to earn a Perfect Attendance Award from that school system, and I repeated this accomplishment in the next school year as well.

In the 1978-79 school year, I started taking 4 high school classes per day with non-disabled students and 2 classes per day with the special education teacher. This would become my schedule for the next 4 years, and I now regard my high school years as the best, most "normal", years in my life. I won many academic awards including the Algebra One Award, National Honor Society membership, Junior Marshal, Honor Graduate, and several other awards as well. I even participated in interscholastic competition in my high school's chess club and math club. Then, in June of 1982, I graduated. For most students, their high school graduation is the beginning of their lives; for me, however, this was the end of my very active social life of high school and the beginning of my personal Dark Age.

I call the twelve years following my high school graduation my Dark Age not because this period of time was all bad because I had plenty of good times mixed in with the bad; not because I did not develop socially or intellectually during this period because I did – though not as much as I would have liked. These years are dark because when they began, I could not see into them and because very little of what I studied in this period applies to my life now.

I knew I could not continue living at home as 2 of the 3 graduates with disabilities from the previous year were doing because my siblings wanted to live their own lives – to pursue their own American Dream – as was and is their right. I also did not want go to a 4-year college program. At this time, I wanted to be a computer programmer, and in the early and middle 1980s, a person did not need a 4-year degree in Computer Science to get and keep a good programming job. My post-secondary education plan was clear: I would take a training program that taught people with disabilities to be computer programmers. That program would then get me a job and I would make enough to pay for my needs and hopefully meet someone to share my life with romantically and sexually. In short, I wanted (and still want) my own American Dream.

Yes, my vocational goal was clear, but where would I live until I achieved it and was able to pay for my own needs? I needed more personal care help than anybody who had graduated from the Gwinnett County special education program up to 1984 even though I was not – and am not – sick. My parents had to help my siblings get started with their lives and prepare for their own retirement. My parents did not make anywhere near enough to do all this and provide in-home care for me.

My parents tried to avoid institutionalizing me, but in Georgia in the early 1980s, Medicaid absolutely refused to pay for any in-home care -- even the 6 hours my parents needed between the time my mom went to work and the time my dad got home. To Medicaid, it was better to pay thousands of dollars per year to keep me in a nursing home than a hundred or so dollars every workday so my parents could keep me at home while they worked. This was the major reason my parents sought nursing home placement for me.

The way to keep long-term care costs down is to maintain family involvement. Once a person stops living with his/her parents, it is almost impossible to re-establish that arrangement or to get other relatives to help provide care. I know for certain that my parents and siblings will never again be my primary caregivers; we do not want that, but if Medicaid had given us what we needed so they would not have had to institutionalize me, they would not have made me leave.

In the first week of October of 1983, about 16 months after graduating from high school, I entered a nursing home: something nobody should have to do – especially at age 22! I believed that I would not be in a nursing home long – or if I were, I could at least use the money from the programming job I was going to get to pay for a private room away from all the loud, confused, sick people who were in general 4 to 7 decades older than I was at that time.

The nursing home had trouble bathing me and getting me up for my ride to class even though I only went twice a week at most. I often could not get up to work on my assignments because of the chronic shortage of staff and because of the low quality of staff this first nursing home had. Being in a nursing home was better than living at home – having siblings fuss over who would do what for me and waiting an hour or more just for one drink – but not much better! Again, with today's family support, there would have been less stress on my family from having to provide my care. As a result, I would have been more inclined to stay home – but NOT WITHOUT APROPRIATE OUTSIDE HELP!

In 1986, I graduated from the Georgia Computer Programmer Project with at least a high B grade, but one reason the Project staff gave for not seeking placement for me was the fact that I was not in control of my care.

The Story of a Friend

I only spent 10 years and 2 months in the nursing home system; this system only stole part of my life. Now, if you will bear with me for a few more paragraphs, I will tell you of a man who died in this repressive, controlling system.

In the first nursing home that I lived in, there were already 3 people with cerebral palsy living there when I entered it. 2 were women in their early to middle 30s: the other was a man of similar age. One of the women died within 2 years of my entering that nursing home; the other left (presumably for another nursing home) about a year before the nursing home I was in withdrew from the Medicaid program. The other man in that nursing home went to "school" with me from the middle 19600s through the early 1970s though I did not know him in "school" due to the difference in our ages: his name was D'Wayne Jones.

In the middle 1980s, D'Wayne and I were roommates with 2 other men in that facility. This nursing home was chronically understaffed in the intermediate care wing where we were. The nursing home was in compliance with state regulations – or told D'Wayne and me that it was --, but I call making people wait an hour or more to use the bathroom, not getting people up in time to go to school or to church, making people get up at 5:00 AM or stay in bed until lunch time, failing to give someone a bed bath for 5 weeks, and many other things that happened to D'Wayne and me inadequate staff to meet the basic needs of residents regardless of what official regulations say or do not say.

In 1986, with help from D'Wayne's friend, Chip, D'Wayne and I sent letters to the Georgia Ombudsman Program requesting its help in dealing with this nursing home. Within 6 to 9

months, we were told that this nursing home was withdrawing from the Medicaid program; therefore, all 5 of its Medicaid residents had to find other places to "live". D'Wayne's mother – fearful of having to pay the private rate – made D'Wayne take the first vacancy that came up: a really bad nursing home in extreme southwest Atlanta. Before D'Wayne moved to this nursing home, I went to look at it, and it was far worse than where we were. I never considered it. My family was more trusting of my judgment and of the nursing home's pledge not to charge while I sought placement elsewhere.

Over the Summer of 1987, D'Wayne moved to a much better nursing home in western Gwinnett County – a facility that was on my list of acceptable nursing homes, and in the Fall of that year, I moved there as well. D'Wayne continued making the direct-care staff give him adequate care, but when it came to dealing with issues such as understaffed shifts, getting residents up too early, and similar problems, he wanted absolutely nothing to do with my efforts to make the nursing home do what was right.

In August of 1989, James D'Wayne Jones, my former roommate, drowned in the lake in the park beside this nursing home. He went there very frequently without a staff member accompanying him, but he was extremely proficient at controlling his powered wheelchair; these were his few moments of freedom. This was as "independent" as Medicaid "allowed" people who only had a physical disability to be in the 1980s. I am glad the nursing home and his family did not try to stop him from going to the park: he died doing what he liked, doing the best he could with the life and the skills he had. What better memorial could any of us hope for?

Conclusion

Now, after ten and one-quarter years of more freedom than D'Wayne ever had, I now work to help other Americans with disabilities get out long-term care institutions. In special education, we have a term "least restrictive environment appropriate for the student" that all students are supposed to be educated in. The U.S. Supreme Court has ruled that adults with disabilities have the right to live in the least restrictive settings appropriate to their needs, but states – Georgia being the ringleader – remain in defiance of the civil rights ruling known as the Olmstead decission. Please, pass S-971 and S-1394 to make it easier for states to comply with the Olmstead ruling. After these two bills become law, however, states that remain in defiance MUST be punished for the sake of all Federal civil rights laws and related court rulings.

Programs for Accessible Living

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April 14, 2004

Senate Committee on Finance
Att: Editorial And Document Section
Rm: SD-203
Dirksen Senate Office Building
Washington, D. C. 20510-6200

Hearing Date: April 7, 2004
Topic: "Money Follows the Person"

Dear Committee:

I am writing regarding needed testimony regarding the hearing from April 7, 2004. As an advocate coordinator here at PAL and works directly with people with disabilities on a daily basis, I feel and others with disabilities that S-971 and HR 2032 that this is most important piece of legist ration. Even though the earlier bill introduced by Newt Gingrich in 1997, was scored by the CBO at $10-20 billion, the current version of the bill has never been scored. A quick review of the cost information and other research from the University of San Francisco indicates that a new CBO score is needed and that it should come in well under the old score of the Gingrich bill. The other historical information indicates the need to even the playing field between home and community services and institutions has been around for 35-40 years. Regarding background information is attached in regards to the cost. I have also included historical perspective on why the "Home and Community based services should be as equally available"

Again please note that is the most important part of work we feel going on in Washington this year and its about time something has happened on these two parts of legistration.

Sincerely,

Kevin Nale
Advocate Coordinator

Historical Perspective on HCBS

Historical Perspective on Why Home and Community-based Based Services Should Be As Equally Available as Institutional and Facility-Based Services

By Michael Oxford, NCIL President

The only barrier to making home and community-based services (HCBS) equal to institutions in any State in the country is political will. While institutions are mandatory and HCBS are only optional under federal law, there is no prohibition to making both types of services mandatory under state law. In fact, we find language and policy encouragement to do so stretching over the last twelve years from the Clinton administration while Donna Shalala was HHS Secretary, through the present with Tommy Thompson under President Bush.

The New Freedom Initiative, Keeping the Promise, various "Dear State Medicaid Director" policy letters, as well as two "Money Follows the Person" initiatives - one forthcoming according to Dennis Smith, Medicaid Director and in bi-partisan legislation co-sponsored by Senator Tom Harkin (D IA) and Senator Gordon Smith (R OR) - and Real Choice Systems Change funding, all point toward ending the institutional bias and certainly not prohibiting any state from undertaking state activities aimed at the very goal of an even playing field between institutions and HCBS.

There are serious policy, especially budgetary, issues to be tackled. These, though difficult, are not insurmountable. This is why we continue to have various multi-million dollar funding opportunities to change systems; systems that are

old, static and that have been in place for almost 40 years. In fact, information has recently emerged that, sadly and amazingly, indicates that the need to "even the playing field" has been identified and worked almost 40 years ago. It appears that as a matter of policy and law, we have been going around and around since as early as 1967!*

We see a remarkably close description of our problem and an incipient solution going clear back to 1967. Public Law 90-248, 81 Stat. 902 (1968) amended section 1902(a)(13) of the Social Security Act requiring that states must provide "for the inclusion of home health services for any individual who, under the state plan, is entitled to skilled-nursing home (the old skilled-nursing facility designation) services." This language came from a bill, S. 1661, sponsored by Senator Frank Moss, Chairman of the Long Term Care Subcommittee of the Special Committee on Aging. This bill had a goal of "...assuring the availability of both nursing home and alternative non-institutional services for recipients ...and to encourage the use whenever professionally determined to be appropriate of non-institutional services...". This bill also required regular medical review of nursing facility residents and review of the "necessity and desirability of continued placement of such patients in such nursing homes and the feasibility of meeting their health care needs through alternative non-institutional services". (S 1661, 90th Cong. $3(a)(2).

In Senator Moss' remarks, while introducing his bill, he stated that the Medicaid program had been justifiably criticized for having a bias toward promoting institutional confinement of public assistance clientele and that services, at times, were only provided and funded if a person was placed in a nursing facility and that there should be an alternative to institutions where appropriate for people able to live independently. He went on to say that there was no evaluation of potential for rehabilitation and discharge and no program of

care directed toward that end.

Senator Ross was remarkably prescient. It is sad to say that his words are still remarkably current. His language, above, passed into law (PL 90-248, 81 Stat. 906), but was later removed upon passage of Nursing Home Reform Act in 1987 where only the ICF/MR retained the requirements to review the appropriateness of placement. However, under the Nursing Home Reform Act, language remained and remains, that requires nursing home residents "have the right to reside and receive services in the least restrictive environment" even though the specific requirement of regular reviews was lost. [PL 100-203, 101 Stat. 1330-183, 188. 42 U.S.C. $1396 (r)].

Clearly, when the specific review requirement was lost, the "least restrictive" language has been ignored. How can appropriateness of placement be monitored and enforced without some sort of review and where required, an enforcement mechanism?

This little history lesson should serve to further point out that not only is there no prohibition to following up and strengthening "equal availability" under state or federal law, it could, and more probably should, be done to better comply with other federal laws like the Nursing Home Reform Act and the ADA / Olmstead decision.

** Historical information provided by Mike Oxford and Steve Gold.*

Relevant background cost information:**

- The costs of nursing homes and institutions as a whole has risen 33% in the past five years even though serving many fewer people.
- Residential care, also known as assisted living, has experienced a 98% increase in the past ten years. This country is once again creating a long term care industry without any kind road map or plan for the array of services we really need into the future. This lack of foresight and planning is how we ended up with a nursing facility industry which grew from $860 million a year just prior to passage of Medicaid to over $60 billion a year in only a couple of decades.
- There is a myth that only the very elderly enter nursing homes these days. The truth is that there has been a 16% increase in working age people going to nursing homes in the past five years while the elderly population has stabilized. Ten percent (10%) or 170,000 residents of nursing homes are working age.
- In the past seven years occupancy rates in the nursing homes have declined by 7% or 126,000 fewer people. At the same time costs have risen 46% on a per capita basis!
- Home and community programs serve over 400,000 more people than nursing facilities and intermediate care facilities (ICF) combined. This is 25% more people served, yet home and community programs only get 30% of the total Long Term Care funding while institutions get 70% of the funding.
- Medicaid Waivers on average cost $17,000 per person. Nursing homes cost between $40,000 and $50,000 per person.
- Medicaid Waiver funding is not evenly distributed across populations:
    - MR / DD programs serve 39% of the people and get 74% of the money.

  - Traumatic Brain Injury and mental health programs serve 1% of the people each and get 1% or the money each.
  - AIDS programs serve 2% of the people and get 1% of the money.
  - Aging and disabled programs serve 60% of the people and get 24% of the money.

- Thirty-three percent (33%) of states have more restrictive financial eligibility rules for home and community based services than for nursing facilities and 42% of states have stricter rules than required by the Federal government.
- There are 158,000 people are on waiting lists for services post Olmstead. Examples include - Georgia has 9,400 people waiting. Indiana has 7,300 people waiting. Wisconsin has 20,000 people waiting. New Mexico has 6,300 and Texas has 50,000 74,000.

Many policy makers say the current system is okay, that it is regulating itself. They feel that there is no need for long term care reform in Medicaid. That increased flexibility and optional programs are also okay, and that there is no need to...

PROTECTION AND ADVOCACY FOR PEOPLE WITH DISABILITIES, INC.

The Protection & Advocacy System for South Carolina

April 19, 2004

Senate Committee on Finance
Attn: Editorial and Document Section
Rm. SD- 203
Dirksen Senate Office Building
Washington, D.C. 20510-6200

Re: Money Follows the Person
Hearing Date: April 7, 2004

Dear Committee Members:

I am writing to offer testimony on behalf of Protection and Advocacy for People with Disabilities, Inc. (P&A) in support of Money Follows the Person (S. 1394) and MiCASSA (S. 971). P&A is a nonprofit corporation and a member of a nationwide system of protection and advocacy organizations. Our mission is to provide legally based advocacy services to people with disabilities in South Carolina. Over the last 4 years we have made it one of our a priorities to help individuals with disabilities live independent lives in the homes of their own choice rather than in institutions or nursing homes. During that time we have provided direct advocacy services to nearly 200 individuals and information and referral services to over 1500 individuals with this problem. P&A staff served on the Governor's Home and Community Based Task Force which was formed in response to the Supreme Court decision in the Olmstead v. L.C. case.

Through this work we have learned how important Medicaid waiver funding is for individuals trying to move from an institution or a nursing home to a home in the community. Medicaid waivers pay for many of the services and supports that individuals need to live independently--attendant care to help with personal needs, motorized wheelchairs to help with mobility, lifts to help with transfers to and from bed, etc.

Unfortunately, access to Medicaid waiver funding is severely limited. Waiting lists for these services are long. This is due, in large part, to the institutional bias in federal Medicaid law. Money Follows the Person (S. 1394) and MiCASSA (S. 971) will reverse this institutional bias and allow more individuals to live in their own homes rather than being forced to live in institutions.

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On behalf of P&A and most importantly our clients I ask you to support these important bills and put the federal government on the side of independent living for people with disabilities rather than institutional care.

Sincerely,

Lesly A. Bowers
Managing Attorney for Advocacy
Protection and Advocacy for People with Disabilities

Cc: The Honorable Ernest Hollings
The Honorable Lindsey Graham

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Raymond Rayford
43 years old.

Philadelphia, PA

Spent 4 years in Philadelphia Nursing Home

I was hit with a pipe and went to Magee Rehab. I could not go home and have my family take care of me. I went to the nursing home because they did not give me a choice of community services. In the community, I have a choice to do the things I like to do. I hope to be able to help others in the nursing homes like someone helped me. Advocates from LIBERT RESOURCES told people in the nursing home they could get out with services. So I heard it from other consumers. It took me 6 months to move out. When I was in the nursing home, I could not leave without a doctor's note. If I wanted to go out, I had to take a drug test. These were the restrictions if I wanted to see my family. If I wanted to go to bed later in the nursing home, I would have to spend the night in my chair. I would feel bad if I had to go back into a nursing home. I would just disappear. I am not going back.

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Eileen "Spitfire" Sabel
53 years old

427 East Washington Lane.
Philadelphia, PA 19144

In an institution for 2 years.

I was a victim of domestic violence and ended up contracting viral encephalitis. I was in the hospital and when I recovered, I had brain damage. My parents put me in an institution and were told to not have any hope for me. While in there, I was raped and almost killed. I would lie in my own waste for hours, waiting to be changed. I was unhappy and wanted out.

An advocate helped me get into Bryn Mawr Rehab where they helped me get back my ability to walk and talk again. They helped me get back into the community and I was able to live on my own. I have been very happy and I get to eat what I want to eat and live how I want to live.

I have become an activist with ADAPT to speak out on institutionalization and help my sisters and brothers live in the community. Nursing homes are death camps! I would rather die than ever go back into one.

Statement by Sandata Technologies, Inc.
Stephen A. Silverstein, President
Mark C. Baff, Vice President
26 Harbor Park Drive
Port Washington, NY 11050
Tel: 516-484-4400

Hearing on Strategies to Improve Access to Medicaid Home and Community Based Services

Committee on Finance
United States Senate

April 7, 2004

Chairman Grassley, Ranking Member Baucus and distinguished Committee members:

We appreciate the opportunity to offer this statement on behalf of Sandata Technologies, Inc., a leading provider of advanced information technology solutions and services, in connection with the Committee's consideration of strategies to improve access to Medicaid home- and community-based care. We commend the Committee's leadership in addressing barriers to community living faced by patients who rely on Medicaid, including individuals with disabilities.

As you know, health care is increasingly delivered in home- and community-based settings, and patient demand for such options continues to increase. To address that concern, the Administration's FY 2005 Budget includes several proposals to expand home- and community-based services for individuals with disabilities, including the Medicaid-financed "New Freedom Initiative" and "Money Follows the Individual" demonstrations.

These proposals are designed to expand access to care in a cost-effective manner, recognizing the considerable constraints on available resources within government-funded health care programs. Improved information technology is a critical tool to accomplish these objectives, because it can help providers deliver quality services more efficiently while preventing the loss of limited health care dollars to waste, fraud or abuse.

To increase providers' utilization of information technology, however, it is critical for the federal government to work in partnership with the private sector to identify and eliminate regulatory obstacles that currently prevent its broader deployment. For example, many State Medicaid programs require handwritten signatures on paper documentation instead of accepting electronic records and electronic signatures. By contrast, Medicare accepts electronic records on a nationwide basis.

Once outdated regulatory barriers are removed, providers can rely on proven information technology known as "telephony for home care" to meet the growing needs of patients in home- and community-based settings. This technology allows providers to deploy a capable management infrastructure to reduce administrative costs and prevent waste or fraud, while ensuring that necessary services are delivered to achieve positive health outcomes for patients.

Telephony for home care ensures that patients receive the quality of care defined in their individual plan of care for the appropriate cost. It delivers important benefits to both payors and providers by reducing costs *without* cutting benefits to patients. For example, the City of New York's Medicaid-funded home care program is estimated to *save 5.5 percent of expenditures* from the difference between authorized hours and actual hours of service provided.

This service is available wherever telephone service is available, even under crisis conditions. During the 2003 blackout in the Northeastern United States, for example, the service continued to collect data to confirm that patients were being served. Given the distance involved in providing home- and community-based services to patient in rural areas, telephony is particularly effective as a management tool in those settings.

In addition, telephony can play an important role in addressing concerns identified by the General Accounting Office (GAO) in its June 2003 report regarding deficiencies in government oversight under Medicaid home and community-based waivers. GAO noted that "[n]o nationwide data are available on states' quality assurance approaches or the status of quality of care for beneficiaries served by waivers for the elderly, but concerns have been identified about the quality of care provided under many of these waivers." With its accurate, real-time data collection capability, telephony can increase management visibility into field operations, track tasks accomplished and match them against the patient's plan of care, and provide a comprehensive, permanent audit record.

In the near term, federal health care programs will continue to face significant budgetary pressures. It is therefore essential to ensure that limited federal resources are targeted in the most cost-effective manner possible. Telephony for home care is a proven, reliable tool to advance that objective by reducing expenditures for both payors and providers without cutting benefits to patients. Of course, the resulting savings to the Medicaid program can be used for a variety of purposes, including expansions of care to individuals in need.

As previously noted, broader utilization of telephony for home care has been impeded by outdated State Medicaid rules barring use of electronic records. Federal policies should remove these barriers by directing States to allow Medicaid-contracting providers to use telephony and other technologies to create and maintain electronic data records in lieu of paper documentation. The federal government should also provide financial support to help States update their health information technology systems.

We look forward to working in partnership with the Committee to strengthen the Medicaid program and improve access to Medicaid home- and community-based services.

Thank you for your consideration of our views.



Southern Tier Independence Center

Access your world.

Senate Committee on Finance
Attn. Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Bldg.
Washington, DC 20510-6200

April 13, 2004
Southern Tier Independence Center (STIC)
Attn: Amber George, Darlene Dickinson
24 Prospect Avenue
Binghamton, NY 13901

RE: The New Freedom Initiative: "Strategies to Improve Access to Medicaid Home and Community Based Services"—April 7th 2004. Washington DC.

My name is Amber George and I work for Southern Tier Independence Center (STIC) in Binghamton, New York. I am writing to urge you to support bringing and end to the institutional bias of America's Medicaid long-term care system.

Many hundreds of thousands of seniors and younger people with disabilities are currently stuck in nursing homes. These people are a diverse group; they may be our mothers, fathers, grandparents, children, or other family and friends, but their desire is the same – freedom! People do not want to live in nursing homes, they want their own homes and the Supreme Court's 1999 Olmstead decision affirms that we all have the right to live independently.

In November 2002, the Southern Tier Independence Center (STIC) launched the Community Integration program, the purpose of which was, and is, to assist individuals of all ages and disabilities in transitioning from institutions into the community. This process entails a great deal of planning, communication with other agencies, service providers, family members, etc. It is often a long process that is frequently held up by long waiting lists to obtain housing that the individual can afford and that meets his/her accessibility needs. Also it takes a great deal of planning to get around the institutional bias that still exists in our New York State communities.

As a Community Integration Advocate, I assist people in their efforts to pull together the supports and services they will need to make this happen. Unfortunately, most of the individuals that I serve do not qualify for the comprehensive services and supports provided by the Medicaid Waiver programs such as the OMRDD Home and Community Based Waiver or the Traumatic Brain Injury Waiver. Due to the fact that money is tight and resources are scarce these people often remain institutionalized because they do not have the financial resources, information, or assistance necessary to meet their needs in their own homes. The Money Follows the Person Act as well as MiCASSA, would address problems such as fragmentation of services, inadequate funding, and bias towards institutional placements over community based services.

New York State must develop a more contiguous delivery of services to people with physical and psychiatric disabilities. These Acts would fill in the gaps that we as both consumers and service providers see on a daily basis. This initiative would truly enrich the lives of many New Yorkers and ensure their safety, success, and survival. It would help direct NYS to develop a more comprehensive plan to ensure that people have the opportunity to live in the "most integrated setting" possible. MiCASSA (Medicaid Community Attendant Services and Supports Act) would bring an end to the bias.

Individuals deserve to have real, meaningful and effective choices in what services they receive, where the receive services, and who provides these services. Our nation must pass legislation that would reform the long-term care system and sever the bind between the institution and funding.

To illustrate my point in the urgency of the matter, I have included some of the stories the Community Integration team at STIC has learned from the actual individuals who were stuck in nursing homes without choice. Their names have been changed as well as some of the logistics of their situations to protect their privacy. However, their stories of being affected dramatically by the institutional biases remain quite real and factual. Included here are only the success stories, there still remain a large number of people who we serve that are waiting to get out but without the supports and services available they must remain until we can pull it all together and make it happen.

Mary is a woman in her mid-forties with Multiple Sclerosis. She and her husband bought a large home in upstate NY after he retired from his job in NYC. The couple had planned to fix up the house and rent half while living in the other. Unfortunately, six months after the move Mary's husband had a heart attack and died suddenly. He was her only caregiver. Since Mary's home was in a rural community, and because she had no family or friends living close by, adult protective was called in to assess Mary's situation and determine whether or not she could continue to live safely in the community. The agency that had been providing skilled nursing for Mary decided that she was not safe at home and pulled out, leaving Mary with even fewer supports. Mary was told that she "would have to be placed in a nursing home" and she was taken off to the county facility where she spent the next three years trying to get the services and supports she needed to return to her home. When asked if she was willing to sell the house and move into a small accessible apartment, Mary said she wanted to go back to her own home. As she struggled to leave the nursing home, Mary was told by home care assessment agencies and providers alike that the rural location and run-down condition of her home, as well as the level of care she required, made it impossible for her to receive services in the community. Therefore, she was encouraged to sell the house and use the money to pay for care in the nursing home until she had used up enough of her assets to make her eligible for Medicaid, which would thereafter pay for her stay. In short, Mary was told that, even if she was eligible for Medicaid outside the nursing home, the county would not authorize enough hours of home care to make her safe in her home. With some advocacy and peer support from the Southern Tier Independence Center, Mary was able to find a creative solution to meeting her needs at home. She became friends with one of the aides at the nursing home and arranged to provide room and board in exchange for personal care. Mary was lucky to find a worker at the nursing facility who was interested in providing live-in personal care in exchange for rent and utilities. The situation proved ideal for both Mary and her caregiver. The live-in and her husband did a lot of work on the house and Mary took on the role of tutor and homework coach for the couple's children. She proved all who told her that she could never return to her home in the community wrong. What's even more important was that she has found a place as a valued member of her household and community.

Mr. and Mrs. Mayor had been highly respected individuals in the community. At one point Mr. Mayor was the mayor of Binghamton as well as a political advisor to one of the presidents of the United States of America. In his home, you can find pictures of him with John F. Kennedy. In one

photograph on the mantle you will find a photo of Jackie Kennedy and Mrs. Mayor having lunch. When they reached the point where they could no longer care for themselves they lost the right to choose where they lived and how they received care. Why then were two prominent people who gave so much to their community denied the right to receive supportive care in their own home? How did this loving couple end up in separate rooms on separate floors in the county nursing home?

These are the questions we had when John Mayor Sr. and his son Joe came to the Southern Tier Independence Center asking for help to reunite husband and wife at home. First of all, the family was told that Mrs. Mayor had been diagnosed with dementia. Her doctor told them that she could no longer remain at home with her husband, but must be placed in a skilled nursing facility where she would receive round-the-clock care. Without having any information about community-based services or alternatives to institutionalization, the family accepted the doctor's decree and Mrs. Mayor became a resident of the county facility where she remained almost until the end of her life. As Mr. Mayor's health deteriorated to the point where he required a wheelchair to move about, he and his children were given the same option that had been presented his wife three years earlier.

A lack of information and/or failure to offer community-based alternatives to institutional care is not the only example of institutional bias in the Mayor's story. Perhaps the biggest instance of the institutional bias that is so pervasive in New York State concerns Medicaid eligibility. When living in their home, Mr. and Mrs. Mayor were not eligible for Medicaid since their monthly income was well above the poverty line. As we know, Medicaid is the only insurance, aside from cost-prohibitive long-term care insurance, that will pay for home care. Without Medicaid coverage, the Mayor family was forced to pay for the care their parents needed out of their own pockets. This became more of a financial burden than the couple of their children could bear over the long hall. Upon entering the skilled nursing facility, however, Mrs. Mayor became eligible for Medicaid in order to pay for institutional care. Her husband signed a spousal impoverishment in order to forestall the dissolution of his home and other assets.

Unfortunately, Mrs. Mayor became ineligible for Medicaid the instant she left the nursing home and returned to the community. Again, Medicaid is the only viable option for provision of home care. This meant that the Mayor family would once again be forced to pay for aide service out of their own pockets. The only possible solution to the problem was to closely examine the lifestyle and habits of the couple in their home and to determine when the needed assistance and what times they felt comfortable on their own.

The Mayors were luckier than most of the people we work with in that they have twelve children and many grand children to assist them. In addition, their family was very approving of their desire to live at home and was willing to fill the gaps in home care and other supportive services.

Woodrow's story is very common to the stories we in the Community Integration Advocates (CIA) Program hear on a regular basis. However, with this story the solutions were within reach provided Woodrow could make some sacrifices to make them happen. Woodrow is a 70 something year old man who served his country in Vietnam. He is a proud veteran who has lived with having MS for over 20 years. He also happens to live in a more rural area of Broome County. His younger daughter who felt like there wasn't much more anyone could do to prevent him from going into a nursing home referred him to our services. At one point in Woodrow's life he had been in the Veterans nursing home because his Dr. and other service providers told him he had no choice. While he was in the nursing home he lost a great deal of his independence and mobility as well as his spirit. After being in the institution for many years, his daughter decided she had had enough of the abuses and maltreatment that her father received there. She fought tooth and nail to get him out and home. She assisted him in setting up some limited aide services. Unfortunately she passed away a couple of

years ago and everything went dramatically down hill after his lost of his most powerful advocate, his daughter.

For a couple of years after he left the nursing home, Woodrow received funding from various agencies such as the Veterans and Office for Aging to help manage his aides and home service care. Because budgets are tight and services sometimes become unreliable he lost total coverage of his aide services. Over the years he was lucky enough to have met a long lasting and dedicated aide named Judy. Even when the funding ran dry, Judy stuck by him to see that he got out of bed each morning, received his meals, and kept his medications straight. For the past year or so, Woodrow was able to pay for part of her services but a good majority of her time went unpaid. For the most part Judy worked for Woodrow on a volunteer basis. After a few months, it became very clear that scraping by with both aide service and low funds could not keep Woodrow home much longer. Both Woodrow and Judy did the best they could but everyone quickly became burnt out and began feeling hopeless.

The CIA team went to Woodrow's house to brainstorm ideas numerous times. For his heroic services in the United States Navy, he receives a bit of extra money for being a veteran. He also receives benefits and income from the Social Security Administration. One would think being a war veteran would grant one a little more freedoms and liberty especially in older age. However, in this situation his extra income (even though at the end of the month he has nothing left) works against him in terms of getting Medicaid funding for aide service. Woodrow does not own a car, a house, or have any outstanding debts to anyone. He's simply a person trying to survive with meager funds that to someone else looks like a lot of money but for him he can barely survive. Overall, Woodrow was simply afraid of losing his extra income for fear he would be put in poverty without it. He felt that poverty would be one step closer to a nursing home.

From our brain storming sessions we figured he could enroll in the Medicaid Buy-In program and we even had found him a job that he could do from home! However, because of his age he was ineligible for the buy-in because it only covers people up until they are 65 years old. We also thought that we could help him set up a Supplemental Needs Trust where he could put his extra money and not have it count against him for Medicaid eligibility. This too has a strict age limit of 65 years or younger. Because he doesn't have a brain injury or meet any other disability criteria for waiver programs he couldn't apply to get the much needed aide coverage. Nevertheless, from our investigation of solutions we found he could not enroll in these waiver programs even if he met the disability criteria because they too have strict age requirements that last up until one becomes older than 65 years.

It took a lot of talking, peer counseling, and organizing to finally have Woodrow see that taking the Medicaid spend-down would be the best way for him to receive more aide coverage and stay in his own home. As it turned out, his spend-down would be about $650.00 less his total income per month, of which he was already spending about $700.00 of his income to pay out of pocket for his aide Judy per month! Once Woodrow realized the huge expense of paying out of pocket and the probability that through the Medicaid program he could receive more hours each week he thought it was a great idea.

We helped him set up a home visit with the Social Security administration to get enrolled with Medicaid services. They visited his home and filled out the paperwork. Within two months he was approved and ready to go with STIC's Consumer Directed Personal Care services. As a result, he was given about 5 more hours than he's ever had previously and was able to give Judy more hours and more reliable pay for her services. Woodrow is thrilled to be at home. However, as time has gone by he has learned that he must live very strictly and on a very tight budget. He is very afraid of not having money and because of the spend-down he needed, he barely covers his bills each month. For him it is an absolute shame that he has to be broke, worry constantly about whether or not he will make ends meat just for the simple privilege of living at home and having community based supports.

These are just a small sample of the kinds of stories and situations that we here at STIC see on a daily basis. As you can plainly see, if we had in place these important pieces of legislation, people would be able to stay at home and find much more meaning to their lives, independently. The ultimate solution to ending the institutional bias, which has stolen the lives of so many seniors and people with disabilities, is very clear. On April 7th, 2004, I and about 10 other advocates from the STIC attended the hearing that the Senate Finance Committee held to address these issues and find real working progress. The hearing was monumental in the disability community, but it's not enough. We need real change now! I want to thank you for having the hearing and also ask that you have more in the immediate future. Please pass MiCASSA! Free our People!

Sincerely,

Amber George

Systems Advocate
Community Integration Advocate

Darlene Dickinson

Community Integration Advocate

Southern Tier Independence Center
24 Prospect Avenue
Binghamton, NY 13901

To: Senate Committee on Finance
c/o Editorial + Document Section

From: Mary Storer, Cary, NC
Date: April 5, 2004
Subject: ADL Care

Please don't make my nephew, John Mulhearn, go into a nursing home. He has CP and is living a full life at home. Please let our tax dollars support Americans if they choose to stay at home and receive in home care. Please let the money follow John and allow him to stay at home with his Mom, Dad, Sister (twin), and his extended family. We love him — Please don't send him away. Please.

pp. 1
Senate Finance Committee
Testimony of Carolyn Stubblefield
Money Follows the Person

April 12, 2004

My name is Carolyn Stubblefield. I am responding to the hearing on April 7th for the Money Follows the Person. My address is 1806 Osborne Rd. Hazel, Ky. 42049.
I work in the disability field and I have seen firsthand the need for attendant services for the disabled. I urge you to pass the Medicaid community-based Attendant Services and Supports Act (MICASSA) and the Money Follows the Person Act. If people have attendants they can stay out of nursing homes and save the state a lot of money, plus having a better quality life.

Thank You,
Carolyn Stubblefield

April 4, 2004

Senate Committee on Finance
Dirksen Senate Office Bldg.
Washington, DC 20510-6200

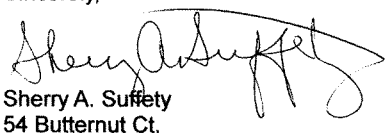
Dear Senators,

This letter references the Senate Finance hearing on "Ending the Institutional Bias" to be held Wednesday, April 7, 2004. I support the inclusion of MiCASSA (S.971) and Money Follows the Person (S.1394) in this hearing and encourage the support of this legislation.

After taking so long for us to finally allow a person the right and dignity to die in their own home with in-home care, why should we even doubt that someone needing assistance in activities of daily living is not entitled to the same respect, to choose to remain in their own home and receive such support. This is vital to each citizen's freedom and independence – the very things that this country is about. Not only would in home care be allowed, but with the passing of this bill, an individual can still receive the financial support to which they are entitled.

Support this legislation!

Sincerely,



Sherry A. Suffety
54 Butternut Ct.
Chelsea, MI 48118

March 19, 2004

United States Senate Committee On Finance
Attn. Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Building
Washington, DC 20510-6200

RE; Strategies To Improve Access to Medicaid Home and Community Based Services

I am writing you today to ask you to vote and pass any bill that would benefit home based Medicaid services. Today there is a greater demand due to the fact our disabled population are not only increased in numbers, but we are getting poorer. Nursing homes are not the answer.

I was disabled in 1995. I worked as a professional nurse until that time. I know from experience, the both sides of life. When a disabled person is placed in a nursing home to live, you might as well sentence him or her to life in prison. It destroys all of any hope for recovery or hope. I am managing well now with my personal care attendant to help me daily. I have returned to college to take a computer based program to add to my medical knowledge. In 2005, I will be qualified for a position as medical case manager. With out my Medicaid based community services I too may just be wasting my years in some nursing home or acute care setting.

Please hear our plea!!!!!!!!!!

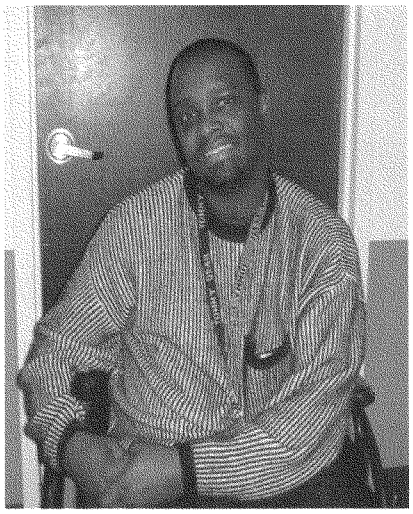
Sincerely;

Beatrice Sylla

Beatrice Sylla
1120 s. 52nd Street
Philadelphia PA 19143

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.



Name: Ken Thomas

Address: 4001 Monument Ave.

City: Philadelphia State: PA Zip: 19131

Age: 34 Phone: 215-477-1915

Type of institution:

Nursing Home X
State Institution/Developmental Disability
State Mental Hospital
Group Home
Rehabilitation Facility

How long institutionalized? 10 years

Please attach a short summary of your time in the nursing home or other institution and how your life has changed now that you are out.

In there, I lost my freedom; I lost my enjoyment of life. I was unable to meet people. The people in the institution were mean to me and told me what to do and when to do it. They took away my wheelchair, which was my only way to get around. Mostly, they took my heart away because they were evil to me.

ADAPT—FREE OUR PEOPLE!

Dennis Tomlin
1500 Wind Creek Farms Road
Alexander City, Alabama 35010

April 9, 2004

Dear Senators,

Unfortunately I am unable to attend these very important meetings in person but would like to offer this letter on my behalf.

Until you have faced a situation that leaves your fate and day-to-day existence in someone else's hands it is very difficult to truly relate with the kind of situations that you are forced to address in these very meetings. Due to a diving accident in 1985 at the age of 15, I have the fortune or misfortune to understand firsthand what it means to live life on the edge. The edge I speak of is a fine line between living in a nursing home and living in a normal home environment.

While in the hospital my physical fate became very clear, unless God or medical doctors could improve my situation I would be a C5 -- C6 quadriplegic for the rest of my life. In layman's terms, I am paralyzed from my chest down with some movement in my arms but no ability to grasp with my hands. I use an electric wheelchair to move me from place to place and highly specialized driving equipment allows me to drive my van. Once I am dressed and in my chair for the most part I am somewhat self-sufficient. However, without someone to dress me, help me with personal hygiene, and to help me with my bowel program not only would I be tied to a hospital bed but also I would be dead. All of the things just listed I cannot achieve without assistance.

That leaves me two choices; make sure someone is available to help me with my personal care on the outside or be committed to a nursing home environment. I am very fortunate that for the first 12 years after my accident my father was able to take care of me. It was not easy and most would question was the fight to live really worth it? I can tell you, yes it was! And yes it is!

In those 12 years I graduated from high school, I graduated from Central Alabama Community College with an associate's degree, and went on to graduate from Auburn University with a bachelor's degree. I had the opportunity to fly over the Grand Canyon and see one of God's truly amazing feats. I have had the opportunity to work with public officials and travel the state doing interviews with country legends. As a college broadcast instructor and a teacher at a local boy's and girl's club I was able to inspire and encourage today's youth. I was able to tell them that there is no dream too great to reach for and every accomplishment, no matter how small, is a building block to their success.

I was able to experience things I never dreamed possible after my accident. As wonderful as the experiences were for myself, I often found others enjoyed my experiences as much or more than myself. I found that I was giving as much as I got. As a "roll model" for Spain Rehabilitation Center I have been able to visit with newly injured spinal cord injury patients and their families. Unlike the psychiatrist that counseled me when I first was injured, I do not show up in a suit and sit behind a big desk speculating what they are going through. I have lived it and I continue to live it every day. I can be brutally honest with them and tell them there will be difficult days. There will be days where the slightest thing will make them cry and beg to die. However, I can also tell them that no matter how severe their injury the only thing stopping them from having a full life is themselves. I tell the hunters they can still hunt. I tell the fishermen they can still fish.

I tell the lovers that they can find love again. I tell them all, they can still live a long fully productive life but they will have to fight for it. No matter what background they have come from or what their life has been like to that point they are now in a fight for life.

Senators, do not think for a moment that I am a hero or for that matter anything special, but I have found that through my own struggles to live a full life I have inspired others around me to battle their struggles head on, face their demons what ever they may be and make their lives as full as possible.

In those first 12 years I also met the love of my life and have been happily married for seven years. Today, I work full-time for the Community College of the Air Force. I have helped to found the organization that I am currently President of, "Rolling Across Alabama." This is the one thing that I am most proud of and it is a very simple thing but I believe it is whom I am and who I am meant to be. I am a person who cares. I hope all of you will join me in this crusade "to care".

I often reflect back on the past 19 years and wonder how different my life would be today if I were forced into a nursing home. My first thought is always the same. I would be dead. If I were to receive adequate care and managed to survive I know that I would not be the same person writing this letter to you today. I would not have finished high school. I would not have graduated with an associate's degree or a bachelor's degree. I would not have had the opportunity to see this great country we call the United States of America. I would not have been able to speak to elementary, middle school, or high school students and touch those students struggling with their grades, struggling from peer pressure, struggling to survive. I would not have been able to tell them they can make it! Tell them not to be afraid to have dreams but to dare to dream, reach for their dreams, and make their dreams become a reality. I would not have been able to meet a young man at a fireworks display and make his day just a little better by seeing someone else there, someone just like him, severely physically disabled, enjoy the fireworks. I would not have been able to offer some hope for his parents that he too can have a wonderful life.

I would not be a Department of Defense employee helping Air Force enlisted members achieve their educational dreams. Yes, someone else could be doing my job but because I did not have to go into a nursing home, because my dreams were able to run wild, because I had a chance to live a full life, I am doing my job! And it is because someone before me fought for my right to live a full life that I am now fighting for my life but more importantly I am fighting for every individual that comes after me.

Dear Senators, join this fight with me! Do not make individuals that are depending upon you call a nursing home their home. Do not tell them their only opportunities in life will come while they are asleep. Dear Senators, let their dream of living a full productive life become a reality.

I thank you for your time.
Respectfully,

Dennis Tomlin
President, Rolling Across Alabama

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Susan Trager
42 years old.

Philadelphia, PA

Spent over a year and a half in two nursing homes.

I went into a coma as a result of my drug use. A visitor of another resident in the nursing home told me about community services and I got myself out. She was gang raped in one of the nursing homes. I was deprived of meals and showers for speaking my mind. Just being free now is great. I would kill myself if I had to go back. Nursing home is jail without a crime. I have been out for 8 years and I am an activist with ADAPT.

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Darryl Tuague
52 years old.

Philadelphia, PA

1 year in Greenleaf Nursing Home.

I have been out for six months. My wife put me in the nursing home after I had a stroke. She didn't think she could take care of me with three kids to raise. I am presently getting a divorce. My friend Calvin from the nursing home told me about the community services. I went to LIBERT RESOURCES to get services to get out of the nursing home and I was able to get out in one month. I like it a whole lot better and I can do more out here. I stopped seeing my kids while in the nursing home because my wife stopped bringing them. Now I am fighting to get visitation with my kids which I can do. I couldn't do this in the nursing home. I feel safe out here. I will never go back. I do miss some of the other people and I go back to visit them. I saw other be abused at the nursing home but I was not. My life is much more together being in the community. I have options out here.

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Marlene Turon
40 years old.

158 N. 23rd Street, Apt. 813
Philadelphia, PA 19103

Main Line nursing home for 9 years.

It took six months to move out of the nursing home due to difficulties in finding housing. LIBERT RESOURCES came to see me about getting a wheelchair and one year later and said I wanted to move out. Since I moved out, I regained my independence and dealing with real life. I do have anxiety over dealing with responsibility; but, I do have more control out here and I feel safe. If I had to go back into a nursing home, "they wouldn't take me alive." I do miss my roommate and my friend's mother from the nursing home. I am resentful for not being told of the choices that IU had out here. I wasted 9 years of my life in the nursing home. I get so depressed thinking about if I had had to spend the rest of my life in a nursing home.



Expanding Opportunities for Veterans
and All Paralyzed Americans

"Money Follows the Person"
Senate Committee on Finance
Wednesday April 7, 2004

Submitted by:
United Spinal Association
75-20 Astoria Boulevard
Jackson Heights, NY 11370
Tel. (718) 803-3782

Contact: Kimberly Ruff-Wilbert
(202) 331-1002

STATEMENT FOR THE RECORD –

Individuals with disabilities want and deserve to live independent lives. The Americans with Disabilities Act (ADA) established over thirteen years ago, is the most comprehensive law focused on protecting the civil rights and promoting the independence of individuals with disabilities. The 1999 U.S. Supreme Court case *Olmstead v. L.C.* was a major test for the ADA. In the Court's *Olmstead* decision, the ADA was upheld when the Court ruled that unnecessary institutionalization constitutes unlawful discrimination under the ADA. As long as the individual agrees, treatment and personal supports and services of an individual with a disability must be conducted in a home or community setting over an institution when deemed appropriate, and of equal or less cost. Implementing and coming into compliance with *Olmstead* means promoting community integration over institutionalism and rebalancing long-term services and supports.

The landmark *Olmstead* decision paved the way for implementing and promoting Federal policies of community integration and support services over institutionalism. However, since this decision, individuals with disabilities and advocates have faced a variety of barriers to community integration. The main barriers to community integration include the inherent institutional basis of the Medicaid Program, the lack of affordable and accessible housing and the critical shortage of quality personal assistance professional and support staff. Steps to alter the unnecessary institutionalism of the Medicaid program are underway. United Spinal Association, a national disability advocacy organization dedicated to enhancing the lives of individuals with spinal cord injury or disease (SCI/D) by assuring quality healthcare and advocating for the civil rights and independence of individuals with disabilities, supports legislation such as the Medicaid Community-Based Attendant Services and Supports Act (MiCASSA), Senator Harkin's Money Follows the Person Act and the Bush Administration's New Freedom Medicaid

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Washington, DC 20036-3726

Tel 202 331 1002
Fax 202 466 5011
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Demonstrations Act, can lead to the rebalancing of long-term supports and services in the Medicaid Program.

MEDICAID AND ITS INSTITUTIONAL BIAS

In order to live independently, individuals with disabilities need full access to home and community based services and supports (HCBS). Most require help with daily activities such as eating, bathing or shopping. Unfortunately, Medicaid requires that states cover the full cost of nursing facility services, which are by nature institutions, making nursing homes the entitlement of Medicaid recipients. Home and community based services and supports, unlike nursing facilities, are optional coverage under Medicaid.

Each state may therefore choose to supply home and community based services. The services are provided in the form of 1915 (c) waivers. HCBS waivers have significantly expanded coverage, but they have far from leveled the playing field between home and community based services and institutionalism. Most state governments do not recognize HCBS waivers as entitlements; they are viewed as optional benefits. This optional benefit coverage results in long wait lists for these high demand/low supply services. The conclusion drawn is that Medicaid is institutionally biased.

Further evidence of this institutional bias is Medicaid spending allocations on institutions versus HCBS. In 2001, approximately 35 percent of total Medicaid funding was spent on long-term supports and services. Of this 35 percent, approximately 71 percent was spent on nursing facilities and intermediate care facilities for the mentally retarded (ICF/MR). In other words, 71 percent of Medicaid long-term supports and services funding was spent on institutional care, where as only 29 percent of such funding was spent on home and community based supports and services or non-institutional care.[1] These findings illustrate the fundamental bias in Medicaid funding towards institutions, and demonstrate Medicaid's reliance on institutionalism. Medicaid spending on long-term supports and services must be rebalanced between home and community based services and institutions.

COMMUNITY INTEGRATION AND REBALANCING EFFORTS

The *Olmstead* decision gives individuals with disabilities and their advocates a vehicle for implementing real choice and self-direction in their long-term care and for rebalancing Medicaid spending. The ruling required each state to develop plans for complying with the decision. United Spinal Association applauds efforts of the disability community, and the Federal and state governments attempts at providing real choice in long-term care for those with disabilities. In addition, these efforts can help state's rebalance their long-term supports and services by implementing their *Olmstead* plans.

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[1] Laura Summer, *Medicaid and Long-Term Care* (Washington, DC: Georgetown University Long-Term Care Financing Project, May 2003, Fact Sheet).

With this is mind, United Spinal Association supports passage of the Medicaid Community-Based Attendant Services and Supports Act (MiCASSA) and/or the Money Follows the Person Act. These bills promote the right to self-determination in long-term care for individuals with disabilities. The purpose of MiCASSA and Senator Harkin's Money Follows the Person Act are to implement the *Olmstead* decision and bring states into compliance through ending unnecessary institutionalism and promote independence for those with disabilities. Moreover, MiCASSA and the Money Follows the Person Act have the potential to bring sweeping reform to current Medicaid policy.

MiCASSA

United Spinal Association supports passage of the Medicaid Community-Based Attendant Services and Supports Act, MiCASSA (S. 971). MiCASSA promotes the right to self-direction in long-term care and provides equal access to community-based supports and services to eligible individuals with disabilities. These changes will promote and give independence to individuals with disabilities.

MiCASSA seeks to amend Title XIX (Medicaid) of the Social Security Act by offering individuals who are eligible for Nursing Facility Services or ICF-MRs to choose where their services will be provided either in the institutional setting or in the community and administrated by community based attendants. These services would be provided based on a functional needs assessment and agreed to by the individual receiving the services. The bill outlines a variety of service delivery models such as vouchers, direct cash payments or via the use of a fiscal agent or the current state or nonprofit agency delivering the services. The key component of MiCASSA is that all services must be provided in the most integrated setting possible and appropriate to the needs of the individual.

Money Follows the Person Act

United Spinal Association alternately supports passage of S.1394 - the Money Follows the Person Act. Money Follows the Person Act, as introduced by Senator Harkin, promotes the right to self-determination in long-term and provides equal access to community-based services and supports to eligible individuals with disabilities. These changes would promote independence in individuals with disabilities and would bring sweeping reform to current Medicaid policy.

Money Follows the Person Act seeks to establish a demonstration project under the Medicaid program to encourage the provision of community-based services to individuals with disabilities. The bill allows for state and Federal Medicaid dollars to follow a person with a disability from an institution into the community. Each state may apply to Department of Health and Human Services (HHS) for these Federal Medicaid dollars, and they may give preference to applications that are designed to rebalance long-term services. As approved by HHS, States will provide community-based services and supports to eligible individuals. The Federal government

will provide a reimbursement of 100% the costs associated with the first year of community services that an individual needs for moving out of the institutional setting.

Individuals eligible for the demonstration project include those who have resided in a Medicaid long-term care facility for at least 90 days and continue to require this type of care. Individuals are allowed to choose the setting in which they desire to receive their community-based services and supports. The bill defines community-based services as any items or services that are an allowable expenditure for medical assistance under the state's Medicaid program (or under a waiver) and that the State determines would allow an individual to live in the community.

THE NEW FREEDOM INITIATIVE MEDICAID DEMONSTRATIONS ACT

The New Freedom Initiative (NFI), announced by President Bush in February 2001, outlines the Administration's nationwide effort to eliminate barriers to community living for individuals with disabilities. NFI outlines proposals for opening doors to people with disabilities in such issues as health care, employment, transportation and education. President Bush also signed Executive Order 13217, "Community Based Alternatives for Individuals with Disabilities", in June 2001. Both NFI and Executive Order 13217 seek to assist states with the implementation of *Olmstead* by promoting home and community based supports and services over intuitionalism.

The Administration's New Freedom Initiative Medicaid Demonstrations Act is the centerpiece of President Bush's New Freedom Initiative. The Medicaid Demonstrations Act proposes the enactment of five demonstrations projects all aimed at helping states comply with *Olmstead*, develop strategies for rebalancing their long-term care systems, and most importantly, increase the independence and quality of life for individuals with disabilities. The demonstration projects include: 1) Demonstration of Respite for Caregivers of Adults; and of Children with Substantial Disabilities; 3) Home and Community Based Alternatives to Psychiatric Residential Treatment Facilities for Children; 4) Demonstration to Address Shortages of Community Service Direct Care Workers; and, 5) Money Follows the Individual Rebalancing Demonstration.

Money Follows the Individual Rebalancing Demonstration

The Money Follows the Individual Rebalancing Demonstration can provide individuals with real choice their in long-term care under Medicaid and help bring states into compliance with *Olmstead*. The demonstration would appropriate $1.75 billion over five years for competitive grants to states that develop and implement a strategy to rebalance their long-term care systems. States would offer individuals a choice between living and receiving their long-term supports and services in an institution, at their home or in their community. The intended results are to reduce Medicaid spending on institutional care and increase use and spending on home and community based supports and services, which would help re-balance overall Medicaid spending on long-term care. The demonstration would allow for self-directed services and encourage individuals to develop a plan of care and services that best fit the individuals' needs.

Financing under the demonstration project would require the Federal government to reimburse 100% the cost to a State's Medicaid program for the first year each individual moves from an institution into home or community based care or non-institutional care. After the initial year, States are responsible for matching payments at their usual matching rate through home and community based waivers or state plan services. Although the Administration's New Freedom Initiative Medicaid Demonstrations Act spells out financing for each of its demonstration projects, United Spinal Association understands that President Bush did not request funding for any of these NFI projects in the FY 2005 Budget Request. We are hopeful that Congress will take action and appropriate significant funding for these types of Medicaid long-term support and services re-balancing efforts.

To conclude, it is an imperative for the Federal and State governments to work in tandem with the disability community and their advocates to alter the institutional bias of the Medicaid program and bring about a re-balancing of long-term supports and services. The *Olmstead* decision gives individuals with disabilities and their advocates a vehicle for promoting self-determination between home and community based supports and services versus institutionalism. It is imperative that Congress supports the disability community giving freedom of choice to individuals with disabilities by enacting legislation such as MiCASSA or Money Follows the Person Act that would provide individuals with real choice in their long-term care, rebalance Medicaid long-term care services, promote the use of home and community based services over institutions, and hasten the implementation of the Supreme Court's *Olmstead* Decision. Thank you.

Senate Committee on Finance
Attn. Editorial and Document Section
Rm. SD-203
Dirksen Senate Office Bldg.
Washington, DC 20510-6200

"Strategies to Improve Access to Medicaid Home and Community Based Services"

Teresa Vangrol
242 West Filbert Street
East Rochester, NY 14445-1802

In my career I have worked with numerous individuals who were forced out of their own homes and into nursing homes. Every one of these people upon admission to the facility were told they would be able to go home within a six week period.

As time moved on they were told that they could not move home because: you don't have a wheelchair, there would not be enough aide service for you to "be safe", you have no family or friends as back up to aide service, your disabilities prohibit you from living in a safe environment in your home. The list of excuses goes on and on. Many people had been in the hospital and were told they had to go to a nursing home for rehabilitation. This rehabilitation turned into an existence of a prisoner behind bars. Their civil rights were violated, they had no choice or options.

One woman I met was told she could not leave the institution because the wound that she had "acquired" since her stay there could not receive the care it needed to heal living at home. Well, she proved them wrong. She was discharged with daily nursing care for the wound and consumer directed attendant services. At home the wound healed nicely and she became involved in the community as an advocate for disability rights issues. Stories such as this are numerous.

We need more of these stories, and the get them, we need MiCASSA!

Sincerely,

Teresa VanGrol

Comment for Public Record
To be **included in the public record** for these proceedings:

10:00 AM on Wednesday April 7, 2004 in 215 Dirksen Senate Office Building – Finance Committee

Topic: **Money Follows the Individual; other New Freedom initiatives**

April 1, 2004

I am a long-time advocate for people with disabilities, and a writer who regularly covers programs that assist people with disabilities in the state of Ohio. I am also the media/pr coordinator for MOBILE Center for Independent Living, located in Columbus, OH. Among the stories I have covered in recent years for disability-related publications are those which spotlight people with disabilities who had been relegated to living in nursing homes for not just one week or one month, two months or three, but for 10, 15, 20 or even more than 30 years of their adult lives. Some of these individuals have been lucky in that they have gotten out alive, and strive to be productive members of society. But supports need to be in place whereby the money used to automatically house a person with a disability in a nursing home could be used instead for that person to take control of his or her own care in his or her own home or apartment. Time and time again, people with disabilities have told me that they are glad to have the freedom to go to bed when they want; go to the stores they want, when they choose; or even have a private conversation on their phone with friends. Please **support** ***Money Follows the Individual*** legislation to discontinue the bias toward nursing home relegation for people with disabilities who do not need that high level, expensive and greatly restrictive way of life. It makes sense, especially in these times of dire financial straits for both government and individual alike, that we seek the most cost-effective, yet least restrictive solutions for Americans with disabilities.

Sincerely,



Shari L. Veleba
Columbus, Ohio

STOLEN LIVES: REAL PEOPLE, REAL VOICES, REAL CHOICES!

SD-215 Senate Committee on Finance to hold hearings to examine strategies to improve access to Medicaid home and community based services.

Alfonso Williams
March 22, 1950 – November 11, 1997

Injured at the age of 16.

Spent 12 years in two nursing homes.

I got out through a service coordinator through Liberty Resources. I was the first of many of m my friends to move out of the nursing home. I was the first one of my friends to ever get an electric wheelchair and the first to attend Community College of Philadelphia. There are so many things that happened in the nursing home while I was there, that I couldn't even begin to describe it. When I moved out into my own apartment, I would invite my friends from the nursing homes to sleep over. And that's how many of them got their first taste of freedom. I have gone to many ADAPT Actions over the years and have given testimony about life in the community versus life in the nursing home. I became a community advocate, went back into the nursing home to talk to residents and I was able to influence one of the people I worked with to move out. I loved being in the community more than anything.

ADAPT—FREE OUR PEOPLE!



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