

**COMMUNITY SERVICES AND SUPPORTS:  
PLANNING ACROSS THE GENERATIONS**

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**HEARING**  
OF THE  
**COMMITTEE ON HEALTH, EDUCATION,  
LABOR, AND PENSIONS**  
**UNITED STATES SENATE**  
**ONE HUNDRED TENTH CONGRESS**  
FIRST SESSION  
ON  
EXAMINING COMMUNITY SERVICES AND SUPPORT, FOCUSING ON  
MEETING THE LONG-TERM CARE NEEDS OF SENIORS AND PERSONS  
WITH DISABILITIES

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JULY 10, 2007  
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(II)

# C O N T E N T S

## STATEMENTS

TUESDAY, JULY 10, 2007

	Page
Kennedy, Hon. Edward M., chairman, Committee on Health, Education, Labor, and Pensions, opening statement .....	1
Prepared statement .....	2
Enzi, Hon. Michael B., a U.S. Senator from the State of Wyoming, opening statement .....	4
Prepared statement .....	5
Harkin, Hon. Tom, a U.S. Senator from the State of Iowa, opening statement .	7
Daniels, Susan M., Ph.D., Daniels and Associates, Washington, DC. ....	9
Prepared statement .....	11
Herring, Monica, Mother of Ellington Herrington, Germantown, Maryland .....	13
Prepared statement .....	15
Faatoafe, Glenda, Home Care Worker, Korean Womens Association, Lacey, Washington .....	17
Prepared statement .....	19
Griffin, Shawn, M.A., Chief Executive Officer, Community Entry Services, Riverton, Wyoming .....	21
Prepared statement .....	23
Imparato, Andrew J., President and Chief Executive Officer, American Asso- ciation of People With Disabilities, Washington, DC. ....	31
Prepared statement .....	34
Fleming, Deborah K., Ph.D., Clinical Professor, University of Wyoming, Col- lege of Health Sciences, Laramie, Wyoming .....	40
Prepared statement .....	41

## ADDITIONAL MATERIAL

Statements, articles, publications, letters, etc.:	
Response to Questions of Senator Enzi by:	
Susan M. Daniels .....	50
Monica Herring .....	50
Glenda Faatoafe .....	52
Shawn Griffin .....	53
Andrew J. Imparato .....	54
Deborah K. Fleming .....	55

(III)



## COMMUNITY SERVICES AND SUPPORTS: PLANNING ACROSS THE GENERATIONS

TUESDAY, JULY 10, 2007

U.S. SENATE,  
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,  
*Washington, DC.*

The committee met, pursuant to notice, at 10:00 a.m. in Room SD-106, Dirksen Senate Office Building, Hon. Edward M. Kennedy, chairman of the committee, presiding.

Present: Senators Kennedy, Harkin, and Enzi.

### OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. Good morning. We want to thank all of our witnesses and we'll come back to an introduction of them and express our appreciation of them individually. We want to thank all of our guests that join us here today. It's a very important issue that we are considering, and I think the wide variety of groups and individuals that have come from far and distant places is indication of the importance of the substance that we are considering here this morning.

Senator Enzi, Tom Harkin, and I were at the door, trying to help people come in, and then, suddenly the hour of 10 arrived and we had to start our hearing. But, we're going—we asked our police officers that are absolutely wonderful individuals—to do the best they can in making this room available, and accessible, for so many of our guests that have traveled far and wide. And I know they are doing their very level best in doing so, and we're very grateful to them for that.

I'll include my statement in the record. But, let me just mention a brief word about how I view our situation in our country.

I was here, in the U.S. Senate, when we passed the Medicare program. We actually lost the Medicare program in 1964, 8 months later. It passed in 1965. Eighteen Senators changed their vote. And, for those that are in this room this morning, ought to understand the power of their vote and political activity. Because, the principal difference between the vote in 1964 and 1965 was the fact that seniors primarily—some in the disability groups—went out across this country and said, "This issue is important. It's a defining issue about how we are going to treat our seniors in this country." And we passed Medicaid shortly after that. In 1965 we said, "We are going to have hospitalizations for those that are elderly. We are going to have the doctor's piece," we didn't include the prescription drug. We eventually come back to that issue. That's a dif-

ferent issue for a different time, about how well we did with that, but we will put that aside, at least we have addressed that.

Then we saw our march for progress continue when we dealt with the American with Disabilities Act, and other issues to get it to work, other kinds of proposals. But what we never really anticipated is the kind of situation that we're faced today, where we as a country are so fortunate to have so many individuals—our parents, our grandparents—who have lived long, full, wonderful lives, and have had many individuals that have been facing some kinds of physical and mental challenges. In the old days they used to call it disabilities, but we're away from those days and now we're talking about the challenges that are out there. And how are they going to be able to live the kind of life of independence and dignity? And have the variety of choices that men and women and younger people who are challenged for the variety of reasons of situations that have arisen during the course of their lifetime. How are they going to do that? And doesn't our society—aren't we a more fair—a complete society when we try and develop the process in the system that reaches that kind of goal?

And, those are general kinds of comments. But I think they underline what we are really trying to do here. We want to respect individuals lives—be able to live independently. We want to respect the rights of choices and for individuals to maximize their choices, and we want to be able to do that in a way that's going to preserve independence. We want to make sure we're going to, obviously, save the Medicaid program as well.

So we have some wonderful individuals that are going to talk about different aspects, including those issues. And then we want to thank individuals in the audience who have come. Going through these hearings today, you might have a few ideas yourself, jot them down. We want to hear from those that are out in the audience, maybe you can do it today, or maybe you can do it when you get home. After you sit through the hearing, you might feel there are some areas that those Senators didn't ask about or are not included. These are the kinds of things we think ought to be given focus and attention as well. We'll go through those and we will—to the extent possible—make them part of the record, and try and include those ideas and suggestions as we move ahead.

I want to thank my colleague and friend, Senator Enzi—we work with so closely. He has added immensely to all of our understanding by talking about the challenges that exist in rural communities. We're going to get to that issue during the course of our panel this morning. Senator Enzi has had some wonderful recommendations and suggestions in that area, as well as the substance of these issues before us and I would like to ask him to say a word at this time.

Senator Enzi.

[The prepared statement of Senator Kennedy follows:]

#### PREPARED STATEMENT OF SENATOR KENNEDY

Thank you all for being here today for this hearing on one of the most pressing and personal issues our Nation will face over the next decade—the crisis of meeting the needs of seniors and persons

with disabilities in ways that promote independence and choice, and help families.

A fair and civilized society is judged on how it treats its most vulnerable citizens. Today in America, millions of senior citizens and persons with disabilities still struggle to obtain the support they need to live fulfilling and productive lives in their communities.

Many of them are members of the Greatest Generation, and it's shameful that we are failing to provide them with a solution for long-term care worthy of their immense contributions to our history.

Many are citizens who worked hard for themselves, their families and their communities, and became disabled as a result of an illness or injury that was not anticipated.

Many are young adults who have spent over 20 years in our educational system to become participating members of their community, but they still need support to make that transition successful.

The issue is about all of us, and those of you here today are the proof that "disabled does not mean unable."

We made progress in past decades through Social Security, Medicare, Medicaid, and the Americans with Disabilities Act.

But countless senior citizens and persons with disabilities still live in poverty with few choices on how they live their lives. That was never the intent of the public assistance programs.

Ten million adults in America currently need long-term services and support. Many are capable, and are eager to live full lives in their communities, but they are forced to give up their independence and self-sufficiency in order to qualify for Medicaid—the only program that can support them because they are too young for Medicare and the barriers to private insurance are too high and too costly.

Our current system forces people into institutions prematurely. It requires them to become impoverished before becoming eligible for the help they need. It fails to provide realistic opportunities for personal life planning, and fails to give families the flexibility to help their family members in need.

Senator Harkin and I have two pieces of legislation that TOGETHER can both improve the current Medicaid system by allowing more individual choice AND create a new voluntary national insurance program that will promote independence, choice, personal responsibility, and quality services for those who need it.

It will empower consumers to decide themselves how this assistance will be spent—for transportation so they can stay employed, for a ramp to make their home more accessible, or for a personal care attendant or a family caregiver.

It will help keep families together—instead of being torn apart by obstacles that discourage them from staying at home.

It will save on the mushrooming costs of Medicaid, the Nation's primary insurer of long-term care services, by offering an alternative for those who can work while preserving Medicaid for those who really need it.

We need a new approach to restore independence and choice for millions of our citizens, and enable them to take greater control of their lives.

Your testimony here today will give us a deeper understanding of the challenge, and inform us about what steps we must take as a nation to meet it.

It's time to respect the rights and dignity of all Americans, and I thank you all for being here today to continue that fight.

#### OPENING STATEMENT OF SENATOR ENZI

Senator ENZI. Thank you, Mr. Chairman, and I appreciate the great summary that you did, and the encouragement for people to share their ideas with us. It's a key thing to have as many people as possible, sharing ideas. We have some people that present their testimony, and people have reactions to that testimony. And sometimes we don't get those reactions, and I'm sure the Chairman will let you know through what mechanism you can get those ideas to us, as well.

And I want to thank the Chairman for his leadership on this important issue. He's been working on it for years and years along with Senator Harkin.

And I also want to thank our witnesses today for taking time out of their busy schedules and, in some cases, traveling many miles to get here. I particularly want to thank Shawn Griffin, the Executive Director of the Community Entry Services in Riverton, Wyoming, and Dr. Deborah Fleming, the Clinical Professor of Medical Education and Public Health at the University of Wyoming College of Health Sciences in Laramie, Wyoming—for traveling here from my home State. It's a pleasure to welcome all of you to the hearing.

Today's hearing will followup on what we discussed during a hearing in April 2005, regarding the need and processes related to advance directives, living wills, health care, and treatment of those who cannot advocate for themselves. The problems and issues we defined and identified at that hearing still exist, and must be addressed.

Today we will be discussing long-term care, community services, and support for millions of people who are aging, or who have disabilities. Most of these individuals would be able to participate in society if they had some additional assistance, so they are able to maintain and perform the daily living skills so many of us take for granted. Many Americans do not have the resource necessary to pay for out-of-pocket, long-term care in an institution.

According to the Congressional Budget Office, fewer than 7 percent of seniors have annual incomes equal to or greater than the annual cost of a nursing home stay. But there are other less costly options available to assist individuals who do not need institutional care, but do need extra help and support. These less costly, community-based services and supports are being actively pursued and funded through provisions of the now-reauthorized Older Americans Act that we passed last year.

Through programs funded by the Administration on Aging, emphasis is placed on empowering persons with disabilities, older people, their families, and other consumers to make informed decisions about, and be able to easily access, existing health and long-term care options. One of the methods for empowerment is to provide streamlined access to health and long-term care through Aging and Disability Resource Center Programs, ADRCs. A grantee admin-

istering an ADRC in my State will describe this initiative in her testimony.

ADRCs provide individuals with disabilities, and seniors, and their families with information on how they may remain in their own homes, with a high quality of life, for as long as possible, through the provision of home and community-based services, including supports for family caregivers.

In short, the goal is to empower people to live with dignity in their own homes, rather than in an institution. The availability of transportation, housing, and the personal care workforce is another topic that will be discussed today, by a provider of services to persons with disabilities, and the aging population of Wyoming.

I hope this hearing will make us all realize that we need to think creatively and figure out ways in which all Americans will be able to access the community services and supports they need, at the price that will fit in their individual budgets. We should not require people to become poor in order to access public programs for the help they need to remain as independent as possible.

Finally, I want to re-state that two of our witnesses will tell us about the success of programs in Wyoming to create a one-stop shopping resource center, and enhance support services for the aging and disabled citizens of Wyoming, as well as other communities—particularly rural communities—throughout the country.

Again, I want to thank the witnesses for their participation in today's hearing, and I look forward to the testimony, and I do request that a fuller, more extensive statement be included in the record.

[The prepared statement of Senator Enzi follows:]

#### PREPARED STATEMENT OF SENATOR ENZI

Good morning. I would like to first of all thank Chairman Kennedy for his leadership on this important issue and for holding this hearing. I would also like to thank our witnesses for taking time out of your schedules to be with us. I particularly want to thank Shawn Griffin, Executive Director of Community Entry Services in Riverton, Wyoming and Dr. Deborah Fleming, Clinical Professor of Medical Education and Public Health at the UW College of Health Sciences in Laramie, for traveling here from my home State. It's a pleasure to welcome all of you to our hearing.

Today's hearing will followup on what we discussed during a hearing that we held in April of 2005 regarding the need for and processes related to advance directives, living wills, health care, and treatment for those who cannot advocate for themselves. The problems and issues we defined and identified at that hearing still exist and must be addressed. Today we will be discussing long-term care, community services and supports for millions of people who are aging or who have disabilities. Most of these individuals will be able to participate in society if they have some additional assistance so they are able to maintain and perform the daily living skills so many of us take for granted.

Many Americans do not have the resources necessary to pay out of pocket for long-term care in an institution. According to the Congressional Budget Office fewer than 7 percent of seniors have annual incomes equal to or greater than the annual cost of a nursing home stay. But there are other, less costly options available to as-

sist individuals that do not need institutional care but do need some extra help and support. These less costly, community-based services and supports are being actively pursued and funded through provisions of the reauthorized Older Americans Act that we passed last year. Through programs funded by the Administration on Aging, emphasis is placed on empowering persons with disabilities, older people, their families, and other consumers to make informed decisions about, and to be able to easily access, existing health and long-term care options.

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I hope this hearing will make all of us realize that we need to think creatively and figure out ways in which all Americans will be able to access the community services and supports they need at a price that will fit into their individual budgets. We should not require people to become poor to access public programs for the help they need to remain as independent as possible.

As we all know, Medicare and Medicaid are the largest funders of long-term care. I am mindful that current entitlement programs like Social Security, Medicare and Medicaid face challenges to their solvency that need to be addressed on a bipartisan basis. The 2007 Annual Report by the Social Security and Medicare Boards of Trustees warn that Medicare's Hospital Insurance is already expected to pay out more in hospital benefits this year than it received in taxes and other dedicated revenues.

Moreover, Medicare Supplementary Medical Insurance and the new prescription drug benefit will continue to require general revenue financing and charges on beneficiaries that will grow faster than the economy and beneficiary incomes over time. This will place more and more pressure on the Federal budget. The challenge of providing long-term care for baby boomers and beyond should be a part of any solution we propose involving the solvency of those programs which are the primary payers for long-term care.

Finally, and on a brighter note, I want to reiterate that two of our witnesses will tell us about the success of programs in Wyoming to create a one-stop shopping resource center and enhance support services for the aging and disabled citizens of Wyoming as well as other communities throughout the country.

Again, I want to thank the witnesses for their participation in today's hearing. I look forward to their testimony.

The CHAIRMAN. Thank you very much, Senator Enzi.

It's a real pleasure to welcome a friend and a leader on so much of what is important in this country in terms of knocking down the walls of discrimination on the basis of disability. And Tom Harkin has been our leader on this committee, and a leader in the Congress and Senate—has made such an extraordinary difference in the quality of life of so many of those that are challenged.

We are not only great friends, but we work very closely together and continue to work closely together. And certainly with all of us here—with this panel—I see my, our friend, Sherry Brown here from Ohio—we have every intention of getting something done. We are not here just to listen, we are here to act, as well.

So, we thank Tom for all of his good work, and all of his efforts. And we would love to hear a word from him now.

#### STATEMENT OF SENATOR HARKIN

Senator HARKIN. Well, thank you very much, Mr. Chairman, for those kind remarks and for holding this hearing today on an issue of extraordinary importance to millions of Americans.

I also want to thank you, again publicly, for your great leadership over all these years. And so many issues that affect the human needs of our people in this country, whether it's health care, whether it's food and nutrition, or people with disabilities. We all, kind of, fall into the wake of Senator Ted Kennedy, because he's always been in the front of all of these fights. And I'm just privileged to share that friendship with you, Senator Kennedy, and to be a member of your committee.

I just want to recognize a few people who are here today. I hate to single out people, but there are a few that I would like to single out.

First of all, Andy Imparato, who is going to be one of our witnesses, said this is his first time testifying here. I didn't realize that. He was our counsel on this committee, on the Subcommittee on Disability Policy, back in the early 1990s, and is now President and CEO of the American Association of Persons with Disabilities.

We never would have gotten the ADA passed had it not been for AAPD. I remember that, just like it was yesterday when I got a call from Kafka, back there, and he said, "You might want to turn on your television tonight." And I said, "Why, what's going to happen?" and he said, "Well, we're going to do something at the Capitol." And I got intrigued by this, you know, I knew about AAPD, I knew about Bob. I've gotten to know him better over the years, to be sure. But that was the time when AADP wheeled up to the steps of the Capitol, and got out of their wheelchairs, and crawled up the steps of the Capitol. And that made the evening news all over America. To me—and that just brought home to Americans everywhere what we were trying to do. And that just gave that final impulse, I think, to get the bill on the floor and to get it moving.

Well, there are a lot of other stories attendant to the passage of ADA, but I wanted to single that out, and just thank Bob Kafka for his leadership and for all of you at AAPD. Senator Kennedy has so eloquently said—you just can't give up on these things, you've just got to keep at it and keep at it, and keep at it, and keep at it. And we've been trying to get MiCASA passed now for 10 years or more. And we weren't quite able to do it.

Well, now we've got the Community Choice Act the successor of that bill. And we've got some new information, thanks again to Mitchell Laplant, who is over here today. Mitch is an Associate Professor at the University of California. He's got an article published this month titled "Estimating the Expense of a Mandatory Home and Community-Based Personal Assistant Services Benefit Under Medicaid."

Well, in this article, Dr. Laplant estimates the cost of personal care attendant services under Medicaid to be \$1.4 billion to \$3.7 billion annually. Well, now that's good news, because as you know the often-sited CBO estimate that was sent to, presented to Newt Gingrich in 1997 was \$10 to \$20 billion.

I also might just add a little note here that I was meeting once with some AAPD people and Bob in the rotunda, the Capitol one day, when who should walk by but the newly-elected Speaker of the House, Newt Gingrich. And Newt saw the people in the wheelchairs, and saw me, and came over. That was his big mistake.

[Laughter.]

But, not really. Because, I introduced him to Bob and others, and he wanted to know what they were talking about, and what we were talking about was personal attendant services, and getting people out of nursing homes, and into the community—MiCASA, basically. And, wouldn't you know it, Newt Gingrich became the chief sponsor of MiCASA in the House.

So, it just shows you—never give up. And keep focusing, because even today he is still a supporter, by the way, of what we now call a Community Choice Act, of getting people out of nursing homes in the community.

Well, I also wanted to recognize people at NCIL, the National Council on Independent Living, their conference is here this week. I know you are having a march down to the Capitol on one of the hottest days of the year. But, NCIL's staff members—John Lancaster, Elizabeth Leaf, all of you, for all of your help on this.

When we passed ADA, Mr. Chairman, we had four goals. There were four underpinnings, so to speak, of the ADA: equal opportunity, full participation, independent living and economic self-sufficiency. Well, some of those we've attained more than others. But the two that are woefully behind are independent living, and economic self-sufficiency. It is a shame that we still have over 60 percent of the people with disabilities underemployed, or unemployed in our country, this many years after the passing of ADA.

To me, the single-most important thing to getting people into jobs—people with disabilities into the workplaces, is to get them out of nursing homes. And to get them out of being warehoused, and to get them into independent living. Because that kind of independence then supports people getting into the workforce, and getting the kind of transportation they need, and all the other things. So, the independent living really has to come first, and we have to get this done.

Community-based services, I believe, will not only transform the lives of people with disabilities, they can live with families and friends, not with strangers. They can be the neighbor down the street, not the person warehoused down the hall. And I don't think

this is asking too much. This is just the barest thing that we ought to ask for every human being.

So, again, we've had some success with your help. We got Money Follows the Person passed last year, CMS is now awarding the grant, but now we have got to get the Community Choice Act passed. That's what every person with a disability wants and deserves, as my nephew Kelly proves every day.

The costs of the Community Choice Act would be mostly offset by the benefits of having people with disabilities who are employed, like Kelly is, paying taxes and contributing to our economy. Now, he gets it because he was injured in the service. So he has all of the veterans' benefits. He has his personal attendant services because he was injured in the military. But that allowed him to have his own business, start his own business, get an education, go to work everyday, pay taxes. Well, if it's good enough for my nephew, it ought to be good enough for everybody else in this country, whether they're a GI, an ex-veteran, or not—that ought to be the standard for every person with a disability in this country, and that's what the Community Choice Act is about. I just wanted to thank you, Mr. Chairman, and thank you, Senator Enzi, again, for your help and your support through all of these efforts to advance this cause, and hopefully we will get it done this year.

Thank you very much, Mr. Chairman.

The CHAIRMAN. Very good. Thank you, Senator Harkin. We'll move on. Our first witness, Susan Daniels, nationally-recognized expert, spokesperson, employment, healthcare, disability policy. Dr. Daniels had 15 years of highly successful executive experience in leading large Federal-State agents, through policy development, organization change, custom service intervention. Dr. Daniels served as a Deputy Commissioner for Disability and Income Programs at the Social Security Administration in 1994 to 2000 where she spearheaded the disability and employment reforms activities, resulting in the passage of the Ticket to Work Incentive Improvement Act of 1999, and in 2004 she was named as the Henry Betts Laureate.

Dr. Daniels, we want to thank you very much. We appreciate your presence here, and look forward to your comments.

**STATEMENT OF SUSAN M. DANIELS, PH.D., DANIELS AND ASSOCIATES, WASHINGTON, DC.**

Ms. DANIELS. Thank you, Senator. I am delighted to be here today. Thank you for the opportunity to see many of you again. I'm not going to regale you today with all of the numbers about whose elderly, and who needs community support, and how many there are, and how big that population is going to be. You don't need to hear all of that. Mitchell Laplant is here, and he'll tell you, that is a sizable number of people.

But, I want to acquaint you with two people that I know. And, because I think they are illustrative of why we need the kind of action you are going to take.

In 1949, my mother discovered that her youngest child, me, had polio. And she proceeded to act on that in a variety of wonderful ways, including making sure that I got an education, an opportunity to live in a community, to go to the same school as my broth-

ers and sister, to participate in my community life, and to have—in fact—a life.

When she turned 80, we gave a big party, a big shindig for my mom. It was very much fun. And, I want to say that at that time she was the sharpest knife in the drawer. She could run rings around all of us, more energy, more happiness, and more commitment than you can ever imagine in a human being.

But, shortly after the 80th birthday, we noticed that Mom was losing a little bit of some of her abilities. In fact, at 82 she decided that she could no longer bring communion to the old people in the parish, that some younger people should be doing that instead of her. She took on helping several of the younger families on her block where she had lived 60 years, one of them going to medical school. Mom decided it was a good thing for her to babysit one afternoon a week for their infant child. Then she decided that she couldn't drive any more, and luckily my brother Harry stepped in, and started driving her around. We all felt a lot safer.

Mom fell down when she was 84 and broke her arm. Well, I have to tell you, she was at a gambling casino. But, it was a break, nevertheless, and my sister Mary flew in from North Carolina to take care of her, and help her as she recovered from that broken arm.

I always said, "Mama, try to stay out of the gambling bawlers, it's not safe there." Well, my mother died about a week before Katrina, in New Orleans. That morning that she died—and she got a wonderful death, a fast and painless one. She had gotten up out of her own bed, on the block where she had lived for over 60 years. She put on her own clothes with a little help, and my brother Harry helped her to the car, and she went to get a medical test. And before that test was taken she had an aneurysm and died. We always say in our family, "Mama finally got what she deserved. Something easy and painless."

We were lucky. We were, all of us, lucky to have that woman in our lives. And as her needs increased, she was lucky because we had no small children at home. All of us were professionals. Where it was necessary we could step in and provide her with the care that she needed. It was our greatest pleasure to do that for her.

But, Senators, luck is not a method. Lucky we were, but we could have been unlucky. She could have had an aneurysm that resulted in a stroke and she would have been in the hospital, or a nursing home for years. We did the best we could, and we were happy to do it. It is a remarkable thing in this country that we have not committed ourselves to the care that our parents, our siblings, our friends, really need to have a life. And we asked them to depend upon all kinds of other people to get the things that they need.

It's time for this to stop. It's embarrassing to live in a country with the riches we have, with the thoughtfulness about liberty that we have, and with the history of caring for one another, to see so many people living in situations that you would not tolerate yourself.

So, I ask you to renew—and I know it's a renewal of your political will—to stand back the naysayers. You know, as well as the people in this room know, that young and old, when they need help, need it desperately. And nothing is more undignified than being unable to care for your personal needs.

Please consider these people. Consider all of the people who would be otherwise productively engaged, just if they had someone to help them take a shower and get on their wheels.

Thank you so much for listening to the story about my wonderful mother, and for renewing your dedication to this. I think you have a lot of supporters. And I know that I myself will be one of them.

Two weeks ago I came upon a young lady that I see often in my neighborhood. She's in a wheelchair, she's about 28 years old. And she hasn't been as lucky as my mother was.

A little bit later I was in front of the building walking my little dog, Lucy, and her boss came out of the building and said, "Do you know of any place she could get some personal assistance?" I said, "Yes, I know. I know several places, but you would have to hire them."

This young lady I saw over a 2-week period frequently getting in and out of a van taking her to and from work. About a month later, she was no longer coming to and from work. She had been fired, and I have to say she was fired because she smelled awfully bad. And she did, I have to admit. I talked to her several times. But she couldn't afford to have a job, and pay a personal assistant to help her with the simple thing of getting clean and ready for work.

So now, we have another person on SSI, or SSDI, unable to work, not working—a person who wanted to work, and did work. She was unlucky, like most of us.

Thank you.

[The prepared statement of Ms. Daniels follows:]

PREPARED STATEMENT OF SUSAN M. DANIELS

Good morning, Senators. Thank you for the opportunity to talk to you about the situation of long-term-care across the age span and to set out some ideas for how the system can be saved and improved.

The long-term care delivery system is a mess. The Census Bureau estimates that in 2050 there will be two and a half times more people age 65 or over. At the same time, societal trends such as the mobility of families and the growing rate of working women reduce the previously available family caregivers. Paid/professional caregivers are poorly paid, receive few benefits including insurance for their own health care, receive inadequate training, all resulting in personnel shortages that will only worsen with time.

PRINCIPLES FOR LONG-TERM CARE REFORM

As a first step in addressing the current problems in the long-term care system, the CMS's Policy Council<sup>1</sup> developed a set of principles for long-term care reform. These principles include:

- Increase consumer choice and control for older individuals, persons with disabilities and chronic illnesses of any age, their family members and caregivers.
- Ensure access to an appropriate array of institutional and home and community-based long-term supports.
- Reverse the institutional bias in long-term care services.

On a similar track, The National Academy of Social Insurance (NASI) is calling for fundamental reforms in financing long-term care.<sup>2</sup> The panel's report finds a high level of public concern about paying for long-term care and widespread discontent with the current system of financing.

"Members of the panel feel strongly that a better long-term care system is essential to enable all Americans, regardless of age or disability, to participate fully in our society. The current long-term care system falls far short of meeting

<sup>1</sup>Policy Council Document September 28, 2006 Long-Term Care Reform Plan.

<sup>2</sup>Developing a Better Long-Term Care Policy: A Vision and Strategy for America's Future November 2005 Report of the Long-Term Care Study Panel National Academy of Social Insurance Study Panel on Long-Term Care, *Co-Chairs* Sheila P. Burke and Judith Feder.

reasonable expectations. Achieving a system that meets individual needs and distributes costs equitably will require greater Federal involvement and financing.”—Sheila P. Burke, the panel’s co-chair.

#### SHORTCOMINGS OF THE CURRENT LONG-TERM CARE SYSTEM

The current long-term care system falls far short of meeting reasonable expectations in several ways:

- *Unmet Needs.* Many people receive inadequate care. Nationally, 20 percent of people living in the community and needing services get less help than they need. As a result they are more likely to fall, soil themselves, or be unable to bathe or eat.
- *Burden on Caregivers.* Unpaid caregivers play a critical role in the system but often pay an economic, physical, and emotional toll. Workers in the formal long-term care system labor under difficult conditions and low wages, frequently without fringe benefits.
- *Financial Jeopardy.* The cost of long-term care can impose financial hardship or even spell financial catastrophe for many families. Few people have any type of insurance against the expense of long-term care, which can reach \$26,000 a year at home and more than twice that amount in an institution.
- *Limitations in Medicaid.* The Federal-State Medicaid program finances long-term care only for those who are or have become impoverished. Its benefits vary widely from State to State, and it requires some people who need help to move to institutions, when they would much rather live in their communities.
- *Quality Problems.* Serious quality problems persist in some nursing homes, partly as a result of inadequate staffing. Quality in non-institutional settings is also a concern.
- *Demographic Challenges.* The long-term care system is unprepared to meet the demands that the large baby boom generation will impose upon it. The coming demographic shift will also exacerbate staffing shortages.

Because the need for long-term care is a risk, not a certainty, the panel recommended that it should be handled through insurance, like other unpredictable and potentially catastrophic events. The study panel did not endorse one particular solution but I do: a payroll based universal access to a basic, limited long-term care benefit.

The Panel recommended three tenets to guide the long-term care system of the future:

- *Meeting Individual Needs.* The needs of individuals should determine the kinds of services available.
- *Preserving Autonomy.* Service delivery should preserve the autonomy of the people receiving services.
- *Promoting Equity.* The costs of services should be shared equitably among individuals, families, and the society in which we live, and services should be similarly available and affordable regardless of the State in which a person lives.

Nearly 10 million Americans need help with basic tasks of living, such as bathing, eating, dressing, or walking, or help with other activities that maintain their independence, such as shopping, cooking, or cleaning. More than 80 percent of those who need care live in their communities, not in nursing homes, and nearly 40 percent of them are under age 65.

You are taking up the cause of long-term care, building coalitions for change, and taking advantage of opportunities for action. We all acknowledge fiscal pressures facing Federal and State Governments. The impending retirement of the baby-boom generation will add to already large demands on the major Federal entitlement programs. As you grapple with these budgetary issues, meeting the needs of the elderly and the disabled for long-term care should have an important place on the agenda and we should not shrink from providing the innovations that will be required.

Thank you.

The CHAIRMAN. Thank you very much Susan. We’ll come back.

I mentioned earlier about welcoming comments, and I was reminded by our excellent staff that we want to ask those who are watching us on television, they can e-mail their comments to share with the committee. And the e-mail address is communityfeedback@help. That’s our committee, Health, Education, Labor, Pensions. So, it’s communityfeedback@help.Senate.gov. I’ll repeat that later on.

Our next witness, we're joined by Senator Murkowski, we thank her very much for joining with us.

Monica Herring is the single parent of a 14-year-old son with significant special needs. Ellington Mallory, Ms. Herring's son, was diagnosed at birth with Edwards Syndrome, which affected him with multiple physical and mental disabilities.

A native of Washington metropolitan area—Ms. Herring has resided in Maryland since 1975—on Ellington's birth at Southern Maryland Hospital, soon learned that as a parent of a child with complex medical and developmental requirements, she would have to become not only the primary caregiver, but also an active advocate on his behalf, and has done so nobly. And we are very grateful to her for sharing this life experience with us, so that we can benefit from that experience and hopefully help and assist others in our society to give the kind of inspired help and assistance that you've been able to give.

Monica.

**STATEMENT OF MONICA HERRING, MOTHER OF ELLINGTON  
HERRING, GERMANTOWN, MARYLAND**

Ms. HERRING. Good morning, Mr. Chairman, Ranking Member and members of the committee. Thank you for convening this hearing on the important topic of long-term care, community services, and supports for individuals with disabilities.

My name is Monica Herring, and I am honored to speak to you as a parent and caregiver of a young man who was born with significant physical and mental disabilities. My intent today is to share with you my vision for my son's future, driven by—what I believe—are his likes, his wants, and needs. I also want to share with you my fears, as I face this inevitable part of our journey. My primary fear is that the vision I have for him, the goals I have strived to achieve with him, may not happen as I had hoped.

As I speak to you, my son Ellington is now age 14, he and I are embarking on a significant and difficult phase of our life journey together. In fact, we are beginning to plan for his transition to adulthood.

From very early on in his life, Ellington participated in the Maryland Model Waiver Program. Through this program he has received all of the essential medical, health, therapeutic, nutritional, and rehabilitation services he needs to be fully a part of our family and our community.

The Model Waiver is a home and community-based waiver. In Maryland, we are fortunate to have, through this program, chair coordination through the coordinating center to help us with eligibility—not only for the waiver program—but also for access to the variety of community supports that have meant so much to me in my effort to provide him with a good quality of life.

It is my dream, my hope, my expectation that Ellington will have the opportunity to do the following—participate fully in community life. Community life is independent living in a community of his choice, with a roommate of his choice, access to community resources that are available to all individuals, participation in community activities that allow for social interaction and can foster the

development of new relationships, and securing supportive employment that would allow him to give back to the community.

Today, Ellington enjoys times out in the community, shopping at the local grocery, trips to the shopping mall, strolls in community, attending family and friend gatherings, his regular appointments to the barber, going to the movies or attending church worship services. I cannot contemplate the idea that my son would not have this option, that he would be considered for a facility or an institution, or would not have the freedom to make his own choices in life.

Next, is to receive funded, quality support services. Ellington, at birth, was given up to 5 years to survive, with no assurance of what his progress, or accomplishments would be. I think his appearance here today is testament to the value of quality support services.

With this being said, I ask myself, "Are my goals reasonable and attainable, taking into consideration Ellington's multiple disabilities, and daily supports needs?" And the answer is "yes, yes." However, listening to the buzz around current State and Federal disability issues, and the voices of family members and service providers, I have developed real fears about whether the innovative support systems put in place over the last decade or so will accommodate him.

Will there be necessary changes in response to increased enrollment, due to the families' willingness to offer independence to their children? Will housing—accessible and affordable—be available for him? Will the changing perspective of the major players in long-term care financing, Federal and State Government give up on the notion of choice, inclusion and independence? Will they find these ideas to challenge and to put in place, despite the fact that maintaining this philosophical approach can truly save costs, while doing the right thing for people with complex needs and disabilities.

The concerns that I bring to this committee today are ongoing struggles to build capacity for inclusion of individuals with disabilities in the community, resulting in families making undesirable placement decisions, such as in nursing homes or assisted living facilities. The tremendous task of navigating a system that is highly complex, confusing, and often intimidating. Some programs income and asset restrictions that can prevent an individual's access to appropriate services, supportive employment, and other community support services that must be expanded, and adequately funded so that individuals with the right supports will be ultimately successful and achieve as best he or she can.

In closing, I urge you to examine the long-term care system as it currently exists carefully, because the families of tomorrow—such as myself—who will need access, will also need to be assured that the principles that people with disabilities have fought long and hard for can be a reality and not an unrealized dream. These principles include the idea that home is better than a nursing home. That people with disabilities are best able to articulate their needs, their desires, their aspirations. That even those individuals most affected by chronic illnesses and disabilities have skills, and gifts, that are theirs alone to give. That there is no disability that is too severe to keep people away from their homes, community,

and families when the appropriate supports are provided and that there is no one who can't benefit—from being respected, from being included, from being valued, from being loved.

Thank you.

[The prepared statement of Ms. Herring follows:]

PREPARED STATEMENT OF MONICA HERRING

Good Morning Mr. Chairman, Ranking Member and Members of the Subcommittee, thank you for convening this hearing on the important topic of long-term care, community services, and supports for individuals with disabilities. My name is Monica Herring and I am honored to speak to you as the parent and caregiver of a young man who was born with significant physical and mental disabilities.

As I speak to you, my son Ellington is now aged 14. He and I are embarking on a significant and difficult phase of our life journey together. In fact, we are beginning to plan for his transition to adulthood. As a maturing young man, he—and I too—are facing an environment that is as yet unknown to us. Although, I am certain to find a new and very complex set of access and eligibility issues, questions about service delivery, and a whole new way to navigate systems and locate essential services concerns me most.

My intent today is to share with you my vision for my son's future driven by what I believe are his likes, wants, and needs. I also want to share with you my fears as I face this inevitable part of our journey. My primary fear is that the vision I have for him, the goals I have strived to achieve with him, may not happen as I had hoped.

From very early on in his life, Ellington participated in the Maryland Model Waiver program. Through this program he has received all of the essential medical, health, therapeutic, nutritional and rehabilitation services he needs to be fully a part of our family and our community. The Model Waiver is a home and community-based waiver. In Maryland, we are fortunate to have, through this program care, coordination through The Coordinating Center to help us with eligibility not only for the waiver program, but also for access to a variety of community supports that have meant so much to me in my efforts to provide him with a good quality of life. Currently, Ellington attends Longview School in Germantown, Maryland where we live. His school program, like his health plan, is individualized to his needs—which are considerable. As his mother, I have significant input into the planning and implementation of his program. The services that he receives include care and service coordination, private duty nursing, respite services, and school-based occupational, speech and language, physical therapy, and vocational services.

In plotting the course for what I hope to be a seamless transition, I am striving to address not only his immediate needs, but also to lay the foundation for the support of long-term life goals. It is my dream, hope, and expectation that Ellington will have the opportunity to do the following:

(1) Participate fully in community life. Community life is independent living in the community of his choice with a roommate of his choice, access to community resources that are available to all individuals, participation in community activities that allow for social interactions and can foster the development of new relationships, and securing supportive employment that would allow him to give back to the community. Today Ellington enjoys times out in the community whether it's shopping at the local grocery, trips to the shopping mall, strolls in the community, attending family and friend gatherings, his regular appointments to the barber, going to the movies or attending church worship service. He thrives from the experience and exposure. I can not contemplate the idea that my son would not have this option, that he would be considered for a facility or institution, or would not have the freedom to make his own choices in life.

(2) Receive funded quality support services backed by service providers that are adequately compensated; certified; educated enough about across-public agency funding and private funding resources that will maximize use of all available resources without jeopardizing his needed benefits; that are well trained in quality assurance and compliance monitoring Federal and State regulation and guidelines; and operate with the understanding that all people are valued—those needing the supports and those helping to provide it. Ellington at birth was given up to 5 years to survive with no assurance of what his progress or accomplishments would be. I think his appearance here today is testament to the value of quality support services.

One of the major issues that concern me—especially since Ellington has come so far—is the fact that there is a dearth of expert attendant care providers who have little or no training in the diverse needs of the consumers they serve, and poor compensation for people who provide such a necessary service to the most vulnerable among us. With this being said, I ask myself are my goals reasonable and obtainable, taking into consideration Ellington's, multiple disabilities and daily support needs? And the answer is yes, yes. However, listening to the buzz around current State and Federal disability issues and the voices of family members and service providers, I have developed real fears about whether the innovative support systems put in place over the last decade or so will accommodate him.

- Will there be the necessary changes in response to increased enrollment due to families' willingness to offer independence to their children?
- Will there be a track record of program successes and failures leading to new best practices designed for young people like my son?
  - Will housing, accessible and affordable, be available for him?
  - Will the changing perspective of the major players in long-term care financing (Federal and State Government) give up on the notions of choice, inclusion, and independence? Will they find these ideas too challenging to put in place, despite the fact that maintaining this philosophical approach can truly save cost while doing the right thing for people with complex needs and disability?
  - And what about the families, the self advocates and the advocacy organizations—will they be able to stand firm for the fundamental rights of all people with disabilities?

The concerns that I bring to this committee today are:

- (1) Inadequate compensation and training for direct care staff resulting in an increased chance of hiring unqualified staff and incidences negatively affecting the health and safety of the individual in their care;
- (2) On-going struggles to build capacity for inclusion of individuals with disabilities in the community resulting in families making undesirable placement decisions, such as in nursing homes or assisted living facilities;
- (3) The tremendous tasks of navigating a system that is highly complex, confusing, and often intimidating;
- (4) Some programs income and asset restrictions that can prevent an individual's access to appropriate services.
- (5) Supportive Employment and other community support services that must be expanded and adequately funded so that the individual—with the right supports—will be ultimately successful and achieve as best as he/she can.
- (6) Day programs that are essentially day care for adults that offer little besides supervision, when people attending the program need to get meaningful services to build on the skills that they have and provide them with community experiences to enhance their lives.

In closing, I urge you to examine the long-term care system as it currently exists carefully. Like so many aspects of health care in the United States, it is fragmented and often managed by people who are not committed to the principles that people with disabilities have fought for long and hard. These principles include the ideas:

- That home is better than a nursing home.
- That people with disabilities are best able to articulate their needs, their desires, their aspirations.
- That even those individuals most affected by chronic illnesses and disabilities have skills and gifts that are theirs alone to give.
- That there is no disability that is too severe to keep people away from their homes, community, and families when the appropriate supports are provided.
- That there is no one who can't benefit from being respected, from being included, from being valued, from being loved.

The CHAIRMAN. Thank you very much, Monica.

I want to tell you that Ellington here—I've been watching him—he's got a great smile. And, he has been watching our wonderful interpreter over here move his hands, and I'll tell you—he's about out of a job, the way this boy is—

[Laughter.]

The way Ellington—

Ms. HERRING. See, we have a job for him, already.

The CHAIRMAN. OK. He's very, very, very touching and captures our hearts, as well.

So, Glenda Faatoafe is a home care worker from Lacey, Washington. A wife and a mother of three grown children. Glenda has provided personal care to seniors, people with disabilities for 11 years. In her work as a home caregiver, she helps with cooking, cleaning, bathing, dressing and transferring. Currently, she cares for a 47-year-old quadriplegic man who has six children. She is a leader in her local union, the SEIU Local 775, the long-term workers union in Washington State.

Glenda how do you do it? Tell us. We look forward to hearing from you.

**STATEMENT OF GLENDA FAATOAFE, HOME CARE WORKER,  
KOREAN WOMENS ASSOCIATION, LACEY, WASHINGTON**

Ms. FAATOAFE. Thank you very much.

Good morning. My name is Glenda Faatoafe, and I have been providing care and support for seniors with disabilities for 11 years.

Each day I arrive at Zebty's home, and we begin with daily routine. It starts with relieving his bowel and bladder. That includes an internal catheter and a bowel program, which is quite invasive for a grown man with a disability. I then prepare and assist him in eating his breakfast. His wife, Jiji, and I get the shower ready. It takes four separate transfers to get him in and out of the shower. After we have gently put him back into bed, I have to rub him down with creams, check for hot spots to prevent bed sores, and then over an hours worth of range-of-motion exercises for his muscles that are contracted into the fetal position.

Then it's time to get dressed, what a feat it is. Every 2 hours I need to reposition Zebty's body, and check his blood pressure. If it reaches a dangerous level—either high or low—I need to quickly assess what might be causing this, and take action. It requires fast thinking and an intimate knowledge of Zebty's unique needs. It's only because I have assisted him for almost 2 years, that I have a thorough understanding of his medical history and can deliver such vital quality care.

Unfortunately, this kind of close relationship and continuity is rare. This is the needed quality care that we need in our United States. Turnover among caregivers is very high, between 40 and 60 percent annually. And, it's because of the low wages, and lack of benefits. Many clients are constantly training new workers and learning to trust them over and over again.

I love the work I do. I have become very close to Zebty and Jiji and their six children. They treat me like a member of their family. The kids even gave me a Mother's Day card last year, or this past year. It really touches my heart, and reminds me of how important my work is in their life. Not just Zebty's, but his children and his wife.

But home care work is not easy. It's often a physically and emotionally demanding job, requiring not just lifting and transferring, but compassion, love and patience. Not just for the client, but for the family. It's not a punch-in and punch-out job. If someone needs additional assistance, caregivers are the ones that provide it, and are oftentimes not compensated.

So, we work more hours than we are paid for. It's a job with few benefits, such as sick and vacation time. Many have no health insurance. I make \$10.12 an hour, but only thanks to the collaborative effort of my fellow union members during bargaining. The average worker makes around \$8.00 an hour, and rarely can they find 40 hours to work in a week.

In my family we have had big sacrifices. On such a meager salary, we don't take vacations, we don't drive new cars, and we can only afford to send one of my three children to college. Home care workers provide the important care that allow people to live independently, but we struggle to make ends meet, and oftentimes are forced to find a better paying job.

Both client and workers struggle for back-up systems. If I can't make it into work, to Zebty's house, it's almost impossible to find back up. There's not enough caregivers trained, effectively, to fill my shoes. Without my assistant he would have a limited life. He would not be able to live in his home, and watch his six children grow up, or participate in the significant events in their life. Like seeing his second grade child perform in a school play, or his youngest graduate kindergarten this year. Without me, he would be a father in a nursing home, and not the dad who helps raise them and gives them guidance in their life. I'm sorry.

Like a lot of Americans, Zebty worked hard and enjoyed spending time with his family. He had a good job, with health benefits, and a 401k plan. He'd been able to start saving for retirement, and the purchase of their first home. But then the terrible car accident came, 2 years ago. It left him paralyzed and unable to provide for himself or his family. He had to spend all of his savings, leaving Medicaid as the only option left for him to get the assistance he needed.

But he fears losing this Medicaid eligibility for the critical services that he gets. His family has to remain poor. His wife worked as a childcare provider, but because they need to stay poor to maintain the eligibility, and because she needs to be on call for the back-up care on the night shift, and the high turnover that we have, she's limited her hours and then eventually had to stop working altogether.

Medicaid-funded home and community-based services provide the cost-effective assistance seniors and people with disability need to live at home, but I don't think it should be the only reasonable way to access the services. People should not have to enter in and remain in poverty to get the needed assistance. We need to invest more in home and community-based services, and the CLASS Act is the one step to improvement to the lives of seniors and people with disability. If the CLASS Act existed, Zebty would not have had to spend all of his savings, and put his family in jeopardy, to be eligible for Medicaid.

Whether you're young or old, one day you may need long-term care, and the choice to live at home without spinning down into poverty should be available to everyone in America. We need to expand the choices of this growing population who needs in home care. Congress should take steps to ensure people have a range of options when it comes to community support and services. Creating an affordable national insurance program, like the CLASS Act, will

enable people to prepare for the likelihood of becoming disabled, especially as we age.

As the baby-boomer generation ages, thousands of caregivers like me are going to be needed to provide the one-on-one personal care that gives people the choice and the freedom to live at home. CLASS Act would provide additional resources to improve wages and benefits. We can recruit and retain a stable professional workforce of dedicated caregivers to provide the quality care we can all count on.

Congress should enact the CLASS Act to ensure good jobs for workers like me, and quality care for consumers like Zebty.

Thank you very much for your time.

[The prepared statement of Ms. Faatoafe follows:]

PREPARED STATEMENT OF GLENDA FAATOAFE

Good morning. My name is Glenda Faatoafe. I've been a home care worker providing assistance for seniors and people with disabilities for the last 11 years. In 2005, I became one of the 400,000 home care workers united in SEIU Healthcare, the largest health care union in the country.

I've traveled here today from Lacey, Washington, to talk to you about the value of home care, and the important work I do assisting others. For almost 2 years, I've been providing care for a 47-year-old man named Zebty Jally who is married and has six children, and is a quadriplegic.

Each day, I arrive at his home, review the night log, we begin his daily routine. It starts with helping him wash his face and relieve his bowel and bladder, including an internal catheter. I prepare and assist him in eating breakfast, and then his wife, Jiji, and I prepare to shower Zebty, which requires a two-man lift and transfer of his 100-pound body four separate times just to assist getting into the shower. After transferring him back to bed, we rub him down with cream, check for "hot spots" and bed sores, do over an hour's worth of range-of-motion exercises, and assist him in getting dressed for the day.

Every 2 hours, I need to reposition Zebty's body and check his blood pressure. If it reaches a dangerous level, either high or low, I must quickly assess what might be causing the spike and take action to regulate it. It requires fast thinking and an intimate knowledge of Zebty's unique needs. It's worth noting that it is because I've assisted him for almost 2 years and have a thorough understanding of his medical situation that I can deliver such vital, quality care.

Unfortunately, that kind of close relationship and continuity is rare. Turnover among caregivers is very high because of low wages and a lack of benefits. So, many clients are faced with training and learning to trust workers over and over again, as workers cycle through on a regular basis.

I love the work that I do. I have become very close with Zebty, Jiji, and their kids. They treat me like a member of their family, and the kids even gave me a Mother's Day card last month. It really touched my heart and reminded me how important home care work is.

But home care work is not easy. It's often a physically and emotionally demanding job, requiring not just lifting and transferring but compassion, love, and patience—for the client and their family. It's not a punch-in, punch-out job. If someone needs additional assistance, caregivers provide it—and are often not compensated. So, we work more hours than we're paid. It's a job with few benefits, like sick or vacation time. Many of us have no health insurance. I make \$10.12 an hour—but only thanks to the collaborative effort of my fellow union members during bargaining. The average worker makes around \$8 an hour.

In my family, we've made big sacrifices. On such a meager salary, we could afford to send only one of our three children to college. We don't take vacations. We don't drive new cars. Home care workers provide the important care that allows people to live independently, but we struggle to make ends meet and often are forced to leave the field for better jobs.

Both clients and workers struggle with poor backup systems, since recruiting and retaining reliable workers is so difficult. If I can't make it one day, it's almost impossible to find backup. There are not enough caregivers who are trained effectively to fill my shoes.

Without my assistance, Zebty would have a limited life. He would not be able to be there every day to watch his six children grow or participate in the significant

events in their lives, like seeing his second grader in a recent school play. He would be in a nursing home and not be around to be a dad and make decisions for his family.

Like a lot of Americans, he worked hard and enjoyed spending time with his wife and kids, but then a terrible car accident almost 2 years ago left him paralyzed and unable to provide for his family.

Before his accident, Zebty had a good job with health care benefits and a 401(K). He had been able to start saving for retirement. When he became paralyzed and needed medical assistance, he had to spend all of his savings, leaving Medicaid as the only option left for him to get the personal care assistance he needs. And he is fortunate to live in a State with a Medicaid program that covers these in-home services. Many seniors and people with disabilities have to live in a nursing home because their State's program doesn't cover sufficient home and community-based services.

Because he fears losing his eligibility for these critical services, his family has to remain poor. His wife had worked as a child care provider, but because they need to stay poor to maintain his eligibility, and because she needed to be on call to provide backup care due to high turnover on the evening shift, she limited her hours and eventually stopped working altogether. They're on a tight budget and the loss of any one support would throw their family into crisis.

Medicaid-funded home and community-based services provide the cost-effective assistance seniors and people with disabilities need to live at home. But I don't think it should be the only reasonable way to access these services. People should not have to enter and remain in poverty to get this needed assistance.

Whether you're young or old, one day you may need long-term care—and the choice to live at home without spending down into poverty should be available to everyone in America. We need to expand the choices for this growing population who need in-home care. Congress should take steps to ensure people have a range of options when it comes to community supports and services. It would be a great idea to create an affordable insurance program that enables people to prepare for the likelihood of becoming disabled, especially as they age.

This kind of program would provide additional resources and help ensure a stable, professional workforce is available. If we do not improve wages and provide basic benefits like health insurance, we will never have a stable, professional workforce of dedicated caregivers to provide the quality care we can count on.

The recent Supreme Court decision to permit home care agencies to continue to deny payment of the minimum wage and overtime to home care workers devalues our work and does little to encourage workers like me to join this workforce and to stay in it.

I'm lucky that Washington State has such a strong minimum wage law that ensures that home care workers in Washington are protected. But Congress needs to take action to protect all home care workers by amending the Fair Labor Standards Act.

As the baby boomer generation ages, thousands of caregivers like me are going to be needed to provide the one-on-one, personal care that gives people the choice and the freedom to live at home. Congress should act to ensure there are good jobs for workers like me and quality care for consumers like Zebty.

Thank you.

The CHAIRMAN. Thank you, Glenda. That's an extraordinary story. And your commitment and dedication is really—truly inspirational. Thank you for all of the good things that you do.

Ms. FAATOAFE. Senator, this is my family I take care of.

The CHAIRMAN. Yes, we've got them right up here. I see how they look at you about the difference that you make in their lives. So, we thank you so much.

Ms. FAATOAFE. Thank you.

The CHAIRMAN. We have a hundred people in the overflow room in Dirksen 628, and they're watching all of this on television. So, we thank them for being here. I had a special feeling for them, because I was the ninth in a large family, and whenever the room was full, I was always put in the extra room.

[Laughter.]

So, I want to say hello to all those people. That's come out in therapy at sometime. It explains a lot about me.

[Laughter.]

But, we'll move on from there.

Senator ENZI. It's my pleasure to introduce Shawn Griffin, whose the Chief Executive Officer of Community Entry Services, in Riverton, Wyoming.

Shawn has over 18 years of program development and administrative experience in the field of rehabilitation. He has extensive knowledge in providing community-based rehabilitation and long-term care for persons with disabilities, including job training and placement, community living supports, and school transitions.

In his capacity as CEO he has participated in nationwide projects establishing core competencies, recruitment and retention for direct care professionals. Shawn has also been heavily invested in the development of affordable and accessible housing projects and transportation services for persons with multiple disabilities in several Wyoming communities.

He received his undergraduate degree and a Masters degree from the University of Wyoming with a concentration in Adult and Post-secondary Education. Advanced studies related to rehabilitation have been completed, also, through the University of Northern Colorado and the Virginia Commonwealth University.

Thank you, Shawn, for being with us here today.

**STATEMENT OF SHAWN GRIFFIN, M.A., CHIEF EXECUTIVE OFFICER, COMMUNITY ENTRY SERVICES, RIVERTON, WYOMING**

Mr. GRIFFIN. Thank you for your kind words and introduction. Good morning, Chairman Kennedy, Senator Harkin, Senator Murkowski, and from my home State, Senator Enzi. I appreciate being here. I also appreciate and thank you for your attention to this important issue to me, and for the insightful words that all three of you shared in the beginning of this hearing. You obviously have a deep-rooted concern.

Since the era of de-institutionalization that began in the 1970's, Medicaid has provided the means for many people with cognitive disabilities to live, recreate, volunteer, vote and participate in their communities, and lead productive lives. One thing I would like to point out is the National Core Indicator Project, where Wyoming ranked high in many of the quality indicators, which is something I am very proud of, coming from a small State. I would also like to thank the other States that participate in that study. It definitely offers some national measures, and baselines for quality indicators.

Medicaid is the primary financing mechanism for long-term support and services in the United States, accounting for approximately 42 percent of all long-term care spending. At this time, I would caution that although Medicaid has worked for millions of people with disabilities, the Nation can not continue to rely solely upon Medicaid for long-term care.

That's why I'm pleased to hear, and eager to learn more about, the Community Living Assistant Service and Support Act, that I understand Senator Kennedy and others have introduced.

I want to outline the multiple challenges currently facing our long-term support system that jeopardizes the opportunities that are now present in the immediate future for many people with disabilities. I believe they demand prompt attention, because we have made life in the community a national goal with the Americans with Disability Act, the Supreme Court's *Omstead* decision, and President Bush's new Freedom Initiative.

With that, if I have some time, I would like to highlight some of the challenges facing providers today.

First, is the inequitable balance between institutional and community supports. Together with the Federal Government, some States have made efforts to rebalance their Medicaid programs, or at least attempt to achieve a more equitable balance between the proportion of total Medicaid long-term supports and service expenditures for institutional services, and those spent for community supports.

If you look at some of the 2004 annual cost of State-operated facilities, averaged \$146,000 per person, compared to community-supported living, and personal assistance care, which was \$21,000 per person.

As you may be aware, Senator Enzi, Wyoming's waiting list for services is basically non-existent, which is something that should be applauded in our State. We are, however, one of the very few fortunate States that do not have a waiting list. Nationwide there are over 75,000 individuals waiting for residential services. Another important fact is that another 650,000 people with developmental disabilities live with their aging parents, who—as their adult child's caregiver—may need his or her own personal assistance within the near future. Very important. Their No. 1 concern is, who is going to care for their son or daughter when they die, or they're no longer able to care for them.

I am going to hurry. The single-greatest challenge facing service providers today, is the inability to recruit and maintain qualified direct care staff, needed to support people with the disabilities to live as independently and safely in the community of their choice. Average hourly wage, that was mentioned earlier, is \$8.54, or \$18,000 a year. In most States, wages paid to direct care professionals are so inadequate, that the income level qualifies them for the same public assistance program as those they are paid to support. A large majority of direct care professionals are single mothers supporting children, and I cannot express enough the fact that we must provide livable wages to these individuals.

As you know, Senator Enzi, Wyoming's leadership and stakeholders have recognized this problem, and have worked diligently to increase wages to direct support staff in our State through financial contributions by our State. However, we are again, even in Wyoming, losing ground to this, and it's due mainly in our State, to a robust economy. And unlike private sector, wages—reimbursement is set at the State and Federal level. We have no wiggle room, so to speak, to adjust our—what we charge for services, we're kind of stuck with what we get.

In working with our National Association anchor, I believe that a good first step in addressing the national workforce crisis lay with bipartisan legislation, the Direct Support Professional Fair-

ness and Security Act of 2007, H.R. 1279, by Representatives Capps and Terry, Capps from California, Terry from Nebraska.

Without additional Federal funding to fiscally strapped States, the accomplishment of a few, short-term, state-by-state initiatives will be at risk.

Last, I would like to just touch real quickly on affordable housing. The price now at 2006 which was presented, or prepared by the Boston Technical Assistance Collaboration details the effects of the housing crisis for people with disabilities. Two disturbing statistics pointed out in the forward, actually by Eunice Kennedy Shriver, are definitely worth noting.

One, that last year, the national average rent for a one-bedroom apartment was up to \$715.00, or 113 percent of a monthly SSI income. And also, for the first time, the national average rent of \$633 for a studio apartment is above the entire Social Security check that a person receives. Very alarming.

Thank you.

[The prepared statement of Mr. Griffin follows:]

PREPARED STATEMENT OF SHAWN GRIFFIN, M.A.

Good Day Chairman Kennedy, Ranking Member Enzi, and members of the committee. My name is Shawn Griffin and I am the Chief Executive Officer of Community Entry Services, a private not-for-profit community rehabilitation program, supporting adults and children with developmental disabilities or acquired brain injuries in central and northwestern Wyoming for over 30 years. It is an extreme honor to be here today and share my knowledge regarding both opportunities and challenges facing Wyoming's as well as our Nation's long-term support systems supporting individuals with disabilities of all ages, particularly those with cognitive disabilities.

My testimony today will focus on four broad themes:

1. The fiscal and societal benefits of home and community-based supports and the progress Wyoming and the Nation have made in the past several decades;
2. The challenges States, the Nation, private providers, and individuals with disabilities face and the adverse consequences that are already endangering our long-term supports systems;
3. Danger of reliance on—actually over-reliance on Medicaid—as the Nation's primary funding mechanism for long-term supports and failure to develop a comprehensive private long-term care financing mechanism to reduce the burden on Medicaid; and
4. Several recommendations to address the barriers that threaten continued progress of home and community-based supports to people with disabilities.

BENEFITS OF HOME AND COMMUNITY-BASED SUPPORTS AND SERVICES:  
A NATIONAL GOAL

Community supports and services are instrumental in assisting persons with cognitive disabilities lead more independent, dignified and productive lives in their communities of choice. Nationwide, people with these disabilities are excelling in jobs, supported living, social networks and recreational activities. Most not only assume, but also expect access to these activities daily. As a nation we have made notable progress toward developing necessary supports for persons with cognitive disabilities within the community during the past three decades when most people with cognitive disabilities were denied the opportunities that all of us take for granted. For Cheryl, having a direct support professional assist her daily in getting out of bed, bathed, dressed and in her wheelchair to go to work; prepare meals and assist her in eating; and helping her with other daily activities such as shopping, going to church, and other activities we all enjoy, means that she can contribute her talents and taxes to the local community in Wyoming. Val is a person who lived in a run down trailer and survived by collecting aluminum cans and through hand-outs from local stores and restaurants. He was also the victim of several beatings and robberies. Community services and supports have allowed Val to reconnect with his family and receive the community supports and training needed to improve his life. With minimal assistance from a direct support professional he takes his medi-

cations regularly and performs personal hygiene tasks. He also learned new job skills and now lives in his own nice apartment, cooks his own meals, knits, and works part time. Most importantly he is able to trust others again and feels safe.

As you can tell, it is imperative that we all earnestly continue the capacity of our long-term supports systems to ensure that the vital supports so necessary for Cheryl and Val—and all other individuals with disabilities—are available for them to enjoy full inclusion and meaningfully participate in the mainstream of American life.

Last week, we all joined in celebrating America's national *Independence Day* holiday—a day when we all come together to share in a common past of struggles, a present full of opportunities, and a future free to live a productive and independent life. Despite the progress of the last few decades, we still have more than 300,000 individuals with cognitive and other disabilities throughout the Nation on waiting lists for services; more than 650,000 individuals living with elderly family caregivers who face limited abilities to support their adult children with cognitive disabilities at home, and thousands of children and adults with disabilities still living in nursing homes as demonstrated in the *Wall Street Journal* article in late June.

I want to outline the multiple challenges currently facing our long-term support system that jeopardize these opportunities now and in the immediate future for many people with disabilities. I believe that they demand our immediate attention because we have made life in the community a national goal with the Americans with Disabilities Act, the Supreme Court's *Olmstead* decision, and President Bush's *New Freedom Initiative*.

#### POSITIVE ASPECTS OF COMMUNITY SERVICES AND SUPPORTS

Since the era of deinstitutionalization, people with cognitive disabilities have been able to work, play, live and recreate within the community. This has been accomplished by providing services and supports that are tailored to each individual's unique needs and preferences throughout their lifetime. Another positive aspect of community supports and services is that these services are less costly than large public institutions. Studies, including the *State of the States in Developmental Disabilities 2005* indicate that institutional costs in some States exceed two to three times the amount of fiscal effort allocated to support similar persons within the community.

As a provider of community-based services I would like to share the numerous accomplishments and individual growth I have witnessed over the years. Unfortunately, I will not have the time needed. Instead, I will generalize just a few of the benefits of community supports.

- People are now able to choose where and with whom they live.
- People are able to select and attend the church of their preference.
- Children are able to attend school with non-disabled peers.
- People are able to shop for their own groceries, clothing, and personal items.
- People are able to take vacations.
- People are able to choose their own medical providers.
- People are able to work.
- Some people own their own homes.
- Many volunteer with community projects.
- People in some cases can even choose their own support staff.
- People participate in civic activities.
- People are able to participate in recreational activities of their choice.

Most importantly, all the opportunities made available to persons with cognitive disabilities in the community promote self worth, a sense of pride, and societal involvement.

At this time I would like to make reference to the National Core Indicators Project. This collaboration between the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute has the purpose of creating performance indicators and data collection that results in the ability to measure system performance. This comprehensive project also seeks input from families and guardians. This project began in 1996 and by the 2005–2006 fiscal year report had the participation of 20 States consisting of Alabama, Arkansas, Arizona, Connecticut, Delaware, Georgia, Hawaii, Kentucky, Massachusetts, Maine, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South Dakota, Texas, Vermont, West Virginia, and my home State Wyoming. I applaud the States that have taken this initiative to measure individual outcomes that is compared to a national average. The purpose is simply to improve services based upon measurable outcomes and service satisfaction. This tool reveals not only many of the positive aspects of community services, but areas needing improvement. It is with bias and pride that I am able to say Wyoming ranks very high in most cat-

egories and leads the way in many of the indicators measured by this project to include:

- Proportion of people who looked at more than one home before deciding where to live.
- Proportion of people who looked at more than one job before selecting a vocation.
- Proportion of people who expressed having a close friend.
- Proportion of people who are able to see their friends when they want to.
- Proportion of people who are satisfied with where they live.
- Proportion that express having appropriate transportation to go where they want.
- Proportion of people who feel safe in their homes and neighborhoods.
- Proportion of women who received a gynecological exam.
- Proportion of people who are physically active.

To be fair, I must point out that Wyoming needs to improve in the area of increasing community inclusion rates. Nonetheless, the above exemplifies some of the performance indicators of the National Core Indicator Project and expected outcomes of being supported in the community. These outcomes also represent the advantages of living and being supported through community services.

Our agency provides services from birth to death with a majority of funding provided under the joint Federal-State, Medicaid Title XIX, Section 1915(c) Home and Community-Based Waiver programs. Services provided to children under the age of 18 are primarily service coordination and respite supports—not only a cost-effective method of serving these children, but one that supports most children to continue living with their families who love them and avoid more costly out of home placements. However, remaining in their homes as most parents desire can be very challenging to some families depending upon the behavioral, physical, cognition, or medical needs of their child. Nonetheless, if asked most families would not exchange this arrangement for anything in the world. I feel strongly it is our duty as a provider to advocate for these families and the supports they need.

On the other end of the spectrum our agency serves many working-aged and senior persons with disabilities. The ability to offer supports avoids premature admissions into a nursing home or medical care facility. Let me provide you with just a few examples of the importance of these supports to older adults:

- 50-year-old woman with Down syndrome, mental retardation, and limited communication skills was able to purchase her own home and work full-time at a local manufacturer.
- 73-year-old woman with moderate mental retardation who is blind in one eye and refuses to retire is able to work part-time and lives with three other senior citizens in a four-bedroom ranch style home.
- 82-year-old man with severe mental retardation and congestive heart failure does not work but volunteers at the local Head Start program and has survived three major heart attacks. I may be wrong but I contribute this to his ability to stay active and do something he enjoys more than anything and that is spending time with small children. I would also like to say this is just one example of how people without disabilities benefit from associating with persons with severe cognitive disabilities. That is, the children he works with love this man dearly and have learned acceptance and tolerance of someone who is a little different than they are. This is a lesson they will carry throughout their lives that cannot be taught without the full inclusion of people with disabilities engaged throughout their lifetime with people without disabilities.

There are many success stories as a result of the supports CES provides as well as those throughout Wyoming and the Nation. These individualized supports within the home and community offers individuals with cognitive disabilities the ability to live their lives with more choices, more failures, more opportunities, more self direction, more chances, more risk, more fear, and more happiness. All of us in this world have one chance at life. Community services and supports allow persons with cognitive disabilities the chance to lead a life similar to you and I and that, I believe, is not asking much at all.

#### CHALLENGES FACING COMMUNITY-BASED SERVICE PROVIDERS

However, given all the accomplishments to date, all the enriched lives made possible through home and community-based supports, there are challenges threatening the stability of services providers—their capacity and ability to support those who depend upon these vital supports to live productive and independent lives in communities across the Nation. These barriers include several challenges that have reached a crisis point for our Nation.

- **Workforce Crisis.** The current inability to recruit and retain a stable, adequately paid national workforce is a crisis nationwide and will only get worse as our Nation's baby boom generation retires and the demand for long-term supports increase and the supply of labor available shrinks. I believe that this direct care support staff is the chief challenge undermining the ability of people with disabilities to remain in or return to the homes and communities that they prefer. Without people to provide the individual supports—life in the community is a hollow promise.

- **Housing Crisis.** The lack of affordable and accessible housing for persons with cognitive disabilities who have limited income has reached a crisis level. Without a home—the foundation of life in the community—working and living and contributing to society are hollow national goals.

- **Transportation.** The lack of available and affordable transportation for individuals with cognitive disabilities isolates them and undermines the ability to take part in all aspects of life in their community.

#### DIRECT SUPPORT WORKFORCE CRISIS

The single greatest challenge faced by service providers today is the inability to recruit and maintain qualified staff. The long-term care service systems face a workforce crisis that without intervention will only worsen with time. These workforce challenges will make it extremely difficult to make needed improvements in quality and safety.

In most States, wages paid to direct care professionals are so inadequate that the income level qualifies direct support staff to qualify for many of the same public assistance programs as those they are paid to support. The Bureau of Labor Statistics reports that nationally the average per hour wage for individuals who provide direct care is \$8.74 per hour—or an annual income of \$18,180. Additionally, a large majority of direct care professionals are single mothers supporting children.

I cannot express strongly enough, the fact that we must provide livable wages. And by that, I mean a wage where someone can afford to live and work independent from public assistance. If a person cannot take care of themselves and their families, how in the world can we expect them to adequately take care of those they are charged to support? Access to insurance benefits and a job that provides retirement benefits should also be made available. However, with the skyrocketing costs of healthcare and lack of appropriate reimbursement it is getting more and more difficult to maintain these benefits.

The funding for the majority of private providers of supports and services to individuals with disabilities is financed through Medicaid programs. Labor costs are the major costs to CES. CES, like other private providers of supports to disabilities, is dependent on reimbursement rates set by local and State Governments. The public funding of supports to individuals who rely on Supplemental Security Income (SSI) as do most of the people that CES supports, means that, unlike other employers in the private sector, the higher cost of labor for direct support professionals can not be passed along to our customers—people with disabilities are based upon the reimbursement rates set by local and State Governments.

Unlike other employers in the private sector, wages for direct support professionals are based upon the reimbursement rates set by local and State Governments. We must contribute to the quality and effectiveness of services through the development of a fairly compensated, well-trained, stable community workforce and a sufficient supply of qualified providers—be they employees of agencies or independent providers—family and friends that are selected and controlled by individuals with disabilities.

In addition, President Bush's *New Freedom Initiative* as well as CMS' new long-term care vision has identified this issue as currently a barrier in achieving the goals of home and community supports. We must contribute to the quality and effectiveness of long-term services through the development of a fairly compensated, well-trained, stable community workforce and a sufficient supply of qualified providers—be they employees of agencies or independent providers. In recognizing the value and efficiencies in providing supports in the home and community and person-centered services, we must provide a parallel shift in the financing to match the preferences and desires of people with disabilities.

Nationwide, the turnover rate of direct care professionals is between 50 percent and 75 percent. As high as this may seem, in my opinion this is a conservative number. Some places have experienced turnover rates in direct care professionals near 100 percent. The ability to provide home and community-based supports—supports that are intimate, highly individualized, and provided on a daily basis with the trust that only comes about from a stable relationship—is difficult at best when this oc-

curs and the health and safety to those supported is severely compromised. Wyoming is not immune to this problem and we continue to struggle with staff recruitment and retention. This problem is very serious and must be addressed. Studies indicate that by the year 2015 an additional 750,000 new direct care professionals will be needed to provide long-term community support for the elderly and disabled. When you add this to the already staggering need for direct support professionals today, we as a nation have a full-blown crisis. I ask that we begin working diligently now to create real solutions because this problem will not go away without action but rather increase to the point of system failure.

A report requested by Congress, *The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities*, January 2006 by the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (APSE) analyzed this shortage and confirmed the workforce crisis. I am proud to note that Wyoming was one of five States highlighted in the report to address workforce shortages and reduce the amount of turnover in direct care professionals. At a time when Wyoming was experiencing direct support turnover rates exceeding 50 percent, service providers were able to work with our State legislature to study the issue and recommend some solutions. Known as Footnote 9 in Wyoming, it authorized a study to determine what wage would be necessary to stabilize the turnover of direct care professionals. The Wyoming legislature authorized State money matched by Federal dollars through the Medicaid Section 1915(c) Adults with Developmental Disabilities Community Based Waiver program to increase wages of direct care workers. At the request of service providers this initiative included an accountability factor requiring every service provider to provide annual documentation that the wages that were designated for direct care professionals were distributed properly. This includes identifying factors for all direct care professionals so that wage increases can be tracked to each person. This mandated annual report also measures turnover.

Fortunately, in addition to the initial increase in 2002 the Wyoming Legislature has recognized the importance of this crisis and approved other increases, including most recently a 3 percent increase that will go into effect after July 1st of this year. The State of Wyoming also purchased registrations for any interested direct care professionals to enroll in the computerized certificate program through the College of Direct Support offered through the University of Minnesota in partnership with other advocates wanting to increase the knowledge and professionalism of this workforce. In combination with the increase in direct support staff wages and access to the College of Direct Support, the State of Wyoming financed an aggressive ad campaign targeting recruitment efforts. In addition to traditional advertisement and proven recruiting efforts, this campaign included an annual banquet recognizing direct support staff award winners publicly and with a financial incentive. This banquet continues to date and awards are presented by the Governor of Wyoming. These initiatives have shown the commitment of the Wyoming provider system and support of policymakers of the highest level. We are thankful for the support we have received in attempts to solve this crucial workforce shortage. This trend lasted for 3 years and then we began witnessing an increase in the turnover rates of direct support staff once again. The aforementioned initiatives showed great promise until Wyoming began to feel the effects of a booming economy related directly to the increased production of gas and oil. This combined with Wyoming's already robust economy aided immensely through coal production, tourism and the mineral industry began to have a negative effect on the ability to recruit and maintain direct care professionals. This also had a large effect on the affordability of homes in Wyoming, adding to the difficulties of enticing direct support professionals to move to our State. The following charts show the direct correlation of a decrease in turnover when wages were initially increased.

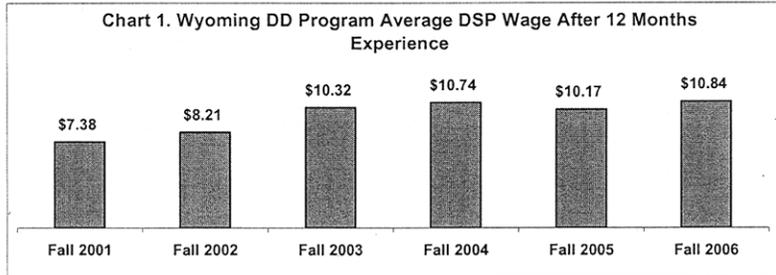


Chart 1: The average total wages of staff with at least 12 months of experience grew by 6.6% from the fall of 2005 to 2006. This reflects the 7% increase given to Providers of DD Services as outlined in the 2006 House Bill 001, section 048, footnote #5.

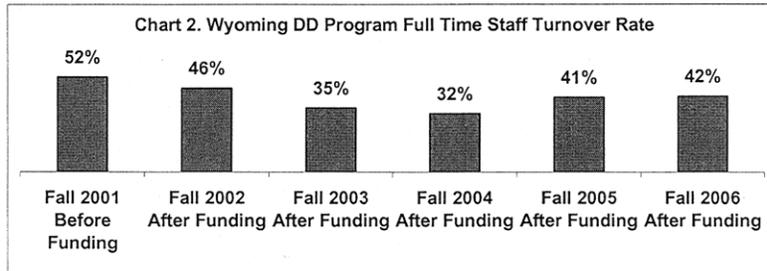


Chart 2: The staff turnover rate has remained flat between the fall of 2005 and 2006. The affects of the 7% wage increase starting July 1, 2006 will not be known until the fall 2007 footnote survey is completed.

Unfortunately, we were being outpaced by the positive economic gains seen in our State. Despite some of the noteworthy efforts of the good people in Wyoming and the State leadership, we as service providers are once again losing ground quickly in a vocational field already experiencing high rates of turnover. Wyoming's seasonally adjusted unemployment rate fell to 2.6 percent in January 2007 far below the national average of 4.6 percent. At the same time, Wyoming's job growth rate was 3.7 percent compared to the national average of 1.6 percent crippling our recruitment efforts even more. Once again, we are seeing turnover rates equaling and in some areas of the State, exceeding pre-footnote 9 numbers.

I must point out that although a very vibrant economy like the one currently being experienced in Wyoming affected recruiting efforts, there are many, many other contributing factors that have led to a State and national shortage of direct care professionals in the community. Low wages and benefits, work demands, lack of interest, lack of training, inexperience, work hours, job isolation, and working with challenging behaviors and intimate personal care issues not only lead to high turnover rates but also contributes to increased reports of neglect and abuse.

In most States, wages paid to direct care professionals are so inadequate that the income level qualifies direct support staff to qualify for many of the same public assistance programs as those they are paid to support. Additionally, a large majority of direct care professionals are single mothers supporting children. I cannot express strongly enough, the fact that we must provide livable wages. And by that, I mean a wage where someone can afford to live and work independent from public assistance. If a person cannot take care of themselves and their families, how in the world can we expect them to adequately take care of those they are charged to support? Access to insurance benefits and a job that provides retirement benefits should also be made available. However, with the skyrocketing costs of healthcare and lack of appropriate reimbursement it is getting more and more difficult to maintain these benefits.

Our program has seen increases in our health insurance at a rate of 18 percent to 30 percent each year for the past 15 years. Despite recent reimbursement increases we have seen in Wyoming, it is very difficult to maintain health insurance

for staff. Being a direct support professional is a demanding job with colossal responsibilities that includes medication access, dealing with challenging behaviors, working alone in many cases, performing intimate person care, and teaching multiple skills. And you do all this and more only to find that in many cases your wages equal to those of a fast-food worker. This is not only embarrassing but also completely inexcusable.

Simply put, you are responsible for the lives of persons with compromised cognitive skills and medical concerns, not to mention the amount of paperwork you must complete.

High turnover rates mandate remaining direct care professionals and managers to work excessive overtime hours. For obvious reasons, we are unable to shut down certain shifts or operate with unsafe staffing levels. These increased demands and increase overtime hours lead to additional staff burnout and turnover, creating what has become referred to as the “revolving door.”

In my travels around the country as a surveyor for the Commission on Accreditation of Rehabilitation Facilities (CARF), I find over and over again that the lack of qualified staff, inability to recruit new employees, and the high rate of staff turnover to be the largest problems faced by service providers. This in turn reduces the quality of services provided and can indeed put the health and safety of persons with disabilities at great risk.

I realize there are no easy answers to workforce shortages experienced by many employers in the United States. You may ask why should the field of community services and supports be any different or garnish more attention and assistance? I can only answer that by saying one thing. These are people. People who must depend upon and trust others to assist them in many, if not all, facets of personal living skills. The inability to find solutions could literally be life threatening.

I believe that a good first step in addressing this national workforce crisis is passage of legislation like the Direct Support Professionals Fairness and Security Act of 2007 (H.R. 1279), bipartisan legislation introduced by Representatives Lois Capps (D-CA) and Lee Terry (R-NE) that is designed, on a voluntary basis, for States to apply for additional Federal funds to increase wages of direct support professionals. As we have seen, without additional Federal funding to fiscally-strapped States, the accomplishments of a few short-term, state-by-state initiatives end without creating the stable conditions needed to develop an adequately paid direct support workforce now and in the future.

#### LACK OF ACCESSIBLE AND AFFORDABLE HOUSING

There continues to be lack of accessible and affordable housing nationwide for persons with cognitive disabilities. There are many programs that assist low-income individuals when purchasing a home. However, many persons with cognitive disabilities do not even qualify for this assistance. Unfortunately, people are forced to live where they can, oftentimes in unsafe neighborhoods and certainly not choice driven.

This year's annual Priced Out in 2006, prepared by the Technical Assistance Collaborative, Inc. in Boston and the national Consortium for Citizens with Disabilities, funded through the Melville Charitable Trust, with the foreword provided by Eunice Kennedy Shriver, outlines in detail the continuing housing crisis facing people with disabilities. Two astounding statistics really brings this issue to light.

- “Last year the national average rent for one-bedroom apartments rose to \$715 per month—this equals 113.3 percent of monthly SSI income.”
- “In 2006—for the first time—the national average rent of \$633 for studio/efficiency apartments rose above the entire monthly income of an individual who solely relies on SSI income. Even this modest dwelling would consume 100.1 percent of someone's income.”

We are not exempt from these staggering figures in Wyoming either. We have areas of high impact to include the counties of Campbell, Sublette, Sweetwater, and an area where our agency provides services, Teton. Teton County has consistently been one of, if not, the most expensive County to live in the United States. The cost to buy or build homes in Wyoming is incredibly high with housing costs across the Nation extreme, especially for those with limited incomes and challenging disabilities. As an example, our agency built a five-bedroom accessible home with a final price tag exceeding \$450,000. We were fortunate enough to receive a Community Development Block Grant for \$300,000, leaving \$150,000 that we had to pay through other privately raised funds. We are thankful for the grant and the ability to provide this housing. However, without grant assistance and the ability to raise private funds, the persons we support could never afford to live here. The hard question then becomes, where do they go? We are running out of options. Add to the cost of housing the increasing costs of food, medical care and energy costs, and

the problem begins to seem unfathomable. Similar to transportation, traditional funding sources do not reimburse room and board charges and funding that is available remains stagnant and only covers a portion of what is needed.

Lastly, as a service provider that manages several HUD projects, I would love to see a relaxing of oversight regulations. This is not only time consuming and burdensome, but in my opinion an ineffective use of resources. I agree that some rules and oversight must be in place to prevent fraudulent use and discrimination. However, relaxing the reporting requirements of a long-term project such as ours, in the 26th year of a 40-year project, with positive proven track records would allow efforts to be focused in other areas, most importantly the development of more affordable and accessible housing.

#### TRANSPORTATION CHALLENGES

I would like to quickly refer to an initiative I am familiar with currently underway in Wyoming resulting in part from the National Reduction Act and New Freedom Act. With initial grant funds provided by the Wyoming Governor's Planning Council on Developmental Disabilities, the Wyoming Independent Living Center program created a voucher program. This project provides vouchers to qualified candidates who then hire their own drivers when they need to go shopping to medical appointments, or other activities. These drivers could be neighbors or friends with simplified reimbursement to entice participation. Touted as being a success, this new project is intended to supplement, not duplicate, current public transportation. Due to the rural nature of our State, in many instances people in Wyoming must travel over 100 miles to seek necessary medical services. This program, which was sponsored substantially by the Wyoming Department of Transportation, not only provides a highly needed service, but also exemplifies what can be accomplished through determination and partnerships.

However, most transportation services provided for persons with cognitive disabilities are done through services providers. Medicaid, which is the primary fund for community services and supports, does not consider transportation as a reimbursable service. Thus, in most cases, fuel prices, vehicle procurement and maintenance, and driver training all become the responsibility of the provider who must depend on other fund raising methods, which many of which are not dependable.

I realize there are many transportation initiatives being conducted across the country and even in Wyoming. I would conclude by stating that individual choice such as the aforementioned voucher program is wonderful but somewhat limited and not guaranteed. Therefore, methods of reimbursement for transportation should be considered when defining future supports and expectations for persons with cognitive disabilities being supported in the community.

As a service provider we are dependent primarily upon State and Federal funding to support persons with cognitive disabilities. Throughout this testimony, I have discussed several pressures we are facing to include workforce shortages and the need for livable wages, skyrocketing insurance costs, subsidizing housing, and non-reimbursable transportation cost. I must point out our inability to cost shift or increase fees relative to the increase in expenses to operate. Therefore, I would appreciate your attention to the following proposals and thank you sincerely for the chance to present this information in this forum.

#### NEED TO DEVELOP A NATIONAL COMPREHENSIVE, ADEQUATELY REIMBURSED SYSTEM

Today, Medicaid is the primary funding mechanism for long-term supports. The development of a comprehensive long-term care program for elderly and disabled people is critical. Without the development of such a program, long-term care expenditures will continue to overwhelm State and Federal health care budgets, limiting needed expenditures for primary and preventive health care. The Nation must develop other options to providing long-term supports in the future—supports based upon the preferences of people with disabilities and the elderly—thereby, reducing the burden on Medicaid.

As you know, this year marks the first year that members of the baby boomers turn 60. I figure that during the 2 hours set aside for public comment—660 individuals have turned 60. The Census Bureau estimates that 7,918 people will be turning 65 each day in 2006. The United States has not begun to prepare for this demographic dynamic. This challenge is not simply about *long-term care* and Social Security, pensions and other income maintenance efforts—its about housing, products and services, technologies, language, learning—every aspect of life. What will 77 million baby boomers like as their favorite drink, how will they prefer to shop, malls, small stores, online, personal shoppers. Included among the baby boom gen-

eration are individuals with life-long disabilities, family caregivers, and a workforce that has been providing a range of daily long-term supports and services.

In addition, when it comes to reimbursing providers, Medicaid is stingier than either Medicare or commercial insurance. Cuts in reimbursement rates have become one of the most expedient means for saving dollars. However, by low-balling compensation, the program ends up reducing the number of providers willing to provide Medicaid long-term supports and services.

I believe that a good first step towards developing a new option for financing long-term supports is *The CLASS Act*.

#### INITIATIVES AND PROPOSED SOLUTIONS

1. Due to the comprehensive nature of the National Core Indicator Project and the ability to uniformly measure individual State performance based upon numerous indicators and input solicited directly from persons with cognitive disabilities and their families, I would suggest exploring the possibility of having all States participate in this project. Ultimately, this could create national benchmarks for quality expectations of service provision.

2. At the national level, I would encourage you to support the adoption of H.R. 1279 referred to as the "Direct Support Professionals Fairness and Security Act of 2007." This amendment to Title 19 of the Social Security Act would provide monies to some States to increase the wages of direct support professionals in community-based Medicaid supported programs. States would be required to develop acceptable wage enhancement plans promoting accountability and good stewardship in getting wage increases to direct care professionals.

3. This suggestion is not presented to debate institutional versus community services and supports. However, I would suggest a review of the inequities in funding and subsequent wage and benefit discrepancies amongst direct support professionals in the private sector and those in public institutions. There must be either appropriate resource shifting to develop community capacity. At the very least services access should be equitable.

4. Review affordable housing options and program incentives to assist in housing development. Additionally, I would encourage a review of HUD rules to determine any measures that may allow for reduced reporting requirements that still incorporate accountability and project compliance.

5. I would like to acknowledge some of the innovation transportation projects similar to the voucher program in Wyoming. Continued support of these projects is recommended. Also, when reviewing reimbursement methods for support services in the community, I would encourage policymakers to consider transportation costs and possible reimbursement methods using traditional means of funding.

6. Without a comprehensive national approach to long-term supports and services, and in the face of the demographics of an increased demand for such supports given a retiring baby boom population and medical technologies that increase the lifespan of all people with disabilities, there will only continue to be increased burden on the Nation's primary financing program for long-term supports—the Medicaid program. I believe an important step in addressing the need for a broader, comprehensive, public and private long-term care system is the *CLASS Act*. I encourage Congress to begin discussion of this legislation right away.

The CHAIRMAN. Thank you very much.

Andy, we are delighted to have you. Andy Imparato is President, Chief Executive Officer, American Association of People with Disabilities, and a good friend. Tom Harkin related about what an extraordinary difference you've made to this committee. You've had an extraordinary career in the areas and we are very, very grateful for your presence here and for your message and for your lifetime commitment to the cause.

#### **STATEMENT OF ANDREW J. IMPARATO, PRESIDENT AND CHIEF EXECUTIVE OFFICER, AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES, WASHINGTON, DC.**

Mr. IMPARATO. Thank you very much, Senator Kennedy, and I want to thank you and Senator Harkin, and Ranking Member Enzi, and Senator Murkowski for all being here at this hearing, and for having this hearing which—the size of the audience and

the size of the overflow room really pales in comparison to the level of interest in this hearing around the country.

I am honored and humbled to testify today on behalf of four very important organizations. One of them I run, called the American Association of People with Disabilities. But when Connie asked me to testify, I told her I wanted to testify on behalf of also ADAPT, and the National Council on Independent Living and self-advocates becoming empowered. Because from my perspective, those organizations are the ones that are showing the leadership on the issues we are talking about today. And I am really honored that they allowed me to testify on their behalf.

The CHAIRMAN. I just mentioned, you received the Secretary's highest recognition award from the U.S. Secretary of Health and Human Services, Mike Leavitt, for commanding leadership of APD. And politically and economically empowering all people with disabilities, through public policy advocacy and programs. So, you come well recommended and well recognized.

Thank you.

Mr. IMPARATO. Thank you very much, Senator Kennedy. I hope that won't come out of my 5 minutes.

[Laughter.]

The CHAIRMAN. You have been around here too long.

[Laughter.]

Mr. IMPARATO. In all seriousness, I really want to acknowledge Bob Kafka, whose been mentioned earlier. Bob helped me a lot with my testimony, he's been a mentor for me for a long time, including when I worked for Senator Harkin on the Disability Policy Subcommittee. I want to acknowledge Bobby Coward, who is sitting next to Bob, who is a brand new board member of AAPD. So, he is making sure that I am doing justice, by ADAPT, and by my colleagues.

For many people in the room today this hearing goes to their most personal, most intimate moments—how and where they live their lives, get out of bed, use the bathroom, eat a meal, play with their children, get to work, participate in worship, socialize with friends and families, and vote. And, I appreciate my colleague, Shawn, who mentioned voting.

I attended a hearing that ADAPT hosted in Nashville, Tennessee, where I heard from over 50 individuals, over 7 hours of testimony, who had spent times in nursing homes and other institutions. And they testified to their experience in those institutions. And I would strongly encourage folks to read the appendix attached to my written testimony, which is the transcript from what we heard at that hearing. I also want to acknowledge Dr. Peg Gianinni, who went with me down to Nashville on behalf of Secretary Leavitt and heard that testimony on behalf of the Administration.

**[Editor's Note: Because of the high cost of printing, previously published materials will not be reprinted. For the above mentioned transcript, go to [www.adapt.org/freecourpeople/aar/nash06/transcript.htm#andyimparato](http://www.adapt.org/freecourpeople/aar/nash06/transcript.htm#andyimparato)3.]**

As a person with bipolar disorder, manic depression, I am particularly sensitive to the human rights issue of forced medication. And one of the things I heard over and over again in Nashville, is that when people are in institutions, and they speak up about their

inhumane living situation, they get forcibly medicated against their will. This is a human rights violation that's going on around the country, and it's happening to people with psychiatric conditions—and to people without psychiatric conditions—as a way to placate them. And it's wrong, and it's something that the government and this committee can do something about.

I have three main points that I'll get through quickly for my oral testimony. First, and a lot of this echoes what you've heard from other witnesses. Our long-term care system is broken, and completely inadequate for the current needs of people with disabilities of all ages, and for the future needs of an aging population. Fixing the institutional bias in Medicaid is a critical first step, but as other witnesses have said, that isn't going to get us everywhere we need to go. We need new creative approaches like the Community Living Assistance Services and Supports Act, or the CLASS Act, which is being introduced today in the Senate and the House. And, I'd strongly encourage Senator Harkin, Senator Enzi, Senator Murkowski, to please co-sponsor that legislation. Take a hard look at it. I commend this committee for looking at these issues in a bipartisan way.

Senator Enzi, your staff have been phenomenal working across aisles to try to do good policy. This is good policy and I really encourage you to look hard at this legislation.

The CLASS Act is not—and it really lines up with what you said in your opening statement, Senator Enzi, the CLASS Act does not require people to leave the workforce and impoverish themselves in order to get services and supports that they need to survive. It encourages people to plan for, and save for, their long-term services and supports needs from the moment they begin working, and it gives people real choices in where and how to receive their supports and services. Everyone on this committee should take a hard look at this legislation, because it's good policy, and it will save the taxpayers money, and it will dramatically improve people's quality of life.

My second point is that we need an oversight hearing on the failure of the States to comply with the *Omstead v. Lois Curtis* Supreme Court decision. That was mentioned by Shawn Griffin, next to me. That was a ground-breaking decision in 1999 where the Supreme Court held that it was a violation of the ADA, to force people to live in segregated institutional settings, when they could be appropriately cared for in the community. And, the States are not complying with that civil rights decision. That's a civil rights issue. It's not a Finance Committee issue, it's a HELP Committee issue. I'd strongly urge this committee to look at that as an ADA oversight issue. And I know you all are doing a lot of oversight, and to me that's a great issue to look at.

And, you know, this is an issue where Senator Clinton fell short—not Senator Clinton, but President Clinton—fell short, and President Bush has fallen short. President Bush did issue an executive order on Omstead implementation, but we are not seeing aggressive enforcement from the Federal Government.

My third point, and last point, is that this committee needs to recognize—and this goes back to Senator Harkin's statement—that the goals of the Americans with Disabilities Act for people with dis-

abilities—the quality of opportunities, full participation, independent living, economic self sufficiency—will never be realized until we have comprehensive health care reform that truly meets the needs of people with significant disabilities across the age spectrum, and across the income spectrum. Piecemeal reform focused on simply covering the uninsured won't be meaningful unless and until it addresses the acute, and long-term care needs of people with significant disabilities and chronic health conditions. Medicaid and Medicare need to be modernized, and support people with disabilities in living independent lives with dignity and choice in the community. Everyone on this committee should support the Community Choice Act as a critical first step in transforming Medicaid, so that it supports the goals of the Americans with Disabilities Act.

The time to act is now. People's lives are being stolen by our inadequate and broken systems. And I am going to close with a brief quote from Samuel Mitchell, who was one of the witnesses that we heard testify in Nashville. He said, "I was an ordained minister and also a truck driver who became disabled. I had a ministry to nursing homes. I went in nursing homes and preached. I thought I knew a little bit about them. After becoming disabled a year later I suffered a stroke. That's when I entered a nursing home and found out just how much I didn't know about nursing homes. The prevailing atmosphere in nursing homes is that we now own you. We own you and everything about you. You become a non-person, your rights, human rights and civil rights are routinely violated. Dignity—there was no dignity."

Thank you very much.

[Applause.]

[The prepared statement of Mr. Imparato follows:]

PREPARED STATEMENT OF ANDREW J. IMPARATO

Chairman Kennedy, Ranking Member Enzi, and Members of the Senate Health, Education, Labor, and Pensions Committee, thank you for giving me the opportunity to testify today regarding the very important topic of community living and long-term services and supports. My name is Andrew J. Imparato, and I am the President and Chief Executive Officer of the American Association of People with Disabilities (AAPD), a national non-profit, non-partisan membership organization promoting the political and economic power of the more than 50 million children and adults with disabilities throughout the United States. With more than 100,000 members, AAPD is the largest national cross-disability membership organization in the country. I am very glad to provide my testimony today on behalf of not only AAPD but also three other national, cross-disability, non-partisan membership organizations—ADAPT, the National Council on Independent Living (NCIL), and Self Advocates Becoming Empowered (SABE)—all of which also share the goals of self-determination and full participation for our community in all aspects of society.

NCIL is the oldest cross-disability grassroots membership organization run by and for people with disabilities, advocating for independent living and the advancement of people with disabilities through consumer-driven advocacy. ADAPT is a national membership organization focused on changing the long-term care system through achieving adequate attendant services in the community and ensuring that individuals who want to leave nursing homes and other institutions to live in their own homes and communities can do so. SABE is committed to ensuring that people with disabilities are treated as equals and are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves.

As a former counsel to this committee's Disability Policy Subcommittee between 1993 and 1994, I have had the pleasure of working closely with bipartisan members and staff on this committee, and I very much appreciate your commitment to civil rights, self-determination, and full participation of children and adults with all types of disabilities in all aspects of society. My testimony is grounded in my profes-

sional experience as a disability rights lawyer and policy advisor and my personal experience as a person with bipolar disorder or manic depression.

Also, as a Senate appointee to the bipartisan Ticket to Work and Work Incentives Advisory Panel, I chair that Panel's committee that has been tasked with developing a new model for providing supports and services to people with significant disabilities. Our new model, which we are calling a "national employment investment strategy," is grounded in higher expectations and more timely investments that will provide a strong return over the lifespan of an individual with a disability. We believe that timely investments will result in cost savings to the Federal Government, higher quality of life for people with significant disabilities, and a new skilled workforce that can help mitigate labor market shortages that are projected over the next several decades.

Perhaps the most important point I could make this morning is that every American is a stakeholder in today's topic. There are currently 10 million Americans in need of long-term services and supports, and that number is expected to rise to nearly 15 million by 2020.<sup>1</sup> These individuals are male and female, adults and children, with a broad range of disabilities represented. This is in no way a static population.

Disability civil rights laws start with the recognition that disability is a natural part of the human experience that in no way should limit a person's right to make choices and participate fully in all aspects of society. Any person at any time can acquire a disability. Some people acquire disability as they age. By 2030, when the youngest baby boomers reach retirement, the population of those age 65 and older will nearly double to 71 million, comprising 20 percent of the American population.<sup>2</sup> Some people acquire their disabilities through birth; some through accident or injury; some through illness. Still others acquire disability while putting their lives on the line for our country. Traumatic brain injury has become the signature wound of the Iraq-Afghanistan wars, with estimates as high as 60–70 percent of all wounded returning vets having TBI.<sup>3</sup> This unprecedented population of disabled soldiers and veterans is expected to have ongoing needs for long-term services and supports over the course of their lifetimes, with some recent reports suggesting the cost of care could be as much as \$14 billion over the next 20 years.<sup>4</sup>

Given the diversity of the disability population across the age spectrum, our country requires a long-term care system that affords people real choice in how and in what environment they will receive the supports they need to live. This means a system built to work for all people without regard to age or disability. One that begins with the assumption that adults with disabilities want to work, children with disabilities want to learn and play with their neighborhood friends, and the vast majority of individuals in need of long-term services and supports would rather receive those supports at home with family and friends. One that looks holistically at people with disabilities and understands that long-term care should be integrated with acute care services; that personal care attendants are a reasonable workplace accommodation; and that people should have freedom in choosing where to live and not be forced into certain types of housing in order to qualify for the supports they need to survive. Only a long-term care system that is comprehensive in scope could satisfy the existing as well as impending demand for long-term care that moves us away from our long legacy of warehousing people with disabilities—simply maintaining them so they can survive another day—and toward investing in them, with an expectation of return. Choice and control should be at the foundation of any comprehensive reform. Sadly, this vision of comprehensive reform is the complete opposite of what we have in place today.

Our current system of long-term care dates back to 1965, when the Medicaid and Medicare programs were first created.<sup>5</sup> Not surprisingly, given the origins of these

<sup>1</sup> Kaiser Family Foundation (July 2006). *Medicaid and Long-Term Care Services*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured; Feder, J., Komiser, H.L., & Friedland, R.B. (June 2007). *Long-term care financing: Policy options for the future*. Washington, DC: Georgetown University Long-Term Care Financing Project.

<sup>2</sup> Alliance for Health Reform (March 2007) *Issue Brief: Long-Term Care Partnerships: An Update*.

<sup>3</sup> Institute of Medicine, the National Academies, *Evaluating the HRSA Traumatic Brain Injury Program*, Washington, DC.: The National Academies Press, Eden, Jill and Rosemary Stevens, Editors, 2006, p. 41.

<sup>4</sup> "One Soldier's Struggle with the Iraq War's Trademark Injury," *Stanford Medicine Magazine* (summer 2007), referencing a report by Linda Blimes of Harvard's Kennedy School of Government and Joseph Stiglitz, Ph.D. of Columbia University.

<sup>5</sup> Hearing on Long-Term Care and Medicaid: Better Quality and Sustainability by Giving More Control to People with a Disability Before the Subcommittee of the House Committee on Energy

Continued

programs, the system continues to exemplify the historically low expectations society has had for people with disabilities for decades. With the expectations for us so low, the mission of the old system was and remains to this day focused on simply maintaining people with disabilities in nursing homes, other institutions, and back rooms, outside of view and away from the mainstream. In 1965, people with disabilities were largely out of sight, because society was inaccessible, both literally and attitudinally. In 1965, States still had involuntary sterilization laws for people with disabilities. Curb cuts were few and far between. There was no Americans with Disabilities Act (ADA). It is 42 years later, and it is an abomination that hundreds of thousands of people with disabilities remain trapped in a broken system that steals lives, saps peoples' spirit, and enriches service providers at the expense of disabled people and their families.

The existing long-term care system in this country is shouldered almost entirely by family caregivers and public programs provided in institutional settings, in overly medical ways that are often unnecessary and needlessly expensive. Private insurance for long-term care comprises only 3 percent of long-term care spending, and a recent study showed that as few as 10 percent of Americans can even afford a quality, private long-term care policy.<sup>6</sup> The rest of the population gains access to the existing public system by "spending down" to a poverty level which triggers their eligibility for Medicaid and in turn, the supports they need.

The Government as well as the private sector has failed Americans in planning for the onset of disability. *Everyone* is paying for the inadequate, problematic system, and we are paying big. Long-term care represents a massive financial imposition on families and States. Approximately \$160 billion was spent on long-term care in 2004, with Medicaid financing approximately 42 percent of that figure.<sup>7</sup> Nearly one-third of Medicaid's entire budget of \$300.3 billion is spent on long-term care annually—that's approximately \$94.5 billion dollars.<sup>8</sup> Sixty-three percent of that \$94.5 billion goes directly into institutional care, despite the fact that the vast majority of those needing long-term care would prefer to get these services in-community.<sup>9</sup> Research out just last year from the University of California San Francisco and the University of Maryland estimates that when compared with Medicaid institutional care, home- and community-based waivers created a national average saving of \$43,947 per participant.<sup>10</sup> As an example, the national average per-participant expenditure for a nursing facility waiver was \$15,784—63 percent lower than the \$42,292 national average per-participant expenditure for a nursing facility.<sup>11</sup> Even more significant savings were reported for Medicaid waiver participants with an "Intermediate-Care Facilities for the Mentally Retarded/Developmentally Disabled" (ICF-MR/DD) level of care (70 percent lower expenditures than ICF-MR/DD expenditures) and waiver participants with a hospital level of care need (84 percent lower than hospital expenditures).<sup>12</sup> Despite these findings, what is guaranteed in the existing public system is a more expensive service that people do not want, while the more cost-effective service individuals would rather use is not guaranteed. How is this morally justifiable or fiscally responsible? Why are we allowing this to continue?

I traveled to Nashville along with representatives from the U.S. Department of Health and Human Services Office on Disability and the National Council on Disability to meet with a large group of survivors of nursing home and other institutions. All of these individuals had been locked away and had portions of their lives stolen despite their strong desire to live in their homes and communities. Their testimony, which lasted almost 7 hours, was submitted to the Medicaid Commission and is a part of the public record. The testimony also appears as an appendix to this written testimony. As I sat and listened, person after person, men and women, of all ages and races, gave accounts of being left in their own urine and feces, tied to their beds, raped, burned, deprived of food, put in bathtubs of cold water—sometimes as a result of neglect but most often as retaliation for complaining about their

and Commerce, 109th Cong. (April 27, 2005) (testimony of Mark B. McClellan, MD, Ph.D., CMS Administrator, Centers for Medicaid and Medicare Services).

<sup>6</sup>Id.

<sup>7</sup>Kaiser Family Foundation (July, 2006). *Medicaid and Long-Term Care Services*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured.

<sup>8</sup>Numbers taken from a report from Medstat Group, Inc., with data taken from CMS 64 reports submitted by States and compiled by ADAPT.

<sup>9</sup>Id.

<sup>10</sup>Kitchener, M., Ng, T., Miller, N., Harrington, C. (2006). Institutional and Community-Based Long-Term Care: A Comparative Estimate of Public Costs. *Journal of Health & Social Policy*, 22, 32-33.

<sup>11</sup>Id., at 38.

<sup>12</sup>Id., at 39.

inhumane living conditions. It was particularly striking to me how many of the witnesses talked about being forcibly medicated by facility staff as a way to keep them quiet. As a person with a psychiatric disability, I am very aware of how people get forcibly medicated in mental hospitals—a practice which I view as a violation of those individual's basic human rights. Based on the frequency of the testimony in Nashville, it appears that forced medication is a tool used by institutions of all kinds as a way to quell dissent and sap people's spirits. Human rights violations are taking place every day in every State in this country, and Congress has repeatedly failed to take decisive action to end the abusive and unnecessary costs of institutional care.

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Which of you, were you to acquire a disability tomorrow that required long-term services and supports, would favor living in a nursing home or other institution, slowly selling off your life as you know it to live in conditions in which you forfeit your freedoms? Which of you would feel any degree of comfort in the knowledge that your loved one was forced to live in an environment with a legacy of human rights abuses?

We have, in addition to this testimony, submitted a 10-minute DVD to the record compiled by ADAPT, which highlights the testimony of these nursing home survivors in Nashville. Each Senator should have also received a copy of this DVD in advance of today's hearing. Many have been quick to say that all we need is "nursing home reform," but nursing home reform is not the answer, and we hope that these peoples' stories will help Senators to understand that. What we need is comprehensive reform that focuses on the community as the first and best option for long-term services and supports.

Although most people think that nursing homes are nice places in which people receive excellent care, thousands of our organizations' members are telling us that their own experiences in nursing homes have been anything but helpful and compassionate. These testimonials do not represent a handful of individuals. According to data from the Centers for Medicaid and Medicare Services, there are over a quarter of a million people living in nursing homes to receive long-term care who want out! Chairman Kennedy, in your home State of Massachusetts, according to data from a CMS report regarding discharge potential and resident preferences to return to the community, as of 2003, there were 7,947 people living in nursing homes in Massachusetts who want out but are "stuck" by the system Congress created.<sup>13</sup> Ranking Member Enzi, in your home State of Wyoming, there were 2,415 individuals as of 2003 living in nursing homes and over 1 in 5 of them—532 of them—said they wanted out.<sup>14</sup> These are people who not only prefer to live in the community; many of these folks have unequivocally testified that they would rather die than suffer the indignities and loss of independence associated with institutionalized care.

Even still, many remain convinced that many of the individuals who want out of the nursing homes are people who could not survive outside of them. This is simply untrue. Not only do these people want to move out of nursing homes, they can, provided they receive the appropriate services and supports to make it happen. Moving someone out of a nursing home and providing the adequate level of supports to foster their independence is not about charity—this is a matter of civil rights and freedom.

Today, in America, the land of the free, we have over a quarter of a million people in captivity—living in institutions for the sole reason that the Federal money stream for the services they require only provides services in those environments.<sup>15</sup> Only approximately 11 percent of adults with developmental disabilities receive formal residential long-term services, and of those who do receive services, 32 percent reside in institutional settings.<sup>16</sup> Today, in America, hundreds of thousands of people with disabilities are on waiting lists for personal attendant services. Over 53,000 individuals with developmental disabilities alone are on formal waiting lists for residential services across the country—and as high as that number is, we can trust

<sup>13</sup>Centers for Medicare and Medicaid Services (December 31, 2003), Minimum Data Set (MDS) Numbers for Question Q1a, available at <http://www.cms.hhs.gov/states/mdsreports>.

<sup>14</sup>Id.

<sup>15</sup>Numbers taken from a report from Medstat Group, Inc., with data taken from CMS 64 reports submitted by States and compiled by ADAPT, July 2006.

<sup>16</sup>Braddock, D., Hemp, R., Rizzolo, M.C., Coulter, D., Haffer, L., & Thompson, M. (2005). *The State of the States in Developmental Disabilities*. Boulder: University of Colorado, Coleman Institute for Cognitive Disabilities.

it is grossly understated because States often do not keep formal lists for fear of lawsuits.<sup>17</sup> In many States, unless you're being abused, severely neglected, or your informal family caregiver dies, you are simply not going to access community services.

Of those individuals who are fortunate enough to find provision of long-term care outside of a nursing home or other institution, many are receiving personal attendant services through an informal family caregiving arrangement. In fact, 85 percent of the 22 billion hours of personal attendant services provided each year are unpaid, exacting an enormous and disproportionate toll on women who represent 69 percent of all caregivers, nearly half of whom live below twice the poverty level.<sup>18</sup> Although the economic value of informal caregiving is estimated to be over \$306 billion a year, personal attendants rarely make a living wage and seldom have access to health benefits, although their jobs are characterized by a high rate of occupational injuries.<sup>19</sup> What will happen when these caregivers require care of their own or pass away? Many families are plagued by these currently unanswerable questions, because there is absolutely nothing comforting about the system as we know it today. Of those individuals with disabilities receiving home and community-based supports, over 21 percent report unmet needs in their personal assistance services.<sup>20</sup> Such individuals with unmet needs are more likely to experience inadequate diet and nutrition, discomfort, isolation, deterioration in health status, and—bitterly ironically—institutional placement and/or increased disability—and so the cycle continues.<sup>21</sup>

It has been 8 years since the Supreme Court ruled in *Olmstead v. L.C.* that the ADA prohibits the unjustified segregation of people with disabilities through official State action and requires States to administer services in the most integrated setting possible, appropriate to the needs of the individual. Still, there is no change in the Medicaid statute, 8 years later. One of the major impediments to *Olmstead* enforcement is States' budget shortfalls. Since nursing homes are an entitlement, and since the optional program ICF-MR have been selected by every State but Arizona, States must fund those services. However, community services remain an optional component, and so if and when they are funded, it's with whatever "leftover" money there is (or is not).

President Bush's New Freedom Initiative included a Money Follows the Person demonstration project to encourage States to try the idea of letting Medicaid dollars follow the person to the location in which they desire to receive their services and supports, thereby integrating people with disabilities into the community. Since January, CMS has awarded 31 States and the District of Columbia demonstration grants for alternatives to institutional care. As a result, 27,000 individuals who want to live in their communities will be transitioned into them from out of institutional care, made possible by an enhanced Federal Medicaid match.<sup>22</sup> States save money, the Federal Government saves money when spending on community care rather than institutional care, and people with disabilities can rejoin their family and friends in the community.

It has been 13 years since Newt Gingrich introduced MiCASA in the same spirit of the Money Follows the Person demonstrations. MiCASA has evolved and was recently renamed the Community Choice Act, introduced as S. 799 by Senators Tom Harkin and Arlen Specter. Thirteen years later, there has still been no markup. Although every State that receives Medicaid must provide nursing home services, community-based services remain optional. The Community Choice Act is a bill that puts highly personal choices back into the hands of those directly affected. It is a bill about real choice. The bill gives equal access to community-based supports for those eligible for nursing home and ICF-MR services and provides enhanced Federal matching funds to help States offer greater flexibility in giving citizens what

<sup>17</sup> Prouty, R., Smith, G., & Lakin, K. C. (2005). *Residential Services for Persons With Developmental Disabilities: Status and Trends Through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living/Institute on Community Integration.

<sup>18</sup> LaPlante, M.P., Kaye, S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *Journal of Gerontology*, 59B, S98-S108.

<sup>19</sup> Arno, P. S., Levine, C., & Memmott, M. M. (1999). The Economic Value of Informal Caregiving. *Health Affairs*, 18, 182-188; Kaye, S. (2007) "Trends in the PAS Workforce: Where Have We Been and Where Are We Going" presentation at "Meeting the Nation's Needs for Personal Assistance Services State of the Science Conference," April 27, 2007, Washington, DC.

<sup>20</sup> LaPlante, M.P., Kaye, S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *Journal of Gerontology*, 59B, S98-S108.

<sup>21</sup>Id.

<sup>22</sup> CMS data, compiled by ADAPT.

they want. The Community Choice Act creates a national program of community-based attendant services and builds on the Money Follows the Person programs, allowing the Medicaid dollars to follow the person wherever the individual or his or her representative chooses to receive necessary services and supports. Rather than make a new entitlement, the Community Choice Act makes the existing one more flexible. It has been 13 years, and it is time this bill passed into law. Researchers have re-estimated the costs of a mandatory Home and Community-Based personal assistance services benefit under Medicaid to be between \$1.4 and \$3.7 billion per year, versus a prior CBO estimate nearly a decade ago in the \$10–20 billion range.<sup>23</sup>

The Direct Support Professionals Fairness and Security Act, H.R. 1279, introduced by Rep. Lois Capps, would also help to improve the sustainability of the long-term care landscape. The act would amend Title XIX of the Social Security Act to provide States with additional funds by which to increase wages paid to direct support professionals who provide assistance to people with disabilities under the Medicaid program to eliminate the current wage gap. The act would also require study of recruitment and retention of direct support workers. Although increasing wages should never be at the expense of the consumer through cutbacks on attendant services hours, increasing wages of long-term care attendants is one way in which the pool of available workers could be increased.

While these bills are vital in reforming Medicaid, which remains a dumping ground that provides inadequate care to people who have already been failed by every other system, their passage alone will not deal with the fundamental problem of the general population's failure to plan for the onset of significant disability. The Community Living Assistance Services and Supports Act, or the "CLASS Act," introduced today in both the House and the Senate, creates a new program that can take pressure off Medicaid and enable people to avoid being forced into poverty. By encouraging people to begin planning and saving for the onset of a disability from the moment they begin working, it creates an alternative funding source to Medicaid for the provision of long-term services and supports that does not require people to impoverish themselves or stop working in order to gain access to the supports they need. It allows the individuals who have saved for the onset of disability spend the benefit however they feel is most appropriate toward their long-term needs, be it a housing or transportation modification, assistive technology, or personal attendant services. The CLASS Act takes a realistic and responsible approach to disability, and like the Community Choice Act, it's about real choice.

At AAPD, ADAPT, NCIL and SABE, we want to see these topics become a leading 2008 election issue anytime candidates discuss their civil rights platforms or health care agendas, so that whoever comes into office in 2009 is committed to seeing these changes through. Many Americans languishing today in institutions all over this country are running out of time.

This is a crisis, and it should be handled like a crisis—with urgency and full governmental support. Unless the Government steps up to address these concerns in a bipartisan, comprehensive way, we are going to see this crisis get even worse. Congress must ensure that the principles undergirding the new infrastructure are based on real consumer choice and meaningful dialogue with stakeholders, including individuals with disabilities. As Congress considers reform of the long-term care system, it will be tempting to make piece-meal change, but the system will continue to falter unless we approach reform with a comprehensive lens. We cannot afford to talk about long-term care without also talking about personal attendant services, attendant recruitment and wages, the integration of long-term and acute care services, integrated housing, accessible transportation, and employment accommodations. We can't afford to address each of these topics in isolation from the others, or we will be having this same conversation again in 10 more years because the system will still not work. Comprehensive reform would entail finding a mechanism to take all these funding streams and mold them into a comprehensive, focused long-term services and supports system that places control in the hands of the consumer not the bureaucrats.

We call on Congress to demonstrate leadership and take the first steps down a path of comprehensive reform of long-term care. We urge Congress to pass the Community Choice Act, which would reduce the institutional bias in Medicaid. Pass the Direct Support Professionals Fairness and Security Act, which would provide funds to States for purposes of increasing the wages paid to direct care workers. Pass the Community Living Assistance Services and Supports Act (CLASS Act) as an alternative to the Medicaid "poverty trap." Direct HHS to enforce the integration man-

<sup>23</sup> LaPlante, M.P., Kaye, H.S., & Harrington, C. (in press). Estimating the Expense of a Mandatory Home- and Community-Based Personal Assistance Services Benefit Under Medicaid. *Journal of Aging & Social Policy*.

date recognized by the Supreme Court in the 1999 Olmstead decision, and encourage CMS to create incentives for discharge planners. Passage of these bills and work on these programs will not "cure the crisis," but it will go a long way in building the necessary groundwork from which to structure future reform.

Senators Dodd, Clinton, Brown, and Kennedy, thank you for your co-sponsorship of the Community Choice Act. And thank you all again for providing me this opportunity to testify. I welcome the opportunity to answer any questions that you may have at this time.

Senator ENZI. I want to thank all the people for their testimony today, and we're now to the finale.

We have Dr. Deborah K. Fleming, a Wyoming native who has a 30-plus year career in education, health care and administration. Her varied background includes 4½ years at the area Agency on Aging of the Navajo Nation Health Department. She's been the Administrator of the Wyoming Aging Division, and she's been the Director of the Wyoming Department of Health.

She was elected to the State Legislature from House District 36, and served as a member of the Labor, Health and Social Services Committee during the late 1990's. Currently Dr. Fleming is a clinical professor of Medical Education and Public Health at the University of Wyoming College of Health Science.

She serves as a co-principal investigator for the Aging and Disability Resource Center grant. She's the co-principal investigator for the Office of Justice training grant on elder abuse, and she designed and now teaches a course on aging and disabilities.

Thank you very much for being with us here today, Dr. Fleming. We look forward to your testimony.

**STATEMENT OF DEBORAH K. FLEMING, PH.D., CLINICAL PROFESSOR, UNIVERSITY OF WYOMING, COLLEGE OF HEALTH SCIENCES, LARAMIE, WYOMING**

Dr. FLEMING. Thank you, Senator Enzi, for that very kind introduction. I must say this is a tough act to follow. This is truly, at this table, a class act. I am very humbled by my colleagues and the fine work that they're doing.

Mr. Chairman, members of the committee, and the Senate staff, I thank you for the opportunity to speak today about long-term care and our country. I have worked in the fields of aging and public health for three decades. And issues relating to older persons and people with disabilities are very close to my heart.

I come from a very rural State, actually it's frontier. And for years I have watched families struggle with the challenges of living in a place with limited options for home and community-based care, a shortage of healthcare professionals, and entrenched systems that make it difficult to access services.

Finally, I am beginning to see some movement toward a convergence. A nexus of disability services and aging services, placing the focus correctly on the needs of the individual, instead of what type of disability or category he or she occupies. Nationally more program designs are granting individuals the right to choose. There are States with pilot projects and successful models that allow this to happen, not only for young persons with disabilities, but also for our elders who, in the past, have been faced with few options when their care needs increased.

As Senator Enzi mentioned, in Wyoming we have an Aging and Disability Resource Center (ADRC) that, since its inception in 2005 has assisted over 300 people in receiving counseling, guidance, and obtaining appropriate levels of service to meet their needs. That same Independent Living Center that sponsors the ADRC, also has a program called Project Out, which assists people in leaving nursing homes, returning to their homes—they've helped over 200 folks return to the communities, and have saved the Wyoming Medicaid program \$6.5 million.

The pilot sites for these kinds of projects need to be expanded and adopted by more communities. Creative use of Federal funds, Medicaid and targeted State dollars can enable States to develop appropriate responses to long-term care needs. The messages from the field are clear. First, we need to accelerate efforts to streamline and consolidate these complicated systems of care. These systems are very difficult for the average individual and their families to navigate. I experienced that some years ago with my own mother, as my sister and I struggled to get the appropriate level of long-term care for her. And it made me think, "I'm a professional in the field, and if my family had difficulty with this, what do other people do?" It's very complicated.

The second point is that we can improve access by providing a single entry point into the long-term care system with professional counselors to guide the process.

And third, we must keep the focus on the needs of the individual, first and foremost. We have a long way to go and a difficult history to overcome, but we are moving forward and it is not a noble gesture or a monumental task, it is simply the right thing to do.

In closing, I would like to thank the Senate committee chairman, members and staff who have assisted me in preparation for this hearing, and have provided the opportunity for me to appear and to also share in writing the issues that I feel passionate about. I thank all of you for your hard work and progress on these critical issues. Indeed, if we as a country are not able to cherish and care for all of our citizens, we have seriously failed ourselves and our children.

Thank you.

[The prepared statement of Dr. Fleming follows:]

PREPARED STATEMENT OF DEBORAH FLEMING, PH.D.

Mr. Chairman, members of the committee, and Senate staff, thank you for the opportunity to speak today about long-term care in our country. I have worked in the fields of aging and public health for three decades, and issues relating to older persons and people with disabilities are very close to my heart. I come from a very rural State, and for years have watch families struggle with the challenges of living in a place with limited options for home- and community-based care, a shortage of health care professionals and entrenched systems that make it difficult to access services.

Finally, I see some movement toward a convergence, a nexus of disability services and aging services, placing the focus correctly on the *needs* of the individual instead of on what type of disability or category he/she occupies. Nationally, more program designs are granting individuals the right to choose, to determine their own pathways to independence, and live in the community as they desire. There are States with pilot projects and successful models that allow this to happen, not only for young persons with disabilities but also for our elders, who in the past have been faced with few options when their care needs increased. The pilot sites need to be expanded and adopted by more communities. Creative use of Federal funds, Medicaid and targeted State dollars can enable States to develop appropriate responses

to long-term care needs. The messages from the field are clear: (1) we need to accelerate efforts to streamline and consolidate these complicated systems of care; (2) we can improve access by providing a single entry point into the long-term care system, with professional counselors to guide the process, and (3) we must keep the focus on the needs of the individual, first and foremost. We have a long way to go, and a difficult history to overcome. But it is a start, and we are moving forward. It is not a noble gesture, or a monumental task. It is simply the right thing to do.

The CHAIRMAN. Thank you very much, Deborah, for your good words and also the work of Shawn Griffin in mentioning some of the additional complexities in rural communities.

Let me get, maybe Andrew and I'd like to ask the others about the value of having individuals maximize their choice between the nursing home and independent living. We have the different proposals, Senator Harkin's proposal—which is an excellent proposal—we've tried to do this with the CLASS Act. What are the really important ingredients and guidance you might give? These are obviously ideas, suggestions we have made. But, what else should we be thinking about? What are really, the elements that help give individuals the maximum ability to have the kind of dignity, have the kind of independence, have the kind of individuality so that they can make these choices and decisions, and avoid the kind of situation that you outlined, Andrew, in your final comments. And how are we best going to be able to do it? Would we be adding to what is the existing system, should we be looking at something entirely different? Give us your insight.

Mr. GRIFFIN. Thank you for that question, Senator Kennedy. I think, you know, the Community Choice Act and the CLASS Act work together well. Both of those acts are about giving people real choices in where they receive the supports, and how they receive the supports that they need to survive. If people don't have a choice, then they are subject to the kind of abuses that I heard in Nashville. And, unfortunately there are lots and lots of Americans today that don't have a choice. So, it starts with giving people a real choice.

We also have to address the issues around who is going to provide the care. If we are not paying people adequate wages to attract caregivers to provide the care, then it's going to fall on the family caregivers. And that's who's providing the vast majority of the care right now. So, we have to have a strategy to address that. I know the Community Choice Act includes that. I think that the CLASS Act would also support that, because it's providing funding that people can use to pay people adequate wages.

And then the third piece, which is something that I am working on right now in the Ticket to Work and Work Incentives Advisory Panel, is I think we need to move away from a maintenance system into an investment system. We should be investing in people with disabilities of all ages, to help them live independently so they can contribute to their own support, so that the Government can obtain a return on that investment. Right now we do the opposite. People who are 18 go down to the Social Security Administration and apply for SSI, and they're basically retiring at age 18. That's bad public policy. We should give young people the ability to work and get the supports that they need, and not lose those supports because they work and save money. So, that's the other piece, to me.

We need to invest in people, so that they can contribute to their own support.

Thank you.

The CHAIRMAN. Let me go to Susan. You talk about the employment, Senator Harkin referenced this. We need skills, even though we have, in my State, 250,000 people that are unemployed, there's 70,000 jobs that are out there, that are looking for people. And we know those with disabilities have talents to be able to—do you have any kind of suggestions for us, so that we can make sure that people aren't going to be discriminated against in terms of employment? You gave us a reference earlier about a sad situation. Are there other things that we ought to note?

Ms. DANIELS. Well, I think you are very correct in assessing that there's strong disincentive for people who need personal assistant services to work, because they want to qualify for Medicaid. And so it becomes a vicious circle for them. If I become poor, and I do not earn enough income, then I can get some help. And that is the situation of so many families and people with disabilities. It's either to go it on your own—all on your own—or give it up and get some help. And that's a terrible, terrible choice. There are very, very few people who actually can make it on their own. And there are a whole lot of people who have given up, who have an awful lot to share.

And so, I think we have to—one of the most important things about whatever steps we take into the future on long-term care is not to make it means tested. I think, I know that actuaries love to make it means-tested, because it keeps the cost down. But, if we go with a social insurance approach, where everybody is paying into the system, and everybody can then access the system, I think we make a much stronger program and one that does not build in—just by its nature—a disincentive for people to help themselves as much as they can.

Now, a lot of people couldn't make it without some help. They don't have the earning capacity. But they can earn something. And I think what we ought to be doing is trying to encourage as much self sufficiency as we can. The only way I know to do that is to get out of means-testing, and get into a social insurance approach. It's the only thing that's fair, really. Because any of us—well, not me—but any of you guys could need long-term care. I already need it, and it costs me about \$50,000 a year to get the care I need. I am going to have to work until I die in order to afford that.

So, again, I say to you Senator, I'm the lucky one. I can work. And so I think we really need to think about sticking with a non-means tested approach.

Can I say something else? I worry about this notion of what everybody calls the "woodwork." The latent need out there, and if we have a program and all of a sudden everybody, almost everybody qualifies for it. I don't really worry about that, because nobody wants another person to come in and help them toilet and get dressed if they can do it themselves. That woodwork effect, to me, is really kind of silly. And, I know it's an actuarial one in money you're going to have to deal with, as people budget out what kind of approach this is. But just think about it—would you want someone help you take a shower if you didn't need it?

The CHAIRMAN. Thank you, Susan. My time is over. But I'm going to just take, extend it for my colleagues.

Shawn, you mentioned these, the 650,000 disabled family members and their parents being concerned about what's going to happen to them. I mean, I think that's an enormous area of anxiety for families, you referenced that. Maybe you can comment a little bit further about how you found families are able to deal with these kinds of challenges. This thing is happening in our society, and we know it's happening. It's not measured in the dollars and cents legislation, but it has incredible importance. And I would be glad to hear you a little, talk a little bit about what you've found in terms of your own understanding of this situation.

Mr. GRIFFIN. Thank you.

I guess from the provider's perspective—usually, these are folks that we don't see until it's too late. I mean, these are folks—and it's probably one of our fastest-growing populations, and I think that's based on some of the demographics of this country. But, as far as people we are serving, these folks—and I don't want to use that woodwork issue, but that's what happens. We get emergency calls from the police force, or from our local Department of Family Services saying, "Guess what? So and so is now in a nursing home, and they have a severely disabled child who is now in their 50's who has never received support that now needs that." And so, then the scramble begins. You know, how are we going to be able—what are their needs, we don't know.

We had an example in a small town called Powell, in Powell, Wyoming. We had some individuals who, their caregiver was very, very elderly and she passed away. And there was, just a scramble to get these folks served. They ended up in our State institution, unfortunately. And that goes back to the question you talked about earlier, as far as resource stuff. I think that services need to—the community capacity needs to be built.

Long story short, these folks are now being served in the community program, and doing quite well. But they never should have had to have gone to an institutional care. That's something, in a lot of States, it's either that or nothing with these people. Because a lot of States try to plan their numbers based on who they know are in the systems, who are coming through the school districts, so they have that seamless array of services, which is better now than it used to be, because they document these kids from birth and going through the school districts, and our other youth waivers. But these people that are staying home their entire lives—and it is a very, very fast growing population, and all of a sudden they are there. And it's more of a reactive response, as far as service provision for these folks. And that's something that we hope to try to avoid.

The CHAIRMAN. Senator Enzi, thank you.

Senator ENZI. Thank you, Mr. Chairman. And I'll direct my first question to Dr. Fleming. I think we need a little more emphasis on the single point of entry. And I would hope that you would give us a little more of an explanation on what the need is for a single point of entry program, such as the Aging and Disability Resource Center.

Dr. FLEMING. Well, thank you for that question, Senator Enzi.

In my written testimony I included a graph, a chart that we were using in the State to kind of show the pathway to access to long-term care issues. And, it looks like an absolute rat maze of people having to jump through several hoops and go through as many as eight different steps to obtain the kind of assistance that they need.

The beauty of a single point of entry—and I know that this is a concept that's been tossed around in the country for a long time and tried at various times, but the ADRC seems to be getting a handle on this—is the fact that people can go to one place, and there are trained counselors there, people who are trained by other programs, Social Security, other independent rehab kinds of programs. They know something about the financial eligibility systems. They can sit down with that person, one-on-one, help walk them through the system.

Now, in some States that have had ADRCs a few more years than we have, they are making greater progress in terms of streamlining the system, so that people can actually do a lot of the eligibility application right then and there. Some of them are having this kind of access online. So, workers can go into people's homes, and help them fill out applications. So, in other words, they don't have to make a stop at the Public Health Nursing Office, the Department of Family Services which, in our State does the financial eligibility, the senior center—they don't have to go four or five different places. They can actually enter the system there, have someone walk them through that, stay with that family, work with them over the period of time for their eligibility, and help them make plans and correct choices.

Many of these folks that come into the Center are at a crisis point. They are not thinking clearly. They are in a panic. And it's very helpful for them to have these folks there by their side throughout the system.

It's not perfect yet. It's in progress. It's a joint project between the Administration on Aging and CMS, and those agencies seem to be working well together to make this happen. In the long run it will save money because people will be able to avoid more costly institutional care. So, it does make some sense from that standpoint. But, certainly for families, it's just a very helpful resource.

The other value of the ADRCs, is that it's there for health professionals who want to—information about what's available, what's out there, what are resources in the community. And, frankly, for baby boomers like myself who might want to make some long-term plans for their own future. So, it serves multiple populations of people. In our State we have it built into a resource database that has thousands of resources throughout the State that people can go online and find out what's available in their own town, without even physically going into that Resource Center.

Senator ENZI. I have some follow-up questions I'll do on that, but since I am running out of time, I'll address that in some written questions. In fact, I have written questions for all of you, and by agreeing to testify, I think you agreed that you would answer questions for us, and we'll appreciate that, because we never have enough time to get the information that we really need to get the kind of legislation that we need to do.

So, I am going to move to Mr. Griffin. In your testimony you mentioned an initiative that's underway that has the result of the National Reduction Act, and the New Freedom Act. Can you further discuss this voucher program, created by the Wyoming Independent Living Center that allows qualified candidates to hire drivers for personal appointments and activities?

Mr. GRIFFIN. It's the transportation, and I think as mentioned earlier, transportation I'm sure is an issue here in Washington, DC., but it certainly is in rural Wyoming. Transportation's always been an issue, and what you've mentioned, and what I referenced in my testimony, was a voucher program that was initially seeded by the Wyoming Governors Planning Council on Developmental Disabilities, through our independent living centers.

And, the voucher program is simply just that. You have, basically, a checkbook if you qualify through your disabling condition, you can use that checkbook to have your neighbor take you to a doctor's appointment, have your neighbor take you shopping, if you need to. And, you basically have a blank check that you write for them, and then they cash that in. And so, what it does, it certainly offers a lot more opportunities, a lot more impromptu stuff, and a lot more natural supports being delivered in our State.

As I said, it was seeded initially by our Governors Planning Council as part of our long-range 5-year plan. And, since then, the Wyoming Department of Transportation has contributed monies to that program, and the voucher program is now being processed throughout the State through our Independent Living Centers.

Senator ENZI. If I had more time I would find out a little bit more about how the one-point entry system coordinates with the sorts of things you're doing. So, I'll address that in writing, as well.

And I appreciate all of you being here today. I've learned a lot from your testimony. Unfortunately, I'm going to have to run to another meeting.

The CHAIRMAN. Thank you very much, Senator Enzi.

Senator Harkin.

Senator HARKIN. Thank you very much, Mr. Chairman, and I too, have a thing I've got to go to very shortly. But I just, again, want to thank you, Mr. Chairman, thank you, Senator Enzi, for having this hearing. I thank all of the people for being here today.

Glenda Faatoafe.

Ms. FAATOAFE. Faatoafe.

Senator HARKIN. Say that again.

Ms. FAATOAFE. Faatoafe.

Senator HARKIN. Faatoafe. Well, thank you. I just wanted to reassure you that this recent Supreme Court decision on the Coat Cast, that we're preparing legislation to overturn that decision. As you know, they based it on the 1975—actually in 1974, Congress passed an expansion of the Fair Labor Standards Act. In 1975, the Department of Labor issued regulations on that. It was to expand the Fair Labor Standards Act to cover more people under minimum wage. They included a lot of things like housekeepers and gardeners and chauffeurs and things, but they said that, "senior companions" were more like babysitters, and therefore were not entitled. And that's what the Court based it on.

So, I just want to assure you that we are working, Senator Kennedy's staff, and I and others are working together to draft legislation to overturn that. So, hopefully we can get that done this year.

I also hope that all of you that are here in this room and the other room watching, and those of you, especially with NCIL who are here this week—I don't mean to exclude ADAP, you can join in, too—we really need you to press forward on getting the Finance Committee of the Senate to have hearings. To have a hearing on both the Community Choice Act and also the CLASS Act. And I want to ensure you, Andy, that I was a co-sponsor of that bill last year and I'm on Senator Kennedy's bill again this year. Rest assured, if there's any doubt about that.

But we need you to really ask members of the Finance Committee to have these hearings as soon as possible. I think the time is right. I think that we have waited way too long on getting both these bills passed. The Community Choice Act has been out for a long time, it's got all the new data now, on the Community Choice Act, and it's time to put this kind of sad chapter behind us. We've been on this now for over, what 10 years now, I guess 12 years, something like that. And, it's time to move on it.

So, I just hope that you will use your presence here to educate members of the Finance Committee about why we ought to have hearings on this.

I have a lot of questions I could ask. All of your testimony has been wonderful. And, I think, again, it just brings home again to us that in this society of ours, we just can't continue on the way we are doing this. Not only is it wasteful money, and all of that kind of stuff, it's just inhumane, the way we treat people now with disabilities in our society.

We have made some great strides in the past. We have opened the doors, and passed a lot of good legislation. But, unless and until we address this issue, well, the two that I mentioned earlier—one of independent living, first and foremost, and then economic self sufficiency. To me, those are the two things that we have really fallen down on. And, all of you have spoke about that, and testified to that. And, I just hope that we can now get the country behind us, and move on both the CLASS Act and also legislation to overcome the Supreme Court decision and getting the Community Choice Act passed.

We need your help. I was here, we were here in the 1970s. We were here in the 1970s and the 1980s, when we led up to the ADA. And, it didn't happen overnight, but it just—we just had to keep pushing and pushing and pushing and pushing. And finally, things came together.

Well, hopefully things are now coming together on these issues here, on independent living and making sure that home healthcare givers, like you, Glenda, are paid decent wages and salaries. And, what could be more important to our society than that? Nothing.

Ms. FAATOAFE. Senator, one of the biggest problems is that in the next 10 years, we are going to need 3 to 5 million more of me.

Senator HARKIN. Yes.

Ms. FAATOAFE. And, because there's a lot of baby boomers getting older every day. And I figure, I am the last one.

[Laughter.]

I was born in 1962, so, technically I'm the last baby boomer, and I'm going to be taking care of the first baby boomers, and I am already.

Senator HARKIN. Right, right.

Ms. FAATOAFE. And so, if we don't get this straightened out now, we are in for a huge, huge problem.

Senator HARKIN. Well, maybe I shouldn't say this, but what the heck, I've got the mic.

[Laughter.]

You know, people talk about the cost of it and everything. Well, we had the \$10 billion to \$20 billion before. Now Dr. Laplant did his study, about one to three—is that right, Andy? Something like that, \$3 billion a year. That's a lot of money. It makes me sick, it makes me sick to think that we are spending \$10 billion a month in Iraq.

[Applause.]

Senator HARKIN. And, we can't spend \$3 billion a year on independent living? Makes me sick.

Thank you, Senator Kennedy.

[Applause.]

The CHAIRMAN. Good.

OK. Thank you, Tom. I think Tom has spoken for all of us on that issue.

[Laughter.]

Monica, I want to thank you, thank your wonderful son, there, Ellington. He's had an enormous, he's got incredible patience, and you've got a wonderful friend who's been with him, but we really appreciate your presence here, and the comments that have been made.

You know it's really—I would hope, just to add to what Tom said about the Finance Committee—we have a lot of Presidential candidates that are out there now, too. And there's no reason that they shouldn't be answering about what they are going to do on these, as soon as they get that nomination. And, as we have here, this is bipartisan, it isn't a defining issue. We had bipartisan support in terms of all the great issues, we had the march forward, we did—we had the bipartisan issue on Civil Rights, we had it on the Medicare, we had it on the Medicaid, we had it on the Americans with Disabilities Act. We have had it all on the issues of human decency, human dignity, human fairness in terms of our society. And you have outlined a compelling case. And it's really up to this country about its response. I think you should feel up here that we are prepared to do it, and the best way we can thank our panelists is to indicate that we are prepared to move ahead, and will do everything that we possibly can.

We need you to let the folks know out there in the field, I think we got the message, I certainly heard it—that's just your intention to do it.

So thank all of our witnesses for coming, you have traveled a long way. Your message has been enormously powerful. We hear it. It's well received, we are going to followup on it. We thank all of you. We thank all our guests that are here. We are enormously impressed by your commitment and dedication. You can help us, as Senator Harkin has pointed out, by helping to get a hold of our col-

leagues and friends and let them know that this country will be a fairer and more just Nation when we pass those pieces of legislation.

This committee stands in recess. Thank you very much.

## ADDITIONAL MATERIAL

## RESPONSES TO QUESTIONS OF SENATOR ENZI BY SUSAN M. DANIELS

Thank you for the opportunity to give additional input.

*Question 1.* In your testimony, you wrote about the need to ensure access to an appropriate array of institutional and home and community-based long-term supports. We have heard testimony today about the Aging and Disability Resource Centers. It seems to me this is the kind of access you want to ensure.

Would you like to see this program expanded?

Answer 1. The resource center concept is an excellent way to organize a service delivery to people who are very vulnerable and in great need. I would recommend that these centers be linked with Independent Living Centers (<http://ncil.org/>) established several decades ago. The accumulated knowledge and experience of Independent Living Centers along with additional funding could provide an extremely strong base for the development of Aging and Disability Resource Centers.

*Question 2a.* From your testimony, I see that you support a social insurance program through payroll deductions that would offer universal access to a basic, limited long-term care benefit. Are you talking about a program that is separate from Medicare and Medicaid.

Answer 2a. I believe that the social insurance approach to funding long-term care is the right one. It is difficult to recommend at this time whether the program fits more comfortably in the Medicare program (using the social insurance approach with a mixture of other funds), the Medicaid program (State administer with the State and Federal dollars) or some new entity. I believe these decisions are primarily administrative. More important is establishing the large contributors' base with sufficient revenue collected and as many people covered as need be. The social insurance model is well suited for funding unpredictable catastrophic costs, which is the basis of any insurance program.

*Question 2b.* Please describe the program you envision.

Answer 2b. I believe that the best program in this arena should reflect the following broad guidelines with substantial room for local and idiosyncratic needs.

1. Choice—give people better choices about the services, supports and providers.
2. Care planning must be person-centered, one person at a time.
3. Quality should be measured by focusing on achieving people's health and social outcomes.
4. Consumers must have opportunities for self-directed care.
5. Mechanisms must be in place for unbiased mediation to help resolve potential disputes between care providers, management organizations and consumers.
6. Workforce: Specific mechanisms must be in place to address job satisfaction, wages and benefits, working conditions and retention efforts, all of which have a direct impact on quality and continuity of care.
7. Consumers' views must inform the management of care provider and management organizations.
8. Organizations providing or managing the new system must be value-driven and those values should be consistent with all the items listed above.
9. Organizations proposing to provide or manage local systems must collaborate with all stakeholders, including consumers, advocates, counties, and private providers.

*Question 3.* This question is for Glenda but all others on the panel may answer it as well. Self-direction has proven to be a cost-effective and efficient model for the delivery of services as the person is in charge of selecting services, negotiating prices, etc. In your opinions, could wages increase or decrease for direct care staff if self-direction, allowing people to select their own staff, was used more broadly?

Answer 3. I do not have any specific information that can answer this question. I believe there has been enough research to find the answer, however. I direct your attention to the Robert Wood Johnson Foundation.

## RESPONSES TO QUESTIONS OF SENATOR ENZI BY MONICA HERRING

*Question 1.* One of the concerns highlighted in your testimony was the complexity of the long-term care, community services and support system. We just heard testimony from Dr. Deborah Fleming regarding one of the goals of the Aging and Disability Resource Center's (ADRC), which is to help navigate such system. Would being able to access a system such as this be beneficial to you as you are helping

Ellington navigate through the system? Did you know that an ADRC is located in Rockville?

Answer 1. Yes, I believe as he ages it will play an integral part throughout his life span. Since moving to Montgomery County, Maryland 2 years ago I have become familiar with the County resources. I have: (1) joined the Montgomery County ARC as a member receiving the newsletters and attending information sessions; (2) made contact with the County's Department of Health and Human Services, Aging & Disability-Community Support Network Office staff to find out what services are available and access requirements for the services; and (3) A fact worth mentioning, I'm a county employee for the Department of Health and Human Services. This will give me the opportunity to stay connected and on top of issues that will impact Ellington's future as a county resident and service recipient.

*Question 2.* What can we do to help get out the word regarding the ADRC's so that more people are aware of and access them?

Answer 2. Since becoming an advocate for my son and others and working with other disability advocates, I believe that individuals and organizations dedicated to reaching out to families are constantly discovering new approaches to reaching out that prove to be effective, however, we must remember that being consistent, open-minded, culturally sensitive, and flexible will be the measurement of our success. From the Federal level I believe that continued support to the State's in funding for outreach is imperative. Speaking for myself, remembering some years ago my frame of mind as a new mom, as a young mom, I choose to extend myself to a new family in whatever capacity they need me to be in to share the information that I know or to refer them to someone who can provide answers to the questions they may have. I've done this by:

- Making myself available by offering my personal contact information to use at anytime.
- Visiting the family and introducing them to mine.
- Introducing them to other families.
- Sharing information that I may receive that could help another family.
- Encouraging a family to become involved in public meetings on issues that impact them.

*Question 3a.* Most families try to save money so they can help their child go to college, pay for a wedding, or other types of major life events. What would happen if you tried to do so for Ellington?

Answer 3a. My understanding so far is that depending on what type of investment vehicle I choose to save for Ellington's future may impact the public benefits he currently receives once becoming of age. Recently the Montgomery County ARC did an Info session on this very topic and what I got from it was that the best option available today would be a special needs trust. Since then, I have followed up with investment experts and talked to other families who have chosen this route to save for there child's future and this is an option that I have chosen for Ellington.

*Question 3b.* So, if you were able to save \$25,000 over the course of your life in order to help Ellington pay for services that would help maintain his life in the community or if Ellington wanted to save for his future in a 401K he would lose his benefits if he were on Medicaid, and then be required to spend that down before being able to become eligible for services? It could not be used to offset some of the Medicaid expenditures?

Answer 3b. I'm not clear what the followup question is? However, in planning for Ellington's future it is my hope that if I should pass before him that what I'm putting away for him now would function as a supplement to his public benefits package and be accounted for and distributed in a way that does not jeopardize that.

*Question 4a.* Do you believe that consumer control or direction should be part of all government-based disability programs—that would include Medicaid, Vocational Rehabilitation, and others?

Answer 4a. Yes. I believe it should be a philosophy of thinking that should spread across all government-based disability programs.

*Question 4b.* How do you see Ellington using self-direction if it were an option? Would he need assistance?

Answer 4b. I see Ellington using self-direction if he were to remain at home to select his direct care staff supports that will assist him in the home and outside the home, similar to how it is now. I look to Ellington for his approval on selection of support staff who will work directly with him. It has been a success thus far. I have learned to observe his body language and gestures that for the most part come

across clear in expressing his likes and dislikes. If the option to live independently in the community was chosen self direction would extend to not only selecting support staff, but where and who he chooses to live with. Through the years Ellington has developed relationships on his own with classmates in his school and I have with the parents. I think about how neat it would be if Ellington were to, as an adult, have the opportunity to live independently with a friend, a buddy that he for the most part grew up with and they share common needs. In fact, as a part of my need now to begin Ellington's future planning into adulthood which is less than 10 years away, I've begun to share this idea with other families with similar future goals for their child in hopes that we can begin to plan our children's future together. At this point we can map out what it is we want to have for our children, assess the current system's ability to deliver and, if necessary, figure out where we need to change agents and advocate for change.

RESPONSE TO QUESTIONS OF SENATOR ENZI BY GLENDA FAATOAFE

*Question 1.* Have you or any of your colleagues participated in professional development activities such as those offered through the University of Minnesota College of Direct Support or ARK Regional Services in Laramie, Wyoming?

Answer 1. Home care workers in Washington State currently receive virtually no training. Most home care workers get 32 hours of very basic introductory training when we are hired, and 10 hours of training every year. That's why we were excited to pass a new law this year that will dramatically improve training in Washington State starting in 2010, including peer mentoring and advanced specialty training.

*Question 2.* In one of your recommendations you suggest reversing the Supreme Court's decision that upheld the exemptions of home care workers from the minimum wage and maximum work hour provisions in the Department of Labor regulations under the Fair Labor Standards Act. Wouldn't mandating a higher wage make these valuable services inaccessible for many people?

Answer 2. A large proportion of the services provided by homecare workers is publicly funded. Medicare and Medicaid account for more than half of the funds paid to free-standing homecare agencies. The Federal and State Governments should not purchase these essential services at prices that depend on workers not being paid consistent with the minimum standards of the FLSA. While SEIU believes cost-containment is important, refusing to pay workers fairly—whether through public or private dollars—for the work they do is not an acceptable way to keep costs down. Suggestions that extending these minimum protections to homecare workers will lead to excessive costs are belied by the fact that a significant number of States already cover homecare workers under the State wage and hour laws. The Federal Government needs to follow the example of these States.

It is precisely because home care services are so important that we need to ensure that a reliable, stable workforce of caregivers like me is available to provide the quality care that our seniors and disabled deserve. Keeping workers like me in poverty with substandard wages would only augment a fundamental barrier to home care: the lack of reliable, professional workers.

One major impediment disabled people face when they try to get homecare is not being able to find a worker who can meet their needs, as well as dealing with continued turnover—both caused in large part by low wages. As you said, home care workers like me provide a valuable service to American families. We allow people to stay at home, where they want to be, and help States keep costs down by providing an alternative to an institution. To address the high turnover that strips people of a viable option to live at home, the compensation workers like me receive should reflect the high value of this extremely challenging work we do.

In fact, continuing to marginalize home care workers from some of our Nation's most basic workforce protections that will restrict access to services, as the relative supply of workers shrink in response to truly inadequate wages. There will be increasingly fewer people willing to commit to this difficult work and resign themselves and their families to lives of poverty and hardship. Even today, American families are being pushed to the brink struggling to find care because there is no stable, professional home care workforce in place. Extending these basic worker protections to this valuable workforce is a necessary first step in ensuring a sustainable model for both workers and consumers and promoting cost-effective, high quality care. States, like my home State of Washington, and others like Michigan, have begun to recognize that we can't afford to continue down the same path with Medicaid funding. Legislators in those States have made the tough choice to invest more money in home- and community-based services, specifically in raises for workers, to

address the high turnover and workforce shortage that compromise the quality of care—by bringing more caregivers into the field and keeping them in the field.

*Question 3.* This question is for Glenda but all others on the panel may answer it as well. Self-direction has proven to be a cost-effective and efficient model for the delivery of services as the person is in charge of selecting services, negotiating prices, etc. In your opinions, could wages increase or decrease for direct care staff if self-direction, allowing people to select their own staff, was used more broadly?

*Answer 3.* SEIU fully supports the right of individuals to direct their own care and believe every effort should be made to consumer direction in a manner that expands consumer access to the services they need, including ensuring an adequate, well-trained, high-quality direct services workforce. Basic economics would say that when demand increases for a service, wages paid to workers for that service would also increase. However, I think the answer here really lies in how States structure their consumer-directed Medicaid programs, and whether individual budgets are sufficient to provide adequate wages for workers. Theoretically, letting individuals hire workers directly, would allow for higher wages, as administrative costs would be lowered. Moreover, home care is much more affordable than premature institutionalization due to lack of viable alternatives. Nevertheless, if individual allowances were so lean that individual consumers could only offer sub-standard wages, or pay for significantly less hours of care than were really needed, consumer direction would fail.

Providing individuals and their families the freedom to decide the care they need and select their providers is of limited use if they are then left to navigate the market on their own. What good is a budget you control if you can't find the worker you need? How is an overburdened consumer or family expected to also take on the added responsibility of being a recruiter, a manager, handling payroll and taxes, and dealing with absenteeism and turnover, as well? To be sure, some families will have the resources to rise to the challenge, but the system should not be built on this assumption.

The most successful consumer-directed programs have been those that included consumer assistance and workforce development components organized as Quality Care Councils. For example, in Oregon, Michigan, Dane County Wisconsin, Massachusetts and California, quasi-public entities governed by community boards (with consumers with disabilities their majority) help match clients and workers, provide training, and have succeeded at growing the workforce, reducing turnover, increasing wages and in some cases, providing benefits, while expanding hours of care. We believe that CLASS does a good job of addressing these issues by encouraging structures that would allow for co-employers to help families with the administrative burdens of consumer direction, and provide opportunities to improve working conditions.

#### RESPONSES TO QUESTIONS OF SENATOR ENZI BY SHAWN GRIFFIN

*Question 1.* You discussed the need to examine a more comprehensive long-term care system. During Dr. Fleming's testimony she spoke about Aging and Disability Resource Centers (ADRC's) serving as "single entry points" into the long-term care system. It seems that this type of "one stop shopping" would be beneficial to address some of the concerns you highlighted in your testimony. Has the Community Entry Services program ever used the assistance of an ADRC? Do you think your program would benefit from this type of assistance?

*Answer 1.* No, Community Entry Services has not used the assistance of ADRC. I do not know enough about the program to comment on our potential usage. I would say at this time that the populations we serve already use an established point of entry that will not be replaced by the ADRC. Programs like CES have been established in local communities for over 30 and 40 years. Therefore, people served by our agencies and their families are usually familiar with contacting our agencies as a resource to enter the "system." I do not think the ADRC programs are disseminated throughout the State or more accessible. I feel it will be beneficial, but not necessarily for those we support.

*Question 2.* In your opinion would a minimum wage mandate help increase wages for direct care staff or per your testimony is this a Medicaid reimbursement issue?

*Answer 2.* The simple answer to this is no, minimum wage mandates would not allow for an increase in staff wages at our agency as we are paying what our budget allows. We do not stand to gain as a not-for-profit by not paying the most we can to our staff and likewise we do not pay exorbitant salaries to our already lean administrative staff. The longer answer is yes it is directly related to the lack of Medicaid reimbursement. Medicaid does not cover costs for services and certainly has

not kept up with the cost of living over the past several years, especially by Wyoming standards. A mandated minimum wage in our industry, based on my program and knowledge in our non-profit world would be impossible without an accompanying increase in funds. Our current starting wage almost doubles the Federal minimum requirement as it stands. We feel a strong need to increase wages substantially in order to stabilize staff turnover and vacancies.

*Question 3.* This question is for Glenda but all others on the panel may answer it as well. Self-direction has proven to be a cost-effective and efficient model for the delivery of services as the person is in charge of selecting services, negotiating prices, etc. In your opinions, could wages increase or decrease for direct care staff if self-direction, allowing people to select their own staff, was used more broadly?

Answer 3. This is a difficult question. I believe all services should be self-directed and allow people to select and hire their own staff, which can be done in the current Wyoming waiver system. More broadly used self-direction toward staff selection and purchase of services may work great for many people. However, as States continue to restrict the eligibility of those qualifying for services, I am concerned that the ability to actually choose one's own staff is compromised cognitively. In some cases the usage of self-direction can actually result in reducing necessary services. I believe it will work great for some people and have devastating effects upon others dependent upon numerous factors. Many people who advocate for this should and can effectively choose and advocate for themselves. In my opinion many of these same people would do fine with minimal or no support but tend to get caught up in this "set our people free" movement, when in fact they are very employable. It is persons with more severe disabilities, without family advocates and/or sincere friends advocating for them that may concern me. Both those with good and bad intentions can exploit these people. As stated above, I believe the usage of more independent self-direction services will be wonderful for many, but should be approached cautiously by others, as it is not a catchall program.

#### RESPONSES TO QUESTIONS OF SENATOR ENZI BY ANDREW J. IMPARATO

*Question 1a.* You state in your testimony that President Bush's New Freedom Initiative included a Money Follows the Person demonstration project to encourage States to try the idea of letting Medicaid dollars follow the person to the location in which desired services and supports could be rendered. You further state that since January, CMS has awarded 31 States and District of Columbia demonstration grants for alternatives to institutional care. Do you see that as a positive trend for the future?

Answer 1a. Yes. However, notwithstanding the recent positive trend, the rate of progress toward community-based supports and services does not come close to meeting the longstanding and ever-growing demand for home and community-based services and supports within the disability and aging populations.

*Question 1b.* I understand that 38 States report that expansions of community-based services are planned for fiscal year 2007. It seems to me the trend is toward providing more of these services. Would you care to comment on this trend?

Answer 1b. Yes, States are slowly starting to respond to the longstanding demand for long-term home and community-based services and supports. So, while it is indeed a positive trend, again, the rate of progress is still inadequate. People's lives are being unnecessarily stolen by our antiquated public policies, and the recent progress does not undo the serious problem that has been around since the beginning of the Medicaid program.

*Question 2a.* In your testimony you stated that you support the Community Choice Act (S. 799) introduced by Senators Harkin and Specter. You state that this bill creates a national program of community-based attendant services and builds on the Money Follows the Person programs allowing Medicaid dollars to follow the person wherever the individuals or his representative chooses to receive necessary services and supports. Does this approach work within the current system to make it more flexible?

Answer 2a. The current system is inherently inflexible because of Medicaid's built-in institutional bias. The Community Choice Act (S. 799) is an excellent way to remedy the fundamental problem with Medicaid. Money Follows the Person programs are a step in the right direction, but they don't solve the problem.

*Question 2b.* What are the estimated costs of such an approach or the cost savings?

Answer 2b. In research released just this year, estimates of the cost of a mandatory home and community-based personal assistance services benefit under Medicaid were projected between \$1.4 and \$3.7 billion per year,<sup>1</sup> in stark contrast to a prior CBO estimate nearly a decade ago estimating costs in the \$10–20 billion per year range.

*Question 3a.* Doesn't this program [the *Community Living Assistance Support and Services Act (CLASS Act)*] create a new entitlement program by increasing withholding taxes?

Answer 3a. No, in fact, the CLASS Act takes pressure off of existing entitlement programs by encouraging individuals to begin saving for the onset of disability from the moment they begin working.

*Question 3b.* I realize individuals can opt out of this program but doesn't that create adverse selection so that only those believing they will need long-term care will have the withholding and the healthy population will opt out of the automatic enrollment?

Answer 3b. There is a small risk of adverse selection. However, because it is a voluntary, opt-out program, an individual will have to affirmatively decide not to participate, and we believe most people will participate. Because the monthly premium is such a small amount of money, our expectation is that individuals will decide to participate in financially planning for the costs associated with the onset of disability or chronic illness.

*Question 3c.* What is the possibility of this changing from automatic enrollment into mandatory enrollment?

Answer 3c. We have received strong commitments from Senator Kennedy and other supporters of the CLASS Act that this will not be a mandatory program.

*Question 3d.* In light of the solvency challenges in the Social Security, Medicare and Medicaid programs, do you believe additional taxes are the answer?

Answer 3d. I do not view encouraging individuals to voluntarily save for the onset of disability to be a tax.

*Question 3e.* Do you think Medicare and Medicaid need to be reformed? And if so, shouldn't the issue of long-term care be part of that reform?

Answer 3e. Yes, I think Medicare and Medicaid need to be reformed, and yes, I think long-term care should be a part of that reform. Please refer to my written testimony for a more thorough address of this topic.

#### RESPONSE TO QUESTIONS OF SENATOR ENZI BY DEBORAH FLEMING, PH.D.

*Question 1.* We know that many in need of long-term care don't know how to begin to find out about or access services. How do ADRCs get to those people most in need of long-term care services and supports?

Answer 1. In developing the program plan for the ADRC in Wyoming, we crafted a marketing strategy that included use of media—a press release to all media outlets, taping of Public Service Announcements on Casper radio stations; appearances on TV news and talk shows; distribution of brochures and flyers; and an open house at the Resource Center. Other, more informal means of distribution included having blurbs in church bulletins, speaking at service club meetings, at the senior center, and informal word-of-mouth. One important role of the ADRC is to establish formal linkages with “critical pathways” to long-term care services and supports. “Critical pathways” are defined as those places, including hospitals and physician offices, where people in need of long-term care are likely to pass through at the point at which they need care. By establishing strong connections with such entities, ADRCs are able to get to those individuals most in need to assist them in understanding the full range of services available and accessing those services that best meet their needs and preferences. To date, nearly half of those individuals contacting ADRCs were referred by critical pathways.

In Casper, ADRC staff made appointments with hospital social workers (discharge planners), nursing home social workers, home health and public health nurses and Department of Family Services staff to educate them about the ADRC and to ask for referrals. A special session was held with outreach and clinic staff at the Community Health Center of Central Wyoming, to ensure that the large CHCCW popu-

<sup>1</sup>LaPlante, MP, Kaye, HS, & Harrington, C. (2007). Estimating the expense of a mandatory home- and community-based personal assistance services benefit under Medicaid. *Journal of Aging & Social Policy*, 19(3), 47–64. DOI: 10.1300/J031v19n03\_04.

lation of Medicare and Medicaid patients would be reached. In years two and three of the grant our target populations will expand to persons with developmental disabilities and to individuals with mental illness, so particular outreach efforts will be made with DD programs, the community mental health center and Wyoming Behavioral Institute.

Not only did ADRC staff provide training to a number of community agencies, they also received extensive training in Social Security Benefits, Medicare (parts A,B,C and D) and participated in cross-training with Wyoming State Health Insurance Information Program (WSHIIP) staff. All of this effort helps get the word out to clients of these other programs, and community staff now knows to refer individuals to the ADRC.

Finally, the establishment of a statewide ADRC Advisory Council and a local Task Force for the ADRC also helped to spread information about the ADRC.

*Question 2.* What about people who aren't eligible for Medicaid and who don't have Long-Term Care Insurance—how do they get services?

*Answer 2.* One of the primary functions of an ADRC is to assist individuals and their families in understanding the full range of services available, both public and private. ADRCs are designed to serve people regardless of income. Medicaid and non-Medicaid consumers are served using the same process of information and assistance. ADRC counselors assist individuals in understanding their unique needs and preferences and aid them in obtaining the assistance, both formal and informal, that will help to meet those needs. Some individuals not eligible for Medicaid-funded services may be served through Older Americans Acts programs, State revenue long-term care services, or programs funded through other sources. Others may have needs that can be met through informal resources such as family, friends, and faith-based programs. Some individuals may have private resources to assist them in obtaining services but need the assistance of the ADRC to help them determine the best use of those resources. In addition, health professionals seeking information to better serve their patients are assisted, as well as baby boomers who want to learn how to better plan for their own future long-term care needs. Of the over 400 individuals served to date at the Resource Center in Casper, there are numerous examples of folks who "fall through the cracks" due to income eligibility, lack of planning or unforeseen circumstances. Here are some concrete examples of the types of help that can be offered by ADRC staff:

(1) Connection to the range of Older Americans Act programs administered by the senior center including in-home chore service, nursing, transportation and meals at a reasonable price. Prevention services include immunizations, screenings, health promotion education and exercise programs. These services are provided using a sliding-fee scale, reasonable set fee or are free. Senior Companion Program services are at no cost to the client. Meals on Wheels operates on a sliding fee scale with a reasonable maximum cost per meal.

(2) Basic financial assessment/referral regarding social security and also low-income housing, energy assistance food stamps, and other income-based programs that may include services to people with incomes above the Medicaid-eligibility level.

(3) Other agencies that serve persons with disabilities would be considered: if the person is in need of a disability assessment, he/she would be referred to the Division of Vocational Rehabilitation—there might be education or employment services appropriate for the individual. There are other employment opportunities in the community, including employment programs for older adults, so referrals are made to the Department of Employment, the senior center and the Wyoming Senior Citizens, Inc. Casper College has information about adult education and special training programs available in the community.

(4) Discussion of health care on a sliding-fee scale, which can be obtained at the Community Health Center, the Veteran's Administration (for veterans) and public health nursing; mental health and substance abuse treatment services at the Central Wyoming Mental Health Center; and some assistance with prescription drugs through Interfaith. ADRC counselors can review the services/information available through the WSHIIP to help provide access to those offerings.

(5) Referral to transportation services of the Casper Area Transportation Coalition (with a per ride cost); Department of Family Services also pays for some transportation in emergency circumstances and for medical appointments. Wyoming Independent Living Rehab operates a voucher transportation service (using private drivers) in several communities.

(6) A referral to a program providing case management services (such as is found in the Developmental Disability programs and some Older Americans Act programs) can connect an individual to a professional with ability to develop a specific plan

of care that will weave together needed services and funding streams. The plans are reviewed on a regular basis to determine changing needs and ensure proper use of funds.

(7) In some cases, there are sources of assistance within the neighborhood (a neighbor who can provide shopping, transportation, etc.) or family members who can do chores or collectively contribute (financially) to the care of a loved one. The counselor can suggest the individual at least consider that kind of help, or refer the person to a professional social worker/case manager. Likewise, at times there are "pockets" of special funding (through Robert Wood Johnson, foundations, private donations) that are available for specific projects in the community. Often the general public is unaware of such opportunities or how to access the services, and the ADRC counselor can direct the consumer to specific assistance.

*Question 3.* Is there a single ADRC model that is being developed across the country?

Answer 3. No. The ADRC initiative has been designed to allow for flexibility based on a State's unique existing long-term care system. AOA and CMS recognize that no State's LTC is exactly the same. ADRC grantees are directed to partner with key State and community-level stakeholders to create an ADRC system that builds on existing State infrastructure and systems to streamline access to long-term care for all ages of consumers with disabilities. A number of different models are emerging across the country. The Massachusetts Area Agencies on Aging (AAAs), for example, are partnering with Independent Living Centers to create an ADRC system serving individuals of all ages and incomes with disabilities. In Alaska, five regional Independent Living Centers are taking the lead in their ADRC systems coordinating closely with community-based senior centers across the State. In Maryland and Illinois, in addition to piloting a AAA-based model, they are piloting models based out of county Health Departments. In New Hampshire and Florida, plans are being made to use the experience of the pilot centers to "take the ADRCs statewide" with regional centers strategically-placed across the State. These are just a few of the models that are emerging to address both existing State systems and community preferences.

In Wyoming, the pilot has been developed by means of the University's Wyoming Institute of Disabilities (WIND) contracting with one of the Independent Living Centers (WILR central office in Casper). Since there are no AAAs in Wyoming but a Single Unit on Aging (the Aging Division of the Wyoming Department of Health), expansion of the pilot will not create the same configuration that exists in other States. States are using existing resources and strengths to build a system that will work best within their unique environment. In our case the frontier nature of the State that involves: expansive geography, limited resources in terms of health professionals and programs, and a personality of rugged independence, which creates both a unique challenge and an opportunity for the delivery of services. We are fortunate to have the State departments of health, family services and the Medicaid office as active partners in the effort.

*Question 4.* If Monica and Ellington were to come into the ADRC in Wyoming tomorrow seeking assistance what help could you provide?

Answer 4. Assistance from our ADRC would focus on Monica as the caregiver, and Ellington who is eligible for various services through the children's waiver. The ADRC counselors would inquire about how well Ellington is being served by the systems available to school-aged children, through the school district, associations for persons with disabilities, governmental agencies and various targeted grant programs. Ellington would likely be eligible for the myriad of services allowed under the Medicaid Children's Home and Community Based DD Waiver, and possibly the Special Family Hab Home Option, among others.

The counselor would also provide any appropriate information to Monica regarding income (social security, energy assistance, food stamps) housing, transportation, employment, access to medical care, caregiver supports (including respite care and support groups), education/training opportunities for parents of a child with disabilities, and referral to any community or faith-based project that could assist her in caring for Ellington and also for herself.

*Question 5.* Self-direction has proven to be a cost-effective and efficient model for the delivery of services as the person is in charge of selecting services, negotiating prices, etc. In your opinions, could wages increase or decrease for direct care staff if self-direction, allowing people to select their own staff, was used more broadly?

Answer 5. This is a difficult question for those of us in a State with very limited experience with this model. It would serve us well to look to Oregon, Washington and other States with years of experience in this arena, and carefully evaluate the

wage history, over time, and how that may have impacted the long-term care industry as a whole.

In response to this very good employment question, it seems logical to me that there would be a variety of factors relating to a particular State (tax structure, worker's compensation rates, unemployment insurance rates, affordability of health insurance, etc.). In theory, overhead personnel costs (of insurance if that is even offered to direct care staff, coverage for worker's comp, materials and supplies, etc.) drive up the costs of long-term care because those expenses are borne by the employer. Supervisors and other administrative staff must be paid. Legal costs associated with employee actions against the employer must be factored into the charges levied against the customer. In order to ensure a profit, wages to direct care staff are kept low. On the other hand, in self-directed care, if individual providers must absorb those expenses, they will need to be paid at higher rates to compensate for those expenses, make it worth the effort and to attract quality workers. It would make sense that just the existence of "choice" will mean that mediocre or poor workers will be weeded out of the employment pool, as people will select those who can provide higher quality of care. The law of supply and demand will dictate higher wages in that case. Conversely, if States are lax about qualifications and training requirements, persons hired to provide direct care may be hired at lower wage levels. In that case, States run the risk of inadequate quality of care of the recipient (a "get what you pay for" scenario.)

Eventhough the individual contracts for his/her own care, there must be adequate levels of oversight to protect against abuse and financial exploitation of consumers, at levels equivalent to oversight found in agency-based care. Some costs of that oversight will be borne by the State. Lack of adequate oversight could result in higher expenses for prosecution and incarceration, in of course the worst case scenario.

**Distribution of Pilot Sites across Model Types,  
FY 2003 and 2004 Grantees (n = 24 States)**

Management		Structure		Consumer Access		# of Pilot Sites	% of Pilots
State	Local	Centralized	Decentralized	Physical	Virtual		
√		√		√		17	33%
√		√			√	14	27%
√			√	√		2	4%
√			√		√	3	5%
	√	√		√		8	16%
	√	√			√	5	10%
	√		√	√		1	2%
	√		√		√	1	2%
73%	27%	86%	14%	53%	47%	51	99%*

\* = Total does not sum to 100% because the results were rounded

[Whereupon, at 11:29 a.m., the hearing was adjourned.]

○