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MOVING TOWARD GREATER COMMUNITY INCLUSION—OLMSTEAD AT 15

HEARING

OF THE

COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS

UNITED STATES SENATE

ONE HUNDRED THIRTEENTH CONGRESS

SECOND SESSION

ON

EXAMINING MOVING TOWARD GREATER COMMUNITY INCLUSION,
FOCUSING ON OLMSTEAD AT 15

JUNE 24, 2014

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MOVING TOWARD GREATER COMMUNITY INCLUSION—OLMSTEAD AT 15

TUESDAY, JUNE 24, 2014

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

The committee met, pursuant to notice, at 2:38 p.m., in room SD–106, Dirksen Senate Office Building, Hon. Tom Harkin, chairman of the committee, presiding.

Present: Senators Harkin, Alexander, Casey, and Hatch.

OPENING STATEMENT OF SENATOR HARKIN

The CHAIRMAN. Good afternoon. The Senate Committee on Health, Education, Labor, and Pensions will come together for a roundtable discussion on Moving Toward Greater Community Inclusion—Olmstead at 15.

Our discussion will focus on developments in advancing the community integration of people with disabilities and the impact of the Olmstead decision 15 years ago. I will also be interested to hear what the panelists think needs to be accomplished to make home- and community-based supports the norm for people with disabilities.

As I said, this Sunday was the 15th anniversary of that landmark U.S. Supreme Court decision. This 1999 Supreme Court decision held that the unnecessary segregation of people with disabilities from society violates their civil rights under the Americans with Disabilities Act.

When Congress passed the ADA, we described the segregation of people with disabilities as a serious and pervasive form of discrimination. Title II of the ADA says that no person with a disability,

> "shall, on the basis of disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity."

One of the most important aspects of the ADA is the integration mandate, which requires public entities to ensure the administration of all programs and services in the most integrated manner possible. In Olmstead, the Supreme Court found that preventing people with disabilities from living in the community with their nondisabled peers constituted discrimination and was a violation of their civil rights under the ADA.

The Court wrote that,

> "Unjustified institutional isolation of persons with disabilities is a form of discrimination. Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life and severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

There remain, however, problems. Despite the Olmstead decision 15 years ago, over 75 percent of States spend a majority of their long-term care dollars on institutional care and support, and the number of people with disabilities under the age of 65 in those settings increased between 2008 and 2012.

That is why, today, I have introduced a bill called the Community Integration Act, a bill that ensures that people with disabilities can choose to live in the community and receive the same supports and services they would receive in institutional settings. Our national policies should no longer have a bias toward institutional care.

I've often wondered—under Medicaid, if you go into an institution, they must pay. If you decide you don't want to go into an institution but you want to live in a community, they don't have to pay. They may or they may not, but they don't have to. But if you go into an institution, they have to pay. That should be changed. Individuals should be able to make a choice about where their long-term supports and services are available, and my bill would ensure that all people with disabilities can make that choice.

So this afternoon, we will hear from a number of individuals who have spent time in institutions, some young people who expect to be served in their communities, and providers who are working to ensure people with disabilities have the same access to the community as their nondisabled peers. I eagerly look forward to our discussion.

Now I invite our Ranking Member, Senator Alexander, to give his opening statement.

OPENING STATEMENT OF SENATOR ALEXANDER

Senator ALEXANDER. I want to thank Senator Harkin for this roundtable and thank the witnesses for coming very much. This has been the subject that Senator Harkin has cared the most about during his long tenure in the U.S. Senate. We all respect him for that.

The Olmstead ruling, as he said, began to reverse a long-term trend of preferring institutions over home-based or community living centers. And he mentioned those benefits, and we're here to celebrate the Olmstead ruling as a big victory for individuals with disabilities.

I hope today that we talk some about three issues. One is Medicaid waivers, one is overtime regulation, and one is workforce training. We rely on State governments to implement Medicaid. I used to be a Governor. I struggled with that myself, and I support giving the States more flexibility.

According to the National Council on Disabilities, if you go to a nursing home, the average cost is about $63,000. At home and in communities, the average cost is about $31,000 for those who prefer that, which many do. That's not only good public policy. It makes fiscal sense, and it allows States to come up with solutions which serve more people at homes and in communities.

Our State of Tennessee wants to be a leader in supporting independent living and competitive employment for all individuals with intellectual and developmental disabilities. Tennessee spent $624 million of State funds to provide long-term supportive services to people in community settings. Eight thousand Tennesseans benefit from the waivers that the State has to get in order to do that. That's a huge accomplishment when you consider that Tennessee's Choices program just got up and running in 2010.

Yet for every person enrolled in Tennessee's program, there's another person with intellectual disabilities on a waiting list. That's true in many States. States have to renew their waivers every 5 years. Tennessee's waiver expires in December. So the first thing I'd like to say is that I would like to see more flexibility for States to use a cost-effective way to expand community-based approaches.

Also, I'm concerned about the Obama administration's proposed regulation on overtime for home care workers. I fear that if it goes through, it will increase the cost of in-home care without a corresponding increase from third-party payers like Medicaid, and that will be fewer options for those who prefer in-home living.

And, finally, tomorrow, the Senate will take up a huge bill that Senator Harkin and I worked very hard on for many years, actually, that reauthorizes the Nation's job training programs. With Senator Harkin taking the lead on this part of it, especially, it will improve accountability to ensure that programs serving individuals with disabilities are doing their jobs, and it focuses on youth transition and increasing opportunities for competitive employment.

That bill has now been approved by every single Senator, it looks like, and it has passed the House. We fully expect that it will pass the Senate and then the House and then be signed by the President, and we look forward to that.

Thank you, Mr. Chairman, for the hearing.

The CHAIRMAN. Thank you, Senator Alexander. Thank you for a very close, good working relationship here on this committee and working together on things. It's just another example that people who probably philosophically disagree can actually get things done. I appreciate this great working relationship that we've had.

Let's introduce our panel. Our first witness is from my home State of Iowa, Emmanuel Smith, who is part of what I call the ADA generation. He's a young person who has grown up with the rights and protections guaranteed by the ADA and by the Olmstead decision.

Mr. Smith has a bachelor's in political science from Drake University in Des Moines. He is a former intern with the Great Plains ADA Center. He currently works at Disability Rights Iowa as an advocate for beneficiaries of social security.

Our second witness is from the State of Utah, and I'm going to yield to Senator Hatch who was here with me when we hammered out the ADA in 1988, 1989 and 1990. We had a great working relationship. I've said many times that Senator Hatch stepped in at the right time to break a little log jam and help us get that bill through. It's just been a great friendship and working relationship with Orrin Hatch for all these years. He's a great supporter of disability rights.

STATEMENT OF SENATOR HATCH

Senator HATCH. Thank you, Mr. Chairman. I want to thank both of you for your leadership in this area. You two are the best Senators I've served with, and this is a very important committee. And I still remember both of us breaking down and crying as we walked off the floor on the Americans with Disabilities Act and saw all of those people in wheelchairs and on crutches and so forth who were just thrilled that we were able to get that through.

But thank for allowing me to introduce a very fine man, Dr. Troy Justesen. In 2006, I was honored to recommend to President George W. Bush that Dr. Justesen be nominated as Assistant Secretary of Education for Vocational and Adult Education, where he did serve for 2 years. Dr. Justesen holds a bachelor of science in education and a master's in special education. I'm proud to say that he earned his degrees at Utah State University before earning a doctorate in higher education from Vanderbilt University.

His impressive credentials include more than 12 years of Federal service. He worked at the Department of Justice in the Civil Rights Division, managing investigations under the Americans with Disabilities Act, and he was the former Deputy Executive Director of the President's Commission on Excellence in Special Education and later worked on implementing the Individuals with Disabilities Education Act at the Department of Education.

He served as Associate Director for Domestic Policy at the White House, where he led President Bush's new Freedom Initiative promoting the full participation of people with disabilities in all areas of society. I am pleased that I had a role in passing the Americans with Disabilities Act and will continue to foster more community-based opportunities for persons with disabilities and, of course, their families as well.

I cherish working with Dr. Justesen. We share a deep and ongoing commitment to fostering opportunity for persons with disabilities and not just talking about it but actually creating sound policy. If you'll look back at the important decision made 15 years ago this week, Dr. Justesen will make it very clear that we need to think more creatively about how to remove barriers preventing persons with disabilities from leading independent lives.

I intend to keep working so that all Americans with disabilities can access the option of home- and community-based services that allow for increased employment and access to educational and social opportunities. We are truly honored to have such an accomplished gentleman as Dr. Justesen with us today. He has worked tirelessly with Federal, State, and local governments for full enforcement of the Americans with Disabilities Act.

I really look forward to his remarks today, although I do have to move on to another assignment. But I want to thank you both for allowing me to make these comments about a very good friend and good person who has made a real difference in these areas.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Senator Hatch.

Our third witness is from the State of Pennsylvania, and I'll ask my colleague, Senator Casey, to make this introduction.

STATEMENT OF SENATOR CASEY

Senator CASEY. Mr. Chairman, thank you for holding the roundtable and for the work that you and Ranking Member Alexander do. I am pleased to be able to introduce a fellow Pennsylvanian, Ms. Norma Robertson-Dabrowski. Ms. Robertson-Dabrowski works as the director of Nursing Home Transitions for Liberty Resources. That's in Philadelphia in Philadelphia's Center for Independent Living. She assists nursing home residents with their transition into the community.

At 16, she was involved in a car accident resulting in her quadriplegia. During the ensuing 7 years in which she was institutionalized, she completed her high school diploma and earned an associate's degree. Liberty Resources helped her move into the community in 1991, and today she has two godchildren and lives on her own. We are grateful she is with us.

We welcome you here to the roundtable along with the other witnesses that are with you today, and we look forward to your testimony. Thanks for being here with us.

The CHAIRMAN. Thank you very much, Senator Casey.

Senator Mikulski was going to be here to introduce our next witness, but she's involved in Appropriations Committee right now and couldn't make it.

Our next witness will be Gail Godwin. Ms. Godwin is the executive director of Shared Support Maryland, an organization which provides person-centered and client-centered supports to people with intellectual and developmental disabilities, including those with intensive support needs.

She is also an executive member of the Maryland DD Council and a member of the Maryland Association of Community Services Board. Prior to founding Shared Support Maryland, Gail has worked as an advocate and service coordinator for people with disabilities for over 20 years.

Thank you for being here.

Next we'll hear from Donna and Ricardo Thornton. Mr. and Ms. Thornton were institutionalized as children. Both wound up at Forest Haven right here in the DC area. In their early 20s, they had the opportunity to move into supported community living. Now they both work in the community at a competitive wage. Mr. Thornton works at the DC public library, and Ms. Thornton works at Walter Reed Medical Center.

The Thorntons have been married for 30 years and are now proud grandparents. They both serve on boards and committees related to the issues they are passionate about. Ms. Thornton is a board member of the ARC of DC. Mr. Thornton is a member of the DC DD Council and a Special Olympics Ambassador.

You have been before our committee before, if I remember right. So thank you for coming back again.

Thank you all for being here today. I'm going to ask each witness to kind of keep your remarks to 3 minutes or so and sort of make your point so that we can get into an open discussion. That's why we call it a roundtable, so we can have an open discussion without having the formalities of a dais and a hearing.

I have your statements. They'll all be made a part of the record in their entirety. But we'd just like you to sum up a little bit what it is that you think we ought to know. And, again, we're trying to get to Olmstead and why it is we're not moving faster, doing better at community integration.

As Senator Alexander said, we've got data that shows it's actually cheaper.

Senator ALEXANDER. Half as much.

The CHAIRMAN. Yes, and so from a budget standpoint, plus people in the disability community would rather make their own choice on where to live and to live with their friends and their families in their community. So it's just always perplexed me why we can't move ahead more aggressively on this.

So kind of keep to that, and maybe if you've got suggestions for us, different things—I know Senator Alexander brought up a couple of things on this. So I'll just start with Mr. Smith, and we'll just work down. Just take a couple or 3 minutes. What is the most important thing you think we ought to know? And then we'll open it for discussion.

Here's the other thing I'm going to say. Once we get through with this—we'll take a few minutes for this—we'll open it for general discussion. So if Mr. Justesen says something and makes a point, and you'd like to add to it or say something, take your name card and just turn it up. If you need help doing that, just give us a high sign or something like that. That way, we'll move to you, and we'll kind of keep a discussion going. OK?

Emmanuel Smith.

STATEMENT OF EMMANUEL SMITH, PROTECTION AND ADVOCACY FOR BENEFICIARIES OF SOCIAL SECURITY (PABSS) ADVOCATE, DISABILITY RIGHTS IOWA, DES MOINES, IA

Mr. SMITH. Thank you so much for having me here today. It's an incredible privilege. I was born with brittle bone disease. I've had 50-plus broken bones in my life. Lest I tempt fate, I think it's fair to say I'll have many more.

So my health has always been in a State of flux, and I've very much depended on my mother and my family to help care for me and help me to live independently. I come from a single parent household. My mother is getting older. I grew up very aware that my health could change in a matter of moments, and the health of my mother could change, and that could put me in a very precarious position.

Unfortunately, to a certain degree, I had to grow up under the specter of the possibility of living in a nursing home at some point in my life. For a young person, that can be incredibly poisonous, especially because we tell young people to get involved with vocational rehabilitation to work and live to the fullest extent that they're able. But then they're forced to do so under the threat of institutionalization, as if the last third of their life is pre-written.

For me, that was incredibly burdensome. That's why I'm so thrilled to be able to come today to speak on Olmstead because I feel as though it affords me the legal protection to defend a life that I've worked hard to cultivate, to defend a career that I'm very much passionate about, and more than anything else, to keep me in my community.

As we discuss Olmstead and as Olmstead is discussed nationally, I always want to make the point that, yes, integration hugely benefits the lives of people with disabilities. But it's not just about us. I think a core premise of the ADA is that we all benefit from diversity and integration, and dare I say that I think my community is better for having me.

We're all better when we have people of different backgrounds and minority groups and beliefs living together and working together. That seems to me to be a uniquely American idea and one that I'm so glad to see brought to fruition through the ADA and, by extension, Olmstead.

[The prepared statement of Mr. Smith follows:]

PREPARED STATEMENT OF EMMANUEL SMITH

Thank-you Senators for having me here today. My name is Emmanuel Smith and I work currently at Disability Rights Iowa. It's certainly an honor to be asked to speak on a law, and by extension a Supreme Court decision which I believe plays an important role in my life.

I have brittle bone disease, and have broken nearly 50 bones. As much as I hate to tempt fate, I will almost certainly break many more. In addition, I have several sub-diseases that could, through time or sudden injury, limit my ability to live and work independently to the degree I am currently able, and overnight drastically increase my need for services. I grew up with this understanding, and I live with this understanding.

As a child from a single parent household, I knew that the family supports I depended on could not last forever. And should, for whatever reason, those family supports fall away just as I was facing significant health issues, it was well within the realm of possibility that I would end up in a nursing home. Thankfully, *Olmstead* addresses that fear directly through the principle it reinforces and the legal protections it affords me.

Through *Olmstead*, I have a clearly defined right to receive the services I need without sacrificing my place in society needlessly. I'm no longer forced to put my dignity, or safety, in the hands of those who may not have my interests at heart. My work with the P and A network has introduced me to a host of attorneys and advocates who will protect me from that, using the legal avenues *Olmstead* affords them.

Agency is everything. The feeling that success is possible, and I and I alone get to shape my life. It is what has enabled me to throw myself fully into my work, and build something lasting and meaningful come what may. To tell young people with disabilities to have high expectations and work toward independence while denying them the supports necessary for basic human dignity later in life would be unfair and frankly poisonous. That is why we need *Olmstead*.

Olmstead is not an embellishment of the ADA, or an addition tacked on through the courts. It is a defense of what Justin Dart Jr called a "landmark commandment of fundamental human morality". That as an American, I have the right to live as I wish, work in a field derived from my passions, and all within a home not just with family, but of my making. A home I spent countless hours in half body casts dreaming of. Most importantly, I believe that my community is made better for having me, for having diversity of all kinds. If nothing else, the ADA is predicated on the idea that we all benefit from living together, and operating in stewardship to one another. *Olmstead* insures that inclusion for generations of people with disabilities, and I so greatly appreciate you all taking the time to explore its incredible human impact and lasting importance.

The CHAIRMAN. Very good. Thank you, Mr. Smith.

Dr. Justesen.

STATEMENT OF TROY JUSTESEN, Ed.D., DIRECTOR OF PUBLIC POLICY, UTAH DEVELOPMENTAL DISABILITIES COUNCIL, ORANGEVILLE, UT

Mr. JUSTESEN. I think what we're talking about today is a need to reform statutes that are over 50 years old. You talked about Medicaid and a little bit about Medicare, and that's the Social Security Act that's been around since 1965. When that legislation was enacted, we had an entirely different society. We had a society that was just on the cusp of including people with disabilities as valued people.

Today, we have realized—and I'm a little bit older than Emmanuel, but not much older than he is. And I am the product of the benefits of the Rehab Act, the IDEA, the work of the ADA. In fact, the very first time I ever left my home State of Utah was to come here to DC to see you at the White House when the ADA was signed. That was 24 years ago. I can't believe it's been that long. You haven't changed a bit, but I've lost all my hair. I just wish mine would go gray before it all falls out.

[Laughter.]

We need to make some fundamental changes that have been improved on the history of the world's greatest success, which is the Social Security Act. But today that act is outdated. We need to reform Medicare, and we need to reform Medicaid so that we remove what many people in the field call the institutional bias. That is that we invest far more money in institutional settings than we do in home- and community-based settings.

In fact, because of the successes of all the public policies that have made my life possible, it'll make Emmanuel's life even more possible than mine has been. We need to move the money that's invested in institutional settings that's overly invested. In the 1960s, that was good. In the 1970s, that was good.

But today we have the ability, because society is more accessible, to live in communities, and we don't want to live in institutions. We need to reform Medicare, probably in the way in which your legislation that you just introduced, Senator Harkin, achieves, so that we have at least an equal balance in the investments made in the institutional settings and home- and community-based settings.

I'm one of the individuals that's a success, an example of the fact that I don't qualify for Medicaid. I have too many resources. My income is too high. That's a good thing. I'm not asking to be Medicaid eligible, and I don't think I'm representing millions of people with disabilities who want to become Medicaid eligible. But we don't want to lose all the resources that we've gained, simply because Medicaid is the only policy, public or private, in the United States that provides long-term services and supports.

I'm looking at the option of reducing my resources so that I can have the option of having attendant services to remain independent. The only choice I have is that I'm entitled tomorrow to walk into a nursing home, declare bankruptcy, and spend the rest of my life in a nursing home. I'm entitled to do that. No one in the country is entitled to take less than half those resources to live in the community and continue working.

The policies that we have made successful in this country on both sides of the aisle have worked. It has brought millions of people to the position I'm at now. We need to take the next step so that we don't take a backward step and have millions more of us move into nursing homes and double the cost of Medicaid.

Whatever your perspective, you're looking at doubling the cost of Medicaid if we all knock on the door of nursing homes tomorrow. I don't think we want to do that. I don't think anyone wants to do that.

I think what we need is to consider ways in which I should use the resources I have to remain independent. But I might need a little bit more to stay independent, to remain a taxpayer, to, frankly, pay more taxes than most people do, because I chose in my life to plan for long-term services. I knew that I would need them. I knew that I needed to make those investments. Since I was about this man's age, I've invested a portion of my income every month so that I would be able to pay for long-term services and supports.

The problem was that 24 years ago, I didn't know it would cost me, on average, $70,000 a year. I don't know why, as a society, no matter what our political perspective is, that we should expect any family in America to have to make those kinds of plans to remain independent in society. So I'm here today to talk about how we can move forward based on the successes that have been made and ways in which, for those of us who need Medicaid, it's there, and it is the greatest success in the world for support systems.

Also, where are we going to be when Emmanuel's children are sitting here? Will they be able to have long-term services and supports and be doctors and lawyers and astronauts and everything else that, by the way, people with disabilities can do, including maybe going to Catholic law school, or if they're good enough—you've called me Doctor so many times, Vanderbilt is going to take it back, because the agreement was I wouldn't say that too much.

But maybe I'll have the chance to have my grandchildren go to the University of Tennessee and be successful. I want that for them, and I think maybe we have a society that wants that for the future generation of people with disabilities in this country.

Thank you.

[The prepared statement of Mr. Justesen follows:]

PREPARED STATEMENT OF TROY R. JUSTESEN, ED.D.

Thank you Mr. Chairman, Ranking Member Alexander, my own Senator, Senator Hatch, and members of the committee, for inviting me to participate in this roundtable discussion about the progress made, current challenges, and the future for more than 56 million Americans with disabilities[1] as a result of the Americans with Disabilities Act[2] celebrating its 24th anniversary next month and the U.S. Supreme Court *Olmstead*[3] vs. *L.C.* decision that was issued 15 years ago this past Sunday. The focus of my comments today surround efforts to realize *Olmstead's* promise of

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[1] About 56.7 million people—19 percent of the population—had a disability in 2010, according to a broad definition of disability, with more than half of them reporting the disability was severe, according to a comprehensive report on this population released by the U.S. Census Bureau July 2012.

[2] Public Law 101-336; Stat. 104 Stat. 327

[3] *Olmstead* V. *L.C.* (98-536) 527 U.S. 581 (1999) 138 F.3d 893, affirmed in part, vacated in part, and remanded.

creating and providing more home and community-based supports and services (HCBS[4]) for individuals with disabilities and their families throughout this Nation.

The *Olmstead* decision requires States to make reasonable modifications in their policies and long-term services and supports (LTSS) so that people with significant disabilities can leave State institutions and nursing homes or not enter such facilities in the first place. *Olmstead* recognized that people with disabilities should have the choice of where they want to live and the services they need should follow them. *Olmstead* reversed a long-time trend of funding institutions and limiting choice to that option only. Since the *Olmstead* decision, an increase of about 1,100,000 people have benefited from HCBS without first becoming institutionalized, and about 300,000 people have left institutions to live in homes and communities of their choice. These changes in policies are to a large degree, based on improvements in the Federal/State partnership in the Medicaid[5] program administered by the Center for Medicaid and Medicare at the Department of Health and Human Services.

However, more changes in Federal policy readily can be made to allow States to implement increased changes that will increase the quality of life even more for people with disabilities. And Medicare[6] can be modernized to reduce costs and provide for LTSS in home settings.

Currently, services for institutional care are mandatory under Medicaid, but merely optional for States to cover when providing HCBS. Despite efforts to reduce institutional care or re-balance Medicaid, the program is still weighted in favor of institutional facilities, instead of providing these services to people with disabilities as they live in their homes and communities. Fifty-seven percent of Medicaid's long-term care funding goes to institutional care. Today, States must request from the Center for Medicaid and Medicare Services a waiver[7] of the law through a complicated lengthy process to use funds for HCBS. This rationale is counter to the Supreme Court's *Olmstead* holding. To illustrate the point in real terms, today people with disabilities are entitled to go to a nursing home at an average cost of $62,750 per year. The same services, by contrast, can be provided in homes and communities at an average cost of $31,341 per year.[8]

However, there is a cost savings solution to part of the problem. Stated simply, Congress could re-balance Medicaid's LTSS funds by equally funding nursing home care and HCBS at a 50–50 percent balance. This would give a 7 percent increase in HCBS without increasing appropriations from either State or Federal dollars. This step would modernize the nearly 50-year-old Medicaid LTSS system. This shift away from a bias toward institutional facilities to creating greater options for community living would also significantly improve the lives of millions of people with disabilities and their families—a cost savings with important and long-term rippling positive results for every American.

Senators, I am an example of the ADA. I have a significant disability. I graduated from college, graduate school, and earned a doctorate from Vanderbilt University, and I paid my own way. I paid off my student loans and rose to the rank of career senior executive service and served as a political appointee. I learned that the complexities of living with a disability required me to become an expert in planning for the fact that I would one day need LTSS. I saved a monthly percentage of my income for the time I would need to pay for LTSS. I am now at that time. I spend more than $4,000 per month in supports to remain in my home. Although I spend $4,000 per month I have no support services after about 7 p.m. weeknights, and no weekend or holiday assistance at all. The compliance process for directly hiring support staff is too complex and regulated to the point that I cannot manage all the

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[4] In 1981, Congress established the Medicaid Home and Community-Based Services (HCBS) waiver program. The HCBS waiver allows States to receive Federal matching funds for a variety of residential services and supports to Medicaid beneficiaries who would otherwise require institutional care.

[5] Medicaid was created by the Social Security Amendments of 1965 which added Title XIX to the Social Security Act. Medicaid is capped based on income and other personal resources.

[6] In 1965 Congress created Medicare under Title XVIII of the Social Security Act to provide health insurance to people age 65 and older, regardless of income or medical history.

[7] States have several options for funding HCBS—the HCBS waiver (section 1915(c)), the HCBS State plan option (section 1915(i)), the Community First Choice (CFC) Option (section 1915(k)), and the section 1115 Demonstration waiver. The 1915(c) waiver is only available to individuals who qualify for an institutional level of care. Under this waiver, States can cap the number of eligible people, keep waiting lists, and limit services to certain geographic areas. Additionally, States must apply for renewal of the waiver from Medicaid which is a complex and lengthy process. The 1915(i) State plan option allows States to provide any number of HCBS to individuals before they need institutional care.

[8] See page 55 of Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers, National Council on Disability, (*www.ncd.gov*), March 18, 2013.

Federal laws to avoid a tax audit or other employment regulatory barriers. The current tax structure does not allow deductions until I reach the Internal Revenue Services' medical deduction threshold. I, like many people with disabilities, was never eligible for long-term care insurance because my condition was considered preexisting. Further, I cannot use Medicare because I am not eligible without first going to a 3-day stay at a hospital each year—by the way, I have not had an overnight stay in a hospital in more than 30 years. I have turned down a college presidency, promotions, and liquidated assets in attempts to simply hire in-home support services. I cannot access my retirement funds without substantial penalties to use for LTSS. I have been encouraged to declare bankruptcy by several program administrators as the only option to become eligible for LTSS. I spend countless hours each month tracking every expense to manage the tax system to remain independent.

I speak with many families and young adults with disabilities capable of pursuing college degrees, wonderful careers, and opportunities to become significant contributors to society and lead independent lives. It is difficult to explain that working hard leads to a lifetime of ineligibility to actually remain independent and that the current system, although not intentional, supports choices that lead to poverty, purposeful unemployment, and forced institutional living.

Olmstead continues to move positive change for our Nation. The time has come to re-evaluate our system of providing long-term supports and modernize the system to encourage more independence especially for the millions of young Americans with disabilities to successfully contribute to their communities rather than live in poverty simply to have services.

While many doors have been opened, the lack of access to services and supports that allow people with significant disabilities to live and work independently while achieving even a modest level of economic security has hindered the progress that might otherwise have been made. For example, allowing States flexibility in a wavier program to create a risk pool for the only 2 percent of people who are ever expected to use LTSS with flexible criterion allowing people with disabilities to remain gainfully employed and advance in their careers would be one option that decouples the need for LTSS from the healthcare paradigm—this is not healthcare, it is support services like a worker helping a disabled professional dress for work every morning. Participation in a risk pool if CMS gave the State flexibility to design the program to promote gainful employment would be an option worth further analysis that could result in millions more Americans returning to higher paying careers if they could have some minimal hours of support at key times of the day.

I am prepared to discuss more specific detailed policy issues to increase access to independence, employment, increased access in the community, and ways to allow States greater flexibility to progress further and modify outdated policies that will fundamentally alter the lives of millions of Americans with Disabilities.

Thank you for the opportunity to appear before you today.

The CHAIRMAN. That was very eloquent. Thank you very much, Dr. Justesen. That was very eloquent.

Now we'll turn to Ms. Robertson-Dabrowski.

STATEMENT OF NORMA ROBERTSON-DABROWSKI, DIRECTOR OF NURSING HOME TRANSITIONS, LIBERTY RESOURCES, PHILADELPHIA, PA

Ms. ROBERTSON-DABROWSKI. Good afternoon, Chairman Harkin and committee. I thank you for the privilege of allowing me to come here and share my testimony.

My name is Norma Robertson-Dabrowski. At the age of 16, I was in a car accident which left me as a quadriplegic. I lived at home with my mother for a year until my mother had to have surgery. My mother asked my physician at the time what services could I get provided with to continue to live at home in the community, because she was no longer able to take care of me. My doctor referred me to a nursing home. I was very unhappy. I was the youngest person residing in the nursing home at that time.

I met a support coordinator from Resources for Living Independently at that time who came out and told me that I was eligible to receive services because my disability happened before the age of 22. Under the Omnibus Budget Reconciliation Act of 1987, anybody who had their disability before the age of 22 would be eligible to receive services to transition out of the nursing home—only those who had the disability before the age of 22. So lucky me.

At that time, I met a support coordinator from Liberty Resources in 1991. I was able to transition out of the nursing home into my own apartment. In 1996, I was hired at Liberty Resources as a support coordinator to transition consumers out of the nursing home like myself.

Today, I am a nursing home transition administrator who assists nursing home consumers like myself to transition to the community, where, proudly, I am a wife, a homeowner, and a godmother of two children. Currently, I've been working at Liberty Resources for the last 18 years. So let me say that again—for the last 18 years, doing what was done to help other people move out as myself.

During the time of my transition, again, because I was eligible to receive services from the OBRA, a lot of people who had their disability after the age of 22, such as a traumatic brain injury, stroke, were not eligible to transition out. So they were left in a nursing home until after Olmstead was passed. There were other additional funding to help people move out with all types of disabilities, as long as they met the waiver requirement.

If you are over the income limit, you are not able to move out. Fortunately, with Olmstead being passed, now a person is able to go file a complaint with the Office of Civil Rights and even file a class action suit to be able to transition out in the community where they want to be.

Since the Olmstead decision, the number of nursing home transition referrals has increased through our agency. Prior to that, we would have to advocate with consumers against their families or nursing home staff because they felt the consumers were not those types of people who wanted to or could move out into the community because they required so-called 24-hour care.

Now, since the Olmstead decision, the referrals have increased. Families are choosing to have their loved ones live at home with the services and supports they need to live independent and productive lives in the community instead of placing them in nursing homes under the false pretense that they will receive 24-hour care.

I would like to conclude by saying Olmstead was a landmark Supreme Court decision, but we need more. We need to end the detrimental and costly institutional bias and mandate the freedom of seniors and people with disabilities to choose to receive community-based services. Costly nursing home placement should be a choice of last resort rather than an automatic replacement.

Again, I thank you for letting me come here and give my testimony.

[The prepared statement of Ms. Robertson-Dabrowski follows:]

PREPARED STATEMENT OF NORMA ROBERTSON-DABROWSKI

Good morning Chairman Harkin, Ranking Member Alexander, and members of the HELP Committee. It's an honor to be here talking to you this morning. I thank you for the opportunity to speak to you and share my personal testimony. My name is Norma Robertson-Dabrowski and I am the administrator of the Nursing Home

Transition (NHT) program at Liberty Resources, Inc. (LRI), the Center of Independent Living in Philadelphia, PA. In 1982, I was in a car accident which caused my quadriplegia. For a year after the accident, I lived at home with my mother, who later needed to have surgery and was unable to care for me at home. When my mother asked my Doctor for assistance, I was referred to a nursing home, where I lived for 7 years. The loss of mobility made me quite angry and depressed. My family remained very supportive of me, yet I still didn't want any part of living in a nursing home. I had great difficulty adjusting to my new physical limitations as well as the institutional structure. In 1990, I was introduced to a Support Coordinator from LRI who informed me that because I received my disability before the age of 22, under the 1987 Omnibus Budget Reconciliation Act (OBRA 1987), I could choose to transition from the nursing home to the community. LRI helped me transition from the nursing home in 1991. In 1996, I was hired to work at LRI as a Support Coordinator. Over the years, I have been promoted to several different positions. Today, I am the NHT Administrator who assists nursing home consumers just like myself transition to the community, where proudly I am a wife, home-owner, and gainfully employed.

I am a living example of true community integration. When I transitioned out of the nursing home in the early 1990s there was no *Olmstead* decision. LRI Staff went into nursing homes to visit Consumers who acquired their disability before the age of 22. Under OBRA 1987, Consumers were able to receive services that would assist them with transitioning to the community instead of expensive and isolating nursing homes. Some Consumers wanted to transition and others chose not to transition at that time. Staff had to go back and visit the consumers every year. Many Consumers change their minds and decided to transition to the community. Unfortunately, OBRA 1987 did not cover persons who may have acquired their disability after the age of 22. Persons who may have had a stroke, amputees, or traumatic brain injury were not covered under OBRA 1987.

With the *Olmstead* decision of 1999 things are much different. With the Minimum Data System (MDS), if individuals indicate in the first 30 days of nursing home placement that they would like to move back home or transition to the community, their names are entered on the Front Door Information System List (FDIS). A NHT Agency visits the individual and asks them if they would like to transition to the community. If the individual chooses to transition, there are NHT Funds to assist with the security deposit, moving expense, set-up fees, furniture, etc. Unfortunately, there are no funds to help a person obtain the necessary documentation to fill out housing applications. The individual needs three pieces of ID: picture (non driver's license), birth certificate and social security card. If a person has a home prior to being admitted to a nursing home, there are no funds to hold the apartment or pay rent.

Prior to the *Olmstead* decision, nursing home consumers who did not meet the waiver requirements such as income limit had no other choice but to stay in a nursing home. Under the *Olmstead* decision, an individual can file a complaint with the Office of Civil Rights and even file class action suits so they can transition from the nursing home. Since the *Olmstead* decision, the number of NHT referrals has increased. Prior to the *Olmstead* decision, NHT Agencies would have to advocate with Consumers against their families and the nursing home staff for consumer's choice to transition. Since the *Olmstead* decision, families are choosing to have their loved ones live at home with the services and supports they need to live independent and productive lives in their communities instead of placing them in nursing homes under the false pretense that they will receive 24 hour care.

CONCLUSION

Olmstead was a landmark Supreme Court decision, but we need more. We need to end the detrimental and costly "institutional bias" and mandate the freedom of Seniors and people with disabilities to choose to receive community-based services. Costly nursing home placement should be a choice of last resort rather than an automatic placement.

The CHAIRMAN. Thank you very much. You're all very eloquent, and thank you very much for telling us that personal story.

Ms. Godwin.

STATEMENT OF GAIL GODWIN, EXECUTIVE DIRECTOR, SHARED SUPPORT MARYLAND, BALTIMORE, MD

Ms. GODWIN. Chairman Harkin and committee, it is an honor to be here. Thank you. I'd like to think that I represent an enormous amount of people that believe Olmstead affects institutions and nursing homes but also affects the community services that are provided outside of those.

For half a century or more, people with disabilities and their allies have demanded community living. Yet many people with disabilities are still removed from their communities in the name of treatment. Many of these people hope to return to homes or start new lives but are told they're not allowed to do so until they reach a certain skill level or meet a particular standard of behavior. And, again, this goes for institutions, nursing homes, and some of the community services that are provided.

This is not a test that we impose on people without disabilities before we allow them to choose their living situations. Yet despite ongoing advocacy, despite agencies implementing what we call best practices and state-of-the-art programming and facility building, countless people with disabilities are not living as real citizens in their communities.

It's popular to think about person centeredness and community living as a philosophy. However, it's past time to execute the delivery of services in that way. People with disabilities of any level, like anyone else, want and are entitled to live in neighborhoods of their choosing, homes of their choosing, with schedules and relationships of their choosing. People want to hire their own staff, and they want to decide where their services come from and if they want services, or if they want services without an agency in charge.

Shared Support Maryland has been in business for almost 8 years and offers fully inclusive, person-directed supports and partnerships with people, their families, and other allies. We are fewer than 100 agencies like this in the United States. Our organization offers the same service types as other organizations—residential, habilitation, employment, support brokering.

We offer support to people with fragile medical needs, with significant behavioral challenges—excuse the labeling—and with severe and profound intellectual disabilities. We use the same funding sources available to all providers and organizations and have found ways to offer personally driven services and/or individual supports to people we support.

We see people as partners in leading the organization. We are not an administration of experts who have years of experience but lack the experience of someone with a disability. Together we tackle the areas of any organization and system—service delivery; staffing management processes; ownership, control, and power; organizational design and structure; quality assurance; and compliance. We work to promote self-determination. We view people with disabilities as competent who deserve to have control of their lives and, because of that, behavior changes.

Housing is separate from services. This is paramount for us and paramount for people. This helps people not have to make the decisions between services and housing. So if they need to fire Shared

Support, they don't lose their home. We don't co-sign leases, and we don't own homes to lease back to people.

People interview, select, and manage their own staff. They have their own individual budgets. Monthly meetings and quick and frequent touching and face-to-face time with people result in accountability for us. People choose with whom they plan and spend time.

We believe that any agency can move further into personalized and individualized supports to make community living a reality. It means a lifetime of changes, challenges, and successes for everyone, and, most importantly, for the people who have chosen us to provide their support and services.

Thank you.

[The prepared statement of Ms. Godwin follows:]

PREPARED STATEMENT OF GAIL GODWIN

For half a century or more, people with disabilities and their allies have demanded *community living*. Yet many people with disabilities are still removed from their communities in the name of treatment. Many of these people hope to return to their homes or start new independent lives, but are told they will not be allowed to do so until they reach a certain skill level or meet a particular standard of behavior. This is not a test that we impose on people without disabilities before we allow them to choose their own living situations. Yet despite ongoing advocacy, despite agencies implementing "best practices" and "state-of-the-art" programming and facility building, countless people with disabilities are not living as real citizens in their communities.

It is popular to think about person centeredness and community living as a philosophy, however, it is *past time* to *execute* delivery of personalized services to all people with disabilities in the real community. People with disabilities of any level, like anyone else, want and are entitled to live in neighborhoods of their choosing, homes of their choosing, with schedules and relationships of their choosing. People want choices in hiring their staff, where services come from, and whether they want to use an agency or an individualized method without an agency.

Shared Support Maryland, Inc. has been in business for 8 years and offers fully inclusive, person directed supports in partnership with people with disabilities, their families, and other allies. We are one of fewer than 100 agencies in the country like this.

Our organization offers the same service types as other organizations: residential, habilitation, respite, employment and support brokering. We offer support to people with fragile medical needs, with significant "behavioral challenges," and with severe and profound intellectual disabilities. Shared Support Maryland uses the same funding sources available to all organizations and has found ways to offer fully person-driven and/or individualized supports to the people we serve.

Shared Support Maryland sees people with disabilities as partners in leading the organization. We are not an administration of experts who have years of experience in the field but lack the life experience of someone with a disability. Together we tackle the areas of:

- Service delivery;
- Staffing management processes;
- Ownership, control and power;
- Organizational design and structure; and
- Quality assurance and compliance.

We work to promote self-determination. We view people with disabilities as competent people who deserve to have control of their lives and, because of that, behavior changes. Housing is separate from services. We do not co-sign leases or own property that is leased back to people. This is paramount and by not doing so we eliminate the possibility of a person choosing to change services and losing their housing. People interview, select, hire and manage their own staff. People have individualized budgets. Monthly meetings result in high accountability. People choose with whom they plan and spend time.

Any agency can offer and provide services so that community living is a reality. It means a lifetime of changes, challenges and successes for everyone and most importantly for the people who have chosen our agencies to provide them with services and support.

The CHAIRMAN. Thank you very much.

We'll turn first of all to Mr. Thornton and then—well, I don't care. You make that decision. All right. We'll turn to Ms. Thornton first.

Go right ahead, Ms. Thornton. Thank you very much. Proceed, and then we'll turn it back to your husband.

STATEMENT OF DONNA THORNTON, WASHINGTON, DC

Ms. THORNTON. Good afternoon, Senators. My name is Donna Thornton. I work at Walter Reed Medical Center. I've been there 23 years, and I have a testimony to tell.

I used to live in Forest Haven when I was a little girl. I had a place that I always wanted to go to, and it was my swing. I always swung on my swing and asked God to help me through my way. So I asked him—I said, "God, I want to say some things to you." From the first time, I asked, "How can we get out of the institution?"

Somebody said that we have to work our way up. And I asked this person, "Well, how can you work your way up?" They said, "You know, you have to go from the bottom on up top." I said, "OK."

After that, I asked another question to Him. I asked my Father,

> "There's a couple of things I want to ask you. I want to get married and—first, I want to get out of the institution. I want to get married. I want to have some children."

Then I asked Him, "Can we all get out of the institution? Can everybody get out of the institution?"

I have a son. His name is Ricardo Thornton, Jr. He graduated from high school. He didn't get to college, but I was praying for him to go to college. Now, he's married. He has three kids. One is Daniel. He just turned 10. And we've got one little baby girl. Her name is Lia. She is 1 year old. And we have a 2-year-old baby girl, and her name is Rita Rae.

I hope that I can see them grow up and go to college, because I didn't go to college. But I want to see them go to college, just like everybody else.

Thank you very much.

The CHAIRMAN. Thank you, Donna.

Mr. Thornton.

STATEMENT OF RICARDO THORNTON, WASHINGTON, DC

Mr. THORNTON. Good afternoon, Mr. Chairman and members of the committee. Again, my name is Ricardo Thornton, and I am also a former resident of Forest Haven. I was just looking over some of this and picking out some spots here, but I think what I'm going to do is close this up a little bit and just speak.

My wife and I both lived at Forest Haven. We got out and moved into the community. But while I was there, I had a sister and I also had a brother who also lived at Forest Haven. The thing that was so hard to believe was we were family. I had no idea who they were—had come out of another institution, and this was the institution that would be the final institution.

We grew up there, and one of the things I had to learn—I didn't make choices. You didn't have choices. You follow. You follow the rules. If you didn't follow the rules, you get punished. There were a lot of things that we didn't like. We had good staff and we had bad staff. We had good days and we had bad days. We had days we wished we could just get away, run away—but not understanding why people were so mean and not understanding.

But we found out that a lot of the staff that worked with us just wasn't trained. They just looked at us as—that's a warehouse. They're labeled. This is what we do day in and day out. Once you have that label on you, that's it. But we were able to see—I was able to see my brother finally and show me some love, because we had family visitors that came out. I didn't know them. I still had to get adjusted to that.

My sister died at that institution because of an overdose—behavior. The only way that they controlled her at that time was with medication. She was about 20—she was in her 20s. But they told me not to worry. "It's not your problem. It's a heart attack. We're just going to let it be at that." But these are things that happen in institutions.

When I call them dark days—you never know. You just don't want to see those things happen. We thought the training really should have been—but it wasn't. For her, I determined I would do more advocating when I got out and make sure that people will leave institutions and not be put in places like that.

You had cottages. They had cottages where I can go. They had cottages where people were isolated that didn't have a say. To break that barrier where we felt that they should be included was through that Olmstead and all those advocating for us for change.

When we left Forest Haven and moved into the community, we were happy, because we had left the place. We were going to have freedom. We were going to have a little more love. We were going to have say. We found out that it was an adjustment. People weren't ready for us. They didn't want us to live next door to them. We were a problem that no one wanted to deal with.

But through all the advocacy and speaking up and telling our story, they found out we weren't that bad. My wife here proposed to me, Mr. Chairman. She proposed to me. She had moved into an apartment, and I was still in a group home, and we would travel back and forth. She proposed, and we thought about a marriage, and they were against it. They were like, "Marriage?" They were not for it. In other words, we just wasn't ready at that time.

This is a picture, Mr. Chairman, I was going to show you of the marriage that took place, where we invited people to come out to see people with disabilities actually living lives just like everyone else. This is in 1984.

And this is my son, who actually graduated from high school. The story with him was that he was a two-pound, 11-ounce baby boy. The odds were against us with raising a child, because they said, "You two come out of an institution. There's no way in the world you can do it."

But they didn't know that there was something that we knew that they didn't know, and that was we have a lot of support people here in the community that offered to support us—got him in Head Start, got him in elementary, and he's graduated from Calvin Coolidge now. So he now has his own little family, which is beautiful.

I'm saying all this to say I'm talking about the past, the present, and the future—is what we're here today to talk about. This is where I'm really concerned. I noticed you were talking about the Medicaid waiver. We have habilitation services. We have in the district a block that sits between—I don't know why this block is there, but one day I hope it gets moved.

Some of the people can get RSA and are eligible. But those that come out of institutions that want to get RSA—sometimes there's a block there that they can't get it for some reason. And they want jobs. They want to work. They want opportunities. I'm just thinking on how we can maybe look at some other way of opening up that door, to move that block.

I know it can be moved, because as we celebrate Olmstead's 15 year anniversary, it can be moved. It's just going to take a lot of advocacy and working with the Senators to find some way to do that.

In closing, I'm encouraging us to continue to—I have seen many who are in group homes and moved into apartments, and I can't tell you how happy they are that they now have a voice. They have a choice. They're riding Metro. They're choosing what their—providers are stepping back now and letting them choose. So I see us waking up a little bit. But I still think we need more, as more institutions are still advocating to keep them open. I want to see them closed. But stories like Donna and us turns that around.

One thing I want to say that Donna didn't say was when her son was born, she asked her doctor—two pounds, 11 ounces—she asked her doctor, "Doctor, will my baby love me?" And the doctor said, "Yes, he will love you." "No, Doctor, will my baby really love me? Look at my abilities. Will he love me?" Today, he's graduated with the support of our services that we have. Today, he's graduated with the support, that we can advocate and tell our story.

Back in the day, we could not sit here in front of the Senate and tell our story and think we're going to go back to that institution and be safe. That's unheard of. I'm just saying it to say it's a story, and we need more stories.

Thank you, Mr. Senator. I could go on and on and on, but thank you. Thank you, Mr. Senator, for your support.

[The prepared statement of Mr. Thornton follows:]

PREPARED STATEMENT OF RICARDO THORNTON

Good afternoon Mr. Chairman and members of the committee. My name is Ricardo Thornton. My wife Donna and I are both are here to testify on where we've been. We're here to talk about the past, the present, and the future.

We both lived in institutions all our lives. I lived in DC Village, then I moved to Forest Haven. At the institutions, you had good staff, and you had bad staff. People working with us didn't know the type of services that we really needed. Being in an institution felt like I was doing time for a crime I didn't commit. We hoped one day we'd get out of the system and be like everybody else.

At Forest Haven you didn't control your own money, so if you got paid for a job, you had to turn in your money. We tried to cash our check once. The punishment was, if you cash your check, you don't get your allowance.

One of the things I learned down at the institution was I had a brother and a sister. They were there waiting for me. I was a little hesitant because I didn't know my family then. But then I got to meet them. My brother was always withdrawing from me because he didn't know who I was at the time. My sister was always happy because she knew she had a brother now who would look out for her. My sister passed away at the institution at one of the cottages. They said it was a heart attack, but I know it was something else. I think more likely she died of an overdose of medicine. To control her they would keep her drugged like a zombie. When that happened, I told myself I would advocate for change, so hopefully no one would have to live in an institution.

Moving into the community was a challenge. It's an adjustment. The rules were still with us. We thought we would be more independent, but group homes have their own style. At some group homes, you didn't have choices. Now, we have choices.

After I left the institution I was appointed by the Mayor to serve on the de-institutionalization board. The board served to monitor group homes in the community and make sure everyone was safe. We were not satisfied until everyone in an institution had moved out safely.

My wife and I both work within our community. I work at the Martin Luther King Library. November will be my 36 years. We used to live in our apartment. We now live in a new home. We have walk-in supervision. You don't have anybody standing over you saying "do this, do that." You're pretty much independent.

I serve on the DD council board, the State planning council. I'm the vice chair of that board. I also served on the Mayor's committee and I'm active on Project ACTION! Self-Advocacy and a number of coalitions. I'm also very active in Special Olympics. I had a chance to go to South Africa and be part of the leadership training over there. It was very educational for me.

We have one son, and when he was born there were questions about us, can we really be good parents to him. They said, "Maybe you may want to think about putting him up for adoption." And we had to convince and show them, with the support we had. We put him in Head Start, and after that he went on to school. He graduated from Calvin Coolidge High School in 2000. The trick was that we worked with his teachers. We asked for extra help in finding out what does he need to do. We had to show the people that said it couldn't be done, that it can be done. We're like any other parent—whatever we can do to help him, we do it.

Today he's now 26. He has his own family. He's married with kids. They're happy. I have two pictures I want to show you. This picture was taken in 1984 when we went and got married. The odds were against us. We did it anyway. And in the next picture, we have the whole family. This is us and our grand kids. So that's the future.

Where do we go from here, Mr. Chairman? We'd like to see more people living more independent lives in the community. Transitioning from school to work is getting better, but we still need a little more work. People with intellectual disabilities graduating from high school today, if they cannot think of what it is that they would like to do, their career choice, maybe give them some assistance and some ideas.

I also want to talk about RSA rehabilitation services. Many are being promised jobs and some are getting them and some for some reason are not. There seems to be a big block that sits and I wonder if it can be moved so that many people who come through their doors can have the opportunity. Many people say they want to work and they're still waiting. Maybe we can come up with some kind of solution.

Let's not look back at the institution as an answer. Let's look forward to the future.

Thank you Mr. Chair for letting us speak here today, and we look forward to answering any questions.

The CHAIRMAN. You're all just fantastic. Thank you very much. I was blown away by Ricardo a few years ago when he first testified, and I'm blown away again. You tell a very compelling story and a compelling life story, and you've paved the way for a lot of other people, too. Both of you have. You've been married 30 years now?

Mr. THORNTON. Yes. We're having our anniversary June the 3d—it will be 30 years.

The CHAIRMAN. Congratulations.

[Applause.]

That's fantastic.

I don't know why we've taken so long to get to this point. Perhaps a lot of us thought after ADA and after Olmstead, things would just happen. But a lot of times, things don't just happen.

You talked about this, Dr. Justesen, that these old laws continue on, and in the new age, they've got to change with this. I think a lot of things also—you're talking about jobs. You can't imagine the number of jobs that are now open for people with all kinds of disabilities, intellectual disabilities, physical disabilities, maybe both, that were never there before because of technology, which we didn't have in those days.

Some of the new technologies are fantastic in terms of the small amount of support that someone might need to do a job. Transportation—we've got that pretty much worked out. But now, seeing the technology, we have to get people out of institutions into their own settings where they can take more control of their lives. There's a lot of technology that helps do that, too. We just didn't have that in the old days when we passed those laws. So these laws have got to be changed to be adaptable for the present situations.

The other thing that's been frustrating to me is, as Senator Alexander said, that we know it's cheaper, and people have got the data to show that. For example, a person in an institution may be covered with all kinds of services and stuff which he or she may not need. They may just need one or two, but they get all of this other stuff that they don't need. So why not let them live in the community and get the one or two support services they need without spending money for all that other stuff.

Hopefully, we can start to make these changes in our Medicaid laws that we talked about. But I'm hoping that a lot of these stereotypes start breaking down.

Ricardo, you said that sometimes the staff are good and sometimes they're bad in these institutions, and they don't have much training. So how about when you're on your own and you're out living in the community—I ask that of everybody here—how do you decide who's good staff? I mean, how do you know if you've got someone that's good? I mean, are you able to control that and make sure you get someone with good training? That's just a question I have.

Mr. THORNTON. I know with us, we're in a program called Community Multi-services, where we have walk-in supervision. And with the walk-in supervision, we have choices now. They don't just come in an watch over. They actually give us a chance to ask questions and things on what we would like.

The CHAIRMAN. It's like an interview.

Mr. THORNTON. So it's like—yes. It's more like a relief. Right, Donna?

Ms. THORNTON. It's a relief. It's very good, you know. You can talk up for yourself, or if you see something wrong, you can ask questions.

The CHAIRMAN. Ms. Robertson-Dabrowski.

Ms. ROBERTSON-DABROWSKI. Through the services and receiving them in your home, you have a choice. You can hire your own attendant or go through an agency model.

The CHAIRMAN. I'm sorry. Say that again.

Ms. ROBERTSON-DABROWSKI. I said you can hire your own attendant or go through an agency model. If it's an agency model, then the agency is responsible for doing the training. If you hire your own person, then you're responsible for doing the training. And, again, it is a choice. If one person doesn't work out, you go to the next. People are people.

The CHAIRMAN. Is there any one better than the other? I suppose both have pluses.

Ms. ROBERTSON-DABROWSKI. Under the agency model, there's a lot of restrictions. They're not able to do certain things. If you hire your own attendant, that attendant is required to assist you with what you need.

The CHAIRMAN. Ms. Godwin.

Ms. GODWIN. Maybe a hybrid of that. Our organization supports people in a couple of different ways through the funding, so there may be some different rules. However, one of them is an opportunity for you to be the employer of record as a person receiving services. The other is you're not, and we would be the employer of record. However, the hiring always starts with the person.

We do a very specific hiring plan with the individual to match interests, character. Skills and training is actually the last thing that we match. CPR and first aid and medication training is not as important, although necessary, as it is to match personality and interests for people.

People are involved in making advertisements to place in papers or wherever they choose to post. All of their screening, interviewing, hiring, and managing the staff is through evaluation.

The CHAIRMAN. One thing I keep thinking about is that as we, hopefully, get deinstitutionalization and people in communities, I want to make sure that people who are providing supports and services are qualified, and that you, the people who are living in the community with disabilities, have the final say, not somebody else saying, "No, you've got to take this person or that person." There's just simple things like personality conflicts, for crying out loud, that can happen, you know, just things like that.

That's one thing that just keeps nagging at me, how we make sure that they're qualified, they're trained to fit the individual's needs. One person's disability is not another person's. One person's need is not another person's. So whoever is providing that support and those services needs to understand that person and their needs, which may be different than somebody else's.

I'll just ask this. Do we have enough different agencies out there that are training people that can fill this kind of a pipeline? I assume there are private agencies out there and non-governmental perhaps. I don't know—church groups.

Mr. SMITH. Just going off my own experience, when I was younger, the waiting list for a worker can sometimes be incredibly daunting. So that's why we had to go to a family member, because we could get a worker much quicker through that process by having my sister trained to do respite, as opposed to getting a respite worker through an agency.

Of course, that carries with it certain problems, in that the burden sometimes can be placed on the family to the degree that, as somebody with a disability, I wouldn't choose. It's more difficult to have self-directed care sometimes. As wonderful as that care may be, there's a certain level of independence and dignity that comes with getting care from somebody outside of your own family and somebody you've chosen. And, unfortunately, that option isn't always as readily available as a family option.

The CHAIRMAN. I think that's another thing. I think that there's this thought that, "Well, if someone was not in an institution and they were at home, their family is taking care of them. Don't bother that. Just let it be."

That sounds nice until you realize that a lot of times, these family members have to do other jobs and work, too, and they've got to make a living. But they do it because it's family, and you do that. I cherish that. But I don't know that that's the answer, because, like I said, they have their own individual lives. They may have to get out and work, too.

I'm taking all the time here.

Senator Alexander.

Senator ALEXANDER. We have different hearings here, and I have to go to another one. But I just wanted to say before I leave how much I appreciated what each of you had to say and how really human it is to me to hear you say it personally.

Mr. Justesen, I would be interested if you would like to send Senator Harkin and me after the hearing any suggestions you have, or any of you have, specifically, for how we can relieve Medicaid's bias toward institutions and what steps we could take. You mentioned changes in the law. What steps should we take in the law to do that? I would welcome that, particularly based upon your study of it.

The CHAIRMAN. Dr. Justesen, to followup on that, you talked about the rebalancing of long-term services and support funding ratio in favor of home- and community-based services. I got that. But are there other changes in other Federal statutes that would further support provisions of these types of community-based services for people with disabilities? Is there something I'm not seeing? Is there something else that we should be looking at? I always worry that sometimes we get focused on one thing, and there's other things out there that we may not see.

Mr. JUSTESEN. Your staff behind you have worked with me for years. So they're all about to panic because they know a Troyism is coming out. I'm going to offer a few thoughts that are completely in a different direction but I think have contributions to make that fundamentally improve the lives of people with disabilities.

The majority of people with significant disabilities receive social security disability insurance, and they want to go back to work. They're afraid of going back to work because they will lose their Medicaid. They need that support. The substantial gainful employment amount of money that a person can make each month right now is $1,070. If a person were blind, their deduction is $1,800 a month.

It is interesting that we make a distinction in that area. In other words, if I were a person receiving social security disability insurance, and I had the extra $630 a month, that would make a substantial difference. That doesn't sound like a lot of money. But that makes a substantial difference in the opportunity to be even more independent and retain the basic foundation of Medicaid.

I'm only speaking in my opinion, Senator, and only in my experience, which is not—it's just limited. But the opportunity to have that little bit of extra income for people with physical and intellectual disabilities, the same as people who happen to be blind, would make a substantial difference in the lives of many people that I know who have physical and intellectual disabilities.

Let me follow the line again and suggest this. A standard deduction on taxes for one group of individuals with a particular type of disability, I think, is about $1,450. I could be wrong, but it's something like that. For all other groups of people with disabilities, there is no standard deduction available. That would make—that's $1,400.

But that means—I can tell you, Senator, in at least three cases I know of in a very small town in your State, by the way, would be a month's worth of attendant services for someone to be out of an institution. Add that to an extra $600 and something a month, and that would create the independence of many people with disabilities while they could maintain their current Medicaid coverage.

The CHAIRMAN. You're right. I knew about the $1,070. I didn't know about that difference, and I didn't know about the standard deduction. Thanks for bringing that to my attention. I didn't know that. I learn something new at these things.

Yes, Donna?

Ms. THORNTON. Yes, Mr. Chairman.

The CHAIRMAN. Can you pull the mic in? My hearing is not the best right now.

Ms. THORNTON. Mr. Chairman, I have a question. I would like to ask you a question. Forest Haven is not the only one that closed. I would like to have—I know it's up to the parents or it's up to the judge.

I would like for them to close the institutions, and if people want to, they have their own choice. This is what I'd like to have. I would like to have them to go out into the community just like us and start on their way. Whatever they want, I would like to have that, to close all of them.

The CHAIRMAN. Your question probably is why aren't we closing them down. And that's a good question.

It's still an attitudinal thing about institutions. It's attitudes that people have, and it's hard to change those attitudes. I think someone said it in their testimony about how people first of all—it's like anything. What you're not used to and what you're not around, maybe you get afraid of.

I can't tell you how many people back in the early 1980s when IDEA was first getting—and late 1970s—it was called the Education of all Handicapped Children Act at that time. I remember when my daughter was in school, public school, at that time, and the first time a young child with a disability was brought into the classroom, a lot of parents got upset about that. This was something they'd never confronted before.

The kids didn't seem to much to give a darn one way or the other. They were fine. It was the parents. But, you know, as time went on, and more kids with disabilities came into the classroom, and kids started associating with them, that breaks down.

I think the same is true in communities. A lot of people just think, "Well, you know"—I mean, you've been through this. Every one of you have been through it. People say, "Well, you're not capable of doing this. You can't do this. We have to take care of you." It's that old attitude.

A lot of that has got to be broken down. But you can't just wait for those attitudes to change. Laws that we do change attitudes. ADA started changing attitudes of people and how they looked at it. IDEA, when kids—grownups today—Emmanuel's age, his age, young people today that came through the ADA generation—they go to work. It doesn't bother them to work next to someone with a disability, because that's who they grew up with.

Perhaps some of the people who haven't had that experience, and they—"I don't want them in my community. Keep them in institutions," and stuff. But I think to the maximum extent that we can change this bias, this bias that we have, and show people that with just sometimes modest supports and services, people live in our communities with their friends. They go to block parties when they have the block parties with their neighbors. It makes for a nice community.

Who was it that said that? Integration is an American ideal. Oh, you said that. Yes, it is, integration of all people, not just racial integration, but age integration, religious integration, national origin integration, people with disabilities integration. That's sort of the American ideal.

Ricardo.

Mr. THORNTON. What I just basically want to say is I found out when coming into the community, one of the things I decided to do was I went to a town hall meeting. I had some people that were in my group home, and we all sat in on a town hall meeting. They had no idea that we were the ones they were talking about.

We were telling our story, that we work—the same story I told here today. I work at the library, and I'm happy with where I work. I'm happy to get a job, and I'm excited about what I have accomplished, and I live right here next door. They didn't have no idea that we were coming to this meeting.

The meeting was about us, about our trash being put outside. But we wanted to—what I found out, Mr. Chair, was I think a lot of stories, success stories, are a big part of changing a lot of those concepts of those trying to come out of institutions.

It takes some of the stories of people who have been very successful and how you have a Senator who sits here and works very patiently and comes up with wonderful ideas on solutions to resolve some of the problems, like you and Ted Kennedy used to do, and a lot of things like that. I think those are the things we need—more of that.

The CHAIRMAN. You just mentioned something I also want to bring up to all of you. Maybe I'll start with Emmanuel here. There is a saying. It's a statement made by some disability groups. I forget which ones. It says, "Nothing about us without us." You've heard that, right?

Mr. THORNTON. Yes.

The CHAIRMAN. You just touched on something very important. Why is it so important for policymakers, like us here or in State government or other places, when they start making decisions and policies about people with disabilities—why is it important to have people with disabilities in on the meetings?

Mr. THORNTON. I agree.

Mr. SMITH. With me, agency is everything. Obviously, by virtue of my disability, I have to put my well-being and sometimes my dignity in the hands of other people for them to care for. If I have to do that, I want to be sure that I'm involved in that process of deciding who gets stewardship over things that are important to me.

Whether it's a discussion on a national level, or whether it's being involved in the IP process, or whether it's being involved in the community integration process, when you include people with disabilities, you're affording them the ability to safeguard their dignity and their safety, more than anything else, for me.

Olmstead makes me less afraid to pursue the kinds of things that you're looking for the ADA generation to move toward, like employment and living independently. Having that safeguard is incredibly important and having a role in a discussion makes me feel more secure as well.

The CHAIRMAN. Yes, Ms. Godwin?

Ms. GODWIN. When "nothing about me without me" is your mode of operation, people don't say, "I want an institution or a nursing home or a group home or a day program." They say, "I want a life that looks like any of the lives that we may have." When a provider listens to that, if a provider is chosen to provide those services, we have an obligation because we've asked, "What do you want?" to make it look as close to that as possible.

That changes the nature of our service provision. It's very intense. It's very intentional. We don't look at things as supported employment, as residential. I use the word, service types, for a reason. Back in my testimony, it is not the kind of service we provide, but it is the mode in which we provide it in terms of funding. We organize it so it works. But when someone comes to you, and you continue to plan like that, and you're accountable to people, because it is nothing about them without them, you have to answer in a way that looks like what they've asked for.

The CHAIRMAN. You mentioned in your testimony—and I think someone else mentioned it—maybe Ricardo did, too—about how in institutions, you have to meet certain standards of behavior or acquire particular skills, sort of like if you don't do that, then there's no hope you can live in a community or something like that. But how do you learn new skills if you're in an institution and people are not providing you the kind of education and support and training you need to get those new skills? It seems like you're just trapped.

One thing I've thought about is that if people go out of institutions and live in the community, there are other things I think we're going to have to be focusing on in terms of job training, skills upgrading. I think maybe Senator Alexander mentioned—I think tomorrow, we actually may pass on the Senate floor a Workforce Investment Act reauthorization. It hasn't happened since 2003. We've been working on it for 5 years.

We finally got it together, and the one part that I've worked on is upgrading the rehab act to provide for the kind of training and skills upgrading for people with disabilities when they're young so they don't get trapped in those kinds of situations, and to make sure that competitive, integrated employment is what's expected of young people with disabilities. You're expected not to go into subminimum wage, but you're expected to try and work and get competitive employment. That should be the first option. It shouldn't be the last option after years and years and years.

Hopefully, we'll get this passed. It'll take a while to start getting it implemented, I understand that. But I guess my question would be—and I guess maybe I'm answering my own question. Which is better for skills upgrading and getting people the kind of training and stuff they need, institution or non-institution?

Ms. GODWIN. Non-institution.

The CHAIRMAN. Probably, obviously, on its face, I suppose, not in an institution. Is that right? They would have better access to programs out there for training and skills upgrading. Maybe there's some more things we have to do.

Troy.

Mr. JUSTESEN. I think the way I would answer your question is which institution? The same institution that the nondisabled kids go to—an elementary school. The same institution that the nondisabled teenagers go to—high school. The regular colleges and technical and community colleges—should be the same places that people with disabilities go to.

Institutions are good. They've been good, historically. They work. A lot of them need to go away now. And the way in which we talk about institutional options should be the same options that people without disabilities go to—colleges, training programs, whatever else. Those are the types of ways I think we need to think about, how we give opportunities for people with disabilities.

The other thing I think is important to kind of emphasize about making policy without me is that—and you know this. But you're looking at a group of people who live the most regulated lives in America. We are regulated about what time we get up in the morning; about how much we can make; about where we can live; about where we can go to school, any kind of school; about whether we have the independence to do anything. We are regulated more than anyone else in this room, more than anyone else within miles of the regulation generation institutions of this country.

The problem for us is that we have learned from the history of how the country treats different classes of people, and we now need to be represented at all levels. We are not represented in the face of society in the ways that other groups have been able to achieve. We will achieve that, but it needs to start happening more frequently now. The leaders of many of our organizations don't reflect us. The policymakers don't reflect us. The leaders of our learning institutions don't reflect us. That will take some time.

Until then, one thought to leave with you is that the idea about more programs or more ways to help might not be the best way for everyone to move in that direction unless we are part of that decisionmaking, or else we will just be over-regulated even further. And we're so regulated that I think for some of us—I'm one of them—it depends on whether I go to church, how I pay my taxes, how I'm audited, what I eat, who I live with, what I learn, what TV I watch.

I'd just leave that word of caution, that more might be more without being an improvement. We're so regulated, I don't know how I'm going to manage another regulation dictating my life.

The CHAIRMAN. That's very good. I've never heard it put that way before.

Ms. Godwin and then Ricardo.

Ms. Godwin, go ahead.

Ms. GODWIN. Are you sure?

The CHAIRMAN. Sure. Go ahead.

Ms. GODWIN. Part of what I mentioned before also was about best practice in programming, and I did not just mean that in facilities. I absolutely meant that in the communities. So to echo that, more programming and best practices does not mean better quality. It means more programs and more rules.

To just watch our investments in the community-based programming that we talk about and listen to what people want versus the services we're very typically providing, because those are programs based on best practices.

The CHAIRMAN. Very good.

Ricardo.

Mr. THORNTON. I just want to say that—there are actually two. I just want to say the Medicaid waiver I was thinking about earlier—I know in the DDS here in the district, we have a Medicaid waiver when we had Judy, who brought in Laura Nuss who created this amazing program—how the Medicaid waiver is getting a lot of people out of group homes and more into community independent settings, which is really amazing.

They have the personal setting where—that's where we're heading to, the personal setting. But I just wanted to say how the Medicaid is really—the waiver is really working. The other thing is institutions. If you're trying to find a solution to put people—how you say that—if you're trying to find a place to put people that you are fed up with, that the system is fed up with, to hide them, it's an institution.

There are a lot of institutions, but you have to break it down to what institutions you are actually talking about. If you're talking about a community institution—but the institution I'm talking about is an institution where we store people and treat them like they are lost, and they are not. They have gifts. They have a lot they want to bring out. The question is who's going to bring it out of them. When they come into a community, we need to continue to open the doors and continue to advocate for that kind of change.

That's basically what I'm saying. We have two different types of—when you're talking about institutions, like the Howard University. That's an institution. They're going to college. But we're talking about warehouses. We're talking about somewhere where we don't want people to go. We want to see them come out and live in the future and be part of a community and be successful. That's what I would love to see.

The CHAIRMAN. I guess when I use that word, institution, my mind is thinking nursing homes, that type of institution. I wasn't thinking about colleges and things like that.

Mr. THORNTON. Oh, OK.

The CHAIRMAN. But I understand. I mean, you're right. There are good institutions out there that do good things. I was just thinking about it in terms of the institutional structure of people with disabilities going in nursing homes. That's what I was talking about. So I didn't make myself clear.

One thing I want to bring up is that some people say that the most severely disabled cannot be served through a program like this. So is person-centered planning only for certain people with disabilities, or is it for everyone? How do you create a person-centered program for someone who has severe intellectual disabilities or multiple disabilities or limited speech, complex access needs?

Do we need to start delineating—not delineating—separating people out because of their disabilities? How about people with complex disabilities? Are they better off in the community than they are in a nursing home institution?

Ms. Godwin, you've dealt with that.

Ms. GODWIN. Way back when, maybe another half a century, kind of like that—I don't know if that's how old everyone is. But person-centered planning came about because of people that you described that lived in institutions. We've heard of people that had severe reputations—some of the lingo and language that's used around person-centered planning and action and practice.

It was created so that a better life could be defined on paper and then implemented for people that had the most significant behavioral issues—and we're using that terminology that we may understand but may not want to use—that have very fragile medical needs, that have very severe and profound intellectual disabilities. It is primarily for those people that person-centered planning came about.

It is absolutely—we have the opportunity to work on a grant through our DD council and through our DD administration that helped people leave institutions in Maryland. We had our Rosewood closure and then another closure soon after that. We used person-centered planning for everyone involved in the project. The idea was to break down barriers with community providers and primarily families that were opposed to this.

Through that process, everyone learns. It's an intense process, and I think one of the reasons it may be a barrier to our service system is the time that it takes to do really good person-centered planning and then actually implementing the plan so you can have the plan. And we see that perversion all of the time, like I have a person-centered plan, but I have no provider or anyone that's able to implement it and really get the supports and services in place for people that you've described and provide that service outside of a facility.

We have that experience with people with all of those labels leaving institutions and nursing homes, living in places that they choose, or if they haven't chosen it, we know that it's the right thing to do based on how we know the person and how they're living in that situation from their end. So really the implementing of the plan is where I think we fall very short.

The CHAIRMAN. I'm sorry. Yes?

Ms. ROBERTSON-DABROWSKI. Yes, Senator Harkin. I just wanted to go back to where you were talking about nothing without us. In part of our job as being a transition coordinator, in having discharge meetings, a lot of times we run across nursing homes that do not want to have the consumers involved. And part of our job as a support group—we will not have a meeting without the person at the table. We cannot make that type of decisions for those types of consumers.

For consumers with all types of disabilities, we have transitioned consumers who cannot speak, consumers who cannot see, consumers with visual impairments. We have done that with transitioning. With the support and technology out there, people are living out in the community. They have that choice.

Again, we go against nursing homes who feel that,

> "OK. How is this person going to live out in the community if they can't speak? How are they going to contact someone if their attendants are not showing up?"

There are communication supports in place for those types of things like that. So we work with people with all types of disabilities.

The CHAIRMAN. Can I followup on that? You, yourself, were institutionalized.

Ms. ROBERTSON-DABROWSKI. Yes.

The CHAIRMAN. You had to break free of that, and I'm sure there were people who told you that you can't do this and you can't do that. How do you overcome—I mean, that's just got to kind of grind on you after a while.

Ms. ROBERTSON-DABROWSKI. It does. It does. And what keeps me going is knowing that I've done it, and that's why I continue to help other people. With the support and family and with the services from Liberty Resources, like having an attendant, someone to come in to assist me, having the support to go out for—what you said about the skills, to learn how to be independent.

At Liberty Resources, we do provide different kinds of skills training to get people back into the community, help them with budgeting, help them with cooking, help them with managing their own attendants. So I was able to move out with the services through the State funds. But now we have waivers which allow someone to live out in the community. Instead of the funding going to the nursing home, the funding is out in the community.

The CHAIRMAN. I just want to ask one little question about housing.

Ms. ROBERTSON-DABROWSKI. That's a big barrier.

The CHAIRMAN. Tell me about housing. I mean, are there still subtle kinds of barriers to people with disabilities getting housing, like if you show up with someone who's disabled, all of a sudden, it's already been rented, or it's already been leased, or that kind of thing, you know, again, the old kind of racial stereotypes. Oh, yes, the house is for rent until an African-American showed up, and all of a sudden it got rented—that kind of stuff. We used to have all that—still do have some of it. But does that happen with people with disabilities?

Ms. ROBERTSON-DABROWSKI. I'm sure it's still out there. I mean, our biggest barrier is just finding subsidized housing that someone can afford to pay the rent, because the majority of our consumers are on social security. So they need subsidized housing.

The CHAIRMAN. Right. Is there enough of that?

Ms. ROBERTSON-DABROWSKI. No, there's not.

The CHAIRMAN. That's obviously right. They do need subsidized housing.

Ms. ROBERTSON-DABROWSKI. So that's one of our biggest barriers.

The CHAIRMAN. And not only subsidized, but subsidized accessible housing.

Ms. ROBERTSON-DABROWSKI. Exactly.

The CHAIRMAN. So that's still a problem.

Ms. ROBERTSON-DABROWSKI. Yes.

The CHAIRMAN. Ricardo.

Mr. THORNTON. I just wanted to say that my wife and I—like I said in my testimony, I spoke about us living in a home. We have a house that we're living in, and it's through DDS and through Community Multi-services and us. It's a partnership to see whether or not we can maintain it and establish—we do pay subsidized toward that. The government takes care of half. But the provider oversees it to make sure that everything in it is running. It's something that they're trying to see if it works.

One of the things we had when we first moved there was neighbors. We have some wonderful neighbors, and we have some that just wonder, "What are they doing over in that yard?" We have to let them know that we're here and it's not a problem and we love you—just try to keep that happiness.

But I think that affordable housing—it would be nice to see more of that, leaving group homes and going into—I would like to see more of it. It works, but I can't wait to see the end when I get back—was it a 2-year project or a 3-year project?

Ms. THORNTON. A 3-year—3 or 4 years.

Mr. THORNTON. But what I'm basically saying—I was asking her was it a 2-year—that lease thing that we have a process with. But more of them started, and I think it's working. I'd like to see more of that type of establishment, because a lot of them who are moving into apartments are still going through a lot of conflicts with something not working or because they're there. We need to improve—or we'll take care of this—we'll do this side but we won't touch that side until they leave or whatever.

Some of that is still there, and it still needs to be cleaned up, because we want to make sure that people have, as you said—that they can live in dignity, they're proud of what they have, and they have confidence in where they're living. Through advocacy, I think it can change and get better. But I would love to see more affordable housing for people with intellectual disabilities.

The CHAIRMAN. I think that's something, again, that we need to pay more attention to, affordable subsidized housing.

Mr. THORNTON. Yes.

The CHAIRMAN. Job training, skills upgrading, high schools, and then this.

Oh, I'm sorry, Ms. Godwin. I didn't mean to cut you off. Go ahead.

Ms. GODWIN. You didn't cut me off, yet. You probably just said it, that when we're thinking about housing for people, the expectation of employment for people that may not have had that opportunity—so people are paying rent, and we do need subsidized housing. But we're also helping people have jobs so they can afford to live.

The CHAIRMAN. Right, exactly, and pay taxes.

Ms. GODWIN. Yes.

The CHAIRMAN. This has been a great panel. I just have one last question, because we're talking about the Olmstead decision. I've got three things. First, are people with disabilities—are their lives better because of Olmstead?

Second, what I'd like to ask is, have you taken a look at the legislation we put in today, and if you see some blind spots that we didn't look at, let us know. I intend to push it hard. That's, taking away that Medicaid bias.

The third thing—is there something I didn't ask or get into that you would like to put on the table before we adjourn? So let me just ask this. Are people's lives better because of Olmstead?

Emmanuel.

Mr. SMITH. I'm a little biased in that I didn't have to grow up in a world without the ADA and largely without Olmstead, and much of my early life has been shaped by that. I have memories of going to the movie theater with my friends, you know, the midnight premiere. That's a product of the ADA and Olmstead. The incredible satisfaction I get and my family and the pride my family has in me being able to live independently—that's a product of that decision.

It would be impossible for me to forget the transformative effect it's had on the entire generation of young people. We're certainly appropriately named, when you call us the ADA generation, because it has shaped every area of our lives, and I hope that Olmstead continues to move things toward an integrated approach.

The CHAIRMAN. Dr. Justesen, are people's lives better because of Olmstead?

Mr. JUSTESEN. Yes, and here's why. Olmstead was a decision that said the ADA is constitutional, and that was absolutely critical.

The CHAIRMAN. Interesting.

Mr. JUSTESEN. And it said this with respect to institutional living. It said the State and the Federal public policy and dollars cannot be solely exclusively used for institutional models of living. That's what it said, to the extent it was reasonable for the State to make modifications in its policies, practices, and procedures. That's essentially what it said.

It didn't say close institutions. It didn't say they are better or worse than home- and community-based living. It said those dollars need to be moved if the person can and wants to live in the community. That established and is the only time—well, I'm not a lawyer, but that was the first time, in 1999, the court basically said, "We've reviewed this statute, and the powers of the Senate and the Congress made this law a civil right across this land."

In terms of public policy, I think this is where you are, Senator. You have that basis from the Supreme Court, and you passed the ADA. You have all the tools you need for the American people to say, "We don't want our public dollars to be spent disproportionately in favor of institutions." At least fund them equally, them being home- and community-based services, at least equally funded to institutional level funding. That's where we are.

You could argue whether we want to spend more money for home- and community-based services. In 20 years, we will be. That's maybe legislation down the road. But at least today, are we not finally at the place where we should say, "Money, every dollar, fifty-fifty?" At least that. At least treat it equally. That could be—I don't know—maybe the most important thing you could do.

The CHAIRMAN. The one thing that I've found that resonates with people—conservatives, liberals, whatever—is that shouldn't the money follow the person? I mean, why should someone here decide—if you're going to have the dollars go out—whoever is benefiting from that or whoever is getting that benefit, shouldn't they have some say-so on that rather than just a bureaucrat?

Mr. JUSTESEN. I used to be a bureaucrat, so they're not all bad people.

The CHAIRMAN. No, they're OK.

Mr. JUSTESEN. But I will tell you this. What you're arguing, I think, is whether people fundamentally believe all people are equal and people with disabilities are equal. I don't know if I'm that good of a philosopher to go that far. The only thing I can say is even if you don't believe that, it's still half as expensive.

The CHAIRMAN. That's true.

Mr. JUSTESEN. It still will save you half your tax dollars. Whether it's OMB or CBO, it's still a lot of money that's saved somewhere. You can give it back to the people, or you can spend it on something else. I don't know.

The CHAIRMAN. Ms. Robertson-Dabrowski, I guess what I'm saying is people's lives—you come in contact with them. Are they better because of Olmstead?

Mr. ROBERTSON-DABROWSKI. Yes, they are better, but I still want to see that the nursing homes—you can go into a nursing home in 24 hours. If you want to get out of a nursing home, it may take 24 years. I want to see the same going in as in coming out.

A lot of people end up in nursing homes because maybe their sugar got high, and they had a home before they went in the nursing home. Unfortunately, when they went into the nursing home, they didn't have funding to continue to pay their rent for their apartment. They lose their apartment at the blink of an eye. So if there's some kind of funding to help people who do have housing to secure that housing while they're in the nursing home for rehab so they don't lose their homes.

The CHAIRMAN. Right. Right. These are the fixes that need to be made.

Ms. Godwin, I'm just going to ask that general question. Are people's lives better in different facets of this?

Ms. GODWIN. I think yes, because people are leaving and avoiding institutional living. I don't think it has pushed the community services provision system enough to do better. And all of us would like not to see the nursing homes and institutions as a gateway to services. But I think we did cover that.

The CHAIRMAN. In other words, that's the way you get services—the gateway.

Ricardo, you and Donna—were you pre-Olmstead? You got out—yes, you've been working there for 30 years. So you sort of got out of the nursing home and Forest Haven.

Mr. THORNTON. I never lived in the nursing home. I lived in a group home.

The CHAIRMAN. Oh, that was Forest Haven.

Mr. THORNTON. Yes.

The CHAIRMAN. You left there, but you've been out of there long before Olmstead, though. Yes, sure.

Mr. THORNTON. Probably, yes, because I came out in 1978.

The CHAIRMAN. Yes. So you're way ahead of the curve.

Mr. THORNTON. But I can tell you Olmstead works. A lot of friends I have that are working and are happy—they feel—you can see the smiles on their face that they have a place to go to, and they feel good about themselves, that they are contributing. So I think it is working. It's very good.

The CHAIRMAN. Is there anything that any of you have on your mind, and you thought, "I just wanted to get this out, and Harkin never asked it?"

Mr. THORNTON. I'll tell you what I have a problem with. I have a question for you. Even though we're now—even though institutions are closing, we have a lot of youth who are going to wind up in correction centers and looking at institutions as a solution, and I don't think they should look at that as a solution.

I've been quiet on it, but I think they need to look at another solution and not look at that as going back. As I said, we must continue to move forward. But there's a lot of youth that's looking at—wanting them in institution settings, and they shouldn't be doing that. That's just something I'm concerned about, hoping that we don't go that route.

The CHAIRMAN. You're not talking about necessarily kids with what we might recognize as disabilities. You're talking about——

Mr. THORNTON. I'm talking about kids that are—no, kids without disabilities, right. They'll wind up in receiving home inclusions, which I'm hoping we don't look at that as putting them in institutions.

The CHAIRMAN. Like juvenile homes or juvenile detention. A lot of them are——

Mr. THORNTON. Yes, because at Forest Haven—we had Forest Haven, we had Maple Glen, and we had Oak Hill, which is now a youth center. We had Cedar Knoll. So you had a lot of youth centers around, and I'm hoping that we don't look at that model and create more institutions in that type of model.

The CHAIRMAN. Good point. Anything else that——

Dr. Justesen.

Mr. JUSTESEN. I just won't be able to sleep if I don't say this. Perhaps I read something that I shouldn't have read, but I don't care. Yes, discrimination against people with disabilities still exists. And if I want to rent an apartment, I'm going to have one of my able-bodied friends go rent it for me first.

It still exists. It exists in employment. It exists in housing. It exists in State and local government services and public accommodations. It still exists, and I think that needs to be said clearly. That is why we're still grappling with these issues. But it does exist.

The CHAIRMAN. Yes, I'm aware of that. I know it does.

Mr. JUSTESEN. You just wanted someone to say it, so I'll say it.

The CHAIRMAN. I'm glad you did, because it is there. We can't sweep it under the rug. It's there. I guess we just keep trying to push the boundaries. I guess things are better than they were—we have a long way to go. But we're finding some enlightened employers now around the country that figured out and found out that people with disabilities can be some of their most productive workers.

I always tell the story of my brother, Frank. Bear with me. So he's deaf. He grew up deaf, went to a deaf school, all that kind of stuff. And they told him he could only be three things when he was at deaf school. He could be a baker, a shoe cobbler, or a printer's assistant. He didn't want to do any of that stuff.

They said, "OK, we're going to make you a baker." They made him a baker, so he became a baker. He never quite liked it. He was pretty good at it, but he didn't like it. That's not what he wanted to do. He got hired when he was in his 30s by a man that had a manufacturing plant in Des Moines who used to come into the bake shop and see him, and Frank, my brother, would teach him some signs. They kind of struck up a friendship.

This guy employed about 150 to 200 people in a manufacturing plant. They made jet engine nozzles, and it was a big machine shop kind of place. So he hired Frank, my brother, and taught him—he had someone teach him how to run these really intricate drilling machines and all that kind of stuff that's done by robots today—but at that time—so he taught him how to do that.

After a few months, the foreman on that line in that shop found out that Frank, my brother, was the most productive worker on the line—never made a mistake, always there. Finally, it dawned on him. This was a very noisy place. The noise didn't bother him one bit. He just kept right on working. So he went out and hired more deaf people. He figured they were his best workers. My brother worked there for 23 years, and he only missed about 3 days of work in 23 years.

More and more people are finding out that—a couple of years ago, I was privileged to go up to Connecticut to a Walgreen's distribution center. Greg Wasson, who is the CEO of Walgreen's, and Randy Lewis—sorry, I lost that name, but Randy Lewis. So we went up there, and he had a meeting. He called together a bunch of CEOs and others of big companies. Best Buy was there and FedEx and Proctor and Gamble and a bunch of others, and I was there.

He has this distribution center. It's one of the largest in the country. It's up near Hartford, CT. So over a small breakfast before we started the day, he announced that he was going to take us through and show us his facility. He said, "You know, you're going to be surprised, but about half of my people, about 50 percent of the people that work here, are disabled." Not 10 percent, not 5 percent, but 50 percent.

He said, "I want you to know also that I'm not doing this out of the goodness of my heart." He said, "This is one of my most productive distribution centers per man hour worked with less mistakes."

And he said, "And when you go through, sometimes you'll see people you'll recognize that are disabled and other people are not."

They're working all together there with minor changes in how they did their jobs—visual cues rather than perhaps voice cues, different things that they did that also made it easier for people without disabilities to do their job, interestingly enough—that universal design concept. And he was right. You go through there, and you see some people are disabled. Some people had physical disabilities. Other people had intellectual disabilities, things like that, maybe both.

It was an amazing thing to see. And he did it because he's making the company money, and the people working there are making money, and they have good jobs, and they have good lives. So it just takes people like Greg Wasson, people like that, that are breaking down these barriers, and it's starting. I mean, it's growing. It's growing. I think Mr. Wasson has also announced that in Walgreen's, they have a goal now that 10 percent of all their employees will be disabled in their stores all around the country, not just for distribution centers. So they're working toward that goal.

I think more and more, people are finding that out, that this old discrimination—well, you're disabled and you can't quite perform—well, there might be something you can't do. There's always something we can't do. I know there's some things I can't do. There's jobs that—but there are things that you can do.

There's also that idea of skills upgrading. I've seen so many young people with disabilities that just—they get through school, high school, and then they just get shunted into a dead end job, a subminimum wage job. They're just stuck there. If you don't provide skills training and upgrading and people bring it along, yes, you just get stuck there.

Hopefully, the rehab bill that we're getting through will start to change that somewhat, too. Everybody can learn. Everybody can do things better by just some teaching and instruction, skills training, that type of thing.

The discrimination is still there. But the more and more we get people in jobs, let them work, get them out of nursing homes, get them into their own homes in their own communities—we've got to break the old discrimination down, and the way to do that is through integration, giving people the ability to do these things.

I didn't mean to go off on that, but you struck a responsive chord when you said that there's still discrimination out there. I know there is. But we've got to do what we can to break it down.

Is there anything else that anybody wanted to say before we adjourn the hearing?

Yes, Donna.

Ms. THORNTON. I'd like to thank you for having us today and thank you for listening to us.

The CHAIRMAN. You're sure welcome. I want to live by what I say, and that is, "nothing about us without us". I don't want to be passing legislation and stuff here without listening and finding out from people what we ought to be doing. That's the way it ought to be.

We need more people with disabilities in public office, too, more people in public office. I mean in city councils. You're on different boards and stuff like that—school boards, city councils, State legislatures, things like that. We need more people with disabilities in these places.

Mr. THORNTON. You're right.

The CHAIRMAN. Thank you all very much. I know some of you came a great distance. I appreciate it very much. Thank you for your example. Thank you for your suggestions and your witness here today. I've picked up a lot of stuff here. The most regulated group in America. I never thought about that.

Again, thank you. Safe travels back home. Look at that legislation. Give us some input. Let us know if we need to do anything differently, and, hopefully, we can start to break down that institutional bias and get some of that money—you're right. I guess you're right. I'm not trying to say to people you've got to shut that down or—but at least public moneys ought not to be just going to one thing.

It ought to be at least—you said evenly divided. I don't know if that's the right formula or not. But it seems to me that the person who's receiving those services ought to be able to say, "No, I'd like to have that in the community. And, by the way, it's going to save you taxpayers money." What's wrong with that?

Thank you all very much. Safe travels home. We'll keep the record open for 10 days for other questions or statements by other Senators. If you have some followup, let us know. The record will stay open for 10 days.

Thank you. The meeting will stand adjourned.

[Whereupon, at 4:29 p.m., the hearing was adjourned.]

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