

**FULFILLING THE PROMISE: OVERCOMING
PERSISTENT BARRIERS TO ECONOMIC SELF-
SUFFICIENCY FOR PEOPLE WITH DISABILITIES**

HEARING
OF THE
**COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS**
UNITED STATES SENATE
ONE HUNDRED THIRTEENTH CONGRESS

SECOND SESSION

ON

EXAMINING OVERCOMING PERSISTENT BARRIERS TO ECONOMIC SELF-
SUFFICIENCY FOR PEOPLE WITH DISABILITIES

SEPTEMBER 18, 2014

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(II)

C O N T E N T S

STATEMENTS

THURSDAY, SEPTEMBER 18, 2014

Page

COMMITTEE MEMBERS

Harkin, Hon. Tom, Chairman, Committee on Health, Education, Labor, and Pensions, opening statement	1
Casey, Hon. Robert P., Jr., a U.S. Senator from the State of Pennsylvania	1
Alexander, Hon. Lamar, a U.S. Senator from the State of Tennessee, opening statement	3

WITNESSES

Kwong, Ann Wai-Yee, Student, University of California Berkeley, El Monte, CA	6
Prepared statement	8
Massey, Hon. Becky Duncan, State Senator and Executive Director, Sertoma Center, Knoxville, TN	10
Prepared statement	13
Lozano, Alison, M., Ph.D., Executive Director, New Jersey Council on Developmental Disabilities, Trenton, NJ	16
Prepared statement	18
Lauer, Geoffrey, M., Executive Director, Brain Injury Alliance of Iowa, Iowa City, IA	20
Prepared statement	22
Herbst, Justin, Human Resources Supervisor, United Parcel Service, Western Springs, IL	26
Prepared statement	28

FULFILLING THE PROMISE: OVERCOMING PERSISTENT BARRIERS TO ECONOMIC SELF-SUFFICIENCY FOR PEOPLE WITH DIS- ABILITIES

THURSDAY, SEPTEMBER 18, 2014

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

The committee met, pursuant to notice, at 9:34 a.m., in room SD-430, Dirksen Senate Office Building, Hon. Tom Harkin, chairman of the committee, presiding.

Present: Senators Harkin, Alexander, and Casey.

OPENING STATEMENT OF SENATOR HARKIN

The CHAIRMAN. Good morning, everyone. The Senate Committee on Health, Education, Labor, and Pensions will please come to order. This morning, our hearing is titled Fulfilling The Promise: Overcoming Persistent Barriers to Economic Self-Sufficiency for People with Disabilities. Both Senator Alexander and I will have opening statements. But there's a joint session of Congress, and Senator Casey, being on the pertinent committee for that, has to go to the House. So I will yield time to Senator Casey from Pennsylvania for a statement.

STATEMENT OF SENATOR CASEY

Senator CASEY. Mr. Chairman, thank you very much. I want to thank you and the ranking member for having this hearing today, and I appreciate the 1-minute that I promised I would adhere to.

I want to thank the witnesses for being here and for your advocacy and your work and what you bring to these issues.

I especially want to commend the chairman for not just today's hearing and for his more recent work on a whole range of issues that are important to and relate to individuals with disabilities, but especially his long, long service in the Senate on a range of issues, in particular, issues that relate to those individuals and their families with disabilities. So I won't be here for the testimony, but, like most of us here, I have very, very capable staff. Gillian Mueller will be here.

I'm just grateful for the work that we've been able to do together and most recently on the ABLE Act, which is a change in the tax code to create a tax advantage savings account for individuals with disabilities. We're trying to get that completed in the near term.

Mr. Chairman, I'm grateful for your leadership, and I know you've got several more months of work and leadership. But I'm grateful to have learned from you and to be inspired by your work. Thank you very much.

The CHAIRMAN. Thank you very much, Senator Casey.

I would just say at the outset that we had this hearing scheduled for some time. People who had purchased tickets had set their plans in order, and then the president of the Ukraine decided to come here and speak to a joint session of Congress. So both Senator Alexander and I decided we would go ahead with the hearing and not reschedule it. That's why you'll see a lot of people not here this morning because they have other committee assignments, like Senator Casey has, to be involved with the Ukraine, which, obviously, is a very important issue.

Thank you very much, Senator Casey.

Good morning, everyone. Today's hearing will focus on the urgent national challenge of people with disabilities living in poverty and what we can do about it. Two days ago, the Census Bureau issued its 2013 report on poverty in the United States. The report had some good news: poverty for the overall population went down a little bit from 15 percent to 14.5 percent. There was even better news with regard to children, where the poverty rate fell almost 2 percentage points. Other groups including Asian-Americans, Hispanics, women, and people in all parts of the country saw declines.

But those with a disability were one of just two groups to see an increase. Shockingly, people with a disability now have a 28.8 percent poverty rate, which is higher than any gender, ethnic, or racial group tracked by the Census Bureau, and twice the rate of people without disabilities. Twenty-four years after the passage of the Americans with Disabilities Act, we confront this.

We have been successful at meeting many of the goals of the ADA. We have increased the accessibility of our buildings, our streets, our parks, beaches, and recreation areas. We've made our books and TVs, telephones, and computers more accessible. For many Americans with disabilities, our workplaces have become more accessible as well, as we'll hear from one of our witnesses.

But far too few people with disabilities are in the workforce. Of the almost 29 million people with disabilities over 16 years of age, less than 20 percent participate in the workforce compared with nearly 70 percent of those without a disability.

If almost 30 percent of people with disabilities are living in poverty, a rate that is going up, not down, and the unemployment rate for people with disabilities continues to be double that of people without disabilities, and only 20 percent participate in the workforce, then we have a very serious problem. We are far from meeting the ADA's goal of economic self-sufficiency, one of the four goals of the ADA.

To state the obvious, not being part of the workforce contributes powerfully to the incidence of poverty. Unfortunately, these negative trends are long-term and entrenched. We have not seen improvements over time and, as I said earlier, compared to last year, the poverty rate for people with disabilities has actually increased. That shouldn't be. It should be going in the other direction.

Because of these stubborn trends, I asked my HELP Committee oversight staff to take a closer look at the problem. I asked them to investigate why people with disabilities live in poverty at a greater rate than those without disabilities and how they fare at moving out of poverty and into the middle class, into the workforce. So our team heard from over 400 people with disabilities from across the country, all of whom had or currently live at or below the poverty level. These participants were generous in sharing their stories and circumstances. Here is a little of what we learned.

Living with a disability in America can be both economically and socially costly. Many people with disabilities fear that earning or saving too much money could cause them to lose access to supports that they need to live independently in the community. People with disabilities often cannot save for emergencies and unanticipated challenges.

People with disabilities often cannot participate in the workforce because they lack reliable, accessible transportation and accessible, affordable housing. People with disabilities continue to report experiencing employment discrimination, discriminatory wages, inaccessible workplaces, and persistently low expectations about what they can accomplish.

I think after 24 years and facing the data that we have from the Census Bureau, with the information that we have obtained—and, by the way, we have published a report—our staff did. It's out today—on what they found in their investigations. I really do believe that Congress needs to address these concerns. We need to have strategies to work with businesses around the country to break through these barriers and to create paths to the middle class for the nearly 29 percent of people with disabilities living in poverty.

Today we'll hear from people with disabilities who participated in this investigation and also from national experts about how to address this persistent problem. We'll learn from their stories and hear their best ideas about how we can increase opportunities for people with disabilities to move out of poverty into the workforce and into the middle class. As I say that, it's so important to remember and to take to heart one motto of a disability group that I learned a long time ago: Nothing about us without us. So as we move ahead, we need to engage the broad spectrum of the disability community in informing us as to what they do need to be able to be successful in the workplace in America.

I now invite my colleague and Ranking Member, Senator Alexander, for his opening statement.

OPENING STATEMENT OF SENATOR ALEXANDER

Senator ALEXANDER. Thanks, Mr. Chairman.

For all of us as we go through life, the question eventually becomes what goes after the comma after our name. For Senator Harkin, who is retiring from the Senate at the end of this year after 40 years, I think what's likely to go after the comma after his name is Champion for Americans with Disabilities.

As a tribute to his late brother, Senator Harkin has fought tirelessly to help individuals with disabilities during the time he has been here, and he has left quite a legacy. He sponsored the Ameri-

cans with Disabilities Act, Individuals with Disabilities Education Act, the Assisted Technology Act, and, most recently, when we re-authorized the Workforce Innovation and Opportunity Act, he was in the middle of what we did about vocational rehabilitation. So thanks to his work, that is what's likely to be after the comma after his name.

We've also worked pretty well on other issues. We've gotten a lot done in this committee over this year. Sixteen bipartisan bills have become law, and another one is on its way to the President's desk, which shows that Congress can function when it wants to.

Identifying and addressing barriers to employment for individuals with disabilities is certainly a top priority in my State of Tennessee. According to the Social Security Administration, as a result of having a disability, we have about 170,000 Tennesseans who receive supplemental security income. Governor Haslam last year signed an executive order convening an Employment First Task Force to identify State agency policies and procedures that create barriers and disincentives for employment of people with disabilities.

In May, Tennessee revealed a new plan to deal with that. It will allow the State to serve a greater number of people in a more cost effective way and help serve more individuals in the community. They will move from paying for around-the-clock residential care to paying more for limited and less costly services.

Despite the great work being done in Tennessee, we have a long way to go. As Senator Harkin said, last year, only 17.6 percent of persons with disabilities had jobs, compared to 64 percent of people without a disability. One major obstacle is that the Federal Government penalizes individuals with disabilities who want to save in order to support themselves as opposed to relying on the government.

To collect Social Security income benefits and Medicaid benefits in most States, individuals can't hold more than \$2,000 in total assets. This discourages individuals from finding employment in some cases. That's why I was happy to be a co-sponsor of the ABLE Act, which Senator Casey mentioned and which Senator Burr and Senator Casey are the principal sponsors. It would allow the creation of an account that would let families of people with disabilities save for expenses in a similar manner as families concurrently do for college expenses. The ABLE Act is a great example of the Federal Government providing support that allows for individuals with disabilities.

Now, I'm going to have a chance to introduce Senator Massey in just a minute, so I won't do that now. I'll just say that the need for help and for opportunities for citizens with disabilities is great in the area of Tennessee from which she and I both come from. In Knox County, there are nearly 10,000 individuals with disabilities currently on SSI. In Blount County, it's 2,600; Sevier County, nearly 1,900; Anderson County, 2,200.

We're talking about real people, people we know, people with whom we live, who could be helped if we would remove some of the barriers that are in the way of individuals with disabilities finding a job. Thank Senator Harkin for the hearing, and I look forward to the testimony.

The CHAIRMAN. Thank you very much, Senator Alexander, and thank you for your very kind and generous words. Let me respond in kind by saying that it's been a great privilege to chair this committee and especially to have such a great working relationship with you. We have had 16 bills go through with one more on the way, the sunscreen bill that we got passed yesterday. So, you know, people can work together. These are meaningful bills, like the Workforce Innovation and Opportunity Act that we worked together on for 5 years. Sometimes, good food takes a long time to prepare, and the same thing with legislation. We have had a great working relationship.

This may be the last time I chair a hearing in the Senate. It's interesting. I just thought of this. The first hearing that I was able to chair when I took over the Disability Policy Subcommittee of this committee—I remember I sat down in that last chair—was on disability policy—my first one in 1986. So this now will be my last perhaps after all these years. But this is an important one. It's important that we move ahead on this issue of employment of people with disabilities.

We have a great panel, a wonderful panel. I'll introduce them all, and then we will come back and hear all your statements.

Our first witness is Ann Kwong. Ms. Kwong is a student at the University of California Berkeley majoring in psychology. She received a Gates Millennium Scholarship, which helps pay for her school expenses. During her studies at Berkeley, she served as co-president of the Disabled Student Union and as a Cal Student Orientation Leader. She recently completed an internship with the Department of Defense Educational Activity in Washington, DC.

Our second witness is from Tennessee, and I'll yield to Senator Alexander.

Senator ALEXANDER. Mr. Chairman, our next witness has several advantages. One of the foremost is that she has a father from Tennessee and a mother from Iowa.

[Laughter.]

So she's in good shape with us. She is State Senator Becky Duncan Massey of Knoxville. She was elected to the Senate in November 2011, and she serves with distinction. She's the only businesswoman in the assembly. She is also a provider of social services. She has been working with the Sertoma Center in Knoxville since 1993 and has run it for the last 15 years.

The senator serves over 100 adults with intellectual disabilities by providing vocational training. She'll tell us more about that. She has a unique perspective, over 21 years of experience working with individuals and disabilities, as well as her service to the people of Knoxville in the Tennessee General Assembly.

She is the sister of Congressman John J. "Jimmy" Duncan, who is my Congressman, and the daughter of the late Congressman John Duncan, Sr. I look forward to her testimony and I'm proud that she is here today.

The CHAIRMAN. Thank you very much.

Thank you for being here, Senator Massey.

Our next witness is Dr. Alison Lozano. Dr. Lozano is the executive director of the New Jersey Council on Developmental Disabilities. She has served as a genetic social worker at the University

of Tennessee's Pediatrics Department—it's Tennessee's day here, I think—and as Chief of Social Work and Technical Assistance Director for the Boiling Center for Developmental Disabilities in Memphis.

She has also served as executive director of the Utah Developmental Disabilities Council. She received her Ph.D. in social work and a Master's in Public Administration from the University of Utah and a Master's in Social Work from the University of Texas.

Our next witness is Geoffrey Lauer. He is the executive director of the Brain Injury Alliance of Iowa and chair of the Olmstead Consumer Task Force. He has served as a regional and national director of State affairs for the Brain Injury Association of America. He has served as the executive director of the Arc of Johnson County and a member of the board of directors of the Community Mental Health Center for Mideastern Iowa.

Our final witness is from the State of Illinois. Senator Kirk would want to be here, but he also has to be at that joint session because of his obligations on other committees.

Our final witness is Justin Herbst. Mr. Herbst works in the Human Resources Department at the UPS facility in Hodgkins, IL. He has worked at a women's shelter and interned at Northern Trust Bank. He has also volunteered at Hinsdale Hospital. He received his bachelor's degree in history with a minor in philosophy from Southern Illinois University.

I just might add parenthetically that Mr. David Abney, the CEO of UPS, was here earlier. He was here to greet Justin, and I think that's a real mark of leadership, that the CEO of this huge corporation, UPS, would actually be here to sort of add his stamp of approval to the fact that we need to employ more people with disabilities. I thought that was very kind of him to be here.

Before we start with Ms. Kwong, I want to introduce—someone told me that Bob Williams is here, too, but I haven't seen him. Oh, Bob is here. He's the senior adviser to the Deputy Commissioner of Social Security, a long-time compatriot of ours. He worked here off and on back in the 1980s and through different administrations and is now at the Social Security Administration. We welcome him here today, also.

All of your statements will be made a part of the record in their entirety. I read them thoroughly last evening. So what I would ask all of you is to just summarize in 5 minutes what you want us to know, and then we can get into a discussion.

Ms. Kwong, we'll start with you.

STATEMENT OF ANN KWONG, STUDENT, UNIVERSITY OF CALIFORNIA BERKELEY, EL MONTE, CA

Ms. KWONG. Thank you. "You will not graduate. Look at the statistics." I've heard those words repeatedly throughout my life, even from my California Department of Rehabilitation, DOR, counselors.

My name is Ann, and I'm a fourth-year student at UC Berkeley. My family and I immigrated from Hong Kong in the year 2000 in search of better opportunities for my brother and I. Although the United States provided this, I am still fully aware that disability related aspects of my life have predisposed me to the risks associated with low self-sufficiency.

In addition to the enhanced risk, systematic barriers include DOR's low expectations and institutional barriers in Supplemental Security Income, SSI. These systems were intended as transitional tools to acclimate students from school to work. However, several aspects of the policies are out of date with the needs of contemporary society, diminishing the effectiveness of these programs.

As my opening quotation implies, societal stigma and preconceived notions impede the possibilities of acquiring educational advancement or work experience to better equip myself for employment. For a period of time, my DOR counselors' disparaging remarks invoked self-doubt. Even if I succeeded in graduating from Berkeley, am I truly capable of obtaining full-time employment? The negativity I felt further decreased my self-esteem as an individual.

My later experiences at Berkeley, my summer internship opportunity, and personal observations not only altered my later self-perception, but further solidified my belief. If policies designed to aid transition for individuals with disabilities are not amended to reflect current demands, the correlation between disability and poverty will only increase.

I found it imperative that instead of discouraging me from pursuing higher education with bleak statistics, my DOR counselors should have empowered me with knowledge and confidence to realize my full potential. The fear that I would not progress toward my employment goal does not justify my counselor's right to diminish my self-worth. She justified her imposed restrictions on my university enrollment as acts of protection. She did not wish for me to fail and squander my time.

I now perceive this as a paternalistic and demeaning view of young adults with disabilities. If students' accountability and progress are of concern, DOR should implement a mandated, goal-directed information and support program to disseminate employment knowledge and help students strategize completion of individual plans of employment. My self-growth emerges as a more confident and knowledgeable individual, and continued professional development can all be traced to a similar type of guidance course that I enrolled in at Berkeley.

The SSI system should also be altered to match the needs of contemporary society. Since average college completion is approximately 5 years, and many students with disabilities take reduced course loads further extending their time, the traditional 22-year age cap of the student exclusionary rule, which deems them ineligible for SSI, is no longer applicable in modern days.

This past summer, I was afforded the opportunity to work at the Department of Defense Education Activity. However, due to my recent birthday in June, I turned 22 and no longer qualified for SSI. Although my internship was paid, the income barely covered my \$4,000 cost of housing. In addition, SSI only allows individuals to have \$2,000 savings in their account. This limit made it especially difficult when paying for my mandated \$4,000 housing installment. How could I pay \$4,000 in one installment when I'm limited to \$2,000 in my account?

Thus, I strongly recommend conducting research to determine modifications to the age restriction and regulations that allow indi-

viduals to exceed the \$2,000 limit for certain situations. Various instances such as down payments for an apartment and acquiring an internship requires such alterations. If individuals can provide evidence of the use and purpose of their savings as an effort to increase their chances of obtaining successful employment, which could include paying for shelter, advancing education to increase opportunities, or money directed for internships and professional development, exceptions should be permitted.

Considerations of the above recommendations to amend existing transitional programs can maximize the intent and effectiveness, allowing persons with disabilities to reach their potential and disrupt the perpetuation of disability and low self-sufficiency.

Thank you.

[The prepared statement of Ms. Kwong follows:]

PREPARED STATEMENT OF ANN WAI-YEE KWONG

Every individual has a unique set of challenges as they attempt to reach success; persons with disabilities face many common systemic as well as societal barriers in an attempt to reach their own success. For persons with disabilities, aspects relating to their disabilities may have already predisposed them to a higher chance of terminating in poverty and limited self sufficiency. Such barriers include institutional barriers in the Supplemental Security Income (SSI) and California Department of Rehabilitation (DOR) systems; these systems were intended as transitional tools to help students acclimate from school to work. However some of the policies are out of sink with the needs of contemporary society, diminishing the effectiveness of these programs. In addition, societal stigma and preconceived notions increases the difficulty for students with disabilities to acquire necessary work experience to be equipped for employment.

This type of stigma also exists within DOR counselors; based on first-person observations, DOR counselors set low expectations and discourage students from pursuing their individualized success. In addition to better training for DOR staff, SSI case workers should also be well versed in their own regulations; even though the student exclusionary rule was designed with the intension of allowing college students to acquire work experience, the 22-year-old age cap is out of sink with contemporary society, and many SSI case workers as well as persons with disabilities are unaware of this regulation. The student exclusionary rule's effectiveness is not maximized if such a valuable transition tool designed to help students, is not being utilized because students are unaware of it. As a result, these barriers that impede people with disabilities chances of achieving success should be deconstructed so they are given equal opportunity to find their individualized success; after all, people with disabilities also have a right to earn and become productive members of society.

My personal journey of attaining success is also filled with the systemic barriers and societal stigma stated above. In addition, my entire family's status as immigrants further increased my risk of limited self-sufficiency rather than attaining success. The first few years when we first moved to the United States were difficult. It was challenging for my parents to find work due to their lack of proficiency in English and level of educational attainment; they were only able to procure low-wage labor intensive jobs. Unlike my other peers, my parents were unable to assist me with homework nor afford the expensive college test preparation courses. Thus, in addition to school work, I had to advocate for myself. If academic educations were not provided, I had to meet with the school administrators and present my case; advocacy, on top of using braille which requires 200 percent time to complete school assignments, is extremely time consuming. This continued throughout my academic career at UC Berkeley, which I currently attends as a 4th year student. In Berkeley, basic accommodations were just the beginning. On several occasions, I had to petition and appeal decisions just to enroll in a course. To illustrate the emotionally taxing and time consuming nature of advocacy, I spent three semesters advocating with Berkeley staff, the Disabled Students Program, as well as the Berkeley ADA compliance officer just to take the same Mandarin course with the same amount of units as my able bodied peers. My family's economic constraints, coupled with time limitations, means that DOR and SSI became is still are integral parts toward achieving my educational aspirations.

Due to my family's status, I have always viewed DOR as an integral system in my process of achieving success and to mitigate some of the effects of my disability. However, their emphasis on attaining employment, meant counselors only focused on encouraging and persuading students to acquire a job as soon as possible without consideration of their aspirations nor potential. During my senior year in high school, I was repeatedly discouraged to attend a 4-year university despite the fact that I had performed well in high school and had been accepted by over five universities. My DOR counselor in Los Angeles would quote grim statistics of college completion by individuals with disabilities. Her plan for my future was to graduate high school, attend an independent living skills center, then a trait school or a community college; attending a university was seen as a "last resort." The ideal success she envisioned was for me to work at a call center or a factory that build boxes. She clearly stated if I did not adhere to this plan, DOR would not provide any financial nor equipment support.

In contemporary society merely attaining any type of job is not sufficient. The pay one earns from working at a call center or factory is insufficient if one decides to have a family and desires to be a contributing member of society. In addition the job market is increasingly more competitive to the point where a high school diploma is simply not enough; higher education and work experiences have become necessities in the process of attaining employment for American youth, but especially for young adults with disabilities. Employers already have low expectations and negative notions about individuals with disabilities and their ability to be effective and productive workers. Through personal experience, I came to the realization that a higher education degree coupled with a strong resumé and prior work experience is indispensable in effacing some of these negative notions; work experience not just "tell" but rather "show" the employers of my ability to be a productive member. If DOR counselors continue to impose their own visions on young people with disabilities, this jeopardizes their ability to become the most effective and productive members of American society and increases the likelihood of poverty and limited self-sufficiency.

In addition to the DOR system, I view SSI as another imperative transitional tool in altering my destiny of poverty. However, some of the regulations around SSI is out of date. In the summer of 2014, I was afforded the opportunity to intern at the Department of Defense Education Activity; however due to the fact I recently turned 22 in June, I no longer qualified under the SSI student exclusionary rule. Although my internship was paid, the income was only enough to cover my rent, which was \$4,000 for 10 weeks; many internships opportunities however are non-paid. In addition, SSI only allows individuals to have \$2,000 of savings in their bank account at one time, however I had to pay my rent all at once before I moved in. How could I pay \$4,000 in one installment when I have less than \$2,000 in my bank account? I was privileged enough to have parents who were willing to lend me a portion of their money to pay the \$4,000 installment until I could repay them with my salary. Internship opportunities and summer work experiences are vital to professional development and possibility of future employment, especially for individuals with disabilities; society has preconceived stigma about my inability to be as productive as an able bodied individual. Thus, I strongly believe that the best way to dispel these preconceived notions is to have work experience to "show not tell" potential employers of my ability to be a productive and contributing member of their workforce.

If students with disabilities, such as myself, cannot save money to cover the cost of internships, nor be allowed to have enough money to pay for housing or down-payment for renting, this places us at a significant disadvantage. In addition, students with disabilities, such as myself, spend most of our time during the semester advocating for academic accommodations. I did not have time to acquire work experiences, like some of my peers, thus I rely on the summer months as time to gain valuable work experience. In addition, the current 22-year-old age cap of the student exclusionary rule should be changed. In contemporary society, many student take an average of 5 years to complete university education; since many students with disabilities have to balance the negative affects of their conditions, many tend to take a reduced course load, further extending the time we are in school from the average of 5 to 6 or even 7 years. As a result, instead of graduating at 22, it is not uncommon to see students with disabilities that are 25 years old. Since I was over 22 and did not qualify under the student exclusionary rule, my internship salary allowed me to afford housing, but not food and transportation costs; and my SSI checks were interrupted because my income deducted the entirety of my SSI checks. Once calculations are done, I was in a deficit after the internship since my entire salary paid for housing and had no money left for transportation and food costs.

My prior experiences at Berkeley and my summer internship coupled with my personal observations further solidified my belief that if policies meant to aid indi-

viduals with disabilities transition are not amended to reflect the needs of contemporary society, the correlation between disability and poverty will further grow. Instead of discouraging students from pursuing higher education, DOR counselors should be supportive. In lieu of breaking down my self-esteem with statistics, I should be empowered with the knowledge and opportunities to realize my full potential. The fear that I will not make progress toward my employment goal should not justify DOR counselor's rights to diminish my self-esteem with grim statistics. I clearly remember that my DOR counselor stated her restrictions of my attendance to a university is an act of protection; she did not wish for me to fail and squander my time. This is clearly a paternalistic and demeaning view of students with disabilities. If the progress of students is of concern, DOR should implement a mandated goal directed information and support program to disseminate employment knowledge and help students strategize their path of employment to keep students accountable and on track for their individual plan of employment (IPE) completion. DOR mandates preliminary assessments for equipment recommendations, thus I believe it is logical to have a structured mandated employment educational program for its clients.

Persons with disabilities should not be told "you will conform to negative statistics and drop out of college" before they are given the opportunity and resources toward their aspirations. DOR counselors should help students with the progression and achievement of their IPE using these employment knowledge programs which provides a supportive environment conducive to the forming of well informed confident workers rather than the college drop-outs with disabilities that were once envisioned. I also recommend the SSI system be altered to match the needs of contemporary society. Since the average college completion is around 5 years, and students with disabilities may take a reduced course load which further extends this, the 22-year-old age cap on the resources of the student exclusionary rule is not maximized to aid students. The age restriction should be raised, and further surveys as well as research should be conducted in order to determine the new age restriction. In addition, SSI should have regulations that allow for individuals to save and maintain over \$2,000 in their bank account for certain situations. Many situations in life, such as leaving down-payment for an apartment and acquiring an internship, require savings which exceed the \$2,000 restriction. Thus, if individuals are able to provide evidence for the purposes that their savings are to be used, which increase their chances of attaining successful employment such as acquiring shelter to live, further their education to increase employment opportunities, or money to be used during internships to buildup their resumé's, exceeding the \$2,000 cap is justified. The above recommendations should be strongly considered; making such amendments to existing transitional programs can maximize its intent and effectiveness, yielding more persons with disabilities to reach their aspirations and interrupting the perpetuation of disability and limited self-sufficiency.

The CHAIRMAN. Thank you very much. You're very impressive. I'm going to suggest you think about taking up motivational speaking, too, because you're a great speaker.

Ms. KWONG. Thank you.

The CHAIRMAN. Senator Massey.

STATEMENT OF HON. BECKY DUNCAN MASSEY, STATE SENATOR AND EXECUTIVE DIRECTOR, SERTOMA CENTER, KNOXVILLE, TN

Senator MASSEY. Thank you, and thank you for inviting me here today to testify on this very important issue to millions of individuals with disabilities across our country.

As an intellectual disability provider in Knoxville for over 21 years, I know firsthand how policies and programs affect these individuals and their families. As a State senator, I understand the process and the challenges that go into making good public policy and the difficulties in the implementation. I hope to bring these unique perspectives to the conversation today.

There are folks that we serve, like Jonathan, who came to our agency from a foster family and an abusive situation. There were 10 people living in a three bedroom home, and it was not good.

When he came to our agency and we showed him his room, it was similar to a scene from *The Blind Side*: “Is this my very own room, and is this my very own bed?”

He is truly happy now, safe, and well taken care of. Now that he has graduated from high school, his goal is to work with police or firefighters. They are his heroes, because they helped save him. But there are many, many, more people like Jonathan in States across the country.

In Tennessee, there are a lot of positive things happening to help more individuals with disabilities to receive their life’s dream of having a paid job that they are good at and that they enjoy, a job that utilizes their skills that they possess. We need to realize that individuals with disabilities are not different from you or me.

But it’s hard to put them in a little box and say, “OK. This one solution is going to be the solution for everybody,” because they have different strengths and weaknesses, just like you and I have different strengths and weaknesses. They just need, oftentimes, a little more help in identifying their abilities and more support in translating those abilities into a successful job.

Senator Alexander talked about Governor Haslam’s Executive order establishing the Employment First Initiative, and they actually issued their first report this week, which I drew some of my written testimony from. Their timing was good for me. But coupled with this, we have received several statewide grants that are focused on changing the culture and helping increase employment for folks with disabilities.

We are working to have people look at Employment First, and we’ve informed the Tennessee Works Partnership, focusing on the three Federal grants now operating in Tennessee. We are one of only two States to have received all three of the national employment grants available in the last 3 years. So we’re working hard.

Also through the efforts of our general assembly, we have increased the opportunities for scholarships available for post-secondary education for folks with intellectual and developmental disabilities. These programs help young people make a successful transition from high school to adult life by providing career counseling and developing academic, vocational, and decisionmaking skills. While there are not enough spots there yet—I went and visited the classroom with them a few weeks ago—it’s still a big step in the right direction, and we have them in all three grand divisions of Tennessee.

There are a number of barriers, some of which you have mentioned already, that are deterrents to employment. One of the big things, I think, is a lack of coordination and flexibility among both the State agencies and the Federal agencies that administer the funding and programs that are so important and vital to our folks with disabilities.

One solution would be—and we’re working on that in Tennessee—is to develop a memorandum of understanding between the agencies that would help facilitate the coordination of the programs. Another would be to look at ways to decrease some of the regulations which are either duplicative or unnecessary. Oftentimes, you’ve got to put in an application here, and then you’ve got to put in basically the same application here, and oftentimes people

just don't know to navigate all those different systems and how to access them, which causes a lot of problems.

We talked a little bit about the inadequacy of transportation and if we could help incentivize cities to develop and improve reliable transportation for individuals with disabilities to get to their jobs. More benefits counselors might help with helping people navigate the system and also lessen the fears—whether they're myths or actualities, and I've heard of both—that the individuals will lose their benefits when they work.

What happens, though, is that they get a job which may only be paying \$7.50 or \$8 an hour or minimum wage. So then they lose their benefits, and then they have trouble making their payments for their apartment or their home that they're living in and all the expenses. If they're only getting their disability income, they actually only have \$30 a month to spare for extras if they're not working. Just think of how quickly you can spend \$30. So that causes problems.

As Ann mentioned, the asset limit—there really is no way to save for emergencies or unexpected expenses or even expected expenses, as she said, to help pull them out of poverty. If you think about it, this \$2,000 limit has been in effect for over 40 years and has not been adjusted for inflation. That \$2,000 today would be equal to about \$13,000 on a calculator I looked at.

The ABLE Act will be wonderful and should really, really help with that. But I also think we should look at that asset limit and either increase it or put in a cost of living inflator that would be automatic every year and at least do something about it going forward.

The waiting lists are terrible across the country. We have over 7,000 people on the waiting list in Tennessee. It tends to affect our younger folks graduating from high school that have gone through post-secondary situations because they can't get services, and they kind of fall through the cracks. The skills they were learning—they go backward oftentimes.

At my agency, we're serving more older folks, and we have to kind of look at different ways to provide those services as they're aging and getting more frail. We need to look at ways to seamlessly do the transitions there.

Some businesses hire individuals with disabilities as a form of charity. Charity is not what these individuals need. They need real jobs that utilize their skills. Only a job can give them a place in this world, not relegated to the shadows and relying upon the charity of strangers in the government. Work would fill their days, offer healthy challenges, and provide relationships.

Every person, regardless of hardship, disability, and prejudice, can excel if given the opportunity. Many people with intellectual disabilities yearn for a job. Though they want to earn a wage, many have never gotten the chance. For them, a job means more than a paycheck. It means truly being a part of the community.

Please do the right thing. This is a nonpartisan issue. I promise you that. Do everything in your power to help make a difference in the lives of those very special people. I thank you for what you're doing.

[The prepared statement of Senator Massey follows:]

PREPARED STATEMENT OF HON. BECKY DUNCAN MASSEY

I want to thank you for asking me to testify before the HELP Committee on Thursday, September 18th. As my role of executive director of Sertoma Center and being a disability provider for over 21 years, coupled with my role in the State Senate of Tennessee, I can bring a unique perspective to the hearings.

I will be reporting on the following:

- Tennessee initiatives.
- Current barriers.
- Suggestions for solutions.

First we need to address the challenge of addressing policy changes for individuals with disabilities. While there is a lot of conversation about people first policy, you cannot put individuals into a nice, neat box. Individuals with disabilities range a wide spectrum from physical to intellectual to mental disabilities. And there is a wide spectrum within each of these types of disabilities with factors of age, IQ and functioning abilities.

Recently through an information gathering process, it was learned that while 75.2 percent of people in Tennessee without disabilities are employed, only 28.2 percent of people with any type of disability find work. Likewise, citizens with mental illness or substance use disorders have substantial difficulty finding and maintaining employment.

TENNESSEE INITIATIVES

There are a lot of good things happening in Tennessee in working to improve employment opportunities and percentages of individuals with disabilities. In June 2013, Governor Bill Haslam signed an Executive Order establishing the Tennessee Employment First Initiative to expand community employment opportunities for Tennesseans with disabilities.

Employment First is a concept to facilitate the full inclusion of people with the most significant disabilities in the workplace and community. Under the Employment First approach, community-based, integrated employment is the first option for employment services for youth and adults with significant disabilities. Integrated employment refers to jobs held by people with disabilities in typical workplace settings where the majority of persons employed are not persons with disabilities, they earn at least minimum wage and they are paid directly by the employer.

The Task Force was asked to identify State policies and procedures that create barriers to employment, to make recommendations to eliminate those barriers, to forge effective partnerships among the related State agencies and other stakeholders and to identify best practices to increase opportunities for "integrated employment." The Employment First Task Force concluded its first year on August 1, 2014 and issued a report to Governor Haslam Tuesday of this week. I am including parts of their report in this document.

TENNESSEE PROGRAMS THAT ARE WORKING

The Department of Labor and Workforce Development

In 2011, the Department of Labor and Workforce Development was awarded a 3-year Disability Employment Initiative Grant to increase the capacity of the America's Job Centers and local workforce investment areas to meet the needs of Tennesseans with disabilities by training Disability Resource Coordinators and Integrated Resource Teams to leverage available funding and resources to help Tennesseans with disabilities get hired.

The Department of Intellectual and Developmental Disabilities

In 2012, Tennessee was selected as one of three States to participate in the Office of Disability Employment Policy's Employment First State Leadership Mentoring Program. The department was awarded the grant that provided funding as well as consultation from experts in converting sheltered workshops to integrated employment.

Vanderbilt Kennedy Center

Later in 2012, Tennessee was awarded a Partnerships in Employment systems and policy change grant for transitioning youth with intellectual and developmental disabilities, funded by the U.S. Administration on Intellectual and Developmental Disabilities. Under the leadership of the Vanderbilt Kennedy Center, this 5-year grant has helped to formalize the statewide employment consortium, the TennesseeWorks Partnership, around the three Federal grants now operating in Tennessee. This partnership is the unifying structure within which all of the grants

collaborate and all public and private stakeholders come together to pursue the goal of increasing employment of Tennesseans with disabilities. Tennessee is only one of two States to receive all three national employment grants available of the past 3 years.

The Tennessee Department of Mental Health and Substance Abuse Services

TDMHSAS recently worked in partnership with the Tennessee Division of Rehabilitation Services to increase the number of individuals with serious mental illness and co-occurring mental and substance use disorders to obtain and retain integrated employment. In less than a year through this program, 154 individuals have been served, with 62 job placements in a variety of jobs and an average hourly wage of \$8.07.

The Division of Rehabilitation Services, Department of Human Services

The Vocational Rehabilitation program, which provides services to help working-age individuals with physical and/or mental disabilities enter or return to employment, closed 1,966 cases with individuals in successful employment in the last Federal fiscal year, and has closed 1,440 cases in this Federal fiscal year.

Other

The Tennessee General Assembly has passed and helped fund scholarships for the four post-secondary programs for individuals with disabilities. These education programs are a 2-year course of study which empowers students to achieve gainful employment in the community. They help young adults with intellectual and developmental disabilities make a successful transition from high school to adult life by providing them with career counseling and developing their academic, vocational, and decisionmaking skills. It is a comprehensive transition program for unique learners, highly motivated young adults whose disability is characterized by significant limitations in both intellectual functioning and adaptive behavior. Upon successful completion of the program, students receive a vocational certificate. These students are eligible to apply for Federal Financial Aid for tuition assistance and are recognized by Vocational Rehabilitation as being tied to employment outcomes.

There has been a dedicated effort to provide a voice to people with disabilities regarding their experiences with long-term support programs in Tennessee by emphasizing Stakeholder feedback in the policy and planning processes. TennesseeWorks has six community meetings with families and individuals with disabilities across the State and also collected 2,200 Family Expectation Surveys.

CURRENT BARRIERS

- A lack of coordination among State and Federal agencies that administer funding and programs for individuals with disabilities.
- A lack of adequate funding to support employment efforts for all those who need assistance in finding and retaining a job, including services such as job coaches, customized employment, and individualized supports.
- Inadequacies in service delivery, including difficulty accessing services and a lack of flexibility.
- Insufficient opportunities for professional development for those who provide services.
- Insufficient resources and opportunities for training and post-secondary education leading to employment for individuals with disabilities.
- Inadequacies in transportation services to and from job sites.
- A cultural mindset of low expectations on the part of professionals, businesses, parents, and individuals themselves that people with disabilities are unemployable.
- The lack of a high school diploma or other competency based vocational diploma that employers want job candidates to have.
- The fear of losing one's benefits if one works. (SSI, SSDI, health insurance) Any cuts at all prevent them from being able to pay their monthly rent, utilities and other bills.
- Asset limitations. There is no way to save for emergencies and other things to help pull them out of poverty. The \$2,000 limit that was established when the program was started is equal to almost \$13,000 in today's dollars. The ABLE act could help with this.
- Lack of information or insufficient information about benefits.
- The need for Supported Employment, particularly for individuals with more significant disabilities.
- The waiting list for services and supports. There are over 7,000 individuals on the statewide waiting list for services for individuals with intellectual disabilities.

As a result of this, the individuals receiving services in Tennessee are older. The youth with disabilities face significant challenges in accessing services and supports.

- Presently, there is no direct support for individuals with developmental disabilities.
- There is not sufficient funding for Vocational Rehabilitation services and other training programs.
- Failure to prepare secondary students for employment while in high school and successfully and seamlessly transitioning them to adult service systems that can help them obtain jobs.
- The need for long-term supports for some individuals who need that level of support to be able to keep their job.
- SSA benefits system is too complex to navigate and understand (examples: Work Incentives, PASS Plans, IRWE's)
- Vocational Rehabilitation system is also difficult to navigate and they often deem people "too disabled to work." They do not focus on those with the most severe disabilities.
- Not enough engagement with employers at the Federal level to promote and incentivize employment for persons with disabilities.
- Lack of adequate funding.

SOLUTIONS

- Encourage Memorandum of Understanding among agencies to facilitate coordination among programs and produce successful outcomes for people with disabilities. Individuals and families struggle to navigate complex systems. Many families need to navigate both the Social Security Administration and Centers for Medicaid & Medicare Services and Rehabilitation Administration. Communication and alignment between these service systems would benefit families served by these systems and promote better outcomes.
- Pass the ABLE act.
- Increase the asset limits for SSI/SSDI. There could be an automatic cost of living inflator put in place even if it cannot be adjusted to today's dollars.
- Engage and support businesses in employing people with disabilities.
- Ensure every student with a disability leaves high school with a smooth transition that would include a choice of (but not limited to) post-secondary education, a job training program, or paid, integrated employment to the same extent as students without disabilities.
- Create policy and infrastructure that allows one to be able to move seamlessly from school to adult supports with a minimum of duplicative application and assessment information, perhaps by creating electronic records much like a person's electronic medical record, that could hold all relevant information and be accessed as authorized.
- Support individuals with disabilities and their families by increasing their knowledge about the benefits of employment as a life goal and about the different supports that are available. Often families and individuals themselves do not see employment as a real possibility.
- Ensure that all working-age individuals with disabilities have access to a system of supports that enables them to obtain and maintain employment in the community throughout their lives. Many people need some level of support (some long-term supports) in order to maintain their employment. Research shows that, for every dollar taxpayers spend on supported employment services, they received between \$1.17 and \$1.77 that is otherwise spent on more expensive services with far less beneficial and preferred outcomes.
- Better dissemination of cost-effective, HCBS aligned, innovative methods for meeting individual needs in person-centered ways across State lines.
- Practical technical assistance for providers in how to convert from a facilities-based model to an Employment model to align with expected CMS guidance on HCBS higher standards and expectations.
- Making One Stop Employment Centers available and accountable for ALL job seekers, not just those who can search for themselves.
- Encourage businesses to have a more accessible employment application process including being able to verbally apply when the person is not able to fill out an online or computer application.
- Reevaluate the Ticket to Work program to address the need for some individuals to have long term supports to be successfully employed.
- Provide incentives to cities to develop and/or improve transportation for individuals with disabilities.

Research confirms that when people with disabilities are connected to work experiences in their communities, achieving goals such as finding a good place to live, having friends and using their talents all become much more likely. For all of us, a good job is about much more than a paycheck. It contributes to a sense of accomplishment, self-worth, and independence. A meaningful job can make a difference in the lives of people with disabilities just as it does for all citizens.

Every person, regardless of hardship, disability, and prejudice, can excel if given the opportunity. Many people with intellectual disabilities yearn for a job. Though they are desperate to earn a wage, many have never gotten the chance. For them a job means more than just a paycheck. It means truly being part of the community.

The CHAIRMAN. Thank you, Senator Massey.
Dr. Lozano.

STATEMENT OF ALISON M. LOZANO, Ph.D., EXECUTIVE DIRECTOR, NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES, TRENTON, NJ

Ms. LOZANO. Thank you, Chairman Harkin and Ranking Member Alexander, for inviting me to appear before you today to talk about poverty issues for people with disabilities. My suggestions today are based on more than 40 years working directly with people with disabilities and also having raised three children with disabilities, a young lady with developmental disabilities and two boys with learning disabilities.

As you mentioned earlier, we still find that 28 percent of Americans with disabilities are living in poverty, whereas in the general population it is approximately 12.5 percent. I want to focus my remarks today on four policies that I would like to suggest could be reformed to build success on past legislation.

The first one is rebalancing the institutional bias in Medicaid. Currently, a person receiving Medicaid with a significant disability is entitled to be housed in an institution, and Medicaid will pay for all expenses involved with that setting. If a person with a disability wants to live in the community, they must be approved for a waiver, and a waiver simply does not cover all of the expenses associated with living in the community. Plus there are limits to how much the waiver will cover and how many people the waiver will cover.

If the Medicaid system was revisited and the norm of care of people with disabilities was the community rather than the institution, more money could be realigned to pay for services in the community. Depending on the State, the average cost of keeping someone in a congregate setting is \$120,000 versus between \$40,000 and \$70,000 to support a person with disabilities in the community. I have to say that in my 40 years of working with people with disabilities, I have never heard of one person who has moved to the community from an institution telling me that they would rather be living in the institution.

Another suggestion is to create an intensive initiative to increase knowledge about the Ticket to Work Program and the Plans for Achieving Self Support, the PASS program under Social Security. Ticket to Work is typical of programs that have been introduced in the last 10 to 15 years to stimulate employment of people with disabilities. It was introduced to assist people to go to work and still maintain their Medicaid eligibility.

PASS is an excellent program but not well known among educators, vocational rehabilitation counselors, or Medicaid specialists.

In addition to Medicaid coverage, the program assists those eligible to find and keep a job.

However, despite these good programs, the rate of unemployment for people with disabilities has remained at 70 percent for the last 20 years. Both of these programs need to receive more attention and publicity.

Another suggestion is the reauthorization of the Individuals with Disabilities Education Act to align with the recently enacted Workforce Innovation and Opportunity Act. The IDEA is a wonderful piece of legislation that benefits millions of children with disabilities and their families.

My husband and I raised his niece and nephew after their mother passed away. Hope, his niece, has a dual diagnosis of developmental disability and mental illness and received special education services both in Tennessee and Utah. She was in our neighborhood school and joined others without disabilities for non-academic classes and activities. She benefited greatly from being around other children without disabilities while she learned academics in a supported setting.

However, her school experience did very little to prepare her for life in the community and the workplace. She is now age 31 and was raised with our other four children without disabilities. As a result, she, like many of her peers, had expectations that she would always live in the community and be employed. She was offered job sampling that consisted of folding towels at the YMCA and collecting shopping carts in the parking lot at T.J. Maxx.

However, she was not taught appropriate job setting behavior, expectations of the workplace, and other skills that those of us who do not have intellectual disabilities learn on the job. As a result, she has moved from job to job as her behavior has interfered with her job performance. At the moment, she is in a workshop setting, still waiting once again for supports to be put in place to support her in the community.

But my experience is that the supports take a long time to put in place and are not comprehensive enough for her needs. The limitations that are placed on vocational services are not commensurate with the needs of the individuals. They need to be expanded and made more flexible. I suggest that the transition planning and services in the language between the IDEA and the WIOA match and coordinate so that there is no confusion between the State educational agency and the designated vocational rehabilitation agency.

I also would like to suggest, briefly, changes to the tax code and tax incentives for people with disabilities. Taxpayers who are legally blind may be entitled to a higher standard deduction on their tax returns than other people with disabilities. For example, people who are deaf should be allowed the same tax savings as people who are blind.

The determination of Substantial Gainful Activity for a person who is blind is \$1,800 while it is \$1,070 for a person who has a disability but is not blind. This needs to be corrected so all persons with a disability receive the same standard deduction on their taxes. A powerful change that would change the lives of Americans

with disabilities would be to eliminate the Federal income tax on their SSDI.

Also, as mentioned previously, the passage of the ABLE Act would provide an opportunity for individuals with disabilities, or the families of individuals with disabilities, to create a tax-free account that can be used for disability related expenses. I know many of the families that I speak to are excited at the possibility of being able to save for expenses related to their child.

Speaking from personal experience, the expenses related to having a child with a disability are vastly different from the child without a disability, particularly as they age. What we experienced as a family is that we still had to provide 24-hour supervision, transportation, and other expenses that you would anticipate a child without disabilities would assume as they age. The passage of the ABLE Act would ease the burden of those additional expenses so the family could have more flexibility in how they manage their finances.

Thank you very much for the opportunity to appear before you today.

[The prepared statement of Ms. Lozano follows:]

PREPARED STATEMENT OF ALISON M. LOZANO, PH.D.

Thank you Chairman Harkin and Ranking Member Alexander and members of the committee to appear before you today. I am here to discuss the current status of the majority of Americans with disabilities living under the poverty level and suggestions to advance Federal policies that can improve this problem. My suggestions are based on more than 40 years directly in the field having worked across the country from New Jersey, to Utah, Texas, and Tennessee. I am also the parent of three children with disabilities who are now adults.

I have seen several Federal initiatives introduced that have sought to raise people with disabilities out of poverty. And yet we still find 28 percent of Americans with disabilities living in poverty while in the general population it is 12.5 percent. In addition, the median earning for a man with a disability is approximately \$41,500 while his peer without disabilities earn \$48,000. For women with disabilities the median income is approximately \$32,000 while their peer without disabilities earn \$37,000 (U.S. Census Bureau).

Today, my remarks focus on four policies that if reformed can build on the success of past legislation. We know more than ever before about ways to shape policy that will lead to greater independence, opportunities, and advances in employability. I will discuss reforms in Medicaid, the Ticket to Work program, reauthorization of the IDEA, income tax, and passage of the ABLE Act.

REBALANCING THE INSTITUTIONAL BIAS IN MEDICAID

I know that I am not the first person to testify that we need to rebalance the bias toward institutional care in Medicaid. Currently, a person receiving Medicaid with a significant disability is entitled to be housed in an institution and Medicaid will pay for all expenses involved in that setting. If a person with a disability wants to live in the community they must be approved for a waiver in order for funds to be used to support them. Further, each State must first request a waiver of the Medicaid law simply to provide for less expensive and restrictive home and community-based options. The Medicaid waiver funds do not cover housing, food and clothing so these expenses are usually paid with each individual's Social Security payment. The waiver funds pay for career planning and supported employment, transportation, attendant support, assistive technology, behavioral intervention, respite, etc. In addition, there are limits in how much the waiver will cover and how many people the waiver will cover.

If the Medicaid system were revisited and the norm for care of people with disabilities was the community rather than congregate settings, more money could be realigned to pay for services in the community. Depending on the State, the average cost of keeping someone in a congregate setting is \$120,000 versus between \$40,000 and \$70,000 to support a person with disabilities in the community.

In my 40 years working with people with disabilities, I have never heard one person who has moved to the community tell me they would rather live in the institution. Foundation of increased access to employment begins with reforms to the largest safety net for millions of people with disabilities—fixing the focus on financially supporting institutions isolated from society to at least equal home and community-based living is the first important step to raising the economic status of people with disabilities. This can be done without any additional Federal or State funds needed.

CREATE AN INTENSIVE INITIATIVE TO INCREASE KNOWLEDGE ABOUT THE TICKET TO WORK PROGRAM AND PLANS FOR ACHIEVING SELF SUPPORT (PASS) UNDER SOCIAL SECURITY

Ticket to Work is typical of programs that have been introduced in the past 10 or 15 years to stimulate employment of people with disabilities. It was introduced to assist people to go to work and still maintain their Medicaid eligibility. PASS is an excellent program but not well known among educators, vocational rehabilitation counselors, or Medicaid waiver specialists. In addition to Medicaid coverage, the program assists those eligible to find and keep a job. However, despite these good programs, the rate of unemployment for people with disabilities has remained at 70 percent for the past 20 years. In fact, the Ticket to Work program has been underutilized in many States. PASS plans are relatively easy to submit to the Social Security Administration. A major challenge in lack of awareness can be an initiative with the Social Security Administration, and the Departments of Labor, Education, and Health and Human Services to target training and awareness to families and key direct support providers.

REAUTHORIZE THE IDEA (INDIVIDUALS WITH DISABILITIES EDUCATION ACT) TO ALIGN WITH THE RECENTLY ENACTED WORKFORCE INVESTMENT OPPORTUNITY ACT

The IDEA is a wonderful piece of legislation that benefits millions of children with disabilities and their families. My husband and I raised his niece and nephew after their mother passed away. Hope, his niece, has a dual diagnosis of developmental disability and mental illness and received special education services both in Tennessee and Utah. She was in our neighborhood school and joined others without disabilities for non-academic classes and activities. She benefited greatly from being around other children without disabilities while she learned academics with additional supports.

However, her school experience did very little to prepare her for life in the community and the workplace. She is now age 31 and was raised with our other four children without disabilities. As a result she, like many of her peers, had expectations that she would always live in the community and that she would be employed. She was offered job sampling that consisted of folding towels at the YMCA and collecting shopping carts in the parking lot at T.J. Maxx. However, she was not taught appropriate job setting behavior, expectations of the workplace and other skills that those of us who do not have intellectual disabilities learn on the job. As a result she has moved from job to job as her behavior has interfered with her job performance. At the moment she is in a workshop setting waiting once again for supports to be put in place to support her in the community. But my experience is the supports take a long time to put in place and are not comprehensive enough for her needs. The limitations that are placed on vocational services are not commensurate with the needs of the individuals. They need to be expanded and made more flexible.

I suggest that the transition planning and services language between the IDEA and the WIOA match and coordinate so that there is no confusion between the State educational agency and the designated vocational rehabilitation agency.

Offer young people who are receiving special education services through the school system the same quality of services offered through WIOA to prepare them for competitive employment. But just as important is the improvement of the transition services from the schools to the vocational rehabilitation system.

CHANGES TO THE TAX CODE AND TAX INCENTIVES FOR PEOPLE WITH DISABILITIES

Tax payers who are legally blind may be entitled to a higher standard deduction on their tax returns than other persons with disabilities. For example, people who are deaf should be allowed the same tax savings as people who are blind. The determination of Substantial Gainful Activity for a person who is blind is \$1,800 while it is \$1,070 for persons who have a disability but are not blind. This need to be corrected so all persons with a disability receive the same standard deduction on their taxes.

A powerful change that would change the lives of Americans with disabilities is to eliminate the Federal income tax on their SSDI payment. This would allow individuals with disabilities additional funds directly in their lives without the need of another program to pay the costs of, for example, attendant supports in their homes. Many States recognized not taxing SSDI income is good policy—this promotes independence away from more costly institutional warehousing.

The passage of the ABLE Act (Achieving a Better Life) would provide an opportunity for individuals with disabilities, or the families of individuals with disabilities to create a tax-free account that can be used for disability related expenses. I know many of the families I meet are excited at the possibility of being able to save for expenses related to their children.

Speaking from personal experience, the expenses related to having a child with a disability are vastly different from the children without a disability, particularly as they age. My experience is that we still had to provide 24-hour supervision, transportation and other expenses that you would anticipate a child without disabilities would assume as they age. The passage of the ABLE Act would ease the burden of those additional expenses so the family could have more flexibility in how they manage their finances.

CONCLUSION

Poverty is an ongoing problem for people with disabilities. Almost all the families that I worked with across the Nation live below the poverty level. We need to have a combination of the issues I raised in order to bring these individuals and families out of poverty.

Medicaid needs to be amended. Schools need to prepare students for the workplace and collaborate with vocational programs. The tax codes need to be amended to offer relief from the additional burdens of services that relate to disability.

Thank you for the opportunity to appear before you today.

The CHAIRMAN. Thank you very much, Dr. Lozano.

Mr. Lauer, please proceed.

STATEMENT OF GEOFFREY M. LAUER, EXECUTIVE DIRECTOR, BRAIN INJURY ALLIANCE OF IOWA, IOWA CITY, IA

Mr. LAUER. Thank you, Senator Harkin. Chairman Harkin, Senator Alexander, thank you for the opportunity to speak with you on these issues today. The organizations that I am honored to work with provide services, support, and advocate for and with hundreds of thousands of Americans with long-term disability from brain injury and other causes. Consequently, I and my colleagues are keenly aware of many barriers with respect to economic self-sufficiency for persons with disabilities.

There are a number of things that I hope to accomplish with my testimony and points to make. But, however, before I get into those specifics, I wish to thank the committee for their support of the Traumatic Brain Injury Act, the TBI Reauthorization Act of 2014. As a modest first step, the TBI Act has been a tremendous success in catalyzing systems change and improvement for Americans with brain injury and their families. Yet there is still a lot to do.

Each day across our country, millions of Americans with disabilities are faced with navigating a shifting maze of daily challenges related to both disability and income. These barriers include an array of environmental, healthcare, social, economic, institutional, and attitudinal components ranging from transportation to a job or just getting to a grocery store to, as Ms. Kwong noted, inexcusably low expectations for people with disabilities from teachers and the professionals that serve them.

Federal programs of public assistance are essential in providing a safety net to prevent many people from falling into extreme poverty. However without question is the fact that many income and

work support programs have eligibility requirements that are blockades to individual and family economic self-sufficiency.

One of the most egregious of those eligibility requirements are impossibly low programmatic limits to assets. Asset limits for a number of Federal programs have the effect of trapping individuals with disabilities in poverty.

Let me share a story about Jason. Jason is a young man with a disability in rural Iowa. He receives SSI benefits and Medicaid. He began working at a local factory recently with his first check totaling \$400 a week gross. However, when his local caseworker found out about this employment, the response was panic. The caseworker told Jason that such income would put his benefits at tremendous risk, including his Medicaid healthcare benefits. This was shared with him despite there being available and well documented State-based options for him to retain his Medicaid while working toward genuine independence.

Jason and his caseworker, like many others, were victims of the widespread belief that substantial work is much more a threat than an opportunity. Support staff, acting in what they feel is the best interest of their clients, are many times the ones that are the barriers limiting people with disabilities in their movement toward self-sufficiency.

Recommendations that I have would be that Congress should significantly increase the outdated SSI asset limits and, as my colleague mentioned, index them to inflation. They haven't been adjusted for so many years. In addition, as has already been mentioned, the ABLE Act would be a huge step forward in providing an opportunity to people to save for expenses and have assets.

Another area is long-term services and supports. Long-term services and supports in State Medicaid programs are a means to provide medical and non-medical services to seniors and people with disabilities in need of assistance. They include services to aid individuals with activities of daily living. They are also provided through Home and Community-Based Service Waivers.

Many people who rely on these services face a perilous reduction in funding for such services if they become substantively employed. The cost of long-term services and supports are seldom sustainable at or beyond the current asset limits and result in millions of people with disabilities concluding that such personal and financial goals are not worth the risk of losing such supports.

Another major barrier are unreasonably long waiting lists, as has been mentioned before, by the Medicaid Home and Community-Based Services Waiver programs in many States. In 2012, there were more than half a million Americans on waiting lists for an average of more than 27 months. Many States are not providing funding to keep HCBS waiting lists reasonable. The result is decreased recovery for individuals with disability from brain injury and increased nursing home placement, increased incarceration, and increased homelessness for individuals with disabilities.

Congress should strive to decouple long-term services and supports from other supports such as TANF, SSI, and Medicaid. Long-term services and supports are simply a key component for being active and being able to be substantively employed and being in the community. Congress should also direct the Center for Med-

icaid and Medicare Services, CMS, to require reasonable movement on waiting lists for HCBS waivers.

Finally, with regards to brain injury, the barriers faced by Americans with disability from brain injury are much the same as those faced by individuals with disabilities from other causes. Yet the medical and cognitive disabilities resulting from brain injury present a unique set of features that demand recognition and response.

As a provider of information, navigation, and support for individuals with brain injury, I've observed that on the medical front, the length of stay for essential acute and post-acute rehabilitation has been pared to a paltry 18 to 21 days on average. That pushes people into the community quicker and sicker than ever before. People used to be receiving months and months of necessary rehabilitation. That's just not the case anymore. In too many cases, discharge is not even to a community setting but to long-term institutionalization lost to any system of care or account.

These rehab limitations often result in prolonged disorders of consciousness with families and communities not prepared to cope with the needs, supports, and changes resulting from brain injury, and far too many experience financial ruin, homelessness, or incarceration. A survivor of brain injury stated to me recently that "We in the brain injury community are no longer the silent epidemic. We are the throw-away group."

Community-based brain injury services are few and far between, and all too frequently individuals with brain injury are faced with seeking services and supports within systems developed for other populations which are resistant to expanding to include brain injury. Support staff often don't understand or address the cognitive and behavioral challenges associated with brain injury, and agencies and programs are resistant to funding services for this population and are struggling to address their mandated or priority populations.

Clearly, more funding at both the Federal and State level is necessary to deploy medical and long-term services for people with brain injury. I thank this committee for your recent passage of the TBI Act. That's a big change.

I also have included in my written testimony recommendations developed by the One Voice for Brain Injury Consortium in the fall of last year. In that document, seven national brain injury organizations presented considered congressional responses to the needs facing Americans with brain injury.

Thank you for the opportunity to testify today, and I look forward to answering your questions.

[The prepared statement of Mr. Lauer follows:]

PREPARED STATEMENT OF GEOFFREY M. LAUER

INTRODUCTION

Chairman Harkin, Senator Alexander, and members of the committee, I am Geoffrey Lauer, the executive director of the Brain Injury Alliance of Iowa, the chairman of the Iowa Olmstead Consumer Task Force, and a member of the board of trustees of the United States Brain Injury Alliance. I have worked for more than 25 years as an advocate and service provider with and for individuals with disabilities. The organizations I am honored to work with also provide services, support and advocate for and with, hundreds of thousands of Americans with long-term disability from

brain injury and other causes. Consequently I am keenly aware of many barriers with respect to economic self-sufficiency for persons with disabilities.

The Brain Injury Alliance of Iowa was the second chartered State affiliate of the Brain Injury Association of America, founded as the National Head Injury Foundation in the early 1980s by my friend and colleague Marilyn Price Spivak.

The Brain Injury Alliance of Iowa more recently is a founding member of the United States Brain Injury Alliance which, with its 21 member States, works to improve the lives of individuals with brain injury and their families through awareness, prevention, advocacy, support, research and community engagement.

Iowa's Olmstead Consumer Task Force was formed in 2003 via Executive order by then Governor Tom Vilsack to advise the Governors' Office on strategies to remove barriers to community living to Iowans with disabilities and promote community integration through changes in State policy and programming.

There are a number of things that I hope to accomplish with my testimony today. However before I get into the specifics I wish to thank the committee for their support of the Traumatic Brain Injury (TBI) Reauthorization Act of 2014. The TBI Act is the only Federal law that authorizes agencies within the U.S. Department of Health and Human Services (HHS) to conduct research and public education programs and to administer grants to States and protection and advocacy organizations to improve service system access and coordination for the 2.4 million civilians who sustain traumatic brain injuries in the United States each year. As a modest first step, the TBI act has been a tremendous success to catalyze systems change and improvement for Americans with brain injury and their families.

I also wish to thank Chairman Harkin for his superlative service to the State of Iowa and to our Nation for more than four decades. His deep commitment as a champion for the civil rights of Americans with disabilities is deeply appreciated from Cumming, IA (his hometown) to every corner of this country.

Yet as the Chairman well knows there is much yet to do. Each day across our country millions of Americans with disabilities are faced with navigating a shifting maze of daily challenges related to both disability and income. These include an array of environmental, health care, social, economic, institutional and attitudinal barriers. These range from transportation to a job or to the grocery store to inexcusably low expectations for individuals with disabilities from the teachers and professionals that serve them.

SELECTED BARRIERS—GENERAL

Asset Limits

Federal programs of public assistance are essential in providing a safety net preventing many from falling into extreme poverty. However without question is the fact that many income and work support programs maintain eligibility requirements that serve as blockades to individual and family economic self-sufficiency. One of the most egregious of these eligibility requirements are impossibly low programmatic limits to assets. Asset limits for a number of Federal programs have the effect of "trapping" individuals with disabilities in poverty. These limits have not only been ravaged by inflation, they are ridiculously low. For example, the current limits for Supplemental Security Income, or SSI, which are set by the Federal Government have been, since 1989, set at \$2,000 for an individual and \$3,000 for a couple or a disabled child living with their parents. Had such limits been linked to inflation they would be more than \$8,500 for individuals and \$12,800 for both couples and families with disabled children today.

These low limits plague programs such as SSI even with well intentioned Federal and State efforts to accommodate employment such as Social Security's "Plan to Achieve Self Support" (PASS). In fact, such programs require such level of sophistication to appropriately access, update, and respond to that many fear making critical errors in planning and implementing employment. Such errors often result in loss of benefits or having to return overpayments and in a belief that employment is not worth the risk of the loss of benefits.

Let me share a story about Jason, which is illustrative. Jason is a young man with a disability in Iowa. He receives SSI benefits and Medicaid. Jason began working at a local factory and his first check totaled \$400 a week gross. However when his local caseworker learned of this income the response was panic. The caseworker told Jason that with such income he would lose all of his benefits, including his Medicaid. This was shared with Jason despite there being available and well-documented State based options for him to retain his Medicaid while working toward genuine independence. Jason and his caseworker, like many others, were victims of the widespread belief that substantial work is much more a threat than an opportunity. Support staff, acting in what they feel is the best interests of their con-

sumers are many times the ones that are limiting people with disability in their movement toward self-sufficiency.

Individuals with Social Security Disability Insurance (SSDI) also face significant asset limits that act as barriers to self-sufficiency. SSDI recipients frequently describe a fiscal or financial “cliff” when seeking to escape public support.

For example, Tom is an Iowan who experienced a disability after many years working in the IT sector. He and his children receive more than \$3,000 per month in support from SSDI. He relies on Medicare for his health care. He is finishing a Masters Degree in Rehabilitation Counseling and has a goal to start a small business providing computer repair and assistive technology design. However, with his benefits threatened with termination if, and when, he earns more than \$1,000 per month he stands at a “fiscal cliff” in that if he is not able to earn in the range of \$40,000–\$50,000 per year he risks a significant cut to his ability to support his family. Tom and hundreds of thousands of others like him would benefit greatly from the option of having their benefits reduce in relation to their income vs. dropping off at an unreasonably low, fixed level. They also need the ability to retain their Medicaid and/or Medicare coverage as they re-enter the workforce vs. current program rules, which drop such coverage when asset limits are met.

Across the States asset limits are inconsistent, and many times set at very low Federal levels, for other Federal programs including Temporary Assistance for Needy Families (TANF), the Supplemental Nutrition Assistance Program (SNAP), and the Low Income Home Energy Assistance Program (LIHEAP).

The result of such limits is an inability to develop and/or retain a modest amount of savings to mitigate against financial set-backs that can result in dire outcomes such as eviction or having utilities shut off. Savings are also key for individuals with disabilities whose goal is self-employment, starting and running a small business, or paying for essential medical or assistive technology products not covered under insurance.

The complexity of the income and health insurance systems results in many feeling as if it would take, as one individual shared with me, “six attorneys and an estate planner” to successfully navigate the impacts of earned income on benefits. Consequently, there is a clear and pervasive perception among individuals with disabilities, their families and service providers that trying to become economically self-sufficient, within the current asset limit caps, simply presents too high a risk of losing essential medical coverage through Medicaid or Medicare as well as income supports through such programs as SSI.

Recommendation—Asset Limits

1. Congress should significantly increase the outdated SSI asset limits and index them to inflation. The SSI asset limits have not increased for more than 25 years, effectively shrinking the amount of money that recipients can hold in savings. Bringing the limits to at least \$10,000 for individuals, \$15,000 for couples and families with disabled children, and then indexing these limits to inflation would alleviate needless economic insecurity among individuals with disabilities and their families.

2. Congress should address the “fiscal cliff” for individuals utilizing SSDI and, in addition, allow an extension of medical benefits for individuals working toward self-sufficiency.

3. Congress should remove asset limits for TANF, SNAP, and LIHEAP. This would create a uniform national standard and remove complexity and variability across States. It would enable families to receive benefits when they fall upon hard times and would enable recipients to build savings and plan for the future.

4. Congress should increase support for disability resource facilitation, navigator, and aging and disability resource center programs.

Long-Term Services and Supports

Long-term services and supports (LTSS) in State Medicaid programs are a means to provide medical and non-medical services to seniors and people with disabilities in need of sustained assistance. Medicaid LTSS includes services to aid individuals with activities of daily living (ADL) and instrumental activities of daily living (IADL). ADLs include eating, grooming, dressing, toileting, bathing and transferring. IADLs include meal planning and preparation, managing finances, shopping for food, clothing and other essential items, performing essential household chores, communicating by phone or other media and traveling around as well as participating in the community. LTSS are provided both as part of State Medicaid programs as well as within Home and Community Based Service Waivers.

There are two major dimensions of long-term services and supports that I wish to highlight. First are the fiscal limitations of State and Federal programs (asset

limits) that support LTSS essential to economic self-sufficiency and independent community living for individuals with disabilities. Many individuals face a devastating reduction in funding for LTSS if they become substantively employed. The costs of LTSS are seldom sustainable at, or modestly beyond, the current asset limits and therefore result in millions of persons with disabilities concluding that such personal and financial goals are not worth the risk of losing such supports.

The second dimension of LTSS I wish to highlight has to do with unreasonably long waiting list for LTSS via the Medicaid Home and Community Based Services Waiver programs that States are allowed to operate. These programs are intended to waive a Medicaid bias toward institutionalization. In 2012, there were more than half a million Americans on waiting lists for an average of more than 27 months (**PAS Center, UC / San Francisco, 2013**). Many States are not providing funding to keep HCBS waiting lists “reasonable” and are inconsistent in their scope of prioritization for services. In fact one third of States are without a process to prioritize services. The result is decreased recovery for individuals with disability from brain injury and increased nursing home placement, increased incarceration, and increased homelessness for individuals with disabilities.

Recommendation—Long Term Services and Supports

1. In addition to the recommendations in the section on Asset limits (above) Congress should strive to decouple LTSS from other supports such as TANF, SSI or Medicaid. The goal must be that if you need LTSS you can access them. The sustained availability of LTSS will open the door for many individuals who seek to achieve increased self-sufficiency. These services should be a basic right in support of community living with copayments beginning only after significant income.

2. Congress should direct the Center for Medicare and Medicaid Services (CMS) to require reasonable movement on waiting lists for HCBS Waivers and to deploy consistent methods to prioritize such waiting lists based on risk to the individual as well as amount of services needed.

Transportation

As we approach the 25th anniversary of the ADA, millions of Americans with disabilities lack access to affordable and available transportation. This is especially true for individuals who live in rural communities. Across Iowa and across much of the country lack of access to regular, reliable and affordable transportation to access basic services, education, appointments, health care, and employment is still a major barrier to individuals with disabilities. You cannot participate if you cannot “get there.”

Recommendations—Transportation

1. As Congress works to address how best to rebuild and repair our Nation’s roads, bridges, railways, and ports, and where and how to prioritize investments in public transportation, it is vital to take into consideration the needs of people with disabilities.

SELECTED BARRIERS—BRAIN INJURY

The United States Brain Injury Alliance (USBIA) represents 21 State members including the Brain Injury Alliance of Iowa. Through member States and their individual members and constituents USBIA works to provide basic information and resource for community level services and supports. Brain Injury is one of many disabilities that can strike at any age. The U.S. Centers for Disease Control and Prevention estimates that there were 2.4 million emergency department visits, hospitalizations, or deaths associated with TBI alone or in combination with other injuries in the United States in 2009. Brain Injury is a leading cause of death and disability in the United States that affects persons of all ages, races/ethnicities and incomes. Any injury to the brain—regardless of type, cause or severity—can change the way a person moves, talks, thinks, feels and acts. TBI can cause epilepsy and increase the risk for Alzheimer’s disease, Parkinson’s disease and other brain disorders that become more prevalent with age.

As a result of brain injury being the “signature injury” of war fighting in the past decade, combined with the increased awareness from sports related brain injury in professional and youth sports, one might think that awareness of the medical and disability needs of this constituency would be better positioned for response. Sadly this is not yet the case.

Many of the barriers to self-sufficiency for individuals with disability from brain injury are those faced by individuals with disability from other causes. However, brain injury presents a unique set of features that demand recognition and response.

The nature of brain injury is highly variable. Injury is often characterized as mild, moderate to severe and outcomes from these injuries are variable as well depending on a host of features unique to each individual injured, the nature of the injury and the speed and acumen of immediate and subsequent response.

However, those of us providing lifelong information, navigation and support for individuals with brain injury recognize that on the medical front the length of stay for essential acute and post-acute rehabilitation has been pared to a paltry 18–21 days on average. Limitations on rehabilitation are pushing individuals with brain injury out of rehabilitation and into the community “quicker and sicker” than ever before. In too many cases discharge is not even to community but to long-term institutionalization lost to any system of care or account.

These limitations often result in prolonged disorders of consciousness. Families and communities are not prepared to cope with the needs, supports, and changes resulting from brain injury and far too many experience financial ruin, homelessness, incarceration, and death. A survivor of brain injury stated to me recently that we are no longer the “silent epidemic”—we are the “throw away group.”

All too frequently individuals with brain injury are faced with seeking services and supports within systems of support that were developed for other populations of persons with disabilities and which are resistant to expanding to include brain injury. Support staff often does not understand or address the cognitive and behavioral challenges associated with brain injury. Agencies and programs are resistant to funding services for this population, as they are struggling to address their mandated and/or priority populations.

Clearly more funding at both the Federal and State level is necessary to deploy needed medical and long-term service and supports for Americans who have disability from brain injury.

Recommendations—Brain Injury

1. Congress should pass the TBI Reauthorization Act of 2014.

2. Attached please find a set of recommendations to strengthen existing legislation and programs for individuals with brain injury developed by the “One Voice for Brain Injury Consortium” in the fall of last year. In this document seven national Brain Injury organizations present considered congressional responses to the gaps and needs facing Americans with brain injury.

Thank you for the opportunity to testify today. I look forward to answering your questions.

The CHAIRMAN. Thank you very much, Mr. Lauer.

And now, Justin Herbst, welcome and please proceed.

STATEMENT OF JUSTIN HERBST, HUMAN RESOURCES SUPERVISOR, UNITED PARCEL SERVICE, WESTERN SPRINGS, IL

Mr. HERBST. Good morning, Chairman Harkin and Ranking Member Alexander and Senators of the HELP Committee. My name is Justin Herbst. I am honored and humbled to be with you today in Washington, DC.

I have cerebral palsy because I was born 10 weeks early, and I had a serious stroke when I was only 3 days old. However, my disability has never deterred me from achieving my goals. I am the perfect example of what the Individuals with Disabilities Education Act can do for American children.

I grew up in Western Springs where I was fully included in regular education classes since kindergarten. Throughout school, I was encouraged to compete with my able bodied peers. I had an Individualized Education Plan and received PT, OT, Speech and other Special Education services. I made plenty of friends and never felt excluded because of my disability.

After graduating from Lyons Township High School, I attended Southern Illinois University thanks in part to a Pell grant and support from the Department of Rehabilitation Services. Southern Illinois University is a great school and gave me many opportunities to grow as an individual. While at Southern Illinois, I received help

through the Disability Support Services Office, including extra time, note takers, and alternative test sites. I am proud to tell you that I achieved a 3.49 GPA with a bachelor's degree in history and a minor in philosophy.

The U.S. Government has assisted me tremendously in helping me get to where I am today. Through the Illinois Department of Rehabilitation Services, I have a personal care assistant to help me get in and out of bed, toilet, dress, shower, cook, and clean. I will always need the support of a personal care assistant, because I am a quadriplegic and I cannot move on my own. It is difficult to be a quadriplegic, but it is the life I live, and I would not trade it for any other, and I welcome the advocacy.

During college, when I was not working, I received Supplemental Security Income, which was approximately \$670 a month, to help me live independently. I always knew SSI was a temporary solution because I wanted to join the workforce and make my own success story, and I, indeed, did.

After graduating from Southern Illinois University, I found a wonderful job working at UPS at the Hodgkins, IL facility. The UPS Chicago Area Consolidation Hub, also known as CACH, is the largest ground package sorting facility in the world. UPS is approximately 4 miles from my home. As a UPS employee, I receive benefits like medical insurance, dental and vision insurance, vacation time, continuing education, and job training. I am also eligible to receive 3.5 percent matching contributions from UPS to a 401 retirement plan.

UPS has been extremely accommodating regarding my disability. They understand my disability and my strengths, and I have always felt like a strong part of the UPS team. Since becoming an employee of UPS, I no longer receive SSI benefits. I am able to give back to Uncle Sam as I am now a taxpayer. Last year, I earned \$27,800 working at UPS and paid \$6,000 in taxes: \$4,500 to the Federal Government and \$1,300 to the State of Illinois.

I am thankful for my parents, family, friends, teachers, therapists, coworkers, Illinois Department of Rehabilitation Services, and the U.S. Government, who have all helped me become the man I am today.

Despite all of the successes I have had in my life, I still face glaring problems in keeping my job. I am not eligible for transportation services from the PACE Disability program because of where I live. I live more than three-quarters of a mile from a fixed bus route and my job is more than three-quarters of a mile from a fixed bus route, so paratransit services are not available to me. My parents, who are behind me, must drive me to work every day. If my parents could not drive me to work every day, I would not be able to keep my job, and that would be a shame.

Also, I cannot fully participate in UPS's employer sponsored 401(k) retirement plan like other employees. Although I am no longer receiving SSI income payments, I am still enrolled through the 1619(b) program so that I am eligible for Medicaid. This means that if I have over \$2,000 in assets I will lose my Medicaid benefits, as my colleagues pointed out.

And, more importantly, if I have over \$17,500 in assets I will lose my personal care assistant benefits from the Illinois Department of

Rehabilitation Services. If I lose my personal care benefit, I cannot work or even get out of bed. So I'll be laying in bed for the rest of my life.

It is unfair that I work hard at UPS and I am eligible for a retirement plan, but the current policies do not allow me to save for my retirement like able bodied workers. If I save for my retirement, I risk losing the benefits that allow me to live a healthy, happy, and full and independent life—my personal care assistant.

I encourage the HELP Committee to eliminate access barriers to transportation, housing, and saving for our retirement so that people with disabilities can live the American Dream. I want my piece of the American Pie.

Thank you for giving me the opportunity to speak with you today. It was an honor.

[The prepared statement of Mr. Herbst follows:]

PREPARED STATEMENT OF JUSTIN HERBST

Good Morning Chairman Harkin and Ranking Member Alexander and Senators of the HELP Committee, my name is Justin Herbst. I am honored and humbled to be with you today in Washington, DC.

I have cerebral palsy because I was born 10 weeks early and I had a serious stroke when I was only 3 days old. My disability has never deterred me from achieving my goals.

I am the perfect example of what the Individuals with Disabilities Education Act can do for American children. I grew up in Western Springs, IL where I was fully included in regular education classes since Kindergarten. Throughout school, I was encouraged to compete with my able-bodied peers. I had an Individualized Education Plan and received PT, OT, Speech and other Special Education services.

I made plenty of friends and never felt excluded because of my disability. After graduating from Lyons Township High School, I attended Southern Illinois University thanks to a Pell grant and support from the Department of Rehabilitation Services (DRS).

Southern Illinois University is a great school and gave me many opportunities to grow as an individual. While at Southern Illinois, I received help through the Disability Support Services Office including extra time, note-takers and alternative test sites. I am proud that I graduated with a Bachelor's Degree in History, a minor in Philosophy, with a solid 3.49 GPA.

The U.S. Government has assisted me tremendously in helping me get to where I am today.

Through the Illinois Department of Rehabilitation Services, I have a Personal Care Assistant to help me get in and out of bed, toilet, dress, shower, cook and clean. I will always need the support of a personal care attendant, because I am a quadriplegic and I cannot move on my own. It is difficult to be a quadriplegic, but it is the life I live and I would not trade it for any other.

During college when I was not working, I received Supplemental Security Income, which was approximately \$670 a month, to help me live independently. I always knew SSI was a temporary solution because I wanted to join the workforce and make my own success story.

After graduating from Southern Illinois University, I found a wonderful job working at UPS at the Hodgkins, IL facility. The UPS Chicago Area Consolidation Hub is the largest ground package sorting facility in the world. UPS is approximately 4 miles from my home. As a UPS employee I receive benefits like medical insurance, dental and vision insurance, vacation time, continuing education and job training. I am also eligible to receive 3½ percent matching contributions from UPS to a 401(K) retirement plan. UPS has been incredibly accommodating regarding my disability—they understand my disability and my strengths—and I have always felt like a strong part of the UPS team, able to give back and work independently.

Since becoming an employee of UPS, I no longer receive SSI benefits—I am now a taxpayer!

Last year I earned \$27,800.00 working at UPS and paid \$6,000 in taxes: \$4,500 to the Federal Government and \$1,300 to the State of Illinois.

I am thankful for my parents, family, friends, teachers, therapists, co-workers, Illinois Department of Rehabilitation Services, and the U.S. Government, who have all helped me become the man I am today.

Despite all of the successes I have had in my life, I still face glaring problems in keeping my job:

I am not eligible for transportation services from the PACE Disability program because of where I live. I live more than three quarters of a mile from a fixed bus route and my job is more than three quarters of a mile from a fixed bus route, so paratransit services are not available to me. My parents must drive me to work every day. If my parents could not drive me to work every day, I would not be able to keep my job.

Also, I cannot fully participate in UPS's employer sponsored 401(K) retirement plan like other employees. Although I am no longer receiving SSI income payments, I am still enrolled through the 1619(b) program so that I am eligible for Medicaid. That means that if I have over \$2,000 in assets I will lose my Medicaid benefits; and more importantly, if I have over \$17,500 in assets I will lose my Personal Care Attendant Benefits from the Illinois Department of Rehabilitation Services. If I lose my Personal Attendant I cannot work, or even get out of bed!

It is unfair that I work hard at UPS and I am eligible for a retirement plan, but the current policies do not allow me to save for my retirement like able-bodied workers. If I save for my retirement, I risk losing the benefit that allows me to live an independent, happy and healthy full life—my personal care attendants.

I encourage the HELP Committee to eliminate access barriers to transportation, housing and saving for our retirement, so that people with disabilities can live the American Dream.

Thank you for giving me the opportunity to speak with you today—it was an honor.

The CHAIRMAN. Well done. Thank you very much, Justin.

Thank you all for wonderful testimonies. We'll start a round of 5-minute questions now.

I will start with Ms. Kwong. You mentioned you had mixed experiences with your State's Department of Rehabilitation agency, which was sort of limiting you. How did you overcome that discouragement and low expectations from some of your counselors? What was that experience like?

Ms. KWONG. For me, although my parents did not speak English, they knew the value of an education. I was very privileged enough to have very supportive parents who told me at a young age that you should go to a university. You are capable of going to a university and succeeding there. They were a huge support. They drove me to my activities, so they were physically there, and they were emotionally very supportive.

And as you had mentioned when you were doing my introduction—I was very privileged also. I applied, qualified, and was eventually honored as a Gates Millennium Scholar. So I did not have to necessarily be restricted or depend on my DOR counselor to financially pay for my college.

But, basically, their low expectations and their vision for me was after I finished high school, although I had a 4.3 GPA, I was not allowed to go to college, because I had to go to an independent training center, and then go to a 2-year community college or a trade school, and then work at a factory or a call center, because statistics reveal that individuals with disabilities do not graduate from college, so they were protecting me.

The CHAIRMAN. You were at Berkeley.

Ms. KWONG. Correct.

The CHAIRMAN. That's the University of California, right, at Berkeley?

Ms. KWONG. Correct.

The CHAIRMAN. How accommodating have they been for you?

Ms. KWONG. I think for the most part they've been—at least, the disability office—they've been very accommodating in providing alternative test formats to textbooks as best they could, and also in providing tutoring for subjects such as statistics. There were some issues when I attempted to take a foreign language with different faculty in various departments at the university.

But, overall, the disability services program has been instrumental, and they also offered a class that discussed basically interview skills and talked about the student exclusionary rule and kind of exposed us to various opportunities and various policies out there that could help us achieve self-sufficiency. So the course was definitely a big part of my knowledge and my professional development that I have today.

The CHAIRMAN. As a point of information, Ms. Kwong, I was recently out near Berkeley a couple of weeks ago to visit a place called DREDF, the Disability Rights Education and Defense Fund. I don't know how close they are. I don't know all my directions out there. But they're very good. If you ever need any help or information, assistance, advice, that's a great group. I don't know if you're familiar with them or not.

Ms. KWONG. Somewhat. Thank you for the information.

The CHAIRMAN. DREDF, it's called, but it's out there and they're great people.

Senator Massey, when you were talking about needing further collaboration between entities—and that's sort of a question I have for Dr. Lozano, too, and others. Even as long as I've been involved with disability policy and laws, I still get confused. There are so many different tentacles out there. When I go out and meet with groups or meet with people in Iowa or other places, all of a sudden, I just realize how confusing it must be for somebody.

I understand what happens is as we go through years here in the Congress, we address one problem and we put that aside, and then we address another one. Pretty soon, silos get built up, and you have all these different strings out there. Can you help us think about how do we start getting this kind of collaboration where you just don't have a mine field out there that you have to weave through to get the supports and services that a person needs?

Senator MASSEY. Thank you, Chairman. It's a difficult question. I know in Tennessee, you have people that do have—whether they're working with an adult provider or they have a great family that is advocating for them and helping them through the system, it's still difficult. And then you have a lot of folks out there that really don't have anybody helping them through the system. I know we didn't really address folks with mental illness as much today, and a lot of those folks really don't have the people that are helping them navigate.

So I think, in Tennessee, we're going to do a memorandum of understanding between our State agencies. We'll have to see how well that goes. I know I've worked with a group of providers and some of the staff at the Department of Intellectual and Developmental Disability looking at regulations that were duplicative. Of course, you'd think that might be easier than not, but it's like you say.

There's the silos. But oftentimes you just have to do everything two and three and four times.

I reached out to a lot of the advocates and the providers in the State before I came over here on Monday, and they sent me a lot of suggestions. One of the things was to come up with kind of an electronic—similar to an electronic medical record, but that would—if somebody was applying for this or applying for that, they could have one record, and they could release it so the next agency could access it so they wouldn't have to fill it out two and three and four and five times every time they do something.

It's difficult, but anything will be an improvement because there are a lot of road blocks there. I appreciate you all's efforts, and I think convening a group of folks that have had to deal with that and establishing a work group with some employees of CMS and Social Security and some of the grassroots people that have faced the barriers and say, "OK. Look at this."

The CHAIRMAN. I'm going to yield to Senator Alexander. But I just heard here that sometimes these things are so confusing that even the support staff, the agency workers, get confused and give misinformation to people.

Senator MASSEY. Absolutely.

The CHAIRMAN. Senator Alexander.

Senator ALEXANDER. Senator Massey, we've talked about the ABLE Act here and the asset limits. Everyone has mentioned the asset limits. As you think about the Tennesseans with whom you work, what would be the effect of the ABLE Act on those individuals?

Senator MASSEY. Thank you, Senator Alexander. I think it would be a huge impact on folks that have active families that could put some money aside for their individual without fear of hurting their benefits. A lot of these families—unfortunately, one of their dreams is to live 1 day longer than their child, because they're just not certain that the systems are in place—even if they've got good providers—to really take care of them. This would give them some peace of mind.

The folks that I worry about a little bit more—probably two-thirds of the folks we serve in our residential programs have no families or they're from very indigent families. So they would not have the ability to open up the savings account and put really anything in it. That's why I think it would—coupled with maybe looking at the \$2,000 asset limit on benefits.

If one of our individuals work—and we've served some fairly severely challenged folks at Sertoma, and a lot of them are aging. Over half are over 50. A couple are in their eighties. The systems are a lot better for living long lives now, because a lot of these folks were only supposed to live to their teens.

They might be able to build their assets up to maybe \$3,000. But then they're able to have it to plan for emergencies and to help with their poverty level and to do things as opposed to having to spend it the second it gets over \$2,000 for fear of losing the benefits. So I think we need to look at that as a two-pronged approach.

The ABLE Act will help hundreds of thousands of folks across the country and I know a lot in Tennessee, and it will be very appreciated. So I hope we pass it soon.

Senator ALEXANDER. Let me ask you one other thing on a little different subject. I'm sure you must have been involved with Governor Haslam's Executive orders which refocuses the way Tennessee spends the available money. The idea would be to shift from paying around the clock residential care to paying for more limited and less costly services like personal assistants with the idea being that you could help more individuals.

What's your thought about that? Do you think that's a good trend to shift priorities in that way? Is it actually going to be of assistance to more people?

Senator MASSEY. Thank you, Senator. They're still working on fine tuning that. They have gone around the State and met with providers and stakeholders about that. It would be moving it more to almost a managed care system. So there's pros and cons with that, and it will be basically a capped waiver.

The good part is that more people would be allowed to be served. I've talked to many families. I had one mother 1 day come in my office in tears and said that she had to lose everything she had to be able to get services for her son, who was significantly behaviorally challenged. Your heart breaks for these folks.

If we could get more folks served, that will be wonderful. My concern is that it is a capped waiver, and as the individuals get older, as their parents pass away, and they really don't have any other caregiver, that personal assistance won't work and that cap won't work. Hopefully, there's going to be a seamless transition so that they can get the services they need as they age.

They really do increase significantly—your folks with Down's get early onset Alzheimer's, and there's just different challenges there that we've experienced at my agency. So I'm hopeful. I'm going to be working with the departments there and doing what I can to give input on tweaking it as they work to write that new waiver.

Senator ALEXANDER. Thank you very much, Senator Massey.

The CHAIRMAN. I want to return just briefly to the ABLE Act, which I'm for and I hope we do get it passed. But keep in mind it only applies to people who have money. If you've got money, you're fine. But you used the terms, two-thirds of people with disabilities don't have families with money. For my family and my nephew, maybe that would be OK. But so many people are indigent, and they don't have that money.

But that's OK. It's a step in the right direction. Just keep in mind that the ABLE Act is only good for age 26 and under. There's a lot of people out there who are older than 26. Justin, how old are you now?

Mr. HERBST. I'm 27.

The CHAIRMAN. So it wouldn't even apply to him. When we first started developing this ABLE Act, we talked about—we wanted to make it \$100,000—any age. CBO came in with a score on it and said it was \$20 billion over 10 years. That sounds like a lot of money, but it's only \$2 billion a year, and that money doesn't just sit there. It's invested. It's growing. It's used in the economy, and it could be used by any age.

It seems to me that would be a small price to pay for the individuality, the peace of mind that parents would have about their children growing old. If you really had \$100,000 you could put away

without losing all your benefits, that could really enable you to get the transportation you need, to get the housing you need, and to make sure that when you got older, you would have some ability to use that money to live on. But now it's only \$25,000, and you have to be age 26 or under.

Like I said, it's better than nothing. But it really ought to be what we started out with, and that would be \$100,000 with no age limit—anybody—to get it. But we couldn't get it because of the so-called cost on it. I wanted to make that clear. We need to do something also for the indigent people who don't have the ability and don't have the families that have the money or the siblings to put that money away.

Mr. Lauer, you also talked about support being so complex that caseworkers don't understand it. We rack our brains on this. How do we improve training for people so that they do understand and they don't get confused? I get confused but I'm not on this every day. We have other things. But caseworkers who are out there—how do we get them better trained?

Mr. LAUER. Senator Harkin, I think that that is a point of question. We have a lot of turnover in Iowa and across the country amongst the individuals who are turned to for those kinds of solid responses and information on how to navigate the system. When you talked about this being a mine field, it very much is.

Having more focus on the folks who are out there helping navigate—mine sweepers, if you will—and there are a couple of programs that have already been shown to be effective. You have appropriations in the Older Americans Act to offer Aging and Disability Resource Centers. The ADRCs are a significant component. So putting more support into those ADRCs and in the D in the ADRC so that people can get rapid, reliable, and relevant information is big.

In the area of brain injury, I can tell you specifically that it's even more compounded because, for many people, not only navigating a system that is complex, to begin with, is siloed, has a huge range of changing factors with inconsistent responses, but also the tool that you're using to navigate it—your brain, your cognition, and having a cognitive disability makes it even more complex for individuals with brain injuries or families.

What we've found in the brain injury community and in many of our State member organizations, the United States Brain Injury Alliance, as well as the Brain Injury Association of America, is a program called Resource Facilitation. It's just exactly what people are asking for, which is help us figure out how to get through these systems. What we do is hire and train staff to know both the disability component, the medical component of brain injury, as well as tool up and stay aware of these many changing systems so that we're able to provide that reliable information.

Sadly, we're not just providing it to people with disabilities. We're oftentimes the ones who are educating the folks who are supposed to already know about these systems. It's not that they don't have a motivation to, but, again, the systems are complex. The siloes are complex, and people don't just show up with one need, as you mentioned. This is a big deal. They have co-occurring dis-

orders. As my colleague mentioned, mental health and brain injury go together—lots of different pieces.

But having navigators that are focused and having funding to support that specialty skill set would make a big difference, because there are too many programs out there to probably focus on.

The CHAIRMAN. Senator Alexander.

Senator ALEXANDER. Thank you. This committee and the Congress and the President recently reauthorized the Workforce Investment Act, and part of that was about helping students with disabilities transition from high school to college or good paying jobs. That was one of the major focuses. I wonder if any of you have had a chance to evaluate the changes that were in that Act and have any comment on them or other changes we still need to make.

I know, Dr. Lozano, you made a number of suggestions in your testimony, and I wonder whether you've had a chance to review the changes in that law or not.

Ms. LOZANO. Let me just say that I think one of the most important things that we can do is to use some of the changes that were made in that Act, specifically around preparation for employment and how to use the system—if we could combine that with some of the recommendations that come out with, hopefully, the reauthorization of IDEA.

One of the biggest problems is the transition from school into the workplace. I happen to know details of this transition problem, not only because I've had children that have been in that system, but also my husband is a vocational rehabilitation counselor. So he works daily with this issue.

I think there is a lack of collaboration between our systems, which has already been mentioned previously, and I think we need to look anew at how those systems can work together for the desired outcome of employment. I mentioned my child who has a developmental disability and also has mental illness. She had great expectations that she would be employed. This has not happened successfully for her at this point, part of the reason being that there are not the supports in place to give her a true employment experience. Some of this, of course, has to do with funding. But some of it also has to do with the lack of preparation that she received in the school system.

Senator ALEXANDER. Does anyone else have a comment on that?

Ms. Kwong.

Ms. KWONG. I think, as I previously mentioned, a lot of times, in order to be able to obtain successful full-time employment, you have to have a good resume and work experience. As you're going through school, academically, I believe that being well rounded and having actual work experience while you're going through academics is important in building up your resume, building up professional development, learning what workplace expectations are.

If there are restrictions as we go through school as students—"Oh, you can't make this much because you'll lose your SSI even though you're not full-time employed yet"—then students are discouraged. Those are the workplace disincentives that are making us not want to go out and gain those necessary work experiences to help us be better equipped and to build those resumes. Oftentimes, not only are the employers hesitant about whether students

with disabilities or individuals with disabilities can serve as functioning members of the workforce, but also sometimes ourselves because we have not had that experience.

I think more opportunities for students or for individuals as they transition to go out and have some sort of internship or part-time experience can help build individual confidence as well as show employers, not just tell them, that, "Look, I've worked before and I've been successful and I was productive."

Senator ALEXANDER. Thank you, Mr. Chairman.

The CHAIRMAN. I just want to say, Ms. Kwong, Senator Alexander and I and our staffs worked very hard to get this new Workforce Investment Act called the Workforce Innovation and Opportunity Act. One part of that is—and a big part of it, I hope—is to mandate that the VR agencies now in States must work with students in school that are under IEPs or IDEA programs to give them internships, summer jobs, summer coaching, that type of thing, just exactly what you're talking about.

That legislation just got signed into law, I think, in July. Hopefully, we'll see a big move in that direction to help young people get the kind of work experiences, buildup their resumes, just like you said. I didn't know if you knew that that was in that new piece of legislation. But it's exactly what you're saying.

Ms. KWONG. Thank you so much.

The CHAIRMAN. Justin, I want to ask you about work. You said that you work, you've got a great job, and you're working for a great company. But you said that you can't participate in the company's 401(k) and simultaneously preserve your Medicaid and personal care attendant benefits.

Mr. HERBST. I know. I know. It's absolutely ludicrous. I went in, and I just heard, if I go over \$17,500 that I lose my personal care benefits, and I was like, "What?" It's like when you're going to Halloween and you're left with an empty candy pumpkin. You reach in for the candy, and you don't find any, and you're like, "Where's the candy?"

It was like I didn't really know what the limits were until I saw \$17,500. And it's really discouraging to have that limit placed upon you and just didn't know that there is a limit. You feel like there's so many limitations, and you really can't go beyond them to move to a further independent goal.

When you feel like you're limited, what purpose is there in saying, "I got a 401(k). I want to buy my wife a house, and I want to have children, and I want to provide for them," when you see a limitation. I'm just saying that it's really discouraging.

The CHAIRMAN. I have to say this again. I have a nephew who is quadriplegic. He has lived a full life, and still is, quite frankly, but he also got married, had children, and has always had support services no matter how much money he made. How did he do it? Because he was injured in the military.

Under the VA. I know we've heard a lot of problems about the VA. But I'll tell you that all my experiences with the VA have been wonderful, both with Kelly, my nephew, and also his father, a World War II veteran.

But under the VA, you can make as much money as you want, and you still get the personal attendant services that he needs, like

you, to get up in the morning, get out of bed, get bathed. But he can go to work and he can make money. If we can do that for our disabled veterans—and it's proven valuable. He's a taxpayer, like you. It would seem to me that these asset limits—and I think I heard this from all of you—are nonsense.

But here's the problem. Every time we talk about raising these asset limits, we get back from OMB—and I don't care whether it's a Democratic administration or a Republican administration—cuts across them all—we get back from OMB the woodwork effect. Do you all know what I'm talking about? It's that people who are now perhaps not doing these things, perhaps being cared for by their families, will come out of the woodwork now because you raised these asset limits, and it will cost us a lot of money.

I don't buy that. I never have. It may cost us, but you're still working and paying taxes. Even if there is some, "woodwork" effect, OK, but they're going to be working and they're going to be paying taxes. So the budgetary impact is not as much as what people—they assume the woodwork, that they would come out, but they don't assume the other end of it, where they're paying taxes in.

The budgeting around here is nonsense. But I don't need to get into that. But they look at the expenditures and they don't look at the other side of the ledger at all, and that's what we have to confront on appropriations committees. Every time we do appropriations or we want to change these laws like this, we see the outgoing money, but we don't take into account the money that would be coming into the Treasury from people who are working.

Anyway, I didn't mean to go off on that. But I think you're all aware of it. We just need to make sure that we address it in a better manner than we have in the past.

I want to ask one other question both of Mr. Lauer and Dr. Lozano. Senator Massey had an interesting suggestion. She said that maybe we should have something like a medical electronic record where everything is put in one place and it can be used by anybody in any one of those silos to access it so you don't have to continually fill out different paperwork. Does that have some semblance of credibility? Can we do something like that?

Mr. LAUER. I think we can, Senator. I think the healthcare industry is being pushed in that direction pretty quickly. One of the big challenges, I think, for many people with disabilities is the tracking and being able to respond consistently to the regular reporting and requests for information from all the different kinds of organizations that they're encountering. If their information was able to be kept in a consistent place, updated consistently, it would probably do a great deal to reduce the confusion and, frankly, the inability of people to find records.

I know that in the population of people with brain injury, obviously, there are some memory issues that people can have, and trying to keep track of records and being able to respond can be very difficult. So I believe that would be beneficial.

The CHAIRMAN. Dr. Lozano.

Ms. LOZANO. I also think it would be very helpful to have even like a clearinghouse for records of people with developmental disabilities. I know when you go from one program to another, they'll

request sometimes an IQ repeatedly, time and time again. It seems like a waste of effort and a waste of money, certainly, to do that.

My only concern is the confidentiality issue. I think this is particularly important when it's for people with mental illness. So I think that would be something that we would have to examine very closely before or as this was established. But, once again, I think it would be a very good idea to do that so that we could reduce some of the duplication of tests and so on.

The CHAIRMAN. Senator Massey.

Senator MASSEY. I think to address that issue, the individual would sign a release for that information. So you would have that safeguard on there for the confidentiality. That way, it would be released only with their permission.

The CHAIRMAN. By the way, I need to make a correction. Regarding the ABLE Act, I misspoke. I said age 26. If the disability occurred before age 26, you're still OK; you can participate. I misspoke on that. But if you're disabled after age 26, you're out of luck, and that doesn't seem to be right.

On the Traumatic Brain Injury bill that passed the House this summer, it passed the Senate on Tuesday of this week and goes back to the House. They're supposed to be in today, maybe tomorrow. They'll either bring it up then, because we worked it out pre-conference with them, but if they don't, they'll bring it up when we come back in a lame duck session. So it's basically done.

Mr. LAUER. Thank you. That's excellent.

The CHAIRMAN. I just wanted to let you know that.

Mr. LAUER. I appreciate that, Senator Harkin.

The CHAIRMAN. The bill called the Community Integration Act that I introduced earlier this year to get rid of the Medicaid institutional bias—well, it's there. Obviously, I don't think it's going to go anywhere this year. We're about done. We'll go into a lame duck session. You never know, but probably not. It's for future Congresses to wrestle with.

But it seems to me—and I think I read it in one of your testimonies. Someone said that the waiver ought to be the other way around. You ought to have to have a waiver to get institutionalized.

Was that you, Dr. Lozano? One of you said that.

Ms. LOZANO. Yes, I did. I said that. I think that would be a wonderful boon, that you had to ask for a waiver to go into an institution rather than the other way around.

The CHAIRMAN. That's the way I feel, too. But, hopefully, future Congresses will take that up and finally get rid of that institutional bias.

Do any of you have anything that you wanted to add that I didn't ask or Senator Alexander didn't ask but maybe you didn't quite point out in your testimony that you would like to bring up before we go?

Yes, Senator Massey.

Senator MASSEY. Thank you, Mr. Chairman. Just one thing. Going back to talking about the asset limit and the \$2,000, while I do think it needs to be totally readjusted, I think at the very minimum—because of the woodwork effect and the problems there, at the very minimum, if a cost of living inflator could be put on it so

it's gradually going up and not stuck there forever, that would at least be a step in the right direction.

We just need to remember that there are the barriers, and if they work, oftentimes in a minimum wage job, it's not enough to lose their benefits over if they do. So we just really need to be looking at that. I would love to see a work group actually looking with both the folks from CMS and SSI and some folks that were actually affected by this to really give it a good hard look and make some recommendations.

The CHAIRMAN. Thank you. I think it ought to be adjusted up, as some of you said, so it would be at the same level it was 20 years ago when it was enacted, which is around \$13,000, and then index it. To me, that is the proper way to go.

Did anybody else have anything?

I'm sorry. Justin.

Mr. HERBST. I think there's very limited housing where I live. It's not that the housing doesn't exist. But as I was telling Mark, I think it's not really community oriented. You don't want to go around and see a bunch of Walmarts and Walgreens and not really go to any bars or any areas where I can socialize.

I'm 27 years old, I need to socialize, and I need to find a wife. Honestly—and I love my parents, but they know and I know that I want to move out and find a wife. I'm looking for more community oriented housing, and I'm looking for more places to just show my extroverted self. I think the extroverted nature of myself needs to come through. I would just really appreciate some more community oriented housing. Thank you.

The CHAIRMAN. You know, this is going out over C-SPAN and everything.

[Laughter.]

Would you like to just say what your email address is?

Mr. HERBST. No, I would not. But thank you, sir.

[Laughter.]

The CHAIRMAN. Mr. Lauer.

Mr. LAUER. It feels like The Bachelor here. That's great.

A couple of additional points, Senator Harkin. Thank you. One is transportation. As Congress looks to rebuild and enhance America's infrastructure and transportation from bridges to highways, really, a focus on transportation for people with disabilities has to be kept front and center. That is just a perennial issue, a challenge in Iowa and rural Iowa and across the country.

A second piece that I want to make sure to emphasize is, again—even though we do have waivers, and I'd like to have a waiver from the waivers or have it reversed—the waiting lists that many people face across this country are, frankly, unreasonable, unreasonable from a Supreme Court decision framework from the Olmstead decision. I know that you've been a champion of that.

But I really do think that Congress, through the Center for Medicaid Services, focusing on CMS and also perhaps the Department of Justice, should look at that and encourage or demand that those waiting lists be reasonable. For people with brain injury, waiting for services is effectively being services denied, and the loss of being able to have access to those supports impacts their rehabilitation.

The final thing I'd like to share with you, Senator Harkin, is a special thank you, and I want you to hear this. I wish to thank you, Chairman Harkin, for your superlative service to the State of Iowa and to our Nation for more than four decades. Your deep commitment as a champion for the civil rights of Americans with disabilities is deeply appreciated from Cumming, IA, to every corner of this country. On behalf of my fellow Iowans and people around this country with disability services, thank you.

The CHAIRMAN. Thank you very much, Mr. Lauer.

[Applause.]

Thank you all very much. Look, I'm retiring from the Senate but not from the fight. I'm still going to be involved. I'm going to be bugging him, see. After I get out of here, I'll knock on his door.

But this is an ongoing development. We're making some progress. We are. We're better off than we were last year or 20 years ago. But we're not quite there yet. On transportation, we're making some good progress. We've got quite a ways to go. Taxis—we're now getting taxis that are accessible. Mayor de Blasio of New York now has committed—and the city council moved that 50 percent of all taxicabs in New York City will be fully accessible by 2020. Pittsburgh came on. They're going to have 25 percent of theirs accessible by 2017. This is now spreading around the country.

I went to London, England about 3 or 4 years ago. Every taxicab in London is fully accessible, every single one of them. We can't do that here? Of course, we can, and we can have better public transportation also.

In employment, we're making good progress. Business owners, like David Abney, the CEO of UPS, have committed themselves to really have affirmative action, to go out and employ people with disabilities. About a year and a half ago, I was privileged to go up to Walgreens up in Connecticut to their distribution center. Mr. Wasson, who is the CEO of Walgreens, pointed out that at that time, 40 percent of all the people that worked there were disabled, 40 percent. And as he said to the assembled CEOs and me—and Pete Sessions from the House was there—said, "I don't do this out of the goodness of my heart." He said, "This is my most productive distribution center." He now has 50 percent of the people employed there.

But with minor changes, little things you could do here and there, a person with a disability can be fully productive, actually more productive in many cases than people without disabilities. I'll give another plug. Mr. Wasson has got his board of directors to agree that they have a goal of 10 percent of all of their employees in all their stores will be people with disabilities.

So these things are happening. I think for a lot of young people, especially with disabilities, their future, Ms. Kwong, is getting brighter and brighter for employment, and not just substandard employment but real, competitive, integrated employment.

Thank you very much for your kind words.

Thank you, Senator Alexander, for being a great partner through this and so many other things.

And to all of my friends here, I look forward to maybe being out there the next time we get together. But it's been wonderful to

work with the disability community at large all over America. You've been a great inspiration to me through all my endeavors, and I just can't tell you how much I have appreciated your input, even when you beat me up sometimes—you've got to do more, you've got to do more. But that's good. That kind of advocacy is very good.

With that, thank you all very much, especially to the panel here today. It's onward, with better employment opportunities, clearer lines of how people work to get the system to work so that they aren't losing their benefits when they go to work, and for young people like Ms. Kwong to make sure that they have every possibility of fulfilling their hopes and their dreams here in America.

Thank you all, the committee will stand adjourned.

[Whereupon, at 11:08 a.m., the hearing was adjourned.]

