

Statement of Alison M. Lozano, Ph.D.

before the United States Senate

Committee on Health, Education, Labor and Pensions

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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 forty 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% of Americans with disabilities living in poverty while in the general population it is 12.5%. 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 towards 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 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 forty 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 institutional 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% 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.