

50TH ANNIVERSARY OF THE
DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

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White House South Court Auditorium

Remarks of Sharon Lewis

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We've seen a lot of change in 50 years. In February of 1963, President Kennedy sent a special message to Congress in which he talked about the millions of people with, using the language of the time, mental illness and mental retardation. He acknowledged the need for a new approach in which, and I quote, "... the reliance on the cruel mercy of custodial isolation will be supplanted by the open warmth of community concern and capability."

So we're here today to honor that legacy. The last piece of legislation the President signed into law is also the first piece of legislation that acknowledged the importance of community over institutions. This law predates much of the contemporary federal disability policy in the country, but the DD Act continues to embody some of the most important and forward-thinking ideas.

As we'll hear from a broad range of speakers today, the world looked pretty different in 1963. In one of the first agency reports on the federal investments on behalf of people with ID/DD, an assistant secretary wrote about "a deepening awareness of the special needs of handicapped people who, because of physical, mental, or social handicaps are unable to achieve their full potential for leading productive, satisfying lives." Our language has since evolved to be more respectful, as has our understanding of the biggest barriers for people with disabilities. We know that disability itself is not the limiting factor in

leading a productive and satisfying life. The challenges are cultural, attitudinal, and environmental in nature.

The DD Act tells us that disability is a natural part of the human experience, yet we still have far too many individuals with ID-DD who do not have the same opportunities as their brothers and their sisters, their friends and their allies.

Ironically, as I was looking at these old reports from the mid 1960's, they all start with this great face plate -- done with an old typewriter, before computers -- that quotes from Title VI of the Civil Rights Act and states that federal grant activities on behalf of people with disabilities could not discriminate against people based on race, color, national origin. It's an interesting juxtaposition 50 years later now that we have the Rehabilitation Act and the Americans with Disabilities Act.

But even with these protections, are they the same? People with intellectual and developmental disabilities are the one part of our society -- and I would include people with mental illness -- for whom we continue to condone segregation.

Some educators still advocate for separate classes and separate schools, justifying the segregation in the name of specialized services. Providers struggle with supporting people in their own homes. And congregate care still dominates our residential service system.

Families grapple with the challenges of being supported in ways that facilitate a good life for themselves and their family members. And adults with ID-DD have trouble finding employers who will

give them a fair shot, and finding ways to be able to make contributions during a meaningful day without being parked in a sheltered workshop or adult daycare.

All of these systems were developed with the best intentions. In 1963, this is what we thought we could do. But we know better now. We have no excuses.

In large part, we know better now because of the DD Act and because of the entities that the DD Act supports, the University Centers, the Developmental Disabilities Councils and the Protection & Advocacy Services as well as the work of families, advocates and other allies.

And because we know that we can achieve the goals of self-determination, independence, productivity, and integration and inclusion in community life -- that these are not aspirational ideals -- we need to find ways to continue to innovate and evolve our thinking, our systems, and our communities.

The good news in all of this is that we have a whole generation of youth and young adults who have grown up under our civil rights laws. And they expect something completely different. They tell us, sometimes with their voices -- sometimes with their signs, sometimes through technology, and sometimes through their behavior -- that they're not interested in our old ways. They don't want to attend school for 22 years to graduate to day programs or their parent's couch. They want to complete secondary school with a meaningful credential. Some of them would like to go to college. They would like to work in competitive and integrated employment or spend their time contributing in other ways. They want to volunteer with friends, live as independently as possible in real and diverse

neighborhoods, and fall in love and create their own families.

One of the most important shifts that's taken place since 1963 is our understanding that not only do we need to honor the preferences of people with intellectual and developmental disabilities but, as Jeff mentioned, we need to support them to be the leaders and the voices of our movement even when it's the most difficult.

Far too frequently the well-intentioned perspectives of others -- professionals, providers, and sometimes, even family members -- dominate. We do not provide adequately for supported decision-making and self-determination among individuals who have the most substantial intellectual, communication and behavioral challenges. We need to stop. And we need to listen... in all the ways that we can hear, as they have much to tell us.

So among the many things that you're going to hear today, I believe that one of the most important challenges for the DD Network over the next 50 years is this: How do we continue to utilize this important statute and all that it brings with it, its many strengths, to ensure that the people at the heart of it, people with developmental disabilities, are the most important voices in our dialogue?

Fifty years from now, as the next generation celebrates the centennial of the first iteration of the DD Act, I hope that we are no longer having this conversation about inclusion and integration as goals, and that lack of equal opportunity is no longer part of our discussion.

Because by 2063, I hope that we will have achieved the vision -- and that all people with ID-DD

will be welcomed, contributing, fully participating, integrated and beloved members of our communities.

Thank you.