AUTISM SOCIETY
Improving the Lives of All Affected by Autism

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Written Testimony
Provided by

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On behalf of
Autism Society of America

For the
United States Senate Aging Committee Hearing

“Supporting Economic Stability and Self-Sufficiency as Americans with Disabilities and their Families Age”

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Thank you Chairwoman Collins, Ranking Member Casey and other Members of the Aging Subcommittee for holding this important hearing and accepting this written testimony. I am submitting this testimony on behalf of the Autism Society of America; however, I will also be sharing my personal story as a father of two adult sons with developmental disabilities.

The Autism Society of America just held its 50th annual conference and Hill Day last week with almost 400 participants. Our grassroots organization was established in 1965 by parents caring for what was then, an unusual disability called "autism." Not much was known about the disability back then. What these parents shared was the desire to keep their children with significant disabilities at home, not in an institution. They shared information and advocated for services to help them raise their loved ones at home along with their siblings. The Autism Society continues this mission.

I am the father of two individuals with significant functional limitations: David, age 19, has autism and Matt,22, has Down Syndrome; both have intellectual disabilities and developmental disabilities. Developmental disabilities are defined in law as physical or mental impairments that begin before age 22, are likely to continue indefinitely, and result in substantial functional limitations in at least three major areas of self-care.
In spite of these limitations, both of our boys are loved and valued members of our family and community. David and Matt are handsome, loving, thoughtful, caring individuals with so much to contribute to our family. We have no regrets regarding the decision to raise them at home. My wife, Elise, and I have been caring for them and our beloved daughter, Tara, their whole lives.

We know that David and Matt will not be able to care for themselves without significant supports. We worry about what will happen to them when we are no longer here to take care of their every need.

During their childhood, we just went day to day surviving. It is hard to find time to plan for their future. As our children are transitioning to adulthood, we are now forced to think about where they will live, how they will be able to find work, and how they will be supported after we are gone.

Elise and I purchased a four-bedroom home in April 2017 to be used as a group home for our son David and other individuals. To this date, David has not been able to move into and the house sits unoccupied. David has severe self-injurious behaviors and is non-verbal. We have been unable to find a licensed agency to operate the home. All agencies have declined due to inadequate provider rates to serve high-risk residents.

We are fortunate to have some resources for this planning but millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care and food and housing assistance. Eligibility for these public benefits

(SSI, SNAP, Medicaid) require meeting a means or resource test that limits eligibility to individuals to report more than $2,000 in cash savings, retirement funds and other items of significant value. To remain eligible for these public benefits, an individual must remain poor.

Thanks to Congress, the ABLE Act recognizes the extra and significant costs of living with a disability, and these individuals will be able to save. These costs include making our house accessible, accessible transportation, trained respite care, personal assistance services, assistive technology, health and behavioral health care not covered by insurance. I am looking into opening one of these accounts right now. Congress must also be aware that many individuals and families will not have the extra money to put into these ABLE accounts. In addition, those individuals diagnosed after the age 26 are not eligible for ABLE accounts.

Many individuals with autism and other developmental disabilities are able and want to work. However, they are prevented from making enough money to be self-sufficient for fear of losing the small amount of income supports they receive through Social Security. Due to the so-called substantial gainful activity level (SGA), individuals cannot make more than $1,900 per month. This is not enough to be self-sufficient. More importantly, they do not dare risking losing health care through Medicaid.

People with disabilities also deserve to make at least minimum wage or above. States need assistance moving away from sheltered workshops to modern models of matching the needs of employers to the abilities and desires of individuals with disabilities. For those who choose not to work or for whom their disabilities make it too difficult to maintain work, there must be opportunities for meaningful activities during the day. Eligibility for Medicaid is tied to Social Security. Medicaid not only provides the comprehensive health care many people with developmental disabilities need (care often not provided by many private insurers), it also provides long-term services and supports many individuals need to continue to be able to live and work in the community. These include supported employment services, behavioral health, and habilitation. Habilitation services help a person learn or improve skills and functioning for daily living (such as physical therapy or training to use public transportation). Unfortunately, these home and community-based Medicaid services are optional for states and there are long waiting lists for them. Home and community based services should be mandatory. Waivers should be required for institutions.

In Pennsylvania, there are 42,820 people over the age of 60 still caring for their family member with developmental disabilities (Braddock, *State of the States in Developmental Disabilities*). There are 52,139 caregivers between 41 and 59. These ranges includes myself and my wife, Elise. We need family supports, like respite care, so that we can take a break, have a date with each other, go on a doctor visit, or to the grocery store. We are also very worried about who will care for our sons when we are gone. We are literally afraid to die. Where will they live? Will they be free from harm? Will they still be able to do the things they love to do, like play baseball, visit their friends, choose their own meals? Many parents share these worries.

In all the years I have been involved in the Autism Society, I have become more worried than ever about the growing number of people with autism and other developmental disabilities coupled with the number of people who are aging and needing long-term care. Congress must find the political will to help states provide these services. Please do not turn your backs on people with disabilities and those of us who are aging. Following are just some of the recommendations the Autism Society has for Congress that might help.

Regarding helping people to work, we recommend that Congress:

- Double the Work Opportunity Tax Credit (WOTC) and the Business Tax Credit to incentive businesses to hire people with disabilities.
- Double the Architectural and Transportation Barrier Removal deduction to help remove access barriers.
- Double the Disability Access Tax Credit for small businesses to provide incentives to businesses to remove barriers.
- Address the constraints put on people with disabilities by having the limit for substantial gainful activity as such a low level ($1,970/month for these who are blind and $1,180 for all others with disabilities) that it discourages people to work, to accept promotions, and to start their own businesses.
- Phase out use of subminimum wage certificates (under the Fair Labor Standards Act) while helping states build capacity to provide competitive integrated employment
- Provide increased Medicaid matching rates to states providing competitive integrated employment to individuals with developmental disabilities.
- Increase the supported employment program and provide demonstrations to increase customized employment best practices.
- Mandate the state Medicaid buy-in program so that people can work and still get health care (now an option for states through Social Security Section 1619(b)).
- Support the ABLE Age Adjustment Act of 2017 (H.R. 1874; S. 817) so that more people with disabilities can save for disability-related needs that may lead to employment

Regarding helping people find home and community-based services, the Autism Society recommends Congress:

- Oppose efforts to cut, cap or eliminate the individual entitlement to Medicaid.
- Oppose work requirements in the Medicaid program.

- Reduce the bias in Medicaid for institutional services and significantly increase the investment in home and community-based services and supports.
- Support the Disability Integration Act and other proposals that support the right to services in the community.
- Create a national long term care system outside of Medicaid.
- Provide funding for new demonstrations for states to test community supported living arrangements to help provide housing options in the community for people with developmental disabilities and those who are aging.

The Autism Society has numerous professionals, family members, and individuals on the autism spectrum with expertise and willingness to help. Please contact me or our national office at 301-657-0881 for more public policy recommendations to address many of the issues addressed above.

Sincerely,

Joseph P. Joyce

Joe Joyce
Chair, Autism Society