



Written Testimony of Joe Joyce

On behalf of the Autism Society of America

For the Autism Interagency Coordinating Committee

January 18, 2023

Thank you, Dr. Gordon and the rest of the Interagency Autism Coordinating Committee (IACC) for allowing me to provide written testimony and brief comments this afternoon. I am providing this testimony on behalf of the Autism Society of America; however, I will also share my personal story as a father of two adult sons with developmental disabilities.

The Autism Society of America is the largest and oldest grassroots organization 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 help their children with significant disabilities live as fully as possible. They shared information and advocated for educational and other services to help them be healthy, able to live at home, and be accepted in the community. The Autism Society continues this mission.

I am the father of two individuals with significant functional limitations: David, age 24, has Autism, and Matt, 26, has Down Syndrome; both have intellectual and developmental disabilities. Developmental disabilities are defined in law (the DD Act) 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 young men are loved and valued members of our family and community. David and Matt are handsome, loving, thoughtful, and 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.

Elise and I were finally able to transition David to a home that we bought for him. However, it was a massive struggle to find direct support professionals and a licensed agency to operate the home. Many agencies 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, food, and housing assistance. Matt continues to live with us as we plan his transition to living more independently but we worry about being able to find a home and professionals that will be able to help him. We know that David and Matt will not be able to care for themselves without significant support. We worry about what will happen to them when we are no longer here to take care of them and coordinate and oversee their services.

The Home and Community-based Medicaid waiver is the program that most individuals and families depend on to get the services they need to keep family members at home, get habilitation, behavioral health, and supported employment. However, the only service that states are required to cover is home health. Most other services are optional. States are also permitted to limit the number of people eligible



for waivers resulting in waiting lists, that in some states are many years long. In addition, states vary in the way they screen and collect data on waiting lists and they vary in the pay rates for direct support professionals.

Waiting list totals across all disabilities for states that self-reported in 2020 were 665,000 individuals. The actual HCBS waiting list number is estimated to be 820,000 individuals as CA, CT, NC, NH, and NM either did not report totals since 2018 or did not submit a complete report of all waiver programs and disabilities. Strikingly, the number of individuals with mental illness waiting for HCBS services for all states was 1,844, while 464,398 individuals (or 251 times the number of their mental health counterparts) with intellectual and developmental disabilities were on a waiting list. Even more troubling, individuals wait on average 39 months to secure services, with reports of some waiting 15 years. There is an urgent need to remedy this crisis as the prevalence of Autism is expected to increase by 15 percent over the next ten years. Pennsylvania reports that approximately 17,000 are waiting for services and is one of only 5 states (FL, IL, IN, ND, PA) that does not provide individuals state plan services while on the waiting list.

New data from ANCOR finds that a significant shortage of direct support professionals has reached catastrophic levels. The longstanding workforce crisis, exacerbated by the COVID-19 pandemic, has led to closures of critically needed services and a denial of access to community-based support. Vacancy rates for full-time direct support positions increased from 8.5% in 2019 to 12.3% in 2020—a roughly 45% increase.

My family experienced this shortage first-hand. During the height of the pandemic, David's day habilitation services (Hope Springs) was completely closed for 12 months, putting significant strain on working parents. Many of the direct service providers sought employment elsewhere, resulting in a significant shortage of staff. We are so fortunate that Hope Springs survived the crisis, thanks, in part to federal government funding packages. However, Due to the staff credentials required for high risk behaviors, David has not yet been able to return to the day program at pre-pandemic levels.

Federal funding for the Covid public health emergency is coming to an end putting the community-based service system in jeopardy of complete collapse. The direct support workforce crisis is due, in part to an inability of providers to offer wages that are competitive with those of hourly-wage industries, such as fast food, retail, and convenience stores. We must find a way to pay trained professionals to help care for our loved ones.

In all the years I have been involved in the Autism Society, I have never been more worried about the state of our nation's service system for people with Autism and other developmental disabilities. We receive way too many calls to our hotline related to individuals and families suffering without services. The Administration and Congress must find the political will to help states provide these services.

Following are just some of the recommendations the Autism Society has for the Administration and Congress to address these issues:

- Reverse the bias in Medicaid, so that home and community-based services and supports are mandated within the state plan.



- Extend the temporary increased funding for the federal Medicaid match (FMAP) authorized under the American Rescue Plan Act.
- Support policies included in the Better Care Better Jobs Act (S. 2210/H.R. 4131 in the 117th Congress) that supports direct support professionals.
- Establish a standard occupational classification (SOC) for Direct Support Professionals. SOCs are used to help all levels of government identify employment trends and design policies, including states' approaches to rate-setting in their Medicaid programs
- 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.
- 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)).
- Implement the many good policy recommendations provided by the RAISE Family Caregiver Councils to support families caring for individuals with Autism.

While we understand that IACC does not have jurisdiction over Congress, we hope that you will use the influence of this body to do what you can within the agencies around this table to make an impact and to make recommendations to Congress to improve services for those with Autism.

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

Sources:

Alice Burns, Molly O'Malley Watts, and Meghana Ammula
[A Look at Waiting lists for Home and Community-Based Services from 2016 to 2021](#) (Nov 28, 2022)

National Council on Disability report: [Strengthening the HCBS Ecosystem](#) (Dec. 2022)

Kaiser Family Foundation: [Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility](#) (2021)

ANCOR and UCP, [The Case for Inclusion 2022 Blazing Trails to Sustainability for Community Disability Services](#) (2022)

ANCOR, [The State of America's Direct Support Workforce Crisis 2022](#)