national down syndrome society
ndss®

The Honorable Cathy McMorris Rodgers
Republican Leader
Energy and Commerce Committee
U.S. House of Representatives
2322 Rayburn House Office Building
Washington, D.C. 20515

September 26, 2022

Dear Republican Leader McMorris Rodgers:

The National Down Syndrome Society is the leading human rights organization for all individuals with Down syndrome. We envision a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.

We are grateful for the attention you have devoted to people with Down syndrome and other disabilities and to the policies that affect their quality of life. Thank you for sharing your concerns and the opportunity to provide comments.

Because we believe it is our duty to amplify the voice of those we serve, in preparing our response, we shared your prospectus and request for information, "Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion," with the Down syndrome community and requested feedback. We are pleased to summarize and share those responses with you here, which come from members of our community across the country and from many different walks of life.

To help you address our community's concerns, we are pleased to offer policy recommendations here based on the questions you've asked, and we look forward to discussing them in greater depth with your office now and in the 118th Congress. We look forward to helping you build a more inclusive system that recognizes the great – and too often untapped – potential of people with Down syndrome and other disabilities.

1. Access to LTSS

Many in the Down syndrome community rely on access to long-term services and supports (LTSS). As noted in your report and request for information, accessing LTSS through Medicaid is often deeply problematic, in many cases preventing members of our community from accumulating wealth or living independently due to the asset limitations for Medicaid eligibility. At the same time there are geographic equity issues because access varies from state to state; and there are lifespan issues as well: members of our community are often cared for by their parents, who, as they continue to age themselves, will eventually become increasingly unable to serve as caregivers. Siblings often take over those duties, but if those siblings live across state lines, and the individual might need to move, services through Medicaid can be lost. At the same time, training of and support for direct service practitioners needs attention, as these critical care providers are too frequently overworked and underpaid. As has been seen in other sectors, one of the longer-term effects of the COVID-19 pandemic has been the exacerbation of existing problems, driving an exodus of personnel.

But perhaps the most decried issue in our community is the length of waitlists for home-and-community-based services (HCBS). People wait for years – we've heard stories of people waiting for more than a decade – to receive these services at home, because they were deemed optional by a system that is progressively out of sync with the times in which we live.

Congress should explore options to promote consistency in service offerings between states, such as through funding the Money Follows the Person program on a permanent basis. Congress should also consider ways to improve program quality, especially by increasing overall system flexibility to better suit a person's specific needs without being unduly costly. Ultimately, Congress should take immediate action to curtail or eliminate waiting lists.

Congress must also act to put an end to the marriage penalties that force members of our community to choose between needed health supports and a sacred commitment to a loved one. The asset limits perpetuate a cycle of poverty for each individual person they affect, but it is even more appalling that they also limit each person's ability to choose to love another and avail themselves of the full panoply of rights and privileges that all other married people receive – and the satisfaction that comes from performing the duties that all married people take on. NDSS has long championed legislative efforts, including the *Marriage Access for People with Special Abilities Act* (H.R. 761), to end the marriage penalty, and we will continue to advocate on the issue until a solution is found.

2. Accommodations in the Community

The ability to communicate effectively is essential for promoting individual autonomy and personal fulfillment. Because some people with Down syndrome utilize nonverbal communication, it is critical that our population has access to augmentative and alternative communication (AAC) devices in any circumstance where a device would facilitate discourse.

The proliferation of smartphones and tablets over the past fifteen years has completely upended the AAC landscape. In the past, AAC devices were highly specialized, comparatively uncommon, and unduly expensive. While Medicaid's policy of defining single-use, medically-necessary items such as wheelchairs, insulin pumps, or, indeed, traditional AAC devices as durable medical equipment (DME) made sense, this definition is a poor fit for modern, smart devices such as tablets with AAC software. Their inherent versatility – the very same characteristic that allowed them to turn the single-use AAC device market on its head – can disqualify them for coverage under Medicaid as DME. To apply these outdated standards to devices that had not yet been dreamt-up when the law was written is to place an unnecessary hardship on the people who rely on them. If a tablet enables a person to communicate as well – if not better – than a traditional, single-use AAC device, the fact it can also be used for navigation or email correspondence or learning a second language does not detract from its medical usefulness in any way. If anything, these secondary functions enhance its utility and make it an even more valuable tool for the person using it. Furthermore, the average cost of a single modern device is significantly less than a dedicated AAC device, so for the same government investment, more people will be empowered to communicate in the way best suited for them.

Based on this feedback from our community, NDSS recommends that Congress consider Medicaid reimbursement for AAC devices that have secondary uses. As long as eligibility is properly established based on medical need, and the device is actually used to fulfill that purpose, incidental uses should not proscribe access. As technology development will continue to outpace legislative updates, in the interest of fairness, coverage of AAC devices should apply to as many patients as possible, regardless of what coverage plan they have. Additionally, opportunities for collaboration with the Association of Assistive Technology Act Programs – perhaps to increase its current capacity – may exist.

As noted in your report and request for information, another way for individuals with disabilities to acquire AAC is through the use of Achieving a Better Life Experience (ABLE) accounts, which provide a tax-advantaged mechanism for people with disabilities to save money without fear of losing federal benefits, and to spend that money on qualified disability expenses such as AAC devices – including modern technology. At present, in order to establish an ABLE account, a person's disability must have onset by age 26. In order to increase access, Congress should enact legislation to increase the upper age limit, such as in the ABLE Age Adjustment Act (H.R. 1219 / S. 331), which raises that limit to age 46. NDSS has been a proponent of ABLE accounts and ABLE-related legislation since the original ABLE Act was passed in 2014, and we will continue to advocate for the growth of the program. While the age increase itself is unlikely to have a strong direct impact on the Down syndrome community, increasing the pool of people served by ABLE accounts will only strengthen the program and make other enhancements to the ABLE ecosystem more likely in the future, such as the provisions of the ABLE Employment Flexibility Act (H.R. 4672), which would enable employers of people with disabilities to contribute to ABLE accounts in lieu of traditional retirement vehicles. This policy would create a synergy between competitive integrated employment, personal savings, and financial freedom without risking government benefits.

An area where accessible health care has proven to be an issue is equitable access to organ transplants. As documented by the National Council on Disability in 2019[1], people with disabilities have faced discrimination when they need an organ transplant – not just by individual bad actors, but also through systemic bias and decades-old cultural ignorance. Across the country, a patchwork of 34 state laws works to prevent this discrimination, but these efforts are inconsistent and do not promote equity or predictability across the country. There is not a transplant center in every state, so both people and organs move across state lines regularly to access transplant procedures; there is clear authority and need for federal oversight as an instrument of interstate commerce. The *Charlotte Woodward Organ Transplant Discrimination Prevention Act* (H.R.1235 / S.3301) provides just such a framework. Named after an adult with Down syndrome on NDSS' staff, the legislation would help providers know the right way for disability to enter patient-focused conversations about transplants and, at the same time, the bill, if enacted, would provide timely legal recourse for individuals facing discrimination.

Another area where people with disabilities can struggle to receive equitable access to health care is in areas of new and emerging science. For those with Down syndrome, one such area is the intersection of Down syndrome and Alzheimer's disease. We know that people with Down syndrome are at a significantly higher lifetime risk than their counterparts in the general public for developing symptoms of Alzheimer's disease and related dementia, but researchers are still working to understand exactly why. One of the genes that can cause the buildup of amyloid plaque, which is associated with Alzheimer's disease, is on chromosome 21, and since people with Down syndrome have three copies instead of two, they are more likely to develop the plaque. Not everyone does, however, and researchers are working to understand the causes of that relationship. Because the science is as yet unresolved, individuals with Down syndrome are likely to be excluded from clinical trials

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[1] https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf

and other Alzheimer's research because of fear of diagnostic overshadowing, as seen in the recent Centers for Medicaid and Medicare (CMS) coverage determination for Aduhelm (aducanumab). Exclusion from research today begets a lack of data tomorrow on how new treatments might affect our community – effectively leaving our population behind when advancements in Alzheimer's treatment are made. At NDSS, we are determined not to let that eventuality come to pass.

Congress must act to ensure that individuals with Down syndrome are proactively included in all Alzheimer's-focused legislation and continue to fund the research that will help the research and medical communities understand how to provide our community the best possible care. An upcoming opportunity to emphasize the importance of including individuals with Down syndrome in Alzheimer's disease policy is in the reauthorization of the National Alzheimer's Project Act (NAPA), which is due in 2025. Even with so much yet to learn, so much has been uncovered since this legislation was initially enacted in 2011, and its reauthorization is a critical opportunity to codify the unique relationship between Down syndrome and Alzheimer's disease and position the federal government to act for years to come.

3. Barriers to Integrated Employment

On a national scale, people with disabilities, as a broad group, are chronically un- or underemployed. In the case of people with Down syndrome, as well as other intellectual or developmental disabilities, the situation is even more challenging because, for some members of the general public, there is a higher attitudinal barrier associated with understanding, accommodating, and working alongside a person with intellectual and developmental disabilities (I/DD) than, for example, someone with limited physical mobility. Put another way, it could be argued that it takes more personal investment to work with a colleague who relies on an AAC device than someone whose accommodations are a responsibility that fall on the employer, such as ensuring wheelchair access to a facility. While facially accurate, this calculation fails to take into consideration the mutually beneficial impact that employing individuals with varying disabilities, and thus diverse skillsets and perspectives, has on employers and employees alike.

Another symptom of this same mindset, compounded by decades of institutional bias, is what has been described as the "tyranny of low expectations," where members of the general public, including uninformed employers, assume that people with disabilities, especially intellectual and developmental disabilities, are characteristically and immutably unable to perform in the workplace. This lack of understanding led to the creation, propagation, and persistence of segregated employment settings and subminimum wages.

NDSS has long been and continues to be a strong opponent to the use of 14(c) certificates. NDSS supports a systemic move towards competitive integrated employment. We applaud Chairman Scott and Leader Rodgers' efforts in introducing the Transformation to Competitive Integrated Employment Act (H.R. 2373 / S.3239). Passing this bill is one of NDSS' core legislative priorities today and will continue to be until it is signed into law.

Regarding workplace accommodations, everyone needs different supports to be at their best at work – whether they have a disability or not. As noted, accommodations are typically inexpensive, one-time efforts, and there are many available resources describing best practices in all parts of the employment process, from recruitment and interviewing to hiring and onboarding, to support and advancement. The career trajectory of a person with a disability should be the same as a person without one, and resources exist to help make it so. Instead, many of the issues employees or prospective employees face getting accommodations are rooted in the sheer ignorance of employers – ignorance not only of how to accommodate, but also that they *should* accommodate. It's been our experience that it is not a function of malice or discrimination, just simple ignorance. Congress should explore opportunities, in concert with the Office of Disability Employment Programs and the Department of Labor, as well as other disability employment organizations, such as the CEO Commission for Disability Employment, of which NDSS is a proud founding member, to promote deliberate, broad-based and far-reaching educational opportunities for employers.

NDSS recognizes that the federal government has an important role to play in both incentivizing and ensuring the quality of accommodations. We do believe that all federal departments should be required to have accommodation programs in place, and, similarly, that tax credits might help encourage private entities to employ and accommodate people with disabilities. More than that, we believe the federal government, as one of the nation's largest employers, can lead by example and provide accommodations to its own employees in a way that is transparent, understandable, and of maximum educational benefit to other employers, whether multi-national corporation or mom-and-pop small business.

4. Conclusion

Thank you again for the opportunity to share the Down syndrome community's experience and for the chance to work with you to address its members' concerns. Whether accessing healthcare, community services and activities, employment, or schools, people with disabilities continue to face a world that still has much to learn about what they need and, critically, just how much they have to offer. We are eager to continue to collaborate with you now and in the future to build a more inclusive society that will benefit everyone.

Sincerely,

Kandi Pick

Kandi Pickard
President & CEO, National Down Syndrome Society