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House Energy and Commerce Committee Republicans  
Leader Cathy McMorris Rodgers

Dear Leader McMorris Rodgers and Committee Members,

The National Down Syndrome Congress (NDSC) writes to provide comments in response to the [Disability Policies in the 21<sup>st</sup> Century: Building Opportunities for Work and Inclusion](#). Thank you for laying out your vision for what more can be done to remove barriers that keep people with disabilities from living up to their full potential and contributing to their communities and for soliciting feedback on this vision. NDSC is the country's oldest national organization for people with Down syndrome, their families, and the professionals who work with them. We provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome, and work to create a national climate in which all people will recognize and embrace the value and dignity of people with Down syndrome.

We agree that ensuring access to long-term services and supports, making communities and daily life more accessible for people with disabilities by supporting access to assistive technologies and enforcing accommodation requirements, and moving the workforce toward integrated employment are all critical priority areas for people with Down syndrome and others with intellectual/developmental disabilities. Individuals with Down syndrome and their families are particularly concerned about the following:

- Eliminating the institutional bias in Medicaid
- Eliminating HCBS waiting lists
- Increasing SSI and Medicaid asset and income limitations
- Eliminating the "marriage penalty"
- Addressing the challenges for family caregivers
- Addressing the shortage of direct service providers through increased wages, training opportunities, and other means
- Addressing the complex rules that are confusing to providers, families, and individuals with disabilities
- Addressing the need for reliable transportation
- Challenges in finding doctors who will accept Medicaid patients

Our specific comments in response to the requests for information are as follows:

## **1.1 Regarding Medicaid's institutional bias:**

### **A. How can Congress reduce or eliminate the institutional bias in Medicaid?**

NDSC believes that individuals with Down syndrome, like all Americans, have a right to live in their own homes, in the community. Adults should control where and with whom they live, and have the freedom to choose their daily routines and activities. Page 5 of this proposal correctly highlights the U.S. Supreme Court's decision in *Olmstead v. L.C.*, which held that the institutionalization of people who could be cared for in community settings was a violation of the Americans with Disabilities Act (ADA). We thank you for raising this important decision for people with disabilities. At its core, the *Olmstead* decision is about giving people with disabilities the choice to live in the community of their choosing. This landmark decision has helped people with disabilities leave institutions and other segregated settings of their own accord when previously it was believed that segregated settings were the only appropriate settings for people with disabilities. There is no doubt that thousands of people with disabilities, including those with Down syndrome have benefited from *Olmstead*.

While enforcement of Federal civil rights law is primarily the responsibility of the Executive Branch, Congress plays an important oversight role. Unfortunately, as Congress has worked to complete its Fiscal Year (FY) 2023 appropriations bills, report language has been included in the FY 23 House Commerce, Justice, Science, and Related Agencies (CJS) Subcommittee Appropriations Bill Report<sup>1</sup> and in the Labor, Health and Human Services, Education, and Related Agencies (L-HHS-ED) Appropriations Bill Report<sup>2</sup> regarding *Olmstead*. The report language included in both bills is contrary to the rights of people with disabilities--the people who are most impacted by *Olmstead*. The language mischaracterizes the impact of *Olmstead* by

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<sup>1</sup> Page 68 of report: Deinstitutionalization.—The Committee is aware of concerns about displacement of vulnerable persons from institutional programs as the result of litigation or the threat of litigation. The Committee also notes that in *Olmstead v. L.C.* (1999), a majority of the Supreme Court held that the Americans with Disabilities Act does not condone or require removing individuals from institutional settings when they are unable to handle or benefit from a community-based setting, and that Federal law does not require the imposition of community-based treatment on patients who do not desire it. The Committee is also aware of concerns that the approach taken by both Federally-supported Developmental Disabilities Assistance and Bill of Rights Act programs and the DOJ in its related prosecutorial discretion may in some instances adversely impact individuals who may be unable to handle or benefit from community integration and do not desire such care. The Committee strongly urges the Department to ensure that the Civil Rights Division properly accounts for the needs and desires of persons with intellectual and developmental disabilities in licensed intermediate care facilities, their families, caregivers and legal representatives, and the importance of affording patients the proper setting for their care, in its enforcement of the Americans with Disabilities Act and the 'Olmstead' decision.

<sup>2</sup> Page 217 of report: The Committee notes that the Supreme Court decision in *Olmstead v. L.C.* (1999) held that the Americans with Disabilities Act (ADA) does not require removing individuals from institutional settings when they are unable to handle or benefit from a community-based setting and that the ADA does not require the imposition of community-based treatment on patients who do not desire it. The Committee notes that actions to close intermediate care facilities for individuals with intellectual disabilities may impact some individuals who do not meet the criteria for transfer to a community-based setting. The Committee urges HHS to ensure that programs properly account for the needs and desires of patients, their families, and caregivers and the importance of affording patients the proper setting for their care.

indicating that people are forced into community settings against their will and against clinical judgment regarding their treatment needs. These statements are in direct conflict with the 3-prong test the Supreme Court created in *Olmstead* to determine when the ADA requires placement of people with disabilities in community settings rather than in institutions. Community based services are required as alternatives to institutional placement when “(1) the State’s treatment professionals determined that such placement is appropriate, (2) the affected person does not oppose such treatment, and the (3) placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others.” *Olmstead v. L.C.*, 527 U.S. 581, 606 (1999).

People using Medicaid waiver services as an alternative to institutionalization have to be offered informed choice of the feasible alternatives to facilities, with the focus being on the “at the choice of such individuals”. 42 U.S.C. § 1396n(c)(2)(C). In summary, the suggestion in the report language that community integration is being forced upon individuals is at a minimum a mischaracterization of *Olmstead* and at worst a legally incorrect interpretation. One way Congress can reduce the institutional bias in Medicaid is by not agreeing to the report language referenced above in FY 23 and not agreeing to similar mischaracterizations of *Olmstead* in future appropriations bills. This report language and similar language like it will potentially work to close opportunities for people with disabilities. This language sets us back in terms of ensuring that people with disabilities can live the life they want to live. The *Olmstead* decision has been settled and while challenges to the ruling continue, it is very alarming to us that Congress would attempt to erode settled law of the land.

**1.2 Medicaid is an essential program for those in need, and it should remain available only to those that need it. In regard to ensuring that Medicaid can remain available to just those that need it:**

**E. Are there means to shield certain assets, like ABLE Accounts and Qualified Income Trusts, that Congress should consider expanding or making more flexible so that more beneficiaries can utilize them?**

We thank the Chair for highlighting an important tool like ABLE Accounts for people with disabilities. The Chair’s leadership on the ABLE program has undoubtedly improved the financial security of people with disabilities. Given the restrictive nature of Medicaid and SSI, particularly for working people with disabilities, Congress should continue to examine ways to protect assets of people with disabilities to ensure their dignity and independence. This includes expanding ABLE Accounts through the passage of the ABLE Age Adjustment Act (S.331/H.R.1219). First, we must raise ABLE account eligibility to a minimum of an onset before age 46, as included in the ABLE Age Adjustment Act. After raising the age, we recommend looking at means to further encourage savings for people with disabilities from low-income families, such as a matched savings program with federal funds.

## **2.1 In order to ensure greater access to more affordable assistive technologies:**

### **C. Should Congress consider increasing the allowable age for qualifying for ABLE Accounts?**

Again, we thank the Chair for her unwavering support and promotion of the ABLE program. It is long past time that Congress increase the allowable age for qualifying for ABLE accounts. Currently, many individuals who could benefit from ABLE accounts are left out, since many conditions can and do occur later in life. These include multiple sclerosis, Lou Gehrig's disease, or paralysis due to an accident. Additionally, veterans who become disabled after age 25 are currently ineligible for ABLE accounts. We should extend the benefits of ABLE to populations who become disabled later in life as a matter of equity. There is also a need to expand the program from a sustainability stand point. The National Association of State Treasurers has stated that to reach self-sustainability for ABLE programs, a greater number of accounts will need to be opened. Currently, 46 states and D.C. have active ABLE programs, resulting in nearly 120,000 open accounts with assets totaling over \$1.1 billion.

The bipartisan, bicameral ABLE Age Adjustment Act (S.331/H.R.1219) would allow people who develop their disabilities before age 46 to establish ABLE accounts, allowing them to save for future disability-related expenses without placing needed disability services, healthcare, and income support at risk. The ABLE Age Adjustment Act will allow an additional 6 million people with disabilities to open ABLE accounts, nearly doubling the current eligible population. The Senate Finance Committee recently unanimously voted to advance the EARN Act, which includes the ABLE Age Adjustment Act. We believe now is an opportune time to pass and enact this critically important bill.

### **Barriers to Integrated Employment**

We thank the Committee for exploring barriers to integrated employment for people with disabilities. NDSC wholeheartedly agrees that Congress must end the practice of paying people with disabilities subminimum wages and we are fully supportive of the Transformation to Competitive Integrated Employment Act (TCIEA) introduced by Chair McMorris Rodgers and Rep. Bobby Scott. Congress should build upon the momentum established by the several states that have phased out section 14(c) certificates and phase the program out at the federal level and authorize funding to assist with transitioning, as provided in the TCIEA.

As it pertains to barriers to integrated employment for people with disabilities, we also encourage Congress to re-examine the AbilityOne Program and the entire Javits-Wagner-O'Day (JWOD) Act. In October 2020, the National Council on Disability (NCD) concluded in a report that the AbilityOne program no longer serves its purpose of promoting Congress' goal of improving employment opportunities for people who are blind or have significant disabilities<sup>3</sup>.

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<sup>3</sup> Federal advisory agency recommends phase out, replacement of federal. (2020, October 14). Retrieved from <https://ncd.gov/newsroom/2020/NCD-releases-AbilityOne-report>

With that being said, in 2016, the Advisory Committee to Increase Competitive Integrated Employment for Individuals with Disabilities (ACICIED) published its [final report](#) to Congress, which outlined additional recommendations to reform the AbilityOne program, the need to identify and test new methods of federal contract operation, and oversight for the program. The ACICIED recommended Congress amend JWOD to fully align with modern federal disability law and policy goals, including the Americans with Disabilities Act, the Supreme Court’s *Olmstead* decision, and the Workforce Innovation & Opportunity Act (WIOA). Additionally, Strategic Objective I of the U.S. AbilityOne Commission’s [FY 2022-2026 Strategic Plan](#) is to “Work effectively with Congress to amend the JavitsWagner-O’Day (JWOD) Act to support competitive integrated employment (CIE) for people who are blind or have significant disabilities.” In summary, we urge Congress to re-examine a program such as AbilityOne and JWOD as both perpetuate a segregated work system for people with disabilities which by definition is a barrier to integrated employment and more importantly Competitive Integrated Employment.

Additionally, the Committee is certainly right to focus on the requirement under the ADA that reasonable accommodations be made and vigorous enforcement of the ADA continue to be pursued by the Federal government. NDSC would urge the Committee to also think beyond accommodations and explore ways to increase access to Competitive Integrated Employment for people with disabilities through customized employment as included in WIOA. Recently, several Federal agencies released a communication and a framework on increasing CIE<sup>4</sup>. Specifically, we want to highlight the following recommendation included in the resource titled [“A FRAMEWORK FOR COMMUNITY ENGAGEMENT – A PATHWAY TO COMPETITIVE INTEGRATED EMPLOYMENT”](#) which states, “Policymakers should focus on aligning policy, practice, funding, and performance measures, to the extent consistent with applicable laws, to encourage and incentivize service providers to provide the community engagement activities and other services necessary for individuals with disabilities to achieve competitive integrated employment.” We recommend that the Committee review these documents and recommendations and consider how Congress can support and/or amplify these efforts at the state and local level.

Thank you for the opportunity to comment on these important issues. NDSC looks forward to working with you on these issues in the future. Should you have any questions or wish to discuss further, please contact Cyrus Huncharek, Director of Policy & Advocacy at [cyrus@ndscenter.org](mailto:cyrus@ndscenter.org).

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<sup>4</sup> See:

<https://www.dol.gov/sites/dolgov/files/ODEP/pdf/ResourceLeveragingServiceCoordinationToIncreaseCIE8-12-22.pdf>; <https://www.dol.gov/sites/dolgov/files/ODEP/pdf/FAQs-CIEBlendingBraidingSequencingResources08-03-22Final.pdf>; [https://rsa.ed.gov/sites/default/files/subregulatory/A%20Framework%20for%20Community%20Engagement\\_0.pdf](https://rsa.ed.gov/sites/default/files/subregulatory/A%20Framework%20for%20Community%20Engagement_0.pdf)