NASDDDS
National Association of State Directors of Developmental Disabilities Services

March 20, 2023

Bernard Sanders
Chair
Senate HELP Committee

Bill Cassidy, M.D.
Ranking Member
Senate HELP Committee

Dear Chair Sanders and Ranking-Member Cassidy,

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) thanks you for the opportunity to respond to your recent request for information from stakeholders on healthcare workforce shortages.

NASDDDS represents the nation's state agencies in 50 states, the District of Columbia, and Puerto Rico providing services to children and adults with intellectual and developmental disabilities and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families. NASDDDS members administer one third of the United States' public long term supports and services (LTSS) spending and approximately three quarters of Medicaid Home and Community Based Services (HCBS) spending. The NASDDDS mission is to assist member state agencies in building effective, efficient person-centered systems of services and supports for people with developmental disabilities and their families.

We write to draw the Committee's attention to the significant shortage of direct care workers serving individuals who are aging or have disabilities. In the service systems administered by NASDDDS members, catastrophic labor shortages and pervasive high turnover rates among the workforce that support people with intellectual and developmental disabilities (I/DD), direct support professionals (DSPs), threatens decades of momentum toward expanded and improved opportunities for community living. A report NASDDDS co-published with the Institute on Community Integration at the University of Minnesota (ICI/UMN) and the Human Services Research Institute (HSRI), *Community Supports in Crisis: No Staff, No Services*, describes how these shortages and high turnover rates have led to

> "community programs for people with IDD across the country have started closing — many permanently. People in smaller residences are being moved to larger congregate facilities or back home to live with elderly parents. Far too many providers are seeking to increase the size of their existing programs or to consolidate them. Waiting lists are growing because there are no staff to open

new programs, deliver support to new people with IDD in their homes or staff old ones."[1]

The National Core Indicators (NCI) State of the Workforce Survey (SoTW) continues to demonstrate the dire situation of the IDD LTSS DSP workforce. [2] In 2021, 3838 providers from 29 states and DC participated in the SoTW survey. Even with a $1.14 increase in the median hourly wage for DSPs to $14.50 an hour, which still does not equal what is considered a living wage in most localities, average vacancy and turnover rates remain extremely high: nationally, the turnover rate was 43%, with some states as high as 58%. This means almost half of the entire DSP workforce is turning over every year. The implications of that rate are troubling; not only is recruitment and onboarding extremely expensive and time consuming for provider organizations, the quality of life for people with IDD can be negatively impacted by lack of quality supports or no access to needed supports at all. Vacancy rates across the nation on average are 20% for full time DSPs and 17% for part time DSPs. SoTW data shows that the large majority of the DSP workforce are minority females, a demographic that has experienced marginalization historically.

The already existing workforce crisis will deepen with the termination of the public health emergency, which will phase out the increased federal Medicaid funding and regulatory flexibilities that states have relied on to ensure continued access to home and community-based services. Additionally, demographic changes threaten to exacerbate this crisis and destabilize the already strained system that supports our nation's seniors and individuals with disabilities, leading to increased safety risks and unnecessary, costly institutionalization. Addressing this workforce crisis requires a concentrated effort at the federal level to support states, localities, and providers to recruit and retain an effective DSP workforce, as just one part of a multistrategic approach to ensure that our nation's long term services and supports system has the capacity to meet the needs of all who rely on it.

To increase the number of high quality Direct Support Professionals, we recommend that Congress:

1. Establish a Standard Occupational Classification (SOC) for direct support professionals within the Bureau of Labor Statistics (BLS). Despite the fact that a

[1] ICI, HSRI, & NASDDDS. Community supports in crisis: No staff, no services. Minneapolis, MN: University of Minnesota, Institute on Community Integration, 2022. https://ici-s.umn.edu/files/hpG-Gjkx93/community-supports-in-crisis?preferredLocale=en-US

[2] National Core Indicators, *2021 State of the Workforce Survey Report*. Alexandria, VA: National Core Indicators, 2023. https://idd.nationalcoreindicators.org/wp-content/uploads/2023/02/2021StateoftheWorkforceReport-20230209.pdf

direct support professionals work requires complex skills, thoughtful decision making, person- centered support, and deep medical knowledge, there is a failure to identify this position on the scale that it deserves. Without a SOC, there is no real measure for identifying staffing needs, gaps in services, projections for the future and the risks for cessation of services. Data provided through a SOC will lead to better understanding workforce shortages and developing long-lasting approaches to fixing them. In addition, when states do not have a SOC for classifying the roles of direct support professionals, they must use other recognized titles and struggle to appropriately set reimbursement rates for services direct support professionals provide. For these reasons, NASDDDS supports the **Recognizing the Role of Direct Support Professionals Act,** which would direct the Office of Management and Budget to establish a separate category within the Standard Occupational Classification (SOC) system for direct support professionals.

2. Authorize and fund workforce development initiatives that help to develop career ladder opportunities, and institutionalize training and credentialing programs that lead to wages commensurate with the level of responsibility and the complexity of this work. NASDDDS recommends Congress pass the **Supporting Our Direct Care Workforce and Family Caregivers Act** to provide federal funding and a framework for states to pursue these workforce improvements.
3. Pass federal legislation to increase wages and access to affordable benefits. Congress should pass the **Better Care Better Jobs Act** to ensure that state HCBS systems have sufficient resources to provide appropriate and competitive remuneration to the direct service workforce.
4. Establish federal and state interagency taskforces. Congress should direct the executive to establish an interagency task force on the direct support workforce with participation minimally from: (1) U.S. Department of Health and Human Services – Administration on Community Living, Assistant Secretary of Planning and Evaluation, Centers for Medicare and Medicaid Services, Health Resources and Services Administration, President's Committee on People with Intellectual Disabilities; (2) U.S. Department of Labor; and (3) U.S. Department of Education. This task force should include staff members from these agencies who have expertise in the direct support workforce or will learn more about this workforce and how their agency can address threats to the sustainability and growth of community long-term services and supports. Additionally, the federal interagency taskforce should intentionally seek engagement from other key stakeholders (e.g. individuals who receive LTSS, direct support professionals, families, employers, state IDD agencies). States should be provided incentives to create similar state-level interagency taskforces on the direct support workforce.

Rebuilding and expanding the direct care workforce can not be the only strategy the federal government employs to ensure that the nation's HCBS systems have the

capacity to fully meet the needs of individuals with disabilities and those who are aging. Demographic realities dictate that our systems must find ways to expand access to high quality services that are not entirely dependent on ideal staffing ratios. Congress must provide policy and funding support to states to pursue innovative systems change to address capacity shortfalls.

## Technology

This should include increasing the appropriate use of technology to enhance LTSS. States realize they must be intentional with policies to increase the use of technology so that people with I/DD can have greater independence in managing their lives, can lessen the need for staff presence in all aspects of support, and can support the work force to be most efficient with supporting people by creating effective administrative reporting.

Technology is not a panacea. NASDDDS members are wary of adopting technology solely as a means of cost cutting or as a tool for staff convenience. However, state DD agencies recognize that when appropriately deployed, technology can add value to the lives of people with disabilities by increasing independence and autonomy, while improving both the efficiency and the outcomes of services so that scarce resources can be focused on improving the service system or reaching more individuals who need services. Federal incentives to states to promote smart home, adaptive and everyday technology for persons with IDD is important.

Our members are also exploring the use of technology to improve the efficiency of the workforce in the DD service system. Information technology that can connect multiple staff and make sure they have easy access to a full range of information about an individual they are serving produces efficiencies and better outcomes for people with developmental disabilities. When, for example, staff can go to one digital place to read an individual's service plan, find out how what services have been delivered to them, check in on their progress toward their goals, read the notes of other staff, check for incident reports, and check their medication schedule, they can quickly access the information they need to provide high quality services, and identify and respond to potential issues. These types of technology uses can also enable increased interaction between frontline supervisors and direct support professionals, not only improving quality oversight opportunities but also facilitating management and mentorship that increases skill. Solutions like this allow more time and resources to be spent on improving services or expanding access.

We recommend the adoption of technology and infrastructure grants for states and service providers. Through this grant program, states could receive funding specifically

for developing provider capacity to both acquire and use technology, in three categories:

1. IT support directly to providers to improve reporting infrastructure and documentation, and streamline availability of standardized data elements to provide state agencies with data needed for quality management efforts;
2. Purchasing of technology (hardware and software) that can be used either to modernize employee practices or to improve direct services; and
3. Delivery of essential training for the knowledge and skill needed for successful utilization of the technology addressed above.

Awards in the first two categories could include funding for essential training requirements, or the funding for essential training requirements could remain as a distinct funding track to make grants also available to states and providers who have already invested in technology and need support to offer ongoing training.

**Sustaining Natural Supports**

"Natural supports," those personal associations and relationships that that exist in almost everyone's lives outside of any paid service system, already play a tremendous role in bolstering publicly funded services and supports to help individuals with I/DD live self-determined lives and fully participate in their communities. The reality of the current and anticipated demographic pressures affecting the potential availability of paid long term supports and services workers demand that our systems find new ways to encourage and sustain these natural relationships. Three major approaches to facilitate this involve system transformation to support people with intellectual/developmental disabilities within the context of their families and communities; centering competitive, integrated employment supports as a foundational service around which other services can be built; and pursuing payment structures that incentivize good outcomes over service hours. Congress can play a role in facilitating each of these approaches by providing funding for research, pilots, and ongoing activities, and by removing barriers to best practices.

**Supporting individuals in the context of their families** Unpaid family caregivers already contribute approximately $600 billion worth of support to our "fractured long-term services and supports (LTSS) system," according to a report just released by AARP.[3] While the involvement of family is not a possibility for all individuals with I/DD,

[3] Susan C. Reinhard, Selena Caldera, Ari Houser, Rita B. Choula Valuing the Invaluable: 2023 Update Strengthening Supports for Family Caregivers. AARP Public Policy Institute, 2023. https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf

and substituting paid supports with an assumption that families are able to fill the gap in perpetuity is a recipe for failure, when family members are present and want to be engaged in supporting their loved one, it is incumbent on the service system to provide resources to encourage, develop, and sustain that engagement, not only to relieve pressure on the paid direct service workforce but also because such family involvement leads to the best outcomes. The federal government has undertaken a number of major initiatives to support family caregivers, including developing a National Strategy to Support Family Caregivers as required by Congress in the RAISE Family Caregivers Act. Congress should continue to prioritize programs and funding that further the goals of this Strategy.

**Paying family caregivers** Further, in order to sustain the engagement of and expand the pool of potential workers, Congress should support states to explore expanding paying family caregivers, as many did during the Public Health Emergency (PHE). While states must consider the need to balance individual autonomy and individual choice when pursuing such strategies, in many instances carefully constructed approaches can lead to better outcomes and greater system capacity. While recognizing that the impact paying family caregivers will vary depending on circumstances, NASDDDS echoes AARP's statement in their recent report that "expanding opportunities to pay family caregivers helps states make the most out of their limited professional direct care workforce and makes family caregiving a sustainable arrangement for caregivers and care recipients who prefer to age at home,[3]" and encourages Congress to ensure states have the flexibility to explore the potential of this approach.

**Expanding integrated employment supports** One of the main ways that all adults in the United States find and cultivate the kinds of connections that support us in times of need is through workplace relationships. NASDDDS members have found that this holds true for the members we serve as well. When individuals with I/DD have the opportunity to work in integrated environments, they often build friendships and develop shared interests that support organic community participation that does not rely on the intervention of paid staff. This is one of many reasons that state I/DD systems are increasingly adopting Employment First policies, building an individual's service plan around a centerpiece of employment supports. However, this benefit does not occur when individuals are employed in segregated environments. NASDDDS calls on Congress to pass the **Transformation to Competitive Integrated Employment Act**, which would among other things provide funding to states and providers to facilitate an overhaul of segregated work supports and environments to ensure that individuals with I/DD have the opportunity to accrue all of the benefits of competitive integrated employment (CIE).

**Value-based payments** The traditional payment structure of Medicaid, the primary funder of public LTSS, involves reimbursing providers for hours of service. This has the

consequence, however, of disincentivizing providers from utilizing strategies to increase independence and assist individuals to achieve their goals without paid intervention. States are increasingly exploring strategies to pay for outcomes rather than hours worked, which would allow providers to focus on increasing independence and would have the ancillary impact of reducing the system's reliance on a paid workforce that may never reach the proportions needed to sustain current "ideal" staffing models. Value-based payments are a key avenue for achieving this systems change. Rather than rely on continuous, intensive involvement of a direct service worker to help an individual maintain a particular outcome—CIE, for example—value-based payments allow providers to focus on assisting the individuals they support to build the skills and personal relationships they need to independently sustain their success, allowing the paid worker to revert to something closer to an ongoing monitoring function, not only freeing up that worker to successfully support several people in the time that would formerly have been committed to one individual, but also leading to outcomes of greater independence and autonomy for the individuals they support.

We appreciate the bipartisan focus to address the health care workforce shortage and urge legislation to address the direct care workforce crisis. This crisis has been growing for decades and will require a multi-faceted approach to successfully address it, one which seeks not only to increase the size of the workforce but also to reimagine how these workers are deployed by our nation's publicly funded LTSS system. We look forward to continuing to work with you on policies to strengthen and ensure access to LTSS. Please contact Dan Berland at dberland@nasddds.org with any questions.

Sincerely,

Mary Sowers
Executive Director
NASDDDS