Making a world of difference
in people's lives

August 7, 2018

Honorable Senator Robert P. Casey
393 Russell Senate Office Building
Washington, D.C. 20510

Dear Senator Casey:

Recently, I had the pleasure of meeting with two members of your staff, Elizabeth (Liz) Weintraub and Michael Gamel-McCormick, to discuss key issues facing the Direct Support Professional (DSP) workforce which were highlighted in the ***Report to the President 2017*** on behalf of the President's Committee for People with Intellectual Disabilities.

Individuals with intellectual and/or developmental disabilities (I/DD) are often referred to as the "most vulnerable" in our population, however, over the past 20 years, individuals with I/DD have been able to participate more fully in their communities, live in integrated settings and seek meaningful employment. The vast majority of this change has been accomplished through the insurmountable dedication of Direct Support Professionals whom day after day wear countless hats to support individuals throughout their daily lives. To accomplish this, DSPs serve through providing medical care (i.e. medication administration, supporting non-ambulatory individuals, wound care), supporting community inclusion (i.e. providing supports in less congregate and more individualized settings, providing job coaching, and providing transportation), advocating for services, providing emotional support, and ensuring people are healthy and safe amongst many other aspects individuals with I/DD need in their daily lives. While the list of skills and abilities needed is vast, it is also ever changing as DSPs must also be aware of state and federal compliance-based regulations, ensure accurate record keeping and maintain current training. The work of this group, comprised of roughly 1.3 million workers[1], is compensated at an average hourly wage of $10.72 per hour – below the federal poverty level for a family of four.

Due to the vast and complex job requirements for a DSP coupled with low wages, DSP turnover rates average 45% of the workforce and average vacancy rates of 9%, indicating a constant churn in workers to meet growing demand for long-term care. This "churn" in the workforce has many implications, including high administrative costs for recruiting and training new DSPs (estimated at roughly $2.4 billion annually), negative impacts on quality of care, and increased occurrences of abuse, neglect or mistreatment.

While there are many causes of DSP turnover, one common denominator to the issue seems to be a lack of a Standard Occupational Code (SOC) through the Department of Labor's – Bureau of Labor and Statistics. While it may seem like a small, incidental causation, the lack of a SOC has many ramifications as outlined below:

Implications on Service Reimbursement Rates: As you are likely aware, States are independently responsible for establishing and setting reimbursement rates for long-term care services. This process is required by the Centers of Medicare and Medicaid Services (CMS) to be reviewed at least every five (5) years to ensure rate adequacy, fairness and transparency. While the rate setting process is complex and includes the analysis of many variables, one of the most significant rate components is direct labor in

[1] Estimate as of June 30, 2013

providing care – Direct Support Professionals. In order to set the overall rate for a service, rate setters look at staffing ratios, staff qualifications, service demand, and comparable SOC classifications (including like job duties and average wage) as a basis for setting DSP wage assumptions. Unfortunately, because there has never been a DSP SOC, rate setters are forced to utilize other, like codes in the process. Most typically, rates are set using SOC 31-1011 (Home Health Aide) and 39-9021 (Personal care aides). While some of the core responsibilities under each of these codes do have similarities to DSPs working with individuals with intellectual and/or developmental disabilities, there are also significant differences. For example, providing supports to an elderly individual or an individual with a physical disability is substantively different than supporting an individual with an intellectual disability whom may have cognitive limitations as well as significant medical and/or behavioral support needs. DSPs are required to have a greater understanding of the multiple layers of support which often requires support to be increased in frequency, duration and scope. Next, home health aides – and often personal care aides – provide supports in a one-on-one setting which are typically less regulated (i.e. the person's own home or a family home). In comparison, DSPs are often tasked with supporting multiple individuals simultaneously in a variety of community-based settings, requiring they manage multiple types and levels of support needs continuously and often without available supervision. When staff ratios are not adequate or there is not an adequate workforce to ensure enough DSPs are available to provide supports, DSPs are often mandated to pick up the additional duties to support additional individuals. Further, a large portion of individuals with I/DD reside in group home settings, intermediate care facilities or other congregate living settings which are highly regulated and require compliance with agency policies & procedures, as well as, state and federally mandated requirements. Due to these differences, and others, it is our opinion that the SOC classifications used in rate-setting activities does not adequately represent the role of a DSP – yet they are the closest available options to choose from. The available SOC classifications and the associated average hourly pay rates underestimate the work of the DSP workforce and, inherently, perpetuate lower pay and benefit levels due to the misclassification.

Lack of Data for Identifying Labor Shortages: As indicated in the ***Report to the President***, organizations rendering long-term care services to individuals with intellectual and/or developmental disabilities identify turnover rates averaging 45% annually with a 9% vacancy rate. As the report indicates, "this means that 9 percent of all available positions go unfilled. Vacancy rates are created by service growth resulting from increased need and demand, as well as high DSP turnover. Unfilled positions undermine the quality of care, overburden DSPs remaining on the job and are a clear symbol of the crisis of providing sufficient numbers of DSPs to meet the needs of persons with ID/DD and their families." While the data, as reported, provides a relatively strong accounting of DSP turnover and vacancy, due to a lack of a SOC, data is collected as a sample through third-party surveying and likely underrepresents the true turnover, vacancy and associated costs with ongoing recruitment and training.

Further, failure to fully measure and act on this workforce shortage impacts only not DSPs, but also individuals receiving supports, their families and the greater national economy. As evidenced in the ***Report to the President***, "the current workforce crisis threatens the health, safety and well-being of people with ID/DD. DSPs who are tired from working long hours or multiple jobs are much more likely to make mistakes and have lower tolerance for stressful situations. When DSPs do not know the person for whom they are providing support, they may not recognize signs and symptoms of illness." Compounding on this, "the impact of the workforce crisis is also evident in the lives and well-being of family members. Being able to entrust loved ones to skilled, committed and well-known support providers is vitally important in order for family members to maintain employment and engage in community outside the family. In the National Health Interview Survey – Disability Supplement of 1994–1995, 53 percent of

parents interviewed reported major career concessions (e.g., not taking a job, working fewer hours, dropping out of the workforce, turning down a promotion) related to having a child with ID/DD." Failing to better understand and mitigate workforce shortages will continue to place greater stress on families and harm the well-being of individuals needing support. Should a SOC classification be developed, State governmental agencies would be better positioned to analyze workforce shortages, develop strategies to mitigate workforce shortages and provide better financial projections of needed funds to state legislative bodies. However, without this data, states, provider agencies and families are left feeling in crisis with no real information to guide systemic, sustainable change to the issue.

***Devaluation of the Workforce*:** *Quality* begins and ends with the direct support professional and today, people with disabilities are achieving meaningful outcomes and valued as fully contributing members of their respective communities, however DSPs must themselves must also be valued and seen as professionals who possess technical skills that many in America are unwilling and unable to perform. Knowledgeable, experienced and compassionate DSPs act not only as caregivers, but also as teachers, mentors and ambassadors – they work with professional intention based on sound research and evidence-based practices. Even though direct support demands complex skills, independent thinking, ethical judgment and the ability to create long-term relationships of trust and mutual respect, the work has not been recognized as a viable profession. DSPs are neither viewed as the key lynchpin of a system of community services, nor compensated and otherwise supported on par with the importance of the work that they do. This is a matter that must be addressed if we are to attend to the current crisis as more and more Americans become reliant on community supports due to aging or other disabling conditions.

While the three areas outlined above are by no means an exhaustive list of challenges caused by a lack of a SOC for DSPs, it is our belief that these areas are primary challenges facing the DSP workforce that could be positively impacted by establishing an SOC specific to DSP in the I/DD field. It is important to note that prior to the latest release of the SOC (2018), an attempt was made to add a Direct Support Professional classification which was denied. As you are likely aware, the DOL/BLS make a determination for recommending a new SOC to the Office of Budget and Management only if the new SOC passes ten (10) guiding principles. In the original request, the DOL/BLS indicated that the new SOC did not pass Principles 1 or 2, indicating that they believe the classification is redundant of 31-1011 (Home Health Aides) and 39-9021 (Personal Care Aides). While we acknowledge that there are similarities in *some* tasks between these two classifications and DSPs, we do believe the role of a DSP supporting individuals with I/DD is substantively different as outlined above. It is our goal to submit and have approved a Direct Support Professional SOC specific to I/DD services.

As stated previously, receiving a SOC code may seem like a relatively simple step in supporting this workforce, but it is our belief that once a more relevant SOC classification is in place, several things may occur. Primarily:

1. Service reimbursement rate reviews will be able to use a more appropriate classification for developing DSP wages. By doing this, it is our belief that, through more accurate data, DSPs may be able to obtain a more livable wage for the work they do. As this occurs, it is anticipated that DSP turnover may decline as a key driver to turnover is low wages and benefits.
2. Reliable data related to the DSP workforce will provide a better opportunity for the Federal government, State governments and local municipalities to mange service demand and service supply by monitoring workforce growth or decline and project against anticipated future demand for services. According to the ***Report to the President***, "between June 1991 and June

2014, the total number of individuals served under the auspices of state ID/DD service agencies increased by nearly four times (390 percent), from 289,370 to 1,128,530." It is not anticipated that this growth will decline in the future. Without better preparing for the continued growth in service demand, individuals with I/DD, their families and the agencies tasked with rendering support will remain in crisis.

3. Develop mechanisms for a standardized training and credentialing platform to provide service quality stability and "career ladders" for DSPs. Currently, there is not a standard credentialing program or training requirements for DSPs. States independently set such requirements, and the Federal government does not currently have any standard guidance for the DSP workforce. It is our intent to utilize a SOC classification specific to the DSP – I/DD workforce to develop and implement standards for training and credentialing that will help ensure: a more well-trained and equipped workforce for supporting individuals with I/DD, provide career ladders so that DSPs can participate in meaningful career advancement through training and credentialing that is correlated to wage enhancements, and promote a DSP credentialing program which provides individuals and their families peace of mind that the DSPs providing support meet rigorous credentialing standards tied to quality of care.

We wholeheartedly believe that these steps, as well as continued advocacy for the workforce, will help stabilize the "crisis" and allow the Medicaid system for individuals with I/DD to see better quality of care, reduced administrative costs due to turnover and promote outcomes-based support that reduces incidents of abuse, neglect and mistreatment through a better prepared workforce.

In closing, while the DSP workforce "crisis" is not new to our field, a "crisis" does not last thirty years. We believe this is a systemic failure and the time to act and implement ways to mitigate the "failure" and stabilize the workforce is *now*. As healthcare and entitlement reform continues to be under consideration by the U.S. House and Senate, systemic changes to funding – through block grants or other constraints – will tighten available funds across entitlement programs – i.e. aging, mental health, physical disabilities, and intellectual and/or developmental disabilities. These potential constraints will "shrink the pot" of funds in already financially stressed systems and increase the competitiveness across fields trying to access DSPs to provide support. However, as the workforce already feels devalued, and turnover and vacancy rates remain high, the dwindling supply of available workers simply can't meet the growing demand. Establishing a DSP-I/DD SOC does not require an action of Congress, but instead, an acknowledgment by the OBM that the work of this group is substantively different than that of Personal Care Aides or Home Health Aides. Once this occurs, it is our intent and belief that meaningful actions can be taken to stabilize the workforce – by evoking sustainable, long-term solutions.

As you spend more time getting to know our field, you may start hearing that we are often "pilot rich and program poor". This means that there is often little support behind implementing long-term solutions to fix systemic issues for the I/DD population. This is likely due to the relatively low number of Medicaid users compared to the larger system. As of December 2015, people with I/DD made up only 1.17% of Medicaid/CHIP enrollment. However, services for people with I/DD was 8.5% of the total Medicaid budget. This high cost is directly tied to the level and complexity of ongoing support individuals with I/DD need. DSPs are the stewards of this system, ensuring that individuals with I/DD are able to not only live healthy and long lives, but lives that are important and meaningful to them. Should we continue to disregard this workforce and devalue their important role, we also disregard and devalue the role of individuals with intellectual and/or developmental disabilities in our society through limiting their access to community engagement.

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We thank you for your consideration in this matter. We know that your past record and actions related to I/DD services show a long track record of support for the lives of persons with I/DD. We look forward to working with you to establish a SOC classification or the DSP workforce and ensure long-term, sustainable solutions to the issue at hand.

With kind regards,

Joseph M. Macbeth
Executive Director
The National Alliance for Direct Support Professionals

/cc
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