SOCIAL INNOVATIONS Journal

Vol. 13 (2022): Human Services System Innovations: Marginalized Populations

Public Policies to Advance the Intellectual and Developmental Disability Sector

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Keywords: human services, intellectual disability, medically underserved, workforce, immigration, public policy

Abstract

Healthcare access and an adequate workforce serve as two mounting challenges for the intellectual and developmental disability (I/DD) sector. Passage of The Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population, or HEADs Up Act, could greatly improve access by creating a medically underserved population (MUP) designation for the I/DD population. New and expanded workforce visa programs could meet the challenges associated with increased demand and limited supply for the Direct Support Professional (DSP) labor pool.

Introduction

Healthcare access and an adequate workforce serve as two mounting challenges for the intellectual and developmental disability (I/DD) sector. Passage of The Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population, or HEADs Up Act, could greatly improves access by creating a medically underserved population (MUP) designation for the I/DD population. New and expanded workforce visa programs could meet the challenges associated with increased demand and limited supply for the Direct Support Professional (DSP) labor pool.

"Change is the only constant"
-Heraclitus

Nonprofits in the intellectual and developmental disability (I/DD) sector have encountered significant change during our current public health emergency (PHE) and in the years prior. We must start to drive change before our fate is chosen for us. In *Forces for Good: Six Practices of High Impact Nonprofits*, Crutchfield and Grant state that effective organizations proactively work with government and advocate for policy and systems change. This article will look at two specific proposals for policy and systems change needed to shape the future of our sector: healthcare access and an adequate direct support professional (DSP) workforce. More specifically, we will explore proposals for creating a medically underserved population (MUP) designation for the I/DD population and the creation of workforce visa programs to increase the labor pool of DSPs. Access issues and labor shortages threaten the future of our industry. Public policy serves as a strong tool at our disposal in determining what lies ahead for the I/DD sector.

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MUP for I/DD Population

The Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population, or HEADs Up Act, sponsored by Representatives Seth Moulton (D-MA) and Brian Fitzpatrick (R-PA) would for the first time designate people with intellectual and developmental disabilities (I/DD) as a 'medically underserved population' or MUP. MUPs have a shortage of primary care health services for a specific population subset within a geographic area. These groups may face economic, cultural, or language barriers to health care. Some examples include: people experiencing homelessness, people who are low-income, people who are eligible for Medicaid, Native Americans, and migrant farm workers.

MUP designations qualify a group for many federal programs and incentives including: allowing doctors to receive higher payments from Medicare and Medicaid, offering repayment of student loans for providers who serve MUP populations and funding for research on topics affecting the group.

According to the Centers for Disease Control, there are 4.5 million people in the U.S. with I/DD. While many people with I/DD live independently and with few or no supports, many others have multiple severe conditions that require highly specialized supports, increased access to primary care and careful care coordination. Some of these conditions include such diverse genetic or neurologic conditions as traumatic brain injury, autism spectrum disorder, muscular dystrophy, cerebral palsy, epilepsy, in addition to mental illness, emotional and behavioral challenges. Medically frail individuals often struggle to find quality primary care due to unfamiliarity with their medical conditions and Medicaid reimbursement rates. Too often, simple health care issues result in trips to the ER and costly hospital admissions for this population.

At Woods, we are already seeing the quality of life improvements created by enhancing primary care for individuals with I/DD. The Medical Center at Woods opened in mid-2018 with extended hours, increased access to medical services such as radiology, and improved coordination and continuity of care. The cornerstone of the medical center is an enhanced provider reimbursement rate negotiated with our Medicaid provider, Keystone First. Much like the enhanced provider reimbursements that a MUP designation provides on a larger scale, Woods' arrangement incentivizes providers to better understand the care needs of I/DD patients and take the time to ensure a holistic approach to their care. Woods is already seeing a reduction in ER visits and health care spending as a result of the Medical Center's efforts. We look forward to sharing detailed data on this trend as more time passes and we believe this bill could help lead to reductions in costly hospital stays for I/DD individuals nationwide.

Whether you represent a nonprofit provider or serve as an interested stakeholder, a relatively simple way to help advance this cause is to contact your members of Congress and ask them to co-sponsor and vote for HR 2417.

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Workforce Visa

The compounding Direct Support Professional (DSP) crisis worsens, regardless of the lens or angle through which you approach it. People with an intellectual disability rely on Direct Support Professionals for daily assistance that allows them to live meaningful days and meaningful lives. Families rely on DSPs for quality, reliable, consistent care of their loved ones. However, finding and retaining DSPs to comprise this workforce has become a mounting challenge. The need for DSPs has reached crisis levels and only continues to grow. Direct Support Professionals provide integral, daily support to people living with intellectual and developmental disabilities. DSPs assist with all aspects of day-to-day life, including bathing, dressing, cooking, cleaning, and administering medication. These workers drive clients to and from activities and medical appointments. DSPs literally walk side-by-side with their clients to ensure that they lead meaningful and vibrant lives. DSPs are essential to adequately meeting the needs of the intellectually and developmentally disabled in this country.

However, the labor pool for this type of worker has begun to run dry.

4.5 million direct care workers nationally serve older adults and people with disabilities, while the need for these jobs is projected to increase 40% over next 10 years. The current pool of qualified workers is not large enough, while the population of working-age adults is shrinking. Currently, there are 32 adults for every adult over 85-years old. By 2050, that number will shrink to 12 adults for every adult over 85-years old.

A 2021 ANCOR provider survey revealed that 77% of providers in our sector have turned away new referrals, 58% of providers reported they have discontinued programs or services, and 84% have delayed implementation of new programs or services.

This picture gets even bleaker. On top of dealing with annual turnover rates of nearly 43%, vacancy rates for part time and full-time workers oscillate between 12-16%. 8.2 million direct care positions will need to be filled by 2028, and 589,940 people are currently waiting in line for the services of direct care workers. We do not even fully understand the depth of the DSP crisis, as we need a separate distinction for DSPs within the Bureau of Labor Statistics.

The levers of immigration and visa programs could make a significant impact on this workforce crisis. However, we must consider targeting specific levers at our disposal to meet growing demand. The below policy recommendations have evolved over the past year, and could be pursued independently or as a package.

1. **Enact a 3-year renewable guest worker program for Direct Support Professionals as a provision under the H-2B temporary non-agricultural worker visa program or as a standalone program to meet macroeconomic and regional labor demands.** We propose the creation a 3-year, renewable guest worker program that would allow qualified, English-speaking, foreign-born individuals to enter the U.S. to work in DSP

that cannot be filled by native-born workers. The United States allows employers to hire temporary workers in the fields of agriculture and hospitality in order to fill labor gaps. Creating an authority to allow a managed migration pipeline for DSP workers would address the DSP crisis directly. Under such an authority, I/DD service providers meeting specific criteria would be allowed to hire foreign-born workers to fill a set of positions designated for DSP roles. Workers would be admitted to the country for a fixed, three-year period with an option to renew the visa if performance criteria are met. Workers would be guaranteed wages and benefits comparable to domestic workers in the same positions. Providers would cover transportation and other costs related to bringing temporary DSP workers on board. If the worker left the employer, that worker would have to return to his or her home country, or find another DSP position placement within a specified time period.

2. **Dramatically increase caps on the H-2B temporary non-agricultural work program to meet increased demand for these type of work visas.** There were 136,000 applications for 33,000 available H-2B visas in the second half of 2021. Even with unprecedented cap increases from the Department of Labor and the Department of Homeland Security of an extra 35,000 available visas, demand still greatly outpaces supply of these workforce visas.

3. **Modify the R-1 program to cover temporary workers in provider organizations that are religiously affiliated.** We support amending or interpreting the definition of 'religious occupation' so it includes direct care services provided by qualifying U.S. employers. We support expanding the definition of 'denominational membership' to include direct care settings more broadly.

4. **Enact Direct Care-Pairer, a new authority under the J-1 visa program, to include direct care workers in addition to child care workers.** Nearly 18,000 au pairs work in the United States each year under this visa program. The J-1 Exchange visa calls for temporary workers to enter the U.S. to provide childcare in a family or professional setting. Often referencing au pairs, these workers must achieve a secondary education, must be proficient in English, and must be capable of providing child care. The new "Direct Care-Pairer" program would be modeled on the au pair program and would be focused on workers who provide direct care services.

5. **Amend NAFTA to include Direct Support Professionals.** The North American Free Trade Agreement (NAFTA) includes authorities allowing individuals from Canada or Mexico to enter the U.S. on a temporary basis to engage in professional activities. The authority stands for three years. We propose that Congress add Direct Support Professionals as a standalone classification of allowable workers under NAFTA. This could allow us to create pipelines similar to bilateral agreements utilized by European countries to fill labor gaps.

6. **Increase the number of refugees and asylees permitted to enter the U.S., and make program adjustments to engage these individuals in DSP jobs.** We support increasing the refugee and asylee cap to create a greater pool of U.S. workers, specifically DSP and Direct Care Workers. English-speaking refugees and asylees can be recruited in a manner to aforementioned authorities to contribute to a labor pipeline. Over 40,000 refugees/asylees enter the United States each year.

7. **Create the DSP Corps.** Over 250,000 AmeriCorps volunteers serve in the United States each year. A program recruiting both foreign-born and domestic recent graduates to fill DSP positions in exchange for graduate school admission, non-competitive federal employment opportunities, and leadership development training could significantly assist in feeling the needed labor pool.

Conclusion

In order to develop a new system of care for the I/DD population that meets the challenges of our rapidly changing landscape, two primary elements are needed: healthcare access and an adequate DSP workforce. Our fellow intellectually and developmentally disabled citizens, their families, and local communities deserve public policies that adequately allow them to lead meaningful days and meaningful lives. A MUP designation for the I/DD population and new visa programming to meet growing DSP demand would allow us to drive change instead of passively accepting crisis states and inadequate standards for the population we serve.

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