

The Where and the How:

Ensuring those with Disabilities have the People Power for Healthy Living

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A.S. is a 33-year-old autistic man who rents the apartment above his parents' garage. He is competitively employed at a 20 hour/week job where he is entitled, through Medicaid, to have the support of a Direct Support Professional (DSP), who serves as his job coach. With the money he earns at his job and his monthly disability payment, he pays for his transportation to and from work and DSP's to support him in community activities after work and on weekends. The rent he pays to his parents covers room and board. His parents support him in kind with oversight of all of his finances, medical care to include daily medications, meals, laundry, housekeeping, coordination of caregivers and ensure his safety in the apartment with the help of a security system. He is currently eligible through the Medicaid Lifespan Waiver to access benefits of \$2700 per year to help him with the cost of personal care or pay for respite services like camp.

C.T is a 43-year-old female with quadriplegic spastic cerebral palsy. She lives in a long-term care facility and relies on a DSP called a residential technician. This individual makes sure she is bathed, dressed, and safely in her wheelchair from which she communicates via an augmentative and alternative communication system (AAC) and moves throughout the campus independently using head and foot controls. Her DSP ensures her choice of clothing and the color of her lighting in the room, gets her to appointments, and assists with technology support when her Facetime, email, or Alexa is not working. CT enjoys spending time with her parents on the weekend and her DSP ensures she is packed and has everything she needs for trips home.

K.B. is a 28-year-old female with moderate autism. She uses verbal words to communicate and lives in an apartment with three roommates and full time DSPs who serve as house managers and staff. She works 20 hours per week at a supermarket and another DSP serves as her job coach. Her house staff accompanies her to all doctor's appointments and errands including a weekly physical therapy session and an outing with a friend. When shopping, they assist with helping her pay and accept change. As she navigates going on a date for the first time, her DSP accompanies her to a healthy relationship class.

These three Delawareans are united by their diagnosis of intellectual/developmental disability (IDD) and by the safe and healthy environments in which they live. As a central tenet of the strategy to make Americans healthier, we are motivated to look closely at the environment and other social determinants that account for health. The environment includes a person's living conditions, their access to transportation, and safety. In clinical settings, we often monitor the health of an individual's living conditions by asking about housing, homelessness, ambulatory status, and isolation.¹ Nationally, 59% of those with IDD live with a family member, while 16% live in a group home (a residential setting with six or fewer individuals), 11% live in their own home, and 9% live in a long-term care facility (a residential setting with seven or more

individuals). When we focus on the population with IDD, we cannot look at living situations nor discuss housing without noting the necessity of those hearts and hands who make it possible.

For those individuals with IDD, assistance is needed at home to complete both activities of daily living (bathing, toileting, dressing, eating, moving) as well as instrumental activities of daily living (shopping, transportation, preparing meals, managing medications, using the phone, cleaning, running errands, and managing finances). Thousands of Delawareans with IDD rely on individuals known as direct support professionals (DSPs) to provide support in completing these activities of living throughout their day. These individuals help with life's essential activities and are integral to healthy living conditions. DSPs perform "some of the functions of clinicians, service coordinators, managers, maintenance, and clerical personnel. They have a code of ethics and a set of core competencies."² DSPs make it possible for adults with IDD to live a more typical life in the community, such as holding a job, going to the store, taking a vacation, or visiting the doctor's office. They also support independence in residential situations. Without these individuals, Delawareans with IDD and their families would not have a choice of safe and healthy environment in which they would like to live. Whether in a parent's apartment, a long-term care facility, or in an apartment with peers also affected by IDD, each location requires DSPs to assist in maintaining the independence and health of the individual.

Yet the DSP workforce has never been more challenged. For the 1.7 million adults with disabilities living in the US, there has been a shortage of support staff for many years because of inadequate funding and high turnover. However, the COVID-19 pandemic has raised it to epic proportions. In 2021, more than half of Delaware agencies serving people with IDD had vacancies for 20-50% of their necessary workforce.³ As a result of labor shortages, half of these agencies were unable to take on new clients and one quarter had to reduce services to existing clients. Government entities, family caregivers and a broad spectrum of disability organizations readily cite the workforce shortage as one of the most urgent challenges facing people with all types of disabilities.

The direct support workforce crisis relates directly to the inadequate funding of services by government, because chronic underfunding translates to low wages for these workers. Just two years ago, State funding in Delaware supported a wage of approximately \$9.00 an hour for these essential workers, who bear enormous responsibility in the care of the people they support. Inflation, a rising caseload, and most recently, a pandemic, has further exacerbated the ability of service providers to hire and retain direct support staff. Both in community settings and in long term care facilities, the vacancies for these positions are staggering.

Already, efforts are underway to begin to address the funding of the IDD system which impacts DSP wages in Delaware. In 2019, a partnership formed by the family advocacy group A-Team Delaware and disability service providers joined together and made history by advocating for the successful passage of the Michael McNesby Full Funding for Adults with Intellectual Disabilities Act. This law mandated the State to fully-fund day and residential services for adults with intellectual disabilities in Delaware based on a 2018 market study. Between 2018 and 2022, The Delaware General Assembly approved \$42 million in State dollars, which will draw more than \$59 million in federal matching Medicaid dollars to fund service providers under contract by the Delaware Division of Developmental Disabilities (DDDS). This combined investment of more than \$101 million is welcome news to meet the increasing needs of Delawareans with IDD and their caregivers. However, even with these additional dollars, the State funding only supports a \$14/hour wage for Direct Support Professionals – far below a livable wage here. The Delaware

Division of Disability Services (DDDS) will undertake an updated market study in the coming year which should reflect the need for higher wages for Direct Support Professionals.

Besides championing higher wages, another solution for the crisis is to recruit and retain the best workforce possible. Delaware's turnover rate for DSPs was reported as 36% in 2020, slightly below the national rate of 43%.⁴ However, it is likely much higher now due to the pandemic. As hundreds of thousands of workers leave the caregiving industry, it is important to focus on renewed and innovative recruitment strategies. Collaborating with community colleges and offering loan forgiveness are two strategies to recruit the best caregivers. New York, for example, trains and certifies DSPs for free through in person or online courses through the state university system.⁵ California offers licensing to more than 5,000 new DSPs each year through free training courses run by the state Department of Education or through "challenge exams" that let experienced caregivers codify their skills.⁶

Focusing on labor and immigration policy is a necessity. [For decades, home health care in the U.S. has been bolstered by an immigrant workforce.](#)⁷ This caregiving, which is often seen as low skill and not adequately respected, falls overwhelmingly on marginalized groups: in Delaware 76% of DSPs are women and more than 70% belong to a minority group.⁴ Until the recent workforce crisis, immigration policy and labor policy have not valued these positions. According to the Bureau of Labor Statistics, home health and personal care aides are the fastest growing industry, [projected to grow 33 percent](#) in the next decade, much faster than all occupations. But there still simply aren't enough workers to fill the demand.⁸ Providing a new category of visa for DSPs may allow those who have caregiving skill to immigrate and start working faster and easier.

Lack of career advancement is another reason often cited for workers leaving the caregiving industry. To create awareness about the career pathway and advancement, many states are sharing successful strategies on a broader scale at conferences and meetings. Sharing best practices regarding continuing education and leadership roles are a great step in bolstering states who may have lagging knowledge. DSP apprenticeships have been implemented to help create this career ladder, demonstrating that the profession is vibrant, and worthy of commitment. Currently, the Ability Network of Delaware, an association of community-based disability and behavioral health services providers, is advocating for the establishment of a Healthcare Workforce Center which would create an apprenticeship program for DSPs in Delaware. This apprenticeship model, which would create an employment pipeline for this career out of vo-tech and other high schools and adult education programs, is already in place in 19 other states. Federal and state governments can also assist with retention by helping support the career ladder in financial and operational ways.⁹

As labor markets reach a new normal with the COVID pandemic, the strain on the DSP workforce faces a new challenge: aging caregivers. Those who live with a family member often share a home with a parent who themselves are aging, and often over the age of 60 years. As individuals with IDD and their parents age in place, two crises are compounded: both need direct support professionals to be companions, makeup artists, chefs, Facetime operating system fixers, walking buddies, cheerleaders, anxiety-busters, friends, and guardians of health. Without these individuals, people requiring DSP services would suffer the threat of loneliness and even loss of life. It is extremely sobering that the waitlist of people who are disabled and need home and community-based services is growing rapidly at the very time the staffing shortage has reached an all-time high. Many private agencies who provide services through DSPs have closed their

doors as these agencies say that America's system for the disabled is nearing collapse.¹⁰ Delaware must build on the success of advocacy around the McNesby Act to ensure DSP staffing in all areas that those with IDD dwell. Now is the time to infuse the DSP industry with innovative ideas and energy in addition to new funding streams. For those with IDD, now is the time to be sure the question "who helps you live" receives as much attention as "where do you live."

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