Crises in Intellectual Disability

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Edited by

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Research is essential to the betterment of the human condition, but has earned a bad name in many circles. One only needs to consider the Tuskegee syphilis study or the Willowbrook hepatitis studies to appreciate the reluctance of families and state authorities to permit or authorize research with human beings. A responsibility to conduct research for the betterment of the human condition remains; however, this research must be respectful of human rights

Supports and services for school aged children are mandated by IDEA. Schools must provide free and appropriate educational services to all children, regardless of handicap. There are no such guarantees for adults who have disabilities. Services are provided, but not all receive them. Insufficient funding has resulted in large waiting lists for adult services.

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PREFACE

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The past 50 years have witnessed paradigmatic changes in how society supports and treats people with intellectual disability. No longer are individuals left to languish in foul smelling overcrowded buildings with minimal activities to occupy their time. In their classic review of the closure of Pennhurst Center, Jim Conroy and Val Bradley provided empirical support for the notion that placement in smaller community homes resulted in increased skill development, increased integration, and greater happiness. Our field clearly embraced Donald Campbell's admonition that all social programs must be evaluated by outcomes rather than intents.

The basic question asked by Conroy and Bradley, "Are they better off?" pertains today. One might suggest that while we have moved from the sorry conditions at Pennhurst and Willowbrook, the need for vigilance remains, particularly in these economically challenging times for social service programs. We need to take steps to ensure that not just the average person with intellectual disability is better off, but that all persons with intellectual disability are better off. And perhaps we need to re-conceptualize the concept of "better off" to include the exercise of choice, individualization, access to health care, and the coordination of services and supports.

In this book, the authors set out to write bluntly about the Intellectual and Developmental Disabilities service sector. How it grew, how far it has come in terms of policy and change, who works in the sector, and why it has evolved the way it has, as well as where it needs to go. The book tells an important story of a well-intended, but misguided sector that wants to undo historical harm, but perhaps in the process continues to harm some people. The good news is we can change that -- and I hope this book will help.

In spite of being highly regulated, services to individuals who have intellectual and developmental disabilities (including people with autism) are highly fragmented with small "mom-and-pop" nonprofit organizations providing many of the services. Over the past 50+ years, care for this population has been largely governed by funding. Until the age of 21, education and human services pay for schooling and some kind of residential or in-home supported care. At 21, people with intellectual and developmental disabilities reach the cliff and exit the childhood mandatory support system for a much less organized and supportive adult system of care. While the childhood system is led by special education teachers, clinicians, social workers and a strong direct care staff network, the adult system is mainly led by social service workers and care coordinators providing much needed support and some housing opportunities depending on need. Missing from the equation is the healthcare system that seems to have been an afterthought or not thought of at all, regardless of the need for much stronger coordination and inclusion of the healthcare system.

As the book also points out, we cannot forget how far we have come. Today, providers who serve people with intellectual and developmental disabilities have the privilege of caring for thousands of children and adults with varying levels of disability, including autism, brain injury and other complex behavioral and medical needs. Fifty years ago, these individuals would have been isolated and effectively hidden away from society. Thanks to advancements like the Americans with Disabilities Act and the U.S. Supreme Court’s Olmstead Decision of 1999, those with intellectual and developmental disabilities enjoy greater freedoms and more opportunities. Those of us in the intellectual and developmental disabilities sector are dedicated to preserving and furthering this progress; that is why the author and contributing writers decided to write this book.

The ADA’s groundbreaking protections against discrimination have been copied around the world. Because of this law, people with disabilities have greater access to housing, employment, education and public spaces. The Olmstead Decision enhanced these protections by outlawing unjustified segregation based on disability and mandating that states provide community-based services when appropriate. The driving force behind both these reforms is the idea that every American, regardless of disability, should have the right to decide how they want to live, work, and spend their time. Everyone agrees that the old policy of forcing people into locked institutions was wrong and discriminatory. Today, there is a trend toward greater community integration, and in fact, living in the community is often a requirement for drawing federal funding. To address the question of Conroy and Bradley, most people are better off.

However, before we celebrate too much, and, as this book points out, we still have far to go to get the services and support of the full intellectual and developmental disabilities sector right. While the policies of community-integration are no doubt well-intended, many still fail to respect people's basic right to choose where they live and work. For example, in most states, regulations unnecessarily restrict the number of individuals with intellectual and developmental disabilities who can live in the same building or community. There are other rules intended to defund sheltered workshops, even though many people with intellectual and developmental disabilities enjoy these jobs and have held them for a long time. States have even gone as far as to dictate the percentage of time persons with intellectual and developmental disabilities must spend outside their home and with whom they can spend that time. Is this any less discriminatory? Doesn't this also violate the principles Justice Ginsberg laid down in Olmstead?

The authors of this book suggest that the policy approach needs to be flexible enough to accommodate the immense diversity within the population of individuals who have intellectual and developmental disabilities. There is no one-size-fits-all solution to their needs. The best way to preserve choice is to honor the decisions made by those with intellectual and developmental disabilities, and for those who lack the mental capacity to choose, we must respect the decisions made by their families and caregivers. We believe this is what Olmstead intended, and this is what we support.

While most individuals with intellectual disability are able to live fully integrated lives in the community with appropriate services and supports, a small percentage of them have complex medical and behavioral needs, are unable to perform self-care activities, lack the ability to effectively communicate their wants and needs, and may require 24-hour access to medical and behavioral healthcare care and support professionals; yet, as you will learn from this book, we have designed a system that mainstreams individuals who have intellectual and developmental disabilities but does not adequately account for acuity levels of care. This lack of acknowledgment that not everyone with an intellectual or developmental disability is the same, compromises the work of some of the most hard-working people, direct support professionals. We wonder why we have a direct-care staff crisis; our system's lack of support and recognition is one reason.

It is obvious that the system needs innovation. The sector needs organizations that have a population health approach, including connecting prevention, wellness, education, housing, employment, recreation, behavioral health, and social services with coordinated and integrated healthcare for individuals diagnosed with extremely complex clinical and medical diagnoses and challenging behaviors. This book highlights the need for models that integrate health care with services and supports that address the social determinants of health for people with intellectual and developmental disabilities and community integration. Woods Services, a provider of services and supports services to individuals with individual and developmental disabilities, has adopted a population health approach.

Founded over 100 years ago, Woods has a long history of providing services to children and adults with intellectual and developmental disabilities, autism, and behavioral and medical challenges. As part of a recent system's transformation effort, Woods leveraged the expertise of its leadership and organized around the principles and practices of population health management to address the social determinants of health for its client population through a comprehensive and coordinated continuum and system of care that connects prevention, wellness, education, behavioral health, and social services with coordinated and integrated healthcare delivery. Additionally, Woods created Woods Resources, a subsidiary non-profit corporation that serves as the umbrella organization for its network of care, which is currently comprised of six organizations that operate as a continuum of care across two states, Pennsylvania and New Jersey. Woods Resources has strategically brought on affiliate partners which have enhanced its ability to ensure continuity of care across the lifespan using its population health approach. These organizations include Woods Services, as well as Allies of New Jersey, Archway Programs, Legacy Treatment Services, Woods Community at Brian's House, and Tabor Children's Services. Collectively Woods Resources serves 22,000 children, adolescents, and adults, employs 6,000 people, accepts referrals from 175 school districts and 23 states, and has annual gross revenue over $300 million.

In a relatively short period, Woods has solidified its continuum of care across its network with results that illustrate the efficacy of the population health approach. Woods has built the capacity of Woods Community at Brian's House to become one of the largest group home providers in the eastern region of Pennsylvania, and a natural continuation of services for young Pennsylvania adults graduating from Woods schools and residential treatment programs into adult services. This means that Woods and Brian's House can ensure a smooth transition into adult services for those who choose to remain connected to the Woods network, and that individuals can continue to see their providers at the Medical Center at Woods. This continuity is critical during this important transition in people's lives, especially because those with severe behavioral and medical challenges struggle to find providers for primary care, psychiatry and other clinical services. Similarly, Woods is building capacity in New

Jersey through its family of services to be able to alleviate the pressure on the adult system of care for people with intellectual and developmental disabilities, several thousand of whom are on a waiting list for residential care. New specialized homes for people who are medical fragile or who have psychiatric disorders in addition to intellectual disability are in the process of being developed.

Woods and its leadership have been driving the conversation on population health for people with intellectual and developmental disabilities and complex behavior and medical challenges on a regional and national level, as an approach which will successfully address the disparities in access to care, health outcomes, and cost that this complex population experiences. Over 5 million people in the U.S. have an intellectual or developmental disability, including autism, and while many live relatively independently (16%) with little support, a portion of this population have medical complexities and behavioral challenges that require higher levels of care. Further, 35% of this population has a mental health diagnosis and other medical challenges. *About one-third of all Medicaid/Medicare expenditures go to support individuals with intellectual and developmental disabilities*; approximately $664 billion is spent on clinical care alone. These costs are largely driven by unnecessary Emergency Room visits and inpatient care utilization.

Despite advances in medicine and the fact that people with intellectual and developmental disabilities receiving services are largely insured, access to health care and significant health disparities remain -- especially for the 35% of people with intellectual and developmental disabilities with a dual diagnosis and an increased risk of multiple chronic diseases. With a steadily increasing prevalence for autism diagnosis added to the mix, the implications for the United States health system are grave. Individuals with autism have higher health care costs than the rest of the population, as more than 50% have high rates of co-occurring medical conditions, such as seizures, psychiatric, immune and sleep disorders, and gastrointestinal symptoms. Health disparities result in part from lack of access to health care. Transportation poses a significant barrier for this population. In addition, many providers do not accept Medicaid, the primary insurer for people with disabilities, in part because visits typically take more time and reimbursements are low; providers are often not equipped to address communication or behavioral challenges; and their exam rooms may lack adequate space or specialized equipment for those with mobility issues. Disparities include much higher rates of co-occurring conditions, sensory impairment, undiagnosed or poorly managed chronic diseases, and lower rates of immunizations. This population is often not included in public health planning, so appropriate and/or adapted interventions that could address preventable chronic conditions are few and far between.

To date, Woods' population health approach has demonstrated positive results in addressing these barriers to care and health disparities. Several strategies have led to these results. Developing the Medical Center at Woods using a Patient-Centered Medical Home approach has resulted in improved care coordination, better use of data to understand outcomes and drive quality improvement, and the ability to target changes on practices which reduce Emergency Room use and hospitalizations. The Medical Center has become an umbrella under which integrated services are delivered -- primary and specialty care, psychiatry and dental services -- and which coordinates services both internally and with external providers. The theory of change was that increasing primary care and using a Patient-Centered Medical Home approach would reduce Emergency Room visits and hospitalizations, and therefore reduce costs. In addition, this approach reduces the trauma that such services may cause for the population Woods serves. The pilot year confirmed the theory of change: the cost of care for individuals receiving care through Woods' coordinated model was 8.7% lower, inpatient hospitalization days were 39% lower, gaps in care reduced by over 15%, while primary care visits intended to lower emergency utilization and inpatient hospitalizations, as expected, jumped by more than 400%. This pilot is currently being expanded to reach more people with intellectual disability who are being served in group homes throughout Southeastern Pennsylvania, and will incorporate telehealth and telepsychiatry to enhance access to needed care.

Furthermore, Woods recently established a partnership with a new local hospital system who's Emergency Room is the closest to Woods. Woods' team of nurse managers worked in collaboration with the Hospital Emergency Room team to 1) educate them about the population Woods serves, and 2) help them incorporate best practices within the ER to create a sensory-friendly environment. These efforts resulted in many fewer Emergency Room visits leading to inpatient hospitalizations, where the greatest costs lie. Internally, Woods implemented new procedures and processes which further reduced the number of people sent to the Emergency Room in the first place. Woods has also turned the population health lens towards its own employees.

Woods is just one example of how the sector can transform. The future of the sector will be influenced by trends we are already seeing. While the services are still fragmented, market consolidation will need to happen as the government and overall payer community are looking for large organizations to organize the market through partnerships, joint ventures, mergers and acquisitions. There is a general belief that in the next ten years, only a third of the current nonprofit developmental disability and behavioral health service organizations will be in business, as many will go bankrupt or be absorbed into larger organizations, following the trend occurring in the hospital merger & acquisition arena.

With growth comes managed care. Funding will become a struggle in the next five to ten years, as aging baby-boomers will continue to qualify for Medicaid and Medicare. This has the potential to lead to cutting services to people with intellectual and developmental disabilities given the limited funding pool. Only the most compromised and complex people with developmental disabilities will be in concentrated locations like Woods with on-site wrap-around services. The technology trend, i.e. telehealth and telepsychiatry, now allows most providers to serve group homes and people living semi-independently at home.

Finally, the direct care staffing crisis will continue to negatively impact the market, especially with states and municipalities moving towards livable wages without increasing their government funding to disability service providers.

Ultimately, the future will depend on how strong the sector becomes and begins to advocate more strategically about the diverse population that are encompassed within the sector. One-size policies don’t fit all, acuity matters and so does the care model that the population with intellectual and developmental disabilities needs. Therefore, to push for change, as the book suggests, we have to become better and more aligned advocates in our sector. Currently, we don’t speak with one voice and a lot more education is needed. At Woods, we have made concerted efforts to educate local, state and federal legislators on the need to use a population health approach as they consider policy and regulatory change moving forward. Woods particularly advocates for a federal special population designation that would allow for funding and complex care that is not tied to a geographic location based on parameters such as Medically Underserved Areas or income levels. This would allow services to be better focused on a specific population and on the types of care and expertise that is frequently required. Second, Woods has put together a model that brings together service systems and funding streams that have typically been separate and fragmented. These include health care, behavioral health, and the services which address the social determinants of health -- long term care, transportation, housing, employment, etc. for people with intellectual and developmental disabilities. This model is being prepared as a demonstration project.

So, what does the future bring for the population with intellectual and developmental disabilities? Will we reach consensus on choice and give people with intellectual and developmental disabilities real options and choices to determine where to live and with whom to live? How do we move forward to support an expensive and much nuanced industry, is the population health approach the right one? At Woods, we certainly think so, especially for the population with the most challenges. Throughout our efforts, we must continue to be motivated by the simple question, “Are people better off?”

INTRODUCTION

Winston Churchill (among many others) said that one can measure the degree of civilization of a society by how it treats its weakest members. Over the past 50 years, the United States has moved from warehousing individuals with intellectual disability in large segregated facilities to serving and supporting them within the general community. To a large extent, these efforts have been successful, with numerous empirical studies demonstrating that people living in the community develop new skills, become a part of the community, and are generally happier than when they lived in institutions. This great social experiment was put to the test and found to have a relatively strong evidence base. After ten years of challenging economic conditions, it is time to re-examine how we are honoring our commitment to support individuals with intellectual disability. There are many signs that the system of services and supports for people with intellectual disability is in need of significant corrections. This book refers to these signs as crises, and it makes the effort to review thirteen of these crises. It also identifies some promising practices and offers policy recommendations.

CHAPTER 1

DIRECT SUPPORT PROFESSIONAL WORKFORCE CRISIS

What is the Crisis?

High staff turnover and staff vacancy rates result in substantially increased overtime expenditures, and they threaten the quality of services and supports provided to people with intellectual disability. In a field that is largely based on relationships, staff turnover and staffing vacancies present significant challenges to the development of relationships. The field continues to have difficulty in attracting and retaining qualified staff.

Direct Support Professionals (DSPs) provide a wide range of supportive and instructional services to individuals with intellectual and developmental disabilities on a day-to-day basis. These services include teaching community and daily living skills, attending to health and emotional needs, assisting in personal care and hygiene, interpersonal support, job coaching, transportation, recreation, housekeeping, and other home management related activities. These services and supports are provided so that people with disabilities can live and work safely and inclusively in their communities, leading self-directed lives to the greatest extent possible. Similar titles for this workforce include Client Care Workers, Residential Counselors, Home Health Aides, and Personal Care Aides. These employees are the core of the business of serving and supporting individuals who have intellectual disability and other related challenges. It is widely understood that the quality of Direct Support Professionals' work determines the quality of the lives of people who rely on them for assistance.

The American Association on Intellectual and Developmental Disabilities (2016) issued a position statement, noting that the field is challenged with high turnover, while demand for additional direct support professionals is peaking. In June 2003, there were 874,000 Full Time Equivalent (FTE)

Direct Service Professionals working with individuals who had intellectual and developmental disabilities in various settings in the United States (U.S. Department of Health & Human Services, 2006). It is likely that this number is a gross underestimate, with the University of Minnesota Institute on Community Integration (2018) reporting that there are almost five million Direct Support Professionals in the United States. Part of the difference between these numbers may be attributable to varying and inconsistent definitions applied to individuals who are employed in the support of others. Without regard to any current count of Direct Support Professionals, all projections seem to suggest that the need for Direct Support Professionals will continue to grow in the foreseeable future. This is because a variety of demographic trends have coalesced to increase demand for Direct Support Professionals. People with disabilities are living longer. Baby Boomers are entering a life phase in which additional supports may be needed. The population continues to grow. Given the current challenges in the recruitment and retention of Direct Support Professionals, the anticipated increase in demand can potentially result in a catastrophe leaving organizations unable to hire the number of Direct Support Professionals required to support the needs of individuals who have intellectual disability. It appears unlikely that providers will be able to manage the continuing excessive turnover rate; fill the many vacant Direct Support Professional positions; or meet the increased demand for Direct Support Professionals with the current government-restrained wages. Short of a significant change in the industry’s compensation practices, we appear unlikely to meet the demand for Direct Support Professionals in the near future. Note that in the home health care field, the inability to hire sufficient number of Direct Support Professionals has resulted in reduced availability of home health services. In Pennsylvania’s intellectual disability field, some programs have closed admissions due to an inability to hire Direct Support Professionals, and other agencies are considering downsizing because of the inability to fill vacant Direct Support Professional positions.

The University of Minnesota Institute for Community Integration (2008) has established that low pay is a key determinant of the current recruitment and retention challenges faced by Intellectual Disability and Autism providers, families, and individuals themselves. A stronger economy than in the past 10 years, low unemployment rates, and wage competition from companies like Amazon that provide a $15 an hour starting wage reduce the competitiveness of Direct Support Professional wages. In addition, various municipalities are imposing minimum wage expectations without providing funding to meet these expectations. Note that Philadelphia recently passed a law requiring a $15 an hour minimum wage on city contracts beginning in 2021. The mandated wage increases largely serves to create alternative employment opportunities for individuals currently working as Direct Support Professionals.

The President’s Committee on People with Intellectual Disabilities (2018) called the current situation a workforce crisis. Hewitt (2013), however, has argued that the difficulties in recruiting and retaining Direct Support Professionals point to a serious system design flaw that has been clearly evident for over 25 years. She argues that a crisis is more of an emergent problem; this matter is a long term ongoing matter. The shortages of Direct Support Professionals have been evident for years. It seems evident that the roots of the ongoing workforce challenges lie in the systematic under funding of social services (Oss, 2017; Spreat, 2017; Spreat, 2019). Highlighting the extent to which Direct Support Professional pay is too low, both ANCOR (2009) and Torres, Spreat, & Clark (2017) have noted that most Direct Support Professionals would qualify for significant forms of public assistance based on their low wages.

The genesis of the workforce problem is of little meaning to the provider that struggles to ensure that adequate supports are provided to individuals who have intellectual disability or autism. Ultimately, the issue is whether providers can fill necessary positions with qualified personnel. As noted by a United States Department of Health and Human Services report (2006), demand for Direct Support Professionals is increasing. Hundreds of individuals are transitioning from living in state-run institutions to living in community based programs operated by private providers. Thousands of people are living at home without services, and hundreds of high school graduates are entering the adult Intellectual Disability and Autism service system every year. The perception within the field is that the workforce situation is bad and getting worse.

Recent research (Spreat, 2019) confirms that there is a significant shortage of individuals who are willing to work as Direct Support Professionals. In a state wide survey regarding Direct Support professionals in Pennsylvania, it was determined that there was an annual turnover over rate in excess of 38% and a vacancy rate of about 20%. The impact of these figures, combined with other legitimate employee absences, creates a situation that for any given shift, one out of three employees may be missing. Because every Direct Support Professional position is essential to the health and welfare of the people they support, the absent Direct Support Professional must be replaced via expensive overtime staff or even more expensive agency staffing. Not only is this approach costly, it compromises the very quality of the supports offered to individuals who have intellectual disability. Services and supports are built on relationships, and if turnover disrupts the formation and maintenance of these relationships, services and supports will suffer.

The challenges with the Direct Support Professional workforce appear to transcend national borders, with Denmark (Hansen-Turton, personal communication, October 2019), United Kingdom (Ward, 1999), and The Netherlands (Ernst & Young, 2019) each reporting concerns with turnover of Direct Support Professionals. While the European rates of turnover do not match the American rates, they are of sufficient concern as to generate literature.

In addition to an excessive vacancy rate (Taylor, 2008), there is concern that Direct Support Professionals are not adequately prepared to deliver the wide range of support services to complex individuals who often have significant disabilities. (Test, Flowers, Hewitt, Solow, & Taylor, 2003). Faced with high vacancy and turnover rates, employers have become less selective in their hiring practices. Reduced selectivity often is associated with increased rates of involuntary separation as employers recognize the shortcomings of their hiring decisions and subsequently take corrective action (i.e., terminating unsatisfactory employees). Spreat (2019) has reported that approximately ½ of all Pennsylvania Direct Support Professional separations involve employees who had worked in the position less than six months. On a more positive note, Bogenshutz, Nord, & Hewitt (2015) have reported that specialized training is associated with reduced levels of staff turnover. Spreat's (2019) survey revealed that current recruitment levels are insufficient to maintain full staffing. Combine the current vacancy rate of 20% with the current annual turnover rate of about 38%, and it is clear that the demand for Direct Support Professionals cannot be met.

The Cause of the Crisis

The President's Commission for People with Intellectual Disabilities (sic) (2018) listed a number of likely reasons for the crisis. These include increased demand for Direct Support Professionals, the growing number of individuals who have autism, longer survival for persons with intellectual disability, non-competitive compensation, and stress associated with the job. For the most part, these are matters deriving from conjecture and reason, with little empirical support.

Wages and compensation, however, have been submitted to empirical analysis. Larson, Lakin, & Bruininks (1998) reported that wages were the most consistent large predictor of turnover among Direct Support

Professionals. This may be a little surprising because within any selected job classification, there tends to be a relatively narrow range of salaries. Compression of any variable used in a statistical analysis tends to minimize the impact of that variable; for wages to remain a good predictor at all suggests how important low wages truly are.

In a position statement regarding Direct Support Professionals, the American Association on Intellectual and Developmental Disabilities (2016) noted that Direct Support Professionals are paid wages that are essentially equal to entry level positions in services industries (and considerably less than Amazon or Wal-Mart). Many Direct Support Professionals must hold multiple jobs or work overtime in order to survive. The American Association on Intellectual and Developmental Disabilities noted that nearly half of all Direct Support Professionals rely on public benefits, and Torres, Spreat, & Clark (2017) suggest that even more would qualify.

One might argue that if Direct Support Professionals were paid a market driven wage, the field would not be experiencing the current workforce crisis. The problem is that provider agencies have little ability to increase Direct Support Professional wages because the providers have no control over the prices for the services and supports they provide. Prices for services are set by the purchaser -- the government. Providers cannot simply increase their prices in order to pay a living wage to Direct Support Professionals.

Of course, concern for Direct Support Professionals wages predates the concerns raised by Larson, Lakin, & Bruininks (1998). Numerous salary surveys have been conducted over the previous 40 years. Some studies focused on the distinction between private community and public congregate care settings, while others made no distinctions. The primary collectors of these data have been researchers associated with the University of Minnesota. Even data attributed to the U.S. Department of Health and Human Services were collected by University of Minnesota researchers (specific articles documented in references). A summary of the wage data is presented in the figure 1 below. All data points on the graph were collected by staff from the University of Minnesota, except the 2009 data points, which were contributed by an ANCOR survey (2009).

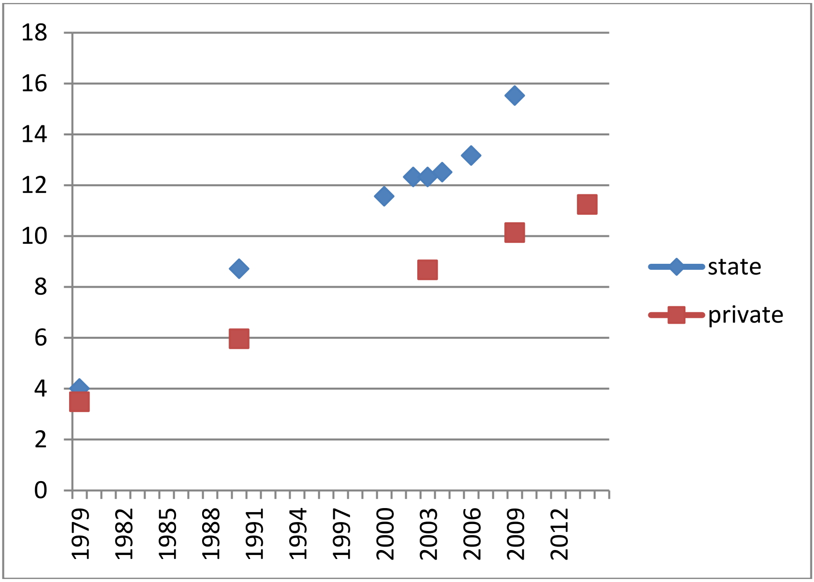

Figure 1. Hourly wage for DSPs (in dollars)

Several factors stand out from this graph. First, no one in this workforce, state employed or privately employed, has made a particularly good living. Even in the relatively recent 2009 ANCOR data collection, Direct Support Professionals employed by state governments made less than $16 per hour (or approximately $32,000 per year). It is abundantly clear that the job of Direct Support Professional is not well appreciated from a financial perspective. Second, Direct Support Professionals who work for private organizations in the community tend to make roughly 2/3 to 3/4 the wages of similarly employed individuals who work for the state. Third, the gap between state and privately employed Direct Support Professionals may be widening (Taylor, 2008). Taylor (2008) opined that this differential between state employees and private agency employees is largely responsible for the cost savings commonly attributed to community based services for individuals who have intellectual disability (cf. Spreat, Conroy, & Fullerton, 2005). Taylor argued that programs in the community cost less at the expense of the Direct Support Professionals.

Because supports and services are now predominantly offered by private providers in the community (Braddock, Hemp, Rizzolo, Haffer, Tanis, & Wu, 2011), this review will focus on wages paid in such settings. Early community based research (Braddock & Mitchell, 1992) reported a mean hourly wage of $5.97 for what are now called Direct Support Professionals. In July 1992, the mean national hourly wage was $10.79 (Data 360) suggesting that Direct Support Professionals in 1992 made about 55% of the national wage average. Available literature suggests that Direct Support Professional salaries have increased over the ensuing 24 years. Durgin (1999) reported a mean Pennsylvania Direct Support Professional salary of $8.13 an hour in 1999. Hewitt, Larson, & Lakin (2000) reported a mean salary of $8.81 an hour, a figure that was generally supported by Polister, Lakin, & Prouty (2003) review study that reported a mean salary of $8.68 an hour. The $8.68 figure was again noted in a study by Lakin & Prouty (2003). The 2009 ANCOR study (ANCOR, 2009) reported a mean Direct Support Professional salary of $10.14 per hour. Wages have increased over time, and to the extent that one can compare across time and studies, it appears that wages have increased at a rate modestly greater than inflation (Bureau of Labor Statistics, 2013). It is clear that efforts have been made to ensure wage growth for Direct Support Professionals, but the result of these efforts is little more than maintenance at an unacceptably low level.

It should be noted that all the above referenced studies reflected economic conditions prior to the impact of the 2008 recession. Bogenschutz, Hewitt, Nord, & Hepperlen (2014) reported the results of a Minnesota survey of DSP wages. The mean hourly rate for Direct Support Professionals was calculated to $11.26. Limiting the analysis to residential services (as opposed to the better compensated day program services), the calculated mean hourly rate was $11.06. This $11.06 figure is approximately 185% higher than Braddock and Marshall's (1992) mean wage of $5.97. Over that same 1992 to 2014 time period, the dollar inflated by roughly 169 percent, meaning that an equivalent 2014 value of $5.97 would be $10.07. Again, there is evidence that Direct Support Professional salaries, while below the national average wage, have increased over time at a rate that marginally exceeds inflation.

The Minnesota study (Bogenschutz, Hewitt, Nord, & Hepperlen, 2014) is the latest in the series of studies from researchers at the University of Minnesota Center for Integration. It is an excellent study that is limited only by its sample restriction to programs operating in Minnesota. Systematic replication (Sidman, 1960) is a reasonable next step in the scientific process, and this need to extend our knowledge through replications served as rationale for conducting such a study within the private Pennsylvania intellectual disability system. Spreat, McHale-Brown, & Walker (2017) conducted such a systematic replication in Pennsylvania, where they recorded a median hourly wage of $11.26 and turnover/vacancy rates of 25% and 11% respectively. The findings of the Spreat, McHale-Brown, & Walker study (2017) are markedly consistent with those of the 2014 Minnesota study (Bogenschutz, Hewitt, Nord, & Hepperlen, 2014), lending credibility to each of the studies. Direct Support Professionals, at the time of the studies, made a little over $11 per hour.

The potential utility of these compensation and stability data warrant establishing a means with which to collect such information on a regular basis. The sponsor of the Spreat, Brown-McHale, & Walker (2017) study, a provider association called PAR, was joined in this effort by six other Pennsylvania associations (MAX, RCPA, The Alliance CSP, The Arc of Pennsylvania, TPA, and UCP of PA) to support a second Commonwealth-wide survey in 2016. Inclusion of the six associations broadened the utility of the findings by significantly increasing the size of the study population. This second compensation study was based on data reported by 121 Pennsylvania providers. These 121 providers employed just over 34,000 Direct Support Professionals. This second study (Torres, Spreat, & Clark, 2017) reported a modest increase in hourly wage to $11.89 per hour (an extreme score makes the median value of $11.50 more credible than the mean figure). Turnover was maintained at 26.0%, while the percent of open positions was reported to be 11.9%. Part Time vacancies (16.0%) were greater than Full time vacancies (10.2%). It should be noted that in both surveys, public comments were made that the reported turnover rates seemed too low.

The findings from this Seven Association survey were reported in legislative testimony to the Pennsylvania House Human Services Committee (Spreat & Torres, 2017), with the proposition that an increase in base Direct Support Professional pay could actually save the Commonwealth money by reducing overtime costs, recruitment costs, and reliance by Direct Support Professionals on public assistance. The findings of the study were coordinated into an effort to help persuade legislators and executive staff of the need to increase wages for Direct Support Professionals.

Temporally congruent with the Seven Association study, the National Core Indicator project released its findings of a 20-state survey of Direct Support Professional compensation practices (NCI, 2018). Pennsylvania was one of the participant states, with 115 Pennsylvania providers providing data regarding the employment of their 15,261 Direct Support Professional employees. The smaller National Core Indicator survey reported a mean residential Direct Support Professional hourly pay rate of $11.86. While the vacancy rate was markedly similar to the Seven Association study at 11.2% for full time Direct Support Professionals and 15.9% for part-time Direct Support Professionals, the National Core

Indicator group reported an appreciably higher turnover rate of 38.3% as opposed to the 26% turnover rate reported in the 7-association Pennsylvania study.

Spreat (2019) recently completed a 3rd statewide survey of Direct Support Professional compensation, benefits, turnover, and vacancies in Pennsylvania programs. While the mean hourly wage increased to $12.83 per hour after legislative efforts to increase Direct Support Professional wages, Spreat noted that turnover had increased to almost 40% per year, and that the percentage of open positions (vacant) approached 20%. The findings of these five post-recession studies are appropriately interpreted to reflect a Direct Support Professional systemic workforce crisis. Because of low wages, employers are unable to fill vacant positions with qualified staff. The resultant excessive reliance on required overtime further increases the challenges of the Direct Support Professional job and the challenges faced by individuals and their families who need stability to help ensure health and safety, which only comes with experience and adequate training.

Selecting a figure to best characterize Direct Support Professional wages is a bit like hitting a moving target. The answer depends upon when and where one collects the data. The 2009 ANCOR survey reported that the average wage for a private provider Direct Support Professional was $10.14 per hour, while the average wage for a state-employed Direct Support Professional was $15.53. This estimate suggests that Direct Support Professional working for private providers make about 65% of that which is made by state-employed Direct Support Professionals. It should be noted, however, that for a 2009 survey, it is most likely that the survey data were collected prior to the impact of the 2008 recession. The most current descriptive information derives from a Minnesota survey conducted by Bogenschutz, Hewitt, Nord, & Hepperlen (2014), in which a mean hourly rate for Direct Support Professionals was calculated to $11.26. Limiting the analysis to residential services, the calculated mean hourly rate was $11.06. It was noted that Direct Support Professionals working in residential services were paid significantly less than those working in day training and habilitation sites. .

It is tempting to allow subjective impressions to shape one's impression of this dollar figure, but it is perhaps more constructive to consider objective frames of reference. The Massachusetts Institute of Technology Living Wage Calculator (MIT, 2016) suggests that the mean Pennsylvania wage of $11.26 per hour is a living wage for a single Pennsylvanian. When a child or a spouse enters the picture, the mean wage of $11.26 falls to a level below the living wage. Note also that a salary of

$11.26 may quality individuals for government support (insurance for children, day care subsidies, etc.).

An alternative frame of reference derives from longitudinal analysis of the consumer price index Our earliest reported study (Braddock & Mitchell, 1992) reported a mean hourly salary of $5.97. Corrected for the 70.2% of inflation since 1992 (Bureau of Labor Statistics, 2013), this would suggest an equivalent 2016 salary of approximately $10.09. From this perspective, it would appear that Direct Support Professionals are marginally beating inflation. We submitted each referenced earlier wage study to the Bureau of Labor Statistics inflation calculator in an effort to ascertain what an equivalent salary would be in 2015 (when our data were collected). These figures appear below. It would appear that wages for direct support Professionals have done slightly better than keeping pace with inflation.

$5.97 -- 1992 -- Braddock & Mitchell2015 = $10.09
$8.13 -- 1999 -- Durgin2015 = $11.57
$8.81 -- 2000 -- Hewitt, et al.2015 = $12.13
$8.68 -- 2003 -- Lakin & Prouty2015 = $11.18
$10.14 -- 2009 -- ANCOR2015 = $11.20
$11.25 -- 2014 -- Bogenshutz, et al.2015 = $11.26

These findings are consistent. Clearly efforts have been made to increase Direct Support Professional salaries, but the resultant wages remain on the low side. The data suggest maintenance rather than growth.

Impact of the Crisis

Low wages among Direct Support Professionals not only affect these workers, but also the recipients of the services and supports they provide. Studies (Larson, Lakin, & Bruininks, 1998; Durgin, 1999) have shown that low wages tend to be associated with higher rates of turnover and increased numbers of staff vacancies. Both turnover and staff vacancies affect quality of care by disrupting social support networks, jeopardizing program continuity, and ultimately, increasing the cost to provide services. At a recent provider meeting, one agency CEO reported that one of her service recipients had been bathed and toileted by 35 different individuals within one month. While the concern may be that many full time employees exist at or near the poverty level, concern must also be directed to the negative impact that these low wages ultimately have on the people being supported.

Relationships are the key to the provision of quality supports and services, and if the actual service providers are an ever-changing band of individuals, we are left with less than desirable relationships. In some cases, we have strangers helping people with some of their most private of needs. There is an assumption that vacancies can be filled via overtime or agency staffing. This is not always the case and some residential agencies are actively considering closing programs because of the inability to staff them.

Families who support family members at home with the assistance of Direct Support Professionals have to worry if their assistance will arrive each day, or if that assistance will be drawn to a better paying job in an unrelated field. Henseley (2018), mother of a child with a disability, noted that losing a valued Direct Support Professional can be devastating.

One might argue that the proper price for a Direct Support Professional is the price for which one can find competent people willing to work. This is a basic economic argument, and it would pertain if providers were able to hire a sufficient number of staff to work as Direct Support Professionals who can be trained to become competent in the position. In addition to a 10-11% vacancy rate (Taylor, 2008 -- higher reports by others), there is concern that Direct Support Professionals are not adequately prepared to deliver the wide range of services and supports to individuals who often have significant disabilities and complex needs. (Test, Flowers, Hewitt, Solow, & Taylor, 2003). In a sense, it would appear that providers have had to become less selective in their hiring practices. Added to this, the Centers for Medicare & Medicaid Services (CMS), the Federal agency that oversees, regulates and funds these services has put forward its Core Competencies for Direct Support Professionals in a final report published August 5, 2013, which lists 77 specific skill statements nested within 14 Core Competencies. These Core Competencies are the standard upon which direct services will be measured and quality determined. There is a significant discrepancy between the complex set of skill standards and the wages of the people expected to exhibit and use the skills to help others. Even prior to these skill standards being widely implemented, the field has been unable to fill all vacant positions (although Bogenshutz, Nord, & Hewitt (2015) report that specialized training is associated with reduced levels of staff turnover). It is noted that New York state has been considering instituting a certification process for Direct Support Professionals (OPWDD, 2016), and the Qualified Approved Behavior Analysis Credentialing Board has developed a behavioral credentialing process for Direct Support Professionals (QABA, undated). It is noted that the mandate for additional credentialing in Physical Therapy around 1990 resulted in substantial pay increases for Physical Therapists, but there were far fewer Physical Therapists than Direct Support Professionals. The additional costs of paying Physical Therapists more could be absorbed, but this is not possible for Direct Support Professionals, particularly in a field in which about 1/3 of providers have expenses that exceed revenues (Spreat, 2019).

Quality of staffing was not addressed in the above referenced studies, yet the literature (Test, Flowers, Hewitt, Solow, & Taylor, 2003) suggests that staffing quality remains a concern, and that if higher standards of staff quality were held, the vacancy rate would be appreciably higher. Based on the turnover and vacancy evidence and on the concerns raised in the literature regarding staff quality, it would appear that the compensation levels for Direct Support Professionals are insufficient to attract a sufficient number of qualified individuals to the job.

The workforce crisis has impacts across several areas. The inability to fill Direct Support Professional positions directly affects the quality of life for the persons supported by Direct Support Professionals. Constant turnover of staff results in a transitory quality in regards to the knowledge held about consumers, as well as consumers themselves losing contact with trusted and relied-upon staff. Both turnover and staff vacancies affect the quality of care by disrupting social support networks, jeopardizing program continuity, and ultimately, increasing the costs of providing services. High turnover negatively impacts the quality of service delivery. Employees are the most critical factor to achieving high-performance outcomes.

The literature documents that individuals who have to either work overtime or subsist on public benefits due to low wages experience diminished health, increased obesity, and hypertension. This low-wage environment has a striking human cost. It minimizes the ability of parents to fully participate in their children’s development, and children of low-wage parents are often forced into the labor market early. Children of low-wage parents are more likely to face educational difficulties, and “trade-offs between spending time with children and earning an adequate wage can trap parents in familial hardship.” Finally, children of low-wage earning parents are more at risk for health problems and complications.

Torres, Spreat, & Clark (2016) noted it may actually be considerably less expensive to pay Direct Support Professionals a living wage, than it is to fund expensive overtime, constantly recruit and train new employees, and provide public welfare benefits to underpaid employees. Paying a living wage might both eliminate the vacancy and turnover problem and be cheaper.

Note that ANCOR and many state provider associations have launched campaigns in attempts to obtain sufficient funding to reduce this workforce crisis. In New York, the legislature committed approximately $55 million to increase wages for Direct Support Professionals, and Pennsylvania has administratively taken a similar action. In both cases, it remains to be determined if the money reached the Direct Support Professionals, or whether it was needed to support other program needs.

What Can Be Done?

If providers were funded sufficiently to enable them to pay a living wage to their employees, the crisis would resolve. Throwing additional money at providers, and in turn Direct Support Professionals, has yet a broader effect. Torres, Spreat, & Clark (2016) noted that higher pay to employees of state developmental centers appeared to be associated with lower rates of turnover. Ohio Civil Service Employee Association president Christopher Mabe reported developmental center turnover rates as low as 10 percent. A similar news report (Hult, 2017), cited a reduction in a 60% reduction staff turnover in a psychiatric hospital following a pay increase. This linkage of pay and turnover led Torres, Spreat, & Clark (2016) to propose increasing Direct Support Professional pay to $15 per hour. They hypothesized that the increase in wages would actually result in a savings to taxpayers. The savings would derive from decreased overtime costs, decreased training costs, decreased recruitment costs, and decreased reliance of Direct Support Professionals on various forms of public welfare. They argued that it might actually be cheaper to pay a living wage.

It must be recognized that when demand significantly exceeds the supply of potential employees, shortages are going to result. While we can investigate other services models (such as paying families to keep family members at home, etc.), the only mechanism for successfully solving the staffing shortage is to increase the prices paid for Direct Support Professionals.

Mechanisms that may help ease the staffing crisis include expediting the process that allows individuals from other countries to work in the United States. It is noted that several years ago, when Ireland’s economy was struggling, many providers recruited Direct Support Professionals from Ireland. Today, perhaps a similar strategy might be successful in Brazil, Russia, and a number of West African countries.

Another idea is to link college tuition subsidies to employment as a Direct Support Professional. One Pennsylvania provider supports medication