

DIRECT SUPPORT **PROFESSIONALS:**

A Workforce Crisis Limiting Security,
Human Rights, and Opportunity for People
with Intellectual and Developmental
Disabilities



DISABILITY LAW CENTER
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EXECUTIVE SUMMARY

People with intellectual and developmental disabilities (IDDs) in Massachusetts face abuse and neglect, human rights violations, and a lack of community integration at rates that are not compatible with our self-image as a national leader in disability supports and inclusivity. The causes and solutions are complex and multi-faceted. Managing the experience of having a significant disability may include the need for long term services and supports, medical care, and assistance in overcoming communication barriers and mobility challenges. While addressing those issues, individuals with IDDs, like all people, also seek:

- meaningful paid or volunteer work;
- fulfilling day activities;
- social and recreational opportunities;
- connections to their community; and
- close family and personal relationships.

On top of this, people with disabilities face an array of barriers that prevent their full, meaningful safe integration into society. For example, rather than adopt principles of universal design, we construct physical barriers in the “built environment” that make it difficult for wheelchair users to navigate their communities.¹ People who use American Sign Language (ASL), people who are neurodiverse, those who are non-verbal, and individuals with mental health or behavioral challenges are regularly denied accommodations. Our cultural norms propagate ableism, stigma, and discrimination, which replicate bias within the minds of people who previously had no preconceived notion of disability and lead to segregation and a risk of institutionalization for people with disabilities.

The state of our direct support professional (DSP) workforce is a major additional barrier, and the topic of this report. Without reliable, compassionate, trained, and supervised DSPs, many people with IDDs are at risk of abuse and neglect and are unable to live integrated lives in their communities. But right now, our IDD DSP workforce is almost invariably underpaid, and often inadequately trained and supervised.

As social science researcher Carli Friedman has written, DSP’s responsibilities are as demanding and varied as

aiding people with activities of daily living...promoting physical and emotional well-being...and assistance with health and safety, relationships, networking, communication, personal care, transportation, advocacy, financial duties, community living, crisis prevention, household

¹ By contrast, universal design is the design and composition of an environment so that it can be accessed, understood, and used to the greatest extent possible regardless of age, disability, or other factors. *What is Universal Design*, National Disability Authority (2020), available at <https://universaldesign.ie/What-is-Universal-Design/>.

tasks, education on self-care skills, promoting self-determination and managing finances.²

In the past, DSPs were seen as caregivers who did things for people with IDD. Now, DSPs focus on helping people learn how to do things for themselves, to gain independence in their lives.³ It can be difficult, demanding work. Today, DSPs “perform some of the functions of clinicians, service coordinators, administrators, managers, maintenance, and clerical personnel.”⁴ DSPs are expected to be the jack-of-all-trades in supporting people with IDDs, without their employers, the providers, affording them the necessary training or compensation.

Not surprisingly, we simply can no longer fill these positions at current wage levels, especially after the COVID-19 pandemic.⁵ Even before the pandemic, our current workforce crisis prevented providers from hiring enough adequately trained staff able to cover all the functions necessary to be a successful DSP. This puts DSP positions in community residences in a constant state of turnover, which directly impacts the ability of people with IDDs to participate actively in their communities and gain independence.

As discussed in this report, Massachusetts has fallen short in providing robust funding, training, oversight and accountability for DSPs, thereby undermining the fundamental goals of IDD services: a safe living environment free from abuse and neglect, integrated employment and social and recreational opportunities, independence, education, and human development. Too often, DLC has seen the lack of training, oversight, and support of DSPs result in subjecting people with disabilities to violations of human rights or abuse and neglect.⁶ Throughout this report, we will highlight real examples from DLC’s abuse and neglect investigations and monitoring activities that illustrate how shocking incidents result when the workforce receives inadequate training, support, and supervision.

² Carli Friedman, *Direct Support Professionals and Quality of Life of People with Intellectual and Developmental Disabilities*, Intellectual and Developmental Disabilities 1, 3 (February 2018) (citations omitted), abstract available at <https://pubmed.ncbi.nlm.nih.gov/30024847/>.

³ *What is a Direct Support Professional and how are they different from Caregivers?*, Regional Centers for Workforce Transformation (2017), available at <https://www.workforcetransformation.org/dsps-different-from-caregivers/>.

⁴ *Id.*

⁵ Massachusetts State Senator Cindy F. Friedman recently testified that, “[a]larming statistics from a recent survey done by the Association of Developmental Disability Providers that looked at day services providers showed that nearly one-third of day habilitation providers said that they have a staff vacancy rate of over 40 percent, and more than 80 percent of the same respondents said they're maintaining a program waitlist due to the inability to hire staff. Without a solution to this workforce crisis, an increasing number of jobs will go unfulfilled, leading to a deterioration in the quality of services delivered to Massachusetts' most vulnerable residents. And in fact, not only will the quality of the services deteriorate, they will not be available.”

⁶ This report is primarily intended to discuss direct support professionals serving individuals with intellectual and developmental disabilities, largely in private provider-run residential and day programs administered by DDS or MassHealth. This is not intended to address personal care attendants, home health care workers, or state employees, who are also sometimes called DSPs, or employees of residential or day programs serving other communities.

In addition, while there are other barriers to inclusion (such as inaccessible and unaffordable housing, the lack of universal design, and societal bias), the lack of an adequate DSP workforce and Department of Developmental Services (DDS) oversight has led to segregated living conditions. Individuals with IDD may live in “community” residences that are not, in fact, of or part of the community. When DSPs are unable to help people with IDD access their communities, these residences begin to take on some attributes of the antiquated institutions they were designed to replace, such as isolation, segregation, confinement, and a lack of person-centered planning, individual choice, and personal decision-making. A well-trained and supported DSP workforce is key to full and safe community integration for individuals with IDD living in state and provider-run community residences.

If we address the DSP workforce crisis through adequate support, training, and oversight, people with disabilities will experience less abuse and neglect and more opportunities for community inclusion and independence.⁷ This report makes seven recommendations for future action, including calling upon the Executive Office of Health and Human Services (EOHHS) to increase pay for DSPs to incentivize new employees to enter and remain in the field, and to create stronger mechanisms for training and overseeing DSPs, in order to ensure they are serving the disability community to the best of their ability.

Section I: BACKGROUND

Protection & Advocacy Authority

As the Massachusetts Protection and Advocacy System (P&A), the Disability Law Center (DLC) has a fundamental and unavoidable interest in workforce issues in the IDD community. Any discussion of abuse and neglect, human rights, or the impact on the ability of people with disabilities to participate in the community ultimately seems to return to this constant, intractable problem.

Across the country, P&As work at the state level to protect the personal and civil rights of people with disabilities by empowering them and advocating on their behalf.⁸ DLC also investigates instances of abuse and neglect against persons with disabilities. Under the Protection and Advocacy for Individuals with Intellectual and Developmental Disabilities (PAIDD) statute, DLC is authorized “to investigate incidents of abuse and

⁷ While this report focuses on staffing in programs run by private providers, similar issues may arise in state operated programs, even if those programs offer greater salaries and benefits. Most recently, an employee in the crisis stabilization unit at Hogan Developmental Center was charged with assault after he allegedly pushed a disabled resident, who later died, into a cement wall. Mike Beaudet, *Worker at Massachusetts care facility charged with seriously injuring disabled resident who died*, Newscast NewsCenter 5 at Noon (Oct. 25, 2021), available at <https://www.wcvb.com/article/massachusetts-worker-charged-with-seriously-injuring-disabled-resident/38058713>.

⁸ *State Protection & Advocacy Systems*, Administration for Community Living (Last Modified Oct. 28, 2021), available at <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>.

neglect of individuals with developmental disabilities if the incidents are reported . . . or if there is probable cause to believe that the incidents occurred.”⁹ Similarly, DLC is equivalently authorized under the Protection and Advocacy for Individuals with Mental Illness (PAIMI) statute for individuals with mental illness.¹⁰

The PAIDD and PAIMI regulations define the terms “neglect” and “abuse” in almost the identical language. The PAIDD regulations define “abuse” as:

any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes but is not limited to such acts as: Verbal, nonverbal, mental and emotional harassment; rape or sexual assault; striking; the use of excessive force when placing such an individual in bodily restraints; the use of bodily or chemical restraints which is not in compliance with Federal and State laws and regulations, or any other practice which is likely to cause immediate physical or psychological harm or result in long term harm if such practices continue.¹¹

The PAIDD regulations define “neglect” as:

a negligent act or omission by an individual responsible for providing services, supports or other assistance which caused or may have caused injury or death to an individual with a developmental disability(ies) or which placed an individual with developmental disability(ies) at risk of injury or death, and includes acts or omissions such as failure to: establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care to an individual with developmental disabilities; or provide a safe environment which also includes failure to maintain adequate numbers of trained staff or failure to take appropriate steps to prevent self-abuse, harassment, or assault by a peer.¹²

DLC also recognizes that its mandate involves protecting the human rights of people with disabilities. These human rights include, but are not limited to, independence, self-determination, and community integration.¹³

⁹ 42 U.S.C. § 15043(a)(2)(b).

¹⁰ 42 U.S.C. § 10805(a)(1)(A). DLC has identical authority under the PAIR statute for individuals who do not fall within the PADD and PAIMI statutes. *See* 29 U.S.C. § 794(e)(f)(2) (stating that P&As have the same investigative authority for people who meet the definition set forth in 29 U.S.C. § 794(a)(1)(b) as the P&A has for people with developmental disabilities).

¹¹ 45 C.F.R. § 1326.19. The equivalent definition of “abuse” in the PAIMI regulations is found at 42 C.F.R. § 51.2.

¹² 45 C.F.R. § 1326.19. The equivalent definition of “neglect” under PAIMI is found at 42 C.F.R. § 51.2.

¹³ *See, e.g.*, 42 U.S.C. § 15001(a)(1) (PADD: “disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, or exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society . . .”); 42 U.S.C. § 15009(a)(2) (PADD: least restrictive environment).

Through DLC’s abuse and neglect investigations, DLC has found that hiring, turnover rates, and the lack of oversight of direct support staff in group homes is frequently a root cause of abuse and neglect. As such, DLC has a vested interest in addressing the workforce crisis, the resulting human rights violations, and the extensive lack of meaningful community engagement for people with disabilities. And, since the COVID-19 outbreak, our concerns have only intensified.

Disability Community Integration Policy in the United States

Disability advocates have long focused on expanding community integration for people with disabilities while also eliminating segregated settings. Over almost 50 years, there have been multiple laws passed with important language on community integration for people with disabilities. In 1973, Congress enacted **Section 504 of the Rehabilitation Act of 1973**, a civil rights law that prohibited discrimination based on a disability in employment by federal agencies.¹⁴ In the Rehabilitation Act (as amended), Congress found that disability “in no way diminishes the right of individuals to: (a) live independently, (b) enjoy self-determination, (c) make choices, (d) contribute to society, (e) pursue meaningful careers, and (f) enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American Society.”¹⁵ This illustrates that Congress was focused on the importance of community integration and human rights for people with disabilities. Then, in 1990, Congress passed **the Americans with Disabilities Act (ADA)**, which, among other things, mandated community integration as a default for persons with disabilities.¹⁶ With the passing of the ADA, Congress acknowledged that “society has tended to isolate and segregate individuals with disabilities and . . . such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”¹⁷ The Supreme Court of the United States enforced the community integration mandate of the ADA in *Olmstead v. L.C.*, 527 U.S. 581 (1999), which requires states to eliminate unnecessary segregation of individuals with disabilities to ensure people with disabilities receive services in the most appropriate integrated settings.¹⁸

Continuing to address the lack of community inclusion for people with disabilities in society, Congress passed **the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)**. The purpose of the DD Act was to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life . . .”¹⁹

¹⁴ 29 U.S.C. § 701.

¹⁵ 29 U.S.C. § 701(a)(3).

¹⁶ *Olmstead v. L.C.*, 527 U.S. 581, 597 (1999).

¹⁷ 42 U.S.C. § 12101(a)(2).

¹⁸ *Olmstead: Community Integration for Everyone*, U.S. Department of Justice Civil Rights Division, available at <https://www.ada.gov/olmstead/>.

¹⁹ 42 U.S.C. § 15001(b).

Additionally, the progression of **Home and Community-Based Services (HCBS)** waivers have aided in a societal shift away from segregated settings toward community integration for people with disabilities. First available in 1983, HCBS waivers are optional waivers of Medicaid rules governing institutional care, allowing recipients to receive services in their home and community rather than in an institutional or segregated setting.²⁰ In 2005, HCBS waivers became a formal Medicaid State plan option.²¹

Then, in 2014, the Centers for Medicare and Medicaid Services (CMS) implemented the **HCBS Settings Rule**, which required every state to ensure that services provided to people with disabilities met the minimum standards of integration, access to community life, choice, and autonomy.²² The need for the HCBS Settings Rule was succinctly summarized by the ACLU:

The HCBS Settings Rule was put in place because of concerns that many states and providers were using federal dollars dedicated to community-based supports to pay for disability services that were still institutional in nature. Too many of the so-called “community” options were exercising the same control and isolation over individuals as larger institutions. By articulating a set of minimum requirements for HCBS funding, the Setting Rule ensures that federal funds are used for their intended purpose and that individuals with disabilities have an opportunity to enjoy the autonomy and freedom associated with community life.²³

For settings to receive HCBS funding, they must: be integrated in the greater community; support the individual’s full access to that community; be chosen by the individual; ensure the rights to privacy, dignity, respect, and freedom from coercion and restraint; optimize individual autonomy; and facilitate individual choice.²⁴ States were given until 2017 to come into compliance with these new setting requirements. However, in 2017, the compliance deadline was extended to March 17, 2022. Unfortunately, due to the COVID-19 pandemic, CMS has extended the deadline for state compliance once again to March 17, 2023.²⁵ The HCBS Settings Rule is an essential part of expanding community integration for people with disabilities.

²⁰ *Home & Community Based Services Authorities*, Centers for Medicare & Medicaid Services, available at <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/index.html>; Marla Root, *What is an HCBS Waiver? How do I get one? What services are available?*, Special Learning, Inc., available at <https://www.special-learning.com/blog/article/53>.

²¹ Centers for Medicare & Medicaid Services, *supra*.

²² 79 FR 2947 (Jan. 1, 2014), <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>.

²³ *The Home and Community Based Services Settings Rule*, American Civil Liberties Union (Jan. 2018), available at https://www.aclu.org/sites/default/files/field_document/aclu_faq_-_hcbs_settings_rule-final-1-10-18.pdf.

²⁴ *Id.*

²⁵ *CMS Extends Deadlines for HCBS Settings Rule*, LeadingAge (July 14, 2020), available at <https://leadingage.org/regulation/cms-extends-deadlines-hcbs-settings-rule#:~:text=The%20final%20compliance%20deadline%20for,compliance%20with%20the%20Settings%20Rule.>

Taken together, these laws and regulations represent our societal impetus for community integration for people with disabilities. Unfortunately, these laws and regulations can only do so much. Due to systemic barriers and years of segregated settings, people with disabilities need supports to integrate into the community fully and seamlessly, which requires a competent, well-trained, and supervised workforce with accountability to government funding agencies.

People with disabilities are often told where to be, how to act, what to feel and what to think. Their desires to live fully independent lives are thwarted by the supports needed to accommodate their disabilities. These supports, however, should not negate personal autonomy to live one's life. We often see people with disabilities in group home settings being told how to live, when all they really need is support to live as they choose. Having a disability does not remove one's ability to envision the life one wishes to live. It is important that DSPs understand this and act as supportive figures instead of as a controlling caregiver to people with disabilities.

Presently, community integration has yet to become a reality. The problem, as noted by the Harvard Political Review, is attributed to structural, attitudinal, and financial barriers, but that is not all.²⁶ The reality of community integration will never be complete without a sustainable, competent, supported, and supervised workforce.²⁷ The workforce will be the catalyst for the success or failure of community integration. We need to simultaneously support and oversee the workforce and promote community integration for people with disabilities.

Section II: THE DIRECT SUPPORT WORKFORCE

Overview of Direct Support Professional Workforce Issues

The DSP workforce has been in crisis since before the COVID-19 pandemic; however, the pandemic exacerbated the problems. During the COVID-19 pandemic, DSPs have been featured in a plethora of articles for their frontline work and the issues they faced day in and day out. Again, however, these issues are not new. According to the American Network of Community Options and Resources (ANCOR), which represents disability service providers across the nation, “[e]ven before the pandemic, providers were struggling to maintain or expand services and keep up standards, but since COVID-19 emerged, circumstances have worsened by nearly every metric.”²⁸ In 2017, the President’s Committee for People with Intellectual Disabilities (PCPID), released a report titled *America’s Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities, and the U.S. Economy*, on the current

²⁶ Katelyn Li, *A Crisis Decades in the Making: Disability Housing Policy and COVID-19*, Harvard Political Review (Oct. 11, 2020), available at <https://harvardpolitics.com/congregate-care-covid/>.

²⁷ *Id.*

²⁸ Michelle Diamant, *Survey Finds Disability Service Providers On The Brink*, DisabilityScoop (Oct. 1, 2021), available at <https://www.disabilityscoop.com/2021/10/01/survey-finds-disability-service-providers-on-the-brink/29513/>.

direct care workforce crisis and highlighted the following factors as contributing to “the untenable crisis”:

- high staff turnover;
- growing demand for services due to the growth and aging of the U.S. population in general;
- increased survival rates for people with intellectual disabilities;
- demographic shifts resulting in fewer people moving into the DSP workforce;
- persistently non-competitive aspects of direct support employment, including low wages, poor access to health insurance, and a lack of paid time off and other benefits;
- high stress and demands of direct support employment, including round-the-clock, seven-days-a-week work;
- insufficient training and preparation for DSP roles; and
- lack of professional recognition and status for skilled DSPs.²⁹

Additionally, Congress has found that “as increasing numbers of individuals with developmental disabilities are living, learning, working, and participating in all aspects of community life, there is an increasing need for a well-trained workforce...to provide the services, supports and other forms of assistance required to enable the individuals to carry out those activities.”³⁰ As will be discussed further below, DSPs working with people with disabilities are required to do more than just the traditional caregiving activities because individuals with disabilities depend on DSPs for accessing their communities as well.

Data on the Massachusetts Direct Support Workforce

In 2009, the DSP workforce was in the top fifteen fastest-growing occupations in Massachusetts, while simultaneously being among the state’s lower-paying jobs.³¹ Direct care worker positions are expected to grow 16% from 2018 to 2028, with as many as 171,500 total openings.³² As of 2020, state-wide data shows that

²⁹ *Report to the President 2017-America’s Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy*, President’s Committee for People with Intellectual Disabilities 1, 8 (2017), available at https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF.

³⁰ 42 U.S.C.A. § 15001(a)(14).

³¹ *State Facts-Massachusetts’ Direct-Care Workforce*, Paraprofessional Healthcare Institute (Aug. 2009), available at <https://www.phinational.org/wp-content/uploads/legacy/clearinghouse/PHI-StateFacts-Mass.pdf>.

³² *Workforce Data Center*, Paraprofessional Healthcare Institute (2020), available at <http://www.phinational.org/policy-research/workforce-data-center/#states=25&var=Employment+Projections>. The term ‘direct care worker’ in the data set covers workers in home care, nursing homes, and residential homes. 49% of home care workers, 67% of nursing home workers, and 75% of residential home workers work full-time at these jobs.

Massachusetts direct care workers totaled 149,900 people.³³ Approximately 58% of these DSPs are employed in home and community-based settings.³⁴

There is a lack of adequate national and state data with specific information on DSPs who work solely with people with IDD. Instead, the Bureau of Labor Statistics Standard Occupational Classification system classifies the direct care workforce as being comprised of personal care aides, home health aides, and nursing assistants. This makes it more difficult to analyze trends in the IDD workforce and ought to be addressed by both state and federal government funding agencies.

The Executive Office of Health and Human Services (EOHHS) of Massachusetts sets rates and model budgets for provider agencies every two years under Chapter 257 of the Acts of 2008.³⁵ These budgets include various rates for DSPs' pay, which are dependent on the model of the program. In 2018, the average rate of pay for DSPs was \$13.08.³⁶ In 2020, the average rate was increased to \$14.25, which is a \$1.17 increase.³⁷ It is important to note that this is just the average rate, so some DSPs are paid higher and lower than this amount.

These rates are extremely low relative to current wages in the labor market. Therefore, many providers and advocates have fought for EOHHS to significantly increase the pay rate for DSPs. For example, the Provider's Council has continuously advocated for EOHHS to utilize the Bureau of Labor Statistics (BLS) data for Community and Social Service Occupations median salaries, which was \$44,950 in 2018.³⁸ However, since EOHHS sets rates for two years in the future and the BLS data is two years behind, a 4-year lag in rates, the Provider's Council has requested that EOHHS pay based on the 75th percentile of the category.³⁹ In 2018, the 75th percentile rate was \$60,390.⁴⁰

Another issue with Chapter 257 is the lack of accountability measures. Service Employees International Union (SEIU) Local 509 has long advocated for accountability mechanisms in Chapter 257 to ensure the money goes directly to DSPs. SEIU has

³³ *Workforce Data Center*, Paraprofessional Healthcare Institute (Last Modified Sept. 2, 2021), available at <http://www.phinational.org/policy-research/workforce-data-center/#states=25>.

³⁴ Paraprofessional Healthcare Institute, *supra*.

³⁵ *Overview of Chapter 257 of the Acts of 2008*, Mass.gov (2021), available at <https://www.mass.gov/info-details/overview-of-chapter-257-of-the-acts-of-2008>.

³⁶ Michael Weekes, *Testimony regarding 101 CMR 420.00, Rates for Adult Long Term Residential Services*, Providers' Council (Mar. 2, 2018), available at <http://providers.org/assets/2018/07/RatesForAdultLongTermResidentialServices.CouncilTestimonyOn101CMR420.final.pdf>.

³⁷ *Testimony in support of 101 CMR 420.00, Rates for Adult Long-Term Residential Services*, Providers' Council (Mar. 20, 2020), available at <http://providers.org/assets/2020/08/AdultLongTermResTestimony.March20.final.pdf>.

³⁸ *Id.* DLC acknowledges that Community and Social Service Occupations don't just encapsulate DSPs in the BLS data. However, it is important for EOHHS to have a benchmark rate to use in comparing IDD DSP salaries.

³⁹ *Id.*

⁴⁰ *Id.*

identified agencies that it believes have not given the rate increases to their employees in the proportions intended.⁴¹ For instance, when one agency's state funding rose 15% over a three-year span, during that time, the CEO's salary increased 29% and the administrative staff expenses increased 31%.⁴² The DSP rates, however, remained stagnant for years before finally increasing 10%.⁴³ In the past, EOHHS has taken a hands-off approach to accountability by only setting rates, not salaries, and assuming agencies use the rates appropriately. Disability justice advocates believe that EOHHS should hold agencies accountable to ensure that any rate increases do trickle down to the DSPs, as intended.

The issue of wages for DSPs must be handled in the Governor's next budget. The economy and cost of living have moved well beyond the prior rate increases. Today, providers are desperate to fill empty shifts and, as such, are competing for workers against the human services industry and other industries that are paying higher wages. Additionally, the next Chapter 257 rate increase will happen in 2022.

Abuse and Neglect Related to the Direct Support Workforce

The consequences for inadequate staffing extend beyond community integration and can be serious, and even life-threatening to the individual. The literature establishes the nexus between DSP wages and turnover, and a range of quality-of-life outcomes for people with intellectual and developmental disabilities. For example, a study by one leading researcher concluded that, *regardless of the level of an individual's support needs*, DSP staff turnover is associated with more emergency room visits, more abuse and neglect, and more injuries compared to similarly situated individuals who were not exposed to DSP staff turnover.

Through our P&A monitoring and investigation of abuse and neglect work, DLC has also identified that the workforce staffing issues are responsible for a greater frequency of incidents of abuse and neglect and human rights violations. Inadequate or inattentive staff often leads to neglect, and then to injury of residents. Poor ratios of experienced staff lead to staff burnout turnover or worse yet, to restraints, injuries, and trauma. Here, once again, providers can minimize these risks through providing staff training emphasizing respect for personal autonomy and human rights, trauma-informed care, identification of antecedent behaviors, techniques for de-escalating conflict through modeling and role-playing conflict, and even practice of self-care and mindfulness. But in the end, the most critical variable is finding enough staff members who are suited for this demanding and difficult work, who are adequately compensated and supervised.⁴⁴

⁴¹ Dan Hoffer, *Testimony on the Proposed Rates for Adult Long-Term Residential Services*, SEIU Local 509 (Mar. 13, 2020) (on file with the author).

⁴² *Id.*

⁴³ *Id.* Providers reply that increases in the cost of medical insurance absorb resources that could otherwise be directed to hourly wages.

⁴⁴ In this report we have highlighted specific illustrations of abuse and neglect related to staffing that we have encountered as the Protection and Advocacy system for the Commonwealth. In doing so, we do not intend to paint

ABUSE AND NEGLECT EXAMPLE:

DLC investigated one group home after receiving a video of staff physically abusing a resident, including punching the resident in the face. The DSPs were criminally charged, but the damage had already been done. A lack of oversight allowed DSPs to physically abuse the residents without repercussions until the legal guardian was able to obtain the video footage of the incidents.

Community Integration Impacted by the Direct Support Professional Workforce

It is crucial that DSPs, provider agencies, and state agencies acknowledge how important it is for DSPs to be trained in not only traditional caregiving but also on person-centered planning in supporting an individual in their social, emotional, vocational, and recreational life. Community integration “requires the inclusion of opportunities for people receiving HCBS to spend time with others who don’t have disabilities and to use community services and participate in activities (e.g., shopping, banking, dining, transportation, sports, fitness, recreation, and church) in their communities to the same degree of access, meaning in the same way, that people who don’t have disabilities do.”⁴⁵

Unfortunately, DLC has observed that most DSPs, especially those in group homes, do not prioritize, or are not able to prioritize, effective community integration programming. For example, we have seen DSPs take group home residents on walks in the park or on a drive in the car and consider those activities as community integration. Simple physical presence in the community does not constitute community-based programming. Group homes often hold large group outings instead of tailoring the activity to individual residents. This means, if the person with a disability does not like the scheduled activity, then they may not have a community-based activity that day or week.

all DSPs or provider agencies with a broad brush. There are extraordinary numbers of DSPs who handle difficult and demanding work with care and compassion each day, working under the supervision of well-run agencies. Our larger point, instead, is that the failure of wages to maintain pace with the economy has led to structural forces which endanger the safety, quality of services and civil rights of people with disabilities and their family members, which threaten to strain or break the finances of provider agencies, and which create stressful and unfair working conditions for those DSPs who ought to be encouraged to remain in this important profession.

⁴⁵ *FAQ – CMS Final Rule (CMS 2249-F/CMS2296-F) Impact on Residential and Non-Residential Services in West Virginia*, WV-BMS-IDDW (Feb. 1, 2017), available at https://dhhr.wv.gov/bms/Programs/WaiverPrograms/WVSWTP/Documents/HCBS%20FAQ%20Document_WV%20IDD%20Waiver_FINAL.0%202.01.2017.pdf.

Group homes overutilize group outings, which are detrimental to people with disabilities by infringing on their right of choice. No one wants constant activities planned for them without direct input. Yet, we have seen group homes consider chores such as van rides as community integration for people with disabilities. Community integration refers to assimilating into a community through outside relationships, community activities, and employment, among others. It is a form of neglect to subject persons with disabilities to unnecessary segregation where they become disenfranchised and isolated, especially while representing to DDS, families, and other interested parties that residents are participating in community-based programs.

The reasons why DSPs do not adequately foster community integration are varied; passive caretaking may have different causes in different workplace settings. For example, there may be a mismatch between the personality, skills and interests of the DSP and the role the position has now evolved to. DSPs working in IDD day and residential settings require significant skills, like independent problem-solving and decision-making. The role of a DSP is complex. As one public report stated:

[T]hey are often isolated and do not have co-workers, supervisors or clinical professionals (e.g., nurses or medical personnel, social workers, occupational therapists, physical therapists) on site to turn to for assistance or guidance. As the shift from congregate care to home- and family-based services continues, DSPs will take ever-greater responsibility and accountability.⁴⁶

Another frequent scenario involves DSPs who lack training about how to assist individuals with IDD in fostering experiences and relationships in the community. Essentially, DSPs are expected to be the jack of all trades, commonly without the specialized training to make them so. DSPs may also reside a considerable distance away and may be unfamiliar with the communities in which the individual lives and works. Some providers have provided training in “community mapping,” but these efforts are often uneven and incomplete. DSPs, many of whom have immigrated to the U.S. from other countries workers, may also face discrimination in the surrounding community, or may be working to overcome their own linguistic or cultural barriers.⁴⁷

Finally, the DSP may understand the expectations of their expanded role and be adequately trained but may simply be unable to execute their obligations to promote active community engagement, despite their best efforts. The staff ratios in the residential setting, determined by the provider agency, may be too thin, without adequately considering a behavioral challenge or a medical need of another resident, the experience levels and recent turnover of other staff, or challenges in arranging for

⁴⁶ President’s Committee for People with Intellectual Disabilities, *supra*, at 15.

⁴⁷ The composition and demographics of the current DSP workforce are not adequately covered in this report. DLC is aware of the complexity of this issue, but believe it is outside the scope of this report, which focuses more directly on individuals with IDs.

medication or accessible transportation. This ultimately leads to falling back upon sedentary and isolated residential life as a strategy for coping with understaffing.

Passive caretaking causes setbacks in achieving the mission of DDS, the federal government, the disability community, and advocacy groups. To shift from sedentary caregiving to providing opportunities for meaningful community integration including work, volunteer opportunities, social and recreational opportunities, and friendships and relationships in the community, we need more staff, who are better supervised, with better training. If we don't have DSPs, or enough DSPs, who fully understand what community integration means, we end up with day and residential services that take on the attributes of the institutions they were meant to replace.

Analysis of the Direct Support Professional Workforce Issues

Scheduling Challenges

DSPs experience unpredictable schedules which result in working irregular hours or additional part-time job(s) to make ends meet. According to a study conducted by the Home Care Aide Council, both employers and home care aides reported schedule and hours of work as major problems.⁴⁸ The study found that agencies reported major challenges in finding workers to fill shifts, while workers reported dissatisfaction with unpredictable schedules and short shifts that led to additional travel time.⁴⁹ After COVID-19, 34% of DSPs report working more hours.⁵⁰ Of those who reported an increase in hours, 29% indicated that they worked an additional one to fifteen hours, while 15% indicated they worked more than thirty additional hours.⁵¹

The unpredictable and irregular hours for DSPs lead to more workplace stress and more turnover, vacancies, and unfilled shifts. Turnover begets more turnover. In response, agencies are forced to rely on temporary/per diem shift workers who do not know the people with disabilities or the unique atmosphere of the program they are filling in for. We have seen far too many DSPs who are working two or three jobs, usually with different employers. Additionally, for group homes, it is far too common for house managers to be assigned to 9-5 weekday shifts, largely hours when people served are not in the home, leaving no managers in the home when people with disabilities are there. If a manager was present during hours that the people served

⁴⁸ Neeta Fogg et al., *Gray Warnings: Challenges in the Direct Care Workforce*, Ctr. for Labor Mkts. and Policy 1, 42 (June 2018), available at https://www.mass.gov/files/documents/2018/10/02/Workforce_report_2018_REVISED.pdf; Hayley Gleason, *2016-2017 Home Care Industry Assessment*, Home Care Aide Council (2018), available at http://commcorp.org/wp-content/uploads/2018/02/Resource_HCAF_Fact_Sheet_Feb-2018.pdf.

⁴⁹ Fogg et al., *supra*; Gleason (2018), *supra*.

⁵⁰ *Results of the Direct Support and COVID-19 National Survey 2020 [hereinafter COVID-19 Nat'l Survey]*, Inst. Cmty. Integration and Nat'l All. of Direct Support Prof'ls (2020), available at <https://ici-s.umn.edu/files/iJphkG6fcN/dsp-covid-survey-results>.

⁵¹ *Id.*

ABUSE AND NEGLECT EXAMPLE:

A group home resident, who is nonverbal and autistic and has no safety awareness skills, left his group home unnoticed during the day and was later picked up by police. The resident was found on a busy road near large woods after an undetermined amount of time alone. This resident had a well-documented history of being a flight-risk, but DSPs claimed to have no knowledge of this. On the day of the incident, the group home was scheduled to have three DSPs for four residents; only two staff were on site. Because one resident in the home required one-to-one supervision, only one DSP had to oversee the other three residents. Here, the resident was neglected and put at risk for serious physical and emotional harm.

were in the home, they could monitor DSPs interactions with residents, which could prevent future abuse and neglect issues.

When DSPs are overworked and fatigued, it may compromise their ability to manage their responsibilities effectively and safely. This is even more so as DSPs move from solely caretaking into a role that includes community integration and the development of supports and relationships.

Direct Support Professionals' Benefits

The benefits available to DSPs are also very limited. According to The Arc of Massachusetts, typical benefits for the human service workforce are health care, dental care, and group life insurance.⁵² 48.4% of DSPs are on MassHealth.⁵³ Additionally, 54% of DSPs report being on at least one public benefit, and 31% of them admit to decreasing their hours to remain eligible for them.⁵⁴ Estimates show that employer costs for employee compensation, wages and salaries accounted for about 70% of total compensation of private industry workers with the remaining consisting of non-wage benefits such as health insurance, retirement contributions (defined benefit and defined contribution), paid leave and supplemental pay, and other legally required benefits.⁵⁵ During COVID-19, 42% of DSPs reported knowing someone who had left their job due to the pandemic.⁵⁶ Of those, 25% left their job due to childcare issues.⁵⁷

⁵² Leo V. Sarkissian et al., *Resolving the Workforce Crisis: Strengthening the Quality and Sustainability of the Direct Support and Professional Workforce*, The Arc of Massachusetts 1, 9 (Dec. 2018), available at <https://thearcofmass.org/wp-content/uploads/2019/01/TheArc-WorkforceProposal.2018.12.07.pdf>.

⁵³ *Id.* at 40. The data is derived from a study of home care aides; however, this data is likely similar to what is happening with DSPs who specifically work with individuals with intellectual and developmental disabilities.

⁵⁴ Hayley Gleason, *Setting the Agenda: Data Driven Advocacy to Address Home Care Aide Policy*, Home Care Aide Council 1, 5 (Feb. 2018), available at https://commcorp.org/wp-content/uploads/2018/02/Resource_HCAF_Setting-the-agenda-data-driven-advocacy-to-address-home-care-aide-policy_Feb-2018.pdf.

⁵⁵ Fogg et al., *supra*, at 32.

⁵⁶ Inst. Cmty. Integration and Nat'l All. of Direct Support Prof'ls, *supra*.

⁵⁷ *Id.*

According to SEIU 509, although most agencies offer healthcare, most DSPs end up opting out of the health insurance because they cannot afford the premium. *Specifically, only 5.0% of DSPs reported having private insurance through the agency.*⁵⁸ *In some cases, the DSP would have to spend up to 18-20 % of their salary for their healthcare under provider insurance options.*⁵⁹ Additionally, SEIU disclosed that one of their provider agencies reported 146 (70%) out of 211 eligible members are not enrolled in the employer-sponsored health plan. Another agency had staff who opted into their employer-sponsored health plan, but those employees had to pay 20% of their paycheck for the insurance. The lack of employer required coverage places a greater burden on the public sector, including MassHealth. Most DSPs who don't qualify for MassHealth would qualify for a low-cost Massachusetts Health Connector plan. It is important to note, according to SEIU and The Arc, EOHHS has a benchmark of around 22% for tax and fringe benefits. Both agencies agree that this is not adequate and should be higher; The Arc has specifically advocated for the tax and fringe benchmark to be 30%. Unfortunately, no matter what the current benefits are, they are not valuable to most DSPs and certainly do not offset the low wages, high turnover rates, scheduling challenges, and other issues.

Low Wages

In 2019, the national median salary for DSPs was \$20,200.⁶⁰ For Massachusetts, the median salary for DSPs was \$22,600.⁶¹ The median wage for DSPs is relatively low considering the quality of work and required skills. Nationally, the median hourly wage for DSPs is \$11.54, with hourly pay rates ranging between \$9.28 and \$14.89.⁶² According to a National Core Indicators report in 2018, the hourly average wage for DSPs in Massachusetts ranged between \$12.50 and \$26.50.⁶³ The Bureau of Labor Statistics (2020), reports a \$16.29 median hourly wage for home and health and personal care aides (general categories) in Massachusetts.⁶⁴ DSP wage increases have largely not kept pace commensurately with increases in the state minimum wage and increases in the wage rates for fast food, restaurant and other service workers. As a result, IDD providers find themselves competing for workers not only among

⁵⁸ Gleason (Feb. 2018), *supra*, at 40.

⁵⁹ Interview with Kerstin Lindgren, Strategic Organizing Researcher, SEIU Local 509 (Sept. 23, 2021) (on file with the author).

⁶⁰ *Workforce Data Center*, Paraprofessional Healthcare Institute (Last Modified Sept. 2, 2021), available at <https://phinational.org/policy-research/workforce-data-center/#var=Earnings&tab=State+Data&natvar=Earnings>.

⁶¹ *Workforce Data Center*, Paraprofessional Healthcare Institute (Last Modified Sept. 2, 2021), available at <https://phinational.org/policy-research/workforce-data-center/#var=Earnings&tab=State+Data&natvar=Earnings&states=25>.

⁶² *Average Direct Support Professional Hourly Pay*, Pay Scale (Jul. 15, 2020), available at https://www.payscale.com/research/US/Job=Direct_Support_Professional/Hourly_Rate.

⁶³ *National Core Indicators Staff Stability Survey Report [hereinafter NCI Report 2018]*, Nat'l Ass'n of State Dirs. Of Dev'l Disabilities Servs. and Human Servs. Research Inst. 1, 34 (2018), available at <https://www.nationalcoreindicators.org/upload/core-indicators/2018StaffStabilitySurveyReport.pdf>. The response indicated resulted from seventy-four agencies in Massachusetts reporting their employee wages.

⁶⁴ *Occupational Employment and Wages, May 2020: 31-1120 Home Health and Personal Care Aides*, U.S. Bureau of Labor Statistics (May 2020), available at <https://www.bls.gov/oes/current/oes311120.htm>.

themselves, and across the health care sector, but also in adjacent areas of the service sector, where work may be considerably less demanding.

Compared to other professions that serve and support people with disabilities, DSPs are paid significantly less. Special education teachers in Massachusetts, for example, make an average of \$77,470 in elementary school settings, \$79,090 in middle school settings, and \$79,510 in high school settings.⁶⁵ So, while Massachusetts invests in the education of students with disabilities, they have significantly neglected those same individuals when they enter adulthood. It is important that Massachusetts provides well-trained support staff to people with disabilities in all phases of life, not just childhood and adolescence.

COVID-19 had minimal impact on raising DSP wages. According to a national survey, DSP workers were slow to be recognized as essential workers.⁶⁶ Of those that participated in the survey, only 24% received extra pay due to COVID-19 risks, with 45% of them receiving an hourly wage increase between \$1.01 and \$2.00.⁶⁷ In Massachusetts, we are aware of agencies utilizing sign-on bonuses to entice workers to apply for their organization, but these amounts vary from agency to agency. Some of these bonuses are only for specific positions or shifts. One agency was offering a \$400 sign-on bonus for their second shift workers and a \$600 sign-on bonus for their third shift workers.

According to SEIU 509, the current wage rates do not consider what an actual living wage is in Massachusetts. For example, the median hourly wage is \$16.29 for DSPs; however, according to EPI's Family Budget Calculator, an adult with one dependent living in Bristol County would need to earn \$29.74 an hour to meet their basic needs. As for Western Massachusetts, the current rates for DSPs are almost half of what is required for a living wage. Plus, living wages are higher the closer someone lives to Boston. The wage rate to support the cost of living in Massachusetts for one parent and one child is \$36.88 an hour.⁶⁸

⁶⁵ *May 2020 State Occupational Employment and Wage Estimates-Massachusetts*, U.S. Bureau of Labor Statistics (May 2020), available at https://www.bls.gov/oes/2020/may/oes_ma.htm#25-0000. Transitioning from educational services to adult services can be extremely overwhelming to people with disabilities and their families. Turning 22 is a major life change and is stressful because people are often "faced with the reality that there is a lack of flexible, individualized support service options available and funding from MA Department of Developmental Disabilities, MA Rehabilitation Commission, MA Department of Public Health and other disability agencies is limited or unavailable." *Turning 22: Transitions & Adult Service Options*, Cooperative for Human Services Inc. (2021), available at <https://cooperativeforhs.org/turning-22/>.

⁶⁶ Inst. Cmty. Integration and Nat'l All. of Direct Support Prof'ls, *supra*. A 12 month follow-up report was issued in September 2021, available at <https://publications.ici.umn.edu/community-living/covid19-survey-12-month-followup/main>.

⁶⁷ Inst. Cmty. Integration and Nat'l All. of Direct Support Prof'ls, *supra*.

⁶⁸ *Living Wage Calculation for Massachusetts*, Living Wage-Calculator (2021), available at <https://livingwage.mit.edu/states/25>.

Massachusetts is one of the most expensive states to live in the United States with the average cost of a home at \$663,942, which is almost three times higher than the national average.⁶⁹ The median rent for a two-bedroom apartment in the United States is \$1,650 per month.⁷⁰ In Massachusetts, the median rent for a two-bedroom apartment is \$2,500, which is 51.5% higher than the U.S. average.⁷¹

Finally, neither the current minimum wage (\$13.50) nor the median hourly wage for DSPs comes close to the amount necessary to cover comfortably housing costs in Massachusetts without financial strain. According to the annual housing affordability study *Out of Reach*, the “state housing wage” (the amount necessary across a 40-hour work week, 52 weeks a year, to pay for rent and utilities in a two-bedroom apartment, without paying more than 30% of income for housing costs) is \$36.24/hr.⁷² Of course, in the Boston area that figure is substantially higher.

High Staff Turnover Rates

Years of low wages, poor benefits, and a lack of career advancements has led to a high turnover rate for DSPs working in IDD day and residential services. This heavily impacts the care of people with disabilities who often have individualized and complex needs. DSPs are most effective if they can utilize a person-centered approach to care but learning the individual needs of the people with whom they are working takes time. Because of the constant turnover, the person with a disability is in a constant state of transition, leading to stress from adjusting to these new circumstances. In addition, staff turnover can slow the individual’s progress in mastering activities of daily living and acquiring and retaining a volunteer job or competitive employment. With long-term exposure to a person with disabilities’ personal characteristics and needs, DSPs would better serve the disability community by improving the quality of life of those served through a supportive and engaged staff.

The turnover rates within the DSP workforce are high. Seventy-eight agencies in Massachusetts reported an average turnover rate of 35.2%.⁷³ Additionally, they reported their employee tenure rates as of December 2018 were roughly as follows: 13% of employees had been employed for less than six months; 13% had been employed by that agency between six and twelve months; 17% had been employed between one and two years; 13% had been employed between two and three years; and 44% had worked for more than three years.⁷⁴ After the start of the COVID-

⁶⁹ *Most Expensive States To Live In 2021*, World Population Review (2021), available at <https://worldpopulationreview.com/state-rankings/most-expensive-states-to-live-in>.

⁷⁰ Chris Kolmar, *Average Rent In Massachusetts For December 2020*, HomeSnacks (Updated Dec. 7, 2020), available at <https://www.homesnacks.com/cities/average-rent-in-massachusetts/>.

⁷¹ *Id.*

⁷² Andrew Aurand et al., *Out of Reach-The High Cost of Housing*, National Low Income Housing Coalition 1, 16 (2021), available at https://nlihc.org/sites/default/files/oor/2021/Out-of-Reach_2021.pdf.

⁷³ Nat’l Ass’n of State Dirs. of Dev’t Disabilities Servs. and Human Servs. Research Inst., *supra*, at 18.

⁷⁴ *Id.* at 21.

19 pandemic, 34% of workers who left the DSP workforce feared becoming infected, 25% had childcare issues, 13% feared infecting others, and 9% left after testing positive for COVID-19.⁷⁵

The Home Health Aide Council (HHAC) surveyed DSPs in Massachusetts to evaluate the turnover rates in DSP positions. A sample out of more than 650 DSPs in Massachusetts found that at the time of the survey about one-third thought it likely they would leave their position as a DSP and one in six were actively seeking a new position.⁷⁶ Similarly, home health care agencies hire on average eighteen new aides every three months, but they lose an average of fifteen home care aides during the same period.⁷⁷

This leads to temporary/per diem hires who do not know the person with a disability or their family. By not knowing the clients, temporary/per diem hires are seen as more of just a body meant to fill an open space instead of a supportive and helpful worker. This, in turn, adds more work to full-time DSPs who must cover for the lack of knowledge of the temporary/per diem hire.

There are many adverse consequences of the high turnover rate. Without reliable staff to support these needs, people with disabilities experience markedly less independence and autonomy. The lack of committed, well-trained, and consistent staff, and empty shifts and high turnover rates lead to human rights violations, particularly an erosion of community-based programming, a right of people with disabilities under the ADA.

High rates of staff turnover are also extremely distressing for family members, who report to DLC the experience of frequently arriving at their loved one's community residence only to meet unfamiliar new workers each charged with assistance in intimate personal care needs or complex medical issues.

Finally, high rates of staff turnover mean poor outcomes for providers and for taxpayers. The indicates that hiring and recruitment costs amount to as much as \$5,000 for each new DSP who churns into and out of the system.⁷⁸

Staff Ratio

Massachusetts does not require a set staff ratio in IDD residential services. However, in the DDS contracts for residential reimbursements, DDS includes the number of full-time equivalent (FTE) employees expected for the agency to hold the contract. The FTE

⁷⁵ Inst. Cmty. Integration and Nat'l All. of Direct Support Prof'ls, *supra*.

⁷⁶ Fogg et al., *supra*, at 22. This data set included non-IDD DSPs, but it is reasonable to assume similar perspectives within the IDD workforce.

⁷⁷ Gleason (2018), *supra*.

⁷⁸ See e.g. *Addressing the Disability Services Workforce Crisis of the 21st Century*, American Network of Community Options and Resources (ANCOR) (2017) at 7, available at <https://cqrcengage.com/ancor/file/ZuL1zlyZ3mE/Workforce%20White%20Paper%20-%20Final%20-%20hyperlinked%20version.pdf> (estimating \$4200 to \$5200 in direct and indirect costs as of 2017 date of publication).

requirements in each contract are based on the type of service provided, the number of clients served, and the needs of the clients served. As such, there is no set standard ratio in Massachusetts because it is dependent on the contracts between DDS and providers. Additionally, we know, unfortunately, that it is highly unlikely that FTE requirements as agreed to in previous contracts have been met during the COVID-19 pandemic.

Massachusetts does, however, have other general staffing requirements, such as who should be on staff during a particular shift. Massachusetts requires that provider agencies simply “have [a] multidisciplinary professional team to meet the nursing, oversight, and care management needs of residents” and have “sufficient staffing at all times to meet the scheduled and reasonably foreseeable unscheduled resident’s needs....”⁷⁹ Additionally, each group home is to have a program director, “who is a health care professional with a bachelor’s degree and a minimum of five years of

ABUSE AND NEGLECT EXAMPLE:

An autistic resident with limited expressive abilities wandered off during the night and was found 8 miles from his group home the next morning. The resident had a history of eloping, and, because of this, there were alarm systems on all doors to notify staff if he was trying to leave the home. On the night of the incident, the alarms had been turned off and the DSPs failed to complete required bed checks, even though they signed a log stating they did. The resident was able to sneak out without anyone noticing. To this day, no one knows how long the resident was wandering the streets, but when he was found, he was wet, shivering, muddy, and disoriented. The resident sustained emotional injuries and, due to the nature of the harm, had a real possibility of sustaining life-threatening injuries.

professional health care experience working with elderly or disabled adults,” and a service plan coordinator.⁸⁰

With the current workforce crisis, even these overarching staffing requirements are often not met, leading to temporary/per diem hires who lack familiarity with and specific knowledge about each individual served. Understaffed IDD day and residential programs struggle to meet the needs of individuals with IDD through community-based programming. With fewer staff, the people served are less likely to have an abundance of community-based program options, which leads to forced interactions with the community, or no interaction at all. This does not meet our goal of seamless community integration.

⁷⁹ Robert L. Mollica et al., *Building Adult Foster Care: What States Can Do*, AARP Public Policy Institute 1, 129 (Sept. 2009), available at <http://www.cshp.rutgers.edu/Downloads/8290.pdf>; *2019 Assisted Living-State Regulatory Review*, National Center for Assisted Living (NCAL) 1, 151 (2019), available at https://www.ahcancal.org/Assisted-Living/Policy/Documents/2019_reg_review.pdf.

⁸⁰ Mollica et al., *supra*.

Lack of Training

As previously mentioned, DSPs often lack the specialized training that is necessary for their full success as a support to a person with a disability. Unfortunately, it can be difficult for DSPs and service providers to offer training courses because of the following issues: “(1) reimbursement rates that cover little more than personnel costs, (2) the dispersal of DSPs across many work sites and the centralized location of training, (3) the widely varying hours worked by DSPs and the difficulty of finding convenient times for training, and (4) the high rate of DSP position vacancies, making it difficult to cover work shifts while DSPs attend training.”⁸¹

In Massachusetts, DSPs are required to have a high school diploma and specialized training due to the varied care needs of clientele.⁸² Plus, home health aides who work for agencies that receive reimbursement from Medicare and Medicaid funds must have a certification that requires 75 hours of training.⁸³ However, it is important to note that many workers in the home health field work in job titles that do not require the certification.⁸⁴ DSPs reported that nearly 27% of new hires during the COVID-19 pandemic did not even receive the typical orientation and preservice training.⁸⁵ However, 66% of those respondents indicated that health and safety training was offered after the start of the pandemic.⁸⁶

ABUSE AND NEGLECT EXAMPLE:

During a monitoring visit, DLC staff noticed two non-verbal residents without any Augmented and Alternative Communication (AAC) devices. DLC staff asked if either resident had ever been evaluated to use AAC or Assistive Technology (AT). DLC learned that both residents were supposed to always have communication books on their person, but the books were locked in an office on another floor. Additionally, one of the residents had been previously evaluated to use AT, but the group home didn't follow up on this. The group home was essentially silencing two residents by failing to understand their communication needs and invest time to ensure the residents could communicate effectively.

All DSPs, no matter their title, should receive specialized training, which should center around how best to serve people with disabilities and promote their independence. Essentially, DSPs should learn how to help a person with a disability make informed decisions, live as independently as possible, and meaningfully participate in their

⁸¹ President's Committee for People with Intellectual Disabilities, *supra*, at 17.

⁸² Sarkissian et al., *supra*, at 8.

⁸³ Fogg et al., *supra*, at 14.

⁸⁴ *Id.*

⁸⁵ Inst. Cmty. Integration and Nat'l All. of Direct Support Prof'ls, *supra*.

⁸⁶ *Id.*

ABUSE AND NEGLECT EXAMPLE:

A resident, who is a wheelchair user living in an IDD group home, was hospitalized due to a stage 4 pressure ulcer from an untreated bed sore. Doctors said the wound was festering for months and life-threatening, but completely preventable. Wheelchair users are at a heightened risk of pressure sores, which are a major cause of infection or even in some cases, death. On another occasion, that same resident's big toe was partially amputated because his foot became infected after he was improperly transferred from his chair to his bed. The resident was severely wounded on multiple occasions due to staff's lack of attention, training, and care.

community. DSPs could foster these important qualities of independence through providing opportunities for people with disabilities to be gainfully employed and/or participate in volunteer activities, to learn about personal hygiene, to learn how to cook for themselves, and how best to manage their money.

Section III: LACK OF SUFFICIENT OVERSIGHT BY THE DEPARTMENT OF DEVELOPMENTAL DISABILITIES

Under Massachusetts law, the Department of Developmental Services (DDS) has the authority to issue licenses “to any private, county or municipal facility or department or ward of any such facility which offers to the public residential and day care services and is represented as providing treatment of persons with an intellectual disability .”⁸⁷

The licensure process is meant to give the providers legal authorization to provide services and supports to individuals with disabilities in Massachusetts. DDS requires the providers to meet threshold requirements to serve adults with IDD. These threshold requirements, which DDS defines as “essential safeguards,” are areas related to:

- personal safety
- environmental safety
- communication
- health
- rights
- a competent and skilled workforce
- goal development, skill acquisition and implementation of Individual Support Plans (ISPs).⁸⁸

⁸⁷ M. G. L. c. 19B, §15(a).

⁸⁸ *Licensure and Certification Procedures Manual, 5th edition*, Commonwealth of Massachusetts Executive Office of Health and Human Services and Department of Developmental Services 1, 6 (2019).

The certification process, however, reviews each provider's supports and sets "standards for specific services that promote quality and responsiveness and when implemented are predictive of positive outcomes in the lives of individuals."⁸⁹ DDS describes the certification indicators as being "tied to the intended outcomes of the specific service model and a focus for continual quality improvement of the provider."⁹⁰

Group homes are reviewed every two years either by DDS or through the self-assessment process. A self-assessment process is offered for both the licensure and certification process for providers with a full two-year license on alternate survey cycles.⁹¹ Allowing group homes to be certified through a self-assessment process means DDS is entrusting a group home to evaluate its own effectiveness in serving people with disabilities in order to be recertified. In the instance of a self-assessment, DDS would only review any licensure or certification indicators that were not met (although they do claim to still evaluate all critical licensure indicators).⁹²

Additionally, DDS regulations consider national accreditation processes as equivalent to the Department's certification review process. This is another group of providers who are not assessed by DDS, but instead presumed to follow Massachusetts certification requirements.

This hands-off approach to licensure and certification is extremely concerning, particularly in light of systemic issues with the DSP workforce. No matter what measures are required through a self-assessment, DDS should be visiting and evaluating every group home to ensure they are meeting the required standards of care for people with disabilities in Massachusetts. Without directly visiting and evaluating a group home, DDS has no way to fully know if a group home is meeting its licensure or certification indicators.

Once everything is reviewed, the provider receives a level of licensure and a level of certification. The levels of licensure are:

- Two-Year License – "standard met" for at least 80% of the licensure indicators and a rating of "standard met" for all 8 critical indicators.
- Two-Year License with Mid Cycle Review – "standard met" for 60-79% of the licensure indicators and a "standard met" for the 8 critical indicators.
- Deferred License – applies when one or more of the 8 critical indicators receive a "standard not met." In this situation, a provider is given the opportunity to make corrections within 60 days. If corrected, the provider receives a Two-Year License with a Mid Cycle Review. If not corrected, a recommendation for non-licensure is made.

⁸⁹ *Id.*

⁹⁰ *Id.*

⁹¹ *Id.* at 24.

⁹² *Id.*

- Recommendation for Non-Licensure – “standard met” for 59% or less of the licensure indicators. Operations can accept this recommendation or develop and implement a 60-day work plan. The results of this plan are subject to follow up by licensure and certification staff within 60 days.⁹³

The levels of certification are:

- Certified – “standard met” for at least 80% of the certification indicators.
- Certified with a Mid-cycle Progress Report – “standard met” for 60-79% of the certification indicators.⁹⁴

Providers do not immediately lose accreditation if they fall below the 80% threshold because DDS treats certifications like an audit, which allows for the provider to take action to improve the services and for DDS to monitor the provider for improvement.⁹⁵ Any provider who requires a progress report must submit that progress report one year from receiving a “certified with a progress report” certification.

To determine which providers are “audited” by DDS, DDS uses a standard formula that “takes into account the number of people served by the agency within each service type, difference between service types, the number of sites, and the number of DDS administrative regions in which the agency has a significant number of sites.”⁹⁶

However, DLC has investigated or monitored multiple group homes across the state within varying provider agencies. Through these reviews, DLC has noted that individual group homes can vary significantly in their level of care, even if they fall under the same provider agency. By not reviewing every group home, DDS is failing to identify areas where a provider may not be meeting the necessary standards of care. As DLC has seen, one group home is not an indicator, good or bad, of a provider agency. Instead, these group homes should be taken together to evaluate effectiveness of the provider in serving people with disabilities.

In summary, DDS reviews provider agencies every two years and, in that time, does not visit every group home under the provider agency to ensure compliance with DDS regulations or the safety of people with disabilities. This is a lack of oversight on DDS’s part. DDS should be able to confirm, through its internal evaluations, that each group home is appropriately serving people with disabilities, but that is not required in any way by the current licensure and certification system.

DLC has seen frequent instances of abuse and neglect that stemmed from a lack of oversight. When no one is around to monitor bad actors or correct bad habits, group homes become unsafe for the people living there. Some long-term incidents of abuse and neglect were taking place for years before reports were made to DLC, meaning that

⁹³ *Id.* at 19.

⁹⁴ *Id.*

⁹⁵ *Id.* at 9.

⁹⁶ *Id.* at 12.

DDS should have noticed the violations during their licensure and certification reviews, but did not.

During the pandemic, DDS service coordinators went completely remote and are still only on a hybrid work model, further impairing the effectiveness of DDS oversight. DDS service coordinators are responsible for monitoring the safety and well-being of their assigned individuals; providing advocacy in human, civil, and legal rights to those individuals; and monitoring the implementation of services provided by the DDS-funded providers. Working remotely impacts a service coordinator's ability to complete their responsibilities, especially for people who need to be evaluated and supported through in-person monitoring, including individuals with more significant disabilities who cannot utilize a phone or computer for communication. Moreover, all people with disabilities in group homes would benefit from a more hands-on approach from DDS service coordinators that included in-person monitoring visits to ensure the well-being of their assigned individuals.

ABUSE AND NEGLECT EXAMPLE:

United Arc was recommended for de-licensure this summer by DDS. The homes, however, were “. . . in good repair and blended naturally into their surrounding neighborhoods” highlighting the need for direct oversight to ensure outer appearances don't mislead DDS employees. The report on United Arc found they failed to: screen for minimum job qualifications; track trainings for staff; provide for the physical, chronic, and preventative health needs of residents; follow protocols of behavior plans, medication treatment plans, and environmental restrictions; train on recognizing signs of illness or administering medication. The report indicates a lack of supervision and oversight of staff leading to multiple human rights violations for the people with disabilities in United Arc's care.

Massachusetts Nurses Association Letter

On September 21, 2021, several employees from the DDS wrote a letter to Jane Ryder, the DDS Commissioner, imploring her to intervene in the patient-care crisis that is taking place at many DDS run group homes.⁹⁷ The group homes in question house citizens with multiple disabilities, most of whom are non-verbal.⁹⁸ Essentially, these people with disabilities require “around-the-clock care from highly specialized nurses and healthcare professionals.”⁹⁹ The staff identified multiple problems, including:

⁹⁷ *Caregivers of the Developmentally Disabled in Western Massachusetts Sound Alarm as Patient Care Inside of Group Homes Spirals Due to Severe Understaffing and Training Failures*, WKYT (Oct. 20, 2021), available at <https://www.massnurses.org/news-and-events/p/openItem/12241>.

⁹⁸ *Id.*

⁹⁹ *Id.*

- Significant increases in DDS clients being sent to the ER; patient falls; and medication errors.
- Medication errors have doubled since the staffing crisis began in April of 2021.
- There have been 126 documented ED visits by group-home clients through mid-September of this year versus a total of 145 in all of 2020.
- Volunteer staff taking open shifts are often not appropriately trained, potentially putting clients' health and safety at risk.
- The credentials of volunteers filling open shifts are generally unknown to supervising nurses and clinicians.
- Having staff untrained in MAP (the state's [Medication Administration Program](#)) violates DDS's policies, but it occurs regularly with volunteer staff and staff who are floated to other homes/facilities without nursing notification.
- When there are no volunteers to cover a vacant shift, DDS management "mandates" staff to work overtime, which means staff members are forced to stay beyond their scheduled shift, often without warning or the opportunity to plan accordingly.
- One MNA leader inside DDS recently commented that a colleague was mandated to work for 48 hours. Mandated overtime can, and often does, result in errors because affected staff are not rested and alert enough to deliver the best care possible.¹⁰⁰

This letter illustrates that the incidents of abuse and neglect that DLC has seen are not simply because of “bad actors” or “bad employees.” Instead, most of these problems stem from structural issues, including lack of pay, high turnover, scheduling challenges, lack of adequate benefits, and a lack of training. These systemic problems cannot simply be fixed with a higher paid workforce, although higher wages are necessary. DDS must offer to provide stronger support and oversight of providers and their DSPs working with people with IDD. Without DDS’ active involvement in changing the current systems, the workforce crisis will continue to lead to people with disabilities experiencing abuse and neglect and human rights violations.

Section IV: IMPACT ON FAMILIES

The problems with the DSP workforce have increased responsibilities for family caregivers. Without safe, inclusive, and reliable day and residential programs, many people with disabilities continue to live and depend on their aging caregivers. Unfortunately, as these caregivers age, many of their adult family members with disabilities may face housing instability or homelessness.¹⁰¹ While it is crucial that people with disabilities have access to safe, affordable housing, it remains out of reach

¹⁰⁰ *Id.*

¹⁰¹ *Policy & Advocacy-Housing*, The Arc (2021), available at .

for millions of people with disabilities and their families.¹⁰² The instability of housing for people with disabilities combined with aging families who cannot care for their loved ones can force people with disabilities into congregate or institutional settings that undermine their independence.¹⁰³

In 2012, the Consortium for Citizens with Disabilities (CCD) and the Technical Assistance Collaborative (TAC) did a joint study focused on housing for people with disabilities. CCD and TAC found that “as many as two million non-elderly people with disabilities reside in homeless shelters, public institutions, nursing homes, unsafe and overcrowded board and care homes, at home with aging parents or segregated group quarters—often due to lack of affordable housing in the community.”¹⁰⁴ Clearly, this problem goes beyond the issues within the DSP workforce; however, it is a qualifying factor in why families may feel like they cannot depend on the system and must keep their family member home, even when it isn’t feasible to do so.

DSPs in IDD day and residential settings that fail to focus on community integration for people with disabilities, put the burden of community integration on family members. This may include helping their loved one find work, participate in activities, or volunteer. The high turnover rate of DSPs also frustrates families who are never fully aware of who is working with their loved one. The turnover rate causes mistrust in family members and disassociates them from the care and inclusion of their loved one.

We’ve been told by numerous family members that they “don’t know what they do all day,” referring to their loved one in a day or residential setting. Families may choose to keep their loved one at home with them; however, without adequate support, this is a daunting task. Families are not fully prepared to care for an adult, who needs supports for community integration and, potentially, for their disability as well, especially if they are working and trying to live their own independent lives. Therefore, it is important to have a reliable, stable, and trained workforce who can support people with disabilities wherever they find themselves living.

Section V: BEST PRACTICES AROUND THE NATION

Massachusetts has a 35.2% turnover rate,¹⁰⁵ which, comparatively speaking, is lower than many rates in many states and is supported by the second highest average wage level for DSPs in the nation, \$15.34/hour.¹⁰⁶ However, this says more about DSP

¹⁰² Anna Bailey et al., *More Housing Vouchers Needed to Help People With Disabilities Afford Stable Homes in the Community*, Center on Budget and Policy Priorities (July 6, 2021), available at <https://www.cbpp.org/research/housing/more-housing-vouchers-needed-to-help-people-with-disabilities-afford-stable-homes>.

¹⁰³ *Id.*

¹⁰⁴ Mary O’Byrne et al., *Tough Choices: People with Disabilities Face Housing Crisis*, Special Needs Alliance (SNA), available at <https://www.specialneedsalliance.org/blog/tough-choices-people-with-disabilities-face-housing-crisis/>.

¹⁰⁵ *Id.* at 18.

¹⁰⁶ Nat’l Ass’n of State Dirs. Of Dev’l Disabilities Servs. and Human Servs. Research Inst., *supra*, at 37.

staffing being a national problem than it does about services for people with IDD in the Commonwealth. With over one-third of staff turning over, a more favorable turnover rate does not translate to positive outcomes for people with disabilities. Additionally, just because Massachusetts has the second highest wage level, it doesn't mean that wages are adequate to support DSPs and, in turn, the disability community. The more important variable is how these wages compare to local costs of living.

DLC has found that best practices have come from individual agencies that utilize different approaches to the workforce crisis. For example, Able South Carolina has created “an innovative marketing campaign for recruitment that offers a fresh perspective on the DSP role paired with disabilities rights training for new and current DSPs.”¹⁰⁷ It is the hope of Able South Carolina to foster DSPs as allies and advocates, which will inspire the DSPs, help them find value in their work and encourage them to stay in the field.

Another agency, RCM of Washington, has focused extensively on advocacy for people with disabilities through their “DSP Academy.” The DSP Academy is a customized vocational training program for future DSPs in Washington, D.C. This program focuses on disability rights, how to plan activities, how to navigate public transportation, relationship building, and other health and wellness projects. This program is one of a kind because it is tailored to helping people with disabilities become DSPs. Essentially, “the customized vocational training program would certify people with ID/DD to work as DSP by using classroom and on-the-job training to complete state DSP training requirements.”¹⁰⁸ RCM hopes that they can revolutionize the labor market by training people with disabilities to become DSPs.

These programs demonstrate that we need new and innovative approaches to address the workforce crisis. Unfortunately, even though Massachusetts is seen as doing better than most states, we still have a significant workforce crisis. What Massachusetts has been doing isn't working for the DSPs nor the people with disabilities. It is time we rethink, reenergize, retrain, and reinvest in the DSP workforce.

Section VI: RECOMMENDATIONS

It is important that Massachusetts tackles DSP workforce issues head-on now to ensure that people with disabilities can live, work, and contribute to their communities, as intended through multiple previously mentioned federal laws and regulations. By addressing some of these longstanding issues within the DSP workforce, DLC hopes that instances of abuse and neglect against people with disabilities in group homes will significantly decrease, creating a better quality of life for those individuals.

¹⁰⁷ *ACL Announces the Blazing New Trails for Community-Based Direct Support Professionals Prize Challenge Grand Prize Winner-Round 2 Winners*, Admin. for Cmty. Living, <https://acl.gov/DSPchallenge> (last modified Oct. 18, 2021).

¹⁰⁸ *Id.*

According to a recent survey done by ANCOR, 58% of providers surveyed are discontinuing programs, 77% aren't taking new referrals, 84% are delaying new program offerings, and 81% are struggling to achieve quality standards.¹⁰⁹ ANCOR says, "[t]his is the first time since the deinstitutionalization movement that we are actually going backwards."¹¹⁰ ANCOR directly cites to insufficient staffing as the root of most of the problems. Essentially, we have no time to waste in addressing this clear and persistent threat to our community models of care for people with disabilities. There is a real fear that people are going to be forced back into institutional and segregated settings. We cannot let this happen and so, DLC makes the following recommendations:

Recommendation I: The Executive Office of Health and Human Services needs to take immediate action to raise DSP wage rates.

DSP wage rates must increase in the Governor's next budget to provide an entry level wage that is consistent with the living wage in the applicable region of the state. Wages need to be indexed to the cost of living and regularly revisited to keep pace both with increases in the state minimum wage and increases in the human services and health care sectors of the state economy. Wages for experienced staff need to be similarly increased with an expansion in the steps available for experienced DSPs. This will help prevent wage compression and promote retention.

In negotiating the increase to wage rates, EOHHS needs to be open and transparent. It is sometimes unclear what reasoning or data EOHHS uses for their recommended rates relating to wages and fringe benefits. Providers, advocates, and other interested parties need to know the rationale behind the recommended rates. Instead, rates are often buried in hard to read documents without a clear indication of where the rationale can be found. Additionally, it is crucial that we are able to measure DSP wages to comparable work to ensure that DSPs are being paid at a proportionate rate.

Massachusetts is receiving approximately \$8.7 billion from the federal American Rescue Plan Act (ARPA). EOHHS has already started using the enhanced federal funding to strengthen certain Medicaid home and community-based HCBS and behavioral health services. We acknowledge and appreciate the commitment of EOHHS to support the HCBS workforce in this manner. The three-phase implementation of initiatives started with approximately \$100 million of the funding to immediate across-the-board payment enhancements to strengthen and stabilize the HCBS workforce. Given that ARPA funds are time limited, the Commonwealth will also need robust strategies for stabilizing and strengthening the IDD workforce over the long term. One-time payments will not sustain a workforce in crisis.

¹⁰⁹ Diament, *supra*.

¹¹⁰ *Id.*

Recommendation II: The Executive Office of Health and Human Services needs to reevaluate their rate-setting system for IDD day and residential services and include accountability mechanisms.

Presently, Chapter 257 sets rates and model budgets that include various rates of pay for DSPs. First, the current wage rates do not consider what a living wage in Massachusetts really is, but instead just what providers pay. It is crucial, for the DSP workforce to thrive, that individuals are paid a living wage. Second, Chapter 257 rates are reviewed every other year, but with the constant cost of living increase, this should be done on a yearly basis. These changes will allow providers to pay DSPs a fair wage, increasing recruitment and retention of staff.

Finally, there is no accountability in place to ensure that these increases in rates are making it down to DSPs. Some agencies don't even pay DSPs the rate set in Chapter 257, but the state takes a hands-off approach in monitoring whether that money goes to DSPs or not. It is important that EOHHS makes sure that providers are paying DSPs their average rate and not spending it on increasing the salaries of upper management. According to SEIU, the CEO pay rates increase at a higher rate than for DSPs, and SEIU has raised these issues for years.

Recommendation III: The Executive Office of Health and Human Services and all private providers should require that all DSPs be trained in the difference between caretaking duties and helping people with disabilities live integrated lives involving social, emotional, vocational, and recreational skills.

The lack of community-based programming in day and residential settings is due, in part, to a lack of understanding from DSPs on what community integration is. We've also seen provider agencies who do not promote the importance of community integration. As such, it is crucial that all DSPs receive direct training on what it means to help a person with a disability integrate into the community. Examples of community integration include meaningful paid or volunteer work, engaging in fulfilling day activities, pursuing integrated social and recreational opportunities, and developing close family and personal relationships. The training should be standardized by EOHHS to ensure consistency in the quality and information of the training.

Recommendation IV: The Executive Office of Health and Human Services should require all provider agencies to create a uniform database to evaluate community integration within group homes and hold agencies who do not engage in community integration accountable.

As previously discussed, we've seen a severe lack of appropriate community-based programming in day and residential settings. There is no standard protocol for providers

to use tracking community integration for the people served. We believe having a uniform system would allow EOHHS, the Department of Developmental Disabilities, providers, and families to monitor community integration and evaluate if it is meeting the needs of those served. This would also allow EOHHS, DDS, and providers to track and address human rights violations. Software is currently available to allow both agencies and providers to track community integration opportunities remotely from central office locations. This would improve the lives of people with IDD in both day and residential settings

Recommendation V: The Executive Office of Health and Human Services and the Department of Developmental Services should strengthen licensing oversight of staffing of programs operated by private providers and related problems from inadequate staffing-abuse and neglect, violations of human rights and a lack of meaningful integration in the community.

In order for a provider to be recertified and relicensed, they must score “standard met” for at least 80% of all the indicators. However, it is unclear how this percentage is impacted if a provider scores extremely low on one indicator, for example staffing, but scores well on the rest of indicators. There are 92 licensure indicators and 8 critical indicators, all 8 of which must get a score of “standard met” for a licensure renewal. There are 54 certification indicators. Although thorough, the current set up, because of its breadth, dilutes the importance of individual scores. DLC is concerned that, due to the number of indicators for licensure and certification, providers can score below 80% on some of the indicators and still receive a licensure or certification renewal. Again, we understand and appreciate the breadth of indicators, but are concerned that the number of indicators may lead to a lack of precision in responding to the quality, or level of success, of a particular provider.

As discussed above, DDS oversight of providers does not always include onsite review of programs. It is important that DDS licensing staff provide in-person oversight to group homes and eliminate self-assessment options for providers. These in-person visits should not be limited to just licensing and certification years. Service coordinators should also visit group homes frequently, monitor their interaction with people with disabilities and evaluate the services they provide. Unfortunately, due to the COVID-19 pandemic, service coordinators have often been working remotely and visiting group homes in-person less frequently. DLC urges DDS to require service coordinators to resume in-person group home visits as soon as possible at the same or greater rate than before the COVID pandemic.

Recommendation VI: The Executive Office of Health and Human Services should work more closely with community colleges in Massachusetts to provide certification courses and promote professionalization for DSPs.

The Association of Developmental Disabilities Providers (ADDP) has been focused on professionalizing the DSP workforce. As such, they have started a relationship with University of Massachusetts Lowell to offer discounted rates on classes for people who want to go back to school. This program started as an applied behavioral analysis (ABA) certification program but is now transitioning into a broad certificate program for DSPs.

EOHHS should work with state colleges to create a certificate program for DSPs. This certificate could include training in community integration and other specialized skills that a DSP needs besides their caregiving skills. It is important for this certificate program to lead to increased pay rates, career ladders, and pathways for DSPs to advance their responsibilities and stay in the field. This would not only help with retention rates, but with the abuse and neglect, and human rights violations we consistently observe in day and residential settings, as discussed above.

Recommendation VII: The Commonwealth should require that the Executive Office of Health and Human Services participate in National Core Indicators Staff Stability Surveys to provide metrics against which our performance may be measured.

As we continue to study the impact of the DSP workforce on people with disabilities, it is imperative that EOHHS participates in National Core Indicator (NCI) surveys every year. This is our best tool for measuring how impactful the other recommendations are.

The NCI Survey started in 2015 and Massachusetts has only participated in the 2018 survey. Some of the questions the survey asks providers are:

- What is the number of DSPs on staff and payroll?
- Basic Demographic information.
- What are the starting and average wages for DSPs?
- What was the tenure of the DSPs who left prior to years end?
- How often are bonuses given, to whom, and what amount?
- What benefits does the provider offer?
- How many part-time versus full-time DSPs are on staff?

The survey data is crucial in assessing what the staffing crisis is and how to work on ways to mitigate it. In 2018, there were 83 provider agency responses to the survey, which was a 44% response rate. The NCI Survey is voluntary in Massachusetts, but

other states require providers to respond. In Oregon, for example, providers are fined if they don't participate in the survey per state statute. Other states who require participation have enforced participation through licensure. Massachusetts should require providers to respond yearly to the NCI survey. This data will only help DDS and EOHHS in handling the workforce crisis.

Section VII: CONCLUSION

As one prominent researcher noted, DSPs are the backbone of long-term services and supports. But as all too often is the case, those charged with the most important and difficult work are paid and supported the least. The efforts of the Commonwealth to increase wages under Chapter 257 deserve acknowledgement, but in the absence of adequate measures to keep pace with changes in the economy, we have once again slid into a full-fledged workforce crisis. Indeed, some commentators have noted that "crisis" is likely the wrong term for what has over decades become a permanent feature in this rough terrain. Our persistent failure to fund wage and staffing increases for DSPs reflects our fiscal and moral failure to recognize fully the dignity of the lives of people with intellectual and developmental disabilities. As one *Boston Globe* columnist aptly put it, "The workforce 'crisis' is, at heart, a 'worker value crisis.'"

People with disabilities, their families, the workers, and organizations that serve them, and the Commonwealth's taxpayers all deserve more. Providing higher wages and greater professionalization, along with more supervision, oversight, and accountability will yield greater efficiency, higher quality services, and more value for taxpayer dollars, with less risk of abuse and neglect. And it will give people with intellectual and developmental disabilities and their families what all people want: safety, security and support in their homes, and opportunities to experience fulfilling work or volunteer positions, and integrated social and recreational opportunities in their communities.

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APPENDIX A

Recommended Reading

ACL [*Administration for Community Living*] *Seeks Inventive Solutions to Address the Direct Support Professional Crisis*, ACL (October 14, 2021), available at <https://acl.gov/DSPchallenge> (detailing how ACL offered a large cash prize to a group that came up with the best solution for strengthening the DSP workforce and increase quality of services for people with IDD. The winner, The Collaborative for Citizen Directed Supports-NJ, created an interactive map showing where DSPs and self-directed employees (SDEs) are located so clients can seek out their services, successfully improving the stability and capabilities of the DSP workforce.)

Addressing the Disability Services Workforce Crisis of the 21st Century, American Network of Community Options and Resources (ANCOR) (2017), available at <https://cqrcengage.com/ancor/file/ZuL1zlyZ3mE/Workforce%20White%20Paper%20-%20Final%20-%20hyperlinked%20version.pdf> (presenting a comprehensive analysis of the state of the DSP workforce, as well as data-driven solutions. This includes increasing investment and wages through state and federal dollars (as most funding comes from Medicaid, and so local employers cannot raise or even negotiate wages), increasing recognition of DSPs as highly skilled and invaluable professionals, using existing technology to help fill job vacancies and help the success of people with IDDs, and implementing numerous work-recruitment strategies to broaden and diversify the field of applicants.)

Report Summary: Addressing the Disability Services Workforce Crisis of the 21st Century, American Network of Community Options and Resources (ANCOR) (2017), available at <https://cqrcengage.com/ancor/file/J7F5Ptur16W/Workforce%201%20Pager%20-%20FINAL.pdf> (consolidating ANCOR's 2017 report on the DSP workforce crisis, stressing the immensely important yet underpaid and underappreciated work of DSPs, as well as potential solutions like "greater federal and state investment," "public awareness campaigns," and "[g]uidelines for more effective use of technology.")

Joan Vennoch, *Bonuses for dishwashers and ice cream scoopers — so why not for the disability workforce?*, The Boston Globe (June 17, 2021), available at <https://www.bostonglobe.com/2021/06/16/opinion/bonuses-dishwashers-ice-cream-scoopers-so-why-not-disability-workforce/> (arguing that Gov. Charlie Baker must do more to deal with a severe labor shortage of DSPs in MA, made worse during the COVID-19 pandemic -- especially by setting a higher pay benchmark.)

Carli Friedman, *Direct Support Professionals and Quality of Life of People with Intellectual and Developmental Disabilities*, Intellectual and Developmental Disabilities (February 2018), abstract available at <https://pubmed.ncbi.nlm.nih.gov/30024847/> (detailing how high turnover rate of DSPs lead to lower quality of life for people with IDDs whom they treat. This high turnover is due to low wages and insufficient training-

and so, wages must be increased including enhancing Medicaid reimbursement, and training standards must be increased, not only for DSPs' benefit but for the people with IDD whom they treat as well.)

Katherine E. Johnson et al., *Direct Support Professionals' Perspectives on Workplace Support: Underappreciated, Overworked, Stressed Out and Stretched Thin*, Intellectual and Developmental Disabilities (2021), abstract available at <https://pubmed.ncbi.nlm.nih.gov/34030180/> (excellent article, summarizing interviews, data analysis, literature review and potential solutions.)

Direct Support Professionals (DSP) Workforce-Joint Position Statement of AAIDD [American Association on Intellectual and Developmental Disabilities] and NADSP [National Alliance of Direct Support Professionals], AAIDD (May 18, 2016), available at [https://www.aaid.org/news-policy/policy/position-statements/direct-support-professionals-\(dsp\)-workforce](https://www.aaid.org/news-policy/policy/position-statements/direct-support-professionals-(dsp)-workforce) (AAIDD and NADSP expressing the desperate need for DSP workers (the U.S. will need roughly a million new workers by 2022), compared to paltry wages (almost half of DSP workers rely on public benefits, and many have to work two or three jobs). Recommendations include increasing federal and state funding, providing credentialing opportunities for increased training and upward mobility (including more training for supervisors), and increasing guidelines for and usage of technologies to decrease the burden on DSPs and enhance care for people with IDD.)

The Direct Support Workforce and COVID-19 National Survey Report 2020: Initial Report, Institute on Community Integration (ICI) and National Alliance of Direct Support Professionals (NADSP) (2020) available at <https://publications.ici.umn.edu/community-living/covid19-survey/overview> (detailing the crucial jobs of DSPs which entail multiple complex skill sets, yet which are critically underfunded and not respected, especially during the COVID-19 pandemic. The article has national statistics ranging from pay increases (which were miniscule) to increased work and risk exposure to COVID-19, to access to PPE and what safety measures were put in place for workers; it also includes recommendations going forward, such as DSPs being officially identified as essential workers, and access to career ladders.)

Direct Support Workforce and COVID-19 National Report: 12-Month Follow-up, Institute on Community Integration (ICI) and National Alliance of Direct Support Professionals (NADSP) (September 2021), available at <https://publications.ici.umn.edu/community-living/covid19-survey-12-month-followup/main> (describing the experiences of DSPs during the COVID-19 pandemic, and how it has changed over the roughly year and a half it has plagued the U.S., with the goal of gathering "information about the experiences of DSPs related to the COVID-19 pandemic to inform efforts to prepare for future waves of this and other pandemics." Despite new options to control the pandemic, much must still be done to protect DSPs and people with IDD, such as vaccination campaigns, reducing wage equality especially for Black/African American DSPs, and educating people with IDD regarding "handwashing, hygiene, and social distancing.")

John M. Keesler, *From the DSP Perspective: Exploring the Use of Practices That Align With Trauma-Informed Care in Organizations Serving People With Intellectual and Developmental Disabilities*, Intellectual and Developmental Disabilities (June 2020), abstract available at <https://www.researchgate.net/publication/341840623> [From the DSP Perspective Exploring the Use of Practices That Align With Trauma-Informed Care in Organizations Serving People With Intellectual and Developmental Disabilities](https://www.researchgate.net/publication/341840623) (showing how Trauma-Informed Care (TIC) has not only been proven to help people with IDD-like leading to less restraint and seclusion, and increased quality of life-but can help DSPs as well. Some aspects of TIC have already been unconsciously added into the DSP work environment, like staff seeking to feel safe and empowered; but other aspects-especially involving collaboration, shared decision-making, and leadership-are not and must be further incorporated into the DSP work environment.)

Jerry W. Smith, *Invaluable: The Unrecognized Profession of Direct Support*, Institute on Community Integration (ICI) (2019), trailer available at <https://ici.umn.edu/products/hlPwEbDwTR6Jhjm3fNuq0w> (honoring, through “stories and interviews with DSPs, family members, advocates, and people with disabilities from across the country,” the critical work -- though “underappreciated and underfunded” -- that DSPs do on behalf of people with IDD.)

Jerry W. Smith, *Invaluable: The Unrecognized Profession of Direct Support-Resources*, Institute on Community Integration (ICI) (2019), available at <https://ici.umn.edu/product/invaluable/resources> (listing-with concise descriptions-numerous resources for DSPs and advocates looking to improve, among other important issues, working conditions, wages, and trainings.)

David A Jordan, *Living wage needed for human services workers-their lives are on the line every day*, CommonWealth Magazine (June 24, 2020), available at <https://commonwealthmagazine.org/opinion/living-wage-needed-for-human-service-workers/> ((describing how DSPs are unsung heroes of the COVID-19 pandemic, in part recognized less because their services are integrated into the community, and also because their undeservedly low wages make them seem “less then.” They perform a variety of highly complex work for people with diverse needs, yet are vastly underappreciated for their services, leading to high turnover which hurts the people they serve; while Governor Charlie Baker has taken steps to increase DSP pay during the pandemic, the measures must be made permanent.)

Shaun Heasley, *Pandemic Exaggerated Pressures On DSPs, Report Finds*, Disability Scoop (May 4, 2021), available at <https://www.disabilityscoop.com/2021/05/04/pandemic-exaggerated-pressures-on-dsps-report-finds/29324/> (detailing the perils and inequities in being a DSP during the COVID-19 pandemic, such as roughly half of workers being exposed to COVID, almost all being considered essential yet only a third receiving a pay bump, and only half guaranteed paid time off if displaying symptoms of COVID.)

Mary A. Onyejose, *Stress, Burnout and Depression Among African Immigrant Direct Support Professionals Working with Adults with Intellectual Disabilities*, Doctoral Thesis (2021), available at <https://scholarworks.waldenu.edu/dissertations/10604/> (noting that an estimated 40% of direct care workers in the US are African immigrants, and reviewing the author's DSP survey and findings, and similar published literature, indicating that African immigrant DSP workers are more vulnerable to emotional exhaustion, stress, burnout and depression than non-immigrant counterparts.)

Michelle Diamant, *Survey Finds Disability Service Providers On The Brink*, Disability Scoop (October 1, 2021), available at <https://www.disabilityscoop.com/2021/10/01/survey-finds-disability-service-providers-on-the-brink/29513/#:~:text=Disability%20service%20providers%20across%20the,and%20struggling%20to%20maintain%20standards> (describing the perilous state of DSP organizations, with 58% [of those surveyed] discontinuing programs or services, 77% turning away new referrals [while] 40% [are] seeing higher frequencies of reportable incidents." This is because of severe labor shortages brought on by substandard wages -- which are constrained by limited Medicaid reimbursement rates -- and is leading to consolidating treatment centers, i.e. reinstitutionalization.)

Rose E. Nevill et al., *The Effects of Aggression Subtypes on Burnout and Caregiver Instability in Direct Support Professionals*, Journal of Positive Behavior Interventions (May 12, 2021), abstract available at <https://journals.sagepub.com/doi/abs/10.1177/10983007211013794> (finding that, while aggression generally contributes to DSP burnout and stress, verbal aggression specifically -- and not just physical aggression -- can cause adverse outcomes as well. DSPs could benefit from techniques to diffuse and redirect verbal aggression and hostility from individuals served, as well as utilize coping strategies to mitigate the effects of it on their emotional well-being.)

Carli Friedman, *The Impact of Direct Support Professional Turnover on the Health and Safety of People with Intellectual and Developmental Disabilities*, Inclusion (May 2020), abstract available at <https://meridian.allenpress.com/inclusion/article-abstract/9/1/63/461592/The-Impact-of-Direct-Support-Professional-Turnover?redirectedFrom=fulltext> (excellent article by leading IDD researcher, who analyzed data and concluded that *regardless of the level of individual's support needs* DSP staff turnover is associated with more emergency room visits, more abuse and neglect and more injuries compared to similarly situated individuals who were not exposed to DSP staff turnover.)

Carli Friedman, *The Impact of Ongoing Staff Development on the Health and Safety of People with Intellectual and Developmental Disabilities*, Journal of Developmental and Physical Disabilities (March 30, 2021), abstract available at https://www.researchgate.net/publication/339883069_The_Impact_of_Ongoing_Staff_Development_on_the_Health_and_Safety_of_People_with_Intellectual_and_Developmental_Disabilities

[tal Disabilities](#) (describing the importance of increasing training for DSPs, which not only leads to upward mobility and increased wages, but is important for people with IDD whom they help. Increased staff training can reduce neglect, abuse, and emergency room visits for their clients with IDD, a group of people uniquely vulnerable to such negative experiences.)

What is a Direct Support Professional and how are they different from Caregivers, Regional Centers for Workforce Transformation, available at <https://www.workforcetransformation.org/dsps-different-from-caregivers/#:~:text=The%20Main%20Difference&text=A%20caregiver%20will%20do%20things,and%20how%20to%20live%20independently> (outlining how DSPs are no longer being trained as caregivers, because the needs of their clients, and hence their roles as DSPs, have changed-including functioning as “clinicians, service coordinators, [and] administrators.” The main difference stressed is that “a caregiver will do things for someone [while] a DSP will work with someone to enable them to do things independently[.]”)