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For people with intellectual and developmental disabilities

Achieve with us.

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Resolving the Workforce Crisis:
Strengthening the Quality and Sustainability
of the Direct Support and Professional Workforce

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Executive Summary

The quality of care and the quality of life for individuals with intellectual and developmental disabilities (I/DD)[1] is at risk in the Commonwealth of Massachusetts. This proposal prepared by The Arc of Massachusetts will demonstrate a need for the Commonwealth to confront the Direct Care (DC) or Direct Support Professionals (DSP) workforce shortage crisis for people with intellectual and developmental disabilities. This shortage reflected across the nation is exacerbated in Massachusetts due to the high cost of living. This proposal attempts to summarize the role and responsibilities of the Massachusetts workforce that support people with I/DD, the current situation of the workforce funding and benefits and finally lays out a strategic vision for tackling the crisis in the direct care and support workforce, identifying a four-part strategy.

The mission of The Arc of Massachusetts is to enhance the lives of people with intellectual and developmental disabilities, including autism, and their families. The Arc believes that a quality workforce is essential to continue to achieve community supports and services that foster social inclusion, self-determination, and equity across all aspects of society.

The Massachusetts workforce supports people with I/DD in a wide range of activities to live successfully in communities, develop relationships, pursue careers and personal goals, and manage their lives safely. The workforce job duties are diverse, constantly changing and based on an individual with I/DD's needs and abilities. Some services may require a professional or clinical component such as nursing assistance for medical complications or cognitive behavioral therapy. Agencies' and families' ability to meet the needs of people with I/DD is severely hampered by the lack of trained staffers in the workforce, including an inadequate number of clinical and specialist teams.

Increasingly, nonprofit human service organizations or providers have not been able to offer DSPs and other staff competitive wages and benefits for the demanding work they do to assist and support people with disabilities. These low wages and benefits make the hiring and retention of qualified staff very difficult, with service provider agencies reporting a high turnover rate. Families and individuals with I/DD who seek to hire support staff also struggle. With limited funding sources, they often search for long periods of time to identify and hire qualified staff, only to have the staff move on soon after. An unstable workforce increases underlying costs through greater use of overtime, increased recruitment and training costs, and higher workers' compensation expenses. The cost associated with such turnover is significant for provider agencies, but continual changes in staffing also have a real human impact. People with I/DD have more success when they receive consistent care, which is more challenging to achieve when staff changes so frequently. The National Alliance of Direct Support Professionals states that to have a qualified, competent and stable Direct Support Workforce "…it is critical that DSPs have the competence, confidence and ethical decision-making skills with the guidance necessary to provide quality support, receive compensation that is commensurate with job responsibilities and have access to a career path aligned with ongoing professional development."

An investment in I/DD services is needed to strengthen the employment of DSPs and ensure the stability and quality of services for people with I/DD.

We propose a four-fold strategy to help combat the workforce crisis:

1.) A significant investment over the next four years to achieve the necessary entry and mean salary levels and improved benefits to recruit and retain a stronger, more qualified workforce.
2.) Innovation and system design improvements, which will not only enhance supports or opportunities but will help offset increased costs for workforce. Innovation and system design improvements could include: implementing the Individuals and Families First program including self or family-directed options; closing existing institutions; employing technology for individuals' advancement and service system improvements; reviewing current state regulations and safeguards for both adequacy and redundancy; and expanding best practices in preparing children or teens for adult life.
3.) Implement a blended funding strategy with Department of Developmental Services (DDS) and Medicaid funded entities (MassHealth, One Care Insurers, Accountable Care Organizations, etc.) to develop clinical teams across regions to ensure that agencies, families and other caregivers supporting individuals with I/DD have access to professionals and related equipment for medical, dental and behavioral needs.
4.) Address the development of human capital in recruitment, training and retention.

It is imperative that we act now to ensure that the disability community's advancements in civil rights and pursuit of the promise of the U.S. Supreme Court Olmstead decision and the Americans with Disabilities Act (ADA) do not falter due to lack of a supportive workforce, and to ensure that dedicated professionals are enabled to pursue and develop careers in this field. However, specific objectives and implementation methods must rely upon the Commonwealth's leadership in both the Administration and Legislature. The first step is to recognize the significance of the crisis. Next, we ask the

Administration to convene policy-makers, stakeholders and the public to develop a plan that will lead to more workers being hired and individuals with I/DD continuing to live their best lives.

People with disabilities and families require our commitment and response: this crisis can be solved.

This paper is divided into the following sections:

1. Introduction
2. Workforce Roles and Responsibilities
3. Present status of workforce funding
4. Present status of workforce benefits
5. A four-part strategy to address the workforce crisis for persons with I/DD and related conditions
6. Conclusion

Introduction

We are facing a severe workforce shortage of Direct Care (DC) or Direct Support Professionals (DSP) and an inadequate pool of qualified clinical specialists in disability services. This workforce crisis has been documented by several different organizations within the disability services field in our state and nationally and has been widely acknowledged for human services in general.[2] It is a major concern at the National Association of State Directors of Developmental Disabilities Services and the trade organizations representing providers. Despite many stakeholders recognizing the problem, we have been slow to make finding and implementing solutions a priority.

Direct Support and Care Professionals play a vital role in our disability services system, as they provide personal care, social support, and physical assistance to individuals with disabilities, including persons with intellectual and developmental disabilities (I/DD) such as Down syndrome, cerebral palsy, autism Prader-Willi syndrome, and other disabilities, in a wide range of activities. The direct services and staff support to people with I/DD and their families is essential to their health, safety and overall well-being.

The Arc of Massachusetts[3] (The Arc) believes that all people "deserve the opportunity for a full life in their community where they can live, learn, work and play alongside each other through all stages of life."[4] DSPs help individuals with I/DD learn independent living skills such as cooking and shopping and make it possible for such individuals to participate in employment and social activities. A qualified workforce is fundamental to facilitate connections with people with I/DD to people, resources, and experiences that foster a full life in the community.

The shortage in the workforce is apparent across all settings including individual and family homes, group homes, employment or day services, recreational settings, and in other public or private provider settings. The annual national turnover rate for the DSP workforce is an "estimated 46%, with about 38% leaving in the first six months and approximately 21% leaving within 6-12 months."[5] Anecdotal feedback and results of a sample group survey of residential, day and home services' providers by The Arc of Massachusetts points to more than one thousand unfilled positions currently

for Direct Support Professionals across Massachusetts. As a result, there are significant unmet needs due to lack of staffing. Providers cannot take on new clients because they lack staffing to do so.

Several important factors play a role in the current workforce crisis. According to a study conducted by the UMASS/Donahue Institute entitled, Who Will Care?" 1 in 4 Massachusetts residents are affected by human services.[6] Helping individuals achieve community integration for people with I/DD requires appropriate staff to patient ratios for preparation, coaching and supports, which is impacted by a shortfall of tens of thousands of workers for the human services sector by 2025.[7] One significant factor is that people with I/DD are living longer. Nationally, the number of adults with I/DD aged 60 and older is projected to double from 641,860 in 2000 to 1.2 million people by 2030.[8] In Massachusetts, 6,209 people served by DDS, or about 1 out of every 4 adults, is aged 55 and older.[9]

In addition, incidence rates of developmental disabilities are increasing. According to the US Centers for Disease Control and Prevention (CDC), about 1 in 6 children in the United States had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism. A CDC report, published in April 2018, states that about 1 in 59 children have been identified with autism spectrum disorder (ASD). This prevalence rate of children with ASD is a 150% increase since 2000.[10] With this growing population, there is an increased demand in the workforce to support the needs of people with I/DD.[11]

Another factor is the high cost of living in Massachusetts (as well as other states on the East and West coasts). Finally, Massachusetts has a low unemployment rate. Employers of all types are competitively pursuing competent workers by offering higher wages. For decades, a significant portion of our present workforce has been composed of immigrants from several continents including Africa through the H-1B Program, a U.S. Department of Labor immigrant worker program. Recently this federal program has been curtailed and if remedies are not applied soon, our crisis will worsen. Several providers have reported to The Arc of Massachusetts that staff who are law-abiding, visa holders are delayed from entering back into the country after visiting their home country or would-be employees are prevented from entering at all.

Family caregivers also face challenges supporting family members with I/DD. Across the country, family members are key caregivers of 71% of individuals with I/DD.[12] When families, siblings or other relatives are caregivers, supports ought to be provided to allow the caregiver to meet economic needs, minimize stress, and address any crises such as dealing with inadequate medical equipment. The number of aging parents (or siblings) providing care within the home continues to be significantly adding to the crisis. According to the Family Caregiver Alliance, in 25% of these homes, the family caregiver is over 60 years of age.[13] Individuals with I/DD live with lifelong cognitive and, often, other functional impairments. DSPs can provide an invaluable service for the families of individuals with I/DD living at home, allowing parents or guardians to take respite time and/or hold full-time jobs. The earlier supports are provided, the greater the likelihood of cost savings and improved quality of life for all.

Instead families and individuals with I/DD who seek to hire DSPs or other staff themselves experience a frustrating process. First, they must find a staff person with the proper training and knowledge to assist

them or their family members' specific needs, which can take several weeks or months. If they do find someone, just as they start to feel comfortable and establish an effective working relationship with that person, they often need to be replaced by someone new. Imagine the impact this would have on your well-being. For many people with disabilities and their families, this is a sobering reality.

Addressing the workforce crisis must also include expanding the availability of clinical specialty consultation and urgent response that is presently too limited. Direct support professionals, front line managers, family caregivers and community health care professionals may require specialty support for a variety of reasons such as addressing a health problem to prevent an unnecessary emergency room visit or psychiatric hospital visit or obtaining guidance on best practices and/or care review. In a 2017 publication of Healthy People, which is a literature review and commentary on the adequacy of health care, the authors note, "Clearly, adults with I/DD are a population experiencing health disparities. Health equity will only be achieved for adults with I/DD if identified health disparities are reduced (Healthy People 2020, 2016b)."[14] (The literature review includes The Arc of Mass/BU School of Social Work research report published in Health and Social Work). The clinical teams, which exist in our field, are limited and waiting periods of 18 months have been reported.[15] In addition, the limited availability of units for behavioral health stabilization or medication transitions have been reported. We must effectively address the lack of specialists and clinical teams missing in Massachusetts community services and supports for people with I/DD.

Massachusetts has long been the leader of the nation when it comes to supporting people with I/DD. Among other things, the Commonwealth was one of the first to legislate a public education to all children (preceding federal public law), including those with disabilities, and similarly led the way in closing institutions and integrating people with disabilities into their communities. The Commonwealth has memorialized an "Olmstead plan," based on the U.S. Supreme Court Olmstead v. L.C. decision, which confirms its commitment to promote opportunities for persons with disabilities to live, work, and be served in community-based settings. Unfortunately, the workforce crisis puts Massachusetts's promise of community integration into jeopardy. Without a long-term commitment to repairing and improving the Workforce crisis, the opportunity for people with disabilities to become full citizens and active community members is greatly diminished in addition to putting their health and safety at risk.

1. Workforce and Family Caregivers Roles, Responsibilities and Issues

This section explores the different roles that formal (workforce) and informal (families) play in the support and services of people with I/DD.

Individuals with I/DD need staff who can address a wide range of activities including health care, safety, travel, recreational and living skills. Staff also require skills and training to assist in community integration including communication and social skills. Organizations that provide only custodial care are deficient in their responsibilities. A diverse and wholistic approach to staffing the workforce by provider organizations, individual with disabilities and their families, and state employees is necessary to successfully support and serve the disability population.

Some examples of staff roles include:

- Educator
- Trainer
- Nursing assistant
- Community Connector / Community Living Specialist
- Relationship Builder / Developer / Facilitator
- Plan Developer
- Family Support
- Personal Care Attendant
- Medical Coordinator
- Job Coach / Employment Specialist

Staff often have more specific responsibilities such as helping individuals with activities of daily living (ADL) including self-care such as eating, dressing and mobility. There are also instrumental activities of daily living (IADL) needs such as money management, community activities, nutrition planning, and assisting with paperwork.

In addition, there are children and adults with complex conditions and varied support needs such as acute behavioral conditions and medical conditions requiring nursing care. As well as intellectual impairments that can result in significant global deficits in safely negotiating their daily life.

We also know that the lack of a qualified workforce has serious implications for those with behavioral health needs or complex medical conditions. Some individuals may be sent to correctional facilities or other restrictive settings due to the lack of staff and proper training. Others may end up on ventilator care due to delays in addressing health incidents.

The workforce in our field serves approximately 20,000 adults in day/employment and residential services (including transportation) at the Massachusetts Department of Developmental Services (DDS). We estimate an additional number (non-duplicated) of 22,000 people are served through MassHealth long term supports and services (LTSS). MassHealth may be able to identify a hard number in the future as it fully implements new assessment procedures. The workforce is employed by providers through the purchase of service (POS) system, individuals and families directly and the Commonwealth (DDS only).

This workforce also includes a professional or clinical component. Some of the professional roles are embedded into specific services while others are consultative in nature. Nursing and behavioral therapists are two examples of roles embedded in the daily services of certain individuals. For instance, individuals with complex medical needs may require a full-time registered nurse (RN) due to the level of medical intervention necessary. Licensed practical nurses and/or certified nursing assistants may be able to assist in these settings too. Direct support professionals (DSPs), may be trained in distributing medications (Medication Administration Program (MAP) certified).

The consultative role of the workforce is a cost-effective strategy to provide clinical direction when positions are not embedded for individuals. For example, a Board-Certified Behavior Analyst (BCBA) may be called in when an individual begins to become aggressive for the first time and the staff are unable to understand the cause of the new behavior, medically or otherwise. In other cases, there could be emergencies in homes or work settings where there are no clinical staff and a clinical team could prevent unnecessary use of emergency rooms and hospital settings. The cost of additional staffing due to overuse of relief staff, increased use of emergency rooms and hospitalization is not a small matter. Health care managed care programs will not solve overutilization caused by an unprepared workforce.

Over the course of the past two decades, access to clinical consultation has become dependent on the use of private or public insurance. Consequently, clinical contact is limited both in time and quality. Service providers, which have large groups of people with complex medical conditions can build nursing consultation into their agency over time. However, the access to specialized consultation varies widely in our system. The impact on the individuals' quality of life is diminished without such resources

Family members often perform the functions of informal staff as caregivers to people with disabilities throughout their lives. As noted in the previous section, family caregivers are all too often over-utilized, under-valued and an under-funded resource. The 2017 FINDS Survey of Caregivers Community Report found that 95% of family caregivers reported being stressed and nearly 50% reporting being very or extremely stressed. This affects the ability of caregivers to meet their own personal needs, balance family responsibilities, and fulfill professional obligations. Almost all FINDS survey respondents who were employed reported that caregiving had a negative impact on their work, whether it was cutting back their hours, turning down promotions, taking a leave of absence, or giving up work entirely to meet the needs of their loved one. It is critical that family caregivers receive assistance and respite from their caregiving roles to ensure the stability of in-home family supports. Otherwise family caregivers may be forced into seeking residential care for their loved ones. Assisting family caregivers is a cost-saving measure that more importantly allows families to stay together.

Agencies' and families' ability to meet the needs of people with I/DD is severely hampered by a steadily growing workforce crisis. This large and varied workforce must be better staffed and prepared to fulfill the demands of their positions.

2. Present Status of Workforce Funding

Our society has evolved in its acceptance of and respect towards people with disabilities and particularly those with intellectual disabilities. We are still in that process of evolution as reflected in that we tolerate a devaluation of caregiving and supports for our most vulnerable and at-risk population. While police officers, nurses and teachers often come to the top of any list of everyday heroes, and rightly so, unfortunately, the overlooked, direct support professionals provide a service that is often unseen and unrewarded by society. The supports and services needed to actualize community integration continue to be drastically under-resourced and underappreciated.

The work of DSPs often requires a high level of skill and responsibility to protect the health and safety of individuals with disabilities. They perform demanding jobs and often work long hours, but their wages do not fairly reflect this essential work. The average salary nationally of a DSP is $8.85 - $14.08 per hour.[16] Due to the low salaries, DSPs often must receive public assistance and/or work multiple jobs, neither of which is in the best interest in those being served or the DSP.

While both private and public sectors have trouble with staff recruitment, the compensation and benefits are higher for state employees than private (POS) and in-home staff. State agencies can also recruit and hire staff from lower paid private positions due to higher pay and benefits, increasing the gap in the private or purchase of service workforce. Rates of reimbursement to private agencies do not take *market compensation* into account, using outdated pay scale methodology. This reimbursement approach has been a barrier for decades.

The disconnect in market competition for staff is stunning when one compares occupations that require less education and training. For example, Massachusetts 2017 Bureau of Labor Statistics (BLS)[17] confirms a mean hourly wage of $16.53 for food prep workers, $17.44 for building and ground cleaning staff and $14.22 for retail workers. Massachusetts nannies average $17.66/hour. File clerks average an hourly wage of $17.53 according to BLS and the role requires a high school degree and no other training.[18] This is in comparison to $13.85/hour mean wage for a personal care aide (general category) in Massachusetts. Direct Service staff or Direct Support Professionals (DSP) in our sector require a minimum of a high school degree and all require specialized training due to the varied care needs of those living with I/DD.

Another factor impacting the ability to recruit and retain staff in disability services is the upward trend in minimum wage in Massachusetts. Today the minimum wage is at $11 per hour and by 2023, it will reach $15 per hour. There also are other mandates such as the EMAC, the Sick Pay Law, Workplace Violence Prevention Regulations and, the impending Paid Family Leave, none of which have been factored into the beginning and mean salaries for direct support professionals (DSP) in the disabilities field.

The Direct Care (DC) or Direct Support Professional (DSP) compensation varies across the state from minimum wage to $15 per hour depending on role and geography. If a person can receive minimum wage of $15 at Dunkin Donuts down the street, why would he/she apply to do the difficult work, both physically and mentally, of a DSP at the same wage? Given skill requirements this can only hamper recruitment efforts.

The salary gaps are also quite large within the professional workforce and management positions. As an example, hourly rates for a Licensed Practical Nurse (LPN) in Massachusetts can average about $27/hour[19]and upwards of $32/hour in other state agencies. However, it is typical for a Registered Nurse (RN) in a community program setting to only be reimbursed between $23-$25/hour. In addition, the current average salary for a residential program director in Boston, Massachusetts is $45,472[20] as compared to a Rehabilitation Director salary nationally of $117,237 to $144,234.[21]

The cost of health care has bearing upon compensation too. Funding of services has not kept pace for salaries (or benefits). As health care premium costs increased over the past two decades, agencies have had to choose between raising wages and paying increased health premium costs. The National Council of State Legislatures (NCSL) data from Health Affairs[22] reflects a rise of 100% in family health premiums since 1999 (see next section).

Prior to the establishment of Chapter 257 of the Acts of 2008,[23] there were one rate review in purchase of service programs in 25 years. Despite the initial and ongoing investment in the relatively new law, these increments did not address the gap across the employment market. Additionally, the rate review process is not based on prospective costs. Retention and longevity are critical to our workforce. The positions require learning about individual needs, desires and plans over time. The current established rates do not account for the need for longevity, higher education or clinical skills required for many job functions.

3. Present Status of Workforce Benefits

Typical benefits for the human service workforce are health care, dental care and group life insurance. No or low-cost benefits include 403(b) retirement plans, of which many are non-contributory. Private agency coverage of health care premiums ranges from 50% to 90% of monthly cost. As noted in the previous section, rising health care premiums have not been fully reflected in reimbursement of services. Massachusetts agencies worry about paying for the state's new Employer Medical Assistance Contribution Supplement (EMAC) as many staff are eligible for MassHealth or subsidized coverage at the Connector. One leader confided that their contribution to their disability benefit will end to fund a new family leave mandate.[24]

A 2015 article from the Kaiser Family Foundation reported on the rising premium costs: "The amount that people with employer-based insurance pay for premiums has risen 212% in the last 15 years, while wages have risen 54% and inflation 43%. Deductibles and other forms of cost sharing have also risen steadily, so much so that about a quarter of privately insured Americans don't have the savings to pay their deductibles."[25] Unfortunately, many employees will move to other jobs to address the financial crunch given that wages have risen more slowly in the workforce field.

We do NOT expect our workforce to receive the same benefit package as Fidelity Investments, but we include its package to demonstrate the range in health and related benefits in the marketplace.[26]

Fidelity offers a variety of benefits to a new employee, which may include:

- Medical Insurance: Provides a comprehensive health insurance plan for employees and their families who work a minimum of 24 hours per week.
- Dental Insurance: Offers a variety of dental services (including preventive, basic, major restorative, and orthodontic treatment) performed by a licensed dentist.
- Vision Insurance: Has coverage for eye exams, savings on glasses and contacts as well as discounts on additional pairs of glasses, non-prescription sunglasses, laser vision correction and more.

- Disability Insurance: Eligibility for full-time employees occurs after 6 months of employment and covers 60% of an employee's base rate of pay.
- 401(k) Retirement Fund: 401(k) contributions deferring from 3% - 5% of eligible compensation on a pre-tax and/or Roth after-tax basis. Fidelity makes a dollar-for-dollar company-matching contribution up to the first 7% of the associate's eligible compensation, subject to meeting initial and ongoing eligibility requirements.
- Student loan assistance: Fidelity pays down student loans with up to $10,000 in contributions.
- Maternity and Paternal leave: 16 weeks of fully-paid maternity leave and 6 weeks of fully-paid paternal leave.
- Additional benefits include but not limited to: Adoption Assistance Program, Backup Dependent Care, Commuter Benefit program, On-site Fitness Centers and Wellness Centers and Subsidized healthy dining.

The costs in recruiting and retaining staff are important to be included in the analysis of the problem of the small amount of benefits offered to the direct support and care workforce. Turnover costs for replacing a direct care provider are estimated to be between $2,413 and $5,200.[27] An example of the cost to a state is in New York wherein 2015 the cost of replacing DSP workers was estimated at $79,804,549 in 2015.[28] Nationally, these costs are estimated at $2,338,716,600.[29] The workforce employee benefits must be adjusted to better align with the market for comparable entry-level workers and counter the high turnover costs. Further, the Institute of Medicine (IOM) calls for increased pay and benefits for the DSP workforce. The IOM states, "Direct-care workers typically have high levels of turnover and job dissatisfaction due to low pay, poor working conditions, high rates of on-the-job injury, and few opportunities for advancement. To help improve the quality of these jobs, more needs to be done to improve job desirability, including improved supervisory relationships and greater opportunities for career growth. To overcome huge financial disincentives, the committee recommends that state Medicaid programs increase pay for direct care workers and provide access to fringe benefits."[30]

4. Four-Fold Strategy to Address the Workforce

The Arc proposes a four-fold strategy to address the workforce crisis for people with I/DD served by the Commonwealth. However, specific objectives and implementation methods must rely upon the Commonwealth's leadership in both the Administration and Legislature. The first step is to recognize the significance of the crisis which we've summarized above. The second is for the Administration to convene stakeholders so that a plan can be developed and phased in for Fiscal Year 2021 through 2023. The recommendations include an FY'2020 request for increased salaries and fringe in Strategy 1. As families and individuals face the same shortfalls in staff recruitment and retention, DDS and MassHealth leadership under the auspices of the Health and Human Services Secretariat would need to be involved. The planning process would require the involvement of three Joint Committees of the General Court: Children, Families and Individuals with Disabilities, Health Care Financing, and Ways and Means. Invited stakeholders should include provider trade representatives, families, and advocacy groups.

We have outlined four key strategies to work toward solving the crisis.

Strategy 1: The Workforce requires a significant investment over four years to achieve the following entry and mean salary levels and improved benefits to recruit and retain a stronger, more qualified workforce. We will benefit greatly from reducing the high turnover costs of the DSP workforce, which could be a cost savings of $19 million.[31]

We request an immediate allocation for FY'2020 House 1 budget. The request would be to implement salary increments of $2 per hour that would be inclusive of compression allowance for managerial/supervisory positions), and a 20% additional allowance for fringe benefits as a stop gap. This allows the field to begin to address the historical rise in health care premiums as well as the Commonwealth's recent policies on minimum wage and other personnel initiatives.

Pay increases and improving benefits are the first and most effective way to deal with this workforce shortage. This will encourage direct support professionals and other human services employees to enter and continue working in community-based support programs. These changes either meet realistic market costs or are slightly lower than other settings where the delta will not discourage employment in our field. It's critical to increase longevity and competencies in our field. Compensations need to be geared to recruit across a competitive market. The compensation would require addressing roles of staff in program management functions and clinical specialists. The funding should address the entire purchase of service (POS) system administered by the Department of Developmental Services (DDS) as well as certain MassHealth programs, which assist people with disabilities including personal care, day habilitation and continuous nursing as negotiated with the Executive branch. The workforce, which addresses individual and family in-home supports, should be included.

Wage Targets:

It is important to set salary targets for professionals in this field. We recommend below three salary targets as examples, subject to the Administration's specific plan with the input of other stakeholders. The three target workforce positions are Direct Support Professional, Frontline Manager and Nurse RN. Other roles such as Psychologist, BCBA or Registered Behavioral Therapist could be determined with appropriate deltas. Addressing market competition should allow agencies to recruit successfully and retain employees so they do not leave for educational, health care or other more lucrative employment settings soon after their training is completed.

The compensation reflects the target salaries to be phased in by ***2023*** and they are based on salaries in the health and education sectors.

Role	Entry	Mean
Direct Support Professional	$24	$32
Front Line Manager	$36	$40
Registered Nurse – Day or Block	$36	$42

For comparison purposes please note that in 2017 the following mean wages were documented by the Bureau of Labor Statistics:

- High School Teacher median annual wage listed as $59,170 ($31/hour)[32]
- Health Services Managers median hourly wage listed as $47.29[33]
- The RN median hourly wage listed as $33.65,[34] however, nurses in hospital and outpatient clinics were listed at $36 per hour.

Possible employee benefits could include:

- Provide reoccurring cost-of-living adjustments - In comparison to the other metropolitan areas in the Northeast, the annual increase in total compensation costs in Boston (1.7 percent) was below that of New York and Philadelphia (3.0 percent each). Boston's 1.1-percent gain in wages and salaries during June 2018 was also below that in New York and Philadelphia (2.8 percent each).[35] The Massachusetts Legislature could increase reimbursement rates for service providers to allow salaries more in keeping with the competitive job market that exists in Massachusetts.
- Use competency-based wage incentives to help raise wages to a livable level. Competency-based pay is not pay-for-performance, but instead depends on workers developing and applying competencies to meet certain performance standards.
- Fund the fringe investment for purchase of services and self-direction (individual/family direct hire) to approximate benefits paid in the health care and educational sectors.
- Initiatives to fund tuition credits at public colleges, universities, and technical schools to recruit younger workers.
- Tuition or loan forgiveness, for example, the Loan Repayment Program for Human Service Workers (S.42/H116) proposed state legislation that creates a loan repayment program for human services workers. Another recommendation could be a ten-year loan repayment program, which could begin 6 months after employment, where the employer pays off an employee's entire college/university/technical school debt after a ten-year period of employment.
- Tax credits to be developed to allow retirees on Social Security to benefit from employment in the human services industry.
- Room and board, access to state health care plans, child care, discounts for DSPs at local retailers, transportation that is paid for, subsidized by or provided by the employer.

Strategy 2: The Commonwealth should invest in innovation and system design improvements to both enhance the quality of life and to help offset increased costs for the workforce.

1. Implement Innovative Practices such as Individuals and Families First, including self or family-directed options:
    a. Provide a package to caregivers of adults which allows for them to maintain family life while addressing adult needs. For example, Massachusetts DDS successfully operates a

partnership for children or teens with the Department of Elementary and Secondary Education (DESE). Despite its cost effectiveness, the program's funding has remained flat since 2010. Similarly, other adult self-directed options have proven to reduce costs. For example, J. who is a thriving, successful adult has less than $50,000 per year of DDS funding. He would require residential services conservatively estimated at $160,000 per year if his family didn't agree to be part of a self-directed partnership.

   b. Provide care management to ensure in-home staffing, Durable Medical Equipment (DME), other resources, access to clinical teams, and conduct timely caregiver fatigue assessment and intervention;
   c. Expand self-directed options for adults by
      i. Enhanced employment and day services,
      ii. Building upon state plan LTSS Services (wrap around with DDS funding), in effect expanding DESE-DDS type supports for adults,
      iii. Enhance resources for supported and/or shared-living programs so more people can receive individualized support or placement services in their own apartments, in the family home or other shared living setting. This includes ensuring the availability of other professionals as well as access to consultation and respite if needed. For example, Georgia offers up to 30 days of "alternate care" to the shared living provider to minimize caregiver fatigue.
      iv. Through Home and Community-Based Services (HCBS) waivers, permit legal guardians to be eligible for compensation for caregiver services.
   d. Develop access to additional life or job coaching as needed so individuals will not fear semi-independent options.

2. Close existing institutions.
3. Implement Technology for individuals' advancement and service system improvements including:
   a. Tools for communication, safety, travel; in short, all activities of daily living;
   b. Medical/assistive devices or tools, which can better anticipate needs, desires, and emotions of people with I/DD;
   c. Video and telehealth for consultation;
   d. Other tools, which can enhance supports and/or minimize the need for staff presence.
4. Review regulations and safeguards for both adequacy and redundancy – Ask constituents who are supported by state services such as individuals with I/DD and their families, agencies, and others to share their feedback about which regulations are working or not working for them and why. These recommendations could be reviewed by a committee to review and identify those for further action.
5. Develop a task force for elementary and secondary schools in the Commonwealth composed of leaders and innovators in the field through DESE, local educational agencies and adult services professionals with the goal to expand best practices in preparing children or teens for adult life. Every year a teen can remain in the family home and his community, costs for residential supports are deferred even with enhanced family support. Involve representatives of the Joint

Committee on Education, Children, Families and Persons with Disabilities and the Ways and Means Committees of the Legislature.

Appendix B is included to demonstrate estimates of potential cost savings of recommended strategies.

Although part of strategy one (1), we repeat that addressing recruitment and quality of our workforce will result in hidden cost savings including:

- Reduction of unnecessary emergency room use and hospitalization (latter when staff miss early signs or health care consultation is unavailable)
- Proactively recognizing antecedents to problematic behaviors before they become acute
- Staff learning to communicate effectively with the persons they support
- Increasing independence of those supported so that staffing levels may be reduced
- Finding generic or community options to supplement tax supported services

Strategy 3: The Commonwealth should implement a blended funding strategy with DDS and Medicaid funded entities (MassHealth, One Care Insurers, Accountable Care Organizations, etc.) to develop clinical teams across regions to ensure that agencies, families and other caregivers supporting individuals with I/DD have access to professionals and related equipment for medical, dental and behavioral needs. The following are our suggestions to achieve this funding strategy:

1. Expand the current clinical team capacity to develop five regional teams composed of appropriate consultants.
2. Provide support to family caregivers and agencies including assessment and intervention and response to urgent needs. (This may require an evaluation of the present DDS state operated model and the Reach program.)
3. Provide consultation to health care practitioners (medical, dental, behavioral and rehabilitative) in the community to better respond to constituents with I/DD. Conduct a review of The Arc's Operation House Call as a possible model.
4. Consider addressing staff requirements for family support centers (Intensive Flexible Family Support Services (IFFS) or other program) to assist in care management.

See the accompanying Appendix A, which is a more detailed discussion of Strategy 3.

Strategy 4: The Commonwealth should address the development of human capital in recruitment, training and retention and account for the same in the rate setting process.

1. Review existing allocations for purchase of service and self-directed contract agreements to ensure adequate support for these functions (e.g., orientation of and annual training costs of staff).
2. Pilot a regional or other employment collaborative for workforce recruitment as an alternative for agencies and families or individuals managing self-directed services.

3. Develop alternative certification standards so that all potential staff, including in-home, have qualitative training in core values and human rights of persons with disabilities. Insure rates cover the cost of certification for required skills with financial recognition of advanced certifications.
4. Staff training needs to address values to ensure that staff become aware of any bias toward people with disabilities, which limits efforts toward independence and choice making.
5. There must be accountability for implementation of staff training in person or online. To provide successful training opportunities, there must be consideration of corollary training costs for staff overtime or paying for relief staff during training time. Staff should be relieved of their shifts rather than asked to work additional hours, which could conflict with other employment or family needs.
6. Agencies in the field must develop career paths that fit their size and organizational structure. Addressing compensation of staff, which includes all the levels related to the management of supports and services will insure that promotions with increasing responsibility are a desired goal for staff in the disability services field.

Conclusion

Massachusetts has long been the leader of the nation when it comes to supporting people with I/DD. Among other things, the Commonwealth was one of the first to legislate a public education to all children (preceding federal public law), including those with disabilities, and similarly led the way in closing institutions and integrating people with disabilities into their communities. The Commonwealth has memorialized an "Olmstead plan," based on the U.S. Supreme Court Olmstead v. L.C. decision, which confirms its commitment to promote opportunities for persons with disabilities to live, work, and be served in community-based settings. A vital part of people with disabilities achieving equality and meaningful community integration is through the supports and services of the DSP workforce.

Unfortunately, the current workforce crisis puts Massachusetts's promise of community integration into jeopardy. Without a long-term commitment to repairing and improving the workforce crisis and retaining adequate DSP staffing, the opportunity for people with disabilities to become full citizens and active community members is greatly diminished in addition to putting their health and safety at risk.

In addition to these recommendations, which require a task force to develop a specific plan for phasing in over four years, we respectfully request an immediate allocation for FY'2020 House 1 budget. The request would be to implement salary increments of $2 per hour (inclusive of compression allowance for managerial/supervisory positions), and a 20% additional allowance for fringe benefits as a stop gap. This allows the field to address the historical rise in health care premiums as well as the Commonwealth's recent decisions on minimum wage and other personnel initiatives.

Individuals and families need and deserve a dedicated professional human services workforce. We believe our recommendations are sound and address the heart of this problem, which although

occurring across the nation, must be solved on the state level. Specific objectives and implementation methods must rely upon the Commonwealth's leadership in both the Administration and Legislature. The first step is to recognize the significance of the crisis. Next, we ask the Administration to convene policy-makers, stakeholders and the public to develop a plan that will lead to more workers being hired and individuals with I/DD continuing to live their best lives.

People with disabilities and families require our commitment and response: this crisis can be solved.

A Product of The Arc Steering Committee on Policy and Advocacy
By Leo V. Sarkissian, Ellen Taverna and Janet Rico with contributions from members

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[1] Throughout this document the abbreviation I/DD will be used when referring to individuals with intellectual and developmental disabilities including autism.
[2] American Network of Community Options and Resources (ANCOR), Addressing the Disability Services Workforce Crisis of the 21st Century, 2017, https://cqrcengage.com/ancor/file/ZuL1zlyZ3mE/Workforce%20White%20Paper%20-%20Final%20-%20hyperlinked%20version.pdf; National Core Indicators Project, Staff Stability Survey Report, 2016- https://www.nationalcoreindicators.org/upload/core-indicators/2016_Staff_Stability_Survey_Report_Final.pdf, with The National Association of State Directors of Developmental Disabilities Services (NASDDDS); Amy Hewitt et al., The Direct Support Workforce Crisis, Impact Brief, Vol.31, 1., University of Massachusetts Donahue Institute, UMass Dartmouth, Providers' Council. "Who Will Care? The Workforce Crisis in Human Services," February 2017. http://www.donahue.umassp.edu/our-publications/who-will-care-the-workforce-crisis-in-human-services.
[3] The mission of The Arc of Massachusetts is to enhance the lives of people with intellectual and developmental disabilities, including autism, and their families. We fulfill this through advocacy for community supports and services that foster social inclusion, self-determination, and equity across all aspects of society.
[4] From Life in the Community Summary Statement at https://www.thearc.org/who-we-are/position-statements/life-in-the-community.
[5] Workforce turnover cited at https://cl.ici.umn.edu/node/6 (ICI at the Univ. of Minnesota, Workforce report in partnership with ANCOR).
[6] University of Massachusetts Donahue Institute, UMass Dartmouth, Providers' Council. "Who Will Care? The Workforce Crisis in Human Services." February 2017. Retrieved at http://www.donahue.umassp.edu/our-publications/who-will-care-the-workforce-crisis-in-human-services.
[7] *Id.* at 1.
[8] Heller, T. et al (2010). Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities, 23(1). U. of Minnesota, Institute on Community Integration.
[9] Massachusetts Department of Developmental Services 2014 Mortality Report (published 2017). Prepared by the Center for Developmental Disabilities Evaluation and Research (CDDER).
[10] About 1 in 59 children has been identified with autism spectrum disorder (ASD) with a prevalence rate increase of 150% since 2000 according to estimates from Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network. Retrieved on November 13, 2018 at https://www.cdc.gov/ncbddd/autism/data.html.
[11] People with I/DD age in a similar manner as the general population, but age-related changes may appear at much younger ages. The average onset of age-related changes in the general population is 65-70 years; in people with IDD, age-related changes may occur early as 45-55 years. Certain medical conditions such as some types of cancer, diabetes, dementia or Alzheimer's disease, osteoporosis and mobility impairment are more common in people with IDD as they age.
[12] Braddock, et al., (2015). "The State of the States in Intellectual and Developmental Disabilities, Emerging from the Great Recession." Washington, DC: American Association on Intellectual and Developmental Disabilities. Retrieved at http://www.nasddds.org/uploads/webinars/StateoftheStates_Braddock_Hemp_ChartsNASDDDSResearch.pdf.
[13] Family Caregiver Alliance website: Caregiver Statistics: Demographics https://www.caregiver.org/caregiver-statistics-demographics (October 12, 2018), citing Heller, T. (2011). Strength for Caring: Older Adults with Developmental Disabilities and Their Aging Family Caregivers.
[14] Heather J. Williamson et al., Health Care Access for Adults With Intellectual and Developmental Disabilities: A Scoping Review, OTJR: Occupation, Participation and Health, July 13, 2017.
[15] Conversation with board members of Assoc. Developmental Disabilities Providers (ADDP), noting that REACH clinic and Dr. J. Moran have wait periods of 18-months, September 28, 2018, Waltham, MA.
[16] Direct Support Staff or Professional (DSP) – U.S. hourly rate range is $8.85 - $14.08 with mean being $10.88/hour Payscale Average Direct Support Professional Hourly Pay, https://www.payscale.com/research/US/Job=Direct_Support_Professional/Hourly_Rate Retrieved on October 30, 2018 at 10:00 am.
[17] Data for various employment categories can be found at https://www.bls.gov/oes/current/oes_ma.htm#21-0000,

Nanny salary can be found at https://www.indeed.com/salaries/Babysitter/Nanny-Salaries,-Boston-MA.
[18] Bureau of Labor Statistics – Massachusetts Occupational Employment and Wages, May 2017, 43-4071 File Clerks at https://www.bls.gov/oes/current/oes434071.htm.
[19] Licensed Practical Nurse (LPN) and Licensed Vocational Nurse salary range can be found at https://www.bls.gov/oes/current/oes_ma.htm#21-0000.
[20] https://www.payscale.com/research/US/Job=Residential_Program_Director/Salary/f8cde075/Boston-MA on October 24, 2018.
[21] https://www1.salary.com/Rehabilitation-Director-Salary.html at September 28, 2018.
[22] NCSL research: HEALTH INSURANCE: PREMIUMS AND INCREASES at http://www.ncsl.org/research/health/health-insurance-premiums.aspx.
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[34] Retrieved on October 21, 2018 at https://www.bls.gov/oes/current/oes291141.htm.
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