



The Arc of Massachusetts  
217 South Street  
Waltham, MA 02453-2710  
781.891.6270  
[sarkissian@arcmass.org](mailto:sarkissian@arcmass.org)  
[www.arcmass.org](http://www.arcmass.org)

*For people with intellectual  
and developmental disabilities*

**Achieve with us.**

September 21, 2021

Scott Borchardt  
President

Chair Michael Rodrigues and Vice Chair Cindy Friedman  
Chair Aaron Michlewitz and Vice Chair Ann-Margaret Ferrante  
Joint Committees on Ways and Means

Leo V. Sarkissian  
Executive Director

Chair Daniel Hunt and Vice Chair John Barrett III  
House Committee on Federal Stimulus and Census Oversight  
State House  
Boston, MA 02133

Re: Joint Hearing on the American Rescue Plan Act (ARPA) Funding

Dear Chairs Rodrigues, Michlewitz and Hunt and Vice Chairs Friedman, Ferrante, and Barrett:

The Arc of Massachusetts (The Arc)<sup>1</sup> is pleased to provide this written testimony for the Hearing of the Joint Committees on Ways & Means and the House Committee on the Federal Stimulus and Census Oversight regarding the American Rescue Plan Act (ARPA) Funding focusing on health care, mental health, substance use disorder, public health, and human services. The Arc's testimony is centered on the use of ARPA and state funds for addressing essential services and supports to constituents with intellectual and developmental disabilities (IDD), including autism, and their families in the Commonwealth. The Arc previously submitted testimony to this Committee regarding ARPA funding on July 20, 2021, as well as to the Executive Office of Health and Human (EOHHS) most recently on August 16, 2021, both testimonies can be found on The Arc's Workforce webpage at <https://thearcofmass.org/workforce>.

We greatly appreciate the Commonwealth's commitment to enhance, expand and strengthen Home and Community-Based Services (HCBS) under the Medicaid program using an estimated \$500 million in federal financial participation (FFP) pursuant to Section 9817 of ARPA. Massachusetts, and this entire country, is facing a workforce shortage crisis for HCBS and direct support workers, which has been compounded by the COVID-19 pandemic. COVID-19 has exacerbated both the need for services and supports for people with IDD and autism and the struggles of the unpaid family caregivers as well as the difficulties service providers face in filling direct support and other staff positions. The Arc is grateful for the \$100 million in Round 1 of the ARPA funding distribution, which will go toward payment enhancements and recruitment to stabilize the HCBS workforce. We are especially thankful to confirm that Family Support Services at the Department of Developmental Services (DDS) and other nonwaiver programs will be included in the emergency rates adoption as supports/services under HCBS. This is extremely important for our family caregivers still reeling from the impact of COVID. Rounds 2 and 3 of ARPA funding will support much needed strategic and structural investments in the Massachusetts long-term supports and services (LTSS) and behavioral health delivery system as well as workforce training.

In addition to the ARPA funding, we appreciate the EOHHS further investment in human services rates of approximately \$39 million. This will increase the benchmark to \$16.79 for Direct Care 1 workers. The rate increases reflect the incorporation of the most current Bureau of Labor Statistics salary benchmarks for rates

---

<sup>1</sup> The Arc is a statewide advocacy organization representing 200,000 individuals with 17 chapters in the state. Its mission is to enhance the lives of people with intellectual and developmental disabilities, including autism, and their families. It fulfills this through advocacy for community supports and services that foster social inclusion, self-determination, and equity across all aspects of society. To learn more, visit [www.thearcofmass.org](http://www.thearcofmass.org).

effective July 1, 2021. This change is a start toward enabling rate payments to reflect the high-quality work of the direct support workforce more accurately.

While these are all important steps in the right direction, there continues to be serious gaps in support and services coverage for people with disabilities and their families. First and foremost, there is simply a lack of workers to hire in our field to support people with IDD and autism. Some provider agencies have started offering \$17 per hour for direct support professionals (DSP) due to the severity of the workforce vacancies and this is still not enough to find qualified workers. Please keep in mind the benchmark is \$16.79, which covers all direct care workers regardless of length of service. The impact is noticeable in DDS-funded Day services where providers cannot recruit enough workers to return to full capacity. Utilization has hovered at about 50-60%, which means people with disabilities are not being served adequately and agencies struggle to capture revenue to hire qualified staff. Even at full capacity (which is not possible at this time) salary levels still would trail behind other job markets, which compete for our workforce.

DSPs are doing critical tasks that support people with disabilities from taking medications, bathing, eating, getting out into the community, as well as job coaching, counseling, and providing transportation. It is difficult work that requires thoughtful planning and communication skills as well as an understanding of ethical principles and practices of inclusion. Our federal and state laws and regulations, which focus on self-determination, inclusion and community integration require staff who are competent and prepared, but the wages do not reflect this level of skill. In addition, the high turn-over of staff has a negative impact on the continuity of services for their clients and their families. Individuals with disabilities build bonds and learn to trust their DSPs. They depend on their staff for emotional support as well as functioning in their daily lives. Starting all over with new staff can be detrimental to progress in goals and can be more difficult each time. Moreover, the lack of support for the workforce means that the responsibility of care and support often falls on unpaid family caregivers. The workforce and earnings losses related to unpaid family caregiving are significant and well-documented in our field.

Even before the pandemic, The Arc has heard from our constituents and families about how the workforce crisis affects their lives and the lives of their loved ones with IDD or autism requiring assistance living in congregate care, independently or with their families. But the past year and a half has been especially difficult. One parent recently shared about their autistic son who turned 22 in July 2021, but must wait to start adult programming until March of 2022, which is tentatively scheduled only if staffing is available. This is heartbreaking for the individual and his family who worked so hard to prepare for his transition from school to adult services and now they are left with no supports. Like Massachusetts public schools<sup>2</sup>, there is also a driver shortage for day program transportation services, which affects these programs' ability to serve their clients. We also hear about stories of isolation and challenging behaviors, even emergency department visits, due to programs not opening and service delays. A family shared about their son's self-injurious behavior and regression of social skills related to the inability to find in-home services. Another parent told us of her son who was able previously able to live in his own home, in the community he grew up in, because of the Self-Direction program and the flexibility it provides to tailor his activities, schedule and staffing in ways that minimize maladaptive behaviors that were previously unmanageable when he was in a residential school for individuals with autism. Now he is left without sufficient services and is experiencing regression of skills and goals of his ISP.

The lack of supports and services means responsibility of care often falls on unpaid family caregivers. A June 2021 CDC study found 70% of parents and unpaid caregivers of adults suffered mental health issues during the pandemic, including anxiety, depression, trauma, and suicidal thoughts. Family caregivers are 8 times more likely to contemplate suicide than others.<sup>3</sup> We must do better to help these families.

---

<sup>2</sup> Scott Neuman, NPR, September 15, 2021, "Massachusetts Calls On The National Guard To Mitigate A School Bus Driver Shortage," found at <https://www.npr.org/2021/09/15/1037307027/massachusetts-calls-national-guard-school-bus-driver-shortage-baker>.

<sup>3</sup> Czeisler MÉ, Rohan EA, Melillo S, et al. Mental Health Among Parents of Children Aged <18 Years and Unpaid Caregivers of Adults During the COVID-19 Pandemic — United States, December 2020 and February–March 2021. *MMWR Morb Mortal Wkly Rep* 2021;70:879–887. <https://www.cdc.gov/mmwr/volumes/70/wr/mm7024a3.htm> and <https://www.nytimes.com/2021/06/17/health/cdc-parenting-mental-health-pandemic.html>.

**We advocate using ARPA funds for an immediate bump to \$19/hour as a baseline minimum wage for the approximate 29,000 DSPs serving the IDD/autism community in the Commonwealth.** This increase should not only support hiring, but to existing staff to promote retention and continued longevity and to ensure a sufficient workforce to avoid using staffing agencies and splitting shifts. As we laid out in our December 2018 Report, “Resolving the Workforce Crisis: Strengthening the Quality and Sustainability of the Direct Support and Professional Workforce,”<sup>4</sup> DSP wages and benefits for people with IDD need to be based on market-based reimbursement rates in the Commonwealth consistent with health and education sectors to be competitive. In addition to increased rates for DSPs, it is also important to increase compensation for front-line managers, clinical positions (such as nursing, allied health therapists or Board-Certified Behavior Analyst positions), and program directors to avoid compression in pay rates. The following agencies and program areas need to be considered. At DDS: Residential, Community-Based Day Supports (CBDS), Day & Employment, Family Support & related programs (Autism Children, DESE/DDS, Intensive Flexible Family Support Services (IFFS), Autism Omnibus (MRC and MCB programs face similar shortages) and Transportation. At MassHealth: Day Habilitation, Adult Family or Foster Care (AFC), Continuous or Block Nursing and any DSP related services such as the Personal Care Attendant (PCA) program. In addition to the immediate wage boost, we recommend using ARPA funds in the following ways to curb the workforce crisis and support individuals with disabilities:

1. We need more options and flexibility for individuals with disabilities to obtain stipends and choose their caregivers. For instance, in the MassHealth Adult Foster Care (AFC) and Personal Care Attendant (PCA) programs, caregivers cannot be the care recipient’s spouse or the legal guardian. If a spouse or guardian parent fulfills the eligibility requirements to be a responsible AFC caregiver or PCA, they should be considered for the position. In addition, better options for long-term supports packages for people with disabilities can help families balance our service system before turning to 24/hour, 7 day a week congregate care.
2. Service providers have not been given proper funding to cover the administrative responsibilities of surveillance COVID testing in their residences. Funding for surveillance testing should be expanded to day programs on a reasonable, consistent basis, weekly or bi-weekly. The current staff, like a nurse or manager, cannot do this type of surveillance in a pandemic, in addition to the main responsibilities required for their job and an individuals’ independent service plan (ISP).
3. Immediate funding should be provided for significant hazard pay and overtime to minimize cross over staffing during exposures and positive cases of COVID-19.
4. Provide additional funding for COVID and post-COVID enhancements to support DDS Day services including CBDS, Employment, and Day Habilitation supplements, which are more limited relative to MassHealth day habilitation enhancements due to restrictions in HCBS waivers. State-only dollars are required if no other reimbursement strategies are apparent to meet the gap in funding.

Thank you again for the opportunity to submit this written testimony regarding the use of the American Rescue Plan Act (ARPA) funding for supports and services to individuals with IDD and autism in the Commonwealth. We greatly appreciate the commitment of the Joint Committees on Ways & Means and the House Committee on the Federal Stimulus and Census Oversight to supporting the direct support workforce and in turn the disability community and we look forward to working together to face this workforce crisis.

Sincerely,

*Ellen Taverna*

Ellen Taverna  
Director of Public Policy

Leo V. Sarkissian, Executive Director  
Maura Sullivan, Director of Government Affairs  
Charlie Fiske, Government Relations Specialist

---

<sup>4</sup> The report can be found at <https://thearcofmass.org/workforce>.