

For people with intellectual and developmental disabilities

August 16, 2021

Secretary Marylou Sudders Executive Office of Health & Human Services (EOHHS) c/o D. Briggs 100 Hancock Street, 6th Floor, Quincy, MA 02171 The Arc of Massachusetts
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Achieve with us.

Scott Borchardt President

Leo V. Sarkissian Executive Director

Re: Public Hearing on 101 CMR 447.00: Rates for Certain Home and Community-based Services (HCBS) Related to Section 9817 of the American Rescue Plan Act

Dear Secretary Sudders,

The Arc of Massachusetts (The Arc) is pleased to provide this written testimony for the hearing regarding the emergency rates of certain Home and Community-Based Services (HCBS) related to Section 9817 of the American Rescue Plan Act (ARPA).

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.

We fully support these increased emergency rates of 10-25% to promote workforce development and strengthen the HCBS workforce and greatly appreciate the Commonwealth's commitment to supporting this workforce and in turn the disability community. Massachusetts, and this entire country, is facing a workforce shortage crisis for HCBS direct support workers, which has been compounded by the COVID-19 pandemic. It has had a devastating impact on the support and services for families and individuals with intellectual & developmental disabilities (IDD) and autism. And while we appreciated these emergency rate increases through the ARPA funding, they are temporary, and the Commonwealth must put forth a long-term investment plan to continue to strengthen and expand the direct support workforce and infrastructure.

The Arc often hears from our constituents about how this workforce crisis affects the life of their loved ones with IDD or autism. Stories include isolation and challenging behaviors, even emergency department visits due to programs not opening for one main reason - staffing shortages. A parent recently shared about their son who turned 22 in July 2021 and now 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 have no supports. Another parent recently shared about her son's self-injurious behavior and regression of social skills related to the inability to find in-home support services.

We ask that Family Support Services (5920-3000) at the Department of Developmental Services (DDS) be included in the emergency rates adoption as those supports should fall under HCBS. The fact that some of Family Support expenses are not reimbursed with federal funds should not exclude these HCBS services/supports from coverage.

Our Arc Chapters have high turn-over rates that have a negative impact on the continuity of services for their clients and their families. Individuals with disabilities build bonds and learn to trust their direct support professionals (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.

DSPs are vital to the community integration and employment of the disability community. People with disabilities can be prevented from entering costly, restrictive, and often segregated institutional settings or in hospital-boarding situations if support staff are successfully recruited, professionally trained and retained. DSPs are doing critical tasks that support people with disabilities with taking medications, bathing, eating, getting out into the community, as well as job coaching and counselors. It is difficult work that requires thoughtful planning and communication skills as well as an understanding of ethical principles and practices of inclusion. Today's 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. Presently their compensation is equal to laundry workers and drivers. Due to low wages, there is an approximate 50% national turnover rate annually, and the average national wage is about \$12/ hourⁱ, making it difficult to provide continuity in services, provide a family sustaining wage, and threatening the quality of care. 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.

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. We estimate 29,000 DSPs serving the IDD/autism community in the Commonwealth, not including those serving other disability populations. In addition to increased rates for DSPs, it is also important to increase compensation for front-line managers, clinical positions, and program directors to avoid compression in pay ratesⁱⁱ. During the period of 1987-2007, there had not been a statewide adjustment to the rates of reimbursement paid by the Commonwealth to human service providers through Purchase of Service (POS)ⁱⁱⁱ. On the Medicaid side (MassHealth), cost of living allocated did not keep pace with inflation or corresponding growth in salaries in the health and education sectors.

The downward pressure of rates has brought many DSP positions wages to minimum wage, and in the case of day habilitation services to barely it. In the recent FY'22 Commonwealth rate determination for DSPs in the Community Based Day Supports (CBDS) programs, the Department of Developmental Services (DDS) set a benchmark of \$15.48 per hour for a "blended" DSP wage. Vi Some provider agencies have started offering \$17 per hour due to the severity of the workforce vacancies, risking health for those they serve. They hope that the 10% federal Home and Community-Based Services (HCBS) bump will result in adequate reimbursement within this fiscal year, even though it is a short-term revenue fix.

At present, there is difficulty not only with the DSP and front-line managers in purchase of service and MassHealth programs, but clinical services as well. The following agencies and program areas need to be considered. At DDS: Residential, CBDS, Day & Employment, Family Support & related programs (autism children, DESE/DDS, 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. Clinical services such as nursing, allied health therapists or Board-Certified Behavior Analyst (BCBA) positions are affected due to individual rates or rates through services in all community-based programs. We ask that the Commonwealth create a Workforce Committee, which includes The Arc and other relevant association, disability groups and providers to receive information regarding relevant workforce numbers and corresponding present pay benchmarks.

As a member of the ADDP AFC Advisory Group, we also ask for a collaboration with the Center for Health Information & Analysis (CHIA) and MassHealth to share the findings led by the Massachusetts AFC Council that are based on careful analysis of the data in the CHIA Cost Reports. The data clearly demonstrated that information being captured in the AFC Cost Reports is not reflective of true and needed costs associated with an AFC program that is fully staffed. Agencies with vacancies are showing a profit in their bottom line because of this, and this is being held against the rates, versus, showing the operational costs of the program. This vacancy data should be included so that a complete program budget is used to truly establish proper rate methodology for fairness in rates and fairness in caregiver stipend funds to agencies.

Thank you again for the opportunity to submit this written testimony regarding the use of the American Rescue Plan Act (ARPA) emergency rates addressing essential supports and services to individuals with IDD and autism in the Commonwealth. We greatly appreciate the Commonwealth's commitment to supporting this workforce and in turn the disability community through the emergency rates adoption. The Arc looks forward to working with EOHHS in reviewing our recommendations.

Sincerely,

Leo V. Sarkissian Executive Director

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Maura Sullivan, Director of Government Affairs Ellen Taverna, Director of Public Policy Charlie Fiske, Government Relations Consultant

Frank, R and Gruber, J. (July 202

ⁱ Frank, R and Gruber, J. (July 2021). Impact of Better Care Better Jobs Act on Home Care and Jobs. https://www.aging.senate.gov/imo/media/doc/Impacts%20of%20Better%20Care%20Better%20Jobs%20Act%20on%20Home% 20Care%20and%20Jobs.pdf; Economic Policy Institute. (2020). There is a Wide and Persistent Gap Between Domestic Workers' Wages and Wages of All Other Workers. https://www.epi.org/publication/domestic-workers-chartbook-a-comprehensive-look-atthe-demographics-wages-benefits-and-poverty-rates-of-the-professionals-who-care-for-our-family-members-and-clean-ourhomes/?chartshare=184356-194214#8

ii Rate setting for purchase of services (POS) or MassHeath programs or positions are set for a two-year period. The rate not only compensates for staff costs in the case of programs, but rent, utilities, training, office expenses, travel and indirect expenses. There are exceptions for certain staff-based programs such as personal care (PCA).

iii Keep in mind, all rates are set for 2-year periods. Thus a 2% increase in rate is equivalent to a one-year increase of 1%.

^{iv} Blended means that the wage benchmark includes ALL DSPs regardless of experience, forcing no increases for experienced staff or minimum wage for entry level. But in 2023, minimum wage will be \$15 per hour, while this rate is in force.