



*For people with intellectual  
and developmental disabilities*

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)

***Achieve with us.***

Scott Borchardt  
President

Leo V. Sarkissian  
Executive Director

July 25, 2021

Senator Elizabeth Warren (D-MA)  
Senator Edward J. Markey (D-MA)  
Representative Richard Neal (D-MA-01)  
Representative James P. McGovern (D-MA-02)  
Representative Lori Trahan (D-MA-03)  
Representative Jake Auchincloss (D-MA-04)  
Representative Katherine Clark (D-MA-05)  
Representative Seth Moulton (D-MA-06)  
Representative Ayanna Pressley (D-MA-07)  
Representative Stephen F. Lynch (D-MA-08)  
Representative William Keating (D-MA-09)

Dear Members of the Massachusetts Congressional Delegation:

This letter was organized by The Arc of Massachusetts<sup>1</sup> and supported by the undersigned organizations and individuals to urge the Massachusetts Congressional Delegation to support the Better Care Better Jobs Act. As Massachusetts and the country continue to recover from the pandemic, the bold investment in Medicaid Home and Community-Based Services (HCBS) outlined in the Build Back Better Plan and the Better Care Better Jobs Act is critical to our state to support people with disabilities, aging adults and both paid and unpaid caregivers. The undersigned Massachusetts organizations and individuals urge our Massachusetts Members of Congress to support this \$400 billion in funding to strengthen and expand the Medicaid HCBS infrastructure and workforce.

During the pandemic, the entire Massachusetts Medicaid program (MassHealth), Department of Developmental Services (DDS), and the Massachusetts Rehabilitation Commission (MRC) which cover most of the long term supports and services (LTSS) available for people with intellectual and developmental disabilities (IDD) and autism, have been under unprecedented strain. This is especially true for our HCBS system as even more aging adults and people with disabilities needed support at home to avoid nursing facilities and other institutions, where the risk of death was exceedingly high. According to the Centers for Medicare & Medicaid Services (CMS) as of July 25, 2021, 4,668 nursing home residents have died from COVID-19 in Massachusetts and 133,513 nursing home residents have died from COVID-19 nationally. At the same time, providers have shut down HCBS programs, workers have been laid off, people with disabilities and aging adults haven't had the supports they need, and their families have been left to fill the gaps, at the expense of their own jobs and responsibilities. Even before the pandemic exemplified the dangers of institutional settings, the vast majority of people with disabilities and aging adults said they want to live in their own homes and communities. Unfortunately, not all individuals who are eligible for Medicaid HCBS can get the services when they need them and are left waiting or forced to enter an institution. Due to a long history of underfunding and lack of investment in the HCBS infrastructure at both the federal and state levels, our state's HCBS system is not able to meet

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<sup>1</sup> The Arc of Massachusetts (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).

the demand or prepare for the future. Receiving long-term services and supports at home is not simply a matter of personal preference, it improves individuals' quality of life and it is more cost-effective for the state.

Massachusetts' Medicaid (or MassHealth) HCBS waivers allow individuals with disabilities and elderly persons to get needed support and services at home rather than in an institution. MassHealth does not cover these home-based services without a waiver. While Massachusetts does not technically have a waiting list, that does not mean that there are not people waiting for waiver services. For example, some families choose residential placement for their young adult children because they lack sufficient in-home supports and cannot wait for those supports to arrive. Another example is lack of access to Personal Care Attendant (PCA) services. In this instance, if an individual with a disability requires reminders or prompting in activities such as bathing or cooking, but do not need physical assistance, the PCA service is not covered and typically left for a caregiver to manage. We have approximately 160,000 people in Massachusetts who may qualify for HCBS waivers. Unfortunately, these HCBS waivers do not always adequately serve everyone in need and unless our state properly funds and supports the direct support professional (DSP) workforce, these HCBS programs will not thrive.

As the population ages, the need for HCBS will increase for both people with disabilities and their family caregivers. Each year, about 1,300 individuals with intellectual and developmental disabilities turn 22, aging out of the school system and into adult services in Massachusetts. The work that the direct support workforce does is invaluable to the IDD community, serving as the linchpin to successfully live the independent life that they choose in their communities. The majority of the direct support workforce are women of color. This workforce includes home care workers, PCAs, and direct support professionals (DSPs), who provide these vital services yet have been devalued and underpaid for decades. They require skills and professional training, and presently their compensation does not reflect their responsibilities and importance. There is an approximate 43% national turnover rate annually for DSPs, and the average national wage is less than \$11/ hour, making it difficult to provide continuity in services, provide a family sustaining wage, and threatening the quality of care for people with disabilities.<sup>2</sup>

Further, the disproportionate burden of the gaps in our HCBS system also fall on women and people of color with limited income and wealth who have the responsibility of providing care—both unpaid and underpaid. 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. Investment in HCBS would help address inequities and strengthen our economy by providing for good jobs for direct care workers and allowing family caregivers to rejoin the workforce.

Thankfully, Congress included a short-term, one-year bump of 10 percent Federal Medical Assistance Percentage dedicated to expanding and strengthening Medicaid Home and Community-Based services in the American Rescue Plan. States are using this funding to recover from the pandemic and fill in the most critical gaps. On June 17, 2021, Massachusetts submitted its initial Spending Plan & Narrative to CMS, which included 3 key structural pillars: 1) Retaining and building a high-quality HCBS workforce; 2) Access to and Promotion of HCBS Services and Supports, including navigation, transitions, family supports, diversion and enhanced care models; and 3) HCBS Technology and Infrastructure, to enable more effective care coordination, access, and delivery. Massachusetts will implement three rounds of initiatives tied to the three structural pillars. Round 1 will invest approximately \$100 Million of the enhanced federal funding in immediate time-limited, across the board payment enhancements to strengthen and stabilize the HCBS workforce. Rounds 2 and 3 will invest the remaining funds to support strategic and structural investments. While this one-time, temporary boost will help Massachusetts and

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<sup>2</sup> Across states, the turnover rate for DSPs in 2019 ranged from 23.8% to 64.8%; the weighted average turnover rate was 42.8%. [https://www.nationalcoreindicators.org/upload/coreindicators/2019StaffStabilitySurveyReport\\_FINAL\\_1\\_6\\_21.pdf](https://www.nationalcoreindicators.org/upload/coreindicators/2019StaffStabilitySurveyReport_FINAL_1_6_21.pdf)

other states cope with the immediate harm and aftermath of COVID-19, longer-term investment is crucial. The baseline that existed prior to the pandemic was inadequate and has been for decades. Instead, to transform our HCBS system to meet the long-term services and supports needs of our residents, Massachusetts needs a long-term investment like the Better Care Better Jobs Act.

This is a critical opportunity to build the HCBS system to support all people who need home and community-based supports and services. We urge our lawmakers and leadership to support the Better Care Better Jobs Act's \$400 billion investment in the Medicaid HCBS infrastructure and the workforce that provides these essential services.

If you have questions regarding this letter, please contact Ellen Taverna, The Arc of Massachusetts Director of Public Policy, at [taverna@arcmass.org](mailto:taverna@arcmass.org) or (703) 850-1438.

Sincerely,

## **ORGANIZATIONS**

The Arc of Massachusetts  
Advocacy Associates of Massachusetts  
Advocates for Autism of Massachusetts  
Advocates, Inc.  
The Arc of the South Shore  
Association Special Needs Activities Programs  
Autism Connections  
Butternut Farm Golf Club  
Charles River Center  
Disability Law Center  
Disability Policy Consortium  
Drumcircle LLC  
Easterseals Massachusetts  
GIA Home Care Services LLC  
Incompass Human Services  
Justice Resource Institute, Inc.  
Latham Centers  
Life-Skills, Inc  
Lifeworks Inc.  
MA MENTOR  
Mariscal Special Needs Law  
Mass Families  
Massachusetts Council for Adult Foster Care  
Massachusetts Down Syndrome Congress  
Massachusetts Law Reform Institute  
Minute Man Arc  
Northeast Arc  
Open Sky Community Services, Inc.  
PartnerOcean  
People Incorporated  
Personal Disability Consulting, Inc.  
Riverside Industries, Inc.  
Road To Responsibility, Inc.  
Seven Hills Foundation & Affiliates  
The Arc of Greater Brockton  
The Foundation for Augmented Intelligence

The Guild for Human Services  
The United Arc, Inc.  
UCP of Western Massachusetts  
Viability, Inc.  
Vinfen  
Work, Community, Independence, Inc.  
WORK, Inc.

**INDIVIDUALS & FAMILIES**

Andrea Katz  
Andrew Scherbina Inc  
Cathy Erwin  
Charlene Mangano  
Cindy O'Connor  
Colin Campbell  
Danny Blanchette's Family  
Debra Noonan  
Donna Bersani  
Dubuc Roberta  
Dr. Mark Wolfe  
Elizabeth Jasse  
Ellio Scott Laughlin  
Ethel C. Bullitt, MD, board-certified child, adolescent, and adult psychiatrist  
Healina Ho  
Helen Waldron and Family  
Herb Cabral  
Ioana Santau  
Janet Hirschhorn LPN  
Jennifer Olson Educational Advocating and Consulting Services  
Jerry and Mary Jane Kelley  
Johanna Seelen  
Kathleen Driscoll  
Kelly Sutton  
Lee Kronick  
Lisa Jennings  
Lisa Perates  
Mary Wallan  
Michelle Howland  
Nancy LeGendre  
Nancy Mulloy  
Nathaniel Gerowe  
Paul Simeone SLP  
Richard P. Faucher Sr  
The Dykens Family  
Theresa Hoberman  
Therese Stone

cc: Governor Charlie Baker  
Senate President Karen Spilka  
Speaker Ronald Mariano

Secretary EOHHS, Marylou Sudders