



*For people with intellectual  
and developmental disabilities*

## **Improving Home & Community-Based Services in MA**

### **What does HCBS and Community Living Mean?**

For too many years, people with intellectual and developmental disabilities (I/DD), including autism, have been isolated and segregated in institutional settings, where they lose the opportunity to be full participants in society. For over 70 years, The Arc has been fighting for people with disabilities to live independently with the right supports and lead the same kind of life as everyone else. People with disabilities and their families want access to a life in the community, no matter the level of supports necessary to make that happen. The Massachusetts Medicaid program (MassHealth) and the Department of Developmental Services (DDS) cover most of the long term supports and services (LTSS) available for people with I/DD and autism in Massachusetts. Both agencies receive federal matching dollars for most of these supports and services. Home and community-based services (HCBS) is a type of LTSS that allows people with disabilities to live the independent life that they choose in their communities with their friends and family. It includes everything from assistance getting around the community, employment supports, and other services to assist with independence. Unfortunately, the current national Medicaid system is set up to always pay for services in nursing homes and institutions, but HCBS continue to be “optional” for states. The right to live in the community has become even more urgent during the pandemic, as crowded institutions and nursing homes have put people at much greater risk of contracting COVID-19.

### **What is the difference in the quality of life in an institution or in the community?**

#### **Institutions**

- Segregating people from society, family, friends
- Limiting choices about day and routine
- Decades of documented abuse, neglect
- Warehousing people out of sight is a loss for us all
- High cost to taxpayers to maintain and staff
- 36 states (including Massachusetts) still operate archaic institutions

#### **We Want A Life in the Community**

- Living near family and friends provides a rich life experience
- Open doors to contributing in the workplace and community
- Treat people with disabilities with respect and dignity
- Individual supports based on a person’s needs lead to a better life
- Less expensive on average to provide

Fortunately, there is a federal trend toward expanding access to HCBS for disabled people. The recently passed American Rescue Plan Act (ARP Act) provides a one-year investment of \$10 billion in HCBS funding (of which \$420 Million is projected for Massachusetts) to respond to the pandemic and address the critical life-threatening needs of people with I/DD and the service delivery system that supports them. While this funding is a critical short-term solution, more needs to be done to support people with IDD in the recovery.

### **MA HCBS – Current Programs and Issues**

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 teen aged children because they lack sufficient in-home supports. Another example is lack of access to personal assistance services if you require reminders or prompting in activities such as bathing or cooking, but do not need physical assistance. 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.

## **Future of HCBS in MA and Nationally**

As the population ages, the need for HCBS will increase for both people with I/DD 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. Often the greatest challenge for these individuals in achieving community integration is the increasing lack of a direct support worker pool, adequate in capacity and skill, to support them. The work that Direct Support Professionals (DSP) do is invaluable to the I/DD community, serving as the linchpin to successfully live the independent life that they choose in their communities. But DSPs 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>1</sup> This crisis has been compounded due to the COVID-19 pandemic. To meet these growing needs, we must remove Medicaid's existing institutional bias to allow investment in community services to grow. **In addition to the ARP Act, the following federal initiatives must be supported to enhance the quality and availability of HCBS.**

- **The Money Follows the Person (MFP) program** incentivizes investment in HCBS by providing federal funding for transitional services for individuals who wish to leave a nursing home or other institution. States will need the program to be stable into the future and funding cannot be allowed to expire.
- **The HCBS Settings Rule**, released by the Centers for Medicare & Medicaid Services (CMS) in January 2014, requires that HCBS programs support settings that maximize opportunities to live, work, and receive services in integrated, community settings. The purpose of the Rule is to ensure that individuals have full access to the benefits of community living and to provide basic protections to participants.
- **The Biden Administration's proposed American Jobs Plan** includes an investment of \$400 Billion to expand access to HCBS and support the direct care workforce.

### **The Arc's Ask for HCBS:**

- DSP wages must be adequate to recruit and retain a qualified workforce and ensure providers can appropriately deliver quality services to people with I/DD.
- Significant investment in the proposed supportive technology additions to the HCBS waivers.
- Address community access needs of individuals and families.

For more information, contact Ellen Taverna at [taverna@arcmass.org](mailto:taverna@arcmass.org).

---

<sup>1</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/core-indicators/2019StaffStabilitySurveyReport\\_FINAL\\_1\\_6\\_21.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/2019StaffStabilitySurveyReport_FINAL_1_6_21.pdf)