

# State of Services for Intellectual and Developmental Disabilities in Massachusetts- June 2024

Written by Irene Tanzman, VOR Legislative Advocacy Volunteer

## Day Habilitation

Massachusetts set up their day habilitation program during the deinstitutionalization process several decades ago. This program was a venue to offer allied health and ADL (Activities of Daily Living) instruction normally received in an ICF/IID. Over the years, the program changed and offered fewer services. Some day habilitation programs still offer nursing services and allied health. Unfortunately, [despite federal regulations governing](#) the treatment of those with IDD, providers determine whether they will offer these services. Up until 2022, wraparound services (i.e., services that were above and beyond what a day habilitation facility regularly provides) were considered a Home and Community-Based Service. With looming March 2023 deadlines for compliance with HCBS rules, Massachusetts shifted the funding of these services to be a pure medical MassHealth (Medicaid) service in 2022.

Because of the change in funding stream for this service, the Department of Developmental Services (DDS) claimed that they no longer have a say or have responsibility for the quality or quantity of these services. Representatives from these day programs are no longer required to attend Individual Support Plan (ISP) meetings. DDS redirects families and guardians to MassHealth if there is any issue with day habilitation.

According to anecdotal reports from the Day Habilitation Facebook Group (316 members), individuals in Day Habilitation receive habilitative services such as allied health services according to the providers' wishes, **not according to need**. There have been reports of little or no access to the community, little or no community-based instruction, little or no access to alternative augmentative communication (AAC), little or no access to instruction on AAC, little or no help maintaining AAC equipment, and little or no allied health or nursing services. There have also been reports of a lack of signed day habilitation plans of care in these services, no access for parents/guardians to see programs, and allegations of abuse and neglect.

As the administrator of the Day Habilitation group, I have also received a handful of stories regarding positive experiences in day habilitation. Because of a lack of data and a lack of transparency in Massachusetts government, it is impossible to have precise information about day habilitation or any other service that Massachusetts offers to individuals with IDD.

In August 2023, *Boston Globe* reporter Jason Laughlin wrote an article titled, "[Thousands with complicated disabilities languish as Massachusetts struggles with staff shortages at care programs.](#)" There are many individuals who do not have day programs or any programs at all in Massachusetts. The more severely impaired the individual is, the more likely the individual does not have services. In Massachusetts' largely privatized system, corporate providers may simply reject individuals based on their difficulty to serve.

At the May 8, 2024 VOR meeting at the Agency for Community Living (ACL) with Administrator Alison Barkoff, Ms. Barkoff said that the state's Protection and Advocacy Center (Disability Law Center) has made her well-aware of the problems with quantity and quality of services in Massachusetts day habilitation. She said that she is working on this issue. VOR made it clear that we did not want these services to be shuttered.

MassHealth has recently proposed and is exploring the idea of an [Independent Assessor Agency](#) to create a single point of access for multiple long-term services and supports (LTSS) programs. This independent assessor agency would affect day habilitation, personal care assistance (PCA) and adult foster care. It is unclear how this would affect these services and supports but it appears that it would eliminate several conflicts of interest currently in the system.

## Other Day Programs

Community-Based Day Supports are an HCBS funded day program which serves individuals with IDD in the community. According to anecdotal reports, some of these programs provide community-based instruction. Others take individuals into community field trips with not much instruction. In general, families appear to be more satisfied with this day program model as opposed to day habilitation, but it is impossible to know for sure because there is no transparency or data. It is worthy to note that this service model is better funded and those enrolled tend to be less impaired than those in day habilitation. This is yet another example of how Massachusetts discriminates against those who are the most impaired. According to a webinar given by the Disability Law Center (Protection and Advocacy), there are more families who wish to enroll in HCBS day services than there are available slots.

Massachusetts offers supported employment and other vocational services. As the administrator of the Day Hab Facebook Group, I have received messages from self-advocates who have had trouble obtaining employment or who are currently unemployed. Some of these advocates have told me that DDS was not helpful. The individuals I corresponded with seemed to be on their own without help or assistance. Again, we have no data or transparency on this issue.

## Shuttered 14C Sheltered Workshops Result: Thousands Unserved

Sheltered workshops have largely been shuttered in Massachusetts. This resulted in a rise in enrollment in day habilitation in Massachusetts before the Covid pandemic. DDS estimates of day habilitation enrollment was up to 10K at one point. After the Covid pandemic, many individuals were not admitted back into day habilitation, resulting in thousands unserved. There is no evidence that closing the sheltered workshops resulted in competitive employment for those with IDD.

## ICF/IID Developmental Centers (Public Intermediate Care Facilities)

There are two remaining intermediate care facilities (ICF) in Massachusetts. One is the Wrentham Developmental Center in Wrentham and the other is the Hogan Regional Developmental Center in Danvers. Both these facilities have multiple openings and declining enrollment despite families advocating for admission for their loved ones into these facilities.

Over the past year, at least seven families have been denied admission to ICF/IID facilities in Massachusetts based on the DDS claim that these facilities “are not the least restrictive environment.”

One of the most compelling cases is that of Kristen Robinson, a Massachusetts woman, who has been stuck in Faulkner Hospital for over two months with no placement to receive her. Kristen has cerebral palsy, is legally blind, a quadriplegic, has pica and dysphasia, epilepsy, and a profound IQ. Boston Fox 25 reported on Kristen’s story in their [news report](#).

Massachusetts has tasked a [state commission on the history of the former Fernald Developmental Center](#) with researching the history of state institutions. There is a provision in the statute that gives the state commission the authority “to include recommendations for... deinstitutionalization...” The state tasked the Commission with looking at the history of the facilities before 1980. That cutoff date would prevent the Commission from looking at the vast improvements to ICF/IID under Judge Tauro that resulted in world class services for individuals with IDD in Massachusetts.

Currently, the ICF/IID is the only model of care in Massachusetts that guarantees individuals access to a wide variety of treatments including onsite medical care, allied health, recreational therapy, and vocational therapy.

HCBS services were supposed to allow the individuals to receive their needed services in community settings. Despite federal laws and regulations to the contrary, community living for those with IDD in Massachusetts has come to mean inadequate or no treatment/ clinical services unless the provider wishes to provide such.

It is difficult to understand the state’s push to deny admission to ICF/IID and to push for closure in an environment where thousands are unserved.

## Group Homes

Massachusetts provides group home services largely through corporate provider agencies. There are a small number of state-operated group homes. All group homes in Massachusetts are under an unwritten, but widely known, restrictive referral system. The Department of Developmental Services prohibits families from visiting providers around the state without explicit permission from the DDS. Providers are also prohibited from showing their programs or speaking to families without the permission of the DDS. There are no oversight procedures that prevent DDS from using their placement-making authority as rewards and punishments for families or providers.

Services offered in group homes are based on what the provider wishes to provide.

In September 2023, *Boston Globe* reporter, Liz Kowalczyk wrote an article about the system for individuals with IDD titled, “[There are no words](#)” While this story was largely about abuse and neglect in children’s services for those with autism or significant impairments, she also mentioned the adult system in her article.

*Peg Doherty, who has searched for a residential school and adult group home for her severely disabled son several times, said it is very difficult for parents to compare providers without public quality and safety information. She also believes the state should demand more for its money. “It’s **totally up to the***

***providers to decide what they are going to do and who they are going to hire,” she said. “The state is paying for the service but has little control over provider operations.”:***

In December 2023, Boston Globe reporter Liz Kowalczyk wrote an article titled, “[Thousands of Massachusetts Children are becoming adults. Many families find the state unprepared to help.](#)”

In the Day Habilitation Facebook Group, we have received reports from families who are saying that DDS has told them that group homes are not the least restrictive environment, and that the individual must fail in a shared living arrangement before they (DDS) will consider a group home placement.

## Shared Living Arrangements

Shared Living matches individuals with disabilities to members of the community who provide care at home. The idea is that these arrangements are similar to being cared for by a family member. While there are claims that individuals gain greater independence and opportunities for an active lifestyle in the community, it is unclear how this happens and how this claim can be verified.

According to [Massachusetts Domestic Servant Law](#), domestic workers have the right to minimum wage, overtime, time off from work, and other protections. Under state law, there are additional rules and added protections for domestic workers related to working and living conditions. Domestic Servant law applies to au pairs and other domestic servants. These are jobs that require fewer skills and are less difficult than caring for an individual with IDD and/or autism and/or complex medical or behavioral needs. Massachusetts either does not comply with Domestic Servant Laws or believes that shared living arrangements are exempt from these laws.

## Self-Directed Services

Massachusetts is currently in the process of creating regulations for self-directed services. At a June 18, 2024 hearing regarding the proposed regulations, individuals and families testified that the DDS approved list of services were too restrictive and resulted in an inability to enact person-centered plans.

In Massachusetts and across the US, recipients of HCBS waivers who have chosen self-directed services have resulted in “empty waivers.” This means that there is funding for services, but no services have been found. Self-directed services are particularly attractive to families who want a say in the treatment and care of their loved ones. It is unclear how self-directed services will work when parent/guardians age and can no longer run a program for their adult children.