

Assessment of Massachusetts Policies and Identification of Gaps in Supportive Housing Provision for Individuals with Profound Autism

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1. Massachusetts Policy Landscape Scan

The current structural framework of Massachusetts policies in supportive housing consists of stakeholders such as the Massachusetts Department of Developmental Services (DDS), MassHousing, the Department of Housing and Community Development (DHCD), and the Massachusetts Housing Partnership (MHP). These agencies and programs have been heavily involved in the transformation of supportive housing and the creation of more inclusive and accessible living environments for individuals with profound autism.

1.1 Massachusetts Department of Developmental Services (DDS): Policy Analysis and Review

The Massachusetts Department of Developmental Services (DDS), founded in 1998, supports individuals with intellectual and developmental disabilities including Autism Spectrum Disorder to provide opportunities for them to be engaged and integrated within their community.¹ Relevant supportive housing policies include but are not limited to: the Family Support Policy, Home and Community-Based Settings Policy, and DDS Policy Use of Technology in Services.¹ The initial Family Support DDS Policy was implemented in 1989 to increase the representation of family members living with individuals with profound autism on the DDS Board, enabling their involvement in the decision-making process and program services.² This policy has since allowed for the creation of the DDS family support program which provides funding for family support programs and services to families with children & adults with disabilities who are living at home.¹ The Home and Community-Based Setting Policy, implemented in 2014, focuses on utilizing Medicaid funding to provide person-centred services and support to individuals with profound autism to live integrated lives in the community.² This policy was crucial to the

development of the home and community-based services waivers for adults with intellectual disabilities where MassHealth-eligible individuals may receive needed services at their personal homes instead of an institution.¹ Additionally, this policy also led to the development of the Home and Community Services Information System (HCSIS), a web-based individual information system to capture healthcare information for individuals served by the DDS.¹ The DDS Policy Use of Technology, implemented in 2022, was a commitment made by the DDS alongside the Innovation and Technology Task Force to use technology to further opportunities for people with an intellectual and developmental disability to live more inclusive and independent lives.²

Currently, funding for the Department of Developmental Services (DDS) is projected to rise as the needs of individuals with profound autism continue to change and evolve. House 2 is allocating \$2.92 billion to DDS, a 5% increase over the 2024 budget.³ The HHS FY25 Budget Proposal is set to fully fund the Turning 22 class. Turning 22 supports individuals with disabilities transitioning from education to the adult service system.³ Furthermore, this budget will also be investing in new homes, community-based service programs and assistive technology to help individuals with disabilities navigate their lives with greater inclusivity and autonomy.³

1.2 MassHousing: Policy Analysis and Review

MassHousing is an independent public agency founded in 1966, responsible for financing affordable housing for residents living in Massachusetts.⁴ This agency operates by raising capital through the selling of bonds and the subsequent lending of proceeds to low- and middle-income homebuyers and owners. The HUD Title VI Elderly Disabled Regulations are a relevant policy proposed by MassHousing to support housing for individuals with autism.⁵ An example of what

this policy covers, which is relevant to supportive housing, involves establishing the number of units designated for non-elderly persons with disabilities. For instance, under this policy, a percentage of the units is reserved for occupancy by families with disabilities or non-elderly persons with disabilities. This is just one section of the regulation that can assist individuals with developmental disabilities in accessing housing. Furthermore, it's also important to note that MassHousing has released a public report and handbook guide titled "A Handbook on the Legal Obligations and Rights of Public and Assisted Housing Providers Under Federal and State Fair Housing Law for Applicants and Tenants with Disabilities". This publication covers the legal obligations and rights under the federal and state fair housing law for residents and tenants with disabilities. This guidebook helps housing providers navigate the laws, questions, and various acts to ensure that spaces are safe and culturally inclusive environments for individuals with all types of disabilities.

1.3 Department of Housing and Community Development (DHCD): Policy Analysis and Review

The Department of Housing and Community Development (DHCD), established in 1968, aims to improve and develop affordable and community-based housing in Washington, D.C. The DHCD works with investors, developers, home buyers, and other stakeholders to strengthen the city's neighbourhoods.⁶ Policies and programs supported by DHCD relevant to housing for individuals with profound autism include the Community Development Block Grant (CDBG), Home Investment Partnerships (HOME), National Housing Trust Fund, Low-Income Housing Tax Credit (LIHTC), and the Annual Owner's Certification of Continuing Program Compliance (AOC). The CDBG funds the DHCD through the U.S. Department of Housing and Urban Development (HUD). This program is used for both housing and non-housing activities.

Examples of CDBG-funded activities include housing rehabilitation, housing development financing, and neighbourhood revitalization projects.⁶ The HOME program provides grants to state and local organizations to build, buy, and rehabilitate affordable housing for low-income families. This program is part of a coordinated joint approach that includes numerous stakeholders and nonprofit groups.⁶ The National Housing Trust Fund complements existing federal, state and local efforts to increase the supply of clean, safe, and affordable housing for extremely low-income housing, which also includes homeless families.⁶ Through the DHCD, there are also private partnership models, such as the LIHTC program. This program, created by the Tax Reform Act of 1986, encourages the private sector to invest in constructing and rehabilitating housing for low and moderate-income individuals and families.⁶

1.4 Massachusetts Housing Partnership (MHP): Policy Analysis and Review

The Massachusetts Housing Partnership is a public non-profit organization that works with the Governor and the Executive Office of Housing and Livable Communities (EOHLC) to increase affordable housing in Massachusetts.⁷ This organization is involved with supporting housing through three sectors: community, rental financing, and homeownership. Regarding community, a few initiatives that are targeted for low-middle-income individuals involve: emergency rental assistance and municipal affordable housing trusts. Furthermore, to address barriers in rural areas, MHP has published numerous reports and articles, for example can be the *White Paper on Rural Housing Issues in Massachusetts*, which has proposed six recommendations to improve supporting housing in Massachusetts.⁷ MHP also provides financing for affordable and mixed-income developments across Massachusetts, accounting for over \$1.4 billion in loans and the financing of over 26,000 units of rental housing.⁷ Finally, this organization supports property ownership for individuals living in the city, as evidenced by their

ONE Mortgage Program. This program offers affordable mortgage options with low monthly interest rates for low- to middle-income first-time homebuyers across Massachusetts. ONE+ Mortgage builds on existing programs such as ONE+Boston and MassDREAMS to promote supportive housing for individuals.

2. Existing Gaps in Supportive Housing Provision

Table 1: Summary of Existing Gaps in Massachusetts Supportive Housing Provision^{8,9}

<ul style="list-style-type: none"> • Non-transferability of services from state to state
<ul style="list-style-type: none"> • Residency Requirement: DDS mandates that applicants must reside in Massachusetts to begin the eligibility process.
<ul style="list-style-type: none"> • Eligibility Determination Delays
<ul style="list-style-type: none"> • Unique Massachusetts Approach: Education vs Non-Education Placement Coordination
<ul style="list-style-type: none"> • Centers for Medicare and Medicaid Services (CMS) Oversight Challenges
<ul style="list-style-type: none"> • Chapter 257 Workforce Rates: There is a need to increase workforce rates for home and community-based services.
<ul style="list-style-type: none"> • Training for Direct Care Workers: Improved training for direct care workers is necessary.
<ul style="list-style-type: none"> • Funding for MassHealth and DDS Programs: Increased funding is required for critical programs such as day habilitation, PCA, and Turning 22.

- Services for Underserved Communities: Gaps exist in programs for unserved and underserved communities, particularly for individuals with profound autism and complex needs.

2.1 Case Study: Keridwen Dionne

Keriwen Dionne, an intellectually disabled individual, and her family faced numerous barriers related to bureaucratic rules and challenges when relocating residence from Maine to Massachusetts.⁸ Her parents requested that their daughter be placed at the Hoan Regional Center in Massachusetts due to her behavioural problems, which require her to live in a secure setting. Despite her currently residing in a private facility in Maine, the DDS stated that they would not even consider this option. This brings us to the first existing gap in supporting housing policies for individuals with profound autism. The DDS mandates that applicants must reside in Massachusetts to begin the eligibility process. However, it raises the question: how can you safely relocate an individual with profound autism without prior assurance of institutional placement and services, when you cannot secure these services without first establishing residency? The second existing gap in supporting housing for individuals with profound autism is the current Massachusetts eligibility process. DDS informed the Dionne family that the eligibility process typically takes 11 months, even though DDS regulations require them to determine eligibility for support and services within 60 days. Internal department emails from DDS revealed that hundreds of individuals are being forced to wait up to a year or more to be deemed eligible for these services. They have stated that the backlog is due to a shortage of psychologists needed to make eligibility determinations on an individual basis. As a result, future policy should aim to address this issue by ensuring a greater availability of these professionals.

Finally, it's important to note that Massachusetts is unique compared to other states in that residential placements for autistic individuals under 22 are education-based, fulfilling the requirements of the Individuals with Disabilities Education Act (IDEA). Keriwen Dionne falls under this eligibility and has suffered from the lack of coordination among numerous agencies. The Dionne family faced difficulties not only with the DDS but also with the Salem School District, which is responsible for overseeing her care. Essentially, residential placements are a mess, with numerous fragmented and inefficient services. As discussed by others in the forum, the Centers for Medicare and Medicaid Services (CMS) lacks a clear understanding of the essential services offered in each state, and many challenges arise in maintaining uniformity and oversight, especially with how a state like Massachusetts may implement supportive housing services differently. As a result, a more integrated approach from all organizations and stakeholders is necessary.

2.2 Community Survey Needs Assessments: The Arc of Massachusetts

The Arc of Massachusetts is a local advocacy group that promotes the inclusion of services and integrated communities for individuals living with disabilities. Recently, they have released a community survey addressing various gaps in the current supporting housing provision for individuals with proud autism and what the next steps should be. In the survey they have identified four key points: increasing Chapter 257 workforce rates for home and community-based services, improving training for direct care workers, funding increases for MassHealth and DDS program, including but not limited to day habilitation, PCA, and Turning 22, and to address gaps in programs for unserved and underserved communities, with concerns regarding those with profound autism and other complex needs.⁹ Building on the success of advocacy in last year's FY25 budget, these are the recommendations for Governor Maura Healey

to include in her upcoming FY26 budget to increase funding for intellectual and developmental disabilities (IDD) and autism programs.

3. Questions for Stakeholders

Table 2: List of Questions for Relevant Stakeholders to Supportive Housing Provision

<ul style="list-style-type: none">● Given the DDS residency requirement, what measures are being taken to address the barriers individuals face in accessing services when relocating to Massachusetts?
<ul style="list-style-type: none">● What steps are being taken by DDS to reduce the delays in eligibility determinations for individuals seeking support, especially for those with complex disability needs?
<ul style="list-style-type: none">● How are families supported during the waiting period, and what interim services are available while eligibility is being determined?
<ul style="list-style-type: none">● How does Massachusetts ensure that CMS compliance is maintained in the delivery of accessibility services for individuals with profound autism, particularly when there is a lack of uniformity in services between states?
<ul style="list-style-type: none">● How are Chapter 257 workforce rates being adjusted to support the growing demand for home and community-based services in Massachusetts?
<ul style="list-style-type: none">● What types of training are being provided to direct care workers in Massachusetts to ensure they meet the complex needs of individuals with profound autism?
<ul style="list-style-type: none">● How do you plan to address funding gaps for critical MassHealth and DDS programs like day habilitation, PCA, and Turning 22 in the upcoming budget?

- What is being done to expand services for underserved communities in Massachusetts, particularly for individuals with profound autism and complex needs?

4.0 Federal Policy Landscape

There are three main federal programs that provide rental assistance in the U.S: Public Housing, Project-Based Rental Assistance (Section 8), and Housing Choice Voucher (Section 9).¹⁰ Public housing is a program that includes approximately 958,000 units across the U.S, designated for extremely low-income households (below 30%).¹⁰ It is important to note that there is no public housing developments specifically designed to address the accessibility needs of adults with Autism Spectrum Disorder (ASD) or Intellectual and Developmental Disabilities (ID/D).¹⁰ The project-based rental assistance allows private owners and developers enter into multi-year contracts with the U.S. Department of Housing and Urban Development (HUD) to provide housing units for extremely low-income families.¹⁰ The housing choice voucher allows the federal government to subsidize rent for low-income households in the private market.¹⁰ It provides rental assistance to about 2.2 million households each year, making it the largest rental assistance program in the country.¹⁰ Overall, despite existing federal rental assistance programs helping 5.3 million households, 16 million low-income households remain without support due to funding limitations.¹⁰

4.1 Implementation of Home & Community-Based Services Rule in Massachusetts

Home and Community-Based Services (HCBS) is a federal policy that provides opportunities for people under Medicaid to receive services in their own homes or communities rather than institutions.¹¹ It emphasizes community integration, individual autonomy, and

avoidance of institutional characteristics. The Home and Community-Based Services (HCBS) rule in Massachusetts ensures that participants in HCBS waivers can access community living benefits. Recently, Massachusetts has demonstrated a commitment to operationalizing this rule more effectively. In a public hearing, the Massachusetts Division of Medical Assistance proposed amendments to the Home and Community-Based Services (HCBS) Waiver Services. The proposed changes include updating definitions and services, modifying eligibility requirements, specifying conditions for payment of waiver services, and adding provisions related to electronic vision and telehealth requirements.¹² This proposed regulation is planned to take effect on January 1st, 2025. Furthermore, under this rule, Massachusetts has submitted a statewide transition plan (SLP) to the centres of Medicare and Medicaid services. This plan covers all steps to ensure that the HCBS waiver participants live and receive services in integrated settings that promote community involvement.¹³ Massachusetts have also established a grievance process. Here, HCBS waiver participants who believe their living arrangements are not standard with the individuality autonomy or quality of life can file a grievance report with the state.¹³ Based on these efforts, it is presumed that Massachusetts is actively implementing the Home and Community-Based Services (HCBS) Settings Rule. However, a few challenges do persist with this rule. For example, Massachusetts must comply with CMS regulations to maintain Medicaid funding. This has adverse effects as it places a significant administrative burden on the state through extensive monitoring, reporting, and policy changes. Additionally, the compliance burden strains state resources, diverting funds from other essential services.

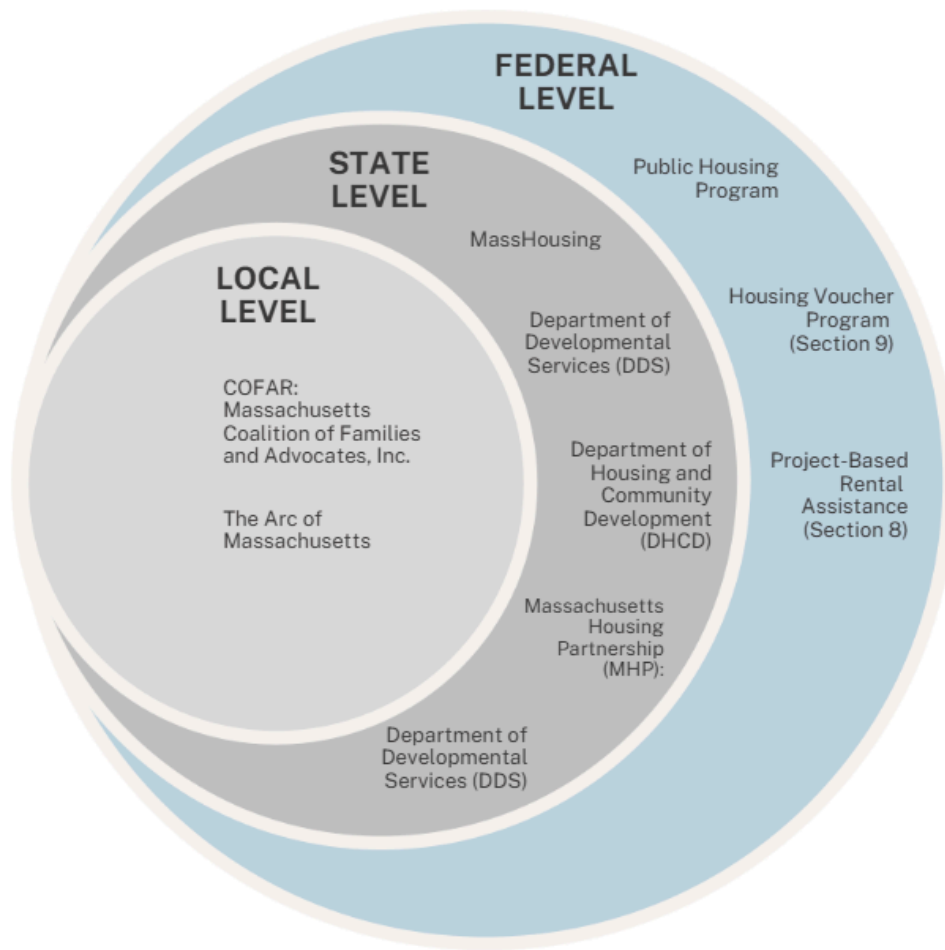
Table 3: Comparative Analysis of HCBS Rule Implementation in California, New York, and Massachusetts^{11,14-18}

Category	California	New York	Massachusetts
HCBS Rule Implementation	Strong focus on person-centred planning and community integration. Expanded funding for self-directed services.	Emphasizes community-based living, reducing reliance on institutional care.	Focus on integrating long-term services with healthcare.
State Waivers & Programs	Offers multiple 1915(c) waivers, including programs for developmental disabilities, aging populations, and mental health services.	Extensive Medicaid waiver programs, including Managed Long-Term Care (MLTC) and Community First Choice (CFC).	MassHealth HCBS Waivers for adults, children, and seniors, prioritizing independent living.
Funding & Support	High state funding, with additional state grants for improving accessibility and workforce development.	Significant investment in MLTC programs with a push for managed care.	Focuses on cost-effectiveness, prioritizing Medicaid recipients.
Integration with Healthcare	Integrated Managed Care Models linking HCBS with medical services.	Strong collaboration between HCBS and Medicaid Managed Care.	Expanding efforts to bridge HCBS with healthcare delivery systems.
Challenges & Barriers	Workforce shortages and high cost of living make home care less affordable.	High demand, waiting lists for certain services, and uneven implementation across regions.	Limited funding and challenges in transitioning individuals from institutional care.
Unique Features	California's Self-Determination Program (SDP) allows more autonomy for individuals with disabilities.	New York's Consumer-Directed Personal Assistance Program (CDPAP) enables individuals to hire their own caregivers, including family members.	The One Care Program integrates Medicare & Medicaid for individuals with disabilities.

5.0 Proposed Massachusetts Policy Framework

This layered policy framework offers a comprehensive overview of the current housing landscape for autistic individuals in Massachusetts

Figure 1: Layered Policy Framework for Autistic Individuals Housing Support in Massachusetts



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