



Massachusetts Independent Living Centers

2024+

Massachusetts's 10 Independent Living Centers

serve people with disabilities of all ages in every city and town in Massachusetts.

Independent Living Centers support people with disabilities to live, work and participate fully in their communities through **5 core services:**

- Information and Referral
 - Peer Support & Mentoring for Youth and Adults
 - Independent Living & Life Skills Training
 - Individual & Systems Advocacy
 - Institutional Transition & Diversion; Youth Transition
-

Massachusetts Residents served in FFY 23

**Total Served:
30,807**

12,146 consumers, family members, partners in the community, municipalities, and government entities received information or referrals from Independent Living Centers.

145 individuals transitioned from institutionalized settings such as nursing homes to the community.

1,012 youth across the Commonwealth received transition services.

11,907 individuals obtained access to health care services they previously did not have.

971 individuals obtained Assistive Technology.

Massachusetts Independent Living Network

FY 2025 Priorities

Budget Priorities

Independent Living Centers Line Item 4120-0200

\$10 Million for 10 Independent Living Centers (increase of \$2 million)

Independent Living Centers (ILCs) are consumer-directed, consumer-controlled, cross-disability nonprofit agencies. ILCs are critical in keeping individuals with disabilities independent in the community and out of costly institutional settings. The \$2 million funding increase is imperative to ensure ILCs can hire and retain staff, and maintain services.

Independent Living Centers are funded in a separate line item with pass-through funds, and not through Chapter 257 rate setting. (As a comparison, Community Integrated Services [CIS] and Acquired Brain Injury [ABI] vendors have received 25% and 10% funding increases in the FY24 and FY25 budgets through rate setting, specifically for staff.) ILCs, on the other hand, have received one line-item funding increase since 2016.

Maintain Funding for Personal Care Attendants

The Personal Care Attendant (PCA) program enables over 40,000 people with disabilities and older adults to live in the community with dignity and independence. **The cuts proposed in the Governor's FY25 budget would cut PCA services for an estimated 6,000 people who rely on this vital service.** PCAs offer crucial support with daily activities such as eating, bathing, toileting, transferring, laundry, shopping, housekeeping, transportation to medical appointments, and meal preparation. Many PCAs, the majority of whom are women and people of color, would lose their jobs.

Those impacted by MassHealth cuts would be people receiving 10 or fewer hours/week of assistance with activities of daily living (such as assistance with eating and toileting), including people who may also be receiving 10 hours/week of services with instrumental activities of daily living (such as assistance with laundry and shopping). Additionally, the proposed cuts reduce meal prep time from 13 hours/week to 7 hours/week.

Outside of the budget process, MassHealth is proposing to place evaluations for the PCA program and other Long-Term Services and Supports in a central "Independent Assessment entity." This could lead to a reduction of services, services that are less responsive to the community, and job losses for employees of local Personal Care Management agencies, including ILCs.

ILCs advocate that the proposed cuts and changes to the program are rejected.

Housing Priorities

For the FY25 budget, we advocate to:

- **Increase the Alternative Housing Voucher Program funding** (Line Item 7004-9030) to \$30 million (\$18.8m + Prior Appropriations continued) and incorporating H.1305 & S.884 into budget language.
- **Increase Accessible Affordable Housing Grants** (Line Item 7004-9031), which offer grants to create or rehabilitate units into accessible housing prioritized for AHVP voucher holders to \$2.5 million.
- **Increase MassAccess Registry funding** (Line Item 4120-4001) to \$300,000 to assist low-income people with disabilities to search for accessible housing.

The Independent Living Network supports continued funding for Assistive Technology and Durable Medical Equipment Programs.

Legislative Priorities

Building a More Accessible Massachusetts

S.1553: An Act Building a More Accessible Massachusetts.

Sponsor: Senator Michael O. Moore

H.2291: An Act expanding the availability of adaptable housing for people with disabilities and seniors.

Sponsors: Representatives Christine P. Barber and Michael J. Moran

We support aligning MA accessibility regulations with federal regulations. These bills would bring the Commonwealth into compliance with federal law by aligning state standards with the 2010 ADA Standards for Accessible Design, and make housing accessible by requiring adaptable units in renovated buildings. These bills would also remove barriers to work by ensuring access for all individuals in both customer and employee areas. When enacted, S.1553 and H.2291 will prevent lawsuits and simplify development by addressing access problems in the blueprint phase, instead of in a courtroom after development has been completed.

Estate Recovery

H.1168 and S.726: An Act protecting the homes of seniors and disabled people on MassHealth

Sponsors: Representative Christine Barber and Senator Jo Comerford

Estate recovery is a federally mandated process by which estates of deceased Medicaid enrollees are recouped to pay back nursing home costs paid by the government after age 55. However, Massachusetts exceeds federal requirements by recovering the costs of *all medical services* paid by MassHealth and CommonHealth after age 55, perpetuating intergenerational poverty. This can result in the sale of the family home, causing excessive financial burden, especially among communities of color and people with disabilities. In many cases, the family is unaware of this burden as MassHealth has not historically informed applicants or members about estate recovery upon enrollment.

This bill seeks to address this issue by making changes to the estate recovery rules to make the statute more equitable for low-income enrollees and families. **It will limit MassHealth to only federally mandated estate recovery**, require MassHealth applicants and enrollees to receive notice and explanations of estate recovery (which is not currently required), establish criteria for undue hardship waivers, and exempt CommonHealth members (a MassHealth work incentive program for disabled adults) from MassHealth estate recovery.

Spouses as Paid Caregivers

H.216 and S.67: An Act allowing spouses to serve as caregivers

Sponsors: Representative Adam Scanlon and Senator Jo Comerford

Some disabled people need caregivers, such as Personal Care Attendants (PCAs), to maintain their independence and ability to live in the community. There is a dire shortage of paid caregivers in the state. Spouses are currently unable to be paid as caregivers by MassHealth, meaning that some are forced to perform unpaid caregiving work, reduce work hours, and even quit their jobs to care for their loved ones.

This bill will allow spouses to be authorized to serve as paid caregivers in the MassHealth program for the provision of certain home-based care and services, just as other relatives are already permitted to serve as paid caregivers.

Support Regional Transit Authorities (RTA)

S.2277 and H.3272: An Act to increase regional transit accessibility in the Commonwealth

Sponsors: Representative Natalie Blais and Senator Susan Moran

While the 15 Regional Transit Authorities (RTAs) serve 250 communities and 55% of Massachusetts' population, they receive just over 7% of transit operating funds. This bill will increase the funding floor for RTAs to support 7-day-a-week service during critical commute hours across all 15 RTAs, create a dedicated fund in statute for RTAs, uplift community needs through an annual RTA Council report, and eliminate profitability as a performance metric for transit agencies.

Changes to the Affordable Homes Act

The Independent Living Network supports The Affordable Homes Act (H.4138) as an opportunity to help alleviate the state's housing crisis.

We advocate for the incorporation of H.1305 and S.884 into the Affordable Homes Act to make several important changes to the Alternative Housing Voucher Program, maintaining \$60M in funding to the Home Modification Loan Program, increasing funding for Community-Based Housing to \$110M, and establishing a Commission on Accessible Housing to examine the diverse housing accessibility needs of people with a range of disabilities.

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