Plain Text version of Disability Policy Consortium’s Legislative Access Agenda

Legislative Access Agenda

2024 Edition

DPC’s mission is to bring the perspectives of people with disabilities to the table on key issues, empower our community through healthcare support and advocacy, participatory research, and expert policy analysis, and lead grassroots campaigns that make Massachusetts more accessible and inclusive. Our credo is "About Us, By Us" — the belief that when decisions are made about people with disabilities, people with disabilities should be the ones making them.

## Key FY25 Budget Priorities

For more information, contact R Feynman at rfeynman@dpcma.org or 617-993-6021.

7004-9031: Retain Accessible Affordable Housing Grants at $2.5M

It can be especially difficult for people with disabilities to find homes that meet their access needs. The Accessible Affordable Housing Grants (AAHG) offers developers and landlords grants to create or rehabilitate physically accessible housing that prioritizes AHVP recipients. This program has funded projects across the state since its inception a few years ago. The Governor’s budget did not include this program.

7004-9030: Incorporate Language Changes and increase total funding for AHVP to $30M ($18.8M + Prior Appropriations Continued)

Champions: Rep. Decker, Rep. Consalvo, and Sen. Eldridge

People with disabilities are more than twice as likely to be homeless than their nondisabled peers. The Alternative Housing Voucher Program (AHVP) provides mobile housing vouchers to low-income individuals with disabilities between the ages of 18 and 60. The FY24 budget (and Governor Healey’s H.2 for FY25) included several changes to the language of the line item. These changes have increased the flexibility, usability, and usefulness of the vouchers. We support retaining that language, and the addition of “Prior Appropriations Continued” to keep money with the program.

Maintain funding for Personal Care Attendants (PCAs)

The Personal Care Attendant (PCA) program enables over 40,000 people with disabilities and elderly people to live in the community with dignity and independence. The proposed cut to the program in the governor’s budget will disrupt this for an estimated 6000 people and many PCAs will lose their jobs. Moreover, MassHealth also proposes to place evaluations for the program in a central entity, which could lead to a medical model of service, taking away the consumer-centrism of the program. We are advocating for an increase in the MassHealth budget by $114 million to reverse the cuts that the governor included in her budget, and thus ensure funding for the PCA program which reduces reliance on nursing homes, thereby alleviating the financial burden on the state associated with higher-cost care.

4120-4001: Increase funding of MassAccess Registry to $300K

MassAccess is an online registry of affordable, accessible units, overseen by the Housing Navigator and MyMassHousing. Increased funding will help more low income people with disabilities find accessible units with up-to-date resources where they’re already looking.

## Affordable homes act priorities

The Affordable Homes Act (AHA)

People with disabilities are disproportionately affected by the ongoing housing crisis in Massachusetts. The Commonwealth’s housing stock is largely old and inaccessible, and thousands of people are in nursing homes, primarily because there is nowhere accessible for them to go. The Affordable Homes Act (H.4138) makes deeply needed investments and policy changes to improve our housing landscape. We support Governor Healey’s bill and encourage the legislature to incorporate the following changes to show a historic commitment to addressing the dire housing crisis for people with disabilities.

Alternative Housing Voucher Program (AHVP)

AHVP provides rental assistance for low-income adults with disabilities age 60 and under. The governor’s version of the Affordable Homes Act includes project-based vouchers for AHVP. We advocate that AHA should incorporate the rest of the changes proposed in H.1305/S.884 (see “Bills We’re Supporting”) including: Increasing the maximum eligibility age from 60 to 62 to align with other programs Updated language for persons with disabilities Creating a payment standard of 120% Small Area Fair Market Rent (SAFMR) Keeping unspent funds with the program rather than revert to a general fund The proposed improvements in H.1305/S.884 would significantly impact program efficacy. Passing them together will allow EOHLC to write new regulations with all of these changes in mind, rather than having to reassess them several times.

$60 Million for the Home Modification Loan Program (HMLP)

HMLP provides funding to modify homes of individuals or families with disabilities or seniors so that they may maintain residency or return home from institutional settings. We support the level funding of this program, as outlined in the Governor’s version.

$110 Million for Community Based Housing (CBH)

CBH funds development and redevelopment of housing for people with disabilities who are leaving or at risk of entering an institution such as a nursing home. The governor’s version of the AHA allocates $55 million for this program. We propose an allocation of $110 million because of limited housing options for people wishing to transition from nursing facilities.

Establishment of a Commission for Accessible Housing

This commission would study existing accessible housing, the demand for more, and examine new accessibility features for housing that would benefit a broader range of people with disabilities.

For more information, contact R Feynman at rfeynman@dpcma.org or 617-993-6021.

## Top Legislative Priorities

S.2546: An Act expanding wheelchair warranty protections for consumers with disabilities

Lead Sponsors: Rep. Jim O’Day, Sen. John Cronin

Status Update: Passed the Senate! Currently in Committee on Health Care Financing
Wheelchairs and scooters are often prone to defects and sudden failure. It is common for consumers to be left stranded or isolated in their homes for weeks, or even months, awaiting repairs. By strengthening warranty protections for Massachusetts residents with disabilities, we can level the playing field for consumers, shorten repair wait times, save taxpayer money, and ensure that we are all treated with dignity and respect. S.2546 expands the existing warranty to two years, and will cover all wheelchair users in the Commonwealth, not just those who are on private insurance or can afford to pay out-of-pocket. It holds wheelchair providers and suppliers accountable to reasonable repair timelines, by requiring that they cover costs consumers face as a result of defective chairs, and stock common parts to service chairs efficiently.

For more information, contact Harry Weissman at hweissman@dpcma.org or 617-977-4084.

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

Lead Sponsors: Rep. Christine Barber, Sen. Jo Comerford

Status Update: Reported favorably out of committee, now in Senate Ways and Means

Estate recovery is the practice of MassHealth recouping the cost of medical services from deceased enrollees’ families. While mandated by federal law, estate recovery is made even more aggressive by requirements under Massachusetts law. It can result in the sale of the family home, causing excessive financial burden and perpetuating poverty, 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. H.1168/S.726 establishes that MassHealth can only recover costs that are federally mandated, limits the recovery for capitated payments, requires notice to applicants and enrollees about estate recovery, establishes criteria for granting undue hardship waivers, expands the obligation to provide information on estate recovery limitations, and exempts the CommonHealth program for disabled adults from estate recovery through MassHealth’s filing of a required waiver with the federal Centers for Medicare & Medicaid Services.

For more information, contact Charlie Carr at charlescarr@dpcma.org or 978-361-6682.

H.1601/S.1037: An Act prohibiting discrimination against adults with disabilities in family and juvenile court proceedings

Lead Sponsors: Rep. Kay Khan, Rep. Jay Livingstone, & Sen. Joan Lovely

Status Update: Currently in Judiciary Committee

Parents with disabilities, especially psychiatric or intellectual disabilities, lose custody or parenting time at alarming rates due to disability discrimination – while 6.7% of parents in the U.S. have a disability, families in which a parent has a disability are disproportionately involved in the child welfare system. Across the board, disabled parents are 22% more likely to have their parental rights terminated, and parents with psychiatric disabilities are 26 times more likely to have their children removed from their homes. Parents should not be denied the right to raise their children solely on the basis of their disability. H.1601/S.1037 will require courts to use evidence, not assumptions, in order to determine if a parent's disability causes actual harm to a child. Courts will have to explain in writing if a parent's disability is a negative factor in custody and parenting time decisions and assess if the harm can be avoided with accommodations (like adaptive equipment or supportive services).

For more information, contact Samantha Fein at sfein@dpcma.org or 617-624-3277.

H.1180/S.753: An Act relative to preventing discrimination against persons with disabilities in the provision of health care

Lead Sponsors: Rep. Josh Cutler, Sen. Adam Gomez

Status Update: Currently in Committee on Health Care Financing People with disabilities are frequently the victims of explicit and implicit bias in the healthcare system, often with harmful and even deadly consequences. Some disabled patients have been denied treatments, medications, and even removed from life support, while others report being pressured to sign Do Not Resuscitate orders–all based on the presumption that the lives of people with disabilities have less worth and are less worth saving than the lives of people without disabilities. During the worst days of the COVID-19 pandemic, our own state government took the same approach, adopting Crisis Standards of Care that would have sent thousands of people with disabilities to the back of the line for lifesaving ventilators and ICU beds. H.1180/S.753 protects people with disabilities from life-threatening discrimination in our healthcare system. It prohibits any healthcare entity from denying or deprioritizing a patient for a healthcare service based on the presumption that their disability makes their life less worthwhile. It puts critical protections in place to prevent disabled patients from being pressured to sign Do Not Resuscitate Orders, and it ensures that decisions about the cost-effectiveness of treatments do not use discriminatory metrics. Finally, it would ensure that, in any future public health crisis, the rules that dictate who gets access to lifesaving care do not discriminate against people with disabilities.

For more information, contact Colin Killick at ckillick@dpcma.org or 617-993-6562.

## Bills We're Supporting

H.1485/S.109: An Act relative to supported decision-making agreements for certain adults with disabilities

Sponsors: Reps. Michael Finn, Sean Garballey, Sen. Lovely

Status Update: Committees on Judiciary/Children, Families, and Persons with Disabilities

This bill establishes the legal framework for Supported Decision-Making in Massachusetts, an alternative to guardianship in which adults can choose a group of trusted supporters to assist them with making and communicating decisions.

For more information, contact Colin Killick at ckillick@dpcma.org or 617-993-6562.

H.2291/S.1553: Building a More Accessible Massachusetts and Expanding the Availability of Adaptable Housing for People With Disabilities and Seniors

Sponsors: Reps. Christine Barber, Michael Moran, Sen. Michael Moore

Status Update: Committee on Public Safety and Homeland Security

This bill ensures more accessible housing units and workplaces are available in the state by bringing such buildings under the purview of the Massachusetts Architectural Access Board (AAB) when newly built or when major renovations take place.

For more information, contact Charlie Carr at charlescarr@dpcma.org or 978-361-6682.

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

Sponsors: Reps. Adam Scanlon, Norman Orrall, Sen. Jo Comerford

Status Update: Committee on Children, Families, and Persons with Disabilities

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.

For more information, contact Charlie Carr at charlescarr@dpcma.org or 978-361-6682.

S.2520/H.945 & H.943: Acts relative to pharmaceutical access, costs and transparency

Sponsors: Reps. Christine Barber, Jon Santiago, William Driscoll, Sen. Cindy Friedman

Status Update: Passed the Senate! Currently in House Ways and Means These bills address high and rising prescription drug costs and reduce co-pays for people with certain chronic conditions.

For more information, contact Harry Weissman at hweissman@dpcma.org or 617-977-4084.

H.1305/S.884: An Act to create affordable homes for persons with disabilities

Sponsors: Reps. Marjorie Decker, Rob Consalvo, Sen. Robyn Kennedy

Status Update: Committee on Housing This bill builds more accessible and affordable homes by improving the Alternative Housing Voucher Program (AHVP) and allowing project-basing of AHVP vouchers.

For more information, contact R Feynman at rfeynman@dpcma.org or 617-993-6021.

## Back page

Full- page stylized drawing of people with a variety of disabilities approaching and standing in front of the Massachusetts State House. They are walking up and standing at the top of a teal ramp, which reads “Research. Advocacy. Access. 2024 Edition”. The crowd has people of different genders, skin tones, mobility devices and access tools. A wheelchair user at the top of the ramp holds their arms up triumphantly with a sign reading “about us by us”.

Underneath the drawing, the text DPC: Disability Policy Consortium

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