

MDDC Public Policy Committee Meeting

May 12, 2026



Meeting Poll Link

Upon leaving the meeting,
please respond to survey below.

We use your feedback to improve
the experience and the
information we share.



[CLICK HERE](#)

- Welcome/Introductions
- State Legislative/Budget Update
- Coalition Updates
- Federal Update
- Council & Community Events
- Partner Updates
- Public Comment

AGENDA





MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL



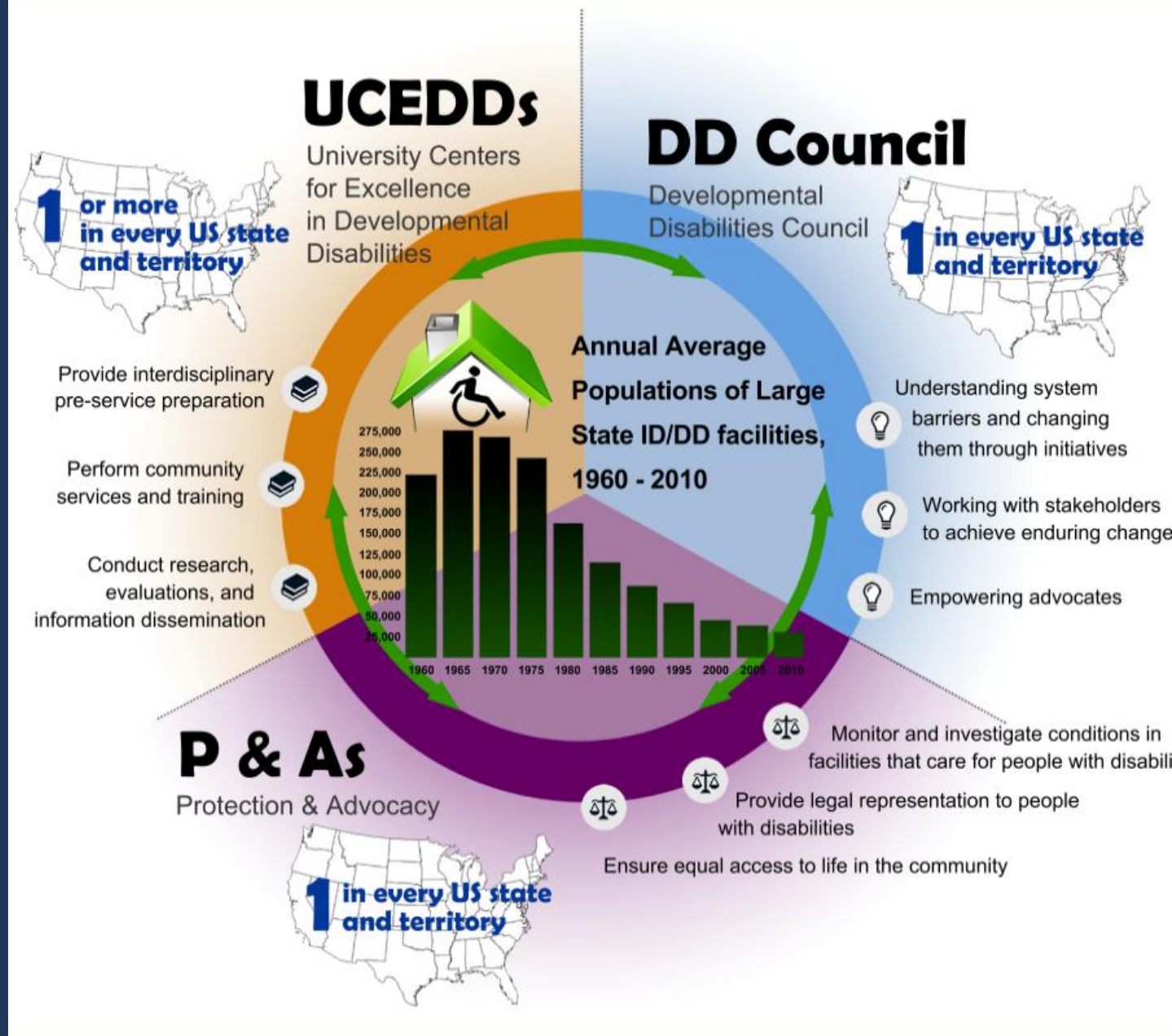
MDDC Mission

Our mission is to provide opportunities for individuals with developmental disabilities and families to enhance independence, productivity and inclusion.



The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)

- Establishment of state DD networks
- Federally funded DD programs in every state and territory - mandated with supporting people with DD and their families





MDDC Policy Team



Gyasi Burks-Abbott

Public Policy
Committee Chairperson



Destiny Maxam

Policy Coordinator



Kaitlin Stober

Policy Research
Associate



Rick Glassman

Legal Disability
Policy Analyst



Jennifer Bertrand

Deputy Director



State Legislative Update



State Legislative Update



- The MA Legislature has about 2 months to finalize bills.
- The state budget is a key focus through the end of June.
- The formal session closes on July 31, 2026.



MDDC Priority/Endorsed Bill Update

- All MDDC Priority/Endorsed legislation have had a hearing.
- Most bills have received a favorable committee report.
- Some bill reporting dates have been extended until June 15th.

[MA Legislature 2025-26 Session Legislative Deadlines & Significant Dates](#)

- 2 policies have been signed into law:
 - Education Access
 - Historical Records

[MDDC Website Homepage](#)
[MDDC Disability Policy Resources](#)
[MDDC Priority & Endorsed Legislation](#)

Snapshot of Status of MDDC Priority Legislation

....as of May 12, 2026





Summary Table (as of 5/12/26), p. 1

Wins	Better-Positioned	Weakly Positioned	Finished for this Session	<i>Comments</i>
<p>H. 650 Assessments and materials in public education. (Passed)</p>				<p>Passed in Governor's 8//5/26 budget</p>
	<p>H. 4852 / S. 115 Supported Decision-Making (SWM & HCF)</p>			<p>House bill has some additional terms related to IEP meetings which must be removed.</p>
	<p>H. 4851 / S. 102 Universal Changing Stations in Public Buildings (SWM & HWM)</p>			<p>What's happening behind the scenes? Are NAIOP and DCAMM opposed?</p>



Summary Table, continued, p. 2

Wins	Better-Positioned	Weakly Positioned	Finished for this Session	<i>Comments</i>
		H. 1481 / S. 1004 Improvements to AHVP Housing (HWM & SWM since Nov./Dec.)		Bill Henning might be the best point of contact, if we need updates.
	S. 149 / H. 242 Enhanced standards of care and and state plan for health care providers on autism and IDD. (HWM and SWM since April)			Is Arc of MA the lead?



Summary Table, continued, p. 3

Wins	Better-Positioned	Weakly Positioned	Finished for this Session	<i>Comments</i>
	H. 4358 / S. 2662 Wheelchair repair bills, as amended (10 business days to repair with stop-the-clock provisions) (HWM & SWM)			Senate passed different bills last two sessions. House has been more difficult. Bills could use more support from IDD community.
		H. 2569 “AAB bill” to expand supply of adaptable housing. (HWM)		Check to see if there is a Senate equivalent in this session? Also NAIOP opposition? (See Carol Steinberg)
		H. 2104 / S. 1325 Funding levels for direct care workforce (HCF & SWM)		The Arc and SEIU 509 have supported different approaches. With H. bill still in HCF, this bill may have too far to go.



Summary Table, continued, p. 4

Wins	Better-Positioned	Weakly Positioned	Finished for this Session	<i>Comments</i>
		H. 1394 / S. 886 Family members as caregivers (H. bill is still stuck in HCF and S. version was sent to study.		We should find out why Sen. Friedman allowed this to be sent to study. May also need to look at other legislation on spouses as caregivers and related state opposition.
	H. 1360 / S. 869 Discrimination in health care (HCF and SWM)			May have too far to go in too short a time.
		H. 1366 / S. 866 Medically frail children and Continuous Skilled Nursing (HWM, with S. version sent to study).		Sen Friedman was co-sponsor and cares about this issue, but S. version sent to study. Why? Is there other legislation that is moving instead?



Summary Table, continued, p. 5

Wins	Better-Positioned	Weakly Positioned	Finished for this Session	<i>Comments</i>
			H. 1852 / S 1164 Discrimination in family and juvenile court. Not favorably reported out of committee; sent to study	Traditionally opposed by DDS. State appellate law is also weak. Historically speaking, US DOJ has provided better support on this issue .



Remaining Priority Bills with Question Marks:

- **H. 752 and S 313 (Improving transition planning and creating commission).**
 - Senate version went from Joint Committee on Education to Rules and then to SWM.
 - House version went to Rules.
 - Who is the current lead in the advocacy community?
- **H. 276 and S. 150 (Federal definition of developmental disability for DDS adult services).**
 - Senate version stuck in Rules since June. Why?
 - House version is in HCF.
 - Who is the current lead in the advocacy community? FASD community?

[MDDC Fact Sheet: H.276/S.150 – Adopting the federal definition of DD](#)

H4358

H4358

- Originally filed as H1278
- Updated language to include a broader definition of Wheelchair
 - Went to House Ways and Means Aug 2025
 - Bypassed Healthcare Financing this year
 - Met with HWM Chairman in January 2026
- Filed as outside section to budget, Amendment 803
- Despite 60% of House signing on to cosponsor, ultimately was not included

Next steps:

- Utilizing press and media coverage to provide outside pressure
- Next meeting with HWM late June
- Advocacy Day at State House

S2662

S2662

- Originally filed as S210
- In October 2025 CPPL asked to consider filing the same language as the House bill (S2662)
 - Redraft included the same language as H4358, with 2 extra provisions requiring the offer of a loaner chair and extension of the warranty to 2 years
- In Senate Ways and Means
- Next Steps:
 - Meeting with Vice Chair 5/15
 - Senate has passed favorably 2x before
 - Concern on Senate wanting the House to act first



Stay connected with the campaign here!



The broken system of wheelchair repairs in Mass.

Wheelchair users suffer from major disruptions in their lives, often as a result of chronically delayed repairs.

by Katherine Gergen Barnett and Anthony J. Mell Updated May 2, 2026, 3:00 a.m.



Wheelchair Users at State House and recent press coverage

Opinion _ Delayed repairs ro...

LETTERS

Delayed repairs rob wheelchair users of their independence

Updated May 6, 2026, 2:20 a.m.



Organizer Destiny Maxam spoke at a hearing at the State House on March 11 to advocate for bills that would aim to facilitate repairs, reduce wait times, and hold manufacturers of wheelchairs accountable to their customers. LANE TURNER/GLOBE STAFF

https://www.bostonglobe.com/2026/05/06/opinion/letters-wheelchair-repair-delays-unacceptable/?p1=BGSearch_Overlay_Results

5/6/26, 8:08 AM

Opinion | Delayed repairs rob wheelchair users of their independence

I was quoted in the May 2 op-ed on delays in wheelchair repair by Drs. Katherine Gergen Barnett and Anthony J. Mell, "[Fixing the broken system of wheelchair repairs in Mass.](#)," in which I was cited as someone who is living this reality. I am also the organizer at the Disability Policy Consortium behind the campaign to address it.

When my wheelchair breaks, my life does not pause. Work still expects me. Medical appointments don't wait. Groceries still need to be bought. The world keeps moving while I am forced to sit still.

On average, wheelchair users wait months just to be seen. Then comes the wait for parts and the repair itself. What should be a basic fix can stretch into six months without access to the very equipment we rely on to live our lives.

This is not an inconvenience. It is a complete loss of independence.

Legislation pending in the Massachusetts [House](#) and [Senate](#) would change that by setting and enforcing real timelines for repairs. No one should have to put their life on hold for half a year just to get their mobility back.

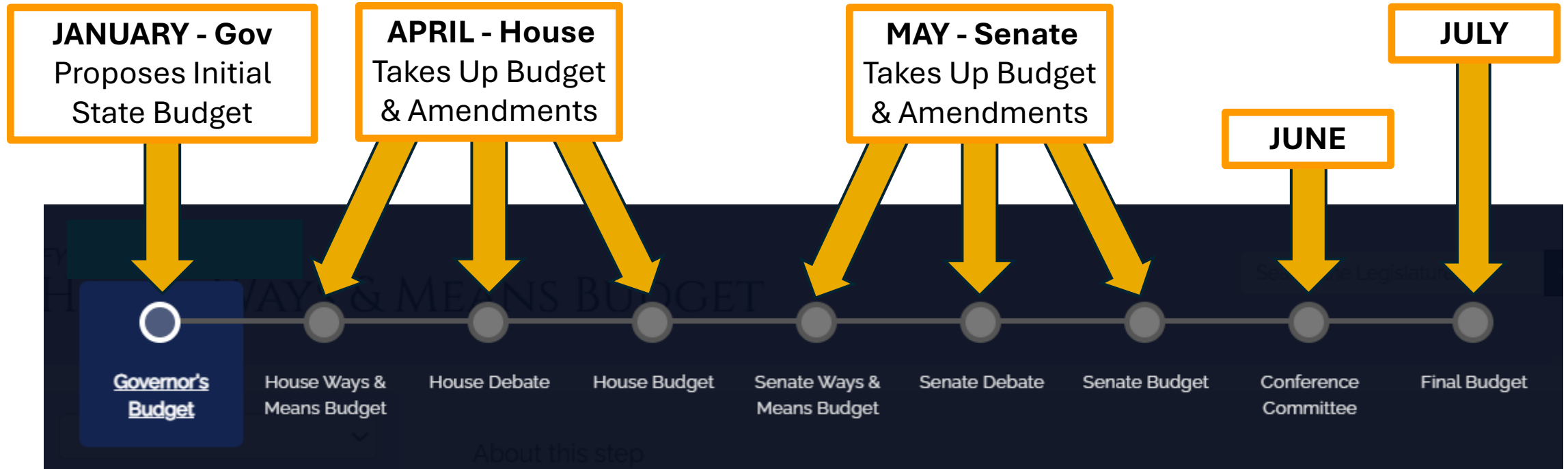
Destiny Maxam



State Budget Update



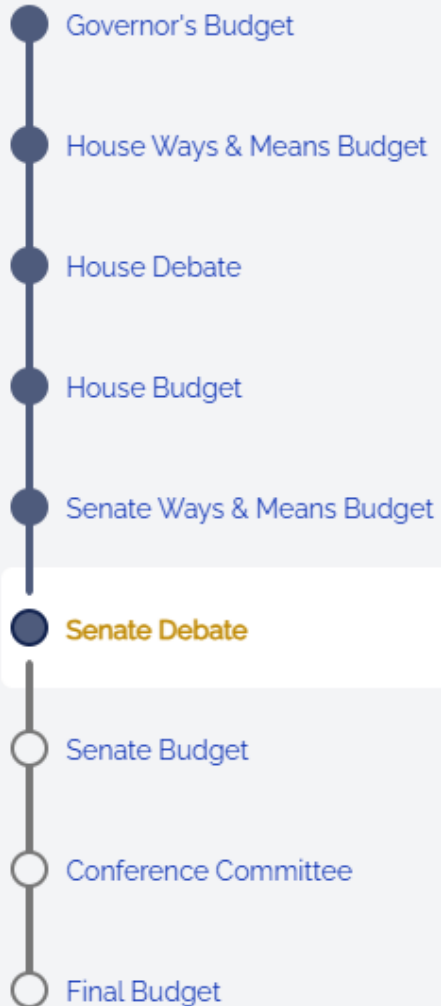
State Budget Timeline



[**CLICK HERE**](#)
to learn more
about the state
budget process.



State Budget Update: House Ways & Means Budget (FY27)



About This Step

- The full Senate considers amendments to the SWMs budget recommendations and debate their inclusion in the bill.
- It is a very busy time for the Senate, as they are constantly working to make sure the concerns and needs of their constituents are addressed in the final budget.



Senate Ways & Means Committee Released FY27 State Budget Proposal

- SWM FY27 proposal contains provisions that include stronger language around Chapter 257, reference to the AFC working group, and importantly, key language from our Turning 22 bill.
- Department of Developmental Services (DDS) and other programs are similar to the Governor and House versions.
- These budget proposals are complex because the detail in the language matters.
- SWM commits to the same \$175 million funding level for Chapter 257 as the Governor's and House's proposals.

[The Arc of MA Senate FY27 Senate Ways & Means State Budget Analysis](#)



MDDC State Budget Advocacy

Educate and inform in the following ways:

- 1. Collect and share stories** from the I/DD community with state leaders and lawmakers each step in the state budget process
[Share Your Medicaid Story With the Massachusetts Developmental Disabilities Council Survey](#)
- 2. Distribute policy resources** that highlight the importance of Medicaid-funded LTSS and Home and Community Based Services (HCBS) and workforce rates
- 3. Meet and collaborate** with state leaders, administrators, and legislators to help ensure people with I/DD do not lose eligibility to services



What can YOU do?

1. Find your legislators
[Find My Legislator](#)
2. Contact them, attend an in-district event, schedule a meeting, and build a relationship
3. Share your story – explain briefly how a policy or the state budget would impact you/your family

The MDDC is here to help!
Reach out to Destiny at destiny.maxam2@mass.gov



Coalition Updates

PCA Program Update

PCA program Budget-

Maura Healey released to the public and asked the PCA workgroup to cut the program by 68 million





Changes to the PCA Program

- **Meal preparation:** A new cap on meal prep hours: no more than 7 hours per week unless the consumer employer submits documentation showing medical necessity.
- **Cap on work hours:** A firm limit has been set. PCAs cannot work more than 60 hours per week total across all jobs, and consumers.
- **New Hire Process:** Consumers must submit all hiring forms, including I-9s, which will be verified via e-Verify. - this will tack on time which will prolong the PCA to be able to work for the consumer employer.



Recognizing, Responding and Reporting Abuse

Disabled Persons Protection Commission (DPPC)

- Helps adults ages 18 to 59
- A person with a disability
- Alleged harm from Partially or fully dependent on another person for care (Paid or unpaid)
- PCA working for agencies or state funded programs are considered mandated reporters based on their role

Aging and Independence

- Ages 60+ living in the community
- Alleged Harm by any individual
- Excludes Cases involving licensed medical facilities
- PCA's are considered not to be mandated reporters under age regulations



Resources

Public Hearing link: <https://www.mass.gov/info-details/masshealth-public-hearings>

DPPC Hotline- 1 800 426-9009 [Disabled Persons Protection Commission – Disabled Persons Protection Commission](#)

Age hotline—1 800-922-2275 [Executive Office of Aging & Independence \(AGE\) | Mass.gov](#)

Link to PCA Council meetings: <https://www.mass.gov/info-details/pca-workforce-general-council-meeting-schedule-for-cy2026>

My contact info: Tamara Huntley tamara.huntley2@mass.gov



REV UP! Update

Brianna Zimmerman
Voting Rights Advocate
Disability Law Center, Inc.



[Bill of Voting Rights - REV UP!](#)



REV-Up! MA

REV-Up! MA Is a statewide coalition of organizations & individuals:

- Educate people with disabilities about voting rights
- Advocate for accessible voting
- Help people register to vote
- Encourage civic engagement of people with disabilities



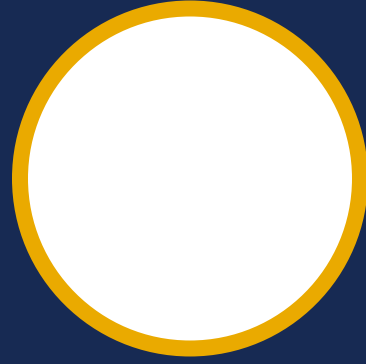


REV-UP! MA

- **Save the Date! May 14th -- REV-Up! MA Webinar:**
 - Voting rights for people with disabilities
 - Other useful information on accessible voting in Massachusetts
- Sign up to receive REV-Up! MA emails about the webinar and other upcoming events:

<https://revupma.org/wp/sign-up/>





GAIN Update

Guardianship Alternatives Innovation Network



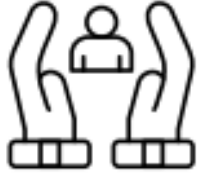
Guardianship Alternatives Innovation Network (GAIN)



- GAIN is led by MDDC and has a focus on guardianship alternatives
- GAIN began as the Guardianship Working Group (GWG) years ago and initially focused on guardianship issues that arose out of a Crocker fellowship.
- In January 2024, members decided to target 3 primary areas: data, training, and a least restrictive framework and/or alternatives.

Unraveling the Mysteries of Guardianship Alternatives

A community conversation with people who live it.



Hosted by the Guardianship Alternatives
and Innovation Network (GAIN)

This panel introduces essential terms, explains alternatives to guardianship, and explores how we can support self-determination at every stage of life.

Featuring:

- Lived-experience advocates
- Clear, accessible explanations
- A supportive space for learning



Wednesday, May 20, 2026

6:00 – 7:30 p.m.

Online via Zoom

Registration is required:
bit.ly/gainpanel



You're Invited!

May 20th @ 6PM

Link to register:

<https://bit.ly/gainpanel>



GAIN GA Panel Discussion Outline

May 20, 2026

6:00pm - 7:00pm

- **Panelist Introduction**
- **Introduce “key” terms**
- **Panelists will share lived experiences using SDM and using SDM while under guardianship**
 1. **Beth Kollett- SDM**
 2. **Craig Kinney and Sandy Heller- SDM & Alternatives**
 3. **Daysiree Perez Batista- limited Guardianship**
 4. **Sam Paster - Guardianship/**
- **Dispel myths about who can use SDM across disability types**
- **Introduction: Showcase practical tools and products share MDDC GAIN Weblink)**

7:00pm - 7:30pm

- **Question & Answer period**



Federal Update



Federal Appropriations

Appropriations means money that is set aside by Congress for a specific purpose.

Reconciliation bills change laws about taxes and how the government spends money. These changes are made to match the goals of the federal budget.

Basically - Congress use reconciliation bills to make big budget-related changes fast, mostly when the majority party doesn't have enough senators to pass them under normal rules.

- The Senate Judiciary Committee released a budget proposal for a budget reconciliation bill to fund:
 1. Immigration enforcement agencies in the Department of Homeland Security (DHS)
 2. Secret Service upgrades related to the President's White House ballroom project
- Congress is also talking about a 3rd reconciliation bill that would invest heavily in the military.



Federal Appropriations Continued

Appropriations means money that is set aside by Congress for a specific purpose.

A markup is like a “legislative workshop” — a meeting of a congressional committee where lawmakers go through the text of a bill, line by line, and decide what changes to make. They can add, remove, or rewrite parts of the bill, and vote on those changes. The goal is to shape the bill into a final version that the whole chamber can debate and vote on.

[Markup: The Ultimate Guide to How Laws Are Forged in Congress \[US Law Explained\]](#)

- Congress is:
 - drafting bills that will include appropriations for different federal government departments and programs.
 - Conducting budget hearings, where they meet with agency leaders who talk about the President's Budget proposal.
 - Holding markups which is when lawmakers meet to work on bills and make updates and changes.

[AUCD | Disability Policy News](#)



Federal Medicaid Data

Medicaid is a public program that provides healthcare and long-term services and supports (LTSS).

The federal government provides funding to help state governments run Medicaid.

Medicaid serves people with disabilities, people who don't make a lot of money, children, and older adults.

Medicaid programs are different in every state.

- Centers for Medicare and Medicaid Services (CMS) data shows that **Medicaid enrollment has dropped by 3.4 million** people between January 2025 and January 2026.
- Most of the eligibility and enrollment changes from H.R.1 have not yet taken effect.
- A Congressional Budget Office (CBO) [report](#) estimates **10 million more people will be dropped from Medicaid and Affordable Care Act coverage by 2034** due to H.R.1.



Texas v. Kennedy

Read more at:

[DREDF](#)

[Disability Scoop](#)



States Sue Over Right Of People With Disabilities To Live In The Community

- Indiana has withdrawn from Texas v. Kennedy, a multi-state lawsuit, where states are challenging the right of people with disabilities to live and receive services in the community as opposed to institutions. (this has been an ongoing lawsuit)
- **These states say that the [2024 update](#) to U.S. Department of Health and Human Services regulations related to Section 504 of the Rehabilitation Act is unconstitutional.**

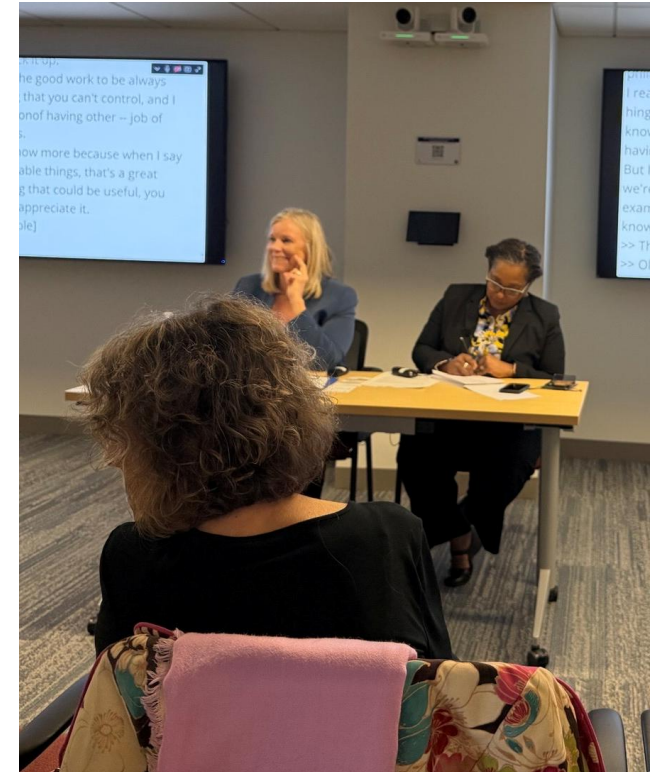
[Indiana Withdraws from Texas v. Kennedy Lawsuit, NHeLP Encourages Other States to Follow - National Health Law Program](#)



Council & Community Events

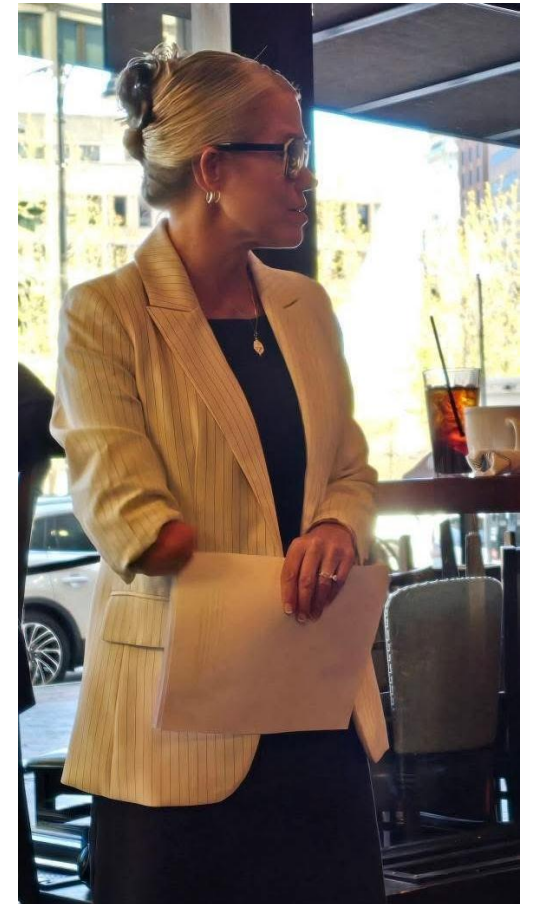


Community Conversation with the Administration on Disabilities (AoD) Commissioner Rebecca Hines





Statewide Family Leadership Series State House Visit





Independent Living Day





QAP HOUSING CELEBRATION SAVE THE DATE!

WHEN: May 21st @ 1PM

**WHERE: Worcester Public Library, Saxe Room
3 Salem St, Worcester, MA**

**MA disability advocates will celebrate an amendment by the
Massachusetts' Executive Office of Housing and Livable Communities
that will increase accessible affordable housing.**

MDDC 2027-31 State Plan Update

Your voice is important!

The Massachusetts Developmental Disabilities Council (MDDC) is doing a survey to learn what is important for people in the developmental disabilities (DD) community living in Massachusetts.

We want to hear from people with developmental disabilities, family members, professionals, and others.

We will include information from the survey in our new Five-Year State Plan. This plan will guide our future work and how we support people with developmental disabilities (DD) and their families in Massachusetts.

Take the survey at surveymonkey.com/r/CGSXQKF



MDDC 2027-31 State Plan

The survey includes questions about possible goals for the MDDC to work on in the next 5 years:

- Disability Identity, Community and Leadership



- Health and Well-Being



- Community Living, Participation and Inclusion



- Thriving Across the Life Span



MDDC 2027-31 State Plan

NEXT STEPS: State Plan committee to draft final 5-year goals and objectives based on survey findings

June-July:

- Present goals and objectives at quarterly Council meeting for discussion and vote
- 45-day public input and review period for State Plan
- Complete a review & analysis of available services, supports, and unmet needs of people with DD in Massachusetts
- Complete other components of the State Plan, including detailed work plan, budget, assurances

By August 15:

- Submit full State Plan to the federal Administration on Disabilities

October 1: Begin new State Plan activities





Partner Updates

Meeting Poll Link:



12th Survey



DD Community Public Comments



Public Policy Meeting Dates

The MDDC Public Policy Committee meets at 3PM on the second Tuesday of most months.

** Veterans Day is November 11th, so the meeting is scheduled for the following Tuesday.*



- August 11, 2026
- October 13, 2026
- *November 17, 2026