



Parent/Professional
Advocacy League, Inc.

The Inside Track

Meri Viano, Associate Director

Pamela Bows, Policy Coordinator



Parent/Professional Advocacy League Training
1/23/2024

Welcome to the Inside Track



- Confidentiality
- Bi-monthly meeting focused on policy, updates and networking
- Knowledge is power– and impact
- PPAL believes that families should have access to all information that affects them, and be able to provide feedback
- You will get a link to the slides and resources within the week that we only share with participants. You can see the meetings prior to check in on policy changes and/or things coming!



Funded by the Klarman Family Foundation

Parent/Professional Advocacy League (PPAL)



A statewide, grassroots, family- run organization in Massachusetts.

PPAL's goal is to promote opportunities for families to become leaders and to ensure that the perspective of families is present in all conversations about children and youth.

Family organizations are an important strategy for boosting family participation, supporting and sustaining family voice (Lazear & Anderson, 2009)



Housekeeping



- Please introduce yourself in the chat – name and role (parent, family support) and where you're from



- Please keep yourself on mute - unless you are speaking - to reduce background noise



- Use the 'raise hand' or chat to let us know when you'd like to speak



- Please type questions into the chat box

Agenda

- **Mental Health Respite Options**
 - Current
 - Future
- **Emergency Department Boarding Diversion programs**
- **What is the Children's Mental Health Campaign?**
- **State Legislation**
 - Advocacy
 - Updates
- **Networking + Resource Sharing**

What is Respite?



General Definition: providing temporary care in relief of a *primary caregiver*

A Big Problem in MA-: Each agency has a different definition for respite.

Research study from 2017 conducted by UMass Medical School did a thorough scan of the landscape.

Not too much has changed, we've worked to find updates since then.

According to a 2014 nationwide scorecard, Massachusetts ranked in the bottom quartile for family caregiver supports.

Programs are difficult to find and are not coordinated in any way

No standard or basic training is required for respite providers by the state, and many of the programs require families to hire and train without support or pay.

Respite options aren't easy to search for, and no indexes contained all respite support options/providers.

Searching for respite with Google or on various Massachusetts support index websites, you'll get mixed results. We searched multiple different phrases and search filters to find different services.

Ideas of Support



Current Programs in Massachusetts

- **Department of Mental Health (DMH)**
 - Home Based Therapeutic Care - no specifics, requires DMH Service Authorization
 - Youth Community Crisis Stabilization through Community Behavioral Health Centers
 - Therapeutic After School Programs- DMH eligibility required
 - Accessing PCA hours, determined by need. (PCS)
- **Department of Children and Families (DCF)**
 - KidsNet (MSPCC)- 10 days per FAMILY (not child) per YEAR. cost is same as the daily rate of support- (32-38\$ a day) ; 5 hours per month per family- \$10.00 hr.
 - Short term respite in a residential placement setting only as agreed upon with area office for high level emergencies.
 - Accessing PCA hours, determined by need. (PCS)
- **MassHealth**
 - Personal Care Attendant Program (PCA)- utilized by DDS / DMH, pays ~\$18/hr, families often pay out of pocket on top of this rate. Hard to find caregivers, state portal but families use care.com, etc.
 - Adult Foster Care- 16+, long-term respite in your home or out with a paid family member or an employee that you hire. Required to need help with Activities of Daily Living (ADLs).
- **Department of Developmental Services (DDS)**
 - Accessing PCA hours, determined by need. (PCS)
 - DESE / DDS Program- ages 6-21, intensive in-home supports to prevent a more restrictive educational or out-of-home residential placement
 - Planned Facility Based Respite Program for Children- Central/West only

Continued

Current Programs in Massachusetts

- **Department of Public Health (DPH)**
 - Early Intervention Regional Care Consultation (RCC) programs- birth-3 with developmental delays, request services through your town
 - Medical Review Teams- short term care for young adults 16-22 with skilled nursing care needs
- **MA Rehabilitation Commission (MRC)**
 - Statewide Head Injury Program (SHIP)- Offers supports for persons with externally caused brain injuries
- **Department of Youth Services (DYS)**
 - JDAI Diversion Program Learning Lab- MAY refer youth to services that include accessing short term caregiver respite through in-home intensive supports.
 - Shelter care directed from courts (domestic assaults)- Intensive Foster care placements as agreed upon in the regions

Mental Health Respite

Current Programs in Massachusetts

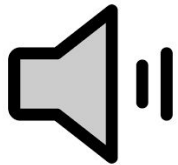
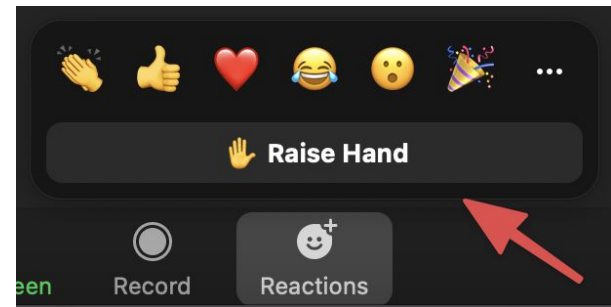
- Private Pay Respite existing through private clinical settings, religious organizations, etc.
- Can be found sometimes through index websites like Family Ties or Network of Care, but they are not comprehensive.
- Fewer options for teens
- “Behaviors” and high support needs usually exclude individuals from participating, even if the individual has gone through an intake process where needs are described.
- Adult Peer Respite (over age of 18) _is available for adults with mental health or substance use needs through Kiva Centers (3 homes- Dudley, Auburn and Bellingham), Wildflower Alliance- Northampton Ma
(Service authorization is not required but you do need a level of independence to qualify)

Discussion:

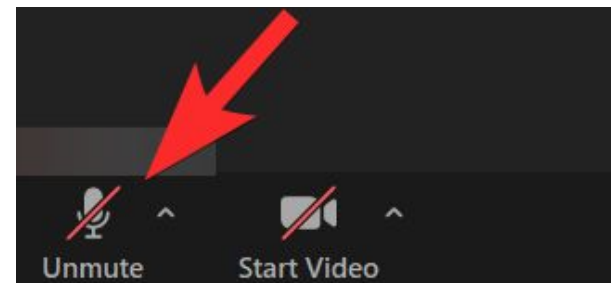
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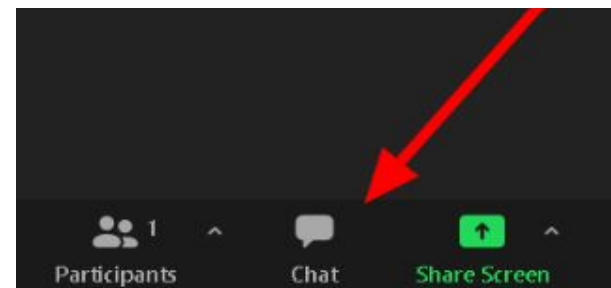
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Type questions into the chat box



Respite Innovations Grant

ARPA Funding

Two-year \$20,000,000 program to promote innovative Respite services that provide relief for family or primary caregivers of individuals with chronic or other health condition, disabilities, or functional limitations. Applications should propose new or enhanced Respite models that enhance, improve, expand, and/or reorganize how Respite is currently provided.

Grant Awardees

AgeSpan, Inc.	Alzheimer's Family Caregiver Support	Senior Care Inc	Toward Independent Living & Learning
Mystic Valley Elder Services, Inc.	Martha's Vineyard Center for Living	Southwest Boston Senior SRVS	Northeast Arc, Inc.
Opportunities for Inclusion	The Arc of Greater Plymouth	Metrocare, LLC	WestMass Eldercare Inc.
Federation for Children with Special Needs	Town of Bourne	Boss Lady Sister LLC (We Rock The Spectrum)	Emissary Health, Inc.
Home for Little Wanderers, Inc.	Seven Hills Family Services Inc.	Childrens Hospital Corporation	Magnifique Health
LUK Crisis Center, Inc.	Premier Home Healthcare of MA	Cooley Dickinson Hospital, Inc.	House of Possibilities Inc.
Advocates Inc.	Incompass Human Services	Archangels	
People Incorporated	Riverside Community Care Inc.	Town of Burlington	
Tri-Valley Inc.	East Point ADHC LLC	Bay Cove Human Services Inc.	
Town of Dennis	South Shore Support Serv Inc.	Lifepath, Inc.	
Grow Associates Inc.	Lynn ADHC, LLC	Charles River Association	
Mental Health Association	The Arc of Bristol County	City of New Bedford	

Respite Innovations Grant

Caregiver 2 Caregiver Respite Federation for Children with Special Needs

Caregiver to Caregiver/C2C Respite Network framework

Parent to Parent (P2P) peer support – successful evidence-based methodology/approach for caregivers of Children and Youth with Special Healthcare Needs

- Utilizes an untapped, fully trained workforce
- Caregivers provide respite to other caregivers of CYSHN with similar health care profiles
- Compensation – private pay, PCA hours, barter
- Mimics Personal Care Assistant (PCA) model – consumer driven; family directed model
- Fosters community/combats isolation
- Low cost – registry, family engagement specialist

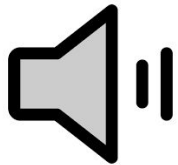
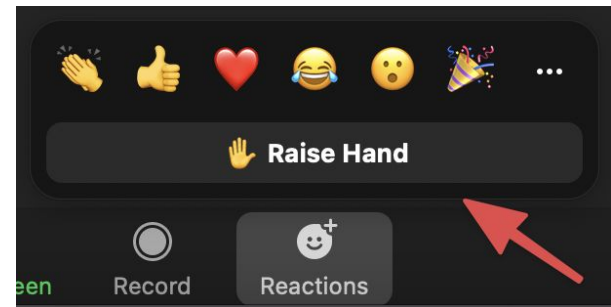
<https://fcsn.org/c2c/#:~:text=It%20draws%20on%20caregiver%20capacity.is%20culturally%20and%20linguistically%20affirming.>

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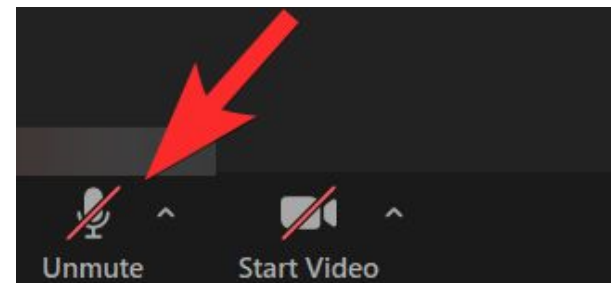
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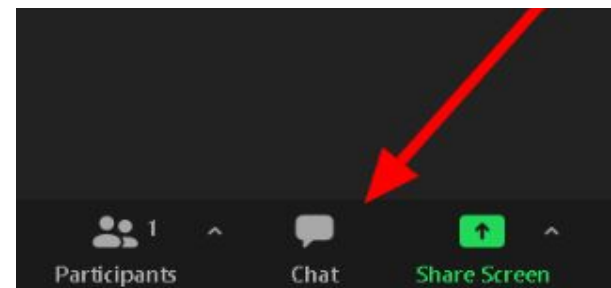
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Massachusetts Emergency Department Diversion

What Is Emergency Department (ED) Diversion?

- Keeps people from boarding in the ED or hospital while waiting for recommended services
- Why is this important?
 - ED Boarding can be very traumatic
 - no supports while waiting,
 - often in a hallway,
 - often mixed adults and children
- NOT the same as inpatient hospital diversion; ED Boarding diversion addresses the gap between folks who don't need hospitalization, but do need a higher level of support than they currently have, & who can't be discharged until the care is lined up.

Massachusetts Emergency Department Diversion

Department of Mental Health Emergency Department Diversion Initiative

- Ages 3-22
- Does not require acute inpatient level of care
- Not eligible for the program if they are already connected to another service or community agency.
- After admission to the ED, hospital staff are supposed to review boarding patients and determine who may be eligible- then they are discharged and the family is followed up with.
- Four to eight weeks in the patient's home with a community-based team. The program starts between 24 or 48 hours after discharging from the hospital.

The program has several benefits for the hospital and their patients:

- Reduces the length of boarding.
- Frees up limited hospital capacity.
- Results in low rates of return.
- Expedites patient access to community supports.

Clinician support- Services include safety planning, family support, regulation skills, coordination of care and referral to long-term support.

Therapeutic support specialist- Specialists work with the clinician to support youth around community integration/connections, managing mental health, and improving communication and social skills.

Parent or caregiver support- A peer with lived experience provides support around parenting, community connections and managing mental health needs.

Massachusetts Emergency Department Diversion

Youth Villages Intercept Program



Prevents children from entering out-of-home care or to reunify them with family as quickly as possible if a period of out-of-home care is necessary (this includes, but is not limited to, foster care, residential treatment, or group home settings). MA offers this program and a transition aged youth program. Youth Villages served 11,110 children in MA in 2023.

- Birth to 18
- Services occur 2-3 times weekly, lasting four to nine months (typically, four to six months for prevention or six to nine months for reunification).

Provides:

- Clinical oversight
- Service coordination- including with schools, court, and other services
- Specific youth support
- Specific parent/caregiver support
- Education and job support
- Financial support
- Assistance building up natural supports

Massachusetts Emergency Department Diversion

Tufts Intensive Hospital Diversion (ED Diversion)



DEFINITION: Intensive Hospital Diversion (IHD) is a specialized service of In-Home Therapy (IHT). The IHD Program will provide intensive short-term (on average, 3-7 days per week for 4 to 6 weeks) in-home crisis stabilization and treatment to youth and their families to support diversion from psychiatric hospitalization and other out-of-home placements.

The clinical goal of this program is to provide youth under 21 and their parents/caregivers with the intensive short-term treatment and support needed to maintain the youth at home safely and to (re)connect them to ongoing outpatient and/or community-based services

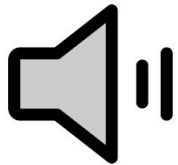
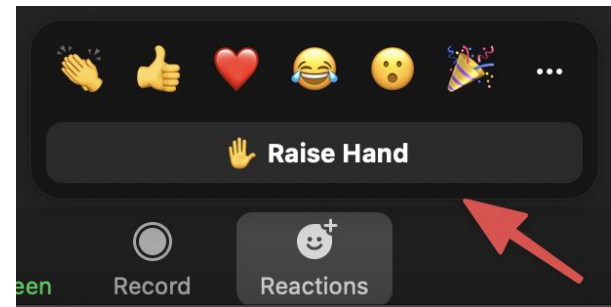
[intensive-hospital-diversion-perf-specs \(tuftshealthplan.com\)](https://tuftshealthplan.com/intensive-hospital-diversion-perf-specs)

Discussion:

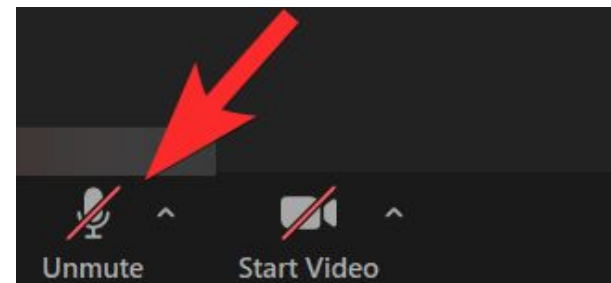
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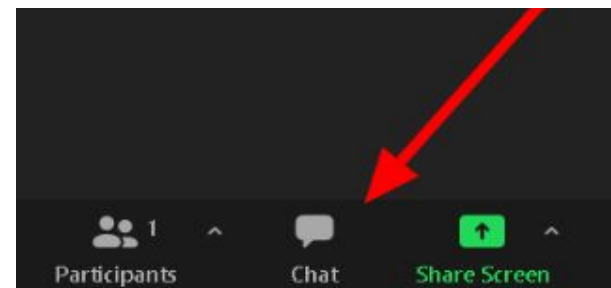
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Children's Mental Health Campaign



Learn More About Children's Mental Health Advocacy and Legislation!

Statewide network established in 2007 that advocates for policy, systems, and practice solutions to ensure all children in Massachusetts have access to resources to prevent, diagnose, and treat mental health issues in a timely, effective, and compassionate way.



PPAL is one of 6 partner organizations, and a founding member.

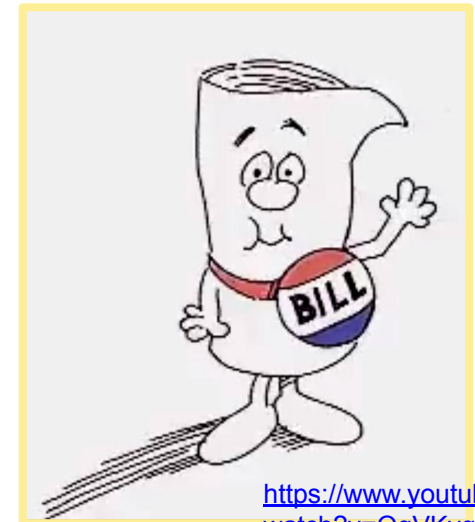
- The Massachusetts Society for the Prevention of Cruelty to Children,
- Boston Children's Hospital,
- Parent/Professional Advocacy League,
- Health Care for All,
- Health Law Advocates,
- Massachusetts Association for Mental Health.

- Focusing on 3 areas: Home, School, Community
- Legislative Advocacy: seeks laws to better protect children's behavioral health care and services;
- Budget Advocacy: aims to protect funding for services vital to children's behavioral health care;
- Regulatory and Administrative Advocacy: seeks to improve regulations and agency policies that impact children's behavioral health services.

Legislation: What Can I Do?

Learn More About Children's Mental Health Advocacy and Legislation!

- Contact your State Senator and Representative
 - Look up yours here: <https://malegislature.gov/Search/FindMyLegislator>
 - Ask them to support the bills that are important to you and your family
 - Are they already supporting it? Thank them for their support– a reminder that it is important!
 - Legislators don't need hundreds of requests to support bills– just a few from their community let them know how important it is. Your voice really makes a difference in local issues!
- Learn more about issues that are important to you!
 - Stay Informed: subscribe to organizations who report out on legislative updates!
- Learn how the Massachusetts Legislature works!
 - <https://www.masslegalservices.org/content/legislative-process-massachusetts-0>



<https://www.youtube.com/watch?v=OgVKvqTltto>

Legislation: What Can I Do?

Learn About Legislative Hearings and Testimony

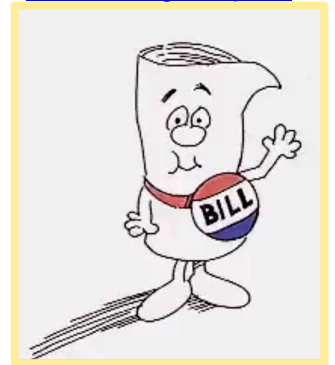
- **What is a Legislative Committee Hearing?**

- Bills that have been introduced go to a committee, based on their topic, to be studied and reviewed.
- Each committee sets a hearing date and invites the public to comment on the bills, called a Legislative Testimony, more below!
- Based on what the committees learn, they decide to, essentially, move the bill forward, edit the bill, refer the bill to a different committee, or decide the bill “Ought Not To Pass.”

- **What is a Legislative Testimony?**

- Any interested party can comment on bills at Committee Hearings!
- Intention is to educate the committee.
- Testimony can be spoken during the hearing, or submitted in writing.
- Spoken Testimony can only be 3 minutes long for individuals, 6 minutes long for ‘panels’ of no more than 3 people.
- See scheduled committee hearings, register to testify here, or watch previously held hearings here!: <https://malegislature.gov/Events>

<https://www.youtube.com/watch?v=OgVKvgTltto>



2023/2024 MA Legislation:

Where Are We In The Legislative Process?

- **What Has Happened**

- This is the 193rd General Court of the Commonwealth of Massachusetts
- Legislative sessions are 2 years, and begin on the odd numbered year– 2023
 - called “First Annual Session” and “Second Annual Session”
- All Legislation filed by the third Friday in January- 1/20/2023
 - House, Senate, and Governor may file bills
 - “by request” - legislators asked to file on behalf of citizens
 - Find current bills <https://malegislature.gov/Bills/Search>



2023/2024 MA Legislation:



Where Are We In The Legislative Process?

- **What Has Happened:**

Joint Committees

- Bills are assigned to Joint Committees
 - Specific topic groups that hear bills based on theme.
 - Made up of House & Senate members
 - Joint Committee on Children, Families and Persons with Disabilities,
 - Joint Committee on Mental Health, Substance Use and Recovery
 - See all Joint Committees: <https://malegislature.gov/Committees/Joint>
- Joint Committee Hearings
 - Most bills have been heard
- Joint Committee Executive Sessions
 - After hearings
 - May be open to the public to watch or private
 - Deadline to report on bills: 1st Wednesday in February
 - “Ought to pass” “ought not to pass” or “study order”
- Formal Joint Committee Sessions end 3rd Wednesday of November- 11/15/2023
- Lawmakers return to session the 1st Wednesday in January- 1/4/2024

2023/2024 MA Legislation:



Where Are We In The Legislative Process?

- **What Will Happen**

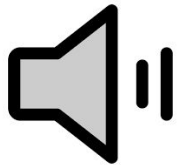
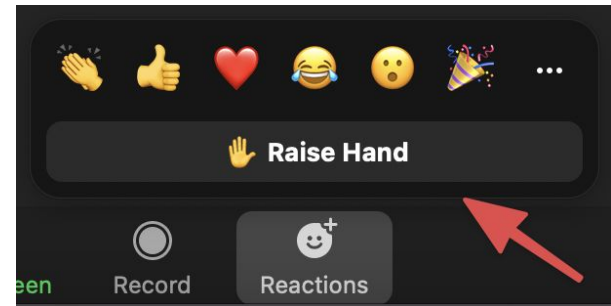
- Joint Rule 10: Joint Committees report on bills by the first Wednesday in February, 2/7/2023
- Reports can be:
 - Study orders
 - the Committee can study this and other related proposed bills
 - often a “dead end” for bills
 - Bills that “ought not to pass”
 - they can be edited if needed and refiled.
 - common, it can take a decade of re-filing and bringing awareness
 - Bills that “ought to pass”
 - moves through the legislative process

Discussion:

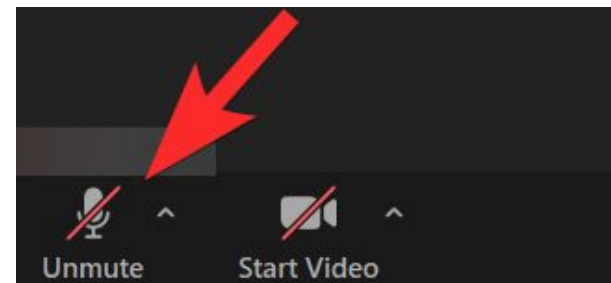
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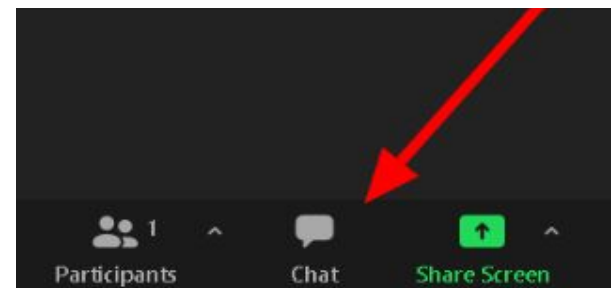
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MA Legislation Updates

S.101 / H.134, An Act regarding families and children in need of assistance.

- PPAL's Meri Viano, Candice Gabrey, and Raquel Negrón, as well as members of the Children's Mental Health Campaign, recently testified in front of the Joint Committee on Children, Families and Persons with Disabilities.
- Would revise the Child Requiring Assistance (CRA) process, as well as raise the minimum age of CRAs to 12 years old.
- No updates available at this time.



MA Legislation Updates

[S.1253](#)/H.1145 **An Act to remove administrative barriers to behavioral health services**

- Joint Committee on Mental Health, Substance Use and Recovery
- Heard on 12/4/2023

[H989](#)/[S610](#) **An Act for supportive care for serious mental illness**

- Joint Committee on Financial Services
- Heard on 6/26/2023, no updates available



MA Legislation Updates

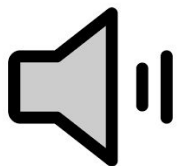
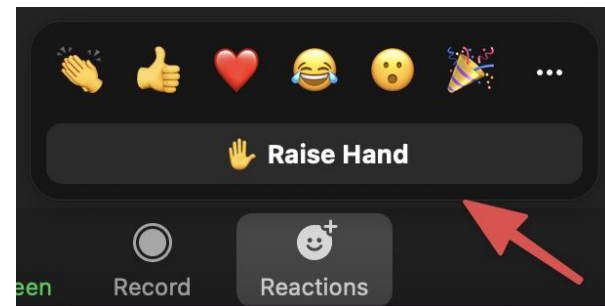
- **An Act relative to mental health education | H.497 & S.240 Rep. Higgins & Sen. Collins**
 - Heard on 10/11/2023
 - Joint Committee on Education
- **An Act relative to MassHealth reimbursement to schools S.794 Sen. Moran**
 - Heard on 7/14/2023
 - Joint Committee on Health Care Financing- later report date
- **An Act establishing a child and adolescent behavioral health implementation coordinating council H.1979 Rep. Decker**
 - Heard on 11/6/2023
 - PPAL's Pamela Bows and other Children's Mental Health Campaign members testified.
 - No updates available, but the committee members expressed their favor for the bill during testimony.

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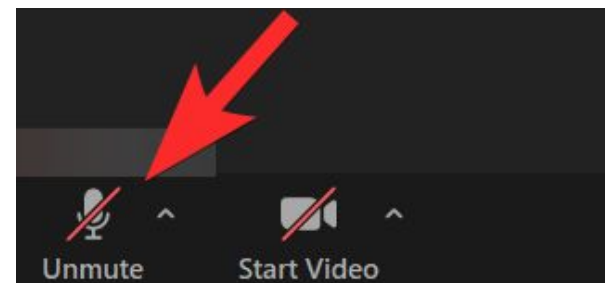
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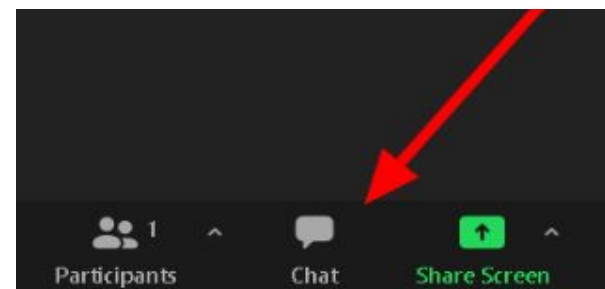
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Question Of The Month

PPAL's **January** Question of the Month

Are you raising a child or supporting a young adult with behavioral health needs?
Are you working closely with someone who is?

RESTRAINTS & SECLUSION

**What is your family's
experience?**



To Answer the Question, Please Visit
<https://ppal.net/question-of-the-month/>

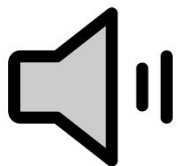
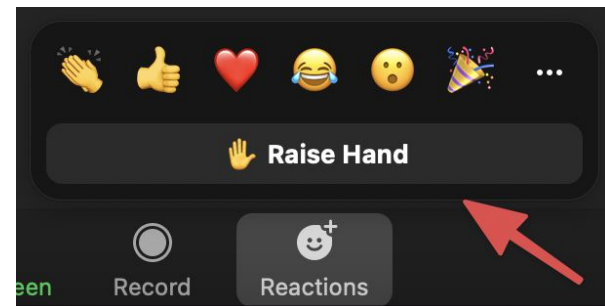


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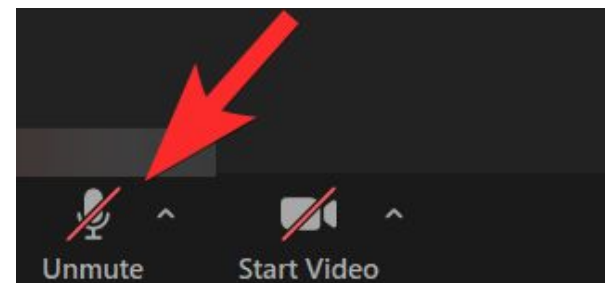
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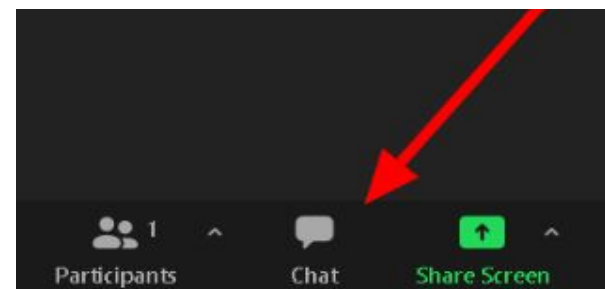
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Networking—

Do you have

Resources

Job Opportunities

Recommendations

Requests

that you would like to share?

Please come off mute, or indicate in the chat that you would like to speak!



Thank You for attending PPAL's Inside Track!

You will receive the bulletins and resources discussed within the next few days.