



Parent/Professional  
Advocacy League, Inc.

# The Inside Track

*Meri Viano, Associate Director*

*Pamela Bows, Policy Coordinator*



Parent/Professional Advocacy League Training  
11/28/2023

# 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



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

- **PANS/PANDAS**
- **Updated Massachusetts Dyslexia Guidelines**
- **Parent's Notice of Procedural Safeguards**
- **Federal MA DESE Investigation**
- **BRYT awarded School Based Bridge Program**
- **School Based Behavioral Health Summit, Dec. 14th**
- **MA Peer Workforce Summit, Dec. 8th**
- **DCF Feedback Sessions for Families**
- **State Legislation**
  - Advocacy
  - Updates
- **Networking + Resource Sharing**

## PANS/PANDAS

### What is PANS/PANDAS & State Legislation Updates

**PANS** *Pediatric Acute-Onset Neuropsychiatric Syndrome*

**PANDAS** *Pediatric Autoimmune Neuropsychiatric Syndrome*

Associated with Streptococcus

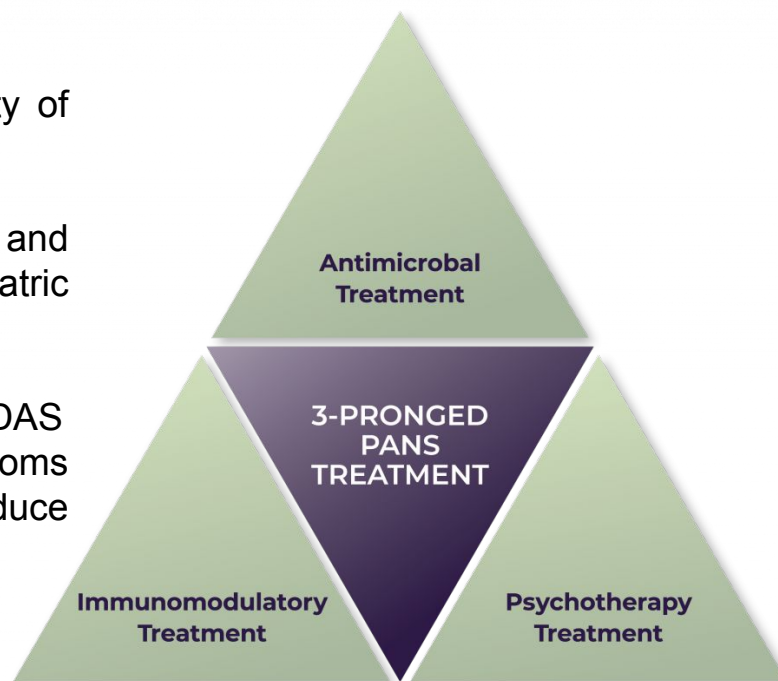
- Misdirected immune responses that result in newly abrupt onset **or worsening** of OCD and/or restricted food intake, concurrently with two neuropsychiatric, cognitive, behavioral, or neurological symptoms in seven categories.
- PANS can be triggered by infections, metabolic disturbances, psychosocial stress, and other inflammatory reactions. Infectious triggers include upper respiratory infections, influenza, recalcitrant sinus infections, mycoplasma pneumonia, and Lyme borreliosis, among others.
- After initial onset, symptoms continue relapsing/remitting.
  - Initial triggers may differ from secondary triggers.
  - During each recurrence, symptoms can worsen, and new symptoms may manifest.

<https://aspire.care/symptoms-diagnosis/symptoms/>

# PANS/PANDAS

## What is PANS/PANDAS & State Legislation Updates

- It is estimated 1 in 200 children will develop PANS PANDAS.
- Some evidence suggests that PANS PANDAS could account for as many as 1 in 10 new pediatric cases of OCD each year.
- The exact numbers are not certain as the majority of PANS PANDAS cases go undiagnosed.
- According to the NIMH, a timely diagnosis and treatment may prevent as much as 25% of all pediatric mental illnesses
- There is clinical urgency to learn about PANS PANDAS to help close the gap between the onset of symptoms and the start of appropriate treatment to reduce suffering and achieve remission.



## PANS/PANDAS

### What is PANS/PANDAS & State Legislation Updates

<https://aspire.care/featured/massachusetts-pans-pandas-updates/>

Bill S.1266, An Act relative to PANDAS/PANS <https://malegislature.gov/Bills/193/S1266>

Testimony heard on 11/6/2023

Bill text:

- Screen all children in psychiatric hospital settings & therapeutic day schools to see if there is a root cause related to PANS/PANDAS (DMH/DOE)
- Study to find:
  - Prevalence of PANS/PANDAS in the above settings
  - Outcomes of misdiagnosed children

### **Calls To Action:**

- Ask your State Representative and Senators to support this bill  
<https://malegislature.gov/Search/FindMyLegislator>
- Tell people in your community about PANS/PANDAS  
<https://aspire.care/resources/pans-pandas-brochures-and-handouts/>
- If you think your child could have PANS/PANDAS, have them evaluated  
<https://aspire.care/symptoms-diagnosis/diagnosing/>



Do what  
you can!

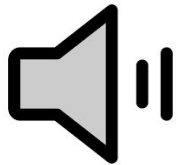
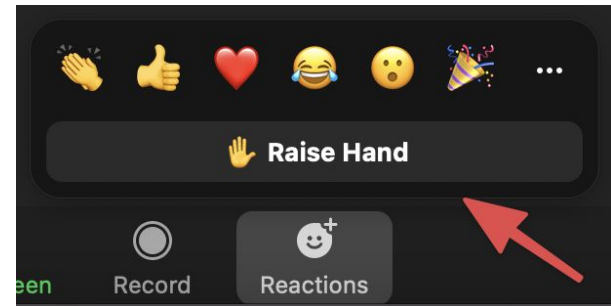


# Discussion:

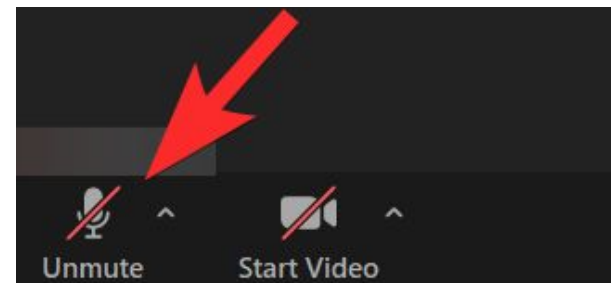
To join in, you can



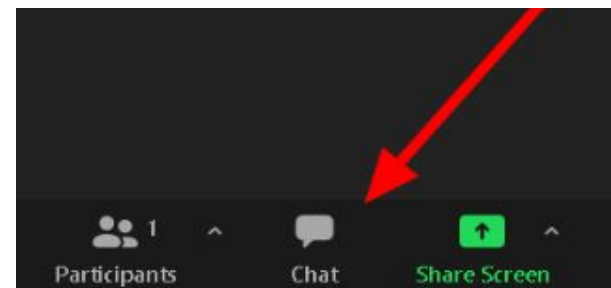
Use the Raise Hand feature



Unmute



Type questions into the chat box



# *Updated Massachusetts Dyslexia Guidelines*

## **Addresses Multilingual Learners**

The Massachusetts Dyslexia Guidelines have been updated to include *new, more robust information to center the unique assets of multilingual learners who are at risk for dyslexia.*

*Chapter 9: Considerations for Multilingual and Bidialectal Learners at Risk for Dyslexia* includes:

- ☐ Screening and supplemental data collection and interpretation for multilingual learners
- ☐ Basics of cross-linguistic transfer and language development
- ☐ Differences between reading difficulty and language acquisition needs
- ☐ Considerations for screening and instruction of bidialectal learners

<https://www.doe.mass.edu/sped/dyslexia-guidelines.pdf>

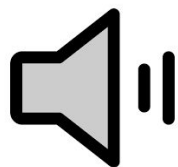
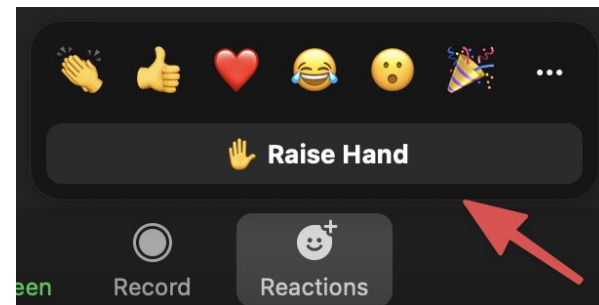
*From Chapter 9: “Dyslexia affects individuals in all cultures and languages and occurs at the same rate among multilingual learners as it does among monolingual students. While home language may impact how dyslexia presents, multilingual learners can be identified as having dyslexia. However, because it can be difficult to determine whether multilingual learners’ literacy needs are the result of ongoing language development or of a learning disability, multilingual learners may experience delayed, over-, or under-identification of disabilities. This chapter addresses important considerations for the successful identification and monitoring”*

# Discussion:

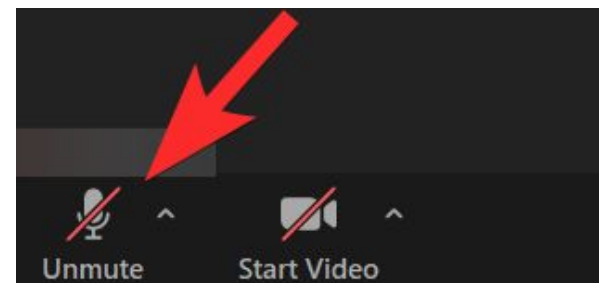
To join in, you can



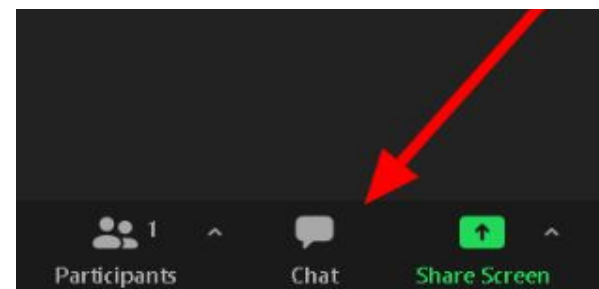
Use the Raise Hand feature



Unmute



Type questions into the chat box



# *Parent's Notice of Procedural Safeguards*

## Recently Updated:

- DESE recently updated the Parent's Notice of Procedural Safeguards (PNPS) website and ensured that all links are current and relevant.
- The PNPS has been translated into two additional languages, Polish and Ukrainian, which can be found on the website.

<https://www.doe.mass.edu/sped/prb/>



### *What is the Parent's Notice of Procedural Safeguards?*

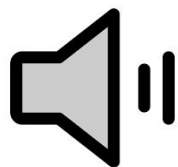
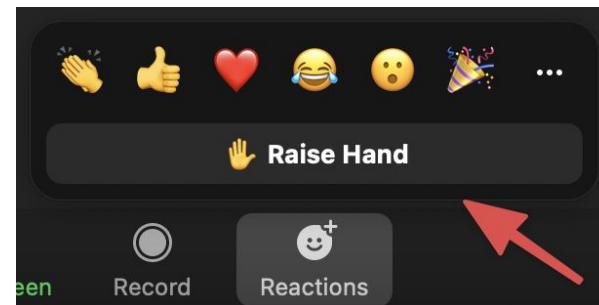
- Must be provided to families each year that a student receives special education services
- Informs families of their rights and their student's rights
- Gives definitions to commonly used terms within special education law
- Goes over the evaluation process, independent educational evaluations, resolving disputes, discipline, transition, and other useful information.

# Discussion:

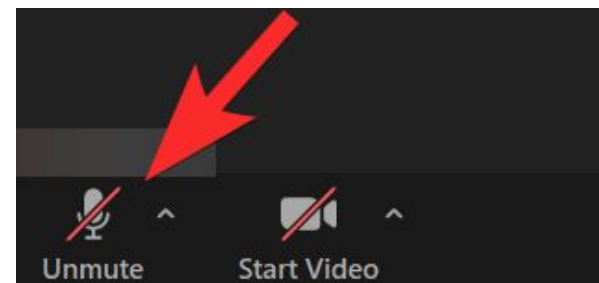
To join in, you can



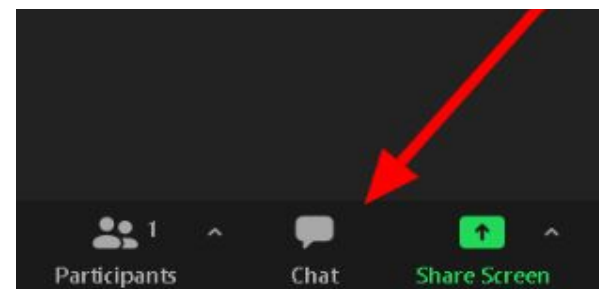
Use the Raise Hand feature



Unmute



Type questions into the chat box



# ***Federal Investigation of Massachusetts DESE***



## **3 Areas of Concern:**

“Citing concerns from families, the federal government is launching a review of the state’s special education system. It is questioning if Massachusetts adequately supports students with disabilities, and whether the state provides proper oversight of public schools or its network of private special education schools.”

**1. State-level Complaints to DESE through the Problem Resolution System (PRS)**

**2. Child Find Procedures**

**3. State-Approved Special Education Schools (766 Schools)**

<https://www.wbur.org/news/2023/10/05/massachusetts-special-education-schools-federal-review>

# *Federal Investigation of Massachusetts DESE*

## **1. State-level Complaints to DESE through the Problem Resolution System (PRS)**

- Allege that DESE only issues decisions on procedural violations & dismisses more substantive allegations raising a denial of a free appropriate public education (FAPE).
- Concerns regarding DESE's State complaint investigation procedures and whether such investigations include activities beyond LEA record review.
- Raised questions about the tracking of State complaints, how the State is ensuring State complaint decisions are implemented, and whether the parent retains the right to file a due process complaint after a State complaint investigation is completed. Parents and advocates have cited delays in the issuance of written decisions and have expressed concern about their ability to enforce the required actions in the State complaint decisions.

### **OSEP is requesting that DESE submit the following information within 60 days:**

- Policies and procedures addressing the investigation of State complaints;
- Any protocols or trainings provided to State investigators regarding the investigation of State complaints;
- Current tracking logs for State complaints;
- Random sample of 20 dismissed or withdrawn State complaints from the last three years;
- Policies and procedures related to the resolution of State complaints;
- Evidence of completion (e.g., tracking logs) of corrective actions required by written decisions on State complaints.

*Read the entire letter from OSEP to DESE:*  
<https://media.wbur.org/wp/2023/10/MA-B-Letter-9.29.23-final.pdf>

# *Federal Investigation of Massachusetts DESE*

## 2. Child Find Procedures

- Under federal law, public schools must look for, find, and evaluate kids who need special education services.
- Federal gov't collected and reviewed an extensive number of LEA policies and procedures and question whether these procedures are consistent with the Individuals with Disabilities Education Act (IDEA).
- Long delays reported in obtaining eligibility for students under IDEA, including students with specific learning disabilities.
- Delays reported in completing evaluations due to the implementation of response to intervention (RTI) activities.
- Unclear how DESE monitors LEAs on the implementation of these requirements, in particular policies, procedures, and practices regarding LEAs' referrals for evaluation as well as LEAs' use of RTI.

### **OSEP is requesting that DESE submit the following information within 60 days:**

- State's policies and procedures for conducting child find, including referrals for evaluations;
- State's policies and procedures to ensure each public agency conducts a full and individual initial evaluation in a timely manner;
- State's policies, procedures, and practices regarding the use of RTI or other multi-tiered system of supports;
- State's criteria for determining whether a child has a specific learning disability;
- State's monitoring protocols addressing child find (including the use of RTI), referral for evaluations, evaluation procedures and eligibility determinations;
- Examples of monitoring reports, State complaint decisions, due process hearing decisions, or other documentation issued within the last three years that include findings of noncompliance related to child find.



# ***Federal Investigation of Massachusetts DESE***

## **3. State-Approved Special Education Schools (766 Schools)**

Concerns regarding the State's oversight of the State-approved private special education schools, referred to as "766 schools," which are schools where children with disabilities are placed by public agencies in order to make FAPE available to such children. Their concerns include:

- The placing LEA's oversight to ensure FAPE after a child is placed in a 766 school:
  - Parents reported they are afraid to address their concerns with the private schools and LEAs for fear of retaliation and loss of the student's placement.
  - 766 schools are monitored by the Office of Approved Special Education Schools (OASES)-- separate from the State's special education monitoring office. Standards measured by OASES appear to address the certification of the school (e.g., health and safety standards), rather than the implementation of IDEA
- Private school implementation of the child's IEP as written upon acceptance to the school
  - Parents/advocates alleged that IEPs are rewritten after enrollment to include services based on the resources the private school currently has available, rather than the individual needs of the child.
- Whether there are qualified personnel available in the private school to provide the required special education and related services.

## ***Federal Investigation of Massachusetts DESE***

### **3. State-Approved Special Education Schools (766 Schools), cont.**

**OSEP is requesting that DESE submit the following information within 60 days:**

- State's policies and procedures regarding the placement of students in 766 schools;
- State's policies and procedures regarding the monitoring of 766 schools, including any monitoring protocols;
- Samples of any memorandum of understanding or other agreements between the SEA/LEAs and 766 schools;
- Examples of monitoring reports, State complaint decisions, due process hearing decisions, or other documentation related to 766 schools that include findings of noncompliance related to IDEA issued within the last three years.

### **Call To Action:**

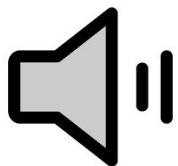
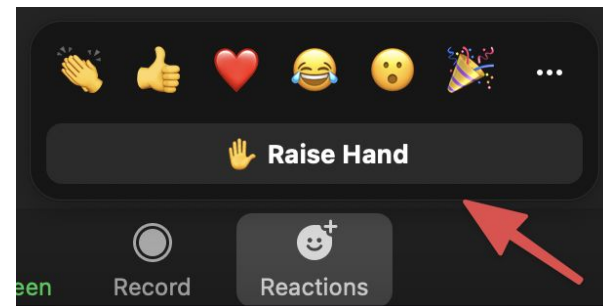
Is this your family's experience accessing special education in MA?  
Connect with PPAL to share your story, connect with other families,  
and receive support!

# Discussion:

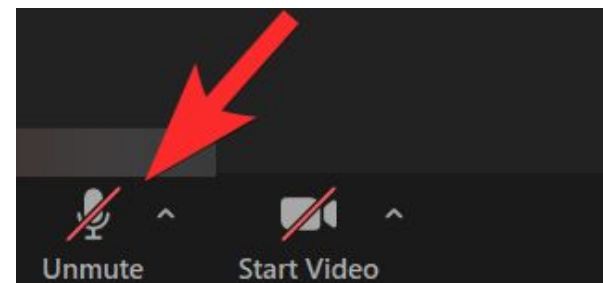
To join in, you can



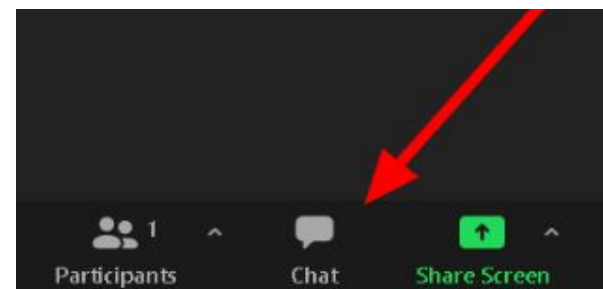
Use the Raise Hand feature



Unmute



Type questions into the chat box



# ***RFR for School Based Bridge Program - UPDATE***

## **BRYT awarded School Based Bridge Program!**



### **“BRIDGE FOR RESILIENT YOUTH IN TRANSITION (BRYT)**

Partnering with schools and families to promote healing, wellness, and academic success for teens returning from prolonged absences.

School re-entry can be overwhelming, fraught with problems including depression, anxiety, and fear of social rejection. These youth disproportionately struggle, attempt suicide, abuse alcohol and drugs, and function poorly at home, in the classroom, and among friends. They are at high risk for academic failure and their families are often in crisis, as well. The challenge of recovery while managing typical adolescent social and academic pressures can lead to a high rate of relapse. Up to half of students with serious mental health disorders drop out of high school.

Each BRYT program approaches staffing, space, and services with a consistent vision, while customizing the specifics for each school population and for each student.”

*-from BRYT's website*

- [https://www.brooklinecenter.org/wp-content/uploads/2018/09/BRYTNotesReport\\_FromTheBrooklineCenter.pdf](https://www.brooklinecenter.org/wp-content/uploads/2018/09/BRYTNotesReport_FromTheBrooklineCenter.pdf)
- <https://www.brooklinecenter.org/services/school-based-support/bryt-program/>

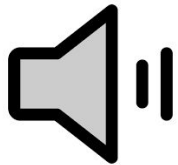
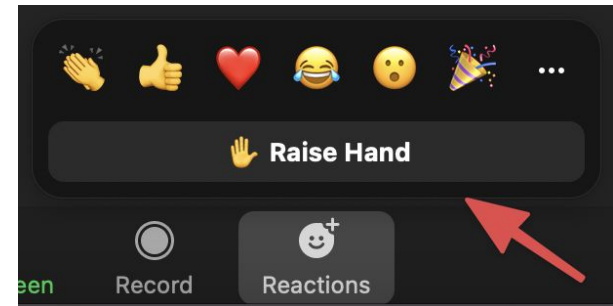


# Discussion:

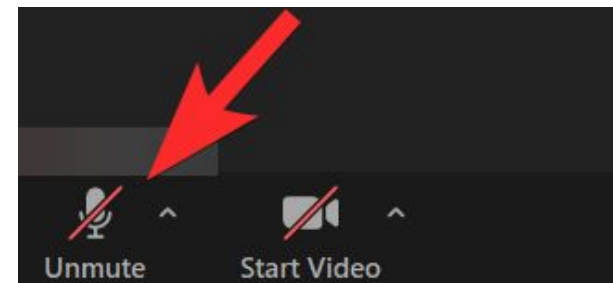
To join in, you can



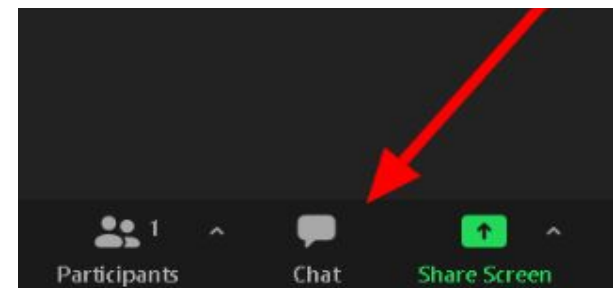
Use the Raise Hand feature



Unmute



Type questions into the chat box



***Thursday, December 14th, 2023***  
**9:00 AM - 3:00 PM**  
**Regis College**

# School-Based Behavioral Health Summit

The Children's Mental Health Campaign and the BIRCh Project team at UMass, invites you to attend the School-Based Behavioral Health Summit on Thursday, December 14th. The day will feature remarks from Secretary of Education Patrick Tutwiler and Secretary of Health and Human Services Kate Walsh, along with panel discussions and interactive breakout sessions.

Join us, and help shape the future of school-based behavioral health in the Commonwealth.  
Secure your spot by registering today! Registration closes on Thursday December 7th.



BIRCh Project

<https://www.childrensmentalhealthcampaign.org/summit/>



# School Based Behavioral Health Summit

*Thursday, December 14th, 2023*

**9:00 AM - 3:00 PM**

**Regis College, Weston MA**



## *Agenda*

### **Working across systems to meet the needs of Massachusetts school communities**

*A conversation with Secretary of Education Patrick Tutwiler and Secretary of Health & Human Services Kate Walsh*

### **Next steps for implementing comprehensive school-based behavioral health for schools in Massachusetts**

*Melissa Pearrow, PhD., Executive Director, BIRch Project, University of Massachusetts  
Shella Dennerly, PhD, LICSW, Director Boston Children's Hospital Neighborhood Partnerships*

#### Choose 2:

**Session 1:** Increase and retain a diverse, well trained and supported SBH workforce

**Session 2:** Ensure access to equitable & sustainable funding to support a full continuum of care

**Session 3:** Formalize and strengthen school and community partnerships



<https://www.childrensmentalhealthcampaign.org/summit/>





# MA PEER WORKFORCE COALITION SUMMIT & CAREER FAIR



Interested in pursuing a career as a Peer Recovery Coach (RC), Certified Peer Specialist (CPS), Community Health Worker (CHW), Family Partner (FP), Young Adult Peer Mentor (YAPM), or Certified Older Adult Peer Specialist (COAPS)?

Look no further! Join us at our inclusive Summit where you'll engage with prominent industry leaders, partake in networking opportunities, on-site interviews, panel discussions, and interactive workshops. Be part of our pioneering efforts in advocacy and shaping legislation to improve our mental healthcare systems and communities!



**FRIDAY** 10AM-3PM  
**12/08/2023**



**DOUBLETREE by Hilton**  
5400 COMPUTER DRIVE,  
WESTBOROUGH, MA



[www.mapeerworkforce.org](http://www.mapeerworkforce.org)





# Are you a parent or caregiver who has direct experience with DCF reports made by your child's school?

Family Matters 1st, Movement for Family Power, and Boston University is conducting a study on school-based DCF reporting. We are seeking to speak to parents who are interested in sharing their stories and raising awareness around this important issue.

**All interview participants will be compensated \$75 for their time.**

For more information,  
contact Andrew King:

✉ [arking86@bu.edu](mailto:arking86@bu.edu)

☎ 857.209.1117



## Media Requests

### Talk about your experience to help others!

*Multiple Inquiries- email [info@ppal.net](mailto:info@ppal.net)*

Looking to hear from:

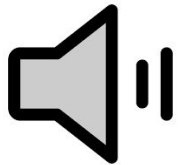
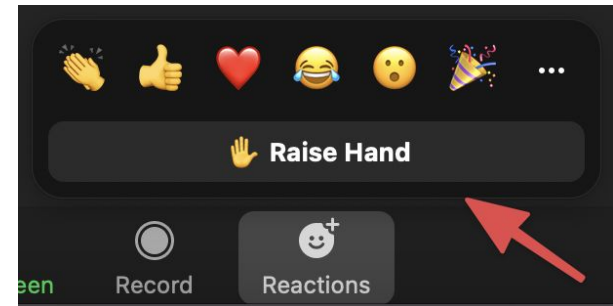
- Families that have multi-agency involvement
  - (including court, CRA and other avenues)
- Peer counseling experiences
- Foster families willing to talk about waiting in ER and not getting assessed timely for mental health crises
- Family experience with CBHCs (Community Behavioral Health Centers)
- 988 and BHHL ( Behavioral Health Helpline)  
Have you used either? How is it working?

# Discussion:

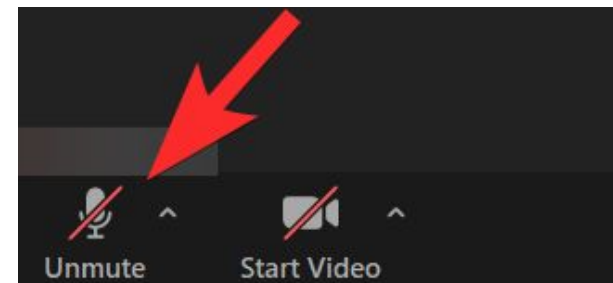
To join in, you can



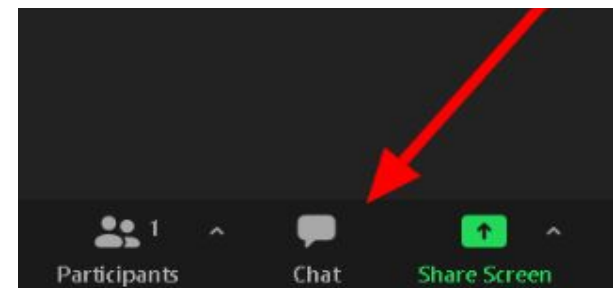
Use the Raise Hand feature



Unmute



Type questions into the chat box



## *Question Of The Month*

### PPAL's **November** 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?

**What's your  
experience with CRAs  
(Child Requiring  
Assistance)?**



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

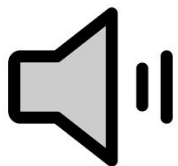
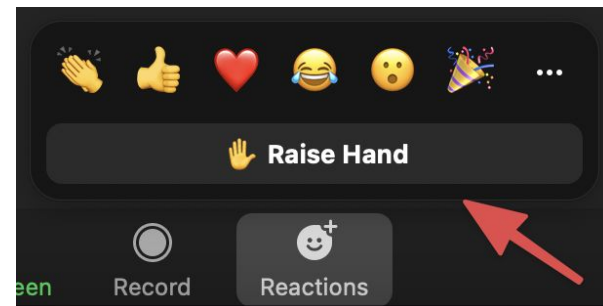


# Discussion:

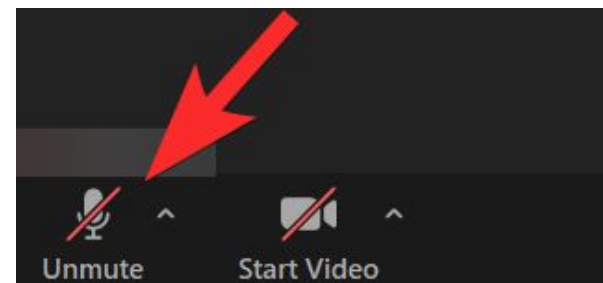
To join in, you can



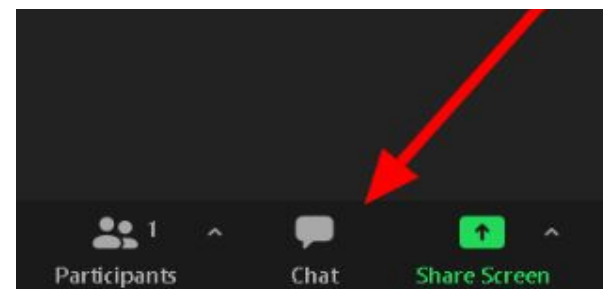
Use the Raise Hand feature



Unmute



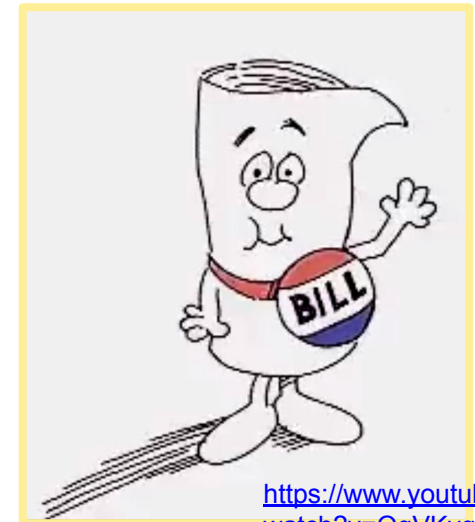
Type questions into the chat box



# 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>

# 2023 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 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



# 2023 MA Legislation:

## *Where Are We In The Legislative Process?*

- **What Will Happen**

- Lawmakers return to session the 1st Wednesday in January- 1/4/2024
- 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” and no study actually occurs
  - 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 - more to come in January’s Inside Track!

# Legislation: What Can I Do?

## *Learn About Legislative Hearings and Testimony*

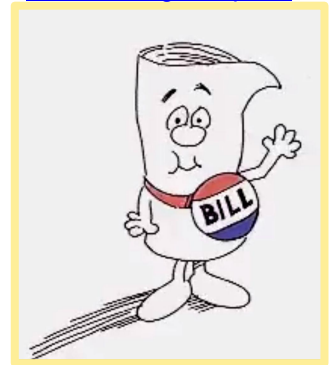
- **What is a Legislative Committee Hearing?**

- 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>

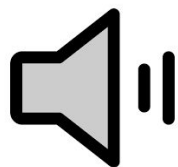
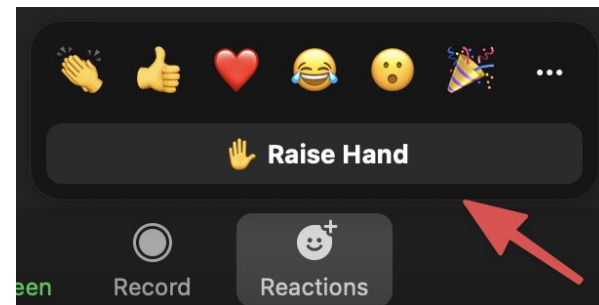


# Discussion:

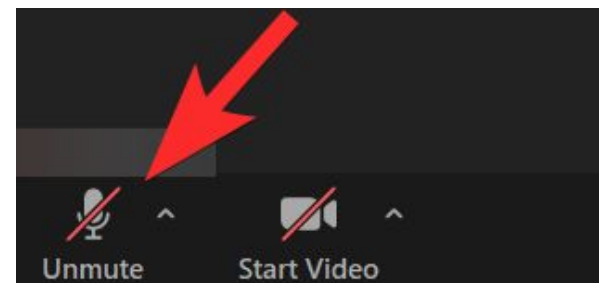
To join in, you can



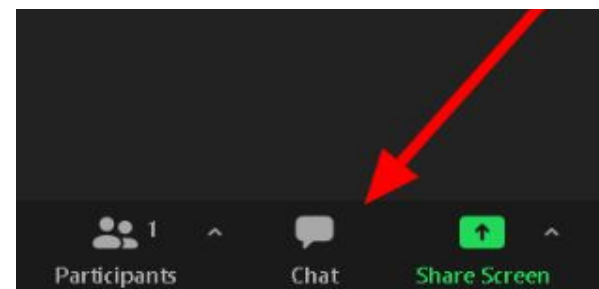
Use the Raise Hand feature



Unmute



Type questions into the chat box



# 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
- Hearing 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

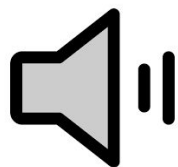
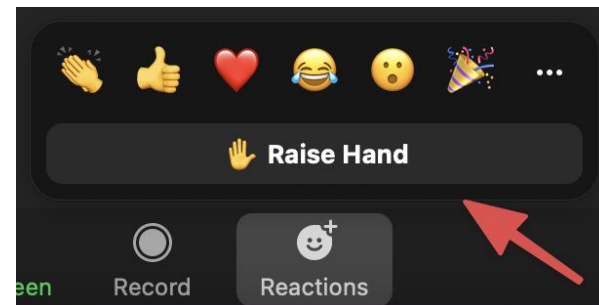
- **An Act relative to mental health education | H.497 & S.240 Rep. Higgins & Sen. Collins**
  - Heard on 10/11/2023
  - Joint Committee on Education
- **An Act relative to MassHealth reimbursement to schools S.794 Sen. Moran**
  - Heard on 7/14/2023
  - Joint Committee on Health Care Financing- later 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.

# Discussion:

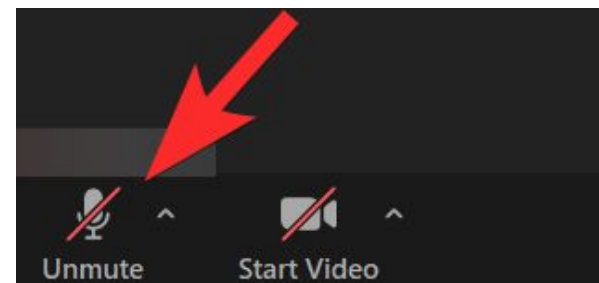
To join in, you can



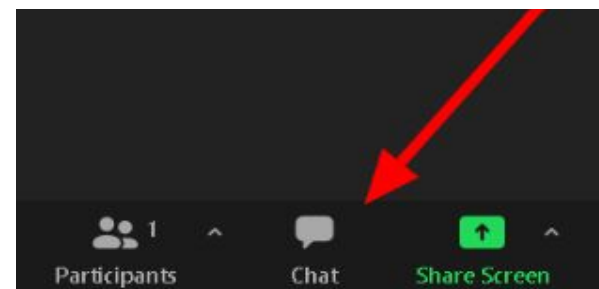
Use the Raise Hand feature



Unmute



Type questions into the chat box

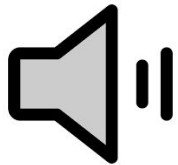
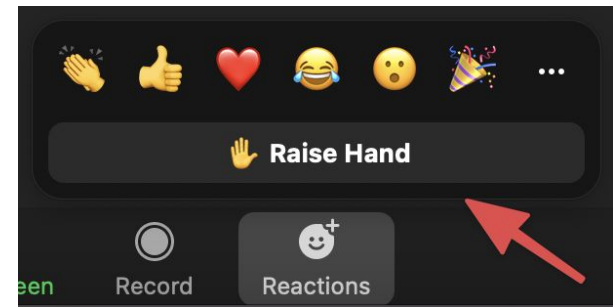


# Discussion:

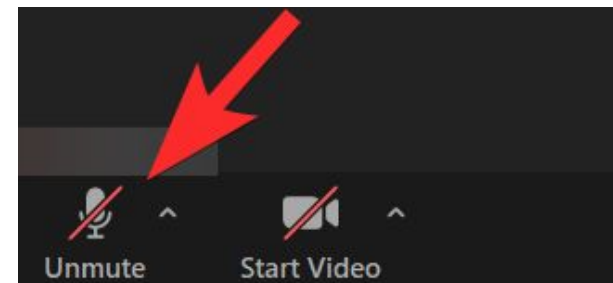
To join in, you can



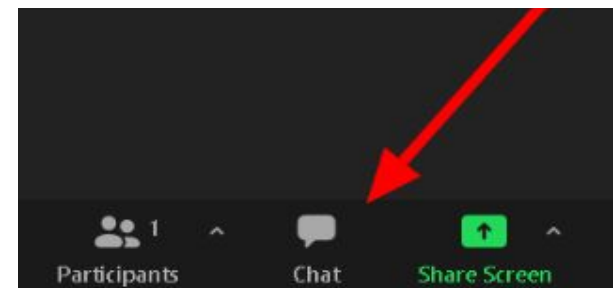
Use the Raise Hand feature



Unmute



Type questions into the chat box





# 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.