

# The Mental Health Needs of Children and Families

## *ASE Statewide Conference*

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The Massachusetts Family Voice for Children's Mental Health

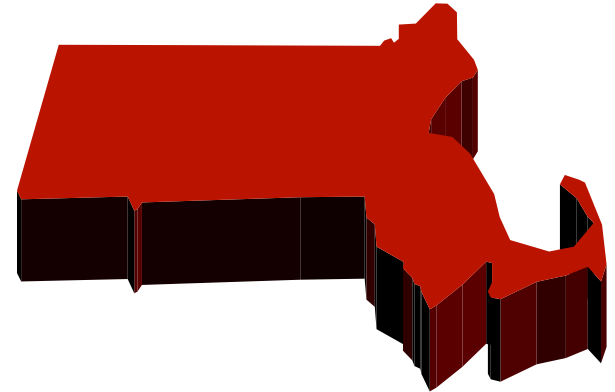
# The personal becomes professional

- It began very early for my family
- Pivotal moments
- Learning to tell my story
- Finding partners, other families
- Changing things for more families than my own



# Introducing Parent/Professional Advocacy League (PPAL)

- A statewide, grassroots, nonprofit, *family-run* organization.
- Founded in 1991, PPAL is the state organization of the National Federation of Families for Children's Mental Health and a founding member of FREDLA.
- PPAL's goal is to promote opportunities for families to become strong leaders and to increase and sustain parent and youth involvement at all levels of the system.



# Our families

- Parents whose children have mental health needs:

- Highest divorce rate of any group of parents whose children have special needs
- More likely to lose their jobs or live in poverty (national survey of children with special health care needs)
- Highest rate of out of pocket expenses for needed services
- Most likely to experience stigma and blame



# Families improve children's outcomes

- Youth receiving residential interventions who have involved families are more likely to achieve positive social and behavioral outcomes (Hair, 2005)
- Youth in the child welfare system who have parental visitation, have lower levels of behavioral problems (McWey, Acock, & Porter, 2010)
- Family acceptance of LGBT youth protects against depression, substance abuse and suicidal ideation (Ryan, et al, 2010)





# PPAL: 26 years ago

- Offered 2 support groups and ONLY worked with families whose children had issues like depression and anxiety
- Worked to convince professionals that families had expertise and services should be family-driven
- Collected anecdotes and taught families to tell their stories – though stigma often stopped them



# PPAL: today

- Support groups across the state
- Families attend policy groups, advisory boards, review documents, participate in advocacy
- Collaboration – with parents, professionals and providers working together – occurs regularly
- Family stories are in the media, told at the state house

The Boston Globe

Money

90.9

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# What does PPAL do?

1. Support via parent peer support for families
2. Advocacy
3. Provide training for families and professionals
4. Family voice in juvenile justice
5. Support and development of youth leadership
6. Research and data collection
7. Outreach to diverse communities
8. Co-occurring substance use and mental health
9. Public education, information and awareness campaigns
10. Information and communications network



The Massachusetts Family Voice for Children's Mental Health



# #1: Support for families

- More than 2,500 calls each year – about 20% from professionals
- Top issues: schools, access to health care, insurance problems and mental health diagnoses
- PPAL family support staff have lived experience raising a child with emotional or mental health needs
- No eligibility, no time limit, can be intensive or as needed
- Support groups, on line support



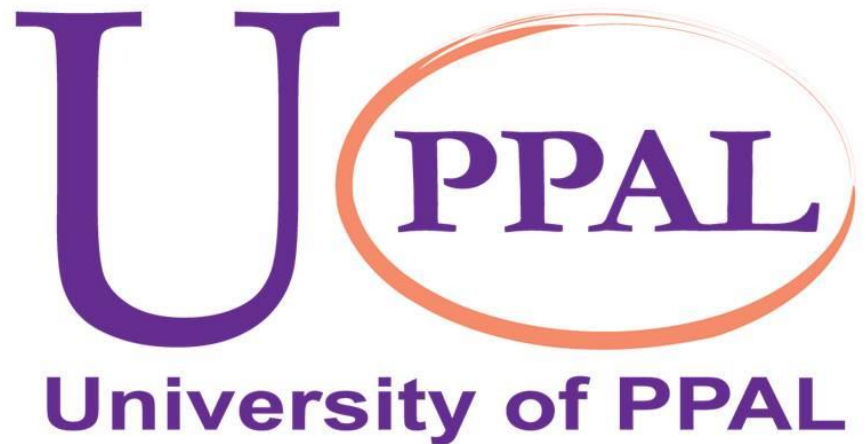
# #2: Advocacy

- Teach parents to advocate for their children
- Individual advocacy for families (education, insurance)
- Systems advocacy for change of policy and practice
- Legislative advocacy (state and federal)
- Insider and outsider advocacy
- Using media stories to promote change



# #3: Training

- Trainings for families
  - Mental health and the IEP
  - Juvenile Justice 101
  - Crisis Planning
  - Transition age youth
- Trainings for professionals
  - Engaging Families
  - Police Pocket Guide
- Trainings for youth by youth
  - Strategic Sharing
  - LGBTQ and mental health



# #4: Family Voice in Juvenile Justice

- Work to teach, engage and involve families whose youth are justice involved
- Diversion away from court
- Teaching parents skills and knowledge to find services and successfully navigate
- Teach engagement to JJ staff
- Training for parents on telling their story



# #5: Youth Leadership

- Youth MOVE Massachusetts is youth-led for youth and young adults 13-29 with lived experience with the children's system
- Two regular youth groups
- Provide technical assistance to youth peer specialists
- Speak on panels, grand rounds, at universities
- Provide youth/young adult voice in policy





## #6: PPAAL studies

- Began in 2000 with a survey about access.
- Subsequent study topics include choices and medications, medical home components, respite care, integrated care, EHRs, boarding
- New study this summer on disparities
- Most recent – 3 “pop up” surveys
- Decided all our studies would be family driven



# #7: Outreach to diverse communities

- Many families from diverse cultures will not contact us or other services
- Our team is bilingual/bicultural
- Outreach to Somali, Asian, Brazilian, Columbian, Cape Verdean and many families who speak Spanish.
- Approach requires individual connection, respect for religion, understanding of how family views mental health



# #8: Co-occurring substance use and mental health

- 3 year project in collaboration with 2 other organizations
- 11 listening sessions across the state
- 1 stakeholder summit
- Development of materials
- Creation of policy position paper
- **Finding:** participants wanted schools to play a role in educating and providing resources and support for youth and young adults with co-occurring disorders.



# #9 Awareness campaigns and stigma

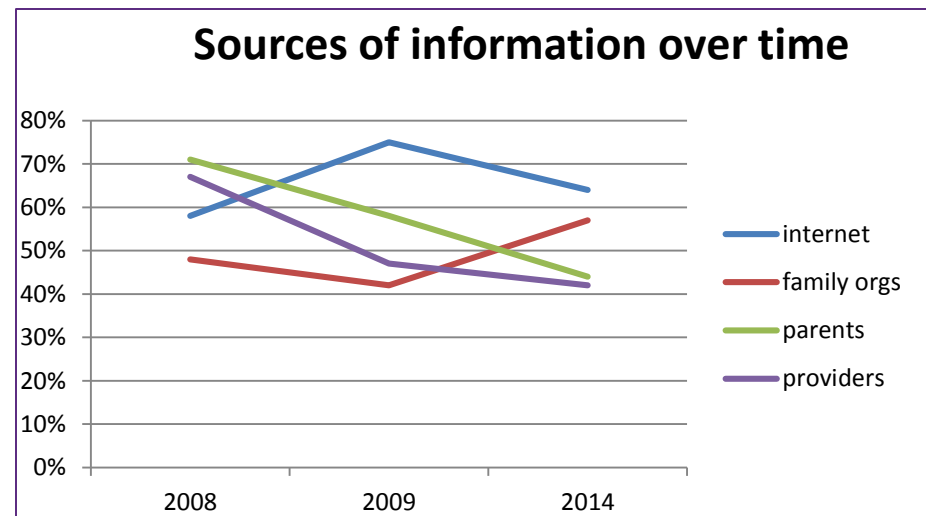
- 69% of parents reported that their child's behavior was seen as a result of poor parenting (2010)
- 40% felt their extended family made them and their child feel unwelcome
- 24% reported the impact of stigma on their family was significant
- 42% reported feeling blamed by the school (2012) but this was ***not true*** for school nurses and special education teachers



# #10 Information and communication

- Although most families (65%) got information from internet many preferred information from family orgs and other “veteran” parents
- In 2012 PPAL study, families reported that good information increased their satisfaction overall
- Best sources to gain knowledge and skills: Internet (64%), family organizations (57%), providers (42%)

*Blogging and  
Social Media*





# PPAL is 25 years old – what has changed?

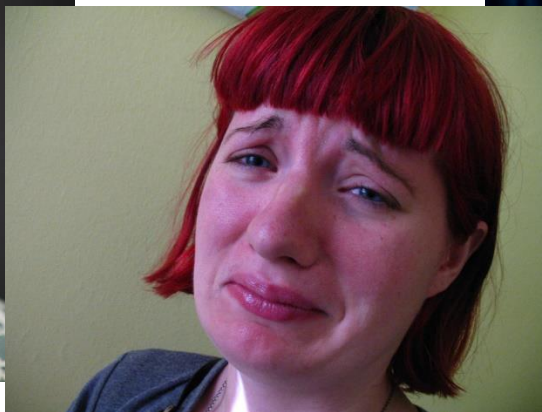
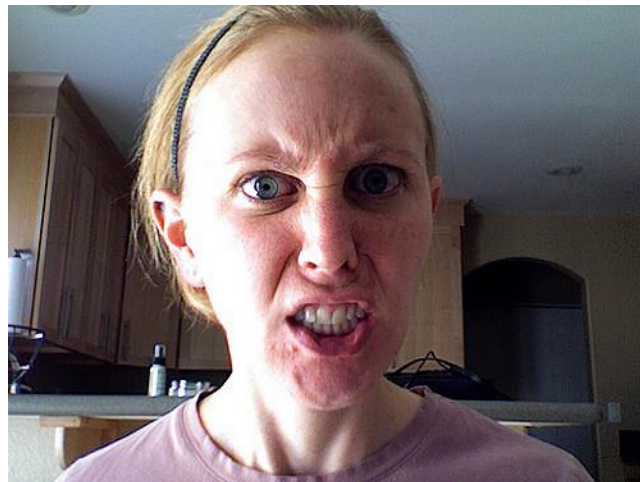
- Parents were routinely blamed for their child's mental health issues. Today, we understand both genetic vulnerabilities and environment play a part.
- Parents were told to let professionals do their work. Today, they are part of the team – mostly
- Parents are from diverse cultures, may be same sex couples, might be grandparents
- 24% of visits to pediatricians are for behavioral health concerns
- Insurers – MassHealth and commercial insurance – are pushed to provide a better range of services/treatment

# What has NOT changed?

- Stigma is alive and well. In 2016, 58% of parents said stigma has stayed the same or increased in the last 5 years despite celebrity stories and anti-stigma campaigns.
- Parents wait an average of 4 years before seeking services.
- Accessing outpatient, emergency and inpatient care often means lengthy waits.
- Families of color still experience significant disparities



# Families haven't changed



# Children's mental health system has changed

- Children's Behavioral Health Initiative
- Brain is better understood
- Less stigmatizing to use medication
- Collaborative problem solving, DBT, CBT, wraparound, other approaches
- Treatment includes families
- Understanding transition age youth
- Screening at well child visits
- Keeping children in community



# Our gains could be in jeopardy

## Changes to Medicaid

- EPSDT
- Block grants don't favor kids
- Essential benefits under ACA

## Changes to SAMHSA

- Require EBTs
- Less support for parent peer support
- Less research/data about systems of care

## Less funding for research





# State funding will be impacted

- When any services/funding is disrupted, children are often the most affected
- When states have to cover basics such as Medicaid, funding to cities and towns is impacted
- When families find services gone or reduced in one arena, they seek services elsewhere
- When insurance mandates increase/decrease, there is often cost shifting to other places

# Strategies in today's environment

## #1 Seek champions

- Congressman, state legislators, visible spokespeople
- Thank and reward them
- Maintain and sustain the connection
- Educate them
- Ask them to participate in speaking publicly

# Sometimes you're an insider, sometimes you're not

- Times to be public and times to work behind the scenes
- Insider Advocacy
  - Build alliances first
  - Pay your dues, show up, be a reliable partner
  - Courtesy, gratitude, sharing information
- Outsider Advocacy
  - Use visibility as with media, public events, social media
  - Verizon network model



# Social media matters

- Social (and traditional) media make a difference
- Easily accessible information
- Connections to others with similar experiences
- Images and information impact stigma
- More families and youth willing to tell their stories
- Hashtag advocacy



# Data matters

- **Consider the difference:** Telling a legislator that families you know are unable to access services OR telling a legislator that 80% of the 400 families you polled stated that they were unable to access services
- Collecting data is easy. Examples: quick polls, phone logs, surveys, social media
- Use your data whenever possible
- Think about advocacy when collecting data



# Collaborate, collaborate, collaborate

- Alliances and coalitions are key to success
- Work with partners in your field and out of it
- Look for unlikely spokespeople—think out of the box
- Stay true to your mission



# Legislative advocacy

- Research the issue and its relationship to current events
- Become articulate – learn sound bites, key words
- Network with others
- Raise awareness of friends, family, colleagues

Letter writing  
Testifying  
Petition signing  
Calls and emails  
Op Eds  
Letters to editors  
Visits  
Participate in Lobby Day  
Post on social media  
Vote!

# Our priorities nationally

- CHIP (Children's Health Insurance Plan) reauthorization August 2017
- Essential benefits for health insurance
- EPSDT – CBHI depends on it
- Training around HIPAA
- Continued funding for Medicaid expansion
- CMS allowance of billing for peer support

# Our legislative priorities in the state

- Children's Mental Health Campaign
  - Ghost networks
  - Children's Mental Health Ombudsman
  - Requiring commercial insurers to cover wraparound
- Juvenile Justice
  - Parent child privilege bill
  - Raising the age

# Other priorities in the state

- Talking to kids about legalized marijuana
- Shining a spotlight on disparities in access and treatment for families of color
- Funding for children's mental health
- Continued discussions on parent concerns about privacy





# Benefits of connecting to family organizations

- Strong relationships to family organizations strengthen and sustain family voice in systems of care
- Strongest relationships are multi-layered, learning communities are developed
- Family organizations provide advocacy for language shifts, practice changes
- Family organizations often have activities to reach diverse families

*Lazear and Anderson, 2009*

# Benefits of collaboration

- Family organizations help families build skills and knowledge
- In a PPAL study, 21% of families said skill building would help them be more effective in accessing services and 20% said they would be more likely to find the resources their family needs
- Effective services matter. 41% said services had made a positive difference. 70% rated medication as the most effective treatment; 58% rated therapy as most effective
- Together we can help make children's mental health a priority



# Contact information

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