

Linking Medical Home and Children's Mental Health: Listening to Families

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Parent/Professional Advocacy League (PPAL)

- A statewide, grassroots, nonprofit, family-run organization in Massachusetts.
- Founded in 1991, PPAL is the state organization of the National Federation of Families for Children's Mental Health and a SAMHSA-funded Statewide Family Network.
- PPAL's goal is to promote opportunities for families to become strong leaders and to ensure that the perspective of families is present in all conversations about children's mental health.
- Surveys of parents since 2000, usually 200-500 respondents



How it started

- PPAL and the Central Massachusetts Medical Home Network Initiative partnered for 4 years.
- CMMHNI was a 4 year HRSA-funded project focused on ways to build and strengthen connections between medical homes and community-based organizations.
- 5th year funding to survey families whose children have behavioral health needs about their experience accessing and coordinating care.
- Pediatric practices noticed parents struggled to find information, resources, services



Survey components

- 5 focus groups attended by 21 parents near CMMHNI medical homes to develop questions
- 54 structured question survey for families whose children have behavioral health needs, 1 open ended
- Available in English and Spanish
- Questions focused on access, coordination and service quality
- Distributed through family-run organizations, conferences, list servs, community organizations
- Online plus paper surveys
- Family driven research

Who were the families?

- More than 200 surveys returned; 171 met criteria
- 41% private insurance, 37% Medicaid; 22% combination
- 68% children ages 9-17; 15% children <8 yrs; 17% 18 to 25 years
- Identified self as parents, foster parents, grandparents
- 14% completed survey in Spanish
- 64% reported mental health professional had diagnosed child; 23% said PCP diagnosed child
- 9 out of 10 reported their child saw mental health specialist
- 74% reported child taking psychotropic medications



Coordination

- 86% reported they were solely responsible for care coordination between primary care and mental health care
- 66% said they had no help from child's providers
- 14% said their child's therapist or pediatrician coordinated care; 9% identified school



Communication

- When there was adequate communication with parents, they said their satisfaction increased
- 46% of families were only slightly or not satisfied with communication
- 59% said communication contributed positively to the quality of care
- 55% said feeling understood was key to quality of care
- 79% preferred phone calls, 57% email 25% used a care plan. 18% said they didn't know what would work.



Quality of Care

Parents commented that the relationship with the provider influenced whether they saw quality as positive or negative

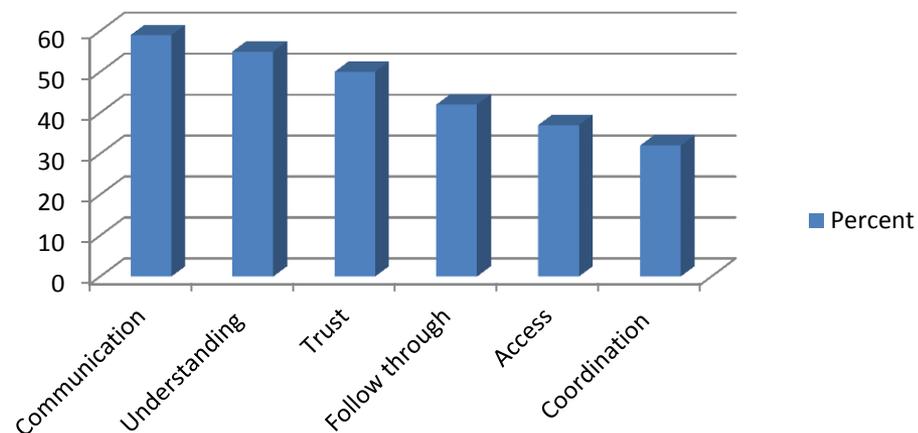
- Parent report on quality of behavioral health care

- 66% somewhat satisfied
- 22% somewhat dissatisfied or dissatisfied

- Parent report on elements that increase quality

- 59% communication
- 55% said being understood
- 50% said trusting provider
- 42% follow through by professional

Contributors to Quality of Care



Information and Resources

Parents reported having good information increased satisfaction

- 70% gained necessary knowledge and information from other parents
- 75% found information on the internet
- 58% reported one to one support
- 42% cited support groups and family run organizations
- 28% said pediatricians were a good source of information
- Yet, pediatricians do not routinely refer to family organizations or employ family partners

Accessing care

- 46% reported that when their child needed mental health care, they found it themselves.
- Only 38% were helped by child's primary care office
- 29% used another specialist
- 20% asked someone at child's school
- In a crisis only 15% called primary care



Waits and travel times

- 73% of families waited up to 3 months to see a clinician, 21% waited 4-9 months
- 67% of families waited up to 3 months to see a psychiatrist and 27% waited up to 9 months
- The majority (46%) travelled 30-60 minutes for an appointment and 11% traveled more than an hour

Sharing information with schools

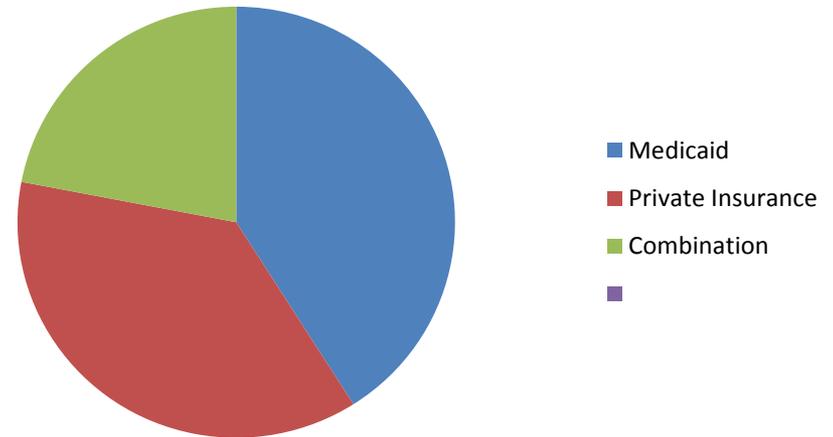
- Parents were concerned about sharing mental health information with schools
 - Half believed schools did not understand mental health issues in children
 - 42% reported feeling blamed by school
 - Only 42% said they would trust school with mental health information
 - 75% would only share a diagnosis or treatment plan
 - Less than 1/3 would allow school to speak to outside providers
 - Of parents who trusted someone at child's school:
 - 37% said expertise or knowledge made difference
 - 23% cited commitment to child
 - 13% said respect for parent or lack of blaming



Care coordination and insurance

- 67% said they had a good idea of their insurance benefits
- 29% knew they could access case management; 71% had no idea this was offered
- 11% had accessed case management
- 71% of those reported being satisfied

Type of Insurance



The bigger picture -- pediatricians

- 90% of Massachusetts residents have a usual source of care
- 24% of all pediatric visits involve behavioral, emotional or developmental concerns
- Sixteen to 33 percent of youth diagnosed with a psychosocial problem in primary care are referred to specialty care, but only about half of these patients will see a mental health provider within six months.
- Only about half of all pediatricians report being able to consult with (44%) or refer a patient (50.9%) to a specific mental health provider often or always
- Pediatricians identify a lack of confidence in their training (65%) and ability (62%) to manage mental health problems as significant barriers to early identification and intervention.

The bigger picture -- families

- Parents of children with behavioral health needs have the highest divorce rate of any group of parents
- They are more likely to lose their jobs or live in poverty
- They are likely to have inadequate health insurance and high out of pocket expenses

The bigger picture -- costs

- Annual average of 4.6 million or 8.6 % of children ages 5-17 had some health care expenses for mental health disorders in 2007-2009
- Annual expenditures for mental health among school age children with such expenses averaged \$2,224 (2009 dollars) per child in 2007-2009.
- Nearly half of expenditures for treatment of mental health disorders for children ages 5-17 years during 2007-2009 were paid by Medicaid.
- For those under 18 years of age, the five medical conditions that ranked highest in terms of the number of individuals with expenses for care in 2008 included acute bronchitis, asthma, trauma-related disorders, otitis media, and mental disorders.

Questions?



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