

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



Beth Pond, Mary Lambert, Meri Viano and Lisa Lambert

June 2012

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



86% of parents reported they had the sole responsibility for coordinating their child's care

The Challenge

Mental health care is important to families. Pediatricians agree. The American Academy of Pediatrics (AAP) has made improving the mental health of children one of its top strategic priorities.¹ Accessing mental health care and coordinating it with a child's medical care can provide challenges. Insurance coverage can be less certain than coverage for medical care. Information can be hard to locate and sift through. Schools are often uninformed about mental health challenges and can blame parents for a child's unwanted behaviors.

On top of all this, the burden of coordinating care and information usually falls on already stressed parents. Medical home is a model with the goal of addressing and integrating quality health care promotion, acute care and disease management in a planned, coordinated, comprehensive and patient or family-centered manner. This approach holds great promise to coordinate care between physical and mental health. "The family is at the center of the medical home, and they are not well served by the fragmentation of having two homes. We have got to collaborate in such a way to provide for the needs in one home," states

Jane M. Foy, MD, chair of the AAP Task Force on Mental Health and a member of its Mental Health Leadership Workgroup.¹

The Central Mass Medical Home Network Initiative (CMMHNI) was a four year project funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA). CMMHNI's project activities focused on ways to improve comprehensive, coordinated, continuous care for children and youth with special health care needs in a group of interested primary care pediatric practices (medical homes). One of its major activities centered on building and strengthening connections between medical homes and community-based organizations. During the fifth year, the project was awarded additional funding to work with Parent/ Professional Advocacy League (PPAL).

PPAL and CMMHNI collaborated to determine what families whose children have mental health needs experience in accessing and coordinating care for their children. Families struggled to find the information and resources they needed and reported that communication and trust influenced how they viewed the quality of

care their child received. The medical home model allows families to work with their providers to create a "holistic" individualized care model. Families are often the specialist, case manager, primary communicator and bring an unmatched expertise. But they can't do it alone. As one parent wrote, "My son has a medical and a mental health condition. When there is a problem with his behavior, I need someone to help me sort this through. Where is the behavior coming from? Is it a problem with pain or a mental health need? That is why medical home is so important to me."

The Families

Families whose children have mental health needs face many challenges. The absence of appropriate care and treatment may prevent them from participating in a range of activities, resulting in isolation from friends and relatives. Often they must learn to cope with the difficult and demanding behaviors of their children and may face staggering out of pocket costs as well as fragmented, uncoordinated care. Families also have many strengths. Numerous families have learned to manage their circumstances quite well and have a range of support networks and strategies they can share with others. They also have a unique view of the strengths and weaknesses of the service system. In short, they know what they need, recognize when they find it and when they do not.

In 2009, CMMHNI and PPAL created a 55 question survey for families of children with mental health needs in order to better understand their experiences. A total of five focus groups were held and attended by 21 parents and caregivers whose children ranged in age from 5 to 23, in locations where the medical home sites were located. Utilizing information from those focus groups, questions for the survey were designed in order to evaluate access, service quality and better understand the challenges families experience trying to interface with mental and behavioral health care systems. The survey was available in English and Spanish and could be either accessed online or a paper copy requested. The survey was distributed it through parent run organizations, conferences, and list serves.

More than 200 surveys were returned and 171 met the criteria for analysis (lived in Massachusetts and were parenting a child with mental health needs). Respondents lived in all regions of the state. 41% of respondents had private insurance while 37% had MassHealth. An additional 22% had a combination of private insurance and MassHealth. The majority (68%) had children between 9 and 17 years, while 15% had children 8 or younger and 17% had children who were 18 to 25 years. Respondents identified themselves as parents, foster parents, grandparents and other caregivers. Fourteen percent of respondents completed the survey in Spanish.

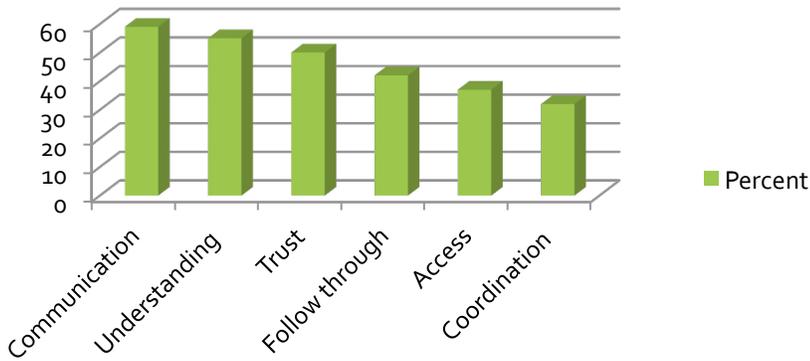
While nearly two-thirds reported that a mental health professional had diagnosed their child, nearly all (94%) reported that their child's primary care doctor also knew of the diagnosis. Nine out of ten parents reported that their child received mental health services from a specialist and 74% reported that their child was taking psychotropic medication. The majority received their prescriptions from a psychiatrist.

Coordination, Communication and Trust

Overwhelmingly, parents reported that they had the primary responsibility both for communication and coordination of their child's care. A large majority (86%) of parents reported that they had the sole responsibility for coordination of their child's care. One parent wrote, "I feel like there is really no coordination between medical providers, mental health providers and school, except what is done by me." Additionally, 66% of the parents surveyed stated that they had no help with coordination from their child's providers. Only 14% said their child's therapist or their pediatrician assumed responsibility for communication with others treating the child. Unsurprisingly, 46% of families were only slightly or not satisfied with the quality of communication. "I don't feel like there is really a "team" – there is me interacting individually with everyone and little to no coordination," one parent noted.

Parents primarily used the phone (79%) and email (57%) for communication and

Contributors to Quality of Care



coordination (many used more than one method). Only 25% used a care plan and 18% said they didn't know what might work. One parent wrote, "I do it all and I had to give up most of my work hours as a result."

Parents noted that when there was communication with them, they felt understood and their satisfaction with services increased. More than half (59%) said communication contributed positively to the quality of care their child received and 55% said understanding was a key factor contributing to quality of care. When parents were satisfied with the care for their child they cited trust, communication and feeling understood as the most important factors, even more important than follow through or access. Similarly when parents were dissatisfied, they cited lack of communication as the major reason. One parent explained how important this is by writing, "I only trust the person who I have created a relationship with that does not judge me or my situation. Right now there is only one."

Bright Futures, an initiative of HRSA, is grounded in the philosophy that each child deserves to be healthy and that health involves a trusting relationship between the health professional, child, family and community.¹ 50% of respondents to this survey identified trust as highly important. Nearly half, 42%, said follow through by the professional was important.

One of the characteristics of medical home is an emphasis on quality. When asked about the quality of the mental health care that was being provided, families responded that the relationship or connection to their child's provider influenced whether they saw the quality of care as positive and or negative. 41% said they are somewhat satisfied with the level of care provided to their child, 25% are satisfied, 12% are very satisfied, 10% are somewhat dissatisfied and 12% reported they were dissatisfied. When asked to identify the elements that increased quality of care, 59% reported that communication was key to quality, followed closely by understanding (55%), and trust (50%). (More than one answer was possible.)



46% of parents found specialty mental health care on their own

Accessing Care

The majority (46%) of families reported that when their child needed mental health specialty care, they found the care for their child themselves. Only 38% were helped by their child's primary care office. Parents also reported that accessing care usually involved lengthy waits and substantial travel time. 73% waited up to 3 months to see a clinician and 67% waited 3 months or more to see a psychiatrist. The majority (46%) travelled 30 to 60 minutes for an appointment and 11% traveled more than an hour. One mother wrote, "This child is extraordinarily demanding to parent and manage and it falls exclusively on me as mom. This is a huge job and prevents me from working to earn income to help support my family, which keeps me in a less-than-ideal marriage. I am drowning in the demands of special needs parenting."

Many parents also explained that their child needed a certain expertise and their insurer would not fund recommended treatments. One said, "We've been unable to find another psychiatrist in our network who treats teenagers. The insurance company put up road blocks that had to be overcome and his new psychiatrist is 1-3/4 hours away." Another wrote, "We've found unnecessary barriers such as requirements to use emergency services rather than going to the clinician's office. Seems like they hope delay and difficult circumstances will discourage families from pursuing appropriate care and unfortunately, it works."

A majority (67%) reported that they had good information about their health plan's mental health benefits but 71% had no idea if their insurer provided case management should they need it.

Finding Resources

Caring for a child with mental health needs requires more than medical treatment. Finding the scout troop, religious education class or afterschool program that accommodates mental health needs can be difficult. Parents value information about resources as well as being directed toward information about their child's diagnosis and treatment. Parents reported that when they had good information, they were more satisfied overall. The majority

(70%) reported that they gained the knowledge and information they required from other parents. 58% reported that one to one support from other parents was an excellent source of knowledge and others listed support groups (42%) and family organizations such as PPAL as valuable resources. Unfortunately, most pediatricians do not refer parents to support groups and family-run organizations. Only 28% said pediatricians were a good source of information.

Parents also looked for formal sources of information. 75% reported they found useful information on the internet and 71% valued books as a reliable source of information. Others responded that therapists (47%) and hospitals (16%) had provided them with information and knowledge.

Schools

While parents desired better communication and coordination between their child's pediatrician and mental health providers, they felt quite differently about schools. Half of parents believed that their child's school did not understand mental health needs and 42% stated that they felt blamed by the school. One wrote, "Most schools I have dealt with blame the parent for the child's behavior and are not trained to understand or assist."

51% reported that they did not trust the staff at their child's school with information about their child's mental health needs. Of the 42% who agreed that they would trust their child's school with information, they were careful about what information they would agree to share. Most were only willing to share a diagnosis (75%) or a treatment plan (72%). Less than a third were willing to sign a release to let school staff speak with outside providers. One parent wrote, "In these economic times, they view the child and the family as the enemy."

When parents did trust someone in their child's school, it was someone who had training and knowledge. 51% said they trusted the special education teacher and 35% trusted the school nurse. Only 22% reported that they trusted the school principal. In the May 2012 issue of *Pediatrics*,¹ the American Academy of

51% of parents reported that they did not trust the staff at their child's school with information about their child's mental health needs

Pediatrics endorses the use of school based health centers in order to ameliorate the barriers to care faced by many youth. After listing the opportunities, the article goes on to say, "Communication among schools, school based health clinics, and community primary care providers should be facilitated." Parents in this study might issue a caveat for communication of behavioral health information to schools.

When asked the basis for the trust in school staff, 37% said that the expertise or knowledge made the difference, 23% said that person's relationship or commitment to their child mattered and 13% noted that the staff person showed respect for the parent or didn't judge. "They sincerely have shown interest and understanding concerning the challenges that my son deals with," a parent explained.

Conclusions

Families whose children have mental health needs identified both barriers to care and factors that increased their satisfaction. While most did not receive care for their child through a medical home, it was apparent that this model would have a positive impact in reducing barriers, increasing communication and relieving parents of the entire burden of coordination.

While a large majority (86%) of parents reported that they had the sole responsibility for coordination of their child's care, only 14% said their child's therapist or their pediatrician assumed responsibility for communication with others treating the child. More than half (59%) said communication contributed positively to the quality of care their child received and 46% of families were only slightly satisfied or not satisfied with the quality of communication they had with their child's providers. In their written comments, parents identified the impact that coordinating care and information has on their time and resources. When parents were satisfied with the care for their child they rated trust, communication and feeling understood as the most important factors, even more important than follow through or access.

The responsibility for finding mental health care and reliable information also fell

primarily on parents. The majority (46%) reported that when their child needed mental health specialty care, they found the care themselves. Only 38% were helped by their child's primary care office. The majority (70%) reported that they gained the knowledge and information they required from other parents, support groups and family organizations such as PPAL. Unfortunately, most pediatricians do not refer parents to support groups and family-run organizations focused on children's mental health. Yet, parents reported that when they had good information, they were more satisfied overall.

Parents had strong views on sharing information about their child's mental health challenges with schools. Fifty percent believed that their child's school did not understand mental health needs and 42% stated that they felt blamed by the school. In addition, 51% reported that they did not trust the staff at their child's school with information about their child's mental health needs. Most parents were only willing to share limited information such as a diagnosis (75%) or a treatment plan (72%). Less than a third were willing to sign a release to let school staff communicate with outside providers.

Families whose children have mental health needs identified the need for better coordination, communication and information. These are all components of medical home, which provides a model for parents to work with their providers to integrate medical and mental health care. As one parent stated, "It would be nice if each family could have one person who is the child's "CEO" and could coordinate all services and understands the child's main diagnosis and treatments."

Thanks and Acknowledgements

We are deeply grateful all the parents and caregivers who provided us with their valuable time and insight. They were instrumental in helping us create the survey through participating in focus groups, helping us pilot the survey, getting the survey out to others and taking the time to take the survey and share with us their personal successes, challenges and barriers with working with the professionals who serve their children. We acknowledge how difficult it is to navigate the mental health system and then, by default, become your child's care coordinator & primary communicator.

Muchas Gracias! Many thanks go to the Spanish American Center in Leominster, Massachusetts who reached out to families who belong to the centers and distributed the Spanish copies of the survey.

Heartfelt thanks go to Richard Antonelli, MD and Christopher Stille, MD for their continued belief in partnering with families and family organizations such as PPAL. Thanks also go to the CMMHNI Medical Home Practice sites and their teams of parents and professionals for their dedication and time in the CMMHNI Linking and Aligning Project .



The **Central Mass Medical Home Network Initiative (CMMHNI)** was a four year project funded by the U.S. Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA). CMMHNI's project activities focused on ways to improve comprehensive, coordinated, continuous care for children and youth with special health care needs in a group of interested primary care pediatric practices (medical homes). One of its major activities centered on building and strengthening connections between medical homes and community-based organizations.



The **Parent/Professional Advocacy League (PPAL)** is the leading public voice for families whose children have emotional, behavioral and mental health needs in Massachusetts. PPAL is the statewide chapter of the Federation of Families for Children's Mental Health, a SAMHSA-funded statewide family network and is dedicated to promoting changes that will improve the children's mental health system statewide.

This project was supported by HRSA Grant H02MCo414

End Notes

¹ www.healthychildren.org/English/our-mission/aap-in-action/pages/Mental-Health-a-Top-Priority-for-AAP downloaded on 6/17/2012

² Elliott, Victoria Stagg. "Mental health home proposed to boost care for psychiatric illness." *Amednews.com, American Medical News*, April 27, 2009.

³ BrightFutures.org. downloaded at www.brightfutures.org on 6/17/2012

⁴ Barnett, Stephen E., MD. "School-Based Health Centers and Pediatric Practice." *Pediatrics* 12(2012) 387-393

Copyright © 2012 by Parent/Professional Advocacy League