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Parents of Children/Adolescents Focus Groups Report

INTRODUCTION

The Massachusetts Department of Mental Health (DMH) contracted with CQI to conduct a series of focus groups with adult and youth mental health consumers and family members across the state to help inform their Unified Behavioral Health planning process.

One area of interest for DMH is the needs and experiences of parents who have children and/or adolescents in the mental health system. This report presents themes that arose from three focus groups with parents on their experiences with the child/adolescent mental health system.

Three topics were covered among the three focus groups: 1) support for families, 2) support for normal development processes, and 3) coordination of care. Although each group focused on one of these topics, similar themes were raised at all three groups.

EXECUTIVE SUMMARY

- Parents had difficulties accessing services because programs were full, too far away, not appropriate for their child's needs, not open to their age group, or not open to their child's diagnosis. Applying for and accessing state services is daunting.
- Parents were not getting the help they needed to coordinate care. Coordination of care across state agencies was very flawed.
- More normalizing activities and relief services for families are needed.
- Clinical and crisis services need to be more supportive of parents and families.
- Parent peer support groups and services were helpful because they provided relevant information about programs and services, offered help navigating the system, and provided some help with advocacy.
- Not enough comprehensive individualized planning is provided.

FOCUS GROUP PARTICIPANTS

There were 29 participants in 3 focus groups with parents of children/adolescents, mostly mothers. The majority of parents were biological, but some were adoptive or foster parents. The majority of parents were white/Caucasian. The parents had children ranging from age 4-19. Children had a variety of conditions including bipolar disorder, Asperger's disorder, Autism, mental retardation, oppositional disorder, and learning disabilities. Two-thirds of the parents were receiving services from either DMH, DSS, or DMR, and roughly one third either did not qualify or had not applied. The three groups were sponsored by the Parent Information Network in Brockton, Project Connect Parent Support Group held at the Norwood Civic Center, and the Parent Support Group at the Manville School in Boston.

THEMES

Difficulties Identifying, Accessing and Coordinating Services

Parents talked about the many difficulties and obstacles they faced when trying to identify and access appropriate services for their child.

A) State Agency Eligibility and Application Process

The application process for state agency eligibility and services is daunting. First, parents did not know which agency would be responsible for their child, given their multiple conditions. Some parents, when applying to one agency, were simply told that they should apply to another, but without help to do that. This was the case even when the parent felt the first agency would best meet their child's needs.

Some parents said they felt discouraged by various professionals from even applying to a state agency, and were commonly told their child would not qualify for services or that few services were available. Staff often assumed a child would not qualify, particularly when they had never been hospitalized or had another diagnosis such as Asperger's Syndrome. Application processes can be emotional for parents, and therefore they wanted to be encouraged to try all possible avenues to get their child the help they needed. Instead they felt discouraged from trying. They wanted staff to recognize it might be difficult for them to apply, fearing rejection, and to support and encourage them in the process.

B) State Inter-Agency Coordination of Care

Many children had multiple and complex diagnoses and needs (e.g. Asperger's and a mood disorder), and therefore their needs fell between two agencies. Often one agency had services their child needed, but the child was not allowed to access those services because another agency had ownership of their case. Service accessibility was not driven by the needs of the family and child, but more by administrative rules and barriers based on inflexible diagnosis or eligibility criteria.

Parents felt that DMH needed to be more flexible with its eligibility criteria, especially because children’s diagnoses are complex and shift as they develop. Many were frustrated with both their lead agency (DSS, DMR, or DMH) for not providing needed services, as well as other agencies that rejected their applications only because they were not the lead agency. Often only one agency provided services that parents thought would benefit their child. One parent described this frustration:

“I applied to DMH. My son has been hospitalized six times but we were rejected because DSS is the lead agency. But DSS doesn’t provide the services he needs.”

There should be a well-established referral service in place for families that do not qualify for state services. Referrals should not be given for programs that are full or unavailable.

Parents also felt that a **neutral** liaison/advocate could help them coordinate services for their child across agencies. Parents felt that agencies were quick to pass their child off to another agency, so they needed a liaison that would not experience repercussions for advocating across agency jurisdictions.

C) Access to Service Providers

Many parents found that there was a shortage of child mental health services, particularly psychiatrists. Thus, they often ended up seeking services after a crisis, which was stressful for parents. Another challenge is that they were often provided with a list of possible services, such as psychiatrists and therapists, and had to call down the list of providers themselves to see if any services were available or would accept them, only to find little help. This was a very time consuming and frustrating process for parents, particularly after a crisis.

Parents said it was particularly difficult finding a therapist and psychiatrist in the same location. Those with private insurance had increased difficulties finding a therapist who would accept their insurance. Those with MassHealth had an easier time accessing child mental health services.

D) Holistic, Comprehensive Service Planning Needed

Services were provided and planned for in a very fragmented way. DMH case managers often dealt with eligibility and referrals rather than comprehensive service planning. Parents adamantly said that no one worked with them to develop a comprehensive individualized plan for their child and family.

A plan would not only help parents but providers. A parent could share with teachers and multiple service providers an individualized plan that included the child’s triggers, preferences for restraints, a crisis plan, etc.. Often, children had multiple service providers (school staff and teachers, physicians, therapists, community services, crisis staff) who had limited information about the child’s individual needs and the family’s

preferences. Staff at programs, particularly those who were not licensed clinicians, did not always understand the child's diagnosis or needs,

Related to more comprehensive planning, most parents did not have experience with wrap-around services, but told us that wrap-around programs such as MHSPY¹ were a good model if long-term (>1 year). In contrast, they said FSTs² were sometimes helpful for short-term information, but not as helpful as longer term programs because therapists were not licensed clinicians. FSTs were usually too short, and for some, did more harm than good as their children adjusted better to longer term relationships and supports. CSPs and Early Intervention were also mentioned as potentially more helpful models than FST or case management alone.

More Normalizing Activities

Parents want more normalizing activities for their child and family. Though parents ideally wanted their kids to be integrated into mainstream social activities, their children did not always do well in these settings. They felt that, especially at first, specialized programs for children with their specific needs were best. Specialized programs were also beneficial because they were less stigmatizing for the child. Parents said programs that work with all the children in the family were especially beneficial.

Outdoor programs and camps were helpful for their therapeutic effects. Family camps and programs for the few weeks after school ended and right before school started were requested. Simple activities other children do regularly, such as bowling are also greatly needed. Those activities are more effective when well trained clinical staff run the programs.

Mentors were seen as an important adjunct here. Mentoring programs were seen as having great potential to help, particularly when the mentor is educated about the child's condition, they communicate with the parents and there are clear standards for their work.

Programs such as programs at YMCAs that tried to integrate kids had benefits for some kids, but were difficult when children had difficulty mixing with other kids. Also kids have different needs depending on their diagnosis (a lot of stimulation or little stimulation), so programs that focused on children with their diagnosis were best.

Because many children attend specialized schools far from home and parents work, access to after school programs is difficult. Nonetheless, after school programs are greatly needed. Parents said onsite, specialized after school programs are most helpful because their children are often not able to access local after school programs.

Also, all day or half-day Saturday programs are beneficial for several reasons: 1) transportation to a longer program (>1-2 hours long) is much easier on parents, 2) children with emotional or mental health issues have difficulty adjusting to transitions so longer programs prevent outbursts, and 3) Saturday programs give parents needed respite.

¹ Massachusetts Mental Health Services Program for Youth

² Family Stabilization Team

Expand Services for Certain Age Groups

There were gaps in services by age of the child. For adolescents, parents were looking for programs that would help their teenagers develop life skills, such as employment skills. More dual diagnosis programs for teenagers were also needed. There are few programs available for younger children, particularly under age seven.

Clinical and Crisis Services More Supportive

Crisis services should be more supportive to parents. Unlike all other forms of medical care for children, parents are not allowed to accompany their children when hospitalized for mental health issues. Parents often feel unsupported, stigmatized, and blamed when accessing crisis or hospitalization services.

“They want you to go away, which is ridiculous because they are coming home to you.”

Crisis services and hospitalizations can be traumatizing for children and parents. Also, ER visits sometimes require 6-24 hours waits which is extremely difficult when a child is acting out. Parents reported getting poor treatment from crisis team and hospital staff when their child was in crisis, including being asked to wait outside, being told “don’t bring him here” and “I don’t appreciate your attitude”.

Parents felt they were not supported when they were trying to prevent hospitalizations and major crises (e.g. your child hasn’t been hospitalized so you don’t qualify for services). One parent said, “most of our kids are on a slippery slope.” Also, little to no discharge planning is done with parents when their children leave a hospital. Most are given a prescription and little to no follow-up information.

Clinicians are reluctant to provide a concrete diagnosis which makes it difficult for a parent to do research on what techniques would best help their child. It can take years for parents to get an accurate diagnosis and helpful information about treatment. Most doctors do not listen to or understand their needs, and parents have had bad experiences with doctors not understanding medications.

Schools

Some parents had difficulty with schools, particularly in public schools when psychologists, support staff and teachers were not respectful to them and their child. Parents said many paraprofessional staff at schools (as well as other programs) do not know how to properly use restraints.

Many parents said they liked specialized schools for their child because they got the attention they needed. Also, they and their child felt less ostracized.

Respect from Staff and Stigma as Parents

Parents often felt blamed by providers for their child’s mental health condition and experienced that stigma while they were seeking services. Parents wanted to be listened

to and understood, especially when their child was in crisis. Because there are gaps in the system, parents often face an uphill battle getting the needs of their child met and become strong advocates for their child. Providers should be sensitive to their struggles, and support their efforts to help their child.

Direct Support for Parents

The pressures of taking care of youth with serious emotional disorder are significant. Parents need both support and time to themselves to rest. In this regard, parents need:

- **Mentors** who spend time with the child (see above).
- **Respite care** for the children to give parents a significant chance to recuperate.
- **Peer Support Groups:** Parent support groups and peer support services provide significant emotional support for parents. They also provide practical support such as current information about appropriate and available activities and programs for kids (e.g. what Girl Scout troop will accept their daughter), and help parents navigate a very complicated service system. Support groups can also help spouses to deal with the stress of balancing work with their different roles providing for their child's needs.
- **Support for holding jobs:** Parents need to be on call 24/7, so it is difficult to hold a job since employers are only so tolerant about letting you leave to help with the kids. Job loss can affect both parents, resulting in lower income and at least one parent not working. Many employers do not follow the Family Medical Leave Act, so parents have difficulty keeping a job if they need a significant amount of time off when their child has a crisis.
- **Peer advocacy:** Some formalized peer support programs also provide a peer advocate that can accompany parents to important meetings with providers. One peer advocate helped a parent when her DMH Case Manager insisted her daughter should be placed in a state hospital, even though a less restrictive community-based setting was in the best interests of her child. Peer support services help ensure that services are family-centered. Peer advocacy programs also provide jobs to experienced parents, including those who may have had to leave the workforce when their child was younger.

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