



Consumer Quality Initiatives, Inc.

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Parents with Mental Illness Focus Group 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 learning about the experiences of parents who have a mental illness. This report presents common themes that arose from a focus group of parents with mental illness and their experience with the mental health system.

EXECUTIVE SUMMARY

- Parents with significant mental illness struggle to stay well while keeping their families together, particular when they have a child with a serious emotional disorder (SED).
- When parents speak of their critical need to have help with “**crisis planning**,” they are referring to establishing a placement (e.g., temporary guardianship) for the child if the parent needs acute care. However, the DMH adult system generally does not provide services to consumers based on their role as parents.
- Mentally ill parents are very concerned that if they need acute care and do not have a crisis plan, DSS will step in and deem them unfit, largely based on their diagnosis. When DSS takes authority over the child, it takes tremendous time and effort to get the child back.
- Parents favor family support programs such as the Employment Option’s Family Project, which offers parents the opportunity “to become effective, capable and independent parents.”¹ They also benefit from “wraparound”² services, which youth do not get except after a long wait.

FOCUS GROUP PARTICIPANTS

¹ From the Employment Options website, retrieved on 5/23/06 at http://www.employmentoptions.org/services_parenting.shtml

² Wraparound is defined as “... individualized, comprehensive services within a system of care for youth with complicated multi-dimensional problems.” SAMHSA, retrieved on 5/23/06 at: <http://www.mentalhealth.samhsa.gov/cmhs/ChildrensCampaign/1998execsum4.asp>

CQI held a focus group on May 15, 2006 with a total of 5 participants, all female. Four were single parents and one was married. All were under the age of 45. People of several races and cultures were represented in the group.

Significantly, all said they had a child who had a serious emotional condition. In addition, no one felt they had the *personal or family* resources to deal with crises that might affect the whole family.

The discussion below is thus by definition focused on parents who: 1) have a child(ren) with serious emotional problems, and 2) do not feel they have the personal or family resources to avert mental health crises.

THEMES

Parental Challenges

Parents with mental illness face special challenges. A major concern is that children may think that the parent's mental illness was their fault. They also found it difficult to provide their children with a routine, as their symptoms came and went. Participants talked also about waking up drowsy from medications, which made it difficult to get the kids ready for school.

Participants particularly need help dealing with schools regarding IEP issues. The Parent Information Network (PIN) in Brockton does help parents deal with schools, but it is primarily a support group for parents. And if their child does have SED, it can be very difficult to get the child services; there is a long wait for eligibility.

The Need for Parent "Crisis Plans" and an Improved DSS Response

When parents speak of their critical need to have help with "**crisis planning**," they are referring to establishing a placement (e.g., temporary guardianship) for the child if the parent needs acute care. However, participants did not feel that their friends or family were capable of taking care of their child; even when friends were capable, they were often mentally ill and thus the participants had an expectation that DSS would deny that placement.³

Also, the participants knew that as part of a hospital admission, if they had no place for their child, a 51A can be filed. Thus, it feels like they are penalized for not having capable friends/family. As a result, they were reluctant to get inpatient treatment.

Participants said that DSS and its policies caused them a lot of anxiety. They believed that DSS will presumptively deem the parent unfit based on a mental illness diagnosis. For example, they may conclude that you're not taking your medications as a reason to remove the child from the home. (But there might be cases where it does not make sense to take medications, such as when someone is pregnant.) Thus, participants were very reluctant to ask for assistance from DSS because that might turn into an abuse/neglect finding, resulting in loss of contact with their children. (They acknowledged that DSS workers could be "good or bad.")

³ Even the married participant, whose husband worked long hours to support the family, felt that she would need a temporary placement for her children if there were a crisis.

DMH Adult System

Participants reported that the DMH adult system generally does not provide services to adults based on their role as parents. Thus, participants reported that they did not get help with a crisis plan that applies to their parental needs. (Day programs help with structure but not with parental needs.) Also, there are few support groups for parents. In addition, there is no respite for children as part of the adult system of care, and little respite for the parent in need of parental relief. As such, parents don't get the necessary help until their child is so sick that s/he becomes eligible for DMH services (e.g., wraparound services, camp, and respite).

Recommendations

Participants said there were two "interventions" that would help them to stay well and keep their families together.

First is a family support program like those offered through Employment Options in Marlborough. For example, the Family Project at Employment Options (see footnote 1) offers parents the opportunity and support "to become effective, capable and independent parents." The Family Project's aims to help the parent with anything they need to succeed. This included going to IEP meetings, crisis planning, frequent staff visits, camp applications, legal assistance, rides, and referrals. It is a model program. One parent explained:

"I lived with kids while I was homeless. Things only began to turn around when I got to Options. Now I get a wraparound kind of approach, with an advocate who helps me get up in the morning, with court and with other advice. They helped me get supervised visits, like day trips. I'm now more independent and skilled, so I have less of a need for Options."

Second is child/adolescent wraparound services, which provide comprehensive supports for the whole family. The goal is to help the child progress successfully while keeping the parents and siblings well.

Participants also felt that the following would be helpful, but not sufficient, to avoid life-changing crises:

- Parenting classes
- A support group with non-mentally ill parents: "parents helping parents." This includes talking to "real" parents about good child care options.
- 24/7 help available for crises.

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