Focus Group Report

Prepared for the Regional Health Commission

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Overview

The content of this report represents the collective insight of more than 30 consumers and family members with severe mental illness in the city of St. Louis, and seven family members from the wider region. These focus groups were conducted in June, August, and September of 2008. The co-facilitators and report writers are mental health professionals who have extensive experience working with consumers and family members from a variety of diverse populations. They conducted the focus groups and prepared this report jointly, using qualitative methods.

**Participant Demographics**

Participants in these focus groups have been in the behavioral health system for as little as one year and longer than 25 years. Some participants have been receiving services since early adolescence. Several have a dual diagnosis of both a mental health condition and a drug or alcohol addiction. Participants recounted entering care due to head injury, family tragedy, homelessness, and psychotic symptoms emerging in early adulthood.

Of the approximately 37 participants, 28 filled out a demographic information survey. Of those reporting gender, 13 were female and 13 were male. Among consumers, one Caucasian person participated in the group, as well as 11 African-Americans and 5 who marked their ethnicity as “other”. All nine respondents at family member groups were Caucasian. Among all focus group respondents, two were older than 75, two were between 65-74, six between 55-64, and the majority were ages 45-54. Three were 35-44, five 20-34, and one was between the ages of 10-19.

Most of the participants reside in St. Louis city, while a few live in St. Louis County and Jefferson County. One reported his county of residence as “other”. Geographically, participants are spread over a wide range of zip codes. These include 63017 (1), 63106 (2), 63108 (1), 63109 (1), 63110 (1), 63112 (2), 63115 (4), 63117 (1), 63118 (1), 63021 (2), 63129 (2), 63031 (1), 63136 (1), 63143 (1), 63147 (1), 63168 (1), 63174 (1), and 63052 (2).

Household income among consumers predominantly fell below $9,999. Two reported income between $10,000 and $14,999, one between $20, and $29,999, and two between $30,000 and $49,999. Seven family members reported income over $50,000, with two between $30,000 and $49,999.

The majority of participants reported Medicaid as their primary insurance. Only one consumer held private insurance, while one utilized Medicare and one received both Medicaid and Medicare. One participant reported having no insurance coverage. The vast majority of family members utilized a combination of private insurance and Medicare.
Summary
In these groups, the Regional Health Commission sought feedback on the issues of service access, barriers to care, stigma, and strategies for overcoming these problems. Consumers and family members who participated in the groups were eager to discuss what they liked and didn’t like about their experiences with the behavioral health care system, and many held strong opinions about how this system could be improved. Common themes included the challenges of mental health crises, stigma perpetuated by providers and the media, finding a healthy balance between consumer independence and family involvement, and the importance of social supports.

Initializing Services and Access to Care

Crisis Precipitates Entry
For most participants in these focus groups, a crisis precipitated their introduction to the mental health system. Some consumers began accessing services in inpatient hospital or criminal justice settings. One described receiving a brain injury at age 12, which created a lifetime need for services. A common theme among consumers is denial about their mental condition, and longstanding resistance to initially accessing care. Family members share, “He is disabled by his illness, but he won’t admit to it.” One consumer said, “Someone told me about ______________(agency), but I didn’t think there was a purpose in it for me.” Another commented, “I first came here in 2004, but I didn’t believe I needed medication.”

Gatekeepers are Key
Most consumers’ initial access came in the form of a referral from a friend or a professional. One consumer related her story as, “I learned about ________(agency) in 2003 from a friend. My mom had passed away, my dad got AIDS when it was still a new thing. There was a lot of stress and I just, you know, couldn’t handle it.” In particular, caseworkers are crucial gatekeepers in the road to accessing care. “My caseworker, tracked me down because I was homeless. Transportation was a problem. It was a terrible experience to start with, but it’s turned out really good,” says one consumer. For others, they were referred to care by agencies such as the Children’s Division or a local substance abuse rehabilitation center.

One consumer was self referred. He described significant losses in a short period of time, resulting in a psychotic episode. In his words, “I went to an agency and told them I was having crazy thoughts . . . I didn’t understand about anger and grief. Now I don’t take medication, but talking is my medication.” This consumer is now working in a steady job.

Barriers to Receiving Care

In the agency where the majority of consumer participants receive services, lack of Medicaid is not experienced as a barrier because this agency receives funding from the State of Missouri to provide care
to the uninsured. One consumer did describe difficulties accessing care in another state due to her lack of insurance.

**Dual Disorders Present Multiple Barriers**
People experiencing dual disorders of a mental health condition layered with a substance abuse problem, often experience higher degrees of chaos and lower views of their personal self-worth. The result seems to be a decrease in their initiative to access services. “I was in flip mode, staying clean, getting high. I am thankful they have a place like this that is both mental health and substance abuse.” These consumers often feel demeaned by professionals. One consumer relates that “A psychiatrist told me if I used again I wouldn’t come back because I was a ‘lifer.’ I believed that and lived under that for a number of years.”

**The Role of Government Assistance**
Social security disability income and Medicaid are advantageous to accessing care. “Once the Medicaid and Social Security benefits were in place, the services came together easily,” said one family. However, accessing services during the initial waiting period is difficult and time consuming. Further, consumers who receive disability income often fear that if they go to work they are risking mental health care and their livelihood. One consumer described her experience as follows, “They took my Social Security check from me, saying there were too many people in my family who work. When I went to the office, they gave it back. But, I went to five psychiatrists and they all thought I was crazy. I said, ‘I know I have a mental condition, but I’m not crazy.’” Individuals participating in the focus group seemed to feel particularly defined by their mental condition. One family member said, “It’s something that you really can’t hide from. It’s always going to be on his record.”

**Basic Needs as a Barrier**
One consumer highlighted homelessness and transportation as significant barriers to accessing care. He states, “I’ve only been receiving services for a year. I’ve been in and out of psych wards and I was homeless. I got referred through a social worker at the hospital.”

**HIPAA as a Barrier to Family Involvement**
Family members reported some different kinds of barriers to accessing care. A common theme was difficulty in communicating with their loved ones’ providers. Family members felt that the HIPAA confidentiality rule was at times taken too far, preventing them from getting needed information and from advocating for their loved one. The lack of formal avenues for communication with family members at some community agencies also prevented access. It was suggested that community agencies needed to educate their staff and create programming specific to the concerns of family members: “Families need to be made part of the process, and _________ (agency) doesn’t address this.”

Family members also expressed concern regarding treatment-planning and goal-setting processes. They felt left out of these conversations, and they felt that the emphasis on
independence in many mental health programs did not serve their family members well. Making a parallel to the treatment of medical illnesses, one woman asked, “In what other illness is independence the major part of the treatment plan? You wouldn’t see that in a program for cancer!”

Stigma

The Role of Media
Family members believe that most people don’t understand what it’s like to live with a mental condition. “People don’t know what mental illness is. . . . People need to realize that mental illness is an illness. Until recently, people didn’t take it too seriously,” they say. One example of a misunderstanding of mental illness in the media was a television news series with the title “Nuts or Normal?” A local radio station also recently advertised its programming as “Insane Broadcasting,” a name that offended a number of family members.

Families acknowledge their own lack of understanding until mental illness directly impacted their relationships. “Now, every time there’s a program on TV about mental illness, we’re watching it, but before . . . .” Family members believe the media plays a large role in shaping public perceptions of mental illness. “They need to show people with mental conditions doing normal things and being productive. Show people with schizophrenia on medications and the good side of their lives.”

Misperceptions in the Faith Community
Ignorance of mental illness was seen as an issue in communities of faith, as well. A mother of a man with schizophrenia related that she had approached her parish nurse about doing an educational program on mental illness. The parish nurse had responded that she did not feel there would be enough interest to justify providing education on that topic. Another family member shared, “Some of the pastors equate mental illness with demonic activity.” Yet another family member talked at length about the struggle her sister had encountered when she was trying to find a church that would accept her illness.

Dual Diagnosis and Stigma
Consumers with dual diagnosis seem to experience stigma on multiple levels. “I have run into a big stigma with the medications I take because they are narcotics. They look at it like you are just wanting to get drugs. I have ADHD and they look at my age. You run into one in five doctors who understand.”

Problems with Providers and Employers
Consumers feel that a great deal of stigma is perpetuated by providers. In describing a local health clinic, one consumer said, “They talk down to people and have nasty attitudes. A lot of people are talking about not going back there.” Another related, “One of the responders told us we were lazy and needed to get a job.”
Stigma was a particular problem for consumers who wanted to work. Behaviors associated with mental illness were often used as an excuse to fire consumers. In addition, because employers knew that consumers were putting their disability income at risk by working, employers often paid consumers less than the market rate or forced consumers to work “under the table.”

**Stigma as a Barrier to Care**
As has been shared in other focus groups, participants in these groups related that stigma itself was a formidable barrier to service access. A couple with a mentally ill son shared that they had seen behavioral signs of mental illness in their son when he was a teenager, but that their own internalized stigma prevented them from recognizing and acting on those “red flags.”

Families felt that stigma prevented their son’s school from taking action, as well: “People at his high school were clueless. They didn’t know what to do. You would think that the teachers and counselors would know more [about how to work with him]. They knew that he had mental problems.” Lack of understanding among school personnel was seen as an especially critical problem because the school system was often the first contact that consumers and families had with mental health or social services: “The schools and the parents, that’s all you have in the early days.”

**Overcoming Barriers and Reducing Stigma**

The Vital Role of a Shared Community
The over-arching themes of hope that ran throughout these focus group interviews were developing a sense of community, case management conducted with dignity, and comprehensive education. Consumers and family members alike emphasized the importance of having a place to turn when they were in need of information, referrals, and support. One family member stated, “It makes you feel good when there is some sort of organization where you can get information and stuff.”

Family groups and other support groups played a key role in helping to reduce internalized stigma. The availability of scientific information about mental illness was helpful, as well. One family commented about a hospital based support group, “It was our lifeline—it gave us some idea of what we were dealing with.” Another mother said about a community-based support group, “You could talk freely and tell the truth, and it was all right.” The agencies that provided these services were not just places to turn, but they were also seen as essential resources for social and emotional sustenance. A consumer shared, “I can tell them when I’ve messed up. They help me figure out where I messed up and why. They’d give me a bus ticket to get me back to work even though they know I just messed up. They never gave up on me. They went above and beyond. Family doesn’t understand, but they do.”
CaseManagers Provide Key Services
Effective case management was brought up again and again as a key to accessing the system of services, overcoming internalized stigma and low self-esteem, and recovery. Consumers described the importance of close working relationships with case managers and the life-saving role that good case managers could play. Case management was important as a gate-keeping service, but also provided advocacy for consumers in crisis.

Case managers assisted with government paperwork and helped consumers solve practical problems of everyday life. One consumer described how his case manager had tracked him down when he was homeless to make sure that he got the services and supports to which he was entitled, and which he desperately needed. In his words, “She saved my life.” A family member shared that her son was in Vocational Rehabilitation, and that the DVR counselor helped her son to feel accepted and treated him with respect. She stated, “That’s all our son wants—someone to like him and to talk to him.” Another mother said of her son’s case manager, “He’s just fabulous.”

Educating Communities and Organizations
Family members offered a number of ideas about how to overcome barriers and reduce stigma. They saw a need for much more education about issues related to mental illness in many different sectors of the community. One way to reduce barriers to care was to provide more education through schools, faith communities, and health care organizations to families who might be coping with mental illness. One couple said, “We thought our son was just being naughty. We were not kind because it was not something you could see.” This couple felt that educating the public on mental illness would help families to be more empathetic and supportive to their loved ones who were struggling.

Family members suggested emulating other kinds of advocacy groups that had helped to change public opinion on other issues, such as AIDS awareness organizations and breast cancer advocacy groups. They felt that re-casting mental illness as a brain disorder would reduce stigma and increase the public acceptance of medical treatments for these conditions.

Focus Group Reports: Common Threads
The Regional Health Commissions’ Behavioral Health Initiative has been tracking the opinions and reactions of behavioral health system stakeholders for almost two years. Although participants have varied widely and have included consumers and family members from different areas of the region, very different background and with different treatment paths, a number of common themes re-appear in almost every focus group that has been conducted. One of the most salient of these themes is the pervasiveness of provider-perpetuated stigma. Behavioral health care consumers note that while system capacity and financial issues can act as barriers to care, more often, consumers turn away from...
behavioral health services because they are not treated with concern and respect. Family members have echoed a similar theme throughout the focus group process.

Interestingly, behavioral health care consumers, family members, and providers also observe that when behavioral health services work well, they are renewing and sometimes even life-saving. When providers reach out a hand to consumers and family members—through the chaos of psychosis, mood instability, and substance use—to help people reclaim their lives and work toward their goals, the effect is profound.

Another theme that echoes throughout these focus groups is that of resilience and hope. Behavioral health care consumers and their loved ones hold onto their dreams and continue to search, often in very creative ways, to achieve those dreams. Faith—whether tied to a religious tradition or not—sustains these stakeholders and helps them to keep moving forward.

Finally, we should note that another common theme among all of the focus group participants is also a limitation – the individuals we have heard from have all had some success in accessing the behavioral health care system. They were all either currently receiving treatment or have been appropriately released from treatment. We have not talked with individuals who are still searching for care or denying that a need for care exists.

**Conclusion**

Consumers and family members in the St. Louis region believe that there is much that is right about the behavioral health services system. In particular, coordination of services by case managers and community support teams was seen as an essential, and much appreciated, service. They reported positive experiences in a number of different sectors. However, problems do remain. Stigma seems to come from all sides, and even when stigma is not present, there is often a lack of awareness of mental illness which leads to a lack of help for those in need. The stakeholders we interviewed expressed a strong desire for more openness, dignity, and humanization of the mental health consumer. They also felt that increased education of the public about mental illness would lead to more positive attitudes, and would encourage individuals in crisis to seek care without feeling shame.