



# **Family Focus Group Final Report**

**As reported to the  
St. Louis Regional Health Commission**

**May 2007**

**St. Louis Region Family Member Report about Behavioral Health Services**  
Prepared by Sharon Bowland, LCSW, ABD and Melissa Hensley, MSW, MHA

**Background**

The Eastern Region Behavioral Health Initiative seeks to ensure that the behavioral health services in the region provide care that is streamlined, easily accessible and focused on the client. In February 2007, consumer organizations involved in the Initiative thought it was important to ensure feedback from consumers and family members affected by mental illness and substance abuse was incorporated into the work of the Initiative. Of particular importance to consumer groups was that these groups offer a confidential environment to consumers and family members so that they would feel comfortable sharing their experiences with the behavioral health care system. In response to the consumer groups' request, the project director coordinated a series of focus groups in March 2007. The final report for groups with consumers is located on the RHC website. In May of 2007, three more groups were conducted, this time with family members of those who live with mental illness. This report represents a compilation of the comments from the May family groups. The groups were conducted by two Ph.D. candidates at Washington University, using consumer feedback and incorporating their stated concerns. Both are social workers with extensive experience in working with clients who have mental illness. They prepared this report jointly, using qualitative methods.

NAMI St. Louis, a consumer group on the Eastern Region Behavioral Health Initiative Steering Committee, paid for the costs associated with the focus groups. This report serves as input that will impact the implementation efforts of the Eastern Region Behavioral Health Initiative of the St. Louis Regional Health Commission.

**Overview**

We collected data in the report from 22 family members and 3 individuals with severe mental illness from St. Louis County, Jefferson County, and the city of St. Louis. These groups were conducted on May 7, 8, and May 12, 2007. Both of the co-facilitators are social workers with extensive experience in working with clients who have mental illness. They conducted the focus groups and prepared this report jointly, using qualitative methods.

Of the 25 participants, all shared at least some demographic information. Of those reporting gender and ethnicity, 7 were men and 16 were women and two did not report this information. There were 6 Blacks and 19 Whites. One participant fell in the age range of 20-34, but the majority of participants were between 35-64. Five participants were 65 or older.

The geographic location of participants ranged from St. Louis City (6), St. Louis County (12) to St. Charles (1) and Jefferson (6) counties.

Most participants had household incomes in the 50,000+ range, with only 2 people reporting incomes under \$20,000. Two participants did not report their income. Seven persons were retired, one person stated he was on disability and another did not indicate employment. The rest of the participants were employed.

Participants reported various types of insurance ranging from private insurance to Medicare, Medicaid/Medicare and no insurance. While some people are receiving public services, the majority have private insurance. Three family members reported no insurance. The majority of their family members with a mental illness, on the other hand, were reported as having Medicaid/Medicare. Five people left this information blank.

### **Organization of this report**

Our report begins with information about how family members entered the behavioral health system. Members of the focus groups felt it was important for readers to understand their personal stories, and these are included in the second section of this document. After this, positive experiences within the behavioral health system are reported. While many agencies were named in the focus groups, as in the first report with consumers, the preparers did not view this report as a report card for individual agency performance, as much as a way to identify critical services and barriers to services. Therefore, agencies are not named in this document. The third section includes family perspectives on struggles and barriers to service. These barriers include inadequate insurance, agency services, and acute care. Additionally, relationships with providers, stigma, cultural competency and gaps in services have been identified. Next, the focus group participants made recommendations for in changing the system. These recommendations are described under each heading. The report closes with stories of participants' own triumphs in the midst of struggles. They offer signs of hope amidst turbulent and challenging lives.

## **Initial Points of Contact for Families in the Behavioral Health System**

Family members who participated in the focus groups had varying points of contact with the system. Some family members had children, as young as three or four years old, who had exhibited early signs of behavioral problems and had sought help right away. In other cases, the person with a mental illness did not show any indicators of disordered thoughts and behaviors until adolescence or early adulthood. Sometimes, families of children or adults with mental illness experienced “denial” of their family member’s disorder and did not seek help until the behaviors had reached a crisis point. In many cases, the person with the illness also showed a lack of insight and resisted obtaining behavioral health care.

The impact of mental illness on these families was devastating and the behaviors that led to contact with the system were often extreme. Families told stories of being beaten up by their loved ones, multiple suicide threats and attempts, and out-of-control substance use. One mother related that when her son was depressed, he would get a big knife and say, “I’m going to stab myself.” First contacts with providers ranged from juvenile justice workers to inpatient hospital care to psychotherapy. Other services utilized included personal assistant services, support groups, family psycho-education, residential care, and psychiatric rehabilitation services.

A number of family members related that when they had first had contact with the behavioral health system, they had relied on their private insurance coverage to pay for care for the ill person. Many of these families, however, exhausted their insurance coverage or needed services that insurance would not cover. Families that were relatively well-to-do were able to rely on their own savings to pay for care, but a number of other families ended up in the public system of behavioral health care.

## **Family Stories about Mental Illness**

Families told many heartbreaking stories about their experiences with an ill loved one. Frequently, mental illness spanned multiple generations, from grandparents to grandchildren. Family caregivers feel caught in the middle of overwhelming needs.

The family members had a variety of types of mental illness. Most of the adults with mental illness had bipolar disorder, major depression, or schizophrenia. Children with behavior disorders had bipolar disorder, attention deficit-hyperactivity disorder, obsessive-compulsive disorder, and post-traumatic stress disorder. A few children also had developmental delays.

Families described many struggles with their ill family members. One father reported that his son's behavior was "confusing and discouraging." Adults with mental illness frequently could not hold down a job, and children had many difficulties at home and at school. At times, violent behaviors forced parents to seek a higher level of care, such as inpatient or residential, to protect themselves and their other children. In other cases ill members refused to allow their families access to healthcare information and to cooperate with their family attempts to secure care for them.

Families grieved many losses related to the mental illness. One woman had lost her 24-year-old son to suicide—the most devastating loss of all. Other family members grieved the loss of the child or young adult they had once known, who had seemingly been replaced by someone with many troubling behaviors. A mother from St. Louis County stated that "Our son had become someone we didn't even recognize."

Substance abuse was an ongoing problem for many of these families. Ill family members sometimes used substances such as alcohol, marijuana, and prescription anti-anxiety drugs to "self-medicate." Families frequently found that the messages they received regarding their loved ones' substance use contradicted what they were told about handling mental illness. One parent noted, "If it's substance abuse you're supposed to give them tough love—if it's mental illness you're supposed to give them as much support as you possibly can—it's very confusing."

Mental illness took a financial toll on these families, as well. More than one family member mentioned that they had lost employment while trying to juggle work responsibilities with the burden of care giving.

Families tried very hard to maintain their own sense of sanity and self-worth, even when care giving responsibilities were overwhelming. Parents stated that their reports of their children's disordered behavior were often discounted when their children were very young; other people outside the family did not understand the problems that the children and their families were facing. The lack of insight of family members created much stress within families, as well. A couple of people discussed the impact of their child's illness on the healthy siblings. As one mother put it, "Getting sick ourselves does not help our family members."

## **Family Member Perspectives on the Strengths of the Behavioral Health System**

Families identified a number of “bright spots”—people, organizations, or particular experiences that had helped them through their struggle with mental illness. Over and over, families mentioned the positive healing experience of participating in peer-led support groups and family psycho-education. They felt that speaking to someone who has been through similar experiences was helpful. One parent stated, “Talking about it is very healing.”

Some parents mentioned school-based programs that had been helpful. Of particular assistance were partnerships among mental health providers and schools, though erratic funding for such programs made them unreliable as ongoing sources of support.

Community mental health centers also offered services that were helpful, to both adults with mental illness and children with severe emotional disturbance. Social workers and in-home counselors provided linkages with resources and assistance with managing difficult behaviors. Especially helpful were counselors and therapists who worked with the entire family, rather than focusing solely on the ill family member.

At times, community-based care was not intensive enough, and families sought inpatient or residential treatment. Parents of children and adolescents noted that although their children resisted going into residential settings, they would later acknowledge that the residential placement had saved their life. The structure of residential care and the close relationships with residential staff served as healing forces.

A number of parents of adults had found high-quality services for their family members, but had been forced to go outside of the St. Louis region to find appropriate care. Families sought care as far away as Texas, California, Minnesota, and Massachusetts. The care was multi-disciplinary and family therapy was an integral part of the service provided. Out-of-state care was almost never covered by insurance.

Contacts with police were frequently helpful and positive. One mother recommended that other parents inform their local police departments about their children’s behavior before a crisis occurred, so that the local authorities would be prepared in case of an emergency.

The consensus was that “having an advocate” was a bright spot in the system. Advocates could be advocacy agency members or leaders, police officers, service providers, or school personnel. As will be seen in the following section, however, advocates were often few and far between, whereas unhelpful experiences abounded in the system.

## **Family Struggles in the Behavioral Health System**

### **Inadequate Insurance Coverage**

As families sought care for their ill relatives, many were forced to do battle with uncooperative insurance and managed care companies. Families felt fortunate to have private insurance, but at the same time they found that having such coverage did not guarantee that needed care would be covered. Ill family members frequently needed types and levels of care that insurance would not reimburse. One parent reported that her insurance company would pay for just one counseling session a month for her ill child—not enough for a child with a severe emotional disturbance. Hospitalizations were labeled as “unnecessary” by insurers, leaving families with thousands of dollars in unpaid bills for care that had been needed to keep their family members alive. Some families noted that when they fought the insurance companies, using the appeals process, they were sometimes able to have more services paid for. “You have to be a master of the system to get what you want.” One woman described the catch-22 of getting her son on Medicaid, which does not consider eligibility without documentation of a disability. In this instance, her son was unable to afford an evaluation that would have led to a diagnosis of a disabling mental illness.

Another frequent problem with insurance was that young adults with mental illness who were applying for their own health care coverage were often denied such benefits on the basis of a pre-existing mental disorder. This forced young people into publicly-funded systems of care. “The focus is on the money rather than care for patient and family.”

### **Inadequate Social Services**

The programs that were available to these families did not always provide the support and resources that were needed. A parent stated that “The mental health center we contacted had a ‘one model fits all people’ philosophy.” It was frequently reported that staff at service agencies had an uncaring, cavalier attitude toward families’ problems. In addition, in outpatient settings, “the groups...weren’t relevant to everyday life...it just didn’t relate to me.” Another parent reported that “I cannot say that there was one psychologist or therapist that changed the way I felt.” One family had to wait three months to obtain an outpatient appointment with a psychiatrist despite multiple trips to the emergency room for their child’s behavior problems. Another mother, whose son was suicidal and suffering from posttraumatic stress disorder, received no help other than a prescription from a psychiatrist and an appointment to return in three months.

### **Inadequate Children’s Services**

A frequent problem with children’s services was that schools and other providers were quick to shunt children off into separate, segregated programs and to underestimate the intellectual potential of emotionally disturbed children. School districts were often slow to act on the concerns of families: one mother reported that by the time an interdisciplinary team was finally convened to address her son’s difficulties, she and her husband had been fighting with the school district for five years. One parent expressed

concern that a school-based program was being cut and that he would have to start over in setting up a multi-disciplinary program for his son.

Parents reported the agony of having to sign custody of their children over to the state in order to obtain certain kinds of services. Parents also had to rigorously document every behavioral episode that their children had, in order to prove the need for intensive programs.

It was particularly difficult to find care for late adolescents and young adults attempting to transition to independent living. A parent stated, “There is not a lot of help for the 18 to 25 age group.” It seemed that if young people had not gained access to the system as children, they were frequently shut out of insurance coverage and many types of mental health care. Many of these young adults had been unable to make the transition to independence.

### **Inadequate Acute Care Services**

Access to intensive levels of care could be problematic. Getting help for ill family members with limited insight was an ongoing struggle. Utilizing an involuntary commitment process was risky because it alienated the ill family member, and because proving “harm to self or others” was difficult. Involuntary treatment, when it was secured, often did not last long enough to address the long-standing problems of the ill family member. Staff people in emergency rooms were at times unhelpful, forcing families to wait for long periods of time to see a professional provider.

Ill members’ lack of insight created obstacles in securing benefits, as well. It was difficult to obtain Medicaid, Supplemental Security Income, and Social Security Disability Insurance for those who refused to admit that they had a disability. Some families pursued legal guardianship, but this, too, alienated family members and tended to create as many problems as it solved. Most often there was no system response that could help family members address these concerns.

### **Feeling Blamed by Care Providers**

Parents were sometimes blamed for their children’s problems by the professionals from whom they sought assistance. Parents were seen as dysfunctional and overprotective, and were denied needed services. One parent noted that he and his wife had tried through the years to get help for themselves and their son, but that “It’s next to impossible—nobody will talk to you.” Another couple reported that they had been viewed by a social worker at an inpatient drug treatment facility as overprotective and that their son had been denied treatment at that facility. By the time this couple’s son was accepted into drug rehabilitation a year later, he had contracted HIV infection as a result of ongoing substance use.

### **Relationships with Psychiatrists and Other Care Providers**

Family members talked extensively about the services they received from providers in their struggle to secure adequate (coordinated) care for ill members. Several noted the key importance of access to psychiatrists and other care providers. In spite of

this, “It’s hard to find a case manager or counselor that will stay with you. It’s hard to find a psychiatrist.” Several said there are limited numbers of psychiatrists, especially psychiatrists who will accept Medicaid as payment, in outlying areas, including Jefferson County. Others noted that they had moved from provider to provider due to the high burnout rate of professionals. Furthermore, they described that from the point of entry they had extremely limited time with their providers, who were quick to diagnose and prescribe. “Doctors often can’t focus and get involved with their patients because they have too many patients. More than 15 minutes is needed with a psychiatrist.”

One participant noted that the DSM (Diagnostic and Statistical Manual), which is used to assess and diagnose psychiatric patients, is very subjective, and that diagnosis is quite complicated. More time would lead to more accurate diagnoses, according to several people whose children had been initially inaccurately diagnosed. Another family member related that providers initially put their young adult son on medication that fed his addiction to alcohol. Someone else stated that meds are given out too freely, before they are adequately tested. A third person reported that their son was diagnosed with bipolar disorder and from this point “they (providers) had preconceived notions about what he should do, be, etc.” Families expressed a wish for providers who were interested in “the whole person”—who were “interested in their story.” As one parent poignantly stated, “If doctors could care about their patients, that would help.”

When their adult children were diagnosed, family members reported that healthcare professionals did not communicate with them about the diagnosis and treatments being prescribed, making it hard to assess or monitor when their ill members were off track. After reporting their concerns to providers, some noted that providers disclosed this information to their children, thus negatively impacting family relationships and making their input into care need more difficult. Families reported, however, that they were aware of confidentiality and HIPAA regulations that make professionals fear lawsuits. One family noted that mental health is the only sector of care where privacy laws are so strictly enforced.

In communicating concerns, members suggested that family members need to educate themselves about the jargon used in behavioral health care in order to communicate effectively and honestly with providers. Concerns about the quality of care versus the cost of care were acknowledged. “Providers are not paid well and they are overworked.” “You can’t get the coordinated approach you need because providers don’t make any money that way.” This lack of coordination leads to providers not taking the time necessary to share information with other providers. Even getting providers to coordinate care through faxing documents was hard to achieve.

### **Services for Family Member Themselves**

Families had a particularly hard time getting their own needs met. Family members felt that their problems and difficulties were ignored, and that care provided in the system tended to focus only on the diagnosis and psychiatric treatment of the ill member, rather than recognizing the needs of the family as a unit. In general, families felt that providers did not communicate well with them and withheld information that

would have been important for them to have. A father commented that “I don’t think there’s anything very positive in the system besides what I’ve gotten from my advocacy agency.”

### **Stigma and Cultural Competency**

Over the course of these three focus groups there were many comments that characterized the ignorance and negative attitudes of our society towards those with mental illness, and several that called for cultural sensitivity in addressing mental illness within the context of a person’s race/ethnicity.

Overall, family members felt that the lack of common knowledge about the biological basis of mental illness is pervasive. Someone said, “Why can’t we have education for mental illness?” There were several comments about the cultural insensitivity of providers who should know better how to work with those from different backgrounds.

Furthermore, the struggle with stigma permeates our families, as observed when family members say, “He doesn’t look sick.” One person stated she has started countering stigma by educating her own family. Another person noted that at an advocacy agency walk to combat mental illness, the gatherings are much smaller than at cancer or AIDS walks, in spite of the large numbers of families affected. In the beginning, when her son was first diagnosed, one woman stated that she was not aware of the large number of families facing this type of illness of a family member.

The general public was viewed as being in denial about the high level of need for behavioral health services. “We all know the symptoms of heart disease, diabetes, and cancer—but we don’t know the symptoms of mental illness. We don’t know that we should go to the doctor.” Even family physicians often don’t appear to have the knowledge to diagnose and refer to appropriate services. One person noted, “Society hasn’t come around to understanding the difference between the mind and the brain. Even doctors don’t get that.”

Schools and their personnel were frequently cited as those in need of further education about mental illness. One parent described how her son was left alone when he was upset because teachers didn’t understand how to respond to someone with a mental illness. Several parents stated that they had a very difficult time getting schools to address the special needs of their children, even though mental illness is a type of special need. As noted above, it is often difficult to get schools to coordinate services, choose the appropriate classroom setting, and make accommodations within the classroom. Bipolar illness, in particular was noted as a type of mental illness that received inappropriate response from school-based professionals. Someone noted that having a mental illness gets confused with having a developmental disability. Children are then not treated in ways that encourage them to develop their capacities. Stigmatization can quickly devolve into a lifelong trajectory of discrimination for children with a mental illness.

Addressing the needs for training among other professional groups, one person suggested that police officers in outlying areas are not adequately addressing the issues of those with mental illness.

### **Other Gaps in Services**

Lack of coordination of services was noted over and over again in the focus groups. One family member stated, “There really is no system.” It was noted that cuts in public sources of funding such as Medicaid had led to gaps in the so-called system. The unreliability of private coverage for mental health care caused problems and gaps, as well. These coverage gaps led to patients being put out on the street without housing or services. In addition, one father commented that “Bifurcation of mental and physical health care is at the root of the problem.”

Families perceived that many mental health organizations held competitive, rather than cooperative attitudes. They observed that the system would run more efficiently if groups would work together and not compete for money and clients. “There are too many organizations—health care and what have you—and none of them work together.”

Other gaps in the system proved troubling, as well. A mother noted that “services are available but not necessarily accessible.” Services in the St. Louis area seemed oriented around crisis, which made getting the right level of care at the right time difficult. Even so, services were largely unavailable on the weekends and in the evenings, leaving families and individuals with mental illness alone and vulnerable during difficult times.

Specific services that were seen to be lacking included appropriate anger management training, parenting training for mothers and fathers with behavior-disordered children, and trauma-informed mental health care. One family member stated that “trauma (i.e., war trauma, physical and sexual abuse, and domestic violence) is being left out of people’s stories.” Another parent noticed that care providers make “no attempt to address the bigger issues. The philosophy is to just medicate...”

## **Recommendations For Next Steps**

Family members had a wide variety of ideas about programming needs and how to improve services for mental illness. Overall, it was acknowledged that additional funding was needed at federal, state, and local levels for research and treatment. Several individuals mentioned that persons with mental illness need comprehensive health coverage—not just for mental health care, but also for medical and dental care. Families felt that existing systems would better serve their loved ones if there were increased coordination of health care services and of medical, mental health, and substance abuse benefits.

Early screening and identification was mentioned as a pressing system need. Families noted a need for one-on-one advice at the time of diagnosis, and they also advocated for better screening processes in schools. “The sooner we can get treatment to people, the better off we’re going to be.”

Many of the needs of people with mental illness were related to needs of everyday living, rather than psychiatric care specifically. Housing was mentioned as an overwhelming and essential need for persons with mental illness, especially for those being released from extended stays in inpatient care. Different levels of housing, from assisted living to independent subsidized apartments, were seen as important to the system. In addition, families mentioned the desire of their family members to hold employment and the many difficulties that their loved ones had faced in trying to keep jobs. Families noted that increased flexibility in the workplace, as well as education for employers about mental illness, would be helpful. One parent mentioned that having advocates for individuals who have a mental illness to help them transition into the workplace would be useful. Family members also mentioned a need for a variety of in-home supports, such as assistance with shopping and laundry, to help their loved ones function successfully in the community.

Persons in the focus groups also observed that many of their family members do not “fit” well within existing service systems due to their behaviors or needs. A parent commented that “The behavioral health system needs to think outside the box.” Services such as sheltered workshops or day hospital programs were noted as being effective for some clients but not for others. A mother with mental illness who also has a child with an emotional disorder stated that “If psychiatrists can see us for who we are, that is the most important thing. Not everything works for everyone.”

Families also described a need for better advocacy services. Parents felt that they were not adequately informed of their rights and of how to get the most out of existing systems of care. The need for information also extended to a need for details about service providers—families expressed that there seemed to be no central database of program information and no way to assess the quality of a service provider ahead of time. In addition, a number of parents felt that medical confidentiality laws needed to be

relaxed to allow family members of adults with severe mental illness to have greater access to their loved ones' diagnostic information and plan of care. Families felt that "family members should get behind their advocacy agency and join an advocacy agency" to meet both support and advocacy needs.

Other service needs included psychotherapy and support services for parents and siblings of individuals with mental illness. Siblings were seen as in particular need of information and reassurance regarding the struggles of their brother or sister. Family members expressed a desire for additional support groups and psycho-education classes, as many support groups meet only once a month, and the availability of psycho-education is limited in some neighborhoods, such as North St. Louis. Parents wanted an "informational booklet or packet of information" about their loved one's diagnosis and treatment, and they observed that "There is no roadmap" for families to follow when coping with mental illness.

As an antidote to stigma, family members suggested that developing an alliance with the media is necessary to help us "put faces and stories to this illness." Someone called for a national spokesperson for bipolar disorder. Members noted that people with mental illness and substance abuse issues reside within our own families and neighborhoods. They are not merely strangers in our midst. They are us.

## **Triumphs In The Midst Of Struggles**

Throughout the groups there were signs of resilience in the face of struggle, stigma, and discrimination. We were struck by the dignity and passion with which family members fight on a daily basis for the quality of their loved ones' lives. This spirit is captured in three stories of wisdom, perseverance, and bravery retold below.

One African American woman stated that cultural sensitivity is not a matter of race. She reported that the best listener she had ever had was a White male psychiatrist. Although they had limited time “he got to know my family, my faith, my beliefs—my whole story—that’s what will break the barriers and help us to cross the cultural divide.”

Another woman told the story that when her son committed suicide she had printed the obituary in the newspaper disclosing that he had struggled with depression and borderline personality disorder. Strangers called and thanked her for telling the truth about his life and death.

Another woman shared the power of her faith in seeing her through the tough times. She stated that she continues to hold God’s vision and promise of a new world of righteousness where none of us will be sick.