



# **Consumer Focus Group Final Report**

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

**March 2007**

## **St. Louis Region Consumer Report about Behavioral Health Services**

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### **Background**

The Eastern Region Behavioral Health Initiative seeks to ensure 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 the process 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 conducted by two Ph.D. candidates at Washington University for consumer feedback incorporating their stated concerns. This report is the result of that effort.

NAMI St. Louis, a consumer group on the Eastern Region Behavioral Health Initiative Steering Committee, paid for the costs associated with the focus groups. The Mental Health Association of Greater St. Louis, the other consumer group on the Steering Committee, dedicated staff time to recruiting consumers to participate in the focus groups. Two additional focus groups for families of persons affected by mental illness will be conducted in May 2007. 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**

The content of this report represents the combined wisdom of 30 individuals with severe mental illness and their family members from across the St. Louis Region who shared their experiences and struggles in a series of three focus groups. These groups were conducted on March 8, 13, and 14, 2007. The groups were held in three different locations: within the city, in the county, and in the St. Charles area. The co-facilitators and report writers listed above are doctoral students at Washington University. Both 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.

Participants in these focus groups have been in the behavioral health system for as little as one week and as long as 25 years. Some participants have been receiving services since childhood. Several of the participants are currently receiving drug and alcohol services. For many of these individuals, a crisis in young adulthood resulted in their entering care for acute mental health symptoms. Stories include those entering due to suicide attempts, being mandated to services through the military, manifesting drug abuse beginning in childhood, developing post-partum depression, and experiencing early childhood diagnosis and continuing system involvement due to developmental disabilities concurrent with mental health issues.

Of the 30 participants, 26 shared demographic information. Of those reporting gender and ethnicity, 15 were men and 11 were women. One Native American person participated in the

group as well as 11 Blacks and 10 Whites. Five participants were aged 20-34, but the majority of participants were between 35-54. Only one participant was 55 or older.

The geographic location of participants ranged from St. Louis City (10), St. Louis County (5) to St. Charles (9) and Lincoln (2) counties.

Income was predominately in the \$0-9,000 range, with only 6 people reporting incomes over \$10,000. Only two participants said they were employed, with half stating that they were unemployed and on disability.

Participants reported various types of insurance ranging from Medicare, Medicaid/Medicare, no insurance and private insurance. While some people are receiving private services, the overwhelming majority are accessing the public behavioral health system (designated as “system”) in this report.

This report begins with consumer perspectives of strengths in the behavioral health system. Comments in this section are organized by types of services that have been found to be helpful. While many agencies were named in the focus groups, 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 second section includes consumer perspectives about areas for improvement in the behavioral health system. These sections are arranged by the type of barrier named. Next, the focus group participants made recommendations for steps in changing the system. Again these are characterized by recommendation and described under each heading. This report closes with a section on hopeful statements made by participants. They are perhaps the best indicators of the resilience of those living with a chronic mental illness. As an addendum, the report preparers make recommendations for next steps, in light of participants’ feedback and their own professional experience.

## **Consumer Perspectives on the Strengths of the Public System**

The participants in the focus groups mentioned a wide variety of community services and supports that they have found to be helpful. People expressed that some hospitals and emergency rooms were responsive to their needs and served as places they can access in a crisis. Relations with mental health providers are also an important source of support. In commenting on positive experiences with their physicians, one woman stated that her doctor treats her “like I’m somebody—like a whole person.” People saw the physician-patient relationship as very important and the struggle to find a good physician as foundational. Finding a decent physician that is “interested in learning about you, not just medicating the symptoms” is hard, but important. Many named the system as having good and caring professionals—but stated that there are just not enough.

Outpatient services appear to provide a backbone to the system. Services such as case management, in-home programs and nutrition counseling, transportation services, and representative payeeship provide structure and stability as people work to recover. One participant stated he had been totally unable to handle his money until he turned over responsibility to an agency to assist him with paying his bills. Case management services that are delivered in a manner that affirms the dignity and agency of the client are empowering.

Psychosocial rehabilitation clubhouse services enhance self-esteem and give people a reason to get up in the morning. Participants enjoy educational classes, work assignments, and fellowship with others. Clubhouse experiences give hope to people that they can gain job skills and set goals for the future. Participants feel like these facilities need them to perform tasks in order for the agency to run properly, and that they are an integral part of a community.

Programs that provide rental assistance and that help people to find housing where they want to live are seen as important to stability and quality of life. Independent living was the most frequently-mentioned housing preference, but some participants are living successfully in assisted living and group home settings, as well.

Being employed—getting a job and having the services to support that process—was mentioned repeatedly as a critical ingredient in recovery. Job placement, job training, and employment support are all vital. Having some assistance in preparing resumes and obtaining job interviews is necessary to success. Individuals with mental illness, however, appreciate services that provide them with support throughout the employment process, so that they not only obtain positions but also stay in those jobs over the long term. Accommodations such as flexible hours can also help a worker with mental illness to succeed. What individuals do not want are sheltered placements that pay below the minimum wage, or penalties on the benefits that they receive leading to an even lower income than they had before they began working. One participant reported that “sheltered workshops only pay 50 cents an hour even though people are working.”

Self-help services are accessed through several agencies. One participant discussed the importance of finding peer support when one is struggling with the illness. Another participant

was thankful for a support group in the community that was aimed at the Black community. Self-help classes and informational services are helpful, as well.

Being able to participate in recreational activities and competitive sports with one's peers plays an important part in enhancing quality of life. Participating on a team and having good relationships with coaches can provide social support. Sports activities can also enhance self-esteem.

Participants repeatedly mentioned the support they receive from family and friends. One man talked about the ways in which his "kids and grand-kids give me hope." The encouragement given by friends and family seems particularly important when a person with mental illness is recovering from a crisis, such as a suicide attempt or a death in the family.

Several individuals from St. Louis City and St. Louis County mentioned the Crisis Intervention Team program as an asset to the community. They feel that having trained police officers to assist persons with mental illness in crisis can help bring positive resolution to some difficult situations.

## **Consumer Perspectives on the Areas for Improvement in the Public System**

### **Staff Training**

Many people reported experiences of being treated like a child or an “animal” in the system. One person asked, “Where is the humanity of the mental health system? The average person treats their pets better than they do us. The system is definitely broken and won’t be fixed until they hear what I am saying—not just listening to but hearing what I am saying.”

People acknowledged that many professionals are not properly trained. Some may not have good training in medication administration. Even some psychiatrists seem to not view persons with mental illness as human beings. This is especially noticeable for one participant in seeking services from a Medicaid provider. Many people reported experiences of disrespect and being treated as if they are mentally incompetent just because they have a mental illness. One participant noted that behavioral health is a service industry and that she wants to be treated as she would in any other service industry.

### **Medication Issues**

Experiences reported with medicines are mixed. Many people have struggled for years before finding ones without debilitating side effects. Others report being overmedicated and having to change doctors. Participants found that they often have to try many medicines before finding ones that work for them. They express particular concern that generic drugs are often not a good substitute for name brand medications. Some stated they have bad side effects and allergic reactions to generic drugs. Many noted that they cannot get access to name brand medicines, and that when they have access to drugs it is often sporadic, based on their finances and pre-approvals. Side effects from medicines can be extremely debilitating—so much so that some participants in this group acknowledged that they have given up on using them. One man reported that he has fought continually with people in the system because professionals haven’t agreed with him about the kind of care he needs. “I am anti-drug. What I need is care from an individual, not a drug,” he said.

Another person said she felt like a guinea pig in a system that is trying out new medicines that might not be safe. There may be differences in experiences around medication based on age at entry as well. One young adult woman reported that professionals did not listen to her because she was an eighteen year old at first diagnosis. “Until last year (9 years later) I wasn’t on the right meds. I went through 20 meds but people don’t listen. It’s hard to be young with a mental illness.”

Overall, participants believe that they are the experts on their own bodies and that they have often had useless struggles with their care providers over side effects and endured physical harms cause by medication. “Some of the drugs I have taken have given me diabetes and raised my blood pressure.” Given reports of these physical problems and clarity about the lack of help received when being forced to use or to stay on particular medicines, additional thinking about medication administration and delivery is needed.

### **Lack of Services & Low Access to Services**

Access to timely services is a problem throughout the mental health system. Long waits were reported by focus group participants—waiting thirty days or more to be enrolled in a service, and then enduring long waiting times when they finally secure an appointment with a provider. Long waiting times are especially a problem when people are in need of acute care. Overnight stays in crowded emergency rooms are a frustrating experience.

Outpatient services were described as “hit and miss.” Whereas some service providers have excellent reputations for providing quality care with dignity, other providers seem to be inconsistent. Some participants reported very positive experiences while others struggled with services. Several participants complained that the system seemed to have an expectation of conformity—that clients would quietly comply with service provider requirements and give up their individuality in the process. One example given was a program in which participants were expected to maintain a “positive” attitude and are asked to leave the program if they express any sort of negative comment. There were a number of focus group participants who report that they would rather be kicked out of a service than be forced to conform to others’ expectations of “correct” behavior. Many individuals reported frustration with providers who treat them like children. A male participant commented that when he refused to adhere to a provider’s behavioral expectations, he “was thrown away like a used lighter.”

A third system issue is the difficulty that participants face in getting out of the system once they are enrolled in services. One individual described her experience as “being stuck in a spider’s web.” The label of “mental health consumer” seems to encompass all aspects of the person’s identity, making it difficult to seek any kind of services or supports outside of the system. Furthermore, financial disincentives to employment make getting off of Social Security Disability or SSI payments practically impossible for many with mental illness.

### **Seclusion & Restraint Policies**

Participants who have had the experience of being in an inpatient hospital, including state-operated and Veteran’s Administration facilities, report negative experiences. The inpatient experience itself is not necessarily seen as negative, but the consequences of crisis-related behaviors are definitely a problem. One person’s comments seem to exemplify the stories of participants entering the system in an acute crisis: “If you are suicidal or upset, you end up locked up. You are restrained but no help is given. This is stressful and leads to depression when you are put in seclusion or restrained.” Participants stated that when they needed help the most they were often left alone. “In a good system you wouldn’t be put in restraints—you wouldn’t have to go into a safe room with a urine stained mattress. It’s a snake pit, and we are treated like children.” The consensus was that hospitals are understaffed, overcrowded, and often unfriendly places to go for care. There was also a fear that too-frequent hospitalizations could result in a loss of outpatient supports and long-term commitment to a state facility.

### **Access to Competent Physicians**

Participants feel that there is a difference in the quality of care delivered by physicians in the Medicaid/Medicare system and those in private practice. One person related that they finally paid a private doctor out-of-pocket because their publicly-funded provider was so bad. Several commented that they did not receive a proper diagnosis for many years. Another stated that

public providers tend to overmedicate their patients compared with private doctors. One person said that he could not get his doctor to reveal his diagnosis to him and had to switch doctors in order to get hold of his medical record. Seeking an appropriate provider proves to be a “Catch-22” for many participants because they need a provider who will accept public funding, yet they do not trust publicly-funded providers to give them quality care.

## **Stigma**

The problem of stigma was identified on three levels: within the general public, within the services system, and internalized in the attitudes and beliefs of individuals with the illness. One participant reported that “stigma follows you around.”

Public stigma shows up in a variety of forms. Especially troubling are news reports that link mental illness with violent behavior. There also appears to be a common assumption that individuals with mental illness are dishonest and manipulative. Participants reported that as a result of stigma, they had lost housing, educational placements, and jobs. Stigma is a barrier to quality of life in the public sphere. A female participant stated, “We don’t have a voice. We are taboo. I had a friend classify my illness as ‘you have demons.’”

As has been mentioned earlier in this report, stigma also plagues the mental health system itself. “The system thinks you are stupid because you have a mental illness,” one individual reported. Stigma affects everyone in the system, from psychiatrists to pharmacists to social workers and community support workers. Participants were acutely aware that many of the professionals who worked with them have their own “fears” and negative attitudes toward individuals with mental illness. They also felt that many of these professionals are unaware of their own attitudes and the need for change. A female participant reported, “There is a problem with stigma within organizations that are supposed to know how to deal with mental illness. Professionals need more training. Everyone should be treated as a person with value and worth.”

Most disabling of all, for many individuals with mental illness, is stigma that is internalized. Individuals with mental illness often experience their illness as a “character defect” or moral failing. Internalized stigma leads to a sense of shame and frequently prevents individuals in need from seeking the help that is available. Persons with dual disorders of substance use and mental illness experience internalized stigma many times over: “A lot of us like to self-medicate to get rid of the pain.” Overcoming internalized stigma can take many years and often involves seeking fellowship with others who experience mental illness or substance use disorders. Taking leadership positions in self-help groups or clubhouse settings can also reduce the sense of shame and incapacity. “People with mental illness need to respect themselves.”

Participants have also experienced discriminatory treatment because they are poor or depend on public services. A number of individuals reported being made to sit and wait for long periods of time at clinics because they had no insurance. In general, people were treated as “less than” due to financial issues. “If you are poor, you are treated badly.”

An additional issue was continuing discrimination on the basis of race. Several Black participants related experiences of having been treated as unintelligent or illiterate because of

their ethnicity. The combination of being Black and having mental illness makes the situation even worse. One Black participant, when asked about Black-White disparities in the mental health system, stated, “No need to talk about it because you’re just going to lose anyhow.” Another participant added that despite the new Crisis Intervention Team program for police officers, as a Black man, he did not feel that he could trust the police to act in his best interest.

Focus group participants shared the belief that if the fundamental problems of stigma and discrimination are not effectively addressed, other attempts at system reform are bound to fail.

## Recommendations For Next Steps

### **Negate the Stigma of Mental Illness and Substance Abuse**

Focus group participants consistently expressed their frustration and intolerance for being treated with disrespect because of the lack of understanding and empathy for people living with mental illness and substance abuse issues. Foundational to the success of all implementation efforts is the need to combat stigma proactively through professional and public education around mental illness and substance abuse. This is the take home message from clients in our Missouri behavioral healthcare system.

### **Integration of Physical/Behavioral Health Care**

A common theme among focus group participants was the belief that systems of care should not be segmented. People with mental illness have a variety of needs that do not directly relate to their mental disorder, but that need to be addressed. For example, individuals with serious mental illness often have physical pain and physical health problems. Many other persons experience developmental and learning disabilities in addition to mental illness. One participant stated that “medical doctors have no interest in mental health problems.” This frustration with primary care providers, especially publicly-funded providers, was expressed frequently. A common concern is that primary care providers are unable or unwilling to communicate with patients’ psychiatrists. Participants feel that they have to choose between whether to address their physical problems or their mental health problems; they feel that there is not enough time or resources to take care of both. As a participant commented, “The stress of trying to get the care you need can lead to problems.”

One area in particular need of coordination is the medical record. Participants reported being asked to relate their medical and psychiatric histories over and over again because providers’ record-keeping systems are not coordinated. “Doctors don’t coordinate care; they don’t talk to each other,” stated one participant.

Lack of coordination leads to concerns about access. Services are frequently unavailable at times when they are needed the most. Mental health crises such as relapse often occur in the evening or at other times outside of “business hours.” Physical impairments often prevent participants from getting from place to place to obtain services they need. Participants observed that agencies appear understaffed, leading to even more problems with organization and access: “You just have to tread water when you can’t get the support you need.”

Participants were clear and direct in their recommendations regarding service coordination and integration. Suggestions included putting as many services as possible in the same building, under one roof, to facilitate access. Another recommendation was to cut down on the number of case managers that any one individual has to interact with, from five or six per person to one. There was also consensus that medical records should be better-coordinated. Participants feel that better coordination will lead to better quality of care, as well as reduce the need for transportation resources. To put it succinctly, “They need to meet people where they are; meet the needs where they are.”

## **Financial Needs**

Concerns with poverty and lack of insurance were common. Several participants note that they have problems affording their groceries every month. Individuals with mental illness frequently need help with rent, utilities, food, transportation, and clothing.

Access to health care is also frequently linked to financial concerns. Medicare and Medicaid increase access to health and mental health care services, and participants observed that those without any insurance had to wait longer for services and often received a lower quality of care. Medicaid spend-down was brought up as a major problem for those with mental illness, leading to a lack of access to medications and professional services. One participant noted, “You have to wait and make appointments at the end of the month. What if I had a problem on the first of the month and had to go to the hospital and ended up with a big bill?” Participants also identified difficulty accessing podiatry, dental, and optometric care due to eligibility restrictions in Medicaid.

Several participants suggested solutions to financial issues, including lowering co-payments on medications covered by Medicare and Medicaid; offering psychotropic medications at a reasonable price; and consistently raising SSI and SSD benefit levels to better keep pace with the cost of living. Eligibility for SSI also needs to be adjusted so that it is in line with the newly-raised minimum wage. In order to recover, “people need a lot more support.”

## **Consumer Feedback**

One of the most consistently identified needs among focus group participants is the need for a mechanism for individuals with mental illness to give feedback to providers and the state about the services they use. Along with this, participants want service providers and political leaders to be accountable for the promises they make. This should be accompanied by a change in attitude toward those with mental illness. Currently, “there is no place for consumers to state their concerns about the system.” Individuals who struggle with mental illness need to be aware of who their representatives are, and they must speak out in order to effect change. Increasing the advocacy potential of those with mental illness is a personal responsibility, but it is also a responsibility of the system that claims to care for those in need.

## **Special Population Needs**

Participants stated often that “one solution doesn’t fit for everyone.” Services must be tailored to the needs of the individual, rather than expecting the individual to conform to the system. For instance, services for several special populations were listed as important needs. Homeless veterans are a group in need of better shelter and support services. Those in jail or prison also need access to services and effective medications. In addition, individuals in crisis who seek inpatient services need to get in the door of the hospital, and once there, they need safety and compassion.

## **Public Information & Education**

Participants stated that for stigma to be reduced there needs to be more public information on mental illness. Two participants suggested that information on mental illness should be posted on billboards so that people will be educated. Public service announcements and other media outreach are also seen as essential.

Education and information not only about mental illness, but also about behavioral health services, is seen as a major need. Participants stated that many people currently find out about services through word-of-mouth because public information on services is so limited. Sometimes brochures are distributed or flyers posted, but oftentimes participants have to seek information on the street. Two underlying problems, lack of resources and stigma, are seen as contributors to the problem of lack of information. “Where is the information for other people to know which direction to go?”

## Reasons For Hope

In spite of struggles with illness, problems accessing services, and the ever-present challenge of stigma, participants named many reasons for hope. Participants held on tenaciously to the sense of hope for a better life. Individuals felt that they knew themselves well and exhibited self-reliance and resilience in the face of many obstacles. Here are their words about hope:

- ∞ “I feel better about myself when I can do things.”
- ∞ “I’m trying to be the best I can be and get off the alcohol and drugs.”
- ∞ “I got a job all by myself. It felt good to do it on my own.”
- ∞ “My first day at the clubhouse, I was able to contribute. It felt good to be able to do a job successfully.”
- ∞ “People have to want to get better in order to make it work.”
- ∞ “People have to have determination to last through the process of waiting for services.”
- ∞ “I ran a mile in 7:23 and got third place.”
- ∞ “I had good experiences working out of high school. I volunteer at a day care center and I feel good about that.”
- ∞ “My educational dream is to get an associate’s degree in computers.”
- ∞ “I have had to learn to rely on myself; people with paranoid schizophrenia know when they are having an episode.”
- ∞ “My friends give me hope.”
- ∞ “My faith gives me hope.”
- ∞ “Things are getting better because people are speaking out.”
- ∞ “There are people out there who want to help people like us.”
- ∞ “Give people a chance to better their life.”
- ∞ “We need to put people first.”

As we work to re-shape the regional system of behavioral health care, let us put people first.

## **ADDENDUM**

### **Echos from Focus Group Facilitators**

#### **Sharon Bowland, LCSW, ABD**

The need for integration between physical health and behavioral health systems of care is described eloquently by consumers in this report. Those living with chronic mental illness experience the brunt of these fragmented systems as they scramble to find the unadvertised services they need, interact with multiple case managers to obtain adequate care, struggle to “keep up” with their appointments as they travel (by bus) back and forth across town, experience long waits because there are not enough providers, repeat their stories over and over again, and have complex mental health problems increasingly confounded with physical illness (due to inadequate care) as they age in the system. Their voices about the lack of coordination of care make the strongest case for the integration of these systems.

As the primary caregiver for my aging mother, who has chronic mental and physical health problems, I am grateful for her eligibility in the Program of All-Inclusive Care for the Elderly (PACE) in St. Louis. This is one model where medical and mental health services are delivered in a coordinated system. I can envision a model of care in the State of Missouri where there are doctors, dentists and mental healthcare providers together in one location, where substance abuse and mental health assessment and referral is part of healthcare (and people who are referred to specialized services are given a “warm hand-off” to engage with those services), and where there is a central database, with one’s physical and mental health information held confidentially, yet accessibly. Too often I have seen consumers seeking treatment and being prescribed medicine in a system that has not done an adequate assessment of their psycho-social needs, and one in which their psychiatrists, physicians, and social workers have never communicated—even in this era of electronic communication. As first steps I recommend that we 1) pilot a model of integrated care based on the success of other integrated care models, such as PACE; 2) develop a central database for health and mental health information; 3) create a universal assessment instrument and train professionals in all agencies and hospitals to perform these assessments; and 4) train administrative staff to be familiar with the range of community services available, as well as assist those at system entry points to make warm hand-offs in referrals for care.

Foundational to the success of all of the above, as many in this report have astutely observed, is the need to combat stigma proactively through professional and public education around mental illness. This is the take home message from clients in our Missouri behavioral healthcare system. Based on their statements I recommend that we 5) set aside funds immediately to provide courses and updated training to professionals to combat stigma and discrimination. My final recommendation is that 6) consumers be given a voice in the public care system by developing a mechanism through which they can continue to give feedback on their needs and concerns. Ongoing consumer input and opportunity for advocacy will make our system much more responsive to those it is set up to serve.

## **Melissa Hensley, MSW, MHA**

As a person who has lived with bipolar disorder for the past eighteen years, I can honestly say that very few of our focus group participants' comments came as a surprise to me. What did surprise me, however, was the pernicious effect of stigma and discrimination on every aspect of our participants' lives. There may be public service announcements about depression on network television, but the crucial message of hope for people with mental illness is still lacking. Individuals with mental illness and substance use disorders who are living in our region deserve to be treated with respect by every segment of society: from their psychiatrists to their neighbors to people at the grocery store. We need a vigorous, visible attack on stigma in the St. Louis region. In this, the twenty-first century, it should no longer be acceptable to discriminate against people with mental illness, or to label them as demon-possessed or worthless. Television stations, newspapers and other publications, locally-sponsored Internet sites, and other regional media need to team up to produce public service announcements, special programming, and advertisements to promote a positive image of people with mental illness. Public education about available services also needs to take place.

An additional message that rings loud and clear from our participants' remarks is that the behavioral health care system must become more organized and coordinated. Recovering from mental illness means more than taking a pill or two every day. Recovery requires resources such as adequate health care, rehabilitative services, attention to basic needs, and connection with others who struggle with mental illness. The providers of these services need to collaborate, to talk with one another, and to coordinate their resources so that people can get the care they need without having to face half a dozen different case managers, each with a different treatment plan and set of priorities. People with mental illness cannot afford to spend all of their time and resources getting from one service provider to another, only to endure long waiting periods once they reach the right office. We can learn from the efforts of providers in the homeless services and family support sectors, who have integrated and co-located programs to the benefit of their clients.

Most importantly, we must hold out hope for recovery for all of those who struggle with mental illness and substance use disorders. Having been considered a hopeless case myself at one point, I know that even those individuals who seem the most mired in crisis, the least able to fend for themselves, and the most prone to struggles and difficulties, have the potential to rise above their challenges and reclaim their lives. Every individual in the St. Louis region who struggles with behavioral health disorders deserves a chance at a better quality of life. It is the responsibility not only of our public system of care, but also of everyone in our community, to make this a reality.