



# **Consumer Focus Group Final Report**

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

**January 2008**

## **St. Louis Region Consumer Report about Stigma Associated with a Mental Health Condition**

Prepared by Melissa Hensley, MSW, MHA and Christi Brandenstein, MA, LPC

### **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 order to assure input from a broad range of system stakeholders, the Initiative has incorporated quarterly focus group sessions as a part of its ongoing evaluation process. Members of the Initiative's steering committee felt that it would be particularly important to hear the perspectives of consumers who are living with a mental condition on a daily basis. The steering committee was especially interested in learning more about consumers' experience with stigma and how it impacts their lives. The Initiative held a provider focus group on November 20, 2007 at the Self Help Center. The group was conducted by two mental health professionals with extensive experience as providers of mental health services. They prepared this report jointly, using qualitative data collection techniques.

The Missouri Foundation for Health has provided funding to the St. Louis Regional Health Commission for the Behavioral Health Initiative. This funding covered the costs associated with conducting the provider focus group and producing this report.

### **Overview**

This report is the compilation of feedback from 20 individuals who are living with a mental health condition. Thirteen of those consider themselves to be consumers, while three called themselves "other". Consumers came from two area mental health agencies which provide a forum for support groups and a "consumers helping consumers" approach to case management. From the stories shared, it is clear that most of the participants have struggled with a mental condition for many years, while a few were more recently diagnosed. Several have the added diagnosis of a drug or alcohol addiction.

Consumers in this focus group have a wide range of experiences in the mental health system, including inpatient hospitalization, medication management, outpatient therapy, case management, and crisis care. The majority were recipients of government funded insurance programs such as Medicaid, Medicare, or VA benefits; only three consumers report having private insurance for their health care.

Of the twenty participants, all shared some demographic information, but did not choose to share in all categories. Of those reporting gender and ethnicity, 12 were men and 8 were women. One Asian person participated, as did 5 African-Americans and 13 Caucasians. Five participants were 20-34, 2 were between the ages of 35-44, 9 were 45-54, 3 were 55-64, and only one participant was over age 65.

The geographic location of participants ranged from St. Louis City (6) to St. Louis County (11) and Jefferson County (3). Fifteen different zip codes were represented.

Annual household income was primarily distributed below \$15,000, with 9 reporting income below \$10,000. Three participants reported income between 15,000 – 19,999, while one was in the \$20,000 – 29,999 range, another in the \$30,000 – 49,999 range, and yet another reporting income above \$50,000.

This report begins by exploring the ways in which stigma is communicated to consumers. As you will see, some are blatant, yet others are as subtle and difficult to capture. The report then goes on to detail primary areas where stigma is perpetuated, how that impedes service delivery, the role of public policy, and the added layer of stigma felt by low-income consumers. There is a closing section on positive factors which neutralize stigma and promote healing. Here consumers provided suggestions for reducing stigma. There is great strength in a collective voice, so you will find many direct quotations from consumers sharing their personal experiences throughout the report.

In the spirit of facilitating an open discussion, the preparers decided not to define stigma for the participants. Rather, we were interested in hearing the experiences and perceptions of the consumers. From their comments, it is clear that stigma is a linear concept experienced and internalized in a unique, yet very real way for each individual.

### **Stigma is Pervasive**

Consumers communicated a sense that stigma was coming at them from every direction of their lives. In particular, they felt disrespected and judged by others. This judgment was frequently communicated nonverbally by people with whom consumers had to interact, such as receptionists, bus drivers, police officers, and mental health care providers. One consumer said, “Stigma is everywhere.”

Another common feeling was the sense of being ignored, again, often by the very people who were supposed to be providing help. A consumer reported regarding his provider’s attitude, “Here he comes again. I’ve got to do all this paperwork. You know what they’re thinking.”

Disrespect was frequent, in the form of being made to wait long hours for appointments, patronizing language, being made to “prove” their disability (such as bus drivers asking, “Where’s your wheelchair? Where are your crutches?” when the mental health consumer produced a “disabled” bus pass), and being held to different standards by landlords and others.

Mental health consumers felt misunderstood, not only by friends and family, but by other people in the community such as police officers. Consumers reported that even Crisis Intervention Team officers seemed to make an assumption that those with mental conditions were violent. Friends and family often lacked understanding that symptoms of mental illness could be managed outside of inpatient or institutional settings, resulting in a loss of relationship.

Stigma was common not only in interpersonal relationships but also in images portrayed by the media. As one consumer put it, “News reports have a lot to do with it, like a person with mental illness murdered someone. They don’t say, ‘Someone with cancer committed this crime.’ That’s where a lot of stigma comes from.”

### **Physicians Have a Significant Impact**

Consumers stated several times that they feel that others define them by their mental condition. Common complaints that consumers voiced about service providers were that providers did not treat them as individuals. Providers asked them the same questions over and over again, which underscored their feelings of being ignored and disrespected. “When I see my psychiatrist, he asks the same questions every time. He wants me to change (rather than change the treatment).”

Many consumers used the word “patronizing” to describe the way providers talk to them. They pointed out that having a mental condition does not mean they are incapable of knowing themselves and understanding their symptoms. One consumer shared her experience like this, “They talk down to you and say things like, ‘You’re going to take all your medicine, now, aren’t you?’ They have my history and they should know that I don’t stop taking my medicine. My medicine stops working and my system becomes intolerant to it. They should know that by now! It makes me so angry! I go there often and they should know that by now!”

In addition, consumers stated that providers don’t take their patients concerns seriously, especially related to the side effects of the medications they were being prescribed. One consumer stated, “I’ve had the experience of a psychiatrist saying, ‘No you’re not having those side effects. My information doesn’t say anything about that’. It’s like their saying, ‘What do you know?’”

Another example of this could be seen in providers’ lack of knowledge of co-occurring disorders and addictions. Many providers seemed to be unaware of appropriate and inappropriate medicines to be prescribed to patients with substance use disorders. “Psychiatrists don’t do a good job checking for side effects of combinations of medications and psychiatric drugs—drug interactions have caused me some serious problems.”

## **Stigma Creates Barriers to Accessing Care**

Stigma can play a major role in discouraging the use of professional services. Consumers can see that if stigma and discrimination were eliminated from the system, more people would be diagnosed with mental illness, and more people would openly seek treatment for their symptoms.

Consumers reported that providers seemed to have little understanding of the impact of mental health treatments on their patients' lives: "People with mental illness come in and their whole lives are affected by this, but the workers are just trying to make a buck." Consumers reported switching hospitals, primary care practitioners, and psychiatrists due to stigmatizing attitudes and practices. Some report dropping out of services altogether and ceasing to take needed medications due to the difficulty of obtaining services.

## **The Role of Public Policy**

Consumers felt that the Medicaid system limited their choices and made finding quality mental health care difficult. Being a recipient of disability/SSI income and Medicaid benefits was commonly cited as an obstacle to obtaining needed services, yet having Medicaid benefits was also frequently the only path into actually receiving services. Being a recipient of disability/SSI and Medicaid also created further stigma for the individual consumer.

Public policy seems to reinforce stigma, primarily by limiting the choices consumers have in treating their condition. Consumers express frustration with limited choices of service providers, low reimbursement rates leading to high turnover among providers, and cumbersome appeals processes when benefits were denied. It was difficult to find a service provider whom the consumer felt was competent, and often, once such a provider was located, that provider would move on to a different community or organization. Consumers felt that this pattern does little to improve their condition. "They should treat it before it becomes a crisis. Maybe if you hadn't tried to commit suicide you wouldn't be so stigmatized."

Being a recipient of Medicaid and disability/SSI in itself also prevents consumers from attaining a certain level of independence. Being a beneficiary of public programs prevented many consumers from being able to work at more than a minimum wage job, a few hours a week. Fear of losing medical benefits kept consumers out of educational and workplace programs. Consumers believe this caused others to perceive them as lazy and unmotivated to reach their potential. In the words of one consumer, "There are caps on disability. You can only work and make so much, but to do more I risk losing my benefits and my condition is unpredictable. There is stigma within society and within myself."

Having to keep one's work and school involvement to a bare minimum level served to perpetuate internalized stigma. Yet, consumers also felt strongly that they could not afford to lose their "safety net": "It's hard to be poor and scared you can't get back on benefits again. We always have hope we won't have symptoms again, but we have to be realistic."

### **Poverty Magnifies Stigma**

The stigma of poverty cut across other social "dividing lines" such as race, geographic location, and age. When the consumers we spoke with talked about stigma other than that directly related to mental illness, overwhelmingly, they brought up issues related to income level. "Being poor and having any other condition is a double whammy." "Poverty is stressful and triggers a lot of our symptoms." "If you need anything you have to sacrifice something else."

The impact of transportation problems, Medicaid spend-down<sup>1</sup> issues, and lack of fresh foods were also cited as problems facing those with mental illness who lived in poverty. "When you're poor and you have a mental condition, you don't have the energy to navigate the system and go from doctor to doctor." "Dental care, fresh produce, clothes, all of these are hard to obtain." Consumers believe these obstacles created by poverty lead to a perception that they are unwilling to take responsibility for their own care.

A person's income level was seen as an important determinant of how she or he was treated in the mental health system as well as in society at large. As one consumer expressed it, "Have a little common courtesy so you aren't waiting 2-3 hours (for an appointment). It's because of your income, because you have Medicaid." Yet another said, "If you're rich, you're eccentric. If you're poor, you're crazy."

### **Factors That Reduce Stigma**

Consumers were able to identify "bright spots" in society and the mental health system. In addition, these consumers had some concrete ideas about how to improve the current situation to be more supportive of persons with a mental condition.

Consumers identified consumer-operated and self-help services as being critical to undoing the effects of stigma. They stated that their peers had been instrumental in breaking down barriers of low self-esteem and shame. "\_\_\_\_\_ (a local agency) has helped me a lot—support, seeing what others have done. It's the only place

---

<sup>1</sup> Medicaid spend-down is defined as the process by which certain elderly and disabled people with incomes above the Federal Poverty Level can qualify for Medicaid benefits by "spending down" their income. These individuals do this by incurring and paying medical expenses each month. The total that must be spent down equals the amount by which someone's net income exceeds the income eligibility requirement for Medicaid. Source: Missouri Foundation for Health (2005). Missouri Medicaid Basics.

to meet and talk with people you feel comfortable with.” “You’re not trading horror stories, you’re trading relationships.”

Basic etiquette plays an important role in breaking down stigma. Consumers suggest that providers at every level, from psychiatrists to receptionists to psychiatric technicians to social workers, receive hospitality training, to learn to treat consumers with generosity, dignity, and respect.

Consumers expressed a strong desire for providers to treat the whole person, and to individualize treatment plans when working with them. In praising her psychiatrist, a consumer shared that, “My doctor asks me about my medical health, my mental health condition, and my social life because they all impact one another. I’m very fortunate. It takes a while to learn about your own condition. I tell them I prefer the least amount of medication with the least dosage. I can communicate well with my doctor.”

When providers offered more information about symptoms and resources to consumers, the consumers felt less stigmatized and more empowered to act on their own behalf. It was suggested that “When people get an initial diagnosis, make sure they get counseling on what is available. Like an orientation about services, resources, the illness itself. They could send you monthly updates about changes, new findings, etc.”

Consumers identified being open and honest about their condition as a significant part of the healing process. When their sharing was greeted with care and respect, stigma was likely to be reduced. A consumer shared the following insight when talking about his process of opening up to his provider, “At first, my pride got in the way, but part of the healing process is being honest and real about it.”

In a world without stigma, consumers stated that they would feel more accepted, “so much better.” One consumer said, “I could talk like it’s a condition, like a bad back and not have to hide it.” Another consumer felt that he would “have a better attitude about going to the doctor.”

Yet one consumer wonders, “Is this even possible?”

### **Conclusion**

Consumers clearly indicate that they experience the impact of stigma related to their mental health condition on multiple levels. They believe that persons with such a condition are often ignored, judged, disrespected, and believed to be dangerous. They attribute the loss of jobs, relationships, and self-respect to stigma. Mental health consumers would like very much to be treated with dignity, but often they are disrespected and their humanity goes unrecognized. They feel others define them by their mental condition, rather than seeing them as a whole person.

Providers of mental health services are not immune to stigma. In fact, consumers feel it is ironic that those who they expect to be knowledgeable about their condition still have attitudes characterized by stigma. This limits consumers’ openness about their

condition, erodes their sense of personal power, and discourages them from being partners in their own treatment. Further, it prevents many from ever being diagnosed.

In addition, it is critical to recognize that poverty worsens stigma and discrimination. Much of the mistreatment that consumers report is linked to their low incomes or receipt of public benefits. This creates a cycle which allows their condition to worsen, resulting in further stigmatization.

Consumers see courtesy and respect as keys to reducing the perception of stigma. They would also like to see more favorable portrayals of persons with mental conditions in the media. Finally, consumers see value in being informed about their condition, empowering them to take responsibility for their own treatment.