



Provider Focus Group Quarterly Report

**As reported to the
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St. Louis Region Provider Report about Behavioral Health Services

Prepared by Melissa Hensley, MSW, MHA and Sharon Bowland, LCSW, ABD

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 providers who work on the "front lines" of the Region's behavioral health system. The steering committee was especially interested in learning more about the effects of stigma on providers' experiences in the system, as well as access and coordination issues. The Initiative held a provider focus group on December 7, 2007 at the St. Louis University School of Medicine. The group was conducted by two Ph.D. students at Washington University, using qualitative data collection techniques. Both are social workers with extensive experience as providers of mental health services. They compiled this report.

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

We collected data in the report from fifteen providers of mental health services. Providers included psychiatrists, other physicians, social workers, counselors, and administrative staff. Providers came from two area mental health agencies which offer a range of services including inpatient care, outpatient psychiatric care, case management, counseling, housing supports, and community psychiatric rehabilitation. One provider was from the local office of the Missouri Department of Mental Health.

The geographic location of participants ranged from central and south St. Louis City, the Kirkwood area, and northwest portions of St. Louis County.

Organization of this report

The objective of this report was to capture the perceptions of providers regarding the day-to-day operation of the behavioral health system. In particular, the report seeks to offer a better understanding of what is going right with the system, as well as the effects that stigma, lack of

resources, and poor system coordination have on care processes. The report will be divided into five sections. The first section summarizes providers' comments about the good things in the current behavioral health system. The second section discusses providers' observations about how the system works—for providers and for clients. The focus is on discussing the impact of system problems on delivery of care: the lack of financial resources, the lack of care options for the most distressed people, and the poor coordination among agencies and organizations in the system. The fourth section examines specifically the effects of stigma on care provision in this region. Fifth, the report will explore providers' comments about what they would do differently, if they could, to eliminate stigma and fragmentation in the behavioral health system.

What is “going right” in this region?

When providers talked about what is going well in behavioral health in the St. Louis region, they repeated over and over again the idea that quality mental health care is dependent upon providers' taking the time to develop rapport with clients as individuals. Providers stated that those who made an effort to understand clients' needs and to meet those needs were able to deliver effective care that kept clients mentally and physically healthy, and out of other social service and criminal justice systems. As one case manager put it, “If you look at the individual client and try to satisfy their individual need, you're more successful.”

Quality was also dependent upon the existence of a range of services and supports. According to providers, individuals with mental illness often had a number of challenges facing them—not just symptoms of their mental illness, but also issues related to poverty and medical comorbidities, for example. Agencies that offered a variety of resources for their clients, such as nutrition classes, smoking cessation classes, support groups, and medical resources, were likely to report high rates of client satisfaction. Addressing health concerns such as weight gain and other side effects of psychotropic medications was also important. Providers stated that even five extra minutes in a clinic appointment, to explain new medications and their side effects, made a difference in terms of client adherence to provider recommendations.

Connections with family also affected quality of care. When providers were able to ally themselves with family advocates, they felt that quality of services improved.

How is the behavioral health system working for clients and providers?

Providers observed that many of their clients were generally satisfied with the services they were receiving. Some of the key services that clients made use of included referrals to a variety of health and social services, assistance with paying bills, help in dealing with government agencies such as Social Security and the Family Support Division, and linkage with self-help organizations. Community-based providers noted that they “do need to advocate” for clients' needs as clients negotiated various service systems. One participant stated, “We're dealing with all these other agencies to get them services.” Another stated that service provision is “not done quickly or easily. It's a cumbersome system and takes too long for things to happen.” Also “cumbersome in agencies who will provide the actual service because of overlap in the county provider community.”

Clinic- and hospital-based providers also noted that many of the needs of their patients were based less in the symptomatology of their illnesses and more in the socioeconomic circumstances in which mentally ill people find themselves. Effective care included not just an accurate diagnosis and appropriate medications, but also connection with entitlements and other resources. Clinicians noted that having specific staff members, such as social workers or benefits specialists, who were trained in assisting clients with eligibility and enrollment processes, tended to be very helpful.

Providers commented on a tension that existed between being the best possible advocate for their client and empowering clients to become more independent. Challenging clients to act on their own behalf needs to be balanced with care and support. Finding this balance was difficult, but providing clients with education about their treatments and services and ensuring that clients had all the information they needed were important first steps.

All of the providers in the focus group agreed that relationships with families affected how well the system worked for clients. Misalignment of expectations between families and providers at some times led to problems in care delivery. If families expected providers to deliver certain kinds of services or achieve certain kinds of outcomes that were unrealistic or not possible, then the process of care was disrupted.

How are providers affected by the systemic problems that exist in this region?

Lack of Financial Resources

Medicaid, while viewed as an essential resource for many people with mental illness to obtain health care, was also seen by providers as a source of numerous problems. “With Medicaid (there are) too many hoops, more paperwork, more oversight and yet the reimbursement is low,” stated one provider. For example, Medicaid spend-down¹ was a common barrier to receipt of appropriate services by people with mental illness. Another frequent problem was low reimbursement rates for provider services. Low reimbursement rates, combined with plentiful paperwork, meant that many physicians and other providers in the community would not accept Medicaid as payment. Some providers had only a few “slots” for Medicaid patients, and getting people into those slots was difficult.

Providers observed that Medicaid also created problems with medication access. Providers reported that some pharmacies refused to waive copayments for patients who could not afford them, despite the law which states that copayments should be waived for patients in financial distress.

Providers’ experience in their day-to-day work with clients indicated that resources for clients without any health insurance were virtually nonexistent. Some outpatient clinics depended on contracts with community mental health centers in order to finance patient services. If clients were not “linked up” with the community mental health center, they had no way of paying for their care. Patients who were “self-pay” could sometimes afford their doctor visits, but then

faced the problem of obtaining lab work and other necessary services to ensure that their treatments were working.

Lack of Service Options for the Most Distressed People

Providers frequently observed that some of the most distressed clients they encountered in the system went without care, due to a lack of appropriate options for them. One provider commented, “How can the system be flexible enough to deal with the severity of the problem?” For example, clients whose illnesses and life circumstances prevented them from keeping regular appointments, or who came to the system with multiple housing and social service needs, were at times turned away because their needs did not “fit” the system. Fear and burnout were also issues that faced providers, and clients were sometimes ejected from care because they were perceived as too dangerous to participate in the system.

Poor Coordination among Organizations

Poor coordination among organizations was observed as a problem with health care organizations, criminal justice institutions, and other social service providers. For instance, providers reported that emergency room providers and other non-psychiatric providers of care frequently lacked an understanding of the needs of people with psychiatric illnesses. This led to assessments that might have been avoided, inappropriate referrals to inpatient psychiatric care, misdiagnoses, and poor quality of services. Poor coordination was also evident in the fact that case managers felt that their input and opinions were often discounted or not even acknowledged by health care providers, even when releases of information were available and in use.

Coordination between mental health organizations and criminal justice organizations posed a particular dilemma for many providers of care. The evolution of increased training for criminal justice professionals, as well as the development of the mental health court, has made some of these problems easier, but many challenges remain. Clinicians observed that the existence of a mental health diagnosis seemed to lead to the client either being unfairly penalized for a minor offense, or, on the opposite side of the spectrum, not being held accountable for illegal acts. Mental health problems also created barriers in the family court, as judges demonstrated an unwillingness to work with parents with mental illness who were attempting to regain custody of their children. Even basic communication between parole officers and mental health case managers was difficult to achieve.

Lack of coordination was a problem with other agencies, as well. Providers reported a lack of cooperation and an abundance of paperwork emanating from the Family Support Division and the Social Security office. Assuring that people with mental illness were enrolled in all of the services and entitlements for which they were eligible was quite challenging as a result. Transportation to and from services created a barrier for some people with mental illness, especially those who did not live in the city. An additional issue with many service organizations was the high rate of turnover among staff. Frequent changes in staffing led to confusion and feelings of abandonment among clients. One provider said, “A lot of clients voice, ‘are you going to leave me?’”

The lack of coordination among the various agencies serving people with mental illness was, in itself, seen by providers as a manifestation of stigma against mental illness. As one provider stated, “Lack of integration of the system is a form of stigma. The psychiatric clinic is here. The medical school is over there. Why is that?”

What effects of stigma do providers see?

Stigma was noticed by providers not only in the disjointed organization of existing services, but also in other ways that the system operated. The emergency room was one service site where having a mental illness could lead to a poorer quality of care. It was noted by the behavioral health providers that emergency room care providers frequently called for a psychiatric consult as soon as they learned that a patient had a mental illness, instead of considering the presenting problem of the patient as the most important factor in that person’s care. Other medical providers were also affected by stigma and poor perceptions of people with mental illness.

The stigma of working with people with mental illness was seen as leading to burnout among providers, as well. Jobs that involved working with people with mental illness were seen as low-prestige, were frequently lower-paying than other positions, and were devalued by society.

Consumers were impacted in other ways, as well. Providers noted that many consumers were reluctant to identify themselves as having a mental illness or psychiatric disability and were also reluctant to associate with other clients who had such diagnoses. Consumers did not want providers and others to think that they were “crazy.” “Clients stigmatize other people with mental illness and don’t want to be seen at a clubhouse with ‘those other people.’”

Providers noticed that stigma affected consumers’ relationships with their families, too. Providers observed that consumers were frequently hesitant to disclose to family member their mental illness diagnosis, which led to a lack of understanding between consumers and their families. When consumers did disclose their struggles with mental illness, and the family responded negatively, providers observed that this also could lead to greater problems for the person with the illness.

Certain coexisting problems added to the issue of stigma. Providers felt that it was significantly more difficult to coordinate care for clients with other disabilities, such as developmental disabilities, deafness, physical disabilities, or neurological problems. Immigrants, especially those who did not speak English, encountered more frequent problems in trying to access services. Providers noted that some in the system also exhibited an “I don’t want to deal with this” attitude when working with clients from different religious backgrounds.

Ultimately, providers saw the most devastating manifestation of stigma in the devaluing of the lives of people with mental illness in the policy arena. Services and programs that serve people with mental illness seemed to be very low on the priority lists of legislators at every level. Housing policies and practices served to bar the clients of many behavioral health providers from having their own apartments and homes. Providers observed that many existing policies seemed to make the lives of people with mental illness more difficult, instead of better.

What would providers do differently, if they could?

The best way to communicate the wishes and dreams of providers in the St. Louis region's behavioral health system is to let them speak for themselves. Following are some quotations from the focus group session that help to articulate the things that providers would like to do differently in the system.

“More recovery driven and consumer focused.”

“I'd spend less time putting out fires.”

“Whole range of types of services. Clients at the center and an equal partner. Staff have better salaries, less turnover.”

“More consumer staff in an agency and people who had a mental illness who are staff wouldn't feel like they needed to hide it.”

“Respect for social workers' profession who work with 'crazy people.' I'm glad someone does that job...”

“Respite care would be available—people who don't need inpatient but can't stay in their home and need some structure.”

“Clients have access to services they need. Wouldn't have to spend time to create resources that aren't out there...more tolerance.”

“More lines of communication open among all providers. See results quickly and accurately and well-rounded.”

“Less angry and frustrated and not having to fight, fight, fight.”

Clinicians and providers in the region's behavioral health care system share a common desire to improve the lives of people with mental illness. They face struggles on the job every day as they seek not only to alleviate the symptoms of mental illness but also to better the quality of life of the people they serve, through a variety of services and supports. Lack of coordination, lack of resources, and persistent stigma create barriers to change. However, providers have not given up hope that the people for whom they work can lead fulfilling, satisfying lives in the community.