Consumer and Family Perceptions of St. Louis Region Behavioral Health Services

Sharon Bowland, LCSW, ABD
Melissa Anne Hensley, MSW, MHA
Consumer Perceptions

• Focus groups sponsored by Eastern Region Behavioral Health Initiative

• NAMI St. Louis and Mental Health Association of Greater St. Louis were involved in underwriting the groups and recruiting participants.
Focus Groups

• Three consumer focus groups were held.
  – St. Louis City and County
  – St. Charles County

• Three family focus groups were held.
  – St. Louis City and County
  – Jefferson County
Focus Group Participants

- 55 individuals participated in the groups.

- Most primary consumers are involved in the public behavioral health system.

- Participants had varied experiences with behavioral health systems.
  - One week to 25 years
Symptoms Reported

• Participants reported symptoms indicating that they struggle with severe mental illness

• Several of the participants had dual diagnoses of mental illness and substance use disorder
Focus Group Participants

- 26 primary consumers shared demo-graphic information.
  - 15 men, 11 women
  - 11 African Americans, 10 European Americans, 1 American Indian.
  - Most participants were between ages 35-54.
  - Income was mostly in the $0 to $9000/year range.
  - Half of the participants were unemployed and receiving SSI or SSDI.
Focus Group Participants

- In the family focus groups, 22 family members and 3 primary consumers shared demographic information.
  - 7 men, 16 women
  - 6 African American, 19 European American
  - Most were between 35-64 years of age
  - 5 participants were over 65 years old
  - Most had incomes above $50,000/year
Points of Contact for Families

- Some families had children under 18 with a mental illness.
- Some families had adult children with mental illness living with them at home.
- Many families reported having exhausted their insurance coverage.
- Though families often had private insurance, their ill family members frequently relied on Medicare and Medicaid-funded services.
System Strengths

- Focus group participants identified several system strengths:
  - Individual physician-patient relationships
  - Outpatient services, such as case management, transportation, and representative payeeship.
  - Psychosocial rehabilitation (i.e., clubhouses)
  - Employment services
  - Self-help and peer support
  - Recreational opportunities
  - Crisis Intervention Team—Police Officers
System Strengths

• Family members noted several strengths, as well.
  – School based programs that bring together mental health providers and educational professionals
  – In-home counselors to provide problem-solving and help for the entire family
  – Residential care to provide structure and intensive therapy to children
  – Advocacy and psycho-education programs offered in the community
Areas for Improvement

• Staff Training
  – Staff working in mental health organizations seemed under-trained and affected by the stigma against mental illness.
  
  – Focus group participants reported poor treatment and disrespect on the part of mental health workers.
Areas for Improvement

• Medication issues
  – Though individual participants reported positive experiences with their physicians, overall there was a sense of dissatisfaction with medication services.
  – Participants felt that their own expertise on the workings of their own bodies was not respected.
  – Participants’ concerns about medication side effects were frequently ignored or not taken seriously.
  – Lack of consistent access to medications
Areas for Improvement

• Service Access
  – Not enough service resources to meet the needs of everyone with mental illness who could benefit.
    • Long waiting lists continue to be a problem.
  – Access to appropriate care is also a problem.
    • Providers frequently have expectations of conformity that make participation difficult.
  – Exiting the system was difficult, as well.
    • Being a mental health consumer seemed to take up the person’s entire identity.
Areas for Improvement

• Seclusion and restraint policies
  – Consumers continue to feel that seclusion and restraints are used inappropriately, when other de-escalation techniques could have safely been employed.
  – Seclusion and restraint seem to be used frequently when inpatient units are under-staffed and overcrowded.
Areas for Improvement

• Access Issues
  – There is a shortage of psychiatrists in the Eastern Region who will accept Medicaid as payment.
  – Waiting times to see good physicians are frequently very long.
Areas for Improvement

• Stigma was a problem on many levels, for both primary consumers and family members.
  – General public attitudes
  – Within the service system
  – Internalized among mental health consumers

• Discrimination was common within the system.
  – Race
  – Socio-economic status
Struggles for Families

• Families with mentally ill members struggled with their own sanity and self-worth as they sought care for their loved ones.

• Families found a contradiction between care for substance use disorders and mental illnesses: Should they use “tough love” or offer all the support they can?

• Parents said that their early reports of children’s problems were discounted.
Struggles for Families

• Similar to the comments of primary consumers, family members noted that the “one size fits all” approach of the service system was unhelpful.
Struggles for Families

• Segregation and labeling of children with severe emotional disturbances continues to be a problem.
  – The intellectual potential of these special-needs children often goes unrecognized.
  – Children are assumed to have developmental delays.
  – Transitional services for late adolescents and young adults are practically non-existent.
Struggles for Families

• Acute care services, such as inpatient beds, are inadequate to meet the need.
• Families are often put in the position of having to involuntarily commit their loved ones to treatment.
• Parents are blamed by care providers for being over-protective and dysfunctional.
• Strict interpretation of confidentiality rules prevents sharing of information between providers and families.
Struggles for Families

• High turnover among staff of behavioral health agencies prevents stability and continuity of care.
• Physicians do not have enough time to spend with patients to make adequate diagnoses and assessments of patients’ needs.
• There is a lack of focus on the needs of the family unit.
What Now?

• COMBAT STIGMA

• Integrate physical and mental health care, and increase access to providers who accept Medicaid.

• Address financial inequities in the system.

• Solicit consumer feedback consistently.

• Make an effort to tailor services to the needs of individuals.

• Provide a “road map” for consumers and families to follow through the system.
What Now?

- Provide psychosocial services such as anger management, parenting, and trauma recovery counseling.
- Emphasize a combination of medication plus psychosocial supports, rather than just meds.
- Invest in early screening and identification services for children and families.
- Provide therapy and support for siblings and parents of individuals with mental illness.
- Increase flexibility in the workplace for people with mental illness and their family members.
What Now?

- Invest in a system that focuses on helping people get well, instead of focusing on the bottom line.
Reasons for Hope

• “Cultural sensitivity is not a matter of race; it’s a matter of getting to know my whole story and crossing the cultural divide.”

• Speaking the truth about our lives and the lives of our loved ones helps others to recover and to fight stigma.

• Faith helps people through the tough times.
Reasons for Hope

• “I’m trying to be the best I can be and get off the alcohol and drugs.”
• “My first day at the clubhouse, I was able to contribute. It felt good to do it on my own.”
• “I have had to learn to rely on myself.”
• “Things are getting better because people are speaking out.”
• “We need to put people first.”