



CONTINUITY OF MENTAL HEALTH CARE FOR YOUNG ADULTS

The transition from youth to adulthood is stressful for almost everyone. It is not surprising that mental health and substance use problems intensify for people in this stage of life. However it is also during this time in life that people are least likely to have health insurance and most likely to experience residential changes. Therefore, young adults face added challenges to the lifelong task of finding and maintaining health care. Our primary goal was to study organizations that provide care for young adults with mental health concerns, and to understand their scope and collaborations. Our secondary goal was to provide information about services in our community.

According to leading epidemiologists, young adults ages 15-24 are more than twice as likely to suffer a psychiatric disorder as 45-54 year olds. At the same time, insurance coverage for young adults ages 18-25 is weaker and more tenuous than for all other age groups. Of over 40 million uninsured U.S. citizens, the rate is highest (30%) among young adults. So young adults are at highest risk of mental health problems at an age when they are least insured against it. As a result, young adults get less care and are most vulnerable to experiencing interruptions in care.

We set out to study "Service Transition Points" (STP) through a research project in St. Louis. We contacted the major city and county organizations that provide care for young adults with mental disorders. We talked to representatives of mental health organizations, schools, substance abuse treatment centers, and child welfare and juvenile justice agencies. We identified 116 different organizations, which served young adults in St. Louis County and City. We designed a survey to ask a person representing each organization about its structure, its relationships with other agencies, and its work with people who had mental health problems. We did not collect private information about individual health consumers.

We interviewed organizational representatives who gave us permission to include them in our survey. To date, we have data from 89 organizations, 22% serving youth only, 25% serving adults, and 53% serving all ages. Most organizations are located within the specialty mental health, education, and substance abuse sectors. The juvenile justice and child welfare sectors are centralized

and in the public domain, so these sectors include a few large agencies, rather than a large number of smaller ones.

The average organization in our sample had 78 fulltime employees, including 34 people directly providing mental health services (social workers, psychologists, psychiatrists, etc.). The average organization had served about 4,000 people with mental health services in the preceding year, operating as a nonprofit with both income and expenses of \$6 million. Schools and mental health care agencies saw clients an average of 18 times per year, for 30-50 minutes per session. Substance abuse centers saw clients more often, for a full hour.

Most organizations provided transition planning (82%) and routinely followed up referrals (71%). A majority provided case management (63%) and/or long-term planning (54%). These indicators, along with others, showed that continuity of care was built into the system through multiple practices. The other most common types of services provided were counseling, family support, and therapeutic groups. About half of the sample provided emergency services, half provided transportation, and a third provided housing services.

Respondents all agreed that their organizations valued the cultural traditions of ethnic and racial minorities, but not all organizations incorporated these values in their practices. Fifty-seven percent matched African American and the same proportion matched Hispanic clients with Spanish-speaking staff. Forty-four percent rarely or never trained staff in principles of cultural competence, and 46% rarely or never monitored caseloads to ensure proportional racial and ethnic representation. Organizations providing continuity of care were more often those that practiced cultural competence as well.

When these representatives evaluated the quality of the regional system of services for young adults with mental health needs, they identified the availability of care as the most pressing problem, stating that the system was impeded by red tape, waiting lists, insurance restrictions, and delays getting appointments. Thirty-two percent thought the system rarely or never provided sufficient service to consumers with insurance. The system as a whole was better at providing accessible,

personalized, trustworthy, and skilled care. However only 46% thought that the system frequently or always emphasized the strengths of consumers with mental illness.

Our respondents were experienced in the field of mental health care, working with these problems an average of 20 years. This survey found that nonprofit organizations that worked to provide mental health services for young adults had collaborative relationships with some parts of the system, but that their view of the system was not always rosy.

In the upcoming months, we will complete our data collection and distribute a directory of services to survey participants. We are starting to compile statistics on many different aspects of the system of care for young

adults, presenting our work to fellow scholars and at professional meetings. We hope that this study will encourage others to study where and how collaborations among organizations promote continuity of care and cultural competence. And we hope that families and providers recognize that young adults may require mental health care, and that they are disproportionately likely to have little or no health insurance.

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I am a sufferer of Obsessive Compulsive Disorder. I have had this disorder from the first days of my childhood. When I was between the ages of about five and nine I washed my hands (for fear of germs) until they cracked and bled. I also had a difficult time performing daily tasks such as getting dressed, doing chores, and walking to school. That is when my parents first suspected I had a problem. I went to a psychiatrist and they told my parents that it was probably nothing and that little kids do weird things. They were wrong. During that period of time I possessed so much shame around the fact that there was something wrong with me that I could not admit this secret to anyone. This denial only added more difficulty to my daily routines because I had to focus on believing the lie that I was just like everyone else. This lie plagued my life until I was 16 when (with the help of my nighttime prayers to God to take this defect away from me) I finally mustered up the courage to tell my parents that I was well aware and had been of this continuing problem. It felt good to finally admit it.

From that point I began to tell my psychiatrist about this secret I had. It was very helpful to me when he assured me that many people have this disorder and that I didn't have to live this way. It was especially helpful when he let me know in no uncertain terms that I was not crazy.

I enjoyed the meetings with my psychiatrist because he made me feel genuinely cared for, not like an interesting case study. He validated my feelings about my disorder with hard textbook facts, but still encouraged me to be an individual. In other words, I felt less alone because a lot of my symptoms had been documented, but I still felt unique. Medication also provided me a little rest from my constant daily battle with my brain. It did not cure me, but it allowed me a choice between whether or not my compulsions were worth my time and energy.

Now that I am 24, I have a little more perspective on what worked for me as an adolescent. The most helpful things to me were a supportive family, a doctor who truly cared for me, medication, as well as a willingness to work with these resources. With supports like these, I don't believe one can go wrong.

What did *not* work for me was the attitudes of certain service providers. I felt that I was very lucky in finding people that really cared about helping people. As an adult, I can now see that there are a lot of service providers (psychiatrists, M.S.W.'s, etc.) who are selfish and look to children with mental health disorders as an opportunity to better their résumés. I have had experiences with mental health professionals who write you a prescription and send you on your way because they are so burned out that they have lost the ability to care. I have dealt with mental health professionals who believe all a mentally ill person can achieve is to become a member of society that does not draw attention to herself. That does not work for me.

I was very fortunate for the most part growing up with OCD. But I have also seen the stigma that is attached to people like me. I have seen us chastised and silenced by "professionals." That is why I am not signing my name. In my personal opinion, I am a professional. I am a professional sufferer of O.C.D. I am not an animal. I am a person with family, friends, wants, needs, dreams, and the ability to carry them out. I am more than another case study. I deserve to be treated with respect and dignity. —Anonymous