

Consumer Quality Initiatives

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TO: Presidents Commission
From Jonathan Delman, MPH, JD Executive Director
Re: Request for Public Comments
Date: January 2, 2003

My name is Jonathan Delman, and I have lived with manic depression most of my life. While I was able to do well in school and obtain advanced degrees, I struggled emotionally and felt alienated from most other people; I would succeed greatly in jobs then be fired as a result of my isolating or "energetic" behavior. In 1990 at the age of 31, I experienced the first of my five hospitalizations and struggled for quite a while, living in a halfway house and working at a sheltered-workshop; upon improvement due to helpful medications and therapy, I faced intense stigma in trying to return to work, this being the most traumatic aspect of my mental illness experience.

In 1999, as a result of my involvement with a mental health consumer advocacy organization (not by conventional job search strategies), I was asked to head a project called "the Massachusetts Consumer Satisfaction Team Initiative", which is now called Consumer Quality Initiatives, Inc. (CQI). Our mission has been to "give consumers a greater voice and an integral role in evaluating the effectiveness of their [our] treatment" through "fair, honest and balanced" reports on consumer needs, interests, satisfaction and perception of quality. This mission also permits MCST "to hope to initiate changes to improve the system for all, consumers and providers alike."

The project was drawn out with some specifics that still drive the organization:

-the organization is led by consumers and staffed by consumers and family members. The executive director and key personnel have mental illness, as do 51% of its board members (per bylaws).

-data regarding the consumer experience of service quality is collected by consumer staff, primarily by interviewing consumers and

former consumers, based on semi-structured interview instruments developed by consumers;

-consumer staff analyze the data, write comprehensive data-based reports with recommendations, and present them verbally to mental health authorities, managed care organizations, providers and advocacy groups;

Relevance to the Commission's Topics of Interest

CQI addresses the Commission's topics of interest in three particular ways: 1) proven methodology of improving mental health care; 2) high-quality needs and systems analysis reports that identify best practices and evidence for more responsive programming; 3) demonstrates that consumers can work productively and creatively, effectively FIGHTING STIGMA.

1) Proven methodology of improving mental health care:

As a consumer-directed research, quality improvement, evaluation and program planning organization working within a Medicaid managed care environment, we have helped both the Medicaid carve-out (the Partnership), the Massachusetts Department of Mental Health (DMH) and providers within their networks improve the quality of their care and develop programs that better meet the needs of network consumers. (A program that works well to improve the experience of care, topic 1)

2) High-quality needs and systems analysis reports that identify best practices and evidence for more responsive programming: We have and are most capable of writing data-based reports that report in an aggregate sense how systems of care can improve care outcomes. (Topics 2-4). Three such reports we are enclosing, though more are available at our website (www.cqi-mass.org).

For DMH, we conducted qualitative interviews with clients and former clients about their vocational needs and interests. Most striking to us was the challenges people faced in moving to the "culture" of work, and the importance of having a caring mentor at the place of employment.

Second, for the Center for Health Care Strategies (of the Robert Wood Johnson Foundation), we wrote a comprehensive report on the

needs of youth aging out of adolescent mental health services, looking at Massachusetts but applicable nationally. Interestingly, mentors as being helpful was also raised by the young adults interviewed, and we are piloting a project currently with DMH by which young adults will mentor DMH youth in locked units as they turn 17 and look to transition out. We also examine the barriers to care in this report and the lack of coordination among state agencies and between the child and adult system.

Third, for the Partnership, we are exploring the quality of life needs of Medicaid clients, and in particular what keeps them out of the hospital. This is an ongoing project, and the pilot report is enclosed. Phase II, in place currently, is to interview a wider range of consumers, and phase III will be to employ the instrument in improve treatment outcomes. We are happy to keep you posted on our results.

3) Consumers can work productively and creatively, effectively FIGHTING STIGMA.

CQI, which I helped to found, has given myself an opportunity to display my talents and fight the tremendous stigma that people with serious mental illness are less able to think rationally and less able to handle pressure. The public does not understand that for people like me, not working causes depression and suicidal feelings, and that work makes me feel alive. In four years, this organization has doubled our budget (not bad in these times), and received a prestigious Consumer Seed action grant from the Center for Health Care Strategies of Robert Wood Johnson.

Myself and others working here have been unemployed or underemployed prior to working here, and have thrived in an environment that expects a lot but is flexible and sensitive to people's needs. One of our staff, formerly a state hospital patient, has thrived as a research associate with good supervision and a job coach. We employ young adults with mental illness who have presented data in public forums, with only a year of experience under their belt. In essence, we are shining example that people with mental illness, under the right circumstances, with some needed more supports than others, can be innovative and contribute productively to mental health systems improvement.

We also demonstrate that while the institutionalized mentally ill have not historically been listened to or thought critically about their

care, they have the capacity to provide important feedback to provider and policy makers given the collegiality of private and confidential interviews with people they can identify with.

Conclusion

CQI plays an integral role in establishing a mental health system in Massachusetts that is responsive to the needs of its consumers and in offering an opportunity for consumers to engage in meaningful work and provide meaningful input to improve care:

- It is independent of any other agency, with its own 501(c)(3) status
- It has consumer interviewers who are well trained to conduct the face-to-face interviews. Consumer interviewers have been able to establish a strong rapport with those interviewed, who having had a good experience, encourage other consumers to be interviewed, raising sample sizes. The interview is especially important because mental health consumers have not historically been encouraged to think critically and /or creatively about their care, so they need some gentle prodding.
- It has experience with both quantitative and qualitative analysis, and statistical methodology
- It prepares comprehensive, readable and useful reports, offering recommendations based on much experience. Incorporates a high level of expertise as consumers, having written 4 years of reports throughout the state, and an awareness of community resources.
- It demonstrates that mental health consumers can carry out responsibilities with creativity, fighting stigma.
- It works well with all stakeholders and holds to its mission of promoting the voice of a wide range of consumers.

Please feel free to contact me with any questions or comments at 617-929-4400 or jdelman@cqi-mass.org.

Enclosures:

Voices of Youth in Transition
DMH Clients and Employment in Western Massachusetts
Quality of Life Needs Assessment Report
Selected List of CQI Accomplishments