Consumer Quality Initiatives

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TO: President's New Freedom Commission
From Jonathan Delman, MPH, JD Executive Director
Re: Acute Psychiatric Care
Date: October 5, 2004

Good afternoon. My name is Jonathan Delman. I am here today in my capacity as the executive director of Consumer Quality Initiatives, Inc., or "CQI." CQI is a not for profit consumer-run research and evaluation organization based in Massachusetts. I am honored to have been asked to testify before the Commission.

Before proceeding to the questions, it is important to provide you with a brief overview on the breadth of my experience with acute psychiatry.

I have lived with manic depression since adolescence. With much turbulence in my life, I completed Law School at the University of Pennsylvania in 1984, worked as an attorney, and completed a Masters of Science in Public Health, with a specialty in Health Services, from Boston University in 1990. After a series of paralyzing depressions, I finally agreed to my first hospitalization in 1991. Talk about culture shock. That was the first of six I had in the 1990's, two of them involuntarily, most at a highly a regarded hospital in Massachusetts. As part of my road to getting better, I lived in a halfway house for a bit, had over 50 ECTs, was on Medicaid, and received Social Security.

As an attorney, I represented Bridgewater State Hospital, the highest security mental hospital in Massachusetts, in 1980's, and indigent patient in the 1990' in commitment and medication guardianship hearings.

I have been executive director of CQI since 1999, when it was founded based on a Medicaid performance incentive for consumers to interview program clients about the quality of care. Our mission is establish a consumer voice that is integral to quality improvement and systems change activities; we do this through confidential face to face

interviews and focus groups, data-based reports with recommendations, and follow-up. We have 5 full time staff, and a number of part-time interviewers. A large majority of funding is through the carve-out- Massachusetts Behavioral Health Partnership (MBHP) and the Massachusetts Department of Mental Health (DMH). We have also evaluation subcontracts with larger research institutions.

Our interviewers are well trained consumer and family members. It is our experience that peer interviewers are better able to establish a strong rapport other consumers. Many consumers have not been encouraged to, and are thus not in the habit of, thinking critically about their care.

With a CQI developed semi-structured survey instrument, CQI has interviewed at all Medicaid funded acute care facilities in Massachusetts, sometimes twice, writing site-based reports with recommendations. After the report is drafted, we meet with hospital and then network management staff of the MBHP. We have interviewed approximately 750 consumers on inpatient units at 35 acute care facilities, some with multiple units. In addition, we have written two industry wide reports (http://www.cqi-mass.org/pdf7.pdf) with recommendations, and are now writing our third. The issues have not changed substantially in the last 5 years.

When we started in 1999, many of the hospitals, particularly those in the eastern part of the state, resisted our involvement. (There was much less resistance from outpatient providers.) Some reported that they already had patients fill out satisfaction forms. Others thought that as consumers we might be disruptive and not objective. Because of our high quality comprehensive work, most hospitals have since opened their doors to us. The point here is that many hospitals can have ingrained cultures that are difficult to change.

How do you define Acute Care?

Acute Care is a system of services that provides safety, relief and comfort to those in severe emotional distress. Those services should offer a platform for clients to get better.

What is your assessment of current Acute Care system? Why?

The acute care system I am familiar with has been made up largely of emergency rooms, emergency referral programs, and locked inpatient units. Many consumers, based on past experience or wanting to maintain dignity and choice, choose to avoid this rigid system of acute treatment, risking escalation of symptoms and sometimes jail. Others want a comfortable and relaxed place, with both clinical and peer support, to have their medications adjusted or to avoid environmental stressors, and enter into this rigid system with reluctance.

<u>Overabundance of locked units</u>

The experience of many consumers is that there is no "continuum" of acute care services. If one is in crisis and needs regular contact with clinical staff the only choice for most is a locked inpatient unit. Emergency rooms (ER), not typically overseen by the state mental health authority, can be a frightening alternative. People with mental symptoms who visit ERs are often treated poorly, locked up in a separate room, facing commitment, and/or having to wait for many hours for a bed. Thus, many people do not consider ERs to be a viable option.

The current acute system was set up in a way that has not taken into account the opinions of consumers. While certain patients who pose a significant danger should be locked up, the overabundance of locked units where basic freedoms and comforts are denied is counterintuitive to an efficient and effective care system. I submit that this "strategy" has been over-applied based on empty assumptions that consumers are in general more dangerous than other people. If most patients are not elopement risks, as I have discovered, why lock them up? On a more base level, how would you feel if as a "voluntary" patient you decided to leave for an important business meeting but hospital staff decided to hold you for three days to double-check your dangerousness quotient? This happened to me about 5 years ago.

MBHP has been moving to establish greater availability of mobile crisis teams, with direct linkages to less restrictive options such as urgent care clinics and crisis stabilization units, but access to those programs is limited. I am aware of some respite services, but there are few beds. A small minority of consumers have access to intensive case management and PACT. Replacing locked inpatient units with

these kinds of care offers the potential of there being a continuity of acute care.

Quality of hospital care

The quality of hospital care varies, but you would not be able to determine what hospital is best for you based solely on the name or affiliation of the hospital (eg., Harvard Medical). And while CQI and MBHP are able to differentiate quality among units, there is no external reporting system, such as report cards, that would allow consumers to shop and compare. And with beds often filled up, there is often no choice of which hospital you go to; so even if you have a preference, you may have to settle.

In any event, much of the hospital care is decent to very good. At a number of units, patients have expressed high satisfaction with their care. Multiple regression analysis we have performed indicates that these units tend to have high ratings of patient involvement in planning their treatment and the degree to which they are treated with respect by nurses. Here, staff is readily available to patients who are in distress, and psychiatrists listen carefully to the patients about their concerns about medications.

On the other hand, we have seen units where many patients are dissatisfied, and sometimes frightened, because they are being treated poorly by some hospital staff, often on particular shifts. And sometimes basic needs, such as the provision of clothing (except for johnnies), are not being addressed It has been troubling when neither hospital management nor others responsible have seen fit to take immediate action to deal with these issues, even when raised by our team. In these situations, patients are usually not aware of an avenue to make complaints, such as to the managed care company or the hospital administration, or they feel that such an act would be useless. Usually, no one knows who the hospital human rights officer is. And of course they are not free to leave.

One of the most difficult issues that hospitals deal with relates to the prescription of medications. Only about two-thirds of our respondents have been satisfied with the information received about medications. Relatively short lengths of stay probably contribute to this low rate, as well as irregular access to psychiatrists and general confusion as to how the newer medications work. Some of the hospitals have done better here, with nurse lead groups on medications, or Internet access to relevant websites.

We have identified some troubling negative trends:

<u>Weekend coverage</u>: At some of the private psychiatric hospitals, staff coverage reduces greatly on the weekends. There are fewer activities and groups and some do not discharge on the weekends.

> *Six years ago, I visited one such hospital on a Saturday asking to be admitted overnight, on the condition that I be seen by a psychiatrist on the Sunday. When I awoke, the unpleasant nurse made it clear to me that they did not discharge on Sundays. I looked at the pills they were giving me and didn't see the Zoloft I depend on. I spoke to a psychiatric resident who explained that she could neither change my medications nor discharge me, even when I asked that she contact my psychiatrist.*

<u>Patients treated as cases not people</u>: On some units, particularly where there is not a strong presence of a psychiatrist, patients can be treated as cases rather than as people. So people with bipolar disorder are automatically taken off their antidepressant medication and put in the quiet room if manic, (as opposed to a music or radio room). This conduct increases the rates of seclusion and restraint and negatively impacts outcomes.

<u>Basic rights to privacy</u> are ignored. In Massachusetts, a bill was passed to establish fundamental rights, only 5 since the powerful hospital lobby defeated the others. Included here are privacy to use the phone and privacy with visitors, unless demonstrated that the patient is likely to abuse the right. Nevertheless, patients usually have to use a phone in the hallway, next to other phones. In some cases, they can ask to use a private phone, but they don't necessarily know that. Visits are usually permitted only a few hours a day and in a room with other people. Other patients in a general hospital are not treated this way, though we visited one unit where patients had phones in their rooms. Rarely are people allowed to go outside, except along with a smoke break. None of this smacks of wellness.

<u>Homelessness</u>: I would estimate that 15% of patients are homeless. They are often discharged that way since substance abuse facilities rarely take people who may be using drugs/alcohol and the price of housing in Massachusetts is so high.

While we have a system that works for some, others are frightened of it… and short of options, are not availed of the system until they are unable to make reasoned decisions.

What do you think would be an ideal acute care system? Why?

I believe that such a system must be developed in line with the principles of the President's New Freedom Commission report, in particular those stated under Goal 2 "Mental Health Care is consumer and family driven." So with a lack of choice in acute care options, how do we make expensive and undignified locked up care the ultimate last resort?

An acute care system should be responsive to the needs and preferences of consumers in the local community, and nimble to the degree that those needs change. There should be a continuity of care and support that places the locus of control in the individuals and their natural support system. "Evidence show that offering a full range of community-based alternatives is more effective than hospitalization and emergency room treatment. Without **choice** and the availability of acceptable treatment options, people with mental illness are unlikely to engage in treatment or participate in appropriate or timely interventions." P. 29.

Choice is not real if a) there are few options and b) it is not informed. Moving to a **report card system** allows consumers to vote with their feet. Consolidating all information on a provider's quality is an important step for a managed care system to truly oversee hospital quality. See CQI White Paper- "*Crossing the Mental Health Quality Chasm in Massachusetts*" (2004) http://www.cqi-mass.org/quality-chasm.pdf. The managed care company should PUBLISH relevant data on providers so that consumers can make intelligent choices. This arrangement will require providers to adjust to meet consumer preferences, as opposed to consumers trying to fit into provider structures, as is now the case. Typically, providers have controlled the flow of information about them. But "consumers" should have a chance to be "consumers," to vote with their feet, not only among hospitals, but among other types of acute services.

The President's report also notes fragmentation of services. This is something that needs to be worked on, but there is no reason to believe that policy makers will ever have **control** over a comprehensive acute care system. There are too many moving parts, including socioeconomics, criminal justice, housing…. Ultimately, the source of this continuity of care should be the person and his/her

natural supports. The cash and counseling voucher approach, as cited in the President's report (p. 35) and now being piloted in Massachusetts, would provide consumers with that level of control. Here, the consumer and his/her chosen community/family supports, is that locus of control of continuity, with the resources to develop his own support network, and ultimately reduce the need for hospital and clinical help. For example, if a person depends on a family member to help with tasks that reduce their anxiety, and that person becomes unable to continue the assistance, voucher money can be used to pay someone else to take care of those responsibilities, ultimately keeping that person out of an acute situation.

A quick note before moving on. I have heard people talk about their recovery stories, and it's clear that many share my thread. When I was in the famous teaching hospital, the psychiatrist was very mean to me asserting that my opinions were not valid. I was unhappy, acted out, etc. I talked to my father, a great advocate, and my therapist. I was provided with more qualified treaters, who made key recommendations that facilitated my improvement. Without my father………

Thus, providing psychoeducation and respite to hard working families, who ultimately can make the difference, is an important feature of acute care.

Lack of coordination is a major issue and I do endorse the movement to more linked teams, including mobile crisis and urgent care. In addition, encouraging people to put together advanced directives, when competent, perhaps using the Wellness Recovery Action Plan approach, and making sure that this document is distributed to the right people, will aid in coordinating care.

Aftercare- People who leave hospitals often do not follow up with key appointments. A successful project funded by MBHP has been "Peer support and aftercare," by which trained peers visit the hospital unit to orient patients to community resources, and offer to help them with follow-up meetings. In Massachusetts, we are also developing "Recovery Learning Centers" consumer run peer support education centers. This would be another option for hospital discharged consumers that is less clinical and helps with crisis and life planning.

Leadership- Any component of care should have a strong leader who is familiar with and believes in a person centered model. That person should establish relevant policies which would soon become

routine practice. For example, when a person is admitted or shortly thereafter, s/he is asked what steps staff should take if he were to act out, not simply restrained or secluded. You can see the attached CQI establishment of PACT leader job description, which the manual did not take into account.

Training All acute care staff should be trained in psychiatric rehabilitation. MBHP has funded the consumer-run organization M-POWER (Massachusetts People/Patients Organized for Wellness Empowerment and Rights) to address the training gap through its "Merging the clinical and recovery" provider trainings. This is a sustained 3 part training, with consumer staff conducting staff orientation, action planning and follow-up.

Here are some necessary suggestions for inpatient units:

Human Rights- Human rights officers should be staff that do not work on the unit and they should hold groups to educate patients on their rights. Patients should be encouraged to raise appropriate complaints.

Privacy- Contact with loved ones can be a key to clinical improvement. Thus, phone calls in private, visits in private and at all reasonable times, and the ability to move about outside should be allowed, unless the hospital can demonstrate the likelihood of resultant danger.

Hospital and housing programs should make a more concerted effort to work together.

There should be nurse or peer lead medication groups and Internet access to relevant sites.

Weekends should be staffed in the same way as weekdays. For example, if new patients are not assessed for medications until Monday, those are wasted days.

To sum up,

-we need less restrictive acute care settings that are better coordinated

-we need a report card system that allow consumers to make informed choices and drives providers to offer the best care possible

-the locus of continuity of care should be placed within the consumer and his support network.

What do you think is needed to move from the current Acute Care system to an ideal (realistically ideal) Acute Care System?

The consumer community has historically been the weakest player at the policy table. Further investments in the consumer community will provide for a more balanced policy discussion as to how money on acute care services should be spent. So how do we move to equal this playing field:

-States should require (or provide financial incentives) for managed care companies to organize and publish quality "report cards" on providers, including client perception of care data;

-States should fund cash and counseling voucher programs that permit consumers to be creative in their care spending. And encourage "consumer cooperatives," where consumers can develop consensus on the kinds of acute care programs they want;

-Change federal requirements that seem to demand locked inpatient units;

-States should fund consumer "Centers of Excellence," which will advance and support care that meets the needs of the community, not simply advocate for the status quo. Massachusetts has invested in CQI for that purpose, and is now investing in a consolidated consumer community. The State received a CMS transformation grant the Recovery Center of Excellence, which will be a technical assistance center to support peer directed and support services.

-Encourage the funding of community options that respond to the expressed preferences of the person, such as Recovery Learning Centers.

In conclusion, the potential of a research supported acute care system is dependent on a shifting of the locus of control to the consumer and his/her supports.

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

Enclosures:
PACT team leader job description
Crossing the Mental Health Quality Chasm in Massachusetts