Testimony to Executive Office of Health and Human Services

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The Honorable Ronald Preston:

You may have read the front page story in the Boston Globe from last Monday titled "At 18, mental patients face perilous change," which was spurred by a research study conducted by our organization, Consumer Quality Initiatives, Inc for the Robert Wood Johnson Foundation. Unfortunately, this story did not include the detailed recommendations we make for building a transition system through a **strengths-based youth development model** based **stronger integration of** working components and **person/family centered** flexible funding. With a variety of different agencies involved in the "Aging Out" process, including DMH, DSS, MRC, DOE, DYS and Medicaid, our report of 37 pages contains a description this confusing process, a summary of findings of 24 qualitative interviews of young adults who had aged out of mental health services, and a blueprint for a change to a system that actually serves these young adults. I am attaching that report for you, and will only briefly summarize it in this testimony.

<u>The Problem</u>: The transition to adulthood is a challenge for all young people in our society, but youth receiving public mental health services travel an onerous path into the adult world. Studies have demonstrated that these young adults often have limited schooling and strained or nonexistent relationships with their families. Public human service agencies are divided into child and adult services. Health insurance and entitlements, such as Medicaid, also provide different coverage for minors and adults. The policies of these payers of mental health services force an "aging-out" process in which individuals who received children's services can no longer receive them upon reaching a birthday deemed to mark adulthood. Eligibility and coverage policies further result in many of these young people losing their mental health services upon entry into adult status. Because of the nature of the mental health services, this forced exit from mental health services also results in the loss of friendships, homes, and support systems. And if a person is eligible for adult services, almost always those services do not meet the needs of these young adults- quoting me- "Finally, a guardian is no longer responsible for their basic needs, so homelessness becomes more likely and the criminal justice system holds them more accountable for any criminal behavior. Not surprisingly, studies have also shown that these young people are often unemployed, homeless and/or in jail.

<u>Some of the Research Findings</u>: When asked to describe the experience of "aging out," a solid majority reported feelings of shock and helplessness, using words like "Scary" Stressful" "Hard" "Traumatizing" and "Awful." For those who found the experience difficult, the following themes emerged:

One-half of all respondents said that the aging out process felt "unstable," as if the ground were moving out from under them. Several had little notice before being moved to their adult treatment setting (e.g., group home, state hospital), didn't have a chance to visit that setting or meet staff, and at times found themselves in environments they did not like. Others, already uncertain as to how they might support themselves, found themselves homeless, and sometimes in prison.

Others said they had an immediate loss of interpersonal support. For some, they no longer had substantial access to an adolescent case manager or therapist they had grown to know and trust. Others missed the general support that had been offered to them as youth, such as being driven to movies or assistance with shopping.

And others commented on the shock of entering "adult" programs or hospitals, with an older group of people with whom they did not identify.

Advocacy: When respondents were asked what kinds of help young adults would need to be advocates, a solid majority said they would need help to "speak up" and "be heard" by people in positions of power. A majority also said that training and education on communication skills, the mental health system, and/or mental illness would be important.

CQI recommendations for system to support Transition to Adulthood

1. The Transition Planning Process should begin by at least age 16;

2. Youth should not only be involved in planning their transition, but their needs and desires should be driving the process, not those of the system;

3. There should be a consistent level of support for young people before and after they "age out," with a strong independent living skills training component throughout

4. There should be age appropriate congregate living services for youth in transition. A Peer Mentorship System should be established. The role of the mentor, a young adult who has experienced mental illness, is to help the youth set goals (e.g., educational, vocational), help them find resources that will move them towards those goals, and to advise in a supportive and friendly way. The young adult mentor serves as a bridge to the adult world based on a direction that the youth decides upon, and provides inspiration and hope to the adolescent. CQI in collaboration with DMH, is piloting a mentorship program for adolescents residing in IRTPs. CQI is currently developing a training curriculum for youth transition mentors and is refining the mentor role in a way to complement staff roles in a locked unit. Peer transition mentors would also be of great service to youth living in group homes sponsored by DSS or DMH. For youth with serious emotional disorders in the community, peer mentors can work with school systems, including residential schools for youth with the most significant disabilities. As Massachusetts moves to a collaborative systems of care approach for youth in the community, such as the Family Focused Care Model, peer transition mentors could be

available for adolescents to have on their "service team," assembled to support the youth's stated objectives.

5. A Youth in Transition Citizenship Website should be developed, for the mentor and youth to collaboratively seek out resources and navigate the health system and to locate rehabilitative resources.

6. A youth advocacy training curriculum for young people who have experienced the mental health system should be established so that these youth may develop a sustained and formalized voice to inform policy makers about their needs and about how the system can best respond to them.

Best Practices

"Youth Development strategies focus on giving young people the chance to build skills, exercise leadership, form relationships with caring adults, and help their communities. Further, the youth development approach acknowledges both that youth are resources in rebuilding communities and that helping young people requires strengthening families and communities." (from Understanding Youth Development: Promoting Positive Pathways to Growth, 1997, United States Department of Health and Human Services) Several existing service models are consistent with this strategy.

As demonstrated in nearby states, key systemic aspects of success here are 1) interagency collaboration, 2) flexible services and resources, and 3) a focus on the strengths of youth, family, school and community, looking to natural settings and all aspects of youths life. Interagency Collaboration and the Transition to Adulthood for Students with Emotional and Behavioral Disabilities, Education and Treatment of Children, Vol. 21, No. 3, August 1998, Malloy, J. et al. Thus, in New Hampshire, "Project RENEW serves youth and young adults with EBD between the ages of 16 - 22, providing comprehensive case coordination for their ongoing education, employment, social/emotional development, and community readjustment. All youth in the project special education and mental health services by virtue of their identified disability." Id at 306. Initially funded by the U.S. Department of Education, Office of Special Education and Rehabilitation Services, its success is dependent on the collaboration of the Mental Health and Education Departments, along with advocates and colleges that provide a "Lifelong Learning Approach."

In Vermont, The Vocational Rehabilitation Department has developed the JOBS (Jump On Board for Success) program, which works with youth who receive(d) services in the public mental health system ages 16-22 to find jobs (in a supported employment model), though eligibility for public child adolescent services ends at age 18. An interagency agreement among the department of Vocational Rehabilitation, Corrections, Social and Rehabilitative Services and Developmental and Mental Health Services specifies the funding responsibilities. Davis, NTAC, p. 11. Of significance, the VRD worked with Medicaid to obtain a "Home and Community-Based 1915(c) waiver, which makes it possible to extend targeted case management for young adults through age 21, allowing mental health services continuity during this process.

Moving Forward: While Massachusetts is facing ongoing budget challenges, there's currently opportunity for positive change. In collaboration with other state agencies, the Division of Medical Assistance is taking steps to offer flexible short-term wraparound services for youth and their families- the Comprehensive Family Focused Care Initiative; similar efforts are taking place in Cambridge and Worcester as well. These kinds of programs provide a strong base for offering skill-building activities to youth through at least their twenty-first birthday. In addition, DMH has had a Youth Development Committee in place for a year, which has consumer representation (and co-facilitators), and is now a subcommittee of the DMH state planning council. DMH has also implemented a peer-mentoring project to assist youth in IRTPs to plan their transition to the community.

We emphasize that MassHealth should consider the use of a Medicaid waiver in offering non-traditional longer-term services such as case management, peer support and skill-building, with the recognition that these services must be "cost-neutral" and are demonstrated alternatives to placing Medicaid-eligible individuals in medical facilities. The Psychiatric Rehabilitation Option also offers an opportunity to provide such services.

Consumer Quality Initiatives: CQI's mission is to "give [mental health] consumers a greater voice and an integral role" in evaluating their treatment and initiating changes that "improve the system for all, consumers and providers alike." (For more information, see www.cqi-mass.org). To provide a forum for the consumer voice, CQI staff conduct confidential interviews with people who have received or are receiving mental health services. After analyzing the interview data, CQI staff write reports that include specific recommendations, and present the reports to mental health authorities, managed care companies and key stakeholders in the community. While we do this for Medicaid and DMH, we are to assist EOHHS pursuant to chapter **6A: Section 16F.**