

CQI

Consumer Quality Initiatives, Inc.

Voices of Youth in Transition

The Experience of Aging Out of the Adolescent Public Mental Health Service System in Massachusetts: Policy Implications and Recommendations

Executive Summary

This study was prepared by Consumer Quality Initiatives (CQI), and funded by the Center for Health Care Strategies, Inc. under the Robert Wood Johnson Foundation's Medicaid Managed Care Program. CQI is a consumer directed and run non-profit organization that integrates the consumer voice into mental health quality improvement, planning, research and evaluation.

Adolescents who receive public mental health services face significant challenges as they “age out” of the youth system and transition to adulthood.¹ As “adults,” they are eligible for fewer services. DSS is out of the picture, eligibility for DMH “adult system” is more strict, and Medicaid dollars support primarily short-term acute care services. In addition, most of these service options are not appropriate to their young age, as they are geared to older adults with more severe disorders. Finally, a legal guardian is no longer responsible for their basic needs, so homelessness and criminal justice involvement become real possibilities

This review presents findings from twenty-four qualitative interviews with young adults (between ages 18 – 25) who had received adolescent public mental health services in Massachusetts about transitioning to adulthood. Attempts were made to interview a variety of young people, whether or not they were still receiving services.

Principal Findings

Demographics of Cohort

A large majority of our cohort was white/Caucasian and had been hospitalized and/or received therapy at some point during their adolescence. Respondents ages ranged from 18 to 26, with a median age of twenty-one. Males and females were represented in equal numbers.

As for their current place of residence, twelve of our respondents were living in a group home or supported housing for people with mental health and/or substance abuse difficulties; nine of those lived in programs that focused on young adult needs. Of the remainder, four were homeless, three were in a state hospital, three lived with family and two with roommates.

¹ For the purposes of this report, “adolescent public mental health services” refers to those services funded or offered by the Department of Mental Health child/adolescent system, the Department of Social Services, and the MassHealth managed care system and its adolescent private provider (vendor) network. “Aging out” refers to the moment when a young person is no longer eligible for DMH adolescent (age 19) or DSS (ages 18-21) services, and at age eighteen for MassHealth clients when vendors are no longer required to treat them with other adolescents, and they are typically treated with older adults.

One-third of the respondents were working part-time. Three quarters of our cohort had graduated high school or obtained a GED, and of those, three had taken college courses but dropped them for psychiatric reasons. Five were currently taking college courses, two full-time.

The Experience of Aging Out

Prior to aging out, just over one-third were living in a group residential setting, (most commonly a DSS sponsored group home), almost one-third were in a locked DMH IRTP (Intensive Residential Treatment Program), with the remainder living with their own families or a foster family (with MassHealth as the primary payor.) Those aging out of IRTPs or group homes were most commonly discharged to another group home or family, though some transitioned to a state hospital.

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.” Five of the respondents reported positive experiences because they did not find adolescent services helpful or did not feel they were treated respectfully.

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.

One-third 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.

One-quarter commented on the shock of entering “adult” programs or hospitals, with an older group of people with whom they did not identify.

When asked what kinds of help could have made the aging out experience better, most commonly mentioned were:

- Adult independent skills training during their transition period, such as money management, socialization skills, and job search skills.
- Advanced planning for the transition
- Involvement in planning for the transition

The Transition Years- Issues Identified and Help Desired

Upon being presented with a list of issues young adults might want assistance with, over one-half of our cohort said that they wanted help with:

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| -mental health | -finishing school |
| -finding an enjoyable job | -issues with friends |
| -independent living skills | -balancing a budget |
| -finding a home | -issues with family |

Significant numbers of our cohort wanted the kind of help with these issues that:

- was readily available
- focused on their strengths and developed their skills
- had staff that listened to them and took them seriously

Current Service Use

Most of our cohort were currently using mental health treatment services, with a majority having DMH case managers.

Our cohort's primary reason for using services was to improve their mental states and/or the quality of their lives. A number who were in young adult programs said they liked being with their peers. For some, the primary motive was that being in treatment was a requirement of their housing contract.

Youth 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.

When asked to rate a series of activities that might promote young adult advocacy by level of importance, respondents rated the highest "A mentor(s) who can give help or feedback on projects," with almost one-half saying this was "absolutely necessary." Informational sessions on advocacy and the service system, the formation of a youth organization, and monetary support were also rated highly. Ranked lowest were activities that included the terms "training," "political," and "business."

About three-quarters said that they personally would want to participate in at least one advocacy activity, primarily in advocacy training and in being a peer mentor to younger people. The most common reason for desiring participation was a recognition that as consumers they had something of value to give back. Most of those who would not participate were very busy in their own lives.

CQI Recommendations to Improve Youth Transition to Adulthood

1. Establishment of a Peer Mentorship System. 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.
2. Development of a Youth in Transition Citizenship Website, primarily for the mentor and youth to collaboratively seek out resources and navigate the health care system.
3. Strong independent living skills training, both before and after the youth ages out.
4. Age appropriate congregate living services for youth in transition.
5. Youth advocacy training so that young people may develop a sustained and formalized voice to inform policy makers about their needs and how the system can best respond to them.

Effective systems change is dependent on a strong consumer and family voice that advocates for interagency collaboration and flexible funding approaches.