Voices of Youth in Transition

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

CQI

Consumer Quality Initiatives, Inc.

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Consumer Quality Initiatives (CQI)

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." 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. Through small group discussions about data among consumers, providers, and health care authorities, CQI is beginning to bridge information gaps and establish a common understanding of quality and mental health.

CQI can make a unique contribution to mental health services improvement because the organization is consumer-run and directed. The interviewers are mental health consumers and family members who have received extensive training in interviewing techniques. Because of their personal experiences with mental illnesses, these interviewers often are able to build a rapport with respondents that would not have been possible otherwise. This rapport appears to help the interviewees speak openly and honestly about their treatment experiences.

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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 – 26) 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

1. *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;

[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.

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.

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.

2. *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), 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 payer.) 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;

3. *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:

-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 that:

- was readily available;
- focused on improved their functioning instead of symptom reduction;
- had staff that listened to them and took them seriously;
- helped coordinate their care.

4. *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.

5. *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. Though considered important by many, activities that included the terms "training," "political," and "business" were ranked lowest.

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 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. 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.

5. 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.

6. 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.

7. 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.

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

Introduction

Young people face new and exciting challenges as they transition to adulthood. They take jobs, complete their education, and find new places to live. Many become sexually active, and some start their own families. Parents and school systems often play significant roles in easing the transition to adulthood as young people take on these new responsibilities.

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. Finally, a legal 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 and homeless.

In this report, we present the findings of a qualitative study of the challenges faced by young adult consumers transitioning out of the public adolescent mental health system in Massachusetts, and include CQI's recommendations for systems change to improve outcomes and life quality for these young people. The findings are based on interviews of 24 individuals between the ages of 18 and 26 who had received public mental health services as adolescents about their experiences aging out of child services, their interest in participating in advocacy, and their ideas of how things could be better.

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 activities.

Transition Issues in a Medicaid Managed Care Environment

In 1992, Massachusetts became the first state in the nation to implement a statewide federal waiver program to deliver mental health and substance abuse services to its Medicaid enrollees (ie, MassHealth) (Callahan et al., 1995). By contracting out the management of "behavioral health" service use to a private for-profit managed care company and several private non-profit health maintenance organizations (HMOs), the state's Division of Medical Assistance ("DMA") was establishing managed care networks, with primary goals of improving care quality and controlling costs. At that time, state expenditures for mental health services in the MassHealth program rose at rate greater than general medical care inflation, while funding for state Department of Mental Health (DMH) was cut significantly, resulting in a bifurcated system (vertical) of public mental health care. It is within this context that we examine the challenges faced by adolescents as they "age out" of the Massachusetts youth mental health system and transition to adulthood,[2] and by young adults generally who seek public mental health care in Massachusetts.

The Massachusetts Managed Care Environment for Youth with Mental Health Disabilities

1 The Department of Mental Health (DMH), the state mental health authority, "…sets the standards for the operation of mental health facilities and community residential programs and provides clinical, rehabilitative and supportive services for adults with serious mental illness, and children and adolescents with serious mental illness or serious emotional disturbance." DMH provides 5,000 youth with continuing care services within its child/adolescent system; upon turning nineteen, they are no longer eligible for this array of services.

2 The Department of Social Services (DSS) provides for the safety and well-being of children who have been abused or neglected in a family setting, or who have been determined to be in need of services due to a behavioral problem. Of 8,000 youth in DSS's care and custody, 2,000 are placed in residential psychiatric treatment settings. Upon reaching age 18 most of these youth lose DSS services. A small portion of them can enter voluntary services until the age of 21 that are designed to improve independent living skills and help youth complete their education. DSS funds many programs to help adolescents develop independent living skills prior to age 18, though there are none that are specifically

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designed to meet the needs of youth with Serious Emotional Disorder (SED) or mental illness.

3. The Division of Medical Assistance (DMA) oversees the provision of Medicaid-funded (MassHealth) services in the state, including mental health services administered to approximately 400,000 children and adolescents. MassHealth can pay for acute mental health services (short term hospitalization, acute residential, and partial hospitalization) and outpatient mental health clinical care. Fifty percent of DMH child/adolescent clients and every child in DSS care and custody are covered by MassHealth, and their care is managed primarily by the Massachusetts Behavioral Health Partnership (MBHP), the for-profit managed care company referenced earlier. MBHP contracts with a network of providers statewide to offer age appropriate services to youth until they reach the age of eighteen. After a MassHealth covered youth has turned eighteen, s/he can and is treated in MBHP's adult provider network; there are limited exceptions, most significantly that youth accepted into DMA/MBHP's proposed, coordinated family-focused care initiative can receive services until age twenty-two, if they are eligible for special education services. In any event, youth generally retain their MassHealth eligibility until they reach the age of nineteen, after which most must reapply for MassHealth eligibility.

4. The Division of Youth Services (DYS) operates secure facilities for juvenile offenders who have been committed to their care by juvenile courts. The agency places less severe offenders in group homes and in foster care.

5. The Department of Education (DOE) is the agency that has oversight responsibility for public school education in Massachusetts. DOE works with local school systems to insure that youth with disabilities who otherwise would not be able to progress effectively in regular education have individualized education plans (IEPs) until their high school graduation or 22nd birthday. Toward that end DOE operates residential schools for youth with severe disabilities. Federal law (Individuals with Disabilities Education Act) also mandates that transition planning be done for all students with disabilities beginning at age 14. This law dictates what transition planning must include, such as the identification and involvement of adult agencies that the student will need after they complete high school. Massachusetts also has state law that dictates adult agency involvement for special education students.

6. The Massachusetts Rehabilitation Commission (MRC) provides independent living and vocational rehabilitation services to individual with disabilities. A large majority of MRC's clientele are people with physical disabilities, with DMH seen as having large responsibility for individuals with mental illnesses.

   Though MRC primarily serves adults, it has initiated several programs to work with youth in transition. The Transition to Adult Program (TAP) provides funding to four Independent Living Centers to work with adolescents to develop the skills and rehabilitative resources to live independently in the community as an adult. In September 2002, DOE and MRC notified schools statewide that MRC was prepared to work with adolescent students with

disabilities, whether or not in special education, to help them plan their career goals and upon completion of their IEP, develop the resources to reach those goals.

Decrease in Number of Service Options

As the descriptions above show, Massachusetts's mental health consumers become too old for the various "child" services between the ages of 18 and 22, adding a further layer of bifurcation (horizontal) to the public mental health system.

Adolescents who have the most serious long-term needs receive an array of services through DMH and/or DSS, including residential treatment in group homes and schools, case management, after-school programs, and flexible support services. Those most at risk are treated in locked intensive residential placement programs (IRTPs). DMH clients age out of the child/adolescent system at age 19, and DSS clients lose eligibility by their twenty-first birthday. In order to receive adult DMH services, youth must meet DMH's criteria for serious and persistent mental illness (SPMI). This is a more narrow definition of eligibility than that used for the child DMH system. Many youth who qualified for child DMH services or DSS residential treatment do not meet the adult criteria. Furthermore, even those who do qualify for the adult system face fewer supportive services.

Those young people who do not meet the stricter diagnostic criteria for DMH adult services quickly lose access to long-term service supports (eg., case management, supported employment and education, housing support). Those individuals can (if eligible) receive acute mental health care within MassHealth's adult services network, which offers only day treatment and limited peer education activities for rehabilitative purposes, and from MRC for help with employment and education. (While the coordination of acute and rehabilitative supports for MassHealth recipients has been lacking, the Division of Medical Assistance, through its Medicaid Infrastructure grant, has recently begun to establish a coordinating center to assist consumers who would like to return to work.)

In addition, to the degree that certain rehabilitative and skills-based services may be available from MRC or DMH, a young person leaving an agency or system responsible for their care (eg., DSS, DMH) may not have sufficient assistance/awareness to take advantage of those options. And with the current state budget woes, MRC and DMH have reduced resources to take on new clients, and MassHealth is cutting back on both eligibility and services.

Lack of Age-Appropriate Service Options

Maryann Davis, Ph.D., Center for Mental Health Services Research, Department of Psychiatry at the University of Massachusetts Medical School, served as CQI's project consultant and is a national expert on the transition to adulthood among youth with SED and mental illness. According to Dr. Davis, adult public mental health service systems are not designed with the needs of young adults in mind. Most of the clients of the adult system are in

their 30's-50's and have experienced many years of very severe mental illness that initially emerged in young adulthood, rather than in childhood. Most of the adults served completed their adolescent development in the absence of mental illness, thus services are designed to rehabilitate functioning rather that to teach skills for the first time. Adult service providers are often not trained in adolescent development and are thus unprepared for the relatively immature psychosocial development of the young adult population and the service and treatment implications of their developmental status. As Dr. Davis points out, young adults have many needs that are closer to those of adolescents' rather than those of older adults. For example, many need help finishing high school or are still very dependent on the support of their parents.

Dr. Davis notes that, in addition, consumers in the public adult system are seen as having a greater responsibility for their care. Unfortunately, the young people entering the adult system from the adolescent system are not prepared for this responsibility. Most have just left the custody of legal guardians (egs., parents, DSS) who had the legal duty to look after their well-being, including their health care and housing needs; upon their entering the adult system, they are suddenly responsible for these basic needs. Dr. Davis notes, "The adult system may assume a level of maturity and skills not yet developed in young people in terms of identifying and coordinating their own services."

The Net Effect

Young adults who "age out" can legally make their own life choices, including those related to their mental health treatment. Ironically, while they are legally able to make more kinds of choices, they are eligible for fewer service options and supports, and they often find these adult services to be undesirable. The results of this breach are serious.

According to Dr. Davis, one-third to one-half of adolescents receiving public child mental health services in Massachusetts do not continue to receive public adult mental health services. While some go on to further education or work, keeping their lives structured and purposeful, many do not have the capacity to do so. Consequently, many find themselves with substance abuse problems, involved in criminal activity and, most significantly, homeless. The transition to young adulthood then becomes a trauma itself, which itself can require treatment.

Survey Method

Survey Instrument

Much of our knowledge about the challenges of transition come from studies that have followed the well-being of youth into adulthood, or surveyed MH administrators and parents (citation: Davis & Vander Stoep, 1997, Davis 2001; Davis & Butler, 2002). Although there are published testimonials from youth (e.g. Davis & Vander Stoep, 1996; Adams, McNulty & Shalansky, 2000), their voices have not been more systematically included in the discussion. As

a result, CQI chose to use a qualitative strategy to collect information about young adults' service use history and background; their experiences of "aging out" of the adolescent system and their suggestions for improving the process of "aging out"; the kinds of help they had needed or wanted since their transition from adolescent services; their interest in advocacy for young adult mental health consumers.

Drawing from CQI's prior experience, Dr. Davis's expertise, and feedback from young adult advisors, CQI developed a semi-structured, largely qualitative instrument that required about 45 minutes to complete. The quantitative portion of the survey consisted of four items requesting respondents to rate on a four-point scale their level of satisfaction with the help they had received through their mental health services; 11 items requesting respondents to rate on five-point scales the importance of various advocacy-related supports; and a number items throughout the instrument requiring respondents to answer "yes" or "no."

Interview Procedure

To recruit young adult participants, CQI created a flyer advertising a $25 incentive for interview completion and a toll-free number for interview scheduling. CQI distributed these flyers to many organizations, service providers, and facilities frequented by young people, including college campuses, homeless shelters, housing programs for young adults with mental health or substance abuse issues, and DMH regional adolescent coordinators. Before recruiting DMH clients, CQI received approval from the DMH Internal Review Board.

From May through August of 2002, CQI received calls from over 30 young people or their providers. (The reasons some were not eligible were that either they had not received public mental health services as adolescents, or had not done so in Massachusetts.) CQI staff arranged to meet individuals who met the project's criteria and agreed to participate in the confidential interviews. These interviews took place at CQI's office in Dorchester, Massachusetts or at a location more convenient to the interview participants. During the interviews, CQI staff recorded comments in respondents' own words as much as possible, although longer responses were sometimes paraphrased. The interviews were conducted by consumers of mental health services, experienced at establishing a rapport with other consumers. Interviews lasted about 45 minutes, ranging from 25-60 minutes.

Participants

CQI interviewed 24 people between the ages of 18 and 26 who had received mental health services as adolescents from the publicly financed (DMH, Medicaid) mental health care system in Massachusetts.

1. Demographics

The 24 survey participants ranged in age from 18 years to 26 years, with a mean and median age of 21 years. Half were female. All but three self-identified as Caucasian or white; of the remainder, two said that they were African American or black, and one said that she or he was multiracial. All of the respondents but four said they were heterosexual or straight; of the remainder, three said they were bisexual and one identified as gay or lesbian. None of the participants had ever been married or had children.

As for their housing, one-quarter lived in DMH sponsored "supported housing" (an apartment with other adult DMH clients with vendor support), and another quarter lived in a group home to help residents deal with mental health or substance abuse difficulties; nine of these twelve were living with other young adults in programs designed for young adults. Of the remaining twelve, three were living in a state hospital (with two in the process of transitioning to a group home), four were homeless (in shelters, the street or with acquaintances), three were living with family (parents or grandparents), and two with roommates.

With regard to employment, eight (33%) said they were working for pay part-time, three worked in relation to their schooling (either just during the summer or through work-study), and one person worked as a volunteer full-time. The remaining twelve said they were not working, though three of them said they were looking for a job.

With regard to educational attainment, three-quarters (18) had attained a high school degree (or a GED). Of those, eight were attending or had attended some college, with five attending college currently, two full-time and three part-time (most at community colleges).

2. Services Received as Adolescents

The age at which survey participants said they had first received services ranged from 4 years to 18 years, with a mean and median age of 12 years. Most respondents had been placed in an inpatient setting at some point and/or received counseling at some point during their adolescence. Inpatient settings for some included intensive residential treatment programs (IRTPs) for DMH clients, and private adolescent hospital units for MassHealth clients; counseling services included individual and family therapy administered through outpatient clinics and residential schools. In addition, about one-half had been in DSS care and custody and received some mental health care directly from DSS

Several others had been involved in day treatment programs or alternative schooling for people with mental illnesses. Fewer individuals said they had received intensive case management services, detoxification services, or medication management services.

3. Current Services

Three of the 24 respondents (13%) said they were not receiving services at the time of their interview. One person who was homeless was unable to access desired DMH services, and two felt they did not need them, one having recently left a young adult program to go to college.

The remaining respondents described the services they were receiving at the time of their interviews. Fifteen individuals (63%) said they were receiving services through DMH; most said that they were receiving counseling and/or housing services through DMH, though others referred to medication management, case management services, day programs, and state hospital.

Only nine individuals (38%) said that they were using services funded by MassHealth, though there was some uncertainty for some. (One of these nine said they were also receiving DMH-funded services.) Several respondents commented that they received therapy and/or medication management services.

Of note, only four people had received assistance from MRC, either in employment or education. In one case, a respondent received financial assistance in going to college.

A large number of those in their 20's, after an otherwise difficult transition period, had found their way into programs that were useful for them. Thus, of the 24 young adults we interviewed, nine were currently in young adult focused group homes or supported housing run by private vendors. That is, they lived with other young adults. While most of these placements were DMH funded, a few were in a grant funded home for young people with addictions. In addition, several additional people we interviewed attended a work/social program for young adults. Thus, almost one-half were in some sort of young adult program.

Data Analysis

CQI analyzed the qualitative data according to established analytic procedures derived from the phenomenological perspective (e.g., Davidson, 1994; Davidson et al., 1995; Giorgi, 1970; Wertz, 1983). For many of the open-ended questions, the principle investigator, the co-investigator, and a young adult advisor independently examined the interview data to identify prominent themes in each participant's narrative. The three researchers then identified themes common to several participants for each question. The two investigators later confirmed these themes by reexamining the interview data.

The Experience of Aging Out

How Our Cohort Aged Out

The young adults interviewed by CQI were living in an IRTP, a group home, or with family prior to aging out of adolescent services. Eight were in an IRTP, with four moving on to a state hospital at age 19 and the remainder moving on to a group home or their family between ages eighteen and nineteen. Nine of our cohort aged out of other types of adolescent mental health-related residences: DSS group homes and residential schools run by DMH or DOE; these

9 young adults transferred to "adult" group homes or their communities between the ages of 18 and 21. Of the remaining seven, five were living with family and two were in foster care; these young adults stopped receiving adolescent services at age 18.

Describing the Experience of Aging Out

Interviewers asked the young adults what it was like when they stopped receiving adolescent services. Most respondents described the aging out experience of shock and helplessness; as one respondent said, "*You have everything and you lose everything at the same time.*"

Other words used to describe the experience included:

"Very scary"
"A mess"
"Traumatizing"
"Awful"
"Stressful"
"Really hard"
"A bitch"

These young adults had good reasons for feeling badly about their transitions, considering the confusing and unstable housing situations many experienced during this period. The housing problems of those in group settings had several elements in common:

- Staff told the young adults that they would be leaving their adolescent services at a certain age, but they often had to wait beyond that age for their new placements. These individuals were left in limbo between one and twelve months without any knowledge of when they would leave their current services and where they would be placed next.

- The young adults were moved quickly to their new setting with little or no warning. One former IRTP resident said she had not been told of her move until the day it occurred, when she was taken to a new hospital by ambulance.

- They had no chance to visit new residential settings or meet staff at the new settings before they were placed there. As one person noted, *"When I first came here, I didn't know anybody."*

Some of the young adult respondents in their 20s said that during their transitions they were moved to several group homes or supported housing programs before they found one that met their needs. These individuals were not comfortable until they found a setting that was oriented toward young adults, or a program that dealt with their substance abuse issues. Other respondents reported that at the time of their transitions, they worked with staff at their IRTPs to find group homes before ending up in a state hospital.

Several people said they were homeless shortly after their transitions from adolescent services, and a few individuals reported that they spent time in jail during that period. One of

these individuals explained, *"I acted like the peer group I met when I was an adolescent. I was scared to go back to foster care. When I became homeless, I violated parole, then I went back to jail and I was really scared."* Another respondent who spent time in jail was given several group home placements, but was evicted from each of these homes because of his violent behavior. In addition, several of the respondents who started college lost their housing after they dropped out of school.

Losing the support of staff from their adolescent services was also a difficult adjustment for many of the young adults during their transitions. These respondents made comments like:

> *I had to lose my DMH case manager, and I had worked with her since age 13. I had to get an adult case manager. It was a hard change.*
>
> *...But I missed the staff that drove us around for fun and recreational things. At that place, there was great staff person who really helped me who I could really trust... I can still call her. [But] now I have to figure out what to do with my own time. We're on our own for day recreation things.*

With so many new stressors related to their mental health services, some of the young adult respondents stopped using services altogether after their transitions. Those who remained in services often reported feeling out-of-place in their new treatment settings, especially in the hospitals and adult day programs. One such young adult reported, *"No one understood me. It was awful. I was in the [private] hospital for a while and couldn't get what I needed. I was one of the youngest people there."* These individuals were not used to the adult system, where, as one interviewee noted, *"you're expected to find a place to live and take care of your money."*

A few respondents were pleased with their transition from adolescent services. These individuals often indicated that the youth system had been too controlling. One such respondent described *"a welcome relief"* because he no longer had to attend youth day treatment or work with a DMH case manager who was *"nosy, bossy, imperious and unfriendly..."* Another respondent was pleased to leave a group home that *"sucked- they used restraints. I proved I could live on my own."* Others were glad to transition out of adolescent services because they did not like them, they had trouble with the school their programs forced them to attend, or they preferred the freedom their age now granted them.

Young Adults' Suggestions for Improving the "Aging Out" Process

When asked what could have made the aging out process better, the young adults had several ideas. A majority thought they could have used more independent living skills training. Some wanted general help:

> *[I want] more people to talk to about being an adult. What can I do to change?*
>
> *[I need to learn] ways to cope on the outside [of an IRTP]. It's difficult from the inside. How do you know what to do.*

Others wanted to learn more specific skills, with money management (egs., budgeting, tax filing, and shopping) most commonly mentioned, followed by socialization skills and job search skills. A few respondents commented that they would have felt more prepared for these adult responsibilities if their adolescent service providers had given them more freedom to experience the outside world:

I wish I could have gotten out more… [and had] more freedom.

I would [want to] leave the hospital more. I got those privileges, but a lot of people did not… [I would want] more passes.

Several of the young adults had suggestions related to the timing of skills training. Most said they needed to learn these skills well before they left adolescent services. Some of these individuals explained:

I don't think you can learn those just when you leave.

They should have had more groups on transition. For example, when I was locked up for five years [in an IRTP], they could have had basic skills training, like with job applications.

Others, particularly those aging out of a non-institutional setting, noted the importance of this sort of training after aging out. One such person remembered, *"It wasn't until I dropped out of college that I found out how little I knew. [Then I could have used] someone to work with me in living with roommates and paying bills."*

Individuals who transitioned from residential adolescent services also had suggestions related to their housing. Waiting for new placements and moving caused a lot of anxiety for these individuals. They believed that this anxiety could have been lessened if staff had given them more information about their impending moves:

I needed to be more clear what was going to happen to me.

I wish someone told me what was going to happen.

[My move would have been better] if I had an idea what kind of place I was going to…if I was made to feel safe.

Much of the needed information could have been gathered during visits to their new placements before moving:

It would have helped me to visit [halfway house] for a week or so . . .I could get used to it and talk about my concerns to staff at my adolescent program.

I would have liked to see this place [state hospital] and got information about it first before I was transferred.

Respondents had other suggestions as well. Several individuals reported a desire for greater involvement and assistance in reaching their goals. Their comments included:

I wanted to feel I had another option…

Leaving the youth system would have been better experience if someone could have helped me return to school … Somebody helping me reach my goal of getting a university degree would have given me hope that I hungered for.

A few reported that they wished more supportive people had been available to them; these individuals could have used more counseling and case management services. As one person stated, *"I wanted to feel like I wasn't alone."* A number of others said that young adults programs they landed in sometime after aging out would significantly eased the process.

Problems Young Adults Have and The Kind of Help They Want

Problems with Which Young Adults Needed or Wanted Help

The young adults included in this survey said that they needed or wanted help with a number of different areas of their lives. The help they needed often fell into one or more of the categories created for this project by a researcher (Dr. Davis) familiar with the needs of young adult consumers. In some cases, interviewers asked the young adults directly whether they had needs or wants in one of the predetermined categories; in other case, the young adults' comments about their needs or wants were placed in the categories after the interview was completed. Analysis of all the data on young adults' needs and wants revealed the following:

Type of Help Needed or Wanted	n	Percent *(N=24)*
Psychological problems	17	71%
Finishing school	15	63%
Finding an enjoyable job	14	58%
Problems or issues with friends	14	58%
Skills needed for independent living	14	58%
Balancing a budget	13	54%
Finding own home or home with friends or romantic partner	13	54%
Problems or issues with family	13	54%
Romantic or sexual relationships or issues	10	42%
Changes in insurance or entitlements	9	38%
Drug or alcohol use	9	38%
Keeping an enjoyable job	9	38%
Medical conditions	4	17%
Childcare or parenting	2	8%
Legal problems	2	8%

The experiences of Zach* and Brittany*, two of the young adults interviewed by CQI, illustrate some of the most common problems:

Zach's Story

Zach was a 22-year-old high school graduate with a history of depression and substance abuse. As a result of his problems with family and school, he entered a residential treatment program when he was 14 years old. At 18, Zach aged out of his residential program and went back to live with his parents. According to Zach, the loss of support from the residential program, combined with his lack of preparation for dealing with his family issues, made it very difficult for him to function well when he moved back home. And since there wasn't anyone requiring him to continue with therapy, he stopped going.

Zach soon began to drink and get high. Eventually, his parents kicked him out of their house. He ended up on the streets in a destructive downward spiral until he finally recognized he needed help. Zach entered detox, where he found the support that he needed to begin to get his life back on track. After detox, he entered a supported housing program for young adults with drug and alcohol problems. This program gave Zach stability, a deeper awareness of his problems, and an opportunity to share and learn from his peers. At the time of his interview, Zach planned to work on completing his college education.

During his interview with CQI, Zach talked about the type of help he wished he had received from his adolescent services. He said, *"I would have wanted to learn more about addiction and my depression, and [about] how to get along with my family."*

Zach's Problems

Like Zach, many of these individuals had mental health and substance abuse problems, including depression, suicidality, anxiety disorders, bipolar disorder, and alcoholism. While Zach wanted more information and training about dealing with his mental health problems, others needed help dealing with the symptoms of their illnesses. Medications were not always a simple solution for these individuals. One person was having trouble *"coming to terms with taking my medications,"* while others needed help obtaining and taking their medications.

Just as Zach struggled with his family relationships, many of the young adult respondents had problematic relationships with family, friends, or romantic and sexual partners. These individuals often had experienced conflict or abuse in their important relationships in the past. They often were looking for ways to get the support they needed from other people in their lives, and a few suggested that family therapy or groups on relationships would be helpful to them. Several individuals said they had difficulty socializing with others and made comments like, *"... My socializing in some ways was limited to church, outside of my family. My problem was [that] I had trouble feeling comfortable in small groups or volunteering."* A few individuals wanted guidance as they explored new romantic and sexual possibilities.

Zach was one of a number of young adult interviewees who had been homeless for a time since they left adolescent services. These homeless individuals needed help finding halfway houses, housing situations with roommates, or other available shelter.

Brittany's Story

Brittany was a twenty-year-old woman who spent much of her adolescence in an IRTP. By the time she left the IRTP to live with a relative, Brittany had already graduated from high school. Her goal was to go to college and find a professional position in human services.

Unfortunately, Brittany found that she was under-prepared and overwhelmed by many of her new responsibilities. She did not know how handle "basic things" like filing tax returns and getting health insurance. In addition, she had to figure out how to apply to college and get financial aid on her own.

For a while, Brittany was concerned that all her new responsibilities would cause her to have a serious setback. She worried about finishing her college applications, and she wished she had received some help while she was in the IRTP.

In the end, Brittany completed the college application process successfully. She is very busy with college now. When she talked with CQI about the type of help that could have made her transition out of adolescent services smoother, Brittany suggested that she needed a different kind of help than her case manager could provide. She said she would have liked *"someone like a sponsor . . . A mentor to show me how to do things . . ."*

Brittany's Problems

Like Brittany, a majority of the respondents needed help preparing for their vocations; these individuals wanted assistance finishing school, finding enjoyable employment, or maintaining enjoyable employment. Many of the young adult participants wanted help obtaining their GEDs or applying to, financing, and finishing their college educations. Individuals interested in schooling also commented on the challenge of finding schools that were sensitive to their mental health needs. Young adults who wanted job-related help listed a wide range of skills they needed to develop, including defining their career interests, sharpening their job skills, and conducting job searches. Most of these respondents asked for general help related to jobs, while one person specifically asked for *"a program that would prepare me for work and help me learn how to find a job."*

Brittany also referred to her troubles handling adult responsibilities like filing taxes; many of the young adults interviewed by CQI felt the same way. These youth did not know how to live on their own, and they needed to learn about everything from house cleaning and clothes washing to independent decision-making. Several needed help balancing their budgets; one such individual explained, *"...I could use help understanding how much money I have coming in, and how much I need to spend on things like food and clothes and going out."*

Maintaining health insurance and entitlements was another source of concern for Brittany and several of the other interviewees. These benefits changed as individuals enter adulthood, and the young adults were often confused by the changes. One individual reported receiving mail she or he did not understand from her or his insurance company; another said, *"I don't understand what is going on with my SSI . . .The amount has been cut and I don't know why."* All this confusion left more than one person without the insurance coverage and income on which they depended.

Why Young Adults Seek Mental Health Treatment

All but one individual had received mental health services within the year prior to her or his interview. (The individual who had not received services in the past year explained that she did not have an illness and had not liked the services she had received in the past.)

When asked why they had used the mental health services they had used in the past year, about half of these individuals explained that they had wanted to improve their mental health and the quality of their lives. These young adults seemed to recognize that they had mental health conditions and that effective treatments could help them. They made comments like:

> *My life was unmanageable. I needed to get off drugs and [get] back on my feet. I needed to take care of myself and get away from nasty relationships.*
>
> *...I needed the medication to stabilize my condition. I needed the therapy to help take care of the problems that the medication could not take care of, such as behavioral problems and anxieties...*
>
> *I used services in order to get my meds and talk about my problems...*
>
> *I need help to think about what I want to do with my life...hooking up with training and financial aid.*

Several respondents sought help because services and people that they liked were available to them. One individual appreciated their service's treatment philosophy that encouraged people to help themselves; the others liked certain people they saw through their services:

> *...They're really nice to me and help me when I'm upset.*
>
> *...I like the young adult group for talking and being with friends.*

A few individuals commented that their primary reason for accepting certain mental health services was that they were bundled with needed housing and basic amenities. These young adults indicated that stable housing was crucial to their recoveries:

> *I needed a place to live, and this program has provided me with a holding spot until I can escape...*
>
> *...Housing was extremely important to me because it was a crucial necessity in helping me to feel better about my life and adding comfort to it.*

Three people were committed to state hospital, and a fourth person was forced to accept services as part of their treatment contract: *"...If I want to stay in this [housing] program, I have to go to therapy; it's not that I want to go."* Notably, all of the respondents who received services they did not want were female.

The Degree to Which Young Adults Received Help that Addressed Their Needs

Those who had received services in the past year rated on a four-point scale the frequency with which they were satisfied with different aspects of their services. A little more than half of these young people reported that help was generally available and in fact helpful, and the people who helped them had enough time for them, and understood them. The remainder found this to be true 'sometimes', with those in programs specifically for young adult more likely to be satisfied:

Survey Item	Always	Often	Sometimes	Never	N
Has the help you have needed been *available?*	26%	35%	39%	0%	23
Have people who have been trying to help you *had enough time* for you?	35%	22%	44%	0%	23
Have people who have been trying to help you *understood* you?	26%	26%	39%	9%	23
Has the help people offered to you actually *helped* you?	22%	35%	44%	0%	23

In addition, although respondents indicated that they had gotten the needed help for many of their problems, some young adults revealed that one or more of their problems had not been addressed. Several individuals had not gotten any assistance with their concerns related to jobs, schooling, budgets, housing, and/or romantic or sexual issues. A smaller number of respondents had other problems that had been ignored, including issues related to friends, family, substance use, changes in insurance or entitlements, independent living skills, and psychological problems. Typical explanations of problems for which young adults had not received help included:

I need a program that would prepare me for work and help me learn how to find a job.

Just help me locate housing for myself. I'd like to get a job so I can have a decent place. I need someone I can trust - someone who doesn't just diagnose me, but who gets to know me.

When respondents whose problems had been ignored were asked what kinds of help they would have wanted, most said they wanted support and guidance from caring people:

I'd like to talk to someone who I felt safe with…

I'd like someone to walk me through the steps to help me because I can't read or write.

Many wanted more information and education about their issues so that they could deal with their problems independently.

I could have used some more information…around these things, especially managing my money.

I would have wanted my therapy to deal with daily issues like budgeting and work. I'd like more education on these issues…

The Characteristics of Help Young Adults Want

In describing what they liked about their help, significant numbers of our cohort wanted the kind of help that:

- was readily available
- focused on improving their functioning instead of symptom reduction
- had staff that listened to them and took them seriously
- helped coordinate their care

Readily Available: Some individuals did not think that enough help was available, or that the service providers did not help them quickly enough. Comments included:

I need to see someone more often. I only saw the psychiatrist every two weeks. I needed more appointments.

They take too long, so a lot of people don't get what they want.

Focused on Improving their Functioning Instead of Symptom Reduction: Many of the young adults also said that the help they had received had met their needs effectively. For example, one individual who received job-related help commented, *"What I liked about the help I got was that it kept me going and allowed me to experience all of the benefits of working."* Another person who received help dealing with his or her anxiety explained, *"When I got this help, it helped me focus more. I got a job and an apartment, and that was great."*

Conversely, several commented that they did not receive all the skills training they needed:

They should help us become more independent - practical things like picking up job applications, taking more of an active role with us.

I need more help in learning skills to manage money, to learn to take care of myself, maybe to live on my own.

Staffed with People Who Listen: When asked what they liked about the help they received, many of the young adults were enthusiastic about the interpersonal support that workers at the different service agencies had given them, with several saying that staff had "*been there"* for them. As one person noted: *"It was good to talk to someone [staff] who wasn't personally involved. They can be more objective."* Another noted: *"I've started getting the help I've needed and have a good therapist now who really listens to me.*

Others explained that they had dealt with staff members who not respect them or did not care:

> *I wish they cared more and paid more attention to me and had more of a focus on recovery.*
>
> *...I don't like being bossed around by staff.*

Coordinated Care: Providing connections to other facilities and services was another common form of help supplied by the mental health service providers. These services helped the young adults by referring them to other services, setting up appointments, and providing transportation to destinations ranging from hospitals to job interviews:

> *... They hooked me up with an evaluation, either with a shrink or [with] someone who could refer me to other services.*
>
> *Young adult staff drove me to the hospital when I was having a problem ...*

Young Adults' Interest in Advocacy Activities

The previous pages show that Massachusetts's public mental health system does not meet the needs of youth transitioning to adulthood. While researchers have made strong efforts to bring this issue to the forefront, effective policy change is not likely to take place until the youth voice is at the table. (Davis, State Efforts to Expand Transition Supports for Adolescents Receiving Public Mental Health Services, prepared for the National Technical Assistance Center for State Mental Health Planning (NTAC), at page 34, cited as NTAC study supra) As such, CQI interviewers explored this possibility with young adult respondents by asking them about their experiences, needs, and interests related to advocacy.

Young Adults' Advocacy-Related Experiences

Although all 24 respondents said they thought that services would improve if policy makers listened to them, only seven (29%) had been involved in planning decisions that might affect their service delivery. As members of advisory councils and participants in group home

meetings, these individuals had been given the opportunity to advocate for themselves and their needs. All but one of these seven individuals believed that their advocacy and involvement in planning decisions had made a difference in their services.

Young Adults' Advocacy Needs

CQI interviewers used two different types of questions to assess the respondents' advocacy needs. First, the interviewers asked the respondents "What kinds of help do young people need to become advocates"? While five of the young adults were unsure how to answer the question, nineteen had some ideas, with two complementary themes emerging: 1) youth will have to be able to "speak up" for themselves directly to policy makers, and 2) specific education and training activities would be necessary to make that happen.

Thus, nine respondents stated explicitly that young advocates would have to "speak up" and "be heard. They said that advocates need to *"Stand up for themselves so they can voice their opinion,"* and "*make sure they're listened to and taken seriously."* They also understood that advocates would have to overcome stigma and other obstacles before others would listen to their messages. As several commented:

> *We need to know how to speak up for themselves. We need confidence. We need to know that if we fight we can win and that the fights are worth fighting.*
>
> *Some young people might also need training in public speaking, depending on their proficiency in that area.*
>
> *There's a huge stigma to people receiving mental health services… They need help overcoming the stigma first so they can build up their self-esteem and learn skills to become leaders and advocates.*

A variety of advocacy skills training needs were identified by respondents to help people learn to "speak up and be heard." These young adults recognized that advocates needed confidence, writing abilities, and public speaking skills; as one person commented: *"we need to know how to make a point cohesively and not combatively."* Other advocacy training needs listed by the respondents included lessons on *"dressing up,"* identifying advocacy issues, and running an organization. As one person noted: *"We would need help getting up and running and learning how to manage things."* A few respondents thought that the best instructors for this training would be *"people who want to work with people with mental illness."* As one person noted *"It helps if they've experienced things first…been hospitalized or been in a residential program."*

Several individuals felt that advocates would need to be educated on the mental health system and psychology because as one person put it: *"[I need to] know better than 'the man' so I can play 'devil's advocate.'"* Some others commented:

[Advocates] need basic psychological training so that they understand how a therapist might see a situation.

[Advocates need] training about what social services are.

[Advocates] need to learn about issues young people face so that they can be as non-judgmental as possible.

After respondents talked about the help that young adult advocates needed, interviewers presented them with a menu of support options that might help young adults become advocates and leaders. Respondents rated the importance of each support option on a five-point scale:

Advocacy-Related Help	N	Absolutely Necessary	Very Important	Important	Somewhat Important	Not Important
I. A **mentor** or mentors who can give help and feedback on projects	24	46%	25%	21%	8%	0%
II. Some **money** to pay for transportation, food, and other costs of doing advocacy	24	42%	13%	33%	13%	0%
An **organization** of young people who work together on advocacy	24	29%	33%	25%	13%	0%
Informational sessions on how the service system works	24	29%	25%	37%	8%	0%
Informational sessions where young people learn how to advocate	24	25%	37%	33%	0%	4%
Gatherings of young people where the group chooses top priority issues to work on together	24	29%	25%	37%	8%	0%
III. **Transportation** to events	24	42%	17%	21%	21%	0%
Peer support for young people who become advocates	23	22%	26%	30%	22%	0%
Training that brings out the strengths of each person	24	21%	42%	17%	17%	4%

IV. **Training** that teaches **politica**l skills on how to make change in service systems	24	12%	21%	33%	25%	8%
Training that teaches skills such as facilitating and chairing **business** meeting	24	12%	21%	38%	12%	17%

As the table above demonstrates, a majority of consumers were very excited about the possibility of having a mentor(s) give them "help and feedback," with almost half feeling it was "absolutely necessary." In addition, young people felt strongly that they would need to have "information sessions," "gatherings" and perhaps and "organization" that would support their advocacy, as well as "money." On the other hand, certain words we used appeared to turn some of our young people off to advocacy participation, such as "training," "political," and "business." It thus makes sense not to use these terms in recruiting youth advocates, but instead emphasizing the guidance they would receive from more experienced adult advocates.

Young Adults' Interest in Advocacy Activities

All but five of the 24 respondents (79%) said that they would like to participate in an advocacy activity. (Of the five who were uninterested in advocacy currently, one indicated that he or she thought advocacy would be *"boring."* The rest said they did not have time for advocacy because of important personal concerns related to housing, jobs, and school.)

When the 19 individuals interested in advocacy were asked the reasons for their interest, several (7) said that their experiences as young mental health consumers made them uniquely qualified for advocacy work because they understood the issues facing other youth and thus *"had a lot to share."* Their comments included:

> *I like giving back what I have learned and I feel I understand the issues well so that I'd want to be part of these things.*
>
> *[I'd do it] so they don't make the same mistakes I did."*

In addition, some respondents indicated they would enjoy the work. One such person explained, *"I like sharing experiences with others."* Another commented: *I'd like to work with younger kids. I know the kinds of help they need.*

When asked what specific advocacy activities interested them, about half of the nineteen respondents talked about the role they might play, either as a peer advocate or peer mentor. These and others were interested in activities that would advance their capacity to take on these roles, such as trainings about peer advocacy and the mental health system, participation in peer support networks, and having the guidance of a mentor.

Although respondents had said that advocacy-related gatherings and organizations were important (see table above), very few individuals were interested in such groups at the time of their interviews. Implicit in this prioritization is the notion that they may not have felt prepared to participate in identifying relevant issues and developing an organization, and a recognition of the need for more experienced adults to help guide them.

Discussion

The findings of this survey give voice to those most affected by the absence of appropriate transition supports: the young people these systems are designed to serve. It should be noted that the voices represented in this report are primarily of those young people who were eventually successful in accessing adult services. It is clear that many young people who need supportive services never obtain them. We can only imagine that their experiences are thus even more arduous than that described by those who were able to access services.

Nonetheless, we have heard loudly from these young people that this is a very difficult time that it is in fact made MORE difficult by the nature of the services and systems that are supposed to help. It is telling that some of these young people expressed RELIEF at not being able to access any services after aging-out because their experience of the child system had been so onerous that no services were preferential to what they had experienced. Overall, the experience of aging out was one of unnecessary confusion and fear.

From their perspective the existing process of aging out could have been greatly improved by several factors:

1) Help in developing the skills for independent living before and after reaching the aging-out ledge.
2) Knowledge about what to expect, both in terms of written/verbal information and experience (i.e. visiting their future home, meeting some of the other folks there in advance, beginning work with a new case manager while still working with the old).
3) Attention to THEIR goals, rather than the system's goals.
4) Connections with others going through or who have already gone through a similar experience.

These young adults also identified the most common domains of help that they desire: getting and keeping desirable employment, handling their psychological difficulties, finishing school, finding and keeping friends, independent living skills and housing, budgeting, and family relationships. The child system has expertise in some of these areas, such as finishing school and family relationships, while the adult system has expertise in other areas such as employment and housing. Clearly the two systems need to work together, and to work with other systems, such as education to help these young people achieve their goals.

The need for the adult and child mental health system to work in concert was also highlighted by the descriptions of the aging-out process. These young people were forced to leave their residential setting, whether it be IRTP or group home, to enter an "adult" setting, not because of a change in the services they needed, but rather because of a change in their chronological age. That is a poor reason for change, particularly when the change is handled in such a disjointed and often traumatizing fashion. If the system can't accommodate youth remaining in their residential settings until they no longer need them, then the 'handoff' process needs to be greatly improved, as described above. In addition youth overwhelmingly expressed a desire for greater continuity across the aging-out crevasse. This can be achieved in many ways, depending on the individual situation, but could commonly include facilitating continued contact with helpers with whom they had formed meaningful relationships in the adolescent system as well as friends that they had made in adolescent settings.

Several existing service models are consistent with the suggestions made by these youth and needed corrections implicitly suggested by their experiences, best embraced by the "Youth Development" model:

> "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)

Consistent with the Youth Development model, Clark and colleagues developed the Transition to Independence System (TIPS) for youth with serious emotional or behavioral difficulties. According to TIPS, the youth's "…interests, strengths and values must drive transition planning, services, supports, and treatment. Young people's goals and dreams provide the direction, and young people are empowered to pursue them…. Services… must be individualized and comprehensive… [emphasizing] natural support systems because these are the people who know the young people, with whom they have established relationships…" Transition to Adulthood: A Resource for Assisting Young People with Emotional and Behavioral Disorders, edited by Clark and Davis, Chapter 14, pgs 268, 269 (2000).

This model requires that at the very least:

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

3. There should be a consistent level of support for young people before <u>and</u> after they "age out."

Recommendations

In making the shift to the model described above, CQI recommends that the state initiate and support five initial steps called for by our cohort : 1) Skill-building and education responsive to individual needs, 2) Age Appropriate services/housing, 3) Peer Mentoring, 4) Youth in Transition Website, 5) Development of Youth Advocacy Program.

Independent Living Skill Building, Education, and Vocational Assistance Responsive to Young Adults' Individual Needs

Before Aging Out:

Many of those we interviewed felt that they lacked the appropriate tutelage to pursue their goals and/or make a successful transition to independent living in the community. Most who expressed such concerns were in institutional settings, having received some help prior to leaving, much of which they deemed inadequate. Primary among skills they wanted were money management, applying to and attending universities, finding a job, and in finding appropriate mental health services.

DMH and DSS currently use the PAYA (Preparing Adolescents for Young Adulthood) independent living curriculum for adolescents aged 16 through 19 in residential programs. It is less clear how "public education" occurs for youth in such setting, including the roles local school districts and the Department of Education.

The clear message from this cohort is that skills training and education must be geared to the needs and goals of the youth in a value-based manner, perhaps with the support of a curriculum or manual, but not with a total reliance on it. Such careful guidance creates an opportunity for growth, including learning gained from making mistakes. Interagency collaboration and flexible and unique approaches are critical to bringing this about.

The following fictional scenario is illustrative: Joan struggles with serious emotional disorder in a group home overseen by DMH or DSS. Joan's goal is to attend nursing or medical school. Joan discusses her goals with program staff, a teacher or a mentor, and they decide that chemistry, biology, physics and relating labs will increase her chances of admission to a good pre-med college program. Staff/teachers/mentors work with Joan to identify resources that will allow her to begin to take these courses, certainly in collaboration with the local school district and/or the Department of Education, and provide support to her in her pursuit. If Joan is uncomfortable at her assigned high school or the necessary courses are not available there, a community college may be a reasonable alternative. As such collaboration among at least DSS, DMH, DOE, Medicaid is very important.

Appropriate staff training is critical here as many mental health youth service providers feel they are at a disadvantage with this model, in particular since they often do not have an expertise with dealing with transition aged youth. Dr. Davis recommends that as youth mental health workers take on a role in transition, they receive appropriate training, which might be received from schools or the child welfare system that has more experience in this area. (NTAC, p. 39)

After aging out:

Many of our cohort, regardless of their prior background, were looking for additional or continued skills training. They were interested in acquiring a variety of skills, falling into 4 broad categories:

Survival

-independent living
-housing
-money
-job

Advancement

-school
-vocational training

Relationships/social

-friends
-family
-sexual/romantic

Health

-insurance entitlements
-mental health support
-substance abuse counseling

Opportunities for such skills training are rare. A large majority of youth who have received public mental health service "age out" find that MassHealth is their primary payer for services, which generally does not cover "skills-training." Some do receive DMH case management services, and others benefit from supported employment programs within DMH or MRC. A very small number eventually land in youth in transition housing programs, and an even smaller percentage find their way into youth oriented skills programs.

An example of the latter is Super Employable People (SEP) in Quincy Massachusetts. SEP helps young adults ages 16 to 22 years who have been diagnosed with mental illness make a successful transition into the work force. New members of the program participate in a six-week Orientation program in which they are introduced to the skills they will need to successfully find and maintain employment. Following graduation from the Orientation program, members are welcome to participate in a variety of services including job coaching, peer support, social activities, and our drop-in center.

How a system that supports individual skill building can be created:

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.

Funding

States that have made significant inroads to providing transition supports have uniformly found new sources of funding. The following are the most common approaches. Medicaid funding for Early and Periodic Screening and Diagnostic Testing (EPSDT) program can be used for young people up to age 21, that is to extend children's public mental health services from age 18 to 21 for youth who qualify for EPSDT. Davis, NTAC, p. 37. Mental Health federal block grant funding has been targeted at the development of transition support services, usually with an emphasis on finding alternative funding after a 'grace' period with these funds. Some states have left the finding of subsequent funding up to the providers that receive the block grant funding, while others work within their system to obtain funding; often taking positive outcome evaluation findings to legislatures to bolster arguments for increased funding. Others have blended small amounts of funding from several relevant agencies to build programs. JOBS, described above, combined this approach, blending VRD, child Mental Health, Medicaid and adult corrections funding and subsequently going to the legislature for additional funding armed with supportive outcome findings. Federal grant programs can help fund pieces of the building process, such as consensus building grants from the Center for Mental Health Services (CMHS),

within the Substance Abuse and Mental Health Services Administration. CMHS also recently funded 5 demonstration sites that will develop TIPS-consistent systems of care for youth in transition. Obtaining funding from this grant program in the future would provide significant funding for a pilot site.

In conclusion, direct collaboration amongst DMH, DMH, DSS, DOE and MRC is critical here important, along with a flexible funding approach and creative thinking.

Age Appropriate Services and Housing

Those who were receiving services or living with other young adults spoke to the benefits of programs focused on their age group, and more basically were more likely to stay in services where they felt comfortable and met their social needs as well. Some of those who were in adult group setting spoke to the discomfort being with older adults, with one state hospital patient suggesting that there be a single unit at the hospital for young adults. Several had been in older adult services and dropped out.

As such, DMH housing providers should continue to or plan to have such specialty housing supports and continue to support programs such as Super Employable People. As noted above, MassHealth should consider increasing the age for young people to participate in programs that are family/adolescent focused.

A Youth in Transition Peer Mentoring System

Young adults we interviewed were looking for mentors, both in helping them navigate a difficult transition to adulthood and in gaining advocacy skills. In addition, several of our young adults showed an interest in mentoring adolescents. This sort of theme was consistent across our cohort, whether or not their care had been institutionally based.

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. The mentor is a "peer" in that s/he has experience first-hand with the mental health system and is in his/her twenties; having experienced some success, they offer **hope** to youth who have been in the most dire of circumstances. S/he is a qualified "mentor" in that s/he has achieved a level of independence and community integration, has a sense of duty and responsibility, and receives the requisite training and supervision. In addition, effective peer counseling requires the mentor to possess "… effective interpersonal and communication skills which included empathy, respect, genuineness, concreteness, self-disclosure, a focus on the 'immediate here and now' and the ability to confront."

In general, the process facilitates the adolescent's awareness of independent living options and how to approach certain situations and seeks to motivate confidence in overcoming external barriers that inhibit independence.

The particular responsibilities of a young adult peer mentor are to:

1. In general, to coach, advise, and support
2. To help youth define his/her needs and goals with regard to transition
3. As needs are identified, help the youth find and connect with transition resources, particularly with regard to their housing, vocational, educational, and health care needs and goals.
4. Through building of trust and effective communication, increase youth's assertiveness and self-reliance.
5. If desired, assist youth with use of website and internet so s/he can use it independently to identify resources
6. After the youth has "aged out," assistance with social networks and "fun"
7. If desired, to assist youth with locating an adult mentor (eg., big brother) who will serve as a guide for the youth as his goals become more defined; thus if the person is interested in a legal career, a lawyer might serve as a mentor. (The goal is to establish a network of adults who volunteer will volunteer to mentor youth who have experienced the mental health system, according to the Big Brother model.)

Youth with mental illness reside in a variety of settings, and given the isolating nature of mental illness, a mentor who has experienced this isolation would serve as the best guide for all such youth. (In fact, 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.) In particular, peer transition mentors would 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.

Youth Citizenship Website and Internet Training

The primary purpose of the website would be post and link informational resources that will assist youth and mentors to navigate their transition and provide the "Voice" of young people struggling with mental illness who are facing transition to adulthood or are in that transition. The website would be of great assistance to peer mentors, youth advocates and councils. In fact, young people are often the most experienced in web design and would design the website.

The website would include:

-General information about youth in transition issues, such as skill-building guides

-Available transition resources in Massachusetts, with specification as to what exists in particular geographic and urban areas in the state (vocational, housing, education, health care)

-Advocacy information for youth in transition, including information about advocacy training and positions taken by a youth advocacy body

-Links to peer support resources, such as the Youth in Transition Writing Collective, a

consumer run program that provides youth an opportunity to write their transition experience and have their story posted or published.

Why the Web:

-There is no database that contains resources for youth with mental illness in transition in Massachusetts

-Information on transition and health care generally changes on a regular basis

-The web is now readily available for use, including in public libraries

-Many youth are very comfortable in cyberspace, and in fact find using it empowering.

In addition, it is important for youth in transition to learn how to navigate the Internet to help them make specified searches in order to identify resources on their own. Training on the web could also be in part offered by experienced peers.

Training Mechanisms to Support Sustained Youth Advocacy

Ensuring that young people's opinions are heard and considered is essential to developing appropriate and appealing transition services [according to state mental health youth directors which has made some progress in this area]. Many states have found that having a youth advisory group or enabling youth to participate in existing mental health groups had a positive impact on service provision. NTAC study (page 34).

This "Systems advocacy" is conducted by a group of individuals who get together to represent, challenge or campaign on issues that affect other individuals or groups. Beside the actual advocacy issues that the group is involved in, group development principals must be implemented to ensure that the structure is strong and will last into the future. It is this kind of advocacy that is critical to sustaining good transition practice.

The primary purpose of a youth advocacy training is thus to provide adolescents and young adults with the skills and support to work as a team to offer input on how services are offered. Graduates are ready to serve on councils or boards that influence policy, raise public awareness of their concerns, and develop workplace transferable skills.

For adults in Massachusetts, M-POWER offers systems advocacy training components, including:

-identification of issues the group can and should raise with policy makers

-making effective presentations to boards or policy makers

-evaluation of strategies to bring issues forward

-negotiation skills

-effective follow-up of advocacy actions

-education modules

-presentation of data

-citizenship training

Collaborative efforts to develop this youth voice will be essential.

Moving Forward

State legislators recognize the need of integrated systems of care that respond to the needs of families and consumers. A comprehensive state law passed this year in fact requires that the state agencies mentioned in this report take steps to establish plans to make this a reality.

In addition, while Massachusetts in 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.

Finally, although this study has been completed, we encourage that the Commonwealth continue to support the voice of youth in planning the service system and programs, as that is integral for effective systems change.