Paving the Way for a New Day for Young Adults in Ohio's Mental Health System

Prepared by:
- Patrice Fetzer, LISW, Community Services of Stark County, Inc.
- Terre Garner, Executive Director, Ohio Federation for Children's Mental Health
- Rick Shepler, Ph.D., PCC-S, Center for Innovative Practices
- Jonas Thom, MA, PCC, Ohio Coordinating Center for ACT
- E. Kelly Firesheets, MA, Ohio Coordinating Center for ACT
- Transition Advisory Group
- With funding support and partnership from the Ohio Department of Mental Health

Transitional youth are the ones in need of the most help because they are at the point in their life where they can either drown in poverty and depression or get the help they need to turn their life around to become productive members of society… Transitional youth need the most funding, the most care and attention. Laws that are keeping this from happening need to change.

—quote from an Ohio young adult with a mental illness who participated in the Transition Advisory Group

This position paper was written to help build consensus around the issues and solutions for transition-age youth served by the mental health system in Ohio. This consensus building process will generate an action plan to support seamless treatment and support services and improved outcomes for transition-age youth. The information provided in this paper is not conclusive, but rather is to be used as a tool for further discussion, research, and planning.

Transition-age youth are adolescents and young adults who have a diagnosable mental illness that has led to impaired functioning in one or more life domains. Examples of life domains include housing, education and employment, functioning and life skills, quality of life, and others. Developmentally, transition-age youth are interdependent, seeking their own identity and independence while still partially dependent on the support of family members, caregivers, and service providers. Complicating this, caregivers and providers have different expectations for the levels of support and services transition-age youth need. At the same time, it is essential that all planning, policy decisions, and programmatic activities be inclusive of and driven by the population they are intended to support: transition-age youth and their families. In addition, mental health service providers use different diagnostic criteria for adults versus adolescents, which ultimately results in gaps

Contents

in services for many youth who were once treated in the child system.

The ultimate outcomes of not providing appropriate service and support options to transition-age youth include increased symptoms of their mental illnesses, homelessness, criminal justice involvement, and alcohol and other drug use and decreased vocational functioning. The direct and indirect costs to the young adult, their families, and the community are significant. We can tell many anecdotal stories of the effect of limited services. However, it is also important to have statewide data that can guide the development and implementation of policies and practices that decrease costly outcomes.

While developing this paper, we identified promising programs and experts available within Ohio's mental health network. These resources can support services for transition-age youth by developing learning communities and networks. In addition, evidence-based and promising practices that Ohio currently supports—such as Assertive Community Treatment (ACT), Supported Employment (SE), and Intensive Dual Disorder Treatment (IDDT) for adults, and High Fidelity Wraparound, Intensive Home Based Treatment (IHBT), and Multisystemic Therapy (MST) for adolescents—can also meet the needs of this population.

In this paper, we present an overview of transition-age youth in this paper. We also discuss promising practices and policy guidelines. Finally, we present recommendations to improve the transition between the child and adult mental health systems and to improve access to care for transition-age youth.

Definitions

Best practices for transition-age youth should incorporate the principles of recovery, resiliency, and cultural competence, and most importantly be youth-guided and family-driven.

Transition-Age Youth

Definitions of transition-age youth vary in the professional literature. Many professionals recognize that the transition from adolescence to young adulthood spans the ages of 14–25. Some professionals extend the age of preparedness for independence from parental support until age 30 due to changing societal and economic realities such as later graduation from college, varied employment patterns, and rising costs of living (MacArthur Research Network on Transitions to Adulthood, 2005). Mental health professionals typically define this group as young people who have been diagnosed with a mental illness that impairs their ability to function. For the purpose of this paper, we define transition-age youth as adolescents and young adults ages 16–25 who have a diagnosable mental illness that has led to functional impairments in one or more life domains.

Transitional Services

Transitional services are the services and supports that focus on assisting a young adult in completing the tasks of adolescence and taking on the responsibilities of adulthood. Typical transitional services support young adults as they:

- complete high school or GED program;
- enter and complete post-secondary education or training;
- obtain vocational support or training;
- find housing and work toward independent living;
- develop and maintain adult social support networks; and
- move to the adult mental health system for services. (Davis, Geller, & Hunt, 2006).

These transitional services need to be provided within the mental health system, as mental health symptoms can prevent young adults from completing the tasks needed to prepare for adulthood. Mental health service providers at all levels need to be skilled in the provision of evidence-based clinical treatment options that are effective with transition-age youth.

Recovery

Nationally and at ODMH, recovery is defined as "a personal process of overcoming the negative impact of a psychiatric disability despite it's continued presence." Recovery is based on the premise that, when given hope and innovative programs, people with mental illnesses can live a productive, satisfying life. The nine essential components of recovery include:

- clinical care,
- peer support and relationships,
- family support,
- work and other meaningful activity,
- power and control,
- overcoming stigma,
- community involvement,
- access to resources, and
- education (ODMH, 2007).

Resiliency

As defined by Ohio's Resiliency Project, resiliency is an inner capacity that, when nurtured, facilitated, and supported by others, empowers people to successfully meet life's challenges with a sense of self-determination, mastery, and hope. Resiliency is an ordinary developmental process that is available to all youth and is an expectation and not an exception for youth with significant emotional or

behavioral challenges. The 12 essential components of resiliency include:

- validation and valuing;
- basic needs, safety, and services;
- sanctuary;
- supportive connections;
- hope;
- contribution and participation;
- self-wisdom;
- competencies;
- justice;
- expectations and accommodations that maximize success;
- courage; and
- sense of meaning and joy.

- Natural helping networks—such as neighborhood organizations, community leaders, and natural healers—can be a vital source of support to consumers. These support systems should be respected and, when appropriate, included in the treatment plan.
- The community, as well as the family, determines direction and goals.
- Programs must do more than offer equal, nondiscriminatory services; they must tailor services to their consumer populations.
- When boards and programs include staff who share the cultural background of their consumers, the programs tend to be more effective (SAMSHA, 2007).

Culturally Competent

As defined by the Substance Abuse and Mental Health Serivces Administration (SAMHSA), culturally competent systems of care provide appropriate services that respect the uniqueness of cultural influences to children and families of all cultures. These systems work best within a family's cultural framework or perspective. Nine principles govern the development of culturally competent programs:

- The family, however defined by other systems or entities, is the individual with a mental illness, also known as a consumer, and usually the focus of treatment and services.
- Americans with diverse backgrounds are often bicultural or multicultural. As a result, they may have a unique set of cultural issues affecting their view of mental health treatment that must be recognized and addressed.
- Families make choices based on their cultural backgrounds. Service providers must respect and build upon cultural knowledge as well as the families' strengths.
- Cross-cultural relationships between providers and consumers may include major differences in worldviews. These differences must be acknowledged and addressed.
- Cultural knowledge and sensitivity must be incorporated into program policymaking, administration, and service delivery.

Youth-Guided and Family-Driven

Youth especially need to feel that they are respected and being heard.

—quote from an Ohio young adult with a mental illness who participated in the Transition Advisory Group

In a system of care that is youth-guided and family-driven, transition-age youth and those people they define as important to them drive and guide all choices. Young adults and families have "voice and choice" in services and supports and are considered experts in their own lives. Transition-age youth and their family members should be considered equal partners in the planning and development of any policy that affects them. As youth enter the transition years and begin their journeys toward adulthood, they need to be granted even greater control over the design, development, and implementation of services and supports available to them and their community. Families are a vital component of the support that the youth will need throughout the transition process and, therefore, are to be respected and valued for their contributions.

Overview of Transition-Age Youth

Approximately 20% of U.S. adolescents ages 12–17 suffer from a diagnosable mental health disorder in a given year. A significant majority of these disorders will continue to affect youth as they move into adulthood (MacArthur Research Network, 2005). More than 3 million transition-age youth have been diagnosed with a serious mental illness (www.bazelon.org). We currently do not have data regarding the number and demographics of Ohio's transition-age youth and what services they use. One of our recommendations (see Recommendation #2 on page 15) is to work with ODMH and providers to compile these data. This will allow us to better understand the scope of the problem and to plan solutions.

The number of young adults in need of mental health treatment is larger than the number of young adults actually receiving mental health treatment. For example, about 85% of 9-year-olds who need individual counseling receive it. On the other hand, after age 18, less than half of young adults who need individual counseling receive it. By age 20, only about a third of young adults who need individual counseling receive it (see Figure 1).

Figure 1: Percentage of youth and young adults needing individual counseling for a mental health problem who are receiving it, by age
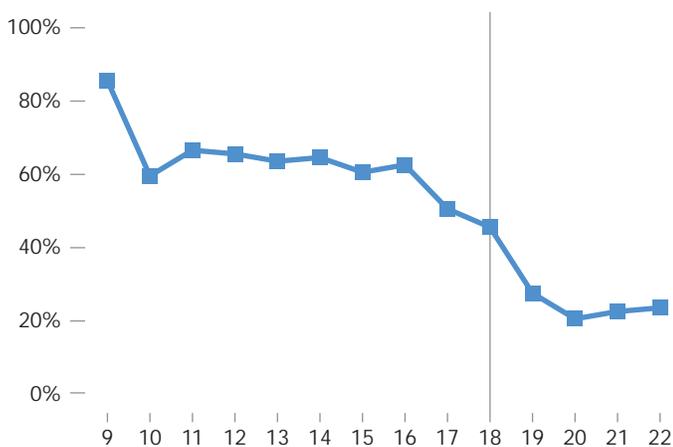
Source: National Adolescent and Child Treatment Study (NACTS)

Historical Perspective

Historically, age 18 has served as a divider between childhood and adulthood. Economic conditions in the early- to mid-20th century allowed most individuals with little or no education to be gainfully employed. Relatively few people completed high school and an even smaller percentage of the population received post-secondary training (US Census Bureau, 2003). As a result, the majority of people achieved financial, and in turn social, independence by their 18th birthday.

Transition to Adulthood in the 21st Century

The 21st century presents new economic and labor market realities and challenges not present in previous centuries. Experts predict that two-thirds

Meet Jessica

At age 6, Jessica was diagnosed with bipolar disorder, obsessive-compulsive disorder (OCD), and attention-deficit/hyperactivity disorder (ADHD). These disorders were further complicated by mild mental retardation and a developmental disorder. Jessica received mental health services from a child-serving agency that included case management, psychiatric care, and counseling services.

When she turned 18, she tried to get similar services from an adult-serving agency. The mental health provider denied her requests because that provider thought that the Mental Retardation/Developmental Disabilities (MRDD) system should meet all her needs. Meanwhile, the MRDD system thought the mental health system should meet her needs.

Between ages 19–22, Jessica was in a psychiatric hospital more than 10 times because she could not get the treatment she needed. A more seamless transition into age-appropriate services and support could have prevented this.

of the new jobs created in the next decade will require post-secondary education (Ohio Business Roundtable, 2006). Earning a living wage with less than a high school diploma is no longer a reality (see Figure 2 on the next page). According to the 2007 *Ohio Health Issues Poll*, 35% of Ohioans with less than a high school education lived below 100% of the federal poverty guidelines (FPG), while only 3% of Ohioans with at least a college degree lived below 100% FPG (Health Foundation of Greater Cincinnati, 2007). In 2006, 100% FPG was an annual income of $20,000 for a family of four.

Figure 2: Percentage of Ohio adults living below 100% FPG in 2007, by highest level of education attained
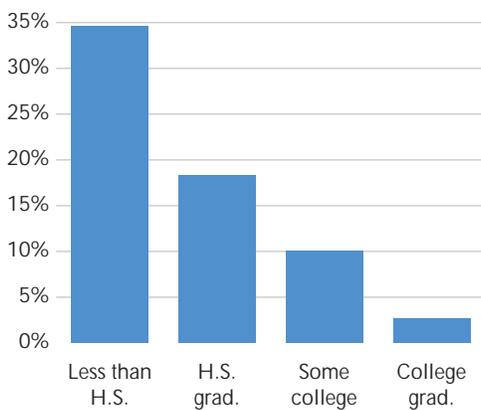
Source: 2007 Ohio Health Issues Poll, The Health Foundation of Greater Cincinnati

Research suggests that relatively few individuals today manage to achieve independence before age 30. In fact, approximately 30% of young adults in the U.S. choose to remain in their parents' home until their late 20s, with the average parent providing more than $2,000 per year in support to each adult child ages 18-34 (Gitelson & McDermott, 2006). Nearly a quarter of the entire cost of raising a child is now spent after the child reaches age 17 (Zvetina & Associates, 2006). However, for many reasons, all young adults do not receive support from their families during the transition to adulthood. Unfortunately, young adults who need the most support may be the least likely to receive it. Researchers estimate that young adults in the top 25% of the family income scale receive three times the support as those in

the bottom 25% (Gitelson & McDermott, 2006). This gap is worse for young adults struggling with mental illnesses.

Developmental Realities of Transition-Age Youth

The transition from adolescence to adulthood is a crucial stage of development in every person's life. The capacity to function in adult roles is determined by the ability to master the critical life skills and rites of passage during the transition. These skills include:

- Completing a high school education or General Education Development (GED) certificate
- Enrolling in or completing postsecondary education or vocational training

Meet Jon

Jon has mental health issues that are complicated by a physical disability and physical health issues. One month before his 18th birthday, Jon and his mother went to a transition meeting at the mental health center that had been treating Jon. At this meeting, the case manager told Jon and his mother that Jon's home visits, psychiatrist visits, and therapy services would stop upon his 18th birthday. The case manager did not provide a plan or referral for continued mental health care.

In addition, Jon and his mother learned that the medical insurance and Social Security payments Jon received following the death of his father would also stop when he turned 18. The case manager did not tell Jon that he could qualify for Social Security Insurance/Social Security Disability Insurance (SSI/SSDI) or Medicaid available to disabled adults. Nor did the case manager offer to help him through the application process, which generally takes 6 months to complete.

No school personnel attended the meeting, and no one offered Jon suggestions for vocational training or job coaching. Jon was left on his own to navigate into adult services and systems.

- Gaining and sustaining employment
- Moving into independent housing
- Forming intimate relationships
- Managing money
- Obtaining reliable transportation
- Learning daily living skills (doing laundry, basic cooking and cleaning, setting up a budget, etc.)

The transition to adulthood is especially challenging for young adults with serious mental health conditions. Whether their mental health conditions began in childhood or presented during their later adolescent years, these young people struggle to complete the developmental tasks required of them. This in turn affects their ability to complete their education, obtain employment, and achieve the skills and supports necessary to live independently (www.bazelon.org). Supporting young adults with serious mental health conditions to not only complete high school, but also to complete vocational or post-secondary education, is essential with today's labor market and economic realities.

Without appropriate services and support, transition-age youth are more likely to drop out of high school, experience difficulty entering the workforce, and fail to gain post-secondary training. Many experience homelessness, poverty, alcohol and other drug abuse, arrests, incarceration, violent relationships, and unplanned pregnancies. We regularly find them in the criminal justice system, child protective system, hospitals, and morgues. Often, they do not show up in the adult mental health systems until they are in crisis, when they need a higher, more intensive and more expensive level of care. By this time, many have burned a number of bridges in their natural support systems, housing options, and other important areas of adult development. They need more costly support to stabilize their lives. Many are never able to reach their full potential once they reach this point.

Cultural Realities of Transition-Age Youth

Respecting the culture of the people we serve is paramount to providing effective treatment (www.mentalhealth.samhsa.gov). The culture of youth is often overlooked in discussions of cultural competency. Adolescent and young adult cultures are distinct from the cultures of children and adults. In fact, youth culture is often misunderstood by adults that serve youth. Youth aspire to increased independence and freedom while still needing the support of adults. On their journey toward independence and identity development, youth take pride in creating "their world," a world separate and distinct from the traditional adult culture.

Youth culture also changes with each generation. Today's youth culture is much different than the youth culture experienced by the professionals treating today's youth. From clothing styles to body piercing to music selections to technology, today's youth--like every previous generation--have developed a culture to call their own. One defining characteristic of their culture is the use of the Internet and other electronic methods to communicate and obtain information and support.

Questions to consider with respect to youth culture in mental health service engagement and delivery:
- Young people prefer to hang out with people who are similar to them. Do we have peer support options available in our service delivery to youth? Do we have young people working at our front desks and peer mentors available?
- Young people spend a majority of their time on computers using e-mail, online communities such as MySpace, and instant messaging. Do we use these modes of communication as a way to advertise our treatment options or as appointment reminders?
- Most young people carry cell phones and many would rather receive a text message than a phone call. Do we text message appointment reminders?

- Young people love their music and usually come into counseling offices with MP3 players or iPods™. Do we talk to them about what they are listening to or just ask them to turn it off?
- Young people love video games. Do we have video games available in our waiting rooms and our counseling offices or do we just have parenting and child development magazines and a toy box?

What Today's Transition-Age Youth Want

What do today's young adults say they want and need from their mental health services and supports? When we take time to listen to them, we find that they speak a common language with common themes that make sense.

In Stark County, Ohio, at a recent intergenerational conference, young people shared their desire to create a Teen Center that they could call their own—a place where they would set the rules and hire primarily young people as staff. They not only want mental health and alcohol and other drug abuse services, they also want a variety of recreational options, leadership classes, life skill classes, employment services, and connections to other resources.

At a recent youth and young adult forum held in Columbus, young people from around Ohio told us they are interested in the following services and support from their mental health system:
- Coordinated services available through a "one-stop shop" that provides services for basic, college entrance and employment, leadership training, and alcohol and other drug and mental health needs
- Leadership development that includes empowerment and advocacy skills
- Peer support, such as mentors, advocates and system navigators, groups, activities
- Socialization opportunities and activities (places to go, things to do) to help them integrate into society

- Inviting atmosphere at service agencies
- Assistance with getting medical insurance
- Web site or a laminated, pocket-sized card that keeps them informed of the community resources and activities available
- College application and entrance support as well as support when accepted into college
- Transportation assistance, such as bus passes to get to appointments or driving lessons, as many public schools no longer provide them
- Housing options
- Employment assistance, because as some youth said, "We do not want to depend on SSI," and "We need decent wages and benefits"
- Caring staff who respect and listen to them and inform them of the options available
- Trained staff who are consistent and trustworthy
- Smooth transitions to new services so that youth do not have "to wait for weeks or months and…retell our story"
- More choices and options as well as respect for self-determination
- More education related to medication, because, as youth said, "We don't want to be 'zombies' or be left with irreversible side effects"

Young people from across the nation with serious emotional disturbance or severe mental illness shared that they prefer the following areas of assistance (Seeking Effective Solutions, 2007):
- Finishing school and career training
- Finding a decent job
- Learning independent living skills
- Managing and living within a budget
- Finding an affordable, safe, and comfortable home
- Dealing with their family issues

Barriers to Transitioning from Child to Adult Services

Transition-age youth face many barriers which prevent them from obtaining the mental health services and supports they need. They are caught between distinct child and adult mental health

systems separated by different policies, funding structures, and diagnostic and eligibility criteria. Barriers to receiving adequate care include different diagnoses and treatment options between the child and adult service systems, lack of medical insurance and other benefits available to this population, and a lack of respect for self-determination and level of supports needed.

Different Diagnostic Criteria

The child and adult mental health systems have different mental illnesses and diagnoses. Child diagnoses tend to be more developmental in nature, while adult diagnoses tend to be more biological and chronic in nature. Both systems have one overarching category that includes the severe mental illnesses for their consumers. In the child system, severe mental illnesses fall under the category of serious emotional disturbance (SED). In the adult system, severe mental illnesses fall under the category of severely mentally disabled (SMD). A youth diagnosed with SED in the child mental health system does not often meet the criteria for SMD in the adult system. In addition, each system recognizes some diagnoses that the other does not. For example, the adult system does not recognize child diagnoses such as Conduct Disorder, Oppositional Defiant Disorder, and Attention Deficit/Hyperactivity Disorder (ADHD). However, these child diagnoses are often precursors to more severe adult diagnoses (Davis, 2005), especially if left untreated.

In some cases, young people experience their first onset of symptoms for adult diagnoses such as Bipolar Disorder, Schizophrenia, and Major Depressive Disorder during childhood or early adulthood. The child mental health system will treat these diagnoses. However, some young adults with an adult diagnosis do not meet the criteria necessary to access adult services, even though they may have received services from the child system. The majority of young adults who have received services from the child system cannot get the same level of service in the adult system, if they can get any services at all. Regardless, transition-age youth

still need access to treatment when they age out of the child mental health system. This will help them move into adulthood and prevent impairments affecting how they function in their daily lives. By getting treatment, the youth increase their likelihood of achieving their full potential.

Insurance and Income

Help us with employment and medical benefits so we do not have to turn to breaking the law to survive.

—quote from an Ohio young adult with a mental illness who participated in the Transition Advisory Group

By age19, a young adult typically loses whatever health insurance coverage he or she may have had. Some parents" policies will cover dependent children until they graduate from college or age 24 if the child is a full-time student, whichever comes first. Young adults often cannot afford private health insurance on their own but also do not qualify for public insurance. In Ohio in 2007, 23% of adults ages 18–29 were uninsured, compared to 14% of adults ages 30 and older (Health Foundation of Greater Cincinnati, 2007; see Figure 3).

Figure 3: Percentage of Ohio adults currently uninsured in 2007, by age
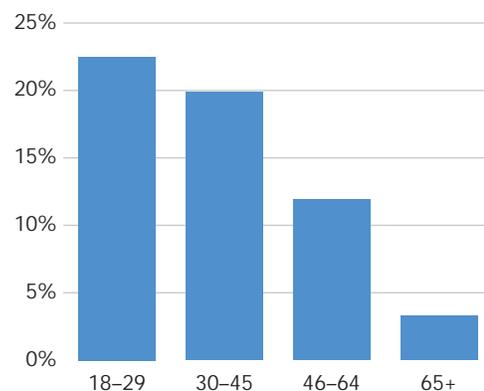
Source: 2007 Ohio Health Issues Poll, The Health Foundation of Greater Cincinnati

Young adults also typically earn less money than adults ages 30 and older. This is most likely because young adults may still be in school and are working part-time, if at all, or because they are working in entry-level positions, which typically pay less. In Ohio in 2007, 21% of adults ages 18–29 lived below 100% FPG, compared to 14% of adults ages 30 and older (Health Foundation of Greater Cincinnati, 2007; see Figure 4 on the next page).

Figure 4: Percentage of Ohio adults living below 100% FPG in 2007, by age
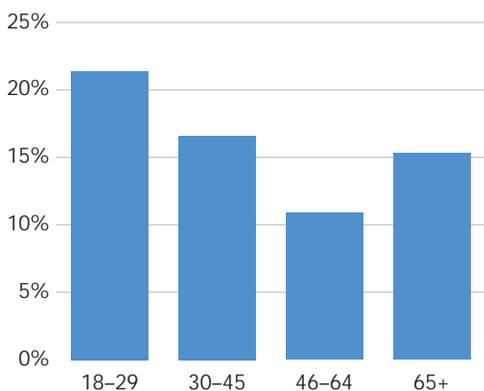
Source: 2007 Ohio Health Issues Poll, The Health Foundation of Greater Cincinnati

Lower incomes and the lack of health insurance can mean high medical debt for many transition-age youth. For example, one 21-year-old man who participated in the Transition Advisory Group is thousands of dollars in medical debt due to a lack of health insurance. Young adults and their families are forced to make the difficult choice between paying for medication and mental health services or paying for rent and food.

Differences in Perspective between Child and Adult Mental Health Systems
Transition-age youth either fail to access or drop out of mental health treatment beginning in their late adolescent years. Many young adults do not feel comfortable in either the child or adult system. Typically, the child system is geared towards younger children, while the adult system is geared towards adults slightly older than transition age.

The mental health system is aware of the need to address developmentally appropriate services and support for transition-age youth. However, it first needs to understand the differences in perspective between the adult and child systems and how transition-age youth fit in both systems.

The child mental health system operates from a developmental perspective, taking into account how a child develops emotionally, intellectually, physically, and socially. This has generally led the child system to be more active than the adult system in recognizing and taking some action to address the developmental treatment needs of transition-age youth. However, the child mental health system often prioritizes the needs of younger children at the expense of adolescents, who are harder to engage in traditional treatment. Also, most child providers do not offer service options to clients beyond the age of 18.

The adult mental health system will accept clients at age 18 if they meet diagnostic criteria. However, the adult system prioritizes services for chronically ill people. If young adults do meet criteria, their symptoms may not be severe enough to get quick access to treatment. Also, traditional adult services do not typically consider developmental stages. Rather adults of all ages are expected to fit into a relatively standard set of service delivery options (Davis, Hunt, 2005). Further, the adult mental health system focuses on restoring skills and capacities, while the child mental health system focuses on building new, never learned skills and capacities (Davis, Stoep, 1996).

Family Involvement
One of the largest hurdles transition-age youth face as they move to the adult system is balancing their new self-determination with how much their families are involved. The child mental health system relies on family involvement to guide the treatment—"We need your parents' signature before we can give you that service"—while the adult system relies on the consumer to guide the treatment—"Your son turned 18 yesterday and

did not sign a release of information so we cannot speak to you"—unless the person is unable to handle his or her own affairs. Transition-age youth need a combination of both: they should be allowed to guide their own treatment with the support and involvement—but not interference—of their family. Service providers in both the child and adult systems could benefit from training on how to engage and respect both the young adult and his or her family members and on how to help everyone balance and respect their changing roles.

As youth journey through identity development and begin to assert their independence, parents, other caregivers, and service providers need to modify their roles to support the youth with the least amount of tension and friction as possible. When young people reach age 18, they still need the support and guidance of their parents, caregivers, and service providers. At the same time, young people need and desire a different type or level of support than they received in their younger years. This knowledge underscores the importance of listening to transition-age youth's voices and choices.

Family members also need support and guidance as their child moves to adulthood. Parents need different skills for parenting young adults versus adolescents versus children, and they often need to amend their skill sets. Furthermore, if transition-age youth have been in residential treatment or foster care, they often return home upon release at age 18 because they have nowhere else to go. Family members and young adults need help reconnecting as the youth rejoin the household.

Anyone serving as custodian or caregiver (not just biological parents) for transition-age youth struggles to achieve a balance between his or her responsibility to care for the youth and the young adults' right to self-determination. Custodians and caregivers of all types still want to be informed so they can help the transition-age youth make good decisions about their own lives, but they are often left out of discussions because the youth is now an adult. At a recent meeting of the Ohio

Independent Living Association (OHILA), an organization made up of professionals and caregivers dedicated to working with youth in foster or custodial care, members shared that they would like improved communication—especially about psychiatric medications and side effects—and better coordination with mental health providers. Members of OHILA would like mental health providers to be more involved in the independent living transition process, especially in residential treatment settings. They reported much confusion about diagnoses and provider changes, which are too often done without consulting with the caregivers or young adults. Members were also concerned that transition-age youth are not empowered to understand their treatment histories or needs.

Housing
Housing is a tremendous barrier for transition-age youth, whether they are moving from residential treatment, foster care, or their family homes. Not surprisingly, this is the age when homelessness begins for many of these youth. This should be a time when efforts are directed at preventing homelessness as a way of reducing costs associated with chronic homelessness among the mental health population. The Corporation for Supportive Housing (www.csh.org) is currently gathering research and promising supportive housing practices for transition-age youth that warrant consideration. Members of the OHILA have also expressed great concern over the lack of supportive housing options for transition-age youth as they move from foster homes, group homes, or residential treatment. Failing to support the development of appropriate housing options for transition-age youth is costly, not only to systems but also to the young adults, their families, and society.

Youth Leadership
The themes of empowerment and involvement resonated with each young adult we spoke with during development of this paper. Young

adults desire to be respected and empowered to participate in decision making and service delivery throughout engagement with the mental health system. Young adults want to serve on forums and committees, to serve as peer mentors and advocates, and to be allowed to play an important role in the betterment of their mental health system. The power and energy of these youth has already been harnessed successfully in a variety of programs. For example, Stark County has successfully used the power of peer mentoring

and advocacy (Clark & Davis, 2000). The Youth Empowerment Program (YEP) of the Coalition on Homelessness and Housing in Ohio (COHHIO) has trained numerous youth in cities throughout Ohio to advocate and participate in policy change efforts that affect them (www.cohhio.org/ programs_YEP). The benefits of empowering young adults and giving them opportunities to serve in our mental health system far outweigh the costs involved in training them.

Failing to Adequately Serve this Population Is Costly

Failing to adequately serve transition-age youth is expensive to society. If they are not supported in achieving their goals while receiving the proper medications and treatment to manage their symptoms, transition-age youth fall into situations that result in higher costs than the provision of appropriate services. For example:

+ Only 10% of adults with serious mental health needs are employed. This is the lowest employment rate of any group of people with disabilities (Herman, 2006).

+ Over 60% of young adults with a serious mental illness are not able to complete high school. They are often unemployed, unable to continue their education, and lack the skills necessary to live independently (Bazelon Law, 2004).

+ Transition-age youth with a serious mental illness have higher rates of alcohol and other drug abuse than any other age group of people with mental illness. They are also three times more likely to be involved in criminal activity than their peers without a mental illness (www. bazelon.org).

The National Technical Assistance Center for Youth in Transition found significant differences in the areas of dropout rate, employment, post-secondary education, independent living, and arrests between youth with mental illnesses as compared to the general population of youth (see Figure 5).

Figure 5: Percentage of the general population and of youth with SED with the following outcomes
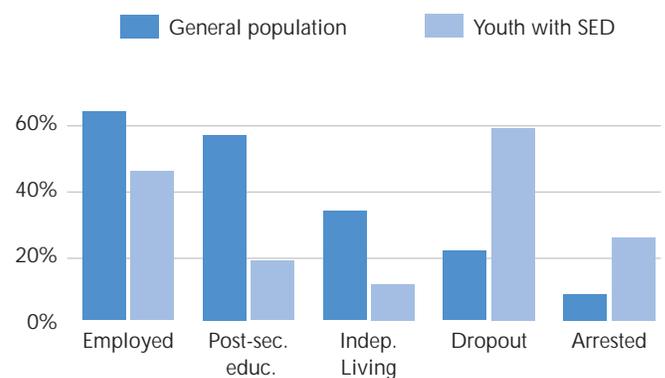
Source: National Technical Assistance Center on Youth in Transition

Promising Practices for Transition-Age Youth

President's New Freedom Commission on Mental Health

Among many mental health issues, the 2003 President's New Freedom Commission on Mental Health addressed issues pertinent to transition-age youth. The Commission's recommendations call for improved cultural and developmental competence of mental health service providers, increased access to early diagnosis and treatment, increased access to supportive employment and housing services, and improved coordination of care among systems. The Commission's Vision Statement said that "We envision a future when everyone with a mental illness will recover, a future when mental illness can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports- essentials for living, working, learning, and participating fully in the community."

Center for Mental Health Services Recommended Policy Guidelines

The following Policy Guidelines (Davis, 2006) are supported by the research literature, promising practices, and an expert federal policy review by the Center for Mental Health Services (CMHS) as recommendations to better address the needs of youth and young adults with mental health conditions:

- Provide continuity of services (care) for youth ages 14 to 16 up to youth ages 25 to 30.
- Support the family role until youth reach age 25 to 30.
- Require coordination and cooperation in providing services across the many relevant systems that serve youth in transition.
- Encourage or require a greater availability of a variety of age-appropriate and accessible services across systems so that appropriate,

individualized transition plans and services can be developed and implemented.
- Develop greater expertise among providers and policy makers about transition-age youth to better serve them.

Promising Practice Guidelines

The Transition to Independence Process (TIP) model developed by Dr. Hewitt B. Clark at the University of South Florida provides a promising practice model for serving transition-age youth. The mission of TIP is to assist young people with serious emotional disturbance (SED) in making a successful transition to adulthood. TIP wants all young adults to achieve, within their potential, their goals in the transition domains of education, employment, living situation, and community life. Each of the guidelines and the elements have empirical support or broad professional consensus indicating that these are promising practices for use with young adults with EBD and their families (www.tip.fmhi.usf.edu). Agencies that have implemented the TIP model have shown improved outcomes in employment, high school and post-secondary education, mental health, and alcohol and other drug abuse (Seeking Effective Solutions, 2007). The TIP model uses seven principles to drive treatment and provide a framework for support by the mental health system and the community. The seven principles are:

- Engage young people in a relationship with a caring, responsible adult to plan for their own future.
- Tailor services and supports to be accessible, coordinated, developmentally appropriate, and build on strengths.
- Respect young people's developmentally appropriate search for independence and social responsibility by acknowledging personal choice and their need to find their own way.
- Ensure a safety-net of support, including family, to reduce risks.

- Strengthen young people's competencies to assist them in achieving greater self-sufficiency and confidence.
- Help the young person maintain a focus on outcomes, and encourage programs and systems to do the same.
- Involve young people, parents, and other community partners in the TIP system at all stages and levels.

The TIP model also suggests that developmentally appropriate services and supports be provided within a continuum of community-based options that address the following transition domains:
- employment and career,
- educational opportunities,
- living situation, and
- community life and personal effectiveness (http://tip.fmhi.usf.edu/)

The TIP model can been effectively used with other evidence-based practices such as Assertive Community Treatment (ACT) Teams, Wraparound, Supported Employment, and Peer-to-Peer Support Models.

Transition Services and Supports in Ohio

Ohio has many innovative services and supports for transition-age youth. An ongoing task and recommendation in moving forward is to catalogue the current mental health services offered for this population. To begin this process, we have created a web site of self-identified providers, advocates, organizations, and boards by county. This site is available at: http://www.ohioactcenter. org/transition.html. In addition, we have started a network list of providers, youth, families, and stakeholders involved in helping this at-risk population.

Transition Services and Supports in Other States

As of the publication of this paper, nine states had specific policies in place for transition-age youth (see Figure 6).

Figure 6: States that have policies for transition-age youth
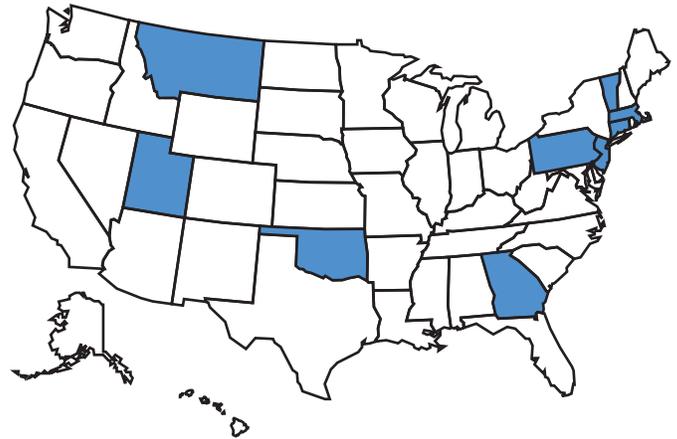
- Connecticut requires that all adult mental health programs provide developmentally appropriate services to young adults (Herman, 2006). Its child mental health system connects 18-year-olds to the adult mental health system where they receive a TIP-based program until age 25 (Herman, 2006).
- Georgia developed a protocol to transition youth into adult services at age 17 (Herman, 2006).
- Oklahoma broadened its eligibility standards so that youth served in the child mental health system are automatically eligible for adult services if they qualify by income (Herman, 2006).
- Montana allows youth to receive services in its child mental health system until age 21. Youth are also allowed into specialized services available in the adult mental health system at age 16 (Herman, 2006).
- Massachusetts and New Jersey made changes to service eligibility and serious mental illness definitions to ease the transition between the child and adult mental health systems (Herman, 2006).

- Pennsylvania's Office of Mental Health and Substance Abuse Services created a transition coordinator position and a Local Transition Coordinating Council that meets regularly to move the agenda for transition-age youth. Pennsylvania has also begun including transition-age youth on advisory committees to ensure that their voices are heard. The state also has used existing training dollars to create a family and young adult training institute (PYT Transition Call, 2007).
- Utah passed a bill to expand Medicaid coverage until age 21 (PYT Transition Call, 2007).

- Vermont offers a TIP-based program that includes intensive case management and employment services for its 16-21-year-olds with serious emotional disturbance (SED). Research has shown that in 2004, this program saved Vermont $687,912 in corrections spending, $42,336 in welfare benefit spending, and $37,911 in social and supplemental security benefit spending in 2004 (Herman, 2006).

Recommendations and Action Steps for Ohio

We developed the following recommendations from feedback from the Transition Advisory Group (TAG), the "Paving the Way for Transition-Age Youth in Ohio's Mental Health System" conference, and the transition-age youth and family and caregiver focus groups.

Recommendation #1: Include youth and young adults in the decision making processes regarding mental health policy, services, and supports for transition-age youth.

Action Steps:
- Create a Youth Advocacy Network in Ohio.

- Establish youth and young adult leadership and advocacy training opportunities in collaboration with Youth Move, COHHIO's Youth Empowerment Program (YEP), and the Ohio and National Federations of Families for Children's Mental Health.

- Establish protocols for supporting of youth and young adults to participate on all local, agency, and state boards and committees that serve youth (training, transportation, stipends).

- Assure that all local, agency, and state boards and committees that serve youth include at least two youth or young adults, as well as a parent or caregiver of a youth or young adult.

- Link and participate with Ohio's A New Day Initiative, the Transformation State Incentive Grant (TSIG) Project, by establishing a content working group specific to transition-age youth.

Recommendation #2: Secure data regarding current service use and demographics of transition-age youth to inform policy review and network development.

Action Steps:
- Secure the following data:
  - Services:
    - » Number of 16–17-year olds and 18–25-year-olds receiving mental health services in Ohio by type
      - ¤ Community vs. institutional setting
      - ¤ Medicaid vs. non-Medicaid services

- Retention:
  - » Number of 16–17-year-olds served vs. number of 18–21-year-olds served
  - » Number of individuals receiving mental health services as youth but not as adults
  - » Number of youth receiving services with a significant gap (3 years or more) in services after age 18
  - » Mandated treatment rates of young adults ages 21–25 who were in services (cannot currently be obtained from MACSIS, the state's information and billing system for the public mental health system)
  - » Number of 17-year-olds who show up in MACSIS at ages 18, 19, 20, 21, and 25
- Cost:
  - » Median, ranges, and top 10% of costs for age ranges:
    - ¤ 16–17-year-olds
      - – Medicaid vs. all MACSIS-billed
      - – Location of services
    - ¤ 18–21-year-olds
      - – Medicaid vs. all MACSIS-billed
      - – Location of services
    - ¤ 22–25-year-olds
      - – Medicaid vs. all MACSIS-billed
      - – Location of services
- Insurance/Payer:
  - » Percentage of 18–21-year-olds served with Medicaid and other insurance
  - » Percentage of 22–25-year olds served with Medicaid or other insurance
  - » Length of time a person who was covered by Medicaid under age 18 spent without coverage before receiving Medicaid again
- Diagnosis:
  - » Prevalence of diagnoses for 16–18-year-olds
  - » Prevalence of diagnoses for 19–25-year-olds
  - » Percentage of diagnoses changes for young adults ages 17–22

Recommendation #3: Use data to help identify needs and create an overarching transition-age youth policy.

Action Steps:
- Enhance services to:
  - Decrease chronicity
  - Better use of recovery tools
  - Better use of services and supports in the right amount, the right type, for the right amount of time
- Engage transition-age youth and other stakeholders to:
  - Clarify roles, rights, and responsibilities from all perspectives within mental health system (consumer, provider, administrator, policy makers)
  - Organize ourselves (rights, roles, and responsibilities) before we engage with others in preparation for cross-system work

Recommendation #4: Convene a workgroup to address differences between child and adult mental health systems.

Action Steps:
- Promote a dialogue between child and adult mental health systems regarding philosophic and service provision differences.
- Identify the overlap of resiliency and recovery.
- Define how family support and involvement are different in the child and adult mental health systems.
  - Family involvement as it relates to self-determination
  - What level of support is mutually acceptable that leads to success?
  - Delineate developmental differences for providers
- Structure and fit of mental health system in regards to transition-age youth and other social services and institutions.

- Define overarching goals for transition-age youth policy
  - Better outcomes earlier
  - Promotion of recovery and resiliency
  - Decrease chronicity: e.g. decrease hospitalizations and incarcerations
  - Increase employment.
- Different definition of "need" and "treatment and services" between child and adult mental health systems.

Recommendation #5: Establish clear continuity of care expectations, guidelines, and consistent protocol for transfer from child to adult mental health services.

Action Steps:
- Develop transfer documentation to support smooth transition from child to adult systems.
- Establish expectations for child provider to remain active and supportive in transfer process for a specified period of time in order to ensure that connection with the adult provider is both secured and effective.
- Design child and adult mental health system cross-training to include promising practice strategies for serving transition-age youth.
- Establish tracking expectations at local board and agency levels to monitor transitions between child and adult systems

Future Action Steps:
- Multi-system cross-training (education, vocational, courts, Job and Family Services, MRDD)
- Establish networking opportunities in local communities and across state for providers, parents, and young adults
- Develop and use of common and appropriate language

Recommendation #6: Establish a learning community or network to develop resources and training for child and adult mental health providers that serve transition-age youth.

Action Steps:
- Develop means for facilitating communication among providers, funders, youth, and families.
- Develop resources for training and best practices integrated into Ohio's existing Coordinating Center of Excellence (CCOE) structure
- Develop training and coaching for all child mental health providers serving youth ages 16 and older as well as all adult mental health providers that serve 18-25-year-olds.
- Work with ODMH and other stakeholders to facilitate transition-age youth policy.
- Facilitate the workgroup detailed in Recommendation #4.

Recommendation #7: Review ODMH policy to ensure the inclusion of the developmental, cultural, and service provision considerations of transition-age youth.

Action Steps:
- Review certification standards
- Review funding mechanisms
- Engage Multiethnic Advocates for Cultural Competence (MACC)
- Engage CCOEs and networks
- Engage all advocacy organizations

References and Resources

Web Sites

- Transition to Independence (TIP) Model
  - http://tip.fmhi.usf.edu
  - http://ncyt.fmhi.usf.edu
- Jim Casey Youth Initiatives
  - www.jimcaseyyouth.org
- Transition Funders Group
  - www.ytfg.org
- Transition Recommendations/Publications
  - www.nasmhpd.org
  - www.bazelon.org/issues/children/factsheets/transition.html
  - http://promisingpractices.net
- Search Institute's 40 Developmental Assets
  - www.search-institute.org/assets/
- SAMHSA's National Mental Health Information Center
  - http://mentalhealth.samhsa.gov/
- Corporation for Supportive Housing
  - www.csh.org
- Youth Empowerment Program (YEP)
  - www.cohhio.org/programs_YEP

Articles and Reports

Clark, H.B, & Davis, M. (2000). Driving the system through young adult involvement and leadership. In H. B. Clark & M. Davis (Eds.), Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties. Baltimore, MD: Brookes Publishing.

Davis, M. (2005). State Efforts to Expand Transition Supports for Young Adults Receiving Adult Public Mental Health Services: Report on a Survey of Members of the Children, Youth and Families Division of the National Association of State Mental Health Program Directors. Prepared for the National Technical Assistance Center for State Mental Health Planning (NTAC). Published online: http://tinyurl.com/39g7ju

Davis, M. & Koyanagi, C (2005). Summary of Center for Mental Health Services Youth Transition Policy Meeting. Published online: http://www.umassmed.edu

Davis, M, & Vander Stoep, A. (1996). The Transition to Adulthood Among Adolescents Who Have Serious Emotional Disturbance. Report prepared for the National Resource Center on Homelessness and Mental Illness. Published online: http://tinyurl.com/2n4vk4

Grantmakers Health (November 6, 2006), Adolescence to Adulthood: Crossing the Threshold.

Greenbaum, P. E., Dedrick, R. F., Friedman, R. M., Kutash, K., Brown, E. C., Lardieri, S. P. & Pugh, A. (1996). National Adolescent and Child Treatment Study (NACTS): Outcomes for children with serious emotional and behavioral disturbance. Journal of Emotional and Behavioral Disorders, 4(3), 130-147.

Herman, M. (September 2006). National Conference of State Legislatures Policy Brief: A Difficult Passage: Helping Youth with Mental Health Needs Transition Into Adulthood.

Health Foundation of Greater Cincinnati, The (2007). Ohio Health Issues Poll. Cincinnati, OH: Author.

MacArthur Research Network on Transitions to Adulthood. (2005). Adolescence and the Transition to Adulthood: Rethinking Public Policy for a New Century. Conference overview available online: http://tinyurl.com/2w64y7

Davis, M., Johnsen, M., Koroloff, N., Starrett, B. E., McKay, C., Pullmann, M., Sondheimer, D., & Gordon, L. (2005). Where are Bridges Needed? Report on the Interrelationships of Agencies in a Center for Mental Health Services Partnerships for Youth Transition Grant Site. Report prepared for the American Institutes for Research under contract to the Center for Mental Health Services,

Substance Abuse and Mental Health Services Administration. Published online: http://tinyurl.com/2ttezo

National Adolescent Health Information Center. (2004). Issue Brief: Best Practices. San Francisco, CA: National Adolescent Health Information Center, University of California, San Francisco. Published online: http://tinyurl.com/2kk2au

Ohio Business Roundtable (May 2006). The Talent Challenge: What Ohio Must Do To Thrive, Not Merely Survive, in a Flat World.

Report of Ohio's Mental Health Commission (January 2001). Changing Lives: Ohio's Action Agenda for Mental Health.

U.S. Department of Labor, Bureau of Labor Statistics (1999).

U.S. Bureau of Census (2002).

Other Resources

Funding Options

- The John D. and Catherine T. MacArthur Foundation developed the Network on Transitions to Adulthood to research policies and programs that support young people as they move into adulthood.
- The William T. Grant Foundation has devoted considerable resources to researching the transition to young adulthood.

Research

- Chapin Hall Center for Children at the University of Chicago
- The MacArthur Research Network on Transitions to Adulthood and Public Policy

Appendix A: Themes from the April 2007 Transition Advisory Group Meeting

- Bring attention to the issues in order to drive policy
- Identify challenges facing this population
- Lengthen process/broaden cushion of transition
- Form a foundation on which to build this transition bridge
- What can we do from a mental health system perspective for this population?
- Considerations to the developmental perspectives
- Build on/collaborate with work that is already being done around this issue
- Increase our political voice for this population
- Raise awareness/create excitement
- Recognize the issues/problems
- Access and disseminate data/numbers (regional and statewide)
- More collaboration/transition between agencies (i.e. – youth to adult services)
- Proactive planning vs. emergency planning (i.e.-connecting to vocational or housing assistance when graduating in a few weeks)
- Make vocational services a priority for this population (sustaining employment is a challenge for this population)
- Resource guide—what is available in each of our communities for this population
- Dissemination of information to various newsletters
- Service levels

- Address diagnosis differences/eligibility factors between child and adult systems
- Consider overlap of child and adult services for a 90-day period for purpose of transition
- Cross training, curriculum development (i.e., learn individual system limitations/differences)
- Use appreciative inquiry for system change efforts
- Integrate cultural competency into this work
- Address dual diagnosis issues/special populations (MRDD, alcohol and other drug treatment providers should be at table)
- Address juvenile detention and jail (both prevention, system/service coordination and re-entry)
- Need age appropriate housing (noticeable increase in homelessness)
- Need supports for college planning and successful integration/adaptation into college expectations/responsibilities – college is so important to success in today's world
- Expand medical coverage for this population/ Pass Medicaid buy in (allow them to work and maintain medical benefits)
- Need "real" life education/preparation/ coaching ("show us, don't just tell us") – walk them through necessary life skills
- Money management education and supports (credit issues, taxes, rent)
- Teach recovery management – disseminate resources that support this
- Teach how to deal with change
- Teach how to fill the day/stay busy

- Include family in service/support planning and delivery
- Stop focus on labeling people
- Be considerate of language (how we refer to young people—they are not "kids")
- Provide peer supports for this population
- Use peer supports as "tourist guides" to maneuver the service/supports maze in their communities
- Need services and supports (e.g., peer supports) that can teach social skills and provide socialization opportunities
- Teach adult providers to work with schools, educational plans, and education supports
- Teach adult providers to work with families
- Improve transition and access to age-appropriate therapists and psychiatrists
- Determine caseload size that leads to maximum effectiveness

Quotes from the day:
- "Nobody in this room knows an 18-year-old (personally or professionally) who was ready to be on their own without supports"
- "Once you become an adult, you have to"
- "Show us, don't just tell us"
- "Help us with employment and medical benefits so we do not have to turn to breaking the law to survive"
- "Do away with labels"
- "Needs don't change at age 18"