



# nami *Beginnings*

Summer 2006 ★ Issue Eight

A Publication Dedicated to the Young Minds of America from the NAMI Child & Adolescent Action Center

## Negotiating the Transition-Age Years

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to Adulthood**

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# Capitol Hill Watch

by **Darcy Gruttadaro, J.D.**, Director, NAMI Child & Adolescent Action Center

## National Children’s Mental Health Awareness Day on Capitol Hill

**T**he Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMSHA) designated May 8<sup>th</sup> as National Children’s Mental Health Awareness Day 2006. This day was established to promote resilience, recovery and the transformation of mental health services delivery for children and youth with serious mental health needs and their families.

On May 8<sup>th</sup>, NAMI joined a group of national partners that gathered on Capitol Hill for a congressional briefing to celebrate and recognize this special day with a presentation on “Children’s Mental Health: The Key to Achieving in Schools and in the Community.” NAMI was pleased to join a group of national partners that included the Federation of Families for Children’s Mental Health, the National Mental Health Association and the National Association of Social Workers.

The goals of National Children’s Mental Health Awareness Day 2006 were:

- To raise awareness of effective programs for children’s mental health issues;
- To demonstrate how children’s mental health initiatives promote recovery and resiliency; and
- To show how children with mental health issues thrive in their communities.

Michael Fitzpatrick, NAMI’s Executive Director, joined a panel of leaders from the other national organizations and SAMHSA. His presentation focused on NAMI’s work to raise awareness about the critical need to improve

the academic outcomes of students with mental illnesses and to increase access to effective community-based programs.

Charlie Curie, the SAMHSA Administrator, opened the presentations with the following remarks:

“As we celebrate successes today and as we move ahead in improving mental health services for children and their families it is critical to keep two key points in mind. First, the widespread adoption of a public health approach to children’s mental health is needed. The public health model is a population-based approach that is concerned with the health of an entire population, including its link to the physical, psychological, cultural, and social environments in which people live, work, and go to school.

Second, it is important to recognize that as a nation and as a society we have come a long way in better understanding mental illness and its impact on children and adolescents. Research has made extraordinary leaps forward and we have a better understanding of the disorders and the evidence-based treatments, services and supports that build resilience and facilitate recovery for children and adolescents.

The future – the children we serve – is the very essence of today’s occasion ...America’s children can no longer be derailed by outdated science, outmoded financing systems and unspoken discrimination because they have staked claim in the transformation process. Each of you is proof positive of the energy and commitment of our country to do what is right for our most vulnerable citizens.”

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NAMI is a grassroots, family and consumer, self-help, support, education, and advocacy organization dedicated to improving the lives of children and adults living with severe mental illnesses. Severe mental illnesses are biologically based brain disorders that can profoundly disrupt a person’s ability to think, feel, and relate to their environment and others.

NAMI web site: [www.nami.org](http://www.nami.org)  
NAMI HelpLine: **1.800.950.6264**



# The Path from Adolescence to Adulthood

by **Maryann Davis, Ph.D.**, Assistant Professor, University of Massachusetts, Medical School

**T**raveling the path that links adolescence to stable adulthood is a challenge for all young people. They must develop and hone the skills that allow them to function as an adult. These skills allow them to complete school, secure rewarding work, have a stable domicile, engage in long-term romantic relationships or marriage and raise children. It may also include effective parenting skills.

Developing these skills requires a foundation of biopsychosocial maturation which includes the ability to think abstractly (for example, to plan for the future), a moral structure based on the golden rule and the greater good, complex processing of social signals, behaviors, and rules, the development of a mature concept of self in society, and physical sexual maturity.

Youth and young adults must accomplish self-sufficiency in a marketplace that increasingly demands higher education degrees and provides fewer job opportunities for those without those degrees, and often includes minimum wage jobs that are worth increasingly less.<sup>1</sup> Adult milestones of completing school, obtaining a steady job that provides enough income to live on independently, and permanently mov-

ing out of the family home are typically not achieved until age 30 or later.<sup>2</sup> These changes in the transition to adulthood, which have occurred over the past 30 years, have made the transition years far more challenging for youth with serious mental health conditions.

Completing high school or obtaining a general equivalency diploma (GED) only occurs for about half of youth with serious mental health conditions served in public settings.<sup>3</sup> The current job market calls not only for high school completion, but also a college education and beyond, which only occurs for a small fraction of transition age individuals with serious mental health disorders.<sup>4</sup> Employment rates and income are lower in this group.<sup>5</sup> In examining a community-based sample (rather than a sample gleaned from those receiving services), researchers found that young adults with psychiatric diagnoses were roughly four times less likely to be engaged in gainful activities — including employment, enrollment in college or a trade school — than their peers, even when socioeconomic status was held constant between the two groups.

Serious mental health conditions typically persist during the transition period. Adolescents with psychiatric disorders are likely to have those disorders, or develop other disorders in young adulthood.<sup>6</sup> Most young adults with psychiatric disorders had their current disorder or another disorder in adolescence.<sup>7</sup> The transition period is a time of increased risk for the onset of new psychiatric disorders.<sup>8</sup>

Research suggests that transition age youth require significant support from their families and effective services throughout the transition period.

While many families of young peo-


ple with serious mental health conditions are a wonderful and central resource for their young adult child, many other families are less able to provide sufficient support because of limited resources due to low income, single-parenting, the challenges of parenting a child with a serious chronic condition, and parental difficulties.<sup>9</sup> Given the increased demands placed on families by job market changes, it is increasingly important that families of transition age youth be supported in their role of providing a safety net and resources to their young adult children.

## Discontinuity and Inadequate Services

Unfortunately services for youth and young adults with serious mental health conditions are greatly misaligned with need. This happens in part because the transition age spans both the child and adult service systems and combines the shortcomings of each system with the problems of coordinating across the two.

**Few Transition Services.** Youth and parents report a real lack of appealing transition services<sup>10</sup>, even when youth want the services<sup>11</sup>. These reports are consistent with recent studies that we conducted of state child and adult mental health systems<sup>12</sup>. We found that there was a complete absence of transition services in half of adult systems and almost a quarter of child systems. Compared to the standard of access to comprehensive transition services throughout the transition period<sup>13</sup>, most types of transition services, like supported housing restricted to this age group, were offered in less than a fifth of the states. There were no transition support services within adult mental health systems in half of the states. It is unlikely that the lack of transition services in mental health systems is

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NAMI was proud to be part of the inaugural National Children's Mental Health Awareness Day. In May 2007, we will ask NAMI grassroots organizations and a broader group of families to join us in this day designed to celebrate our accomplishments and raise broader awareness about what still must be done. Stay tuned ... 

made up for by other systems. The greatest attention to this population has come from special education<sup>14</sup>. Yet, students who qualify for special education services under the emotional disturbance category fared worse than any other disability group in young adult outcomes<sup>15</sup>. There is little evidence of transition services for this particular group in other human service systems.

**Fragmented Systems.** Child systems are not well connected to adult systems. Eligibility criteria or target population definitions are uniformly different between child and adult mental health systems. The adult criteria are typically more narrow.<sup>16</sup> These policies support the arbitrary loss of services when a youth reaches an adult age. Further connections between the two systems are typically limited, with few lines of communication linking child and adult service systems,<sup>17</sup> and few programs offering any treatment or therapeutic continuity across the adult age threshold.

Current policies do not encourage continuous, coordinated, and appropriate transition supports. In a recent analysis of federal programs affecting this group, the Bazelon Center for Mental Health Law identified fifty-five programs that are run by twenty or more different agencies in nine departments of the Federal government.<sup>18</sup> The fifty-five programs included in the report are quite different in purpose, target population, funding and organization. There has been no attempt to align the programs or their rules. Eligibility differences result in an individual youth being eligible for some programs but not others, or being eligible at one age but not consistently eligible through age twenty-five.

Funding may go directly to states, local nonprofit entities or some combination of public and private entities. As a result, there is not one organization or program serving transition-age youth with serious mental health conditions that is eligible to apply for most Federal programs. Though a significant number of programs are designed to help youth address transition issues, many have substantial drawbacks, including age limitations, financial eli-

gibility criteria, low funding levels, uncertain future funding, broad mandates that may dilute the funds available for this group of youth, and other rules that hamper youth participation.

**Promising Practices**

Clearly greater availability of a variety of age-appropriate services is needed. While the research on our systems and young adult outcomes is growing, research on promising practices has lagged behind.

Several specific and thoughtful approaches to effective transition services have been described, many of which are captured in the book *Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties*.<sup>19</sup> These approaches included supported education, vocational and housing support, service coordination, mental health and substance abuse treatment, and approaches to maximize family and youth involvement in treatment and services. Several of the service approaches were supported by research, though none of them have been rigorously tested.<sup>20</sup> These programs are generally consistent with the conceptual guidelines developed by Dr. Hewitt “Rusty” Clark and colleagues for transition-age individuals with mental health conditions, called the Transition to Independence Process (TIP) system.<sup>21</sup> This model has not been rigorously tested but supportive research is available.<sup>22</sup>

Each of these approaches emphasizes the need for an individualized approach, person-centered transition planning, youth-driven processes, age-appropriate family involvement, and developmentally appropriate, comprehensive, coordinated, continuous services that emphasize the development and support of young adults’ skills and competencies.

Generally, in each approach, the young person works with someone who has specialized knowledge about the age group and the disability. That person also maintains a small caseload. This service specialist also functions much like a wraparound specialist, helping a young person assess their

strengths and needs, working closely with the young person to help them identify and develop goals and then working with a team of individuals that the young person has identified as his or her resource network to develop a plan using person-centered processes. Some of the most innovative approaches use peers of the young adult in the process, to serve as a paired peer-advocate and transition specialist. These approaches emphasize that every step is used as an opportunity for the young person to hone his or her skills in self-reflection, organization, resource identification, communication, self-advocacy, future planning and similar activities, and that the skills needed to realize their goals are identified and developed or refined.

The school failure rate is of great concern to youth with serious mental health conditions. Mary Wagner and I recently reviewed practices related to school success both for a population of youth with mental health conditions and for an “at-risk” population. We identified several dimensions that they share.<sup>23</sup> These included the “new” three Rs that were identified by the Bill and Melinda Gates Foundation for “at-risk” youth. The “three Rs” are *relationships, rigor, and relevance*. Approaches that promote positive *relationships* emphasize the opportunity for students to form meaningful relationships as the foundation for their engagement in school. These include bonds to pro-social friends, teachers, parents, and mentors. Approaches that promote *rigor* offer challenging curricula provided by well-prepared teachers in inclusive environments with the supports needed to help students succeed academically. *Relevance* is achieved by keeping an eye towards “authentic learning” of content and skills that are relevant to students’ interests and future plans, particularly in the area of work.

We have added the following 2 factors to the “three Rs” (1) addressing the needs of the whole child and (2) student and family involvement in transition planning. In reviewing data from a recent nationally representative study of secondary school students in

special education, we found that for students in the primary disability category of emotional disturbance, exposure to best practices (which includes the “three Rs,” addressing the needs of the whole child, and student and family involvement) has improved since the 1980s and is now similar to that of students with other disabilities. Despite that progress, significant opportunity for improvement remains in each of the five dimensions (adoption of the “three Rs,” addressing the needs of the whole child, and student and family involvement in planning).

**Future Directions**

Recently, the Center for Mental Health Services (CMHS) convened a group of experts to review the Bazelon Center’s analysis of federal policy and to make recommendations for changes that are necessary at the federal level to better address the needs of youth and young adults with mental health conditions.<sup>24</sup> The recommendations are consistent with the following policy guidelines, which are also supported by the research literature on the characteristics and needs of the transition-age population and what is known about promising practices.

1. Provide continuity of services for youth ages 14 to 16 up to youth ages 25 to 30.
2. Support the family role until youth reach age 25 to 30.
3. Require coordination and cooperation in providing services across the many relevant systems that serve youth in transition.
4. Encourage or require a greater availability of a variety of age-appropriate and accessible services statewide and across systems so that appropriate individualized transition plans and services can be developed and implemented.
5. Develop greater expertise among providers and policy makers about this age and disability group to better serve these youth.

These policy guidelines suggest some specific changes that should be made at the federal level and also have

**M**indzone is a mental health web site designed specifically for teens. The site was created by The Annenberg Foundation Trust and all content on the web site has been reviewed by a psychiatrist specialized in child and adolescent psychiatry.

This web-based resource provides important information for teens about facts and statistics related to mental illnesses and the impact of these illnesses on teens. It includes important information in a user-friendly and accessible format that promises to appeal to teens and to better educate them about mental



illnesses.

Please share this important web-based resource with teens and families in your community. You can access the Mindzone web site at [copecaredeal.org](http://copecaredeal.org).

implications for local policy changes. Some of the specific recommendations that were made in the policy guidelines include:


1. Extend programs that only support youth up to age 18 to age 25 or 30 for youth who are (depending on the program):
  - “Vulnerable” (have disabilities, are in foster care, are in the juvenile justice system, are homeless or runaways, are low-income);
  - Youth with disabilities; and
  - Youth with serious mental health conditions.
2. Remove provisions from transition-age programs that disqualify youth with a history of criminal activity or a juvenile record.
3. Better address the needs of transition-age youth in the existing programs for individuals with serious mental health conditions, including the following:
  - State mental health and substance abuse block grants (SAMHSA/CMHS)
    - a) Define transition-age youth and young adults as a priority population;
    - b) Require a state plan for the block grant to address transition-age services;
    - c) Require that age-based eligi-

- bility barriers be removed;
  - d) Encourage a broader array of programs for transition-aged youth in child and adult service systems;
  - e) Require interagency planning, decision-making, service and support implementation and accountability for this age group;
  - f) Plan for work force development to address the unique needs of transition-aged youth; and
  - g) Require youth advisory councils for the block grant program and plan for their input.
- Extend and expand the current Partnerships for Youth Transition Program (SAMSHA/CMHS).
  - Encourage states to opt for the Chaffee Independent Living Program which provides funds and support programs for youth aged 18 to 21 leaving foster care.
  - Expand the technical assistance, provided by the Center for Medicare and Medicaid Services (CMS) and establish a center of technical assistance for youth in transition at the Center for Mental Health Services (CMHS).
4. Develop a new federal program that funds statewide efforts towards collaborative, interagency transition programs

for youth and young adults with serious mental health conditions. This program should do the following:

- Use language adapted from part C of the Individuals with Disabilities Education Act (IDEA) requiring state level interagency plans to address a population that is outside of school age;
- Target youth with serious mental health conditions that are aging out of all child-serving systems;
- Provide waivers for age-based eligibility for federal programs such as SSI/Medicaid;
- Reward states for building on existing federal programs that address transition-age youth;
- Require states to address accountability and outcomes in transition-age programs;
- Within accountability, require analyses of subgroups so that groups that are not well served can be identified and strategies can be developed to better address the needs of these subgroups.

In summary, the transition to adulthood is particularly difficult for youth and young adults with serious mental health conditions. While we have promising practices for them, transition support services are sparse across the country; this is especially true in adult systems. Quite simply, child and adult systems are disconnected.

Federal policies provide some supports for transition needs, but these programs are scattered across agencies each having a different focus, rules, eligibility criteria and funding levels. Given these circumstances, it is not surprising that young people with serious mental health conditions struggle in young adulthood. It is time that more resources and research be focused on improving the systems, their infrastructure, and the supports and treatments available to help this group of vulnerable young people and their families as they search out their paths to adulthood. 

## Psychiatric Medications for Children

by Mark Perrin, M.D.

List Price: \$19.95

Hard Cover: 119 pages (2005)

Publisher: Stillwater Press, Inc.




This book is a terrific resource for families. One that parents and caregivers of children living with mental illnesses should have readily available as they contemplate the appropriateness of psychiatric medications for their child. It walks parents and caregivers thoughtfully through the complex issues that families face when medication is recommended as part of a treatment plan.

Dr. Perrin covers the important questions that most families struggle with like “should my child be on medication” and “what, if any, are the effects of medication on the development of a child’s brain ... and what are the possible long term consequences?”

The book removes much of the mystery by describing the part of the brain that specific medications target and the effect that they have on the function of the brain. The book outlines the medications used for the most common childhood mental illnesses, the side effects associated with each of the medications, monitoring that should be done when using the medications, warnings associated with the medications, and practical additional facts included in the “what else you need to know” category.

This family-friendly and practical book will lead to families making better informed treatment decisions for their child. It comes highly recommended as an effective resource for families and professionals that work with children with mental illnesses.

*Editor’s Note:* Dr. Perrin is a practicing internist with The Summit Medical Group in New Jersey. He currently serves as the President of NAMI New Jersey and President of the New Jersey Parents’ Caucus. 

<sup>1</sup>BLANK, 1997; DANZIGER & GOTTSCHALK, 1995; LEVY, 1998; CORCORAN & MATSUDAIRA, 2005.

<sup>2</sup>SETTERSTEN, FURSTENBERG, & RUMBAUT, 2005.

<sup>3</sup>WAGNER, 1995; DAVIS & VANDER STOEP, 1997.

<sup>4</sup>SILVER, UNGER & FRIEDMAN, 1994; BLACKORBY & WAGNER, 1996.

<sup>5</sup>DAVIS & VANDER STOEP, 1997.

<sup>6</sup>INGRAM, HACHTMAN & MORGENSTERN, 1999; HOLLIS, 2000; LEWINSHON ET AL. 1999; PINE ET AL., 1998; KASEN ET AL., 2001; PETERSON ET AL., 2001.

<sup>7</sup>KIM-COHEN ET AL., 2003.

<sup>8</sup>MEICH ET AL., 1999.

<sup>9</sup>SEE DAVIS & VANDER STOEP, 1997.

<sup>10</sup>DAVIS & BUTLER, 2002; DAVIS & VANDER STOEP, 1995; ADAMS, NOLTE & SCHALANSKY, 2000; SOUTO, 1996.

<sup>11</sup>SILVER, UNGER & FRIEDMAN, 1994.

<sup>12</sup>DAVIS, GELLER, & HUNT, IN PRESS.

<sup>13</sup>CLARK ET AL., 2000.

<sup>14</sup>E.G. CHENY & BULLIS, 2004; BULLIS & FREDERICKS, 2002.

<sup>15</sup>WAGNER 1995.

<sup>16</sup>DAVIS & KOROLOFF, IN PRESS.

<sup>17</sup>JOHNSON ET AL., 2005.

<sup>18</sup>THE BAZELON CENTER REPORT, TITLED *MOVING ON ANALYSIS OF FEDERAL PROGRAMS FUNDING SERVICES TO ASSIST TRANSITION-AGE YOUTH WITH SERIOUS MENTAL HEALTH CONDITIONS*, CAN BE ACCESSED AT THE BAZELON WEB SITE AT [WWW.BAZELON.ORG/PUBLICATIONS/MOVINGON/INDEX.HTM](http://WWW.BAZELON.ORG/PUBLICATIONS/MOVINGON/INDEX.HTM).

<sup>19</sup>DAVIS & CLARK, 2000.

<sup>20</sup>E.G. BRIDGE, DAVIS & FLORIDA, 2000; BULLIS ET AL., 1994; HAGNER, CHENEY & MALLOY, 1999.

<sup>21</sup>CLARK ET AL., 2000. YOU CAN LEARN MORE ABOUT THE TIP SYSTEM BY VISITING THEIR WEB SITE AT [TIP.FMHL.USF.EDU/SYSTEMDESC.HTM](http://TIP.FMHL.USF.EDU/SYSTEMDESC.HTM).

<sup>22</sup>CLARK ET AL., 2004; KARPUR ET AL., 2005.

<sup>23</sup>WAGNER & DAVIS, FORTHCOMING

<sup>24</sup>THE RECOMMENDATIONS ARE AVAILABLE ONLINE AT [WWW.UMASSMED.EDU/ENTITIES/CMHSR/UPLOADS/YOUTHTPM.PDF](http://WWW.UMASSMED.EDU/ENTITIES/CMHSR/UPLOADS/YOUTHTPM.PDF).



# The Mismatch between the Transition Goals and School Programs of Youth with Emotional Disturbances

by **Mary Wagner, Ph.D.**, Director, Center for Education and Human Services, SRI International.

**T**he period of late adolescence and early adulthood has been dubbed the “floundering period”<sup>1</sup> because of the challenges faced by most youth in achieving a solid education, employment, and social foundation for adult life. As noted in the article by Maryann Davis in this issue, challenges are even greater for youth with mental health needs. Recognizing this fact, federal special education disability policy, codified in the Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004), requires that transition planning be conducted with and on behalf of youth who receive special education services in secondary school. Best practices in transition planning dictate that this planning process be “person-centered,”<sup>2</sup> meaning that it should be “driven by the young person’s interests, strengths, and cultural and familial values.” The goals of young people approaching the transition out of high school to the adult world are an appropriate lens through which to view the preparation they receive in high school.<sup>3</sup> Those goals serve as a yard stick against which to assess the appropriateness of their school programs.

The National Longitudinal Transition Study-2 (NLTS2), being conducted by SRI International for the U.S. Department of Education, provides information on the transition goals and school programs of a nationally representative sample of students who were ages 13 through 16 and receiving special education in grades seven and above when the study began in 2001.

School staff that were best able to describe the overall school programs of individual NLTS2 youth were surveyed in the spring of 2002, when youth were ages 14 through 18. The school staff reported on the youths’ transition goals, school programs, and the suitability of those programs in helping youth achieve their transition goals.

Obtaining competitive employment is the most common post-high-school goal of youth identified under IDEA with emotional disturbances; this includes youth with mental illnesses. Of these youth, 58% identified competitive employment as their goal, and 44% identified their goal as postsecondary vocational education to support later employment.<sup>4</sup> However, their instructional programs are heavily academic. In a given semester, virtually all take English or language arts, 93% take math, a similar percentage take social studies, and 84% take science. These rates of academic course taking mirror those of students in the general population,<sup>5</sup> and in the case of science and social studies, the rates of enrollment have increased significantly since the mid 1980s.<sup>6</sup>

Meeting the academic expectations of this kind of school program is likely to present a serious challenge to many youth identified under IDEA with emotional disturbances. Results of the standardized academic achievement assessment given to youth as part of the NLTS2 study demonstrate that the majority of youth have significant learning deficits. The average percentile scores in reading comprehension and mathematics calculation for youth

identified with emotional disturbances, are 25 in reading comprehension and 26 in mathematics calculation.

Whereas the average percentile score for youth in the general population on this assessment is 50 (i.e., half of youth in the general population score at or above the 50<sup>th</sup> percentile and half score at or below it). The study showed that 64% of youth with emotional disturbances have scores equal to the lowest-performing 25% of youth in the general population on reading comprehension, as do 55% of youth with emotional disturbances on mathematics calculation. Not surprisingly, almost one in five secondary school youth with emotional disturbances are reported to receive grades that are “mostly Ds or Ds and Fs,” and one-third who take a general education academic class are reported not to be able to keep up with the academic requirements in reading and math classes, even though virtually all are expected to do so.<sup>7</sup>

If they are able to succeed in their academic courses, then the emphasis on academic achievement may well benefit the 44% of youth with emotional disturbances who have a goal of attending a two or four year college. However, these kinds of academic courses do not directly support reaching the employment and vocational training goals of the majority of youth with emotional disturbances. In contrast to the academic courses taken by a large majority of youth with emotional disturbances, only 60% take vocational education in a given semester, a lower rate of vocational courses than among youth in the general population.<sup>8</sup> In fact, vocational

course taking has declined significantly among youth with disabilities since the mid 1980s.<sup>9</sup> Fewer than one in five has any school-sponsored work study experience in a given school year, although 53% obtain paid employment outside of school on their own.

This discrepancy between the vocational goals of the majority of youth with emotional disturbances and the heavily academic focus of their school programs may help explain the responses of school staff when asked how suitable the overall school programs for youth are in helping them achieve their post-school goals. The school programs of one-third of youth with emotional disturbances were described as “very suitable,” whereas 43% had programs school staff reported to be “fairly suitable.” The school programs of the remaining one-fourth of youth did not rate these levels of suitability. The mismatch may also help explain why youth with emotional disturbances are the least likely of all disability categories to finish high school. Although there has been a 16 percent increase in youth with emotional disturbances completing high school,<sup>10</sup> still only 56% of out-of-school youth with emotional disturbances finish high school. It may be difficult for many youth to persevere in school programs that even school staff admit do not provide a high likelihood of helping youth in achieving their goals.

Clearly, the current movement toward holding schools accountable for improving the academic performance of all students, reflected mostly powerfully in the No Child Left Behind Act of 2001 (NCLB), is focusing the attention and resources of schools on better teaching and learning in the academic areas covered by the mandatory standardized tests. As a result, many schools are making “adequate yearly progress” toward the goal of universal proficiency in tested subjects. But the apparent mismatch between the post-school goals and the school programs

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of youth with emotional disturbances raises concerns that these youth may be left behind as the instructional pendulum swings heavily toward academic instruction.


Fortunately, there are some signs that the potential danger of this academic emphasis for students with emotional disturbances and other groups who are at risk for not completing high school is being recognized. Ramping up the emerging efforts to create “multiple pathways” to high school completion through academically challenging career and technical education<sup>11</sup> could restore a balance between the academic

Kincaid, D. (1996). Person-centered planning. In L. K. Koegel, R. L. Koegel, & G. Dunlap (Eds.), *Positive behavioral support: Including people with difficult behavior in the community* (pp. 439-465). Baltimore: Paul Brookes Publishing Co.

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and vocational needs of youth. This would improve the odds that these youth would enter the post-secondary transition period with a high school diploma and access to the opportunities that accompany it. 

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<sup>9</sup>HALPERN, 1992.

<sup>10</sup>KINCAID, 1996.

<sup>11</sup>CLARK, DESCHENES, & JONES, 2000, P. 31.

<sup>12</sup>CAMETO, LEVINE, & WAGNER, 2004.

<sup>13</sup>WAGNER, 2003

<sup>14</sup>WAGNER, NEWMAN, & CAMETO, 2004

<sup>15</sup>BLACKORBY, CHOROST, GARZA, & GUZMAN, 2003.

<sup>16</sup>WAGNER, 2003.

<sup>17</sup>WAGNER ET AL., 2004.

<sup>18</sup>WAGNER, NEWMAN, CAMETO, & LEVINE, 2005.

<sup>19</sup>SEE, FOR EXAMPLE, JAMES IRVINE FOUNDATION, 2005.



# A Family Bond Built on Mental Illness

by Tammy Swasey-Ballou

I became involved with NAMI when my youngest son, Taylor had his initial break. After his first hospitalization it became apparent to me that much of what he needed would be up to me to find. I had to become educated about his diagnosis in order to find what we needed. Unfortunately his diagnosis kept changing so my education was a work in progress. We started with a diagnosis of ADHD, which changed to depression and anxiety disorder, then to oppositional defiant disorder and finally to Asperger's Syndrome and Bipolar Disorder.

Being a parent of a child with a brain disorder is a major challenge. It is a challenge that cannot be met by using the typical parenting skills. I learned very early on that Taylor needed to be parented in a very different way than I was used to. We had to develop crisis plans that included what we would do when he became manic or suicidal, how other family members would be taken care of, when to remove the family pets from the immediate area, when to go to the hospital and when to "ride it out." When Taylor was 9 years old, my husband and I were told to start looking for a residential facility because Taylor would never be able to live in the community safely. At that time, I made a vow that not only would he be in the community but he would be a contributing part of the community. It has been a long and painful road with many ups and downs and undoubtedly more to come, but my son is well on his way to being that contributing member of the community.

The concessions that we made were all worth it. They included learning to parent differently, using medications that I thought that I would never have considered giving to a child, advocating strongly and consistently to get his needs met, trying and failing but trying again to get him the services he needed, standing up to the stigma surrounding mental illness, biting my tongue when people spoke of there being "no such thing as childhood

mental illness" and saving my energy to get my son's needs met, the vast quantity of providers we worked with, team meetings that only led to more team meetings, and special education and school staff that commented about how "he is manipulating and his mother is over protective." It has been enough to make your head spin.

Taylor's illness affected every aspect of our life and because of it our lives changed. When the illness led us to financial devastation we learned that we didn't really need material things to be happy. I have learned to always find the good in things. That has not always been easy and sometimes the positive was just that we were all still breathing, but it still remained a positive. Along with always finding the positive is simply "thinking positive." It wasn't "if I can do this" it was "when I do this." This was very important for Taylor because we sent the message that if he wanted to achieve something – he could. I also learned that advocacy can be powerful, but power wrongly used, defeats the oppressor as well as the oppressed! There were many other things we learned through our "school of hard knocks." The list is long and I am grateful to have learned important life lessons. One lesson from remaining positive about Taylor's illnesses is that it has made me and my entire family better people!

When I finally made contact with NAMI Maine it was after many, many calls and plenty of voice mails and unreturned calls. I was given the NAMI Maine number at a workshop and thought that I would give it a try. Strangely enough, there was actually a living, breathing person on the other end of the phone line and I asked a question and got an immediate answer, not a response that the person would look into it. From that phone call on, NAMI has been a very important part of my family's life.


In 2002, I accepted a Service Coordinator job in the NAMI Maine office. Through that job I became the

state Family-to-Family trainer and Program Director, and was trained to be the state trainer for the Support Group Skills training. I have attended four of the last five NAMI National Conferences with my son Taylor and my husband.

In addition to NAMI, I sit on the State of Maine Planning Council for Federal Block Grant Funds; am a member of the State Quality Improvement Council – Children's Committee; have been a Peer Reviewer for NIMH grants on children and mental health issues; and participate on several other local community councils and committees related to brain disorders and mental health.

I am looking forward to helping to re-energize NAMI's Teen Advisory Group because I have witnessed first hand that an important part of a teen's recovery is to be connected with other teens that have similar experiences and challenges. Putting a face on teen mental health issues is a powerful message that needs to be shared.

There are many projects that I would love to work on with NAMI teens including Stigma busters, Teen Support Groups, mentoring opportunities for teens, media requests and a speaker's bureau, a teen version of "In Our Own Voice," encouraging more teens to work with NAMI state and affiliate organizations and much more. The projects and direction will be established based on the interest of the teens. All teens chosen to participate in the teen advisory group will be an important voice for NAMI!

I live in Camden, Maine with my husband, Andy and our youngest son, Taylor. I have five children between the ages of 17 and 31, and seven grandchildren. 

To learn more about the NAMI Teen Advisory Group contact Tammy Swasey-Ballou at Coastal Area NAMI in Camden Maine at (207)236-6110 or by email at [tsballou@verizon.net](mailto:tsballou@verizon.net).

# Taking the First Step: Overcoming Stigma

by Stacy Hollingsworth

It's a feeling I've come to know well—the knot in my stomach, the palpitations, the racing thoughts that question the potential consequences of what I'm about to do. Should I tell them? Is it possible they'll understand what I'm going through? Will they think any less of me once they find out? Questions such as these run through my mind every time an otherwise uneventful conversation suddenly turns into a highly personal one, oftentimes beginning with the phrase “I have a mental illness.”

By the time I entered high school, I knew something was wrong. I noticed that I was depressed more often than not, was disinterested in activities I once enjoyed, and wanted to spend considerable time alone. After researching disorders on the Internet, I finally realized that I was facing a severe case of major depressive disorder. No matter how hard I tried, I could not identify a single cause or event that was responsible for the tremendous pain I was experiencing. It didn't make any sense to me. My life was just so picture perfect, and yet there I was, so miserable. I nearly convinced myself that things would get better without appropriate intervention, as my condition continued to deteriorate.

Because of the stigma surrounding mental illness, I felt compelled to hide my suffering from the outside world; even those closest to me were unaware of my battle with depression. However, I could not hide from the fact that I was a walking time bomb. I was desperate for an end to the immense pain and therefore spent much of my time pondering suicide.

Unlike many of my peers, for whom college represented independence, exciting new social opportunities, and an intellectually stimulating atmosphere, my personal transition into college was most notably a symbol of my

entrance into the mental health care system—an opportunity to reclaim the life that had been stolen from me as a result of the depression.

I still recall the first day I set foot into a counseling center on campus. I somewhat reluctantly got off the shuttle bus and quickly made sure no one who knew me saw where I was headed. At first, opening up about the illness was incredibly awkward. I was so nervous that I'm not even sure I was speaking in coherent sentences. Since then, though, I've had plenty of opportunities to discuss the illness with psychiatrists, therapists, and other people suffering from mental illness.


Because I was relatively treatment resistant, it took a lot of patience to get through the many failed treatment attempts, which included a variety of different medications, repetitive transcranial magnetic stimulation, acupuncture, and electroconvulsive therapy (ECT). Electroconvulsive therapy, also referred to as “shock therapy,” has quite a controversial history that extends into present day. So, in addition to the fact that I was coping with a stigmatized illness, I was now also undergoing a rather stigmatized treatment. The use of medications in treating depression has gained acceptance in society, but shocking the brain? How barbaric, right?! Ironically, in our culture, it's perfectly acceptable to shock a heart in order to save someone's life, but it's not okay to shock a brain. Remember, the brain is an organ, too. Although ECT was personally ineffective, it did serve as a reminder that what I was dealing with was a disabling medical disorder—not a character flaw.

Getting comfortable with the disorder to the point where you can speak about it openly does not happen overnight. It's a process, but one that does get easier over time. For me, it first took personal acceptance of the



Stacy Hollingsworth

disorder, followed by the recognition that not everyone out there will understand or will want to understand the nature of the disorder. We cannot blame them—they haven't been educated about mental illness. All we can do is be ourselves. We shouldn't have to apologize for having to deal with a disorder that was uninvited in the first place.

Early intervention can improve your overall prognosis—not to mention spare you years of suffering. You have to ask yourself what's more important—that everyone thinks you're doing well...or that you truly are doing well. This illness IS treatable. You CAN feel better. What are you waiting for? 

*Editor's Note:* Ms. Hollingsworth is a junior at Rutgers University in New Jersey, where she is starting a NAMI Campus-Based Affiliate. NAMI-Rutgers will open its “doors” to students and faculty in the fall and already has quite a bit of interest on campus and an ambitious line-up of activities. NAMI-Rutgers will educate the campus community about mental illnesses, promote the early detection of mental illnesses and early intervention, provide support for students with mental illnesses, reach out to family members and friends of students living with mental illnesses and combat the unfortunate stigma that continues to exist with these illnesses.

# Frameworks: A Promising Suicide Prevention Program

by **Kenneth Norton**, MSW, LICSW, Frameworks Project Director, NAMI NH

In the United States, suicide is the third leading cause of death, after accidents and homicides, for youth ages 10 to 24. The US Centers for Disease Control (CDC) reports that more youth and young adults in the US die from suicide than from cancer, heart disease, AIDS, birth defects, stroke and chronic lung disease combined. Suicide deaths provide only a limited view of the enormity of the issue. Suicide attempts account for hundreds of thousands of hospital emergency room visits and subsequent inpatient admissions. Surveys of high schools students indicate that approximately 10 to 20 percent of students report having contemplated suicide, and know first hand, the toll it takes on family and friends.

NAMI NH is getting national and international recognition for an innovative community based suicide prevention program called the Frameworks Youth Suicide Prevention Project. The Frameworks Project Director recently presented on the project at a conference in Belfast, Northern Ireland. The conference included delegates from across Ireland who came together to learn about state of the art suicide prevention programs and to develop a national suicide prevention strategy. Closer to home, the Substance Abuse and Mental Health Services Administration (SAMHSA) recently awarded NAMI NH a grant under the Garrett Lee Smith Memorial Act for the Frameworks project for suicide prevention.

With support from SAMSHA and private foundations NAMI NH has led the development of the Frameworks Project. Frameworks works within the cultural context of communities by strengthening community coalitions and developing coordinated and effective strategies for youth suicide prevention, intervention, and postvention

(after a suicide death) activities.

At the heart of the project are evidence-supported protocols. The protocols identify practices in suicide prevention, intervention and postvention to address issues related to lack of skill and fragmented systems. They are designed to narrow the gaps between and among social service and treatment delivery systems that exist in states throughout the country and are used to train providers in these systems. The protocols also attempt to remove the stigma barrier associated with mental illness and suicide and improve access to healthcare. Volunteers were an important part of the protocol development. Over 120 service providers, youth, suicide survivors, family members, and policy leaders contributed 1,500 hours in creating the protocols for responding to suicide events.

The Frameworks Project trains coalition members on how to:

- Recognize warning signs and risk factors for suicide including mental illness and substance abuse;
- Connect or communicate with “at risk” youth and connect them with appropriate resources -- including clergy, primary care providers, mental health providers, school nurses, guidance counselors or other professionals who are trained to assess their risk level and ensure that they are connected with appropriate services; and
- Connect community coalition members working together on suicide prevention and helping high risk youth.

The protocols guide service providers and gatekeepers, including youth, families, and others, in how to recognize and respond to at risk youth, youth who have made suicide threats or attempts, and communities where there has been a suicide. The protocols

include specific procedures for key service providers including: dispatchers, law enforcement, emergency medical services, hospital emergency departments, educators, school administrators, social service agencies, Judges, primary health care providers, mental health and substance abuse providers, funeral directors, suicide survivors, clergy, community coalition coordinators, medical examiners and others.

With training and technical assistance from NAMI NH, the protocols are being implemented by community coalitions in three areas of the state. The first community implementation was done with the Mascoma Valley Health Initiative (MVHI), which is implementing Frameworks in five rural communities. The Executive Director of MVHI observed that “although Frameworks was developed as a youth suicide prevention program, the project materials clearly apply across the lifespan which is an added bonus.”

Using a “train-the-trainer” model, community leaders are identified and trained from each of the key service provider groups (listed above). Those trained then train their colleagues. The project also focuses on identifying and training gatekeepers (family, friends, neighbors and other community members who have frequent contact with youth and young adults). Dr. Kristine Baber from the University of New Hampshire, Center on Adolescence, is evaluating the process and outcomes of the pilot site implementation and serves as our evaluator on the Garrett Lee Smith grant.

The Frameworks model extends well beyond suicide prevention and broadens the safety net for all at risk youth. By teaching those participating in the Frameworks project about the skills needed to recognize risk factors and warning signs and how to connect



with youth, Frameworks provides early detection and intervention for mental illnesses, substance use, delinquency, domestic violence, harassment and other issues that trouble youth. The project also works with a community coalition to help identify and address the unique risk and protective factors of the community and the specific cultural attributes of both the community and individuals living in that community.

In 2004, NAMI advocated for passage of the Garrett Lee Smith Act

which the President signed into law. The law provides the first dedicated funding for suicide prevention programs and assists states in implementing their youth suicide prevention plans.

The Frameworks project complements the NH state suicide prevention plan. Because of that and NAMI NH's leadership in suicide prevention, NH's Department of Health and Human Services designated NAMI NH as the state applicant for the Garrett Lee Smith grant program and funding.

While nearly all of the other fourteen Garrett Lee Smith grant recipients across the country are state agencies, NAMI NH's application represents a unique public and private partnership. Grant activities that will move the NH suicide prevention plan forward include expanding the Frameworks project to additional communities, strengthening NH's Youth Suicide Prevention Assembly (YSPA- a coalition of service providers and citizens interested in youth suicide prevention), working with state agencies to increase

## Your Teenager with ADHD<sup>i</sup>

**Y**our child with ADHD has successfully navigated the early school years and is beginning his or her journey through middle school and high school. Although your child has been periodically evaluated through the years, this is a good time to have a complete re-evaluation of your child's health.

The teen years are challenging for most children; for the child with ADHD these years are doubly hard. All the adolescent problems—peer pressure, the fear of failure in both school and socially, low self-esteem—are harder for the ADHD child to handle. The desire to be independent, to try new and forbidden things—alcohol, drugs, and sexual activity—can lead to unforeseen consequences. The rules that once were, for the most part, followed, are often now flaunted. Parents may not agree with each other on how the teenager's behavior should be handled.

Now, more than ever, rules should be straightforward and easy to understand. Communication between the adolescent and parents can help the teenager to know the reasons for each rule. When a rule is set, it should be clear why the rule is set. Sometimes it helps to have a chart, posted usually in the kitchen, that lists all household rules and all rules for outside the

home (social and school). Another chart could list household chores with space to check off a chore once it is done.


When rules are broken—and they will be—respond to this inappropriate behavior as calmly and matter-of-factly as possible. Use punishment sparingly. Even with teens, a time-out can work. Impulsivity and hot temper often accompany ADHD. A short time alone can help.

As the teenager spends more time away from home, there will be demands for a later curfew and the use of the car. Listen to your child's request, give reasons for your opinion and listen to his or her opinion, and negotiate. *Communication, negotiation, and compromise* will prove helpful.

### Your Teenager and the Car.

Teenagers, especially boys, begin talking about driving by the time they are 15. In some states, a learner's permit is available at 15 and a driver's license at 16. Statistics show that 16-year-old drivers have more accidents per driving mile than any other age. In the year 2000, 18 percent of those who died in speed-related crashes were youth ages 15 to 19. Sixty-six percent of these youth were not wearing safety belts. Youth with ADHD, in their first 2 to 5 years of driving, have

nearly four times as many automobile accidents, are more likely to cause bodily injury in accidents, and have three times as many citations for speeding as the young drivers without ADHD.<sup>ii</sup>

Most states, after looking at the statistics for automobile accidents involving teenage drivers, have begun to use a graduated driver licensing system (GDL). This system eases young drivers onto the roads by a slow progression of exposure to more difficult driving experiences. The program, as developed by the National Highway Traffic Safety Administration and the American Association of Motor Vehicle Administrators, consists of three stages: learner's permit, intermediate (provisional) license, and full licensure. Drivers must demonstrate responsible driving behavior at each stage before advancing to the next level. During the learner's permit stage, a licensed adult must be in the car at all times.<sup>iii</sup> This period of time will give the learner a chance to practice, practice, practice. The more your child drives, the more efficient he or she will become. The sense of accomplishment the teenager with ADHD will feel when the coveted license is finally in his or her hands will make all the time and effort involved worthwhile. 

<sup>i</sup>NATIONAL INSTITUTE OF MENTAL HEALTH. ATTENTION DEFICIT HYPERACTIVITY DISORDER. BETHESDA (MD); NATIONAL INSTITUTE OF MENTAL HEALTH, NATIONAL INSTITUTES OF HEALTH, US DEPARTMENT OF HEALTH AND HUMAN SERVICES; PGS. 32-34 (ACCESSED ONLINE AT WWW.NIMH.NIH.GOV/PUBLICAT/NIMHADHD.PDF).

<sup>ii</sup>BARKLEY RA. *TAKING CHARGE OF ADHD*. NEW YORK: THE GUILFORD PRESS, 2000, P. 21.

<sup>iii</sup>U.S. DEPARTMENT OF TRANSPORTATION, NATIONAL HIGHWAY TRAFFIC SAFETY ADMINISTRATION. *STATE LEGISLATIVE FACT SHEET*, APRIL 2002.


awareness about suicide prevention, helping to standardize training for staff, and improving the capacity to respond to families and communities who survive a suicide death.

The project continues to offer NAMI NH the opportunity to build non-traditional partnerships that promise to help reduce stigma and promote help seeking behaviors and early intervention for youth and others living with mental illnesses. Like many states, suicide pre-

vention work in NH largely takes place through the public health authority. The connections that NAMI NH is developing with public health agencies and providers, and the opportunities to provide education, training and support to families is strengthening the push for the early identification of mental illnesses in youth and treatment intervention.

NAMI NH would like the Frameworks suicide prevention pro-

gram to become a national suicide prevention program and expand into many states and communities and be successfully driven by trained NAMI members along with professionals. Stay tuned...

To learn more about the Frameworks project, please contact Ken Norton, Project Director at the NAMI New Hampshire office at (603)225-5359 or by email at [knorton@naminh.org](mailto:knorton@naminh.org). 

## ASK THE DOCTOR

# Negotiating the Transition from Adolescence to Young Adulthood

by **Suzanne Vogel-Scibilia, M.D.**, Psychiatrist in Beaver, PA and NAMI National Board President

**W**hile all parents worry about how their children will manage the period from dependent adolescent to independent young adult, the presence of a mental illness increases both the difficulties for youth and anxiety for the parents. It is important to think of this transition period as a fluid ongoing process that each adolescent negotiates uniquely with the help of supportive family members. Many variables can alter how this process is successfully accomplished. This article covers seven common ones:

### 1) Severity of illness

Each child's illness directly affects how the transition is accomplished. When the mental illness is severe or other problems exist, such as substance use or intellectual deficits, the transition period can be prolonged. Some youth with mental illnesses find significant challenges in transitioning to independent adult living. Their goal for transition becomes one of changing from an entirely dependent youth into a partially supported young adult. Ultimately many young consumers have difficulty living independently and need to remain with their families



*Dr. Vogel-Scibilia and her son Tony*

longer than anticipated or move to supported housing programs.

Often the teen years prove to be the most difficult time for consumers as they struggle both with the mental illness and in developing an adult identity. The old adage for "chronically normal" adolescents of "parents want to bury their teenager in the backyard at 14 and dig them back up again grown at 21," is certainly true for teens grappling with an unstable mood or psychosis during adolescence. The impact of age-appropriate hormonal changes makes these symptoms more promi-

nent. Additionally, young adult consumers, like other teens, want increased independence which may not be feasible given the mental illness. Several strongly contested areas include freedom to associate with chosen friends, increased curfew hours, the importance of abstinence and driving a motor vehicle. Parents and caretakers will find more success in fostering progress if they have already established a pattern of clear and consistent limits and an enforceable behavior plan that does not use corporal punishment.

### 2) Educational environment

Despite the mandates of IDEA (the Individuals with Disabilities Education Act), many find the educational system to be one of the most trying aspects of the transition period. Schools are often under-funded and overburdened with the educational needs of their students. Teenagers with special needs often complain of being "warehoused" into learning environments that do not meet their needs but continue to promote them without educational challenges that meet their potential. Students with serious psychiatric illness or with co-occurring learning disabilities are more likely to slip through the cracks than students that do not

face these challenges. Parents advocating for their child need to be aware of their child's legal rights and all options open to them. Youth consumers may resist attempts to strengthen the educational work load and may seem content to continue with a less challenging curriculum.

Often parents must come into conflict with the school administration to help ensure that their child's academic and functional needs are met. The child may be reluctant to have the parent raise concerns with the school. At one point when my son Tony was being expelled from a class because he missed one day of school due to depressive symptoms, I began to draft an email asking for a meeting with his IEP team to discuss this issue. Tony, with his characteristic sarcasm joked, "look Mom, give me a crack at them first and don't send any hate mail until I try to talk to my Mock Trial teacher..." Honoring the teen's wishes and allowing them to negotiate educational issues provides a valuable learning experience for young consumers on how to negotiate and manage adult level issues.

Transition services are mandated under IDEA, but the law does not specify the type of vocational services that are available or most appropriate for teens. Each state has an office of vocational rehabilitation that is charged with helping individuals with disabilities plan for their career. Parents should not wait for the school to refer their child to the vocational rehabilitation office. In my clinical practice, I schedule appointments with the vocational rehabilitation office for each high school junior during their spring semester.

Setting the tone for transition is also important. As a clinician, I begin a dialogue about future aspirations during a young consumer's freshman year of high school and follow up by talking with the youth about the extracurricular or summer activities that might help the teen consider different vocations during the sophomore year.

### 3) Personality and Temperament

Each young consumer's personality and temperament affects the nature of

the transition period from childhood to adulthood, and how actively they lobby to live independently. Often parents need to set limits and should pick and choose their battles. The focus should be on safety, respect, truthfulness and accountability, along with the teen's needs and desires. Parents should offer reasonable choices instead of a large number of options that may overwhelm their child. Much of the work of the transition period involves having the teen and parents reach consensus about how best to proceed with challenging issues. Adults should model good problem solving behavior, while the young adult practices how to negotiate and achieve their desired outcomes. These are good skills for all young adults to learn, including those living with a mental illness.

### 4) Community Resources

Many communities have mental health programs that assist young adults in moving beyond high school into a supported education or employment program. Whether it is a vocational-technical program, credit for work experience, enrollment in a community college, or matriculation into a four year college, many school districts provide guidance to help smooth the transition. Parents should familiarize themselves with what the school district offers and the relevant community agencies.

### 5) Family Resources

Many families have special resources available to them. This may include economic, social or job-related resources all of which have the potential to lead to a more smooth transition from youth to adulthood. Some families can encourage a young consumer to talk with other family members or friends who are slightly older. One of our family members who had already negotiated the transition hurdles takes younger relatives out for a snack at a local diner to discuss future goals.

### 6) Specific Objectives

Each teen brings strong wishes and desires to the transition period. Having a clear plan with concrete parameters to accomplish the young person's goals

allows more independence and responsibility. Devising a timeline and breaking down the specific goals that must be met so that the young adult can effectively move forward is very helpful.

### 7) Family Dynamics


Each family, with its individual mix of personalities, helps to foster the way that young adults reach emancipation. Having each family member play to his or her strengths and having regular communication between all parties is essential.

It is always beneficial to hear directly from youth and young adults about their experience in the transition-age period. For that I turned to my son Tony. His comments reinforce the challenges that many youth and families face when a child moves from dependence to independence. His comments also reinforce the reality that many young consumers fail to have their needs met by our nation's schools. Surely we can do far better in addressing the social, economic, academic and societal needs of transition-age youth, especially those living with a mental illness.

### Comments from Anthony Scibilia

I was in support classes in high school, however I wasn't learning anything. This year I am a junior and I am taking night classes for reading and writing at the Community College of Beaver County instead of the support classes. This summer I am scheduled to take Algebra. I still take history and English at my high school in the morning. In the afternoon I go to the YMCA or Baden Bowl for my gym class. I like the community college because there are people of all ages in my classes and I feel like I am starting to move on with my life.

I am getting ready to take my learner's permit test because I want to drive. My mother wants me to practice riding the bus to the YMCA but I have to change buses so I think it will take too long and waste my time.

My biggest complaint is that my parents don't give me enough freedom to make my own decisions and they treat me like I'm younger than I am. I don't need to have the teachers talk to my parents all the time. 



# Speaking Out on Transition-Age Services

by Naomi Verdugo, Ph.D., NAMI Arlington, Virginia

*Editor's Note:* Naomi Verdugo developed a statement similar to the one below to present to the local community services board in Arlington, Virginia on the need for effective transition-age services.

**T**oo long the needs of youth and young adults with mental illnesses have been overlooked in this county and beyond. Public services fail to be offered until youth are in crisis, homeless, incarcerated, drug addicted, or a danger to self or others. Usually the crisis hits in the mid- to late twenties. By this time, these young adults are quite ill, disabled, and largely unable to function as independent and productive adults. They have fallen far behind their peers.

What do youth, young adults and families want in transition-age services? Many families can provide health coverage and housing to meet their child's needs during these years. However help is also necessary to address the following needs:

- Vocational services – job assessment, job training, resume writing, acquiring interview skills, job mentoring and coaching, job placement services, and acquiring interpersonal skills;
- Connecting youth with educational support services through contact with local community colleges, and disability services and supports offered on college and university campuses;
- Life skills training – designed to help young adults effectively use public transportation, effectively manage and understand finances, understand job responsibilities, understand how to secure appropriate and safe housing and related skills; and
- Case management services.

Our county has a model for these services that could be adapted. Youth with mental retardation who graduate from high school are provided shelter, supported employment, case management and transportation services.

These services are funded by the county government, however only for young adults with mental retardation and not for those living with mental illnesses. We need to make services available that set young adults with mental illnesses on a path toward independence and that allow them to reach their full potential.

These services should be part of the county's base budget and available to youth and young adults with mental illnesses regardless of whether they receive social security income (SSI) or social security disability income (SSDI) benefits. It is an investment that will reap benefits when these individuals gain greater financial independence and rely less on publicly funded services.


Research shows that early intervention with intensive services helps to reduce the long-term severity and cost of mental illnesses. This keeps youth and young adults from falling behind their peers and increases their chance of becoming contributing members of society. It stands to reason that by providing appropriate and effective mental health and related services at younger ages, we will increase the chance that these youth will achieve greater success in their lives. They stay healthier, require fewer services and are better equipped to obtain and retain competitive employment. It also increases the likelihood that they will stay in school. Moreover, young adults will require fewer overall public services if they can find a job that provides a living wage and health insurance. It also means that they contribute to the tax base.

Our county, state and nation can no longer afford to ignore the needs of youth and young adults with mental illnesses. It does not make good business sense to ignore their needs early on so that increased public funds are needed down the road.

So what can our county do to better

meet the needs of youth and young adults living with mental illnesses? Here are six goals that the county should reach:

- Educate staff in youth and young adult serving agencies about the benefits of providing intensive life skills, supported education, supported employment and vocational services;
- Get to know the experts in implementing effective supported education, supported employment and vocational rehabilitation services. Learn from their work and consider contracting with them to advise the county on the most effective approach to broader implementation of transition-age services;
- Partner with universities that are studying mental illnesses in young adults and effective transition-age programs and policies;
- Work with state legislators to obtain local funding for demonstration projects that focus on improving transition-age services and show effective outcomes;
- Ensure that the county budget includes the necessary funds for appropriate staffing and effective programs and examine how implementing effective transition-age programs leads to lower overall public funding for services; and
- Work in partnership with youth, families and advocacy groups in designing effective transition-age services.

Our county needs to take a more comprehensive and proactive approach to providing effective transition-age services. It is not just the humane and right thing to do, it is the most effective way to reduce public spending for youth and young adults living with mental illnesses. They have hopes and dreams just like the rest of us. They deserve the opportunity to reach them. 

# Online Resources and Reports on Transition-Age Issues



The National Longitudinal Transition Study – 2 –this study is being funded by the U.S. Department of Education to document the experiences of a national sample of students, who were 13 to 16 years of age in 2000, as they move from secondary school into adult roles. We greatly appreciate Dr. Mary Wagner’s contribution to this issue of *Beginnings* related to her work with this project. Learn more about this study by visiting their web site at [www.nls2.org](http://www.nls2.org). The National Center on Youth Transition – the mission of the center is to improve practices, systems, and outcomes for transition-age youth and young adults (14-25 years of age), including those with mental illnesses. The center was created to provide technical assistance through a SAMHSA funded grant program and is working with grant sites around the country to develop more effective transition-age programs. Learn more about NCYT by visiting their web site at [ntacyt.fmhi.usf.edu](http://ntacyt.fmhi.usf.edu).


The Transition to Independence Process (TIP) System – Hewitt B. “Rusty” Clarke, Ph.D., has developed the TIP System to engage youth and young adults in their own futures planning process, to provide them with developmentally appropriate services and supports and to involve them, their families and other informal key players in a process that moves them forward. Learn more about the TIP System by visiting their web site at [tip.fmhi.usf.edu](http://tip.fmhi.usf.edu).

The Center for Mental Health Services and Research at the University of Massachusetts, Medical School – Maryann Davis, Ph.D., has worked with colleagues on research and in publishing a number of reports on transition-age issues. These reports cover a number of topics, including state efforts to expand transition supports for young adults receiving adult public mental health services, policy issues related to transition-age services and more. Review copies of these reports and related research done by Dr. Davis and colleagues at the center’s web site at [www.umassmed.edu/cmhsr/working\\_papers/](http://www.umassmed.edu/cmhsr/working_papers/).

Moving On: Analysis of Federal Programs Funding Services to Assist Transition-Age Youth with Serious Mental Health Conditions – the Bazelon Center for Mental Health Law developed this report that includes an analysis of 57 federal programs offer-

ing resources to assist youth with serious mental health treatment needs in making the transition from childhood to independence. The report, along with fact sheets on the 57 federal programs referenced in the report, can be found on the Bazelon Center’s web site at [www.bazelon.org/publications](http://www.bazelon.org/publications) (click on the Moving On report).



Transition to Adulthood: Strategies for Overcoming Stigma and Achieving Positive Outcomes for Young Adults – the ADS Center (a resource center developed by SAMHSA to address discrimination and stigma) held a training conference call on May 25, 2006, on the topic of transition to adulthood. The training included several presenters talking about transition-age issues. You can learn more about the training teleconference and how to access the toll free teleconference by visiting the ADS Center web site at [www.stopstigma.samhsa.gov](http://www.stopstigma.samhsa.gov) (under “Featured Pages” click on “Listen to Previous Training Teleconferences” and then on the May 25<sup>th</sup> topic). 

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