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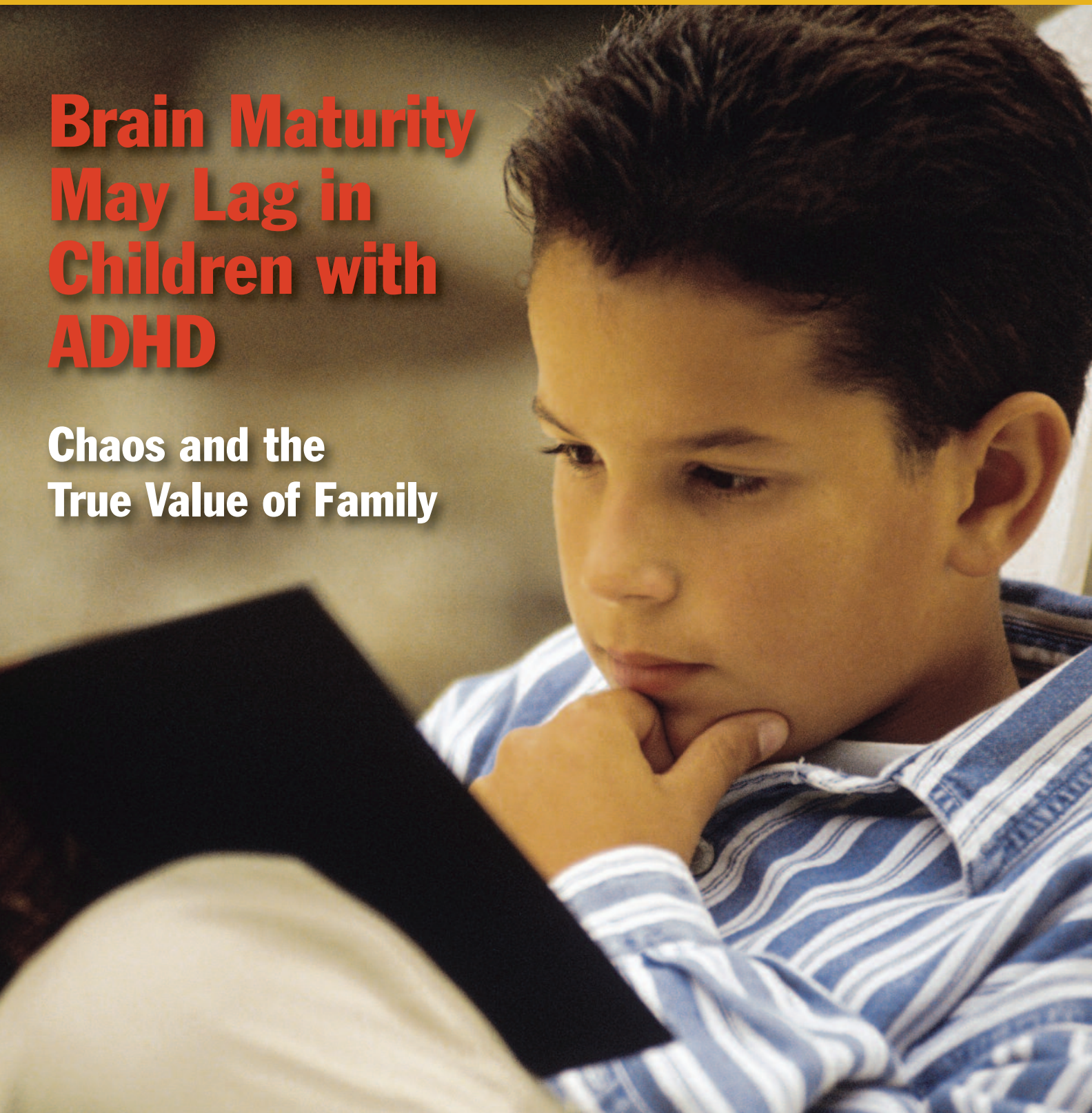
National Alliance on Mental Illness

Beginnings

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

Brain Maturity May Lag in Children with ADHD

Chaos and the True Value of Family



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Capitol Hill and State House Watch

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

Federal Focus on Transition-Age Youth and Young Adults

The U.S. General Accounting Office (GAO) will be releasing a report on transition-age youth and young adults with serious mental illnesses in late June. NAMI provided information to the GAO about the unique needs of this group. The GAO conducted an extensive study of this population of young people. Fortunately, national and state leaders are increasingly focusing on the lack of effective services and supports for transition-age youth and young adults with mental illnesses.

NAMI applauds Representative Pete Stark (D-CA) and Senator Gordon Smith (R-OR) for asking the GAO to complete this study. They asked the GAO to determine the characteristics of youth and young adults in the U.S. with serious mental illnesses, the extent to which they must depend on others for care, and to provide recommendations on what states and the federal government can do to fill the gap in services these youth experience when they age-out of federally-funded health and other support programs.

Federal legislation will likely be drafted in response to the findings outlined in the GAO report. NAMI will notify members and friends when the report is released. We will also work to help ensure that federal legislation addresses the unique needs of youth and young adults with mental illnesses.

National Children's Mental Health Awareness Day

NAMI is helping to organize a Capitol Hill Congressional briefing that will be held on National Children's Mental Health Awareness Day on May 8, 2008. The partner organizations, in addition

to NAMI, involved in the planning for this year's Congressional briefing include the Bazelon Center for Mental Health Law, the National Federation of Families for Children's Mental Health, and Mental Health America. There are also a number of additional colleague organizations that are co-sponsoring the briefing.

The focus for the Congressional briefing will be the reauthorization of the Substance Abuse Mental Health Services Administration (SAMHSA) and the value of school-based mental health programs. The briefing is designed to help educate and inform U.S. Congressional members about the importance of SAMHSA reauthorization and to highlight effective school-based mental health programs.

Versions of the draft SAMHSA Reauthorization bill have been circulated and include the following critical provisions for children and adolescents living with mental illness and their families:

- Renewal and expansion of *The Garrett Lee Smith Memorial Act* that supports state and local efforts to replicate successful strategies for youth suicide prevention and college-based mental health programs;
- *The Keeping Families Together Act* (S 382) that authorizes planning grants for states to implement strategies designed to address the tragic and unnecessary policy of forcing families to relinquish custody of their child as a condition for accessing mental health services;
- Support for school-based mental health services and programs, including positive behavioral supports;

NAMI *Beginnings* is published quarterly by NAMI, Colonial Place Three, 2107 Wilson Blvd., Suite 300, Arlington, VA 22201-3042. Ph: 703.524.7600 Fax: 703.524.9094

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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
NAMI HelpLine: 1.800.950.6264

- Efforts by Senator Chris Dodd (D-CT) and others to expand federal regulation to end the inappropriate use of restraint and seclusion, particularly for adolescents in schools and placed in juvenile justice facilities; and
- Support for multiple grant programs including the Center for Mental Health Services (CMHS) Systems of Care grants, the Safe Schools-Healthy Students grants and other effective programs.

The draft SAMHSA reauthorization bill also includes provisions that will benefit adults living with mental illnesses and their families. To learn more about SAMHSA reauthorization visit the policy section of the NAMI web site at www.nami.org.

In addition to the Congressional briefing, there will be other activities for National Children’s Mental Health Awareness Day that are being organized and spearheaded by the CMHS Child, Adolescent, and Family branch. You can learn more about these activities at www.systemsofcare.samhsa.gov.

State House Activity

NAMI continues to work with a small group of national organizations focused on children’s mental health. Our group was formed largely in response to anti-psychiatry activity targeting state legislators.

NAMI chairs the work group, which consists of the following national organizations: the American Academy of Child & Adolescent Psychiatry (AACAP), the American School Counselors Association (ASCA), Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD), the Child and Adolescent Bipolar Foundation (CABF), the National Federation of Families for Children’s Mental Health (FFCMH), and Mental Health America (MHA - formerly the National Mental Health Association).


In the fall of 2007, our organizations completed a state advocacy tool kit to share with the grassroots leaders affiliated with our respective organiza-

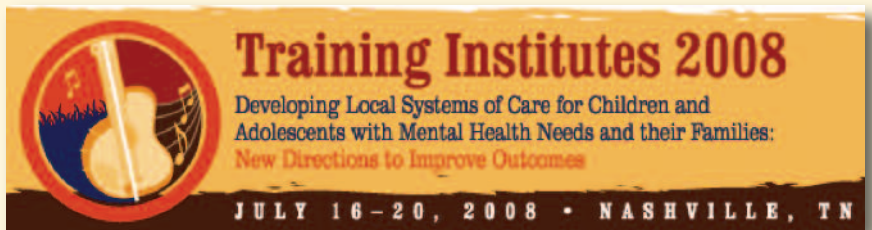
tions. There is a tremendous amount of misinformation that has been shared with officials in many states about children’s mental health. It is our hope that the tool kit resources will be used to help set the record straight about children’s mental health. The tool kit includes the following resources:

- Tips on Effective State Legislative Advocacy
- Sample Anti-Mental Health and Anti-Psychiatry State Legislation From Previous Legislative Sessions
- Letters to Legislators and Governors Jointly Sent by Our Organizations
- Sample Opinion Letters and Letters to the Editors in Response to Anti-Mental Health Legislation
- Recommendations on Helpful Ways for Educators and Families to Talk about Mental Health Related Concerns
- A Fact Sheet on Improving the Mental Health and Well-Being of Children

- A Fact Sheet on Schools and Families United for the Mental Health and Well-Being of Children

The tool kit is currently posted on the NAMI web site at www.nami.org/CAAC. We would strongly encourage you to review the documents and to share them with legislators and policy makers in your states and communities. You may also share them with school professionals who may be interested in learning more about helpful ways to talk with families about mental health related concerns.

Our group will continue to develop joint resources that can be used in your advocacy efforts to help raise awareness about children and adolescents living with mental illnesses. Stay tuned for updates ... 



TRAINING INSTITUTES

July 16-20, 2008, Nashville, TN. Developing Local Systems of Care for Children and Adolescents with Mental Health Needs and Their Families: New Directions to Improve Outcomes.

In-depth, practical information on how to develop and operate systems of care and how to provide high-quality, effective, clinical interventions and supports within them. Special focus on three “new directions” to strengthen systems of care and improve outcomes, each comprising a distinct track: Implementing a Public Health Approach, Partnering

With Schools, and Partnering With Child Welfare. For more information, contact the National Technical Assistance Center for Children’s Mental Health at Georgetown University, 3300 Whitehaven Street, NW, Suite 3300, Washington, DC 20007, (202) 687-5000, or email Institutes2008@aol.com, or visit the website at <http://gucchd.georgetown.edu>.

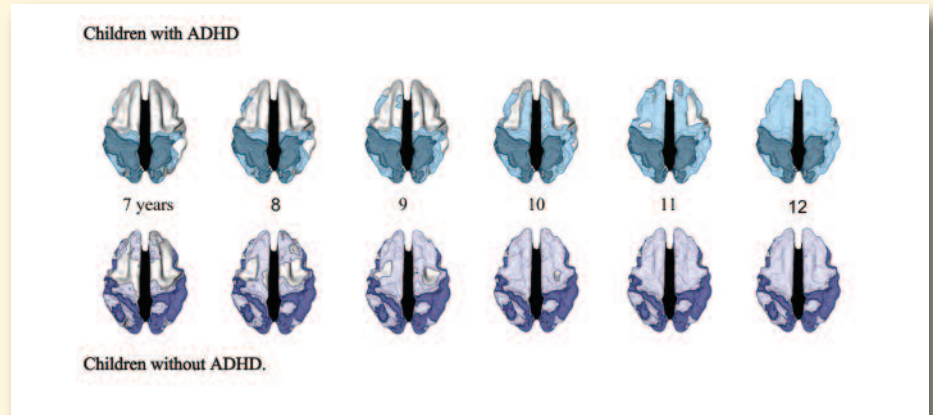
Brain Maturity May Lag in Children with ADHD

by Philip Shaw, M.D. Ph.D., Child Psychiatry Branch, National Institute of Mental Health

Attention Deficit/Hyperactivity Disorder (ADHD) is the most common childhood mental disorder — affecting more than one in every twenty children. Since ADHD was first described, there has been a debate over whether it is due to a delay in brain development or due to a complete departure from the pattern of brain development in children who do not have the disorder. To try to answer this question, our study looked at the development of the cortex, the brain's outer crust or gray matter. We measured the thickness of the cortex across thousands of points in the brain in four hundred and forty-six (446) children — half of whom had ADHD and half of whom did not — and looked at how the cortex developed.

For children with and without ADHD, the cortex starts off relatively thin in early childhood, then gets thicker, and reaches a peak thickness before getting thinner throughout adolescence. We looked at the age at which the cortex reached its peak thickness, using this as a marker or milestone of brain development and we found a major difference between children with ADHD and those without the disorder. While children without ADHD reached the milestone of peak thickness at about age seven, children with ADHD “peaked” a few years later at around age ten. This delay was most marked in frontal parts of the brain, which control attention and action.

However, while there was delay in children with ADHD, the overall sequence or order in which different parts of the cortex matured was similar for children with ADHD and for those who did not have the disorder. If ADHD was a complete departure from the pattern of typical brain development, we would expect this sequence



Here are a series of pictures of the brain viewed from above—the front of the brain is on the viewer's right. Looking first at the pattern of brain development in children without ADHD, in purple, as each part of the brain matures—or reaches its peak cortical thickness—it turns light purple. As you can see there is a distinct pattern of development, and the last region to mature are parts near the front of the brain, which are important for the control of action and attention. Now compare this brain development to the children with ADHD—everything is delayed by a couple of years. If we compare the brain patterns at age ten, you can see most of the cortex has reached its milestone of peak thickness in children without ADHD, but there is still some way to go in the kids with ADHD (lots of parts of the cortex are still white—so they have not reached their peak thickness yet). However, in another few years, the kids with ADHD will reach this milestone and in the same general order as healthy kids.

to be completely disrupted, but it was not. This provides some support for the idea that ADHD is associated with a delay in brain development.

This finding does not, however, mean that the brains of children with ADHD completely “normalize” by age ten, or that ADHD is a temporary condition. Much of the delay we found is carried forward into adolescence and we know from other studies that there are many differences in brain structure and function in teenagers with ADHD. Thus, it is very important for children and teens with ADHD to get the best possible treatment, to ensure that they have every opportunity to succeed in school and to enjoy their lives with family and friends. **IB**

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ADHD and Substance Use: The Importance of Integrated Treatment

by **Adelaide Robb, M.D.**, Associate Professor of Psychiatry and Pediatrics, Children's National Medical Center

Attention Deficit/Hyperactivity Disorder (ADHD) affects 6 to 8% of children and adolescents and 4 to 5% of adults throughout the world.^{1,3} Teens with ADHD struggle with paying attention, sitting still, and acting impulsively. Younger children with ADHD often have other difficulties including learning disabilities (15 to 20%), oppositional defiant disorder (40%), or conduct disorder (14 to 20%). These co-morbid disorders make treating ADHD more difficult and can make school more challenging for students both academically and socially.

One of the more common co-morbid disorders is substance use disorder (SUD), which occurs in 13 to 21% of teenagers and young adults living with ADHD. This article will discuss the presentation and prevention of SUD, the diversion of ADHD medications, and treatment of ADHD and SUD in teenagers.

Epidemiology and Prevention

SUD and ADHD co-occur frequently. ADHD symptoms often precede the development of SUD.^{4,7} In a series of large studies of boys and girls with ADHD, ADHD specialists at Massachusetts General Hospital found

Rates of Alcohol Use and Substance Abuse

	Rates of Alcohol Use	Rates of Substance Use
Girls with ADHD	4%	13%
Girls without ADHD	0%	3%
Boys with ADHD	26%	21%
Boys Without ADHD	16%	11%

that youth with ADHD had the onset of SUD at younger ages and at higher rates than their same gender peers without ADHD.^{8,9} Above is a table depicting the results of this study.

Many recent studies have examined whether ADHD treatment can change the rate of SUD in adolescents and young adults. Parents have worried that the use of stimulants might lead to increased rates of substance abuse. Multiple recent studies have examined this theory. These studies have shown that teenagers with ADHD plus an externalizing disorder (either conduct disorder or oppositional defiant disorder) are more likely to develop SUD than teens with just ADHD.^{10,11}

Another study by Massachusetts General Hospital compared rates of SUD in young adults without ADHD, young adults with untreated ADHD,

and young adults with ADHD treated with stimulants.¹² In the young adults with untreated ADHD, rates of SUD were 75% while treatment with stimulants reduced the rate of SUD to 25%, close to the 18% seen in their non-ADHD peers in this age group.

Abuse and Diversion of Stimulants

Another area of concern related to ADHD treatment and the use of stimulants exists when teens use their ADHD medication to get high (abuse) and when they divert their medication by selling or trading it with friends and classmates (diversion). Stimulants are Schedule II medications, meaning they have the potential to cause dependence. In a review of twenty-one (21) studies of over 113,000 youth, Dr. Timothy Wilens, Associate Professor of Psychiatry at Harvard Medical School,

¹Faraone SV, Sergeant J, Gillberg C, Biederman J. The worldwide prevalence of ADHD: Is it an American condition? *World Psychiatry* 2003 Jun;2(2):104-113.

²Kessler RC, Adler L, Barkley R, et al. The prevalence and correlates of adult ADHD in the United States: Results from the National Comorbidity Survey Replication. *The American Journal of Psychiatry* 2006 Apr;163(4):716-723.

³Polanczyk G, de Lima MS, Horta BL, Biederman J, Rohde LA. The worldwide prevalence of ADHD: A systematic review and metaregression analysis. *The American Journal of Psychiatry* 2007 Jun;164(6):942-948.

⁴Faraone SV, Wilens T. Does stimulant treatment lead to substance use disorders? *The Journal of Clinical Psychiatry* 2003;64 Suppl 11:9-13.

⁵Fischer M, Barkley RA. Childhood stimulant treatment and risk for later substance abuse. *The Journal of Clinical Psychiatry* 2003;64 Suppl 11:19-23.

⁶Barkley RA, Fischer M, Smallish L, Fletcher K. Does the treatment of attention-deficit/hyperactivity disorder with stimulants contribute to drug use/abuse? A 13-year prospective study. *Pediatrics* 2003 Jan;111(1):97-109.

⁷Wilens TE, Faraone SV, Biederman J, Gunawardene S. Does stimulant therapy of

attention-deficit/hyperactivity disorder beget later substance abuse? A meta-analytic review of the literature. *Pediatrics* 2003 Jan;111(1):179-185.

⁸Biederman J, Monuteaux MC, Mick E, et al. Psychopathology in females with attention-deficit/hyperactivity disorder: a controlled, five-year prospective study. *Biological Psychiatry* 2006 Nov 15;60(10):1098-1105.

⁹Biederman J, Monuteaux MC, Mick E, et al. Young adult outcome of attention deficit hyperactivity disorder: a controlled 10-year follow-up study. *Psychological Medicine* 2006 Feb;36(2):167-179.

¹⁰August GJ, Winters KC, Realmuto GM, Fahnhorst T, Botzet A, Lee S. Prospective study of adolescent drug use among community samples of ADHD and non-ADHD participants. *Journal of the American Academy of Child and Adolescent Psychiatry* 2006 Jul;45(7):824-832.

¹¹Wilens TE, Gignac M, Swezey A, Monuteaux MC, Biederman J. Characteristics of adolescents and young adults with ADHD who divert or misuse their prescribed medications. *Journal of the American Academy of Child and Adolescent Psychiatry* 2006 Apr;45(4):408-414.

ADHD Facts & Stats

Children with ADHD

- 3 to 5% of children have ADHD — approximately 2 million children in the United States. This means that in a classroom of 25 to 30 children, it is likely that at least one will have ADHD.
- About 20 to 30% of children with ADHD also have a specific learning disability.
- Effective treatments for ADHD are available and include behavioral therapy, social skills training, parent skills training, and medications.
- Research shows that long-term combination treatments (medication management and behavioral treatment) and medication management alone were superior to intensive behavioral treatment and routine community treatment for treating children living with ADHD.
- 1/3 to 1/2 of all children with ADHD, mostly boys, develop oppositional defiant disorder (ODD). About 20 to 40% of children with ADHD may eventually develop conduct disorder (CD).
- Children with ADHD are at higher risk for behavioral problems, including delinquent behaviors and substance abuse.

Transition-Age Youth with ADHD

- ADHD is not just a childhood

disorder, it can continue through the teen years and into adulthood.

- Left untreated, ADHD can have long-term adverse effects into adolescence and adulthood.
- 13 to 21% of teenagers and young adults living with ADHD also have a substance use disorder.
- Youth with ADHD, in their first two to five 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 young drivers without ADHD.

Adults with ADHD

- 30 to 70% of children with ADHD continue to exhibit symptoms in their adult years.
- 80% of children who require medication for ADHD still require medication treatment as teenagers. Over 50% require medication treatment as adults.
- Adults with untreated ADHD may repeatedly lose jobs because of their untreated illness. They may have a history of school failure and problems at work. Often they have been involved in frequent automobile accidents.
- At any age, treatment can help!

ADHD Facts & Stats gathered from the National Institute of Mental Health's website at www.nimh.nih.gov.

examined rates of abuse, misuse, and diversion of stimulant medications and the risk factors that predisposed youth with ADHD to these acts.¹³

Rates of nonprescribed stimulant use in grade school and high school students are 5 to 9%. Studies show that 16 to 29% of teenagers and young adults with ADHD are approached to give, sell, or trade their ADHD medications. Youth with conduct disorder, or

SUD in combination with ADHD, are the most likely to divert or misuse their stimulant medications. Hispanic and Caucasian youth have rates of stimulant misuse three times the rate seen in African American youth and two times the rate seen in Asian American youth.

Medications that are rapidly delivered to the body and last several hours (immediate release) were more likely to

be misused and diverted than medications that are delivered to the body over a longer time period (extended release) or non-stimulant treatments.

Treating Teens with ADHD and Substance Use Disorder

In treating teens with co-occurring ADHD and SUD, the treatment of one disorder cannot take precedence over the other. Doctors treating teens with ADHD need to inquire about substance use and provide treatment for both disorders whenever they co-exist. Several studies have examined the importance of treating teens and young adults who have both ADHD and SUD. These studies recognize the importance of identifying the presence of both disorders. It is also important when treating teens with ADHD and SUD to choose medications to treat the ADHD that are less easy to be abused such as non-stimulants (atomoxetine, bupropion, or modafinil), prodrugs — which are administered in an inactive or less active form (lisdexamfetamine), or long acting and transdermal forms of medication — which are delivered by an adhesive patch in specific doses through the skin (methylphenidate or amphetamine).

Most clinicians who specialize in SUD treatment recommend stabilizing the SUD first and then slowly adding in a non-stimulant medication treatment for ADHD.¹⁴ ADHD specialists tend to recommend treating both disorders simultaneously with behavioral treatment for the substance use and medication for the ADHD. The simultaneous treatment for both disorders is sometimes called dual diagnosis treatment.

Recently, the National Institute of Mental Health (NIMH), the National Institute of Drug Abuse (NIDA), and the pharmaceutical industry have recognized the importance of treating these frequently comorbid disorders. All three groups have increased the number of studies on treating teenagers and young adults with dual diagnoses. Several research trials for teens and

¹²Biederman J, Wilens T, Mick E, Spencer T, Faraone SV. Pharmacotherapy of attention-deficit/hyperactivity disorder reduces risk for substance use disorder. *Pediatrics* 1999 Aug;104(2):e20.


¹³Wilens TE, Adler LA, Adams J, et al. Misuse and Diversion of Stimulants Prescribed for ADHD: A Systematic Review of the Literature. *Journal of the American Academy of*

Child and Adolescent Psychiatry 2008 Jan;47(1):21-31.

¹⁴Riggs PD. Clinical approach to treatment of ADHD in adolescents with substance use disorders and conduct disorder. *Journal of the American Academy of Child and Adolescent Psychiatry* 1998 Mar;37(3):331-332.

young adults with ADHD and SUD are listed on the National Institutes of Health's clinical trials website at www.clinicaltrials.gov. These trials provide another resource to help parents and teenagers struggling with the dual diagnosis of ADHD and SUD better understand effective treatments.

Conclusion

Teens with ADHD are at higher risk of developing SUD than teens without the disorder. They may consider misusing their medications or be approached by classmates to sell or trade their prescriptions. Parents and physicians should be aware of risk factors, such as conduct disorder, that put teenagers with ADHD at higher risk for the development of SUD. While teens with ADHD and conduct disorder are at the highest risk of developing SUD, effective treatment of ADHD can greatly reduce that risk. Treatment for dual diagnoses is available and can make a major difference in the lives of teens with both disorders. 

ADHD Medication Guide for Parents



The American Academy of Child and Adolescent Psychiatry (AACAP) and the American Psychiatric Association (APA) released a new parent's guide to Attention Deficit/Hyperactivity Disorder (ADHD) medications.

The guide, *ADHD Parents Medication Guide*, is designed to help families and physicians make informed decisions about obtaining and administering the most appropriate care for a child with ADHD. The guide provides information to families on ADHD symptoms, the side effects of medication, and co-occurring disorders.

The guide can be downloaded at www.parentsmedguide.org.

Chaos and the True Value of Family

by Evelyn Polk Green, President-Elect, Attention Deficit Disorder Association

Like most women in 2008, every day I wear many hats. These include early childhood educator and administrator, child and family advocate, president-elect of the Attention Deficit Disorder Association (ADDA), active member of several mental health advocacy groups, and more. But, everything I have done during the past 22 years has been deeply influenced by the fact that I am a mother, and more importantly the mother of two wonderful sons, both diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD).

The Road to a Diagnosis

My oldest son was diagnosed with ADHD at age seven. But before the official diagnosis, life with Perry was...well...let us just say — different. Like all new parents, from the moment we brought him home we knew he was special...but we had no idea just how special he really was!

Unlike many babies with ADHD, he slept through the night early in his life. He was alert, happy, and seemed to be aware of everything going on around him. He rarely cried. But as he grew older, things began to change.

Because of my background in early childhood education, I quickly realized that something was not quite right. My son did not interact with others like other children his age. We were politely told that our two year old just did not "fit in" with the other kids at the day care center, so perhaps we should look for a "more suitable" placement. He was unbelievably stubborn, his temper tantrums were long and uncontrollable, and yet at times, he could be the sweetest, most loving child in the world. We struggled daily with the notion that we were bad parents, especially when well-meaning friends and family, not to mention total strangers, accused us of being

bad parents.

Eventually we decided that we needed help. We sought advice from everyone imaginable including family, our pediatrician, social workers, educators, and psychologists. During our long search for help, we heard everything from "he is just stubborn," to "perhaps you need to change your parenting style." Along the way, we heard a variety of diagnoses including hyperlexia and pervasive developmental delay. Although he exhibited some of the characteristics of these diagnoses, nothing we heard seemed quite right. Finally, one of his teachers suggested that we have him evaluated for ADHD. It took more than five years of struggle, doubt, and worry before our oldest son was diagnosed with ADHD at the age of seven.

There are no words to describe the relief that we felt to have a name for our son's behavior, to finally have a plan to help him and, most of all, to know that it was not our fault.

But the diagnosis was only the start of our journey — the real fun began once we were truly living with ADHD and making the necessary adjustments to manage it within our family. Perry is 22 years old now and I am incredibly proud of him, as I am of his brother. He has turned into a caring, compassionate, and thoughtful young man with strong convictions, especially on social justice issues. That is not to say that I did not experience frustration as he grew up nor that I still do not occasionally experience frustration or continue to worry about him. Yet, I can now look back with pride and know that we made it through some pretty trying times together.

Certainly we would not have made it to this point without some key factors. We learned the importance of acceptance, finding support, the ability to forgive and to accept forgiveness, and

perhaps most importantly — the value of humor!

Acceptance

I have tried to be a good parent to Perry and his brother, to teach them both about life. I have taught Perry the importance of growing into a young man of integrity living with ADHD, not in spite of it. I am well aware that I have learned as much from my son as he has learned from me, beginning with acceptance.

Accepting my own ADHD was made easier by observing Perry's daily struggles and gradual acceptance of his differences. I have learned so much just from our struggle with accepting the fact that, for us, medication is necessary to successfully managing the disorder. I can still vividly recall how we wrestled with the idea of putting Perry on medication when he was first diagnosed at age seven. That was probably the most difficult decision we had to make as parents.

My younger son, Robert, was diagnosed with ADHD at age 13. He has accepted that he has ADHD and has to take medication to manage it. He has not shown a hint of resistance to medication. Perry would have been appalled to disclose his ADHD to anyone at this age, however, Robert discusses it matter of factly with friends and teachers. I can only hope that his acceptance of being a teen with ADHD will transfer to an acceptance that will influence many of the activities he engages in — especially driving.

Do I wish that my sons did not need medication to manage their ADHD? Or for that matter that I did not need medication to manage my own ADHD and depression? Of course I do...but then again I also wish that I did not need glasses, now that I am over 40!

From the very beginning, I discussed with Perry the notion that ADHD might make him “different” from his peers. But I think that one of the most important gifts I gave both my sons was the acceptance of differences and the soul deep belief that different does not mean inferior. In fact, we tried to instill the notion that different can sometimes be a very good thing!

Support

I am convinced that one of the reasons that we are able to accept ADHD, and co-occurring anxiety and depression, is that we have each found a support system in our lives. For me initially, it was meeting other parents with ADHD and the formation of our Chicago Children and Adults with Attention Deficit/ Hyperactivity Disorder (CHADD) group. Later it became fellow National CHADD Board members, some of whom are as close as family now. My children also became part of that extended family. Much of their support systems developed around the kids of CHADD board members, with whom they share the common bond of living with ADHD.

Over the years, I have continued to grow my support system, which now includes an adult ADHD support group in suburban Chicago. It also includes friends and fellow board members that I have met through ADDA.

My kids have also continued to develop their own support systems. These consist of other kids with ADHD and their siblings, school friends, and trusted adults. Perry has even joined my adult support group and Robert is close friends with the teenaged children of several support group members.

These support systems have been so important for all of us. Knowing that I am not alone and that there are folks out there who have “been there — done that” is an enormous relief. I know that when I am ready to scream in frustration because of something Perry has done, I need only pick up the phone and connect with any number of people who will understand and empathize with my situation. In the same way, when I have driven Perry right to the edge, he has folks that he can call on too. The most amazing thing is that often the folks that receive our calls are either the same person or in the same family!

Forgiveness

Being able to forgive each other and accept forgiveness is another secret to our family success. Part of our acceptance of ADHD is understanding that sometimes we say or do things without thinking through the consequences. We recognize the need to forgive each other



Evelyn Polk Green


and accept forgiveness when that happens. The most important lesson I have taught my children is to never be afraid or ashamed to apologize. Moreover, we understand that the foundation of our love is built on something much stronger than the hurtful words that sometimes get hurled about.

Humor

We most often express forgiveness through humor. Our ability to laugh at each other and ourselves has been the most important factor in allowing us to not just survive, but to thrive in our “ADHD household.” Laughter has been both a method of communication and a stress reliever. We have made jokes, not always appropriate or politically correct, about everything imaginable.

We choose to laugh because life is too short and there is little that we can do to truly upset the balance of nature. Finding humor has defused volatile situations, given us time and space to think through our actions, and brought us closer together as a family. I think that Perry and Robert would agree that humor has been key in getting us through good and bad times.

Humor, along with our acceptance of each other and ourselves, and relying on each other and our support systems when necessary, coupled with the ability to forgive and accept forgiveness — has allowed me to raise my two wonderful sons. I am so proud of them and hope that I have been the mother that they deserve.

The journey has certainly not been an easy one...and it is far from over. But I must say that the ride thus far has been exhilarating! Raising Perry and Robert in our very “ADHD household” has been both incredibly challenging and gratifying. We call it “Chaos Theory in Action,” but it works for us — chaos and all! 

High Expectations and The Right Team

By Perry Green, University of Louisville student

“Backpack...Check”
 “Assignment Notebook...Check”
 “Math Folder...Check”
 “English Folder...Check”
 “Social Studies Folder...Check”

Like many, that was my daily routine before heading off to school. Quite honestly, even at age 22, it continues to be my routine. My name is Perry Green and I have Attention Deficit/Hyperactivity Disorder (ADHD). Currently, I am finishing my undergraduate degree at the University of Louisville, where I am a Pan-African Studies major. I was diagnosed with ADHD when I was seven years old.

When I finish my degree, I plan to go on to graduate school, and after that, who knows. What can I say? I have ADHD. One thing I know for sure is that my future is boundless.

As I write this article, I am staring at the paper bomb that has exploded over my desk and in my work area. My bedroom is a mess and my backpack looks like I am still in elementary school. At one point, medical experts suggested that people “outgrow” ADHD. I beg to differ. Everyday has its challenges, victories, and ADHD moments, like when I forget to grab the right notebook for class or miss the bus because I was on Facebook or MySpace.

I am always asked by parents of younger children with ADHD, “how is it that you are so successful and able to manage your ADHD?” Depending on how jovial or serious the person is, I usually respond in one of two ways — “you know I really do not know...some days I wonder” or “my parents.” The correct answer is “all of the above and then some!” One of the most important lessons I have learned about successfully managing my ADHD is that it takes a team. If it were not for the countless teachers, my parents, and other professionals, I would not have made it to college, let alone finished high school.



Perry Green

One of the most important lessons I have learned about successfully managing my ADHD is that it takes a team.


One of the other elements of successfully managing ADHD in my life is lining the pockets of business owners in Silicon Valley...technology has been a huge help to me. From the time I was 15, I have consistently used a PDA (personal digital assistant) to help me with appointments, school assignments, managing my time, and staying organized.

However, if it were not for my parents, I would not be where I am today. One of the most important things that my parents did for me was to EXPECT MORE! It saddens me that in some households, schools, and communities — ADHD is used as an excuse. My parents never allowed me to use ADHD as an excuse for anything. I am not saying that my parents were precision-driven drill instructors (although at times I saw them that way), but they

knew when something challenged me and yet, still always expected me to do my BEST. I was always frustrated with teachers who did not have similar high expectations for me.

The other key factor for me in successfully managing my ADHD was to find and discover my passions. All too often, young people with ADHD hear about how awful they are, or about all the things they do not do well or struggle with. I deeply believe that despite the fact that these negative attitudes are the norm — it should be the other way around. When I was a freshman in high school I began debating, it was my passion, and something that I became very good at. That was my “ticket out” of always hearing about all the things I could not do well.

If there is one thing that I could say to those interacting with children and teens, especially those with ADHD, it would be to celebrate their successes and to focus on their victories and the obstacles they have overcome, rather than the on-going roadblocks and challenges they so often face. Not to say that people do not need to work on their challenges, but trust me, we already know our failings and do not need to be reminded of them.

I know that I will continue to face many of the same challenges as an adult with ADHD that I did as a child and teen. Just one look at my mother, who also has ADHD, convinces me of that. But I also know that the great foundation that I have in my “ADHD management team,” which includes my family, my teachers, and my doctors, is the support I need as roadblocks are thrown into my path. The support of my team is what gives me the drive and desire to want to become an advocate for other people facing challenges in their lives. 

Editors Note: Perry is the son of Evelyn Polk Green, who provided the Family Voice article for this issue.

The Ultimate Challenge: Treatment Adherence in Transition-Age Youth

by Ken Duckworth, M.D., Medical Director, National Alliance on Mental Illness

One of the most compelling and challenging aspects of clinical work can be “getting to yes” on treatment with youth and young adults between the ages of 17 and 22 who live with a mental illness. This “transition age” population is in that gray zone between youth and adulthood and between systems of care typically designed to treat one age group or the other.

The expression — “getting to yes,” is preferred over “compliance” or “adherence,” when it comes to engaging transition-age youth in treatment. “Compliance” implies simply following the doctor’s orders and fails to capture the dynamic interplay between the young adult and their physician when it comes to treatment decisions. The statement — “no alliance, no compliance,” speaks to the importance of this treatment relationship when it comes to following a treatment plan. A positive relationship and trust are essential components to effective treatment outcomes. “Treatment adherence” is now the preferred term by many to describe the process of a young adult following a treatment plan. Whatever you prefer to call it — “getting to yes,” is not easy, but is often essential in moving youth forward in their development.

“Normal” adolescence and the young adult years are not easy for most individuals. The substantial changes in body, brain, and hormones are coupled with significant developmental tasks, like working on an identity and developing a way to separate from one’s parents. Activities during adolescence



Dr. Ken Duckworth

may also include early exploration of sexuality and relationships, contending with the power of peers and peer pressure, access to alcohol and drugs, and dealing with school or work. Living with a mental illness most often makes these life experiences much harder. Also, in some cases, peers and younger siblings without mental illnesses are moving ahead developmentally, which may add humiliation to the mix for those who feel left behind.

The years from ages 17 to 22 may also coincide with the onset of many psychiatric conditions, including anxiety, depression, substance use

disorder, eating disorders, bipolar disorder, and schizophrenia. Natural transitions from home to school and from high school to college or to a job are natural stress points in life. A person who turns 18 is also responsible for their health care information. This limits family access to health information, and raises the importance of a strong therapeutic alliance between a young person and their treating provider. Without such an alliance, the young person may choose not to follow their treatment plan and the family may not have leverage to encourage continued treatment.

The following ten suggestions may help parents and caregivers in effectively “getting to yes,” when it comes to treatment adherence in transition-age youth and young adults:

1. Always remember that adolescents and the transition years to adulthood are not easy and are made much more complex when a young person has active psychiatric symptoms.
2. Do not argue over a diagnosis with your transition-age loved one. It can impair your relationship and alliance and it does not get you anywhere. Many people cannot see that they have a psychotic illness. Acknowledge a difference of opinion and move on. Lack of insight is part of many people’s experience with mental illness, it makes treatment adherence harder, but recognize that they often cannot help their lack of insight.
3. Find an area of interest for the young adult and pursue it. This may include a job, a girl or boy friend, or a course of study. It is

helpful to find supports to help address these normal areas of functioning. For example, young adults who participate in the Boston University Psychosocial Rehabilitation program get a student identification card that allows them access to the university's gym and other student facilities. Participating in these types of activities adds to a person's positive social identity.

4. Taking psychotropic medications is often a real challenge for transition-age young adults. Adolescents and young adults often do not like to take any type of medication. Lead with love in this and in all potential struggles. Find out about side effects that are troubling them and see if they can be minimized or if the medication or dose can be changed. Sometimes finding the right medication at the right dose can make all the difference. If absolutely necessary, consider other strategies related to treatment adherence, including guardianship or a representative payee arrangement, but remember these strategies can tax relationships.
5. Natural consequences are often a good teacher. If your loved one drank too much and did not take his or her medication and got into trouble with the police, ask if he or she learned from the experience. Life is a continuous learning exercise. Natural consequences of treatment refusal and poor choices can lead to catastrophic outcomes in this population, so this is a very delicate balancing act for those who love and those who treat young people.
6. Consider a learning style evaluation. Neuropsychological testing can help a person address weaknesses in their cognitive abilities and find ways to work around their weaknesses. This is particularly important for this age group because so many tasks are dependent on learning.
7. Focus on the young person's strengths and build on them. We all need to be good at a few things. This is especially true for youth with mental illnesses who may be feeling especially vulnerable.

A person who turns 18 is also responsible for their health care information. This limits family access to health information, and raises the importance of a strong therapeutic alliance ...

8. Social security disability income can be a blessing and a curse. For some young adults, it creates disincentives for pursuing school or work activities, both of which can be beneficial to them in the long term. Every person is unique, so make sure that this decision is made carefully.

9. Remember that many young adults associate social life with alcohol. To a young person who is not in recovery, it may be just having a few drinks with their peers. It is unusual for a person to be in active recovery in the transition-age years, it often takes time and unfortunate consequences. It is still important to discourage substance use. Attendance at Al-anon meetings for families and Alcohol Anonymous (AA) or Smart Recovery for youth can be very helpful. However, it is important to see this as more of a marathon than a sprint.
10. It is important for caregivers to be good to themselves and to get all the support they can. The transition-age years are a challenge for everyone, however, they are made all the more difficult with the existence of a mental illness. It is important to remember that your loved one needs you now and in the future.

It is extremely encouraging that leaders at the national, state, and local levels are playing much closer attention to the unique needs of this age group. The transition-age years lay the foundation for the future of all individuals and much work remains to be done to ensure that the futures of those with mental illnesses are bright. **DB**

Educating the Whole Child



The Association for Supervision and Curriculum Development (ASCD) recently launched, with strategic partners, *The Whole Child*, an initiative that recognizes that to do well academically, students must be healthy, safe, engaged, supported, and challenged.

The initiative recognizes that students who are struggling emotionally are unlikely to do well academically. This is certainly true for students with mental illnesses in our nation's schools.

ASCD encourages community members — including parents, mentors, doctors, lawyers, business owners, and civic leaders — to actively support their school's efforts in creating an environment that promotes the development of the whole child. To learn more about *The Whole Child* visit www.wholechildeducation.org. To learn more about ASCD, visit www.ascd.org.

The Launching of NAMI Basics

by Teri Brister, Ph.D., Director of Programs for Young Families, National Alliance on Mental Illness

The first U.S. Surgeon General's report on mental health in 1999 stated that approximately four million children in the United States were living with a serious mental illness, and 22% of the nation's children between 9 and 17 years of age had diagnosable mental or addictive disorders that caused at least minimal impairment at home, school, or with peers. In June 2005, a National Institute of Mental Health (NIMH) press release for a large epidemiological study headlined the fact that half of all lifetime cases of mental disorders begin by age 14. Mental illness in children and adoles-

cents is a national health concern.

Families of children and adolescents with mental illnesses have diverse and complex needs. They routinely struggle with finding the most appropriate and effective treatment for their child in a fragmented mental health system. They also struggle with securing the services their child needs to ensure an adequate and appropriate education, and dealing with their own feelings of guilt and inadequacy in caring for their child, along with the rest of the family. Support and education for these families is a national priority for NAMI.

NAMI's agenda and advocacy on children's issues has grown tremendously through the work of the Child and Adolescent Action Center. The logical next step in that growth was the development of a NAMI national



Dr. Teri Brister,
Director of NAMI
Basics



www.nami.org/basics

The NAMI Basics Education Program was developed in 2007. It is the core educational course for what will become a variety of helpful resources for ... serving families

signature education program designed specifically for parents and caregivers of children and adolescents with mental illness.

The NAMI Basics Education Program was developed in 2007. It is the core educational course for what will become a variety of helpful resources for NAMI state and local affiliates to use in serving families with children with mental illnesses in their communities. The curriculum was developed with input from an Advisory Committee comprised of parents and other caregivers from across the country. These individuals are actively involved in education and support services for families with children with mental illnesses. NAMI Basics was built around time tested NAMI family education course elements, which have been extensively tested and found to be highly effective in the field, including:

- Recognition of mental illness as a continuing traumatic event for the child and family;
- Sensitivity to the subjective emotional issues faced by family caregivers and well children in the family;
- Recognition of the need to help improve the day-to-day objective burdens of care and management;
- Gaining confidence and stamina for what can be a life-long role of family understanding and support; and
- Empowerment of family caregivers as effective advocates for their children.

The course was compressed into six — 2.5 hour classes that can be taught either weekly for six weeks, or bi-weekly for three weeks. This allows the flexibility necessary to accommodate the hectic schedules of the parents and caregivers who will benefit most from this program. Each class builds on the

one before it, and prepares participants for the class to follow. Classes focus on the following topics:

1. It is not your fault — mental illnesses are brain disorders;
2. The biology of mental illness — getting an accurate diagnosis;
3. Treatment works — an overview of treatment options;
4. Acknowledging the strains of family burden and the impact of mental illness on each family member;
5. Understanding the mental health, school, and juvenile justice systems; and
6. Building an advocacy team for the child.

NAMI has run pilot classes in Illinois, South Carolina, and Utah. These states were chosen based on a set of criteria that included existing education, support, or advocacy services for children and adolescents, the capacity to take the NAMI Basics program statewide after the pilot, and the willingness to teach the entire program in six different locations between January and May of 2008. This program expansion is necessary to accommodate the program evaluation. The pilot classes will be evaluated by Dr. Paul Deal, a psychologist with Missouri State University in Springfield.

All NAMI Basics teachers are either the parent or primary caregiver of an individual with a mental illness who began experiencing symptoms before age 13. Teachers are required to participate in a rigorous weekend training during which they learn the curriculum content and the techniques necessary to assist class participants in processing the information that they are learning.

Teachers have been trained in each of the three pilot states (IL, SC, and UT). Here are some of the comments from teachers that completed the training:

What a great experience! NAMI Basics has been a class that has been a need for a long time. The information in each class is exactly what parents are looking for and have been asking for.



Dr. Teri Brister, Kathy Grieve, and Andrea Blair during the NAMI Basics training in Utah. (from left to right)

I was able to see just how much my son struggles with his own mental illness. I feel like I have a much better understanding, and much less guilt.

The program takes families step by step through the system and how to access information and programs. I am so, so excited to get started teaching this class. It is going to change and improve so many lives.


What's next?

Plans are underway for the development of stand alone, topic specific training modules that will be available to states that are implementing the NAMI Basics program. The first two modules to be developed will be on transition-age issues and on how to develop an effective Individualized Education Plan (IEP). These modules will allow states and affiliates to provide additional training for parents and caregivers above and beyond what is available in the core NAMI Basics curriculum.

The NAMI Basics webpage (www.nami.org/basics) includes *Frequently Asked Questions* about the program, including information on how to find a class in your area. The website also features NAMI's Medical Director, Dr. Ken Duckworth, on video clips answering a series of questions that are commonly asked by parents and caregivers. This webpage will be continually updated with resources for parents and caregivers.



Participants in the first NAMI Basics training in North Carolina (from left to right standing) Heidi Cranford, Dr. Barbara Burns, Chary Sundstrom, Peggy Hawthorne, Sandy Nagle, Cathy Swing, Nathania Allen, Yvonne Burdick, Briana Fishbein, Linda Swann, Dr. Kimberly Hoagwood, Lynn Stipe, Donna Reilly, Lisa Cook and Gail Ling and (from left to right sitting) Jacqueline Clemons, Terry Brown, Kathryn Hill and Dr. Teri Brister.

For more information on NAMI Basics, visit www.nami.org/basics or contact Teri Brister, Ph.D., Director of NAMI Programs for Young Families, at tbrister@nami.org. 

The Evolution of Teen and Parent Support Groups

by **Cathy Hatch**, Executive Director, NAMI Polk County, Florida.

NAMI Polk County is a grassroots affiliate located in central Florida between Tampa and Orlando. We serve several cities and rural communities in our county. We recently started a support group for teens living with a mental illness and a parallel group for their parents. The two groups meet at the same time and in the same building, but in separate rooms.

The seed for these groups was planted two years ago when we held our first *Parents and Teachers as Allies* (PTAsA) presentation. Although PTAsA is designed as a teacher in-service training program, we have not yet been invited to deliver the program in the school system. So instead we decided to offer PTAsA as a community event, inviting parents, teachers, and mental health professionals to attend. We used PTAsA as the foundation for our event but then built on it.

We invited local mental health providers to come to the event and set up information booths so parents and teachers could meet local providers at the resource fair. We were able to get a local hospital to provide CEU's for mental health professionals and the public school system gave teachers professional credit for attending. The event was held on a Saturday at First Presbyterian Church of Lakeland, which donated the space. We had 125 people attend the event.

To make the most of the day, we began with the basic PTAsA presentation. Then we added to the program by including a local college professor, Dr. Richard Marshall, a child psychologist, who spoke about parenting children with mental illness. After

Participants expressed a need for both parent and youth support groups.

Dr. Marshall's presentation, we included Dr. Paul Suich, a psychologist on staff at the hosting church, who spoke about the importance of support. We ended the day with Lt. Brian Garrett of the Polk County Sheriff's Department who explained Crisis Intervention Training (CIT) and told families how to call 911 to request a specialized officer during a mental health crisis.

This entire event was filmed by the local county government television station. The television producers were so impressed with the presentations that they showed them on local television 11 times! The cost of the event was covered with grant funds and those attending paid \$10 to cover the cost of lunch, which was provided by the church.

During the *Parents and Teachers as Allies* presentation, we offered an evaluation form to those attending. In addition to our standard evaluation questions, those completing the form

were asked if they were interested in participating in a support group. This allowed us to identify the local need for and interest in support groups.

Participants expressed a need for both parent and youth support groups. However, no one in the community stepped forward at that time to become group leaders. We found that the children's story — *The Little Red Hen*, applied to our situation — everyone wanted to eat, but no one wanted to work. So for more than a year the idea of support groups for parents and youth lay dormant.

Then in the summer of 2007, I was asked to visit an adult support group in Winter Haven, Florida. When I walked into the group on a Thursday evening and looked around the room, I saw the smiling faces of a dozen people ranging in age from about 40 to 80 years old...and then there was Lindsay. Among the consumers gathered in that group sat a petite young lady with bright blue eyes and braces on her teeth — all of 15 years old. Lindsay had recently been diagnosed with bipolar disorder. Through the support and encouragement of her father, she attended this adult support group faithfully and participated wholeheartedly.

It was during that adult support group meeting that Lindsay and her father asked if we had a group for teens. I told them that we did not, but if they were interested in helping start one I would do all that I could to make it happen. Two months later the first teen and parent support groups debuted in our county.

Everything fell into place miraculously. The same week that Lindsay and her father volunteered to help begin a group for teens, two other people

contacted me asking if they could volunteer to help me with something — anything. Bill, an adult consumer who is an ordained minister, has a background in mental health counseling and teaches at a local college. Doris, a young woman who works for a community mental health provider as a forensic case manager and had once taught Exceptional Student Education (ESE) to middle school students, also came forward. I asked Bill if he would help Lindsay’s father begin a parent support group and he agreed. Then I asked Doris if she would help Lindsay lead a teen support group and she agreed.


The next obstacle was to find a location for the group meetings. After making a few phone calls, I located St. John’s United Methodist Church. They readily agreed to be the host location for the groups at a cost of \$5 per night. News of the support groups spread quickly and the local newspapers ran several articles announcing their formation.

Three teens and eight adults participated in the first meeting. That may sound like a small beginning, but we were thrilled and saw it as the beginning of great things for those attending. At the time of the writing of this article, the groups are just over one month old.

I wanted to share the process of beginning these groups. As an executive director my approach to leadership is to identify the energy that is around me. If there is enthusiasm and energy for a project, then it is likely to succeed. If there is a champion for the cause, then the cause is likely to succeed. In the case of these groups, we found both the energy and the champions. In fact, the groups really came to us.

Finally, I would be remiss to not mention the role of the faith community in this project. Most of those who stepped up to help with the leadership of these groups are people of faith who feel called to help other people. The local churches mentioned in this article have been essential to our success by

allowing us to use their facilities. I must add that I believe that faith has played an important role in my success as a NAMI leader. My husband is the pastor of a church and I count on his prayers for my ongoing and continued success.

For more information about the recently launched teen support group in Polk County, contact Cathy Hatch (ph: 863.616.9642 or email: namipolk@verizon.net). 

In the case of these groups, we found both the energy and the champions. In fact, the groups really came to us.

B O O K R E V I E W

I’m Not Alone: A Teen’s Guide to Living with a Parent Who Has a Mental Illness

by **Michelle D. Sherman, Ph.D.**, and **DeAnne M. Sherman.**


List Price: \$20.00
Soft Cover: 129 pages (2006)
Publisher: Seeds of Hope Books

One of very few books written specifically for teenagers with a parent living with a mental illness, “I’m Not Alone” offers detailed advice, examples, and exercises to help teens address the challenges they face when their parent has a mental illness. Designed as both an educational guide and a workbook, this book offers both information and exercises for readers that examine their feelings and coping strategies.

The book is divided into three parts, with the first focusing on the basics of mental illness, substance use, and treatment; the second discussing life with a parent with a mental illness — teens’ feelings about it, self-care, and coping skills; and the last part representing a wrap-up section that includes commonly asked questions, a resource list, lists of common feelings and reactions to living with a parent



with a mental illness, and activities to help teens through the rough times.

The book’s tone is relaxed and friendly. The authors maintain a realistic view of the challenges that adolescents face when dealing with a parent with a mental illness. Teens represent a large percentage of family members living with a loved one with a mental illness, which presents its own set of challenges. These challenges are then coupled with the life changes that teens routinely undergo. Teens, as a unique and sometimes overlooked age group, need guides like this one to remind them that they are not alone. 

Editor’s Note: A special thanks to our reviewer, Ann Wroth, for her valuable contribution in reviewing this book.

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This publication is funded by an unrestricted educational grant from McNeil Pediatrics Division of McNeil-PPC, Inc. According to NAMI policy, acceptance of funds does not imply endorsement of any business practice or product.



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