Sensory Processing Disorder and ADHD

Collaborative Problem Solving
Co-occurring Mental Health and Substance Use Disorders in Young Adults
Federal Health Reform: What Does It Mean for Children and Youth Living with Mental Health Conditions?

On March 23, 2010, President Obama signed into law The Patient Protection and Affordable Care Act, comprehensive health reform legislation. The new law includes many provisions that will benefit children, youth and their families by improving access to coverage and the quality of health care, including the following:

- **Requires health insurance coverage for all.** Beginning Jan. 1, 2014, the law requires all Americans to purchase health insurance.

- **Creates a national high risk pool.** Establishes a temporary high-risk insurance pool program for individuals with a pre-existing condition and those who have lacked insurance coverage for at least six months. This begins 90 days after enactment of the law and ends on Jan. 1, 2014.

- **Creates insurance exchanges.** By 2014, states must establish state-based insurance exchanges that allow individuals and small businesses to purchase affordable insurance coverage. Income tax credits will be available for families with incomes less than 400 percent of the federal poverty level to purchase insurance coverage. The law requires all health plans in the exchange to offer mental health and addiction services.

- **Expands Medicaid.** In 2014, the law expands Medicaid to all individuals under the age of 65 with incomes up to 133 percent of the federal poverty level.

- **Extends CHIP.** Preserves and extends the Children’s Health Insurance Program (CHIP) through Sept. 30, 2019. CHIP helps to ensure that low-income children receive health care coverage.

- **Prohibits pre-existing condition exclusions.** Insurers are prohibited from denying insurance coverage to individuals with pre-existing conditions. Any individual denied coverage because of a pre-existing health condition will be eligible for assistance through the national high risk pool until Jan. 1, 2014 at which time insurers are prohibited from using pre-existing conditions to deny health coverage to individuals.

- **Extends coverage for young adults on their parents’ plans.** Beginning six months after enactment (Sept. 23, 2010), insurers must allow young adults to remain on their parents’ insurance plans through age 26.

- **Applies mental health parity.** The federal mental health parity law protection applies to all health plans purchased through insurance exchanges and all private health insurance plans.

- **Prohibits lifetime and annual limits on benefits.** Beginning six months after enactment, insurers are prohibited from setting lifetime limits on benefits for individual and group health plans. Beginning Jan. 1, 2014, insurers are prohibited from setting annual limits on benefits for individual and group plans.

- **Extends Medicaid for foster youth.** Beginning in 2014, the law extends Medicaid coverage to all youth up to age 25 who were previously in foster care for a minimum of six months.
Collaborative Problem Solving

by Ross Greene, Ph.D., author of The Explosive Child and Lost at School and associate clinical professor, Department of Psychiatry, Harvard Medical School

Why do some children have significant behavioral challenges while others do not? Research over the past 30 years provides some clear answers. There is a compelling body of research indicating that behaviorally challenging children are lacking crucial cognitive skills, especially in the general domains of flexibility/adaptability, frustration tolerance and problem-solving. While much of this research has been conducted on children categorized by specific diagnoses—such as attention deficit/hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), conduct disorder (CD), nonverbal learning disability (NLD), autism spectrum disorders (such as Asperger’s disorder) and mood and anxiety disorders—it is the lagging skills, rather than the disorders, that help you understand why a child is behaviorally challenging.

For example, while it may be useful in some ways to know that a child has been diagnosed with ADHD—especially if you are hoping people will take the child’s difficulties seriously—it is even more informative to know that a child lacks the skills to:
• shift efficiently from one mindset or task to another;
• do things in a logical sequence or prescribed order;
• persist on challenging or tedious tasks;
• reflect on multiple thoughts or ideas simultaneously;
• maintain focus;
• consider the likely outcomes or consequences of his actions; and
• consider a range of solutions to a problem.

It is not hard to imagine how these lagging skills may set the stage for challenging behavior. Of course, these lagging skills can be found in children who carry diagnoses other than ADHD as well as in children who carry no diagnosis at all.

Similarly, while it could be helpful to know that a child meets the diagnostic criteria for Asperger’s disorder or NLD, it is likely to be far more informative to know that the child is a very concrete, literal, black-and-white thinker and lacks the skills to:
• handle unpredictability, ambiguity, uncertainty or novelty;
• deviate from rules and routines;
• shift from his or her original idea, plan or solution;
• take into account situational factors that would suggest the need to adjust a plan of action;
• attend to or accurately interpret social cues and social nuances;
• appreciate how his or her behavior is affecting other people;
• appreciate how he or she is coming across or being perceived by others; and
• appreciate another person’s perspective or point-of-view.

Once again, it is these lagging skills that set the stage for challenging behavior in the children who lack them. And, again, these difficulties can be found in children who carry diagnoses other than Asperger’s disorder or NLD, as well as in children who carry no diagnosis at all.

In sum, the research of the past 30 or more years has helped us understand that children are challenging because they are lacking the skills not to be challenging. In other words, challenging behavior represents a form of developmental delay. Of course, the fact that behaviorally challenging children are lacking crucial cognitive skills could lead to the assumption that lagging skills are the only factor contributing to challenging behavior. However, challenging behavior does not occur in a vacuum. It occurs when the cognitive demands being placed upon a person exceed that person’s capacity to respond adaptively. This definition of challenging behavior applies not only to challenging children—it applies to all of us. In other words, challenging children are not terribly different from the rest of us. However, because they are lacking some crucial skills, they may be behaviorally challenging more easily, more often and in ways that are more extreme than those who are not lacking these skills.

The circumstances or situations in which the cognitive demands being placed upon a child exceed his or her capacity to respond adaptively are called unsolved problems. Fortunately, each challenging child has an identifiable and predictable set of unsolved problems. For example, if a particular homework assignment requires skills that a particular child is lacking and, therefore, increases the likelihood of challenging behavior, then that homework assignment is an unsolved problem. Other common home-based unsolved problems, include:
• completing chores;
• the amount of time a child is spending in front of a TV or computer screen;
• what or how much a child is eating;
• brushing teeth;
• adhering to curfew; and
• more.

The goal of interventions is to solve these problems. Once they are solved, they will not continue to cause challenging behaviors.

This, of course, leads us to an interesting question: has our improved understanding of the factors contributing to children’s challenging behaviors changed how we try to help them? The answer: not as much as you may think. In many settings—homes, schools, inpatient psychiatry units, residential facilities, detention settings—the primary way in which the problems giving rise to challenging behaviors are solved is through unilateral problem solving, continued on page 4
Prohibits dropping insurance coverage when people get sick. Beginning six months after enactment, insurance companies are prohibited from withdrawing coverage when a person gets sick as a way of avoiding covering the costs of the person’s health care needs.

This is by no means an exhaustive list of the provisions that are included in the recently enacted federal health reform law. The law includes many other provisions. NAMI continues to develop tools related to the implementation of the law and the interplay between this law and the federal mental health parity legislation. Stay tuned for updates and alerts!

State Advocacy 2010

In light of the budget crises in nearly every state, NAMI recently added a new State Advocacy 2010 section to the NAMI website. It includes tools, resources and advocacy materials that can be used to oppose proposed budget cuts to mental health services and supports and to build an effective advocacy agenda.

All too often, the mental health and social service systems are the first on the chopping block when governors and local community leaders are forced to cut budgets. It is critical that advocates speak up for children, youth and young adults living with mental health conditions to take funding services for this population off the chopping block. Those causes with the loudest protectors are often the last to be cut! It is our hope that the new State Advocacy 2010 section of the NAMI website will help support your work as we raise our collective voices. To access this new website, visit www.nami.org/stateadvocacy.

NAMI Basics Education Program

The Fundamentals of Caring for You, Your Family and Your Child Living with Mental Illness

The NAMI Basics education program provides parents and other family caregivers of children and adolescents living with mental illness with the information and support they need to make the best decisions possible for their children, families and themselves and to cope effectively with their situation. To learn more about NAMI Basics, visit the NAMI Basics website at www.nami.org/basics.
Two “Look-alikes:” Sensory Processing Disorder and Attention Deficit/Hyperactivity Disorder

by Carol Kranowitz, M.A., author of The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder

Picture Brian. While the other children are settling down to a workbook task, Brian rocks in his seat, whining, “Owwwu,” and rubs his arm where a classmate grazed him en route to her chair. Abruptly, he stands and shoves his desk away from passing children.

The teacher frowns and says, “Sit down, stay put and start working, Brian!”

He wriggles in his seat and asks, “Um, what are we supposed to do?”

The teacher replies, “Pay attention! Page 36, even-numbered questions.”

He gropes inside his messy desk, finally locates the workbook and drops it. Retrieving it, he sags to the floor. He plops into the chair again, grips a pencil like a dagger and starts writing—but plops into the chair again, grips a pencil like a dagger and starts writing— but presses so hard that the point breaks.

He hurls the pencil across the room and screams, “I hate this!”

Brian is inattentive, impulsive and fidgety. Does he have attention deficit/hyperactivity disorder (ADHD) or sensory processing disorder (SPD)? Recognizing the differences between these two disorders and providing appropriate treatment can greatly benefit children and adults like Brian.

Like ADHD, SPD is a neurological problem affecting behavior and learning. Unlike ADHD, SPD is best treated with occupational therapy using a sensory integration framework. This therapy addresses underlying difficulties in processing sensations that cause inattention and hyperactivity.

In The Out-of-Sync Child, I define SPD as the “difficulty in how the brain takes in, organizes and uses sensory information, causing a person to have problems interacting effectively in the everyday environment.” Sensory stimulation—too much, too little or the wrong kind—may cause poor motor coordination, incessant movement, attention problems and impulsive behavior as the child strives to get less—or more—sensory input.

Brian’s central nervous system inefficiently processes tactile sensations. The slightest touch overwhelms him. As a “sensory avoider,” he is over-responsive and cannot regulate, or “modulate,” sensory input. Also, touch stimulation confuses him. As a “sensory jumbler,” Brian cannot discriminate differences among sensations.

How does his SPD play out? Brian cannot interpret how objects feel when they contact his skin. His chair, desk contents, workbook, pencil and classmates bother or befuddle him. Fidgeting and squirming, he pays a lot of attention to averting ordinary tactile sensations. Meanwhile, he pays scant attention to the teacher’s words or classroom rules.

Imagine Dana, a child who processes movement and balance sensations very slowly. This under-responsive child, or “sensory disregarded,” has difficulty starting or stopping an activity. With encouragement, she eventually settles into a swing, enjoying the movement that helps her nervous system get organized. However, Dana does not know when to stop. She swings and swings, inattentive to her own body-centered sensations screaming, “Enough!”

Envision Jayson, a “sensory craver” who needs much more action than his peers. An impulsive “bumper and crasher,” he seeks intense, vigorous movement. Constantly, he rocks, climbs, gets upside-down and gyrates, darting from one experience to another. He pays much attention to satisfying his craving for movement and little attention to his mother’s instructions or where he left his shoes.

Before jumping to conclusions, professionals, parents and teachers should consider the whole child to thoughtfully determine the best support.
observe his or her behavior and ask: Where, when and how often does his or her inattention occur? What is happening, or not happening, when he or she concentrates well? What is his or her “self-therapy?”

When overloaded, an over-responsive child needs less stimulation. How can we help? We can undo something! Over-the-counter first aid for this child may be decreasing the offending sensations. We can make his or her environment softer, dimmer, quieter and calmer.

Then, we can do something! Comfort the child with “deep pressure” such as a massage or bear hug. Create a retreat under the dining room table or in a classroom corner with pillows and a sleeping bag to burrow into. Apply deep pressure on skin and muscles to get the child organized and ready to participate and learn. Provide heavy-work activities, including pushing a grocery cart, pulling a wagon, lifting weights or carrying a book carton. Ensure daily outdoor play (movement always helps, so the more recess, the better). Jog together around the block or playground. Offer opportunities for gentle roughhousing. Give the child a rolling pin for pressing dough, a shovel for digging, a bar for chinning, a hammock for swaying, a wad of gum for chewing or a trampoline for jumping.

When “underloaded,” an under-responsive or sensory-seeking child needs extra sensory stimulation. Again, we can do something! Provide sensory-motor experiences like those mentioned above. The under-responsive or seeking child needs them, too, in varying degrees. Similar activities may calm one type of child and invigorate or satisfy another.

Providing just the right sensory-motor input will certainly help a child with SPD. No surprise, sensory-motor input will also help the child with ADHD. Indeed, it will help everyone, because we all require frequent, daily sensory-motor experiences.

A sensory diet may be the best “medicine” for the child experiencing attention problems as a result of SPD. An occupational therapist can develop an individualized sensory diet with appropriate touch and movement experiences. An approach that excludes medications and includes movement, deep pressure and heavy work never hurts and often helps the inattentive child whose problem is not ADHD but developmentally delayed sensory processing.

To learn more about SPD, contact Carol Kranowitz, M.A., at CarolKranowitz@out-of-sync-child.com.

**Suggested Reading:**

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**A Focus Group Report: A Conversation with CIT-trained School Resource Officers**

A focus group in Lake Charles, La. with approximately 30 school resource officers (SROs), SRO supervisors and related personnel who had previously received CIT training with a focus on youth. The SROs who participated in the focus group provided comments on the training they received and shared their thoughts on areas in which additional and more intensified training would be helpful as they addressed the needs of students with mental health needs.

NAMI developed a focus group report titled, *A Conversation with CIT Trained School Resource Officers,* that outlines the valuable feedback, input and thoughts the SROs provided during this focus group. The report also includes recommendations on topics that NAMI believes should be covered in CIT for Youth training and changes that should be made in schools and other child-serving systems to improve the school environment for SROs, school staff and all students, especially those living with mental health needs. To view the report, visit the Child and Adolescent Action Center website at [www.nami.org/caac](http://www.nami.org/caac).
After Virginia: Billy Inches Toward Normalcy

by Woody Hawthorne, parent and author of Billy: One Family’s Insane Journey through the Virginia Mental Health System

Introduction
After our 26-year-old son, Billy, arrived home with us in Merritt Island, Fla, in April 2008, my wife and I were praying that the change in location would help our son better cope with his attention deficit/hyperactivity disorder (ADHD) and bipolar disorder. I had just finished documenting our story of a 10-year battle in Virginia with his Dextromethorphan (DXM) and alcohol addictions and his mental health conditions in, Billy: One Family’s Insane Journey through the Virginia Mental Health System, and had convinced myself that things certainly could not get any worse. After all, we were away from the gloomy winter weather that had contributed to his depression and also away from mental health and legal systems that did very little to help him cope with his mental health conditions. As we found out, that did not mean that things would be necessarily getting better.

Ever since I had moved the family to Northern Virginia in 1995, my son and wife, Janice, had been after me to move back to Florida. Our son had a very active but normal childhood there and we had convinced ourselves that things certainly could not get any worse. After all, we were away from the gloomy winter weather that had contributed to his depression and also away from mental health and legal systems that did very little to help him cope with his mental health conditions. As we found out, that did not mean that things would be necessarily getting better.

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Ever since I had moved the family to Northern Virginia in 1995, my son and wife, Janice, had been after me to move back to Florida. Our son had a very active but normal childhood there and neither he nor my wife had really adjusted to the busy lifestyle of Sterling, Va. This is where the problems with alcohol and DXM addictions, ADHD and bipolar disorder started taking hold of our son’s life and each year seemed to bring a new suite of problems. We had all hoped that moving back to Florida would give him a new start.

Billy had just finished serving a 14-month sentence in Charlotte Courthouse in Virginia for a hit-and-run charge in April 2008. The incident was precipitated by him taking one of our cars and driving up to a shopping center to get alcohol and hitting another car in the rear as he was making a turn. While in jail, Billy received no mental health care and little exercise time. His stay cost the state of Virginia more than $50,000—money that, in our opinion, would have been much better spent toward his long-term mental health care.

Crisis Intervention Team Officers Made the Difference
In Florida, Billy returned to his addictions, which earned him several stays in a hospital. However, in Florida, getting him to the hospital was much easier because all the officers sent to help were Crisis Intervention Team (CIT) officers. CIT is a dynamic collaboration of law enforcement and community agencies and organizations committed to ensuring that individuals with mental health conditions are referred to appropriate mental health services and supports rather than thrust into the criminal justice system. Instead of being treated as a wanted criminal who needed to be thrown to the ground and handcuffed, Billy was treated quietly and with respect.

Most of the time, Billy was convinced to ride to the hospital willingly. He was treated like a young man who needed help instead of like a dangerous criminal.

Wild Rides
During our fresh start in Florida, I asked Billy to come with me to a baseball game in Tampa Bay, Fla. He was more than happy to go. We had been to Tropicana Field before and thoroughly enjoyed ourselves. This time, however, Billy became manic on our walk to the park from our hotel, imagining that we were going to be taking on gangsters and car thieves prowling in the neighborhoods nearby. The mood did not change after the game ended, after I went to sleep, Billy met a gangster and took my car through the mean streets of Tampa, witnessing drug and prostitution deals. At one time while driving through the worst neighborhoods, he had a gun to his head. He told me later he was feeling invincible and like he was living a video game. Luckily, I had woken up at 4 a.m. and saw the car was stolen. We tracked his whereabouts to a Walmart, where he tried to get cash, and sent the police over to apprehend him and his gangster friend. The gangster was released, but Billy was taken to a Tampa mental hospital where he remained for nine days.

That was the last time we went to a ballgame of any kind.

Following this incident, things calmed down somewhat. He found a new girlfriend in December 2008 and started college at Everest University. When things seemed to be going well, he slipped back to abusing alcohol and was arrested at our home for resisting arrest.

The judge in the case recognized Billy’s mental health conditions and addiction and allowed him to go to a halfway house in Lake Park, Fla. This, unfortunately, turned out to be a bad mistake. Unlike a rehabilitation facility, this halfway house was accountable to no one and Billy was given almost complete freedom. To our horror, addicts were actively shooting up and using in the house. The final straw came when actively using roommates stole much of his property and offered him money for his prescription medicine, only to steal it from him later when he refused to sell it. When Billy got angry because of all the thefts and the complacency of the program director, he was dismissed from the program and dropped off at a Lake Park street.

Billy is now returning to a more traditional program with the support of the courts and we all are expecting him to do well there.

Accomplishments
Although Billy’s struggles are not over, he has made some major strides in

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conquering his conditions. In May 2009, he completed a motorcycle safety course and obtained a Florida motorcycle license. This required him to overcome his fear of tests and many roadblocks that related back to his hit-and-run accident in Virginia. In July 2008, he aced his first college course in psychology at Everest University. With that, he became the first child in our family to get college credit—something he can now brag about to his two older brothers and sister. Not bad for someone whose probation officers in Virginia told me to abandon him in the streets to see if he would “sink or swim.”

Moving Forward: One Step at a Time
With time, comes some maturity and determination. Today with our support, Billy continues his battles, but now he is much more diligent about taking his medication and staying away from DXM and alcohol. Billy plans to resume his studies at Everest and Janice and I are letting him move forward one step at a time. He is also planning to write a book describing what it was like to cope with addiction and mental health conditions, with the hope of spreading some optimism to others with similar challenges.

Creativity and Overcoming Self Destruction
by Alex M. White

Everything started in seventh grade. I began to hear voices. At first I thought it was just someone calling out my name, but as time went on the voices grew stronger, louder and increasingly self-destructive. My auditory hallucinations were so severe that I could not fall asleep without headphones on blasting music in an attempt to drown out the screams. Eventually the voices wore me down and convinced me to kill myself. That was my first suicide attempt.

I was placed in a psychiatric hospital for two weeks. Initially, I was diagnosed with schizophrenia because of the auditory hallucinations. At the time, it was not widely recognized that this could be a symptom of adolescent bipolar disorder. I began taking antipsychotic medication but after much research, I decided to try to go off of them. I did okay for about one year. I got good grades in school, kept busy with sports, band and other activities and functioned as normally as any young teenager. However, in the spring of my freshman year, I was also diagnosed with a panic disorder and prescribed Paxil.

The Paxil ignited a severe manic episode and I lost control. I could not keep track of my dosages and I accidentally overdosed. I was hospitalized again, taken off of Paxil and had a complete breakdown. I had severe withdrawals and did not move for nearly two months. I lay in bed staring at the ceiling, barely eating and not speaking to anyone for days except for the occasional one-word verbal utterance to my father confirming I was still alive. I was an empty shell of a human being.

During this time, I was properly diagnosed with bipolar disorder. Even with the proper diagnosis, the struggle had just begun. Determining the right combination of the right doses of the right medications while I was going through puberty was worse than trying to shoot a moving target—it felt impossible. I eventually dropped out of high school and was home schooled. Every semester I would try to go back but could not handle it. With the exception of a few close friends, I was completely isolated. Suicide seemed like not merely the only option, but the only way to find relief from this unrelenting perpetual depression. I spent weeks planning what would be the least painful way to end my life. Two attempts and a hospitalization later, I was still hopeless.

I began trying to write to get all of the dark, painful emotions out, but I could never find the words that would express how I truly felt. On the outside I looked physically healthy, yet on the inside my mind and spirit could not be in more pain or turmoil. This baffled the people around me and I desperately wanted to explain to them why I was acting the way I was.

Around this time, I started looking at films differently. I realized that the only true escape I felt from what seemed like perpetual misery and instability was when I was watching a
movie. I could put myself in that world. I would forget (or at least be distracted from) my problems for a hour or two. It did not always happen, but what an experience that momentary escape offered when it did. I remember one incident in particular, when after coming off of a prescribed anti-depressant medication, I did not sleep for four days straight. The severe withdrawals caused me to be awake and conscious for over 90 hours straight. It was not until I put on a window of escape. Reception grew into a means of expression. I found that my inability to write down my feelings—the “verbal paralysis” that my illness caused—did not mean I could not be creative or express myself. What I lacked in words I made up for in imagery: an ominous cloud formation, the cracks of a light bulb, an empty street at night or a seemingly bottomless pit. I could not explain how I felt, but if I was lucky I could compose a frame or take a photograph that would convey my feelings in a truer sense than any combination and sequence of words I could draw up.

This “artistic therapy,” along with a therapist who believed in combining traditional and nontraditional treatments, began to help me regain control of my life. By using a Cranial Electrotherapy Stimulation device, I was able to reduce the doses of my prescriptions to a level that did not leave me feeling like a zombie and unable to function. I was able to graduate from high school in four years, something I never thought I was going to be alive for, much less have the chance to walk with my graduating class.

Three-and-a-half years later, I graduated with honors from Montana State University with a B.A. in film. I made an award-winning short film, Une Vignette de Mélancolie, about my depression and suicidal ideation that has played internationally. There were moments I did not think I would make it, days I was tired of fighting and times when I wanted to give up. But through the years, I have learned that I was more than “bipolar disorder.” I was a human being with goals, hopes, dreams and a young man with the best friends and best family you could ask for—a filmmaker with a future.

Editor’s Note: Alex White is a member of the young adult Expert Advisory Group that worked with NAMI to create StrengthofUs.org, a social networking website for young adults living with a mental health condition. Check it out at www.strengthofus.org. We applaud Alex for his tremendous accomplishments and for his contribution to this new online community.

NAMI Launches Social Networking Website for Young Adults

In March 2010, NAMI launched StrengthofUs.org, a new online community for young adults living with mental health conditions.

Developed by young adults, StrengthofUs.org is a user-driven social networking website where young adults can connect with peers, provide support and share personal stories, creativity and helpful resources by creating profiles, writing and responding to blog entries, instant messaging, posting on “The Wire,” engaging in discussion groups and sharing videos, files, photos and other news.

The website also includes an online resource center that addresses topics young adults identified as being critically important to them, including:

- Healthy relationships;
- Campus life;
- Finances;
- Housing;
- Employment;
- Friends and family;
- Independent living;
- Mental health services and supports; and
- Much more.

For this project, NAMI conducted a national survey of more than 280 young adults in the 18-to-25-year-old age group on their social networking habits, resource preferences and support needs. The survey report became the blueprint for StrengthofUs.org. NAMI also worked in close consultation with a young adult Expert Advisory Group. This group was involved in all aspects of the development of the website, including design, social networking components, content and other key features.

StrengthofUs.org was developed in light of the 2008 report by the U.S. Government Accountability Office that highlighted the lack of services and supports available to meet the unique needs of young adults living with mental health conditions. These young adults often straddle the child and adult mental health systems, with neither completely meeting their needs. NAMI was determined to meet young adults where they are, online, in the hopes of reaching those who are looking for information, peer support and resources in their communities as they navigate the unique challenges and opportunities of the transition-age years.

There are already more than 700 active users and lots of activity on the website. Encourage young adults to join the conversation and community by checking out www.strengthofus.org today!
Co-occurring Mental Health and Substance Use Disorders in Young Adults: A Conversation with the Nation’s Leading Expert

by Kenneth Minkoff, M.D., national leading expert on integrated treatment of individuals with co-occurring mental health and substance use disorders and clinical assistant professor, Department of Psychiatry, Harvard Medical School

1. When we talk about dual diagnosis, what does that mean?

Dual diagnosis is a term that often has multiple meanings, which is one of the reasons it is beginning to be phased out. In the past, dual diagnosis has been used to refer to people who had both a mental health condition and a substance use disorder, as well as to people who had both a mental health condition and a developmental or intellectual disability. This can be confusing.

In addition, we are beginning to phase out the term “dual diagnosis” because many people do not want to be labeled by their “diagnosis” and many seek help with multiple issues well before any one knows whether they have a diagnosis or not. Further, we are realizing that the majority of people who are seeking services have multiple conditions, not just two, so the term “dual” can be misleading.

The newer terminology is the term “co-occurring disorders” or, even more recently, “co-occurring conditions.” With regard to mental health and substance use, I define the term as follows:

Any person of any age who has any combination of any mental health issue AND any substance use issue, including trauma, gambling and nicotine dependence, whether or not they have already been diagnosed.

In addition, we are increasingly using the term “people with co-occurring conditions” to reflect the expectation that individuals will often have issues that require attention and intervention including, mental health, substance use, trauma, medical, housing, parenting, legal, disability, financial, cognitive learning and so on. In this way, we are beginning to think about how to design services to reflect the complex needs of the people coming through our doors.

2. How often do young adults living with a mental health condition experience a co-occurring substance use disorder? How do co-occurring mental health and substance use disorders impact the lives of young adults?

Even without accounting for nicotine or caffeine, co-occurring conditions are “an expectation” among individuals with serious mental health conditions. There are a number of epidemiologic studies that indicate that approximately 50 percent of adults with serious mental illness have a life time substance use disorder (abuse or dependence).

In studies looking at generally stable individuals in the community, about 25 to 30 percent have been actively using in the last month, though some studies show that about 75 to 80 percent of the individuals who have any substance use issue will have used in the last year. These figures for current active use are higher among younger adults and even higher, usually in the range of 60 to 80 percent depending on the community, for younger individuals who are in crisis, in acute hospital settings, in trouble with the law or homeless.

As can be seen from the above information, substance use issues are associated with generally poorer outcomes in the lives of young adults who have serious mental health conditions. These individuals are more likely to:

- Relapse and be re-hospitalized;
- Be labeled as “treatment resistant and non-compliant;”
- Engage in self-destructive, suicidal or violent behavior;
- Have co-occurring health issues of all kinds (including Hepatitis C and HIV);
- Become homeless;
- Get in trouble with the law;
- Have difficulty with parenting and child welfare;
- Have financial issues; and
- Most painfully, young adults with co-occurring illnesses are more likely to die, and to die prematurely, from overdoses, accidents, violence and a variety of medical issues.

An important factor to keep in mind is that poorer outcomes are associated even with very mild substance use in young adults with serious mental health conditions. Because young adults with serious mental health conditions have very vulnerable brains, patterns of substance use that are “normal” in their friends and relatives without mental health conditions, are likely to interfere with their recovery.

In fact, research has shown that patterns of use more often than once a week, occasional episodes of intoxication and even occasional use of powerful hallucinogens and stimulants are disruptive enough to the fragile brain equilibrium that over time young adults will do worse than if they were totally abstinent, or, if not addicted, had only an occasional beer or glass of wine.

3. Does alcoholism or drug abuse trigger a mental health condition and/or does a mental health condition trigger alcoholism or drug abuse?

These individuals are more likely to:

- Be labeled as “treatment resistant and non-compliant;”
- Engage in self-destructive, suicidal or violent behavior;
- Have co-occurring health issues of all kinds (including Hepatitis C and HIV);
- Become homeless;
- Get in trouble with the law;
- Have difficulty with parenting and child welfare;
- Have financial issues; and
- Most painfully, young adults with co-occurring illnesses are more likely to die, and to die prematurely, from overdoses, accidents, violence and a variety of medical issues.

An important factor to keep in mind is that poorer outcomes are associated even with very mild substance use in young adults with serious mental health conditions. Because young adults with serious mental health conditions have very vulnerable brains, patterns of substance use that are “normal” in their friends and relatives without mental health conditions, are likely to interfere with their recovery.

In fact, research has shown that patterns of use more often than once a week, occasional episodes of intoxication and even occasional use of powerful hallucinogens and stimulants are disruptive enough to the fragile brain equilibrium that over time young adults will do worse than if they were totally abstinent, or, if not addicted, had only an occasional beer or glass of wine.

3. Does alcoholism or drug abuse trigger a mental health condition and/or does a mental health condition trigger alcoholism or drug abuse?
The answer is yes to both. In fact, there are multiple pathways to developing both mental health and substance use conditions at the same time, including:

- Some people live with a severe psychiatric illness that they inherited genetically and they also may develop an independent problem with substances, either abuse or dependence, which can also be hereditary.
- Some people develop a psychiatric illness independently, due to heredity or other factors, and then find that their previously “normal” substance use pattern has now become a problem that has to be addressed.
- Some people have triggered the onset of a severe and persistent mental health condition that may or may not have started on its own during a period of heavy (and usually out of control) substance use. Methamphetamine, cocaine, hallucinogens and marijuana are common culprits, but this can happen with alcohol, opiates and so-called club drugs (like ecstasy) as well.
- Some people begin using substances after developing a mental health condition in order to cope with painful feelings or symptoms, cope with social isolation or escape from despair. Some of these individuals may continue to abuse substances, but do not become addicted; others may go on to develop substance dependence or addiction.

4. What steps can young adults take if they live with a mental health condition and are concerned that their drug or alcohol use is getting out of control? Should they avoid drugs and/or alcohol altogether?

It is very important for young adults to feel empowered, supported and inspired to have hope for recovery and to be able to take ownership of their own recovery process. No young adult wants to develop a serious mental health condition and figuring out how to make their own decisions about how best to have a happy and productive life is hard, slow work. If they are worried about their substance use, it is their job, and their right, to figure out how to make the best decisions regarding substance use, including nicotine, in order to have the happiest, most successful, productive life they can possibly have.

In this spirit, it is a good idea for young adults to find people they trust, including professionals, family members and friends and, very importantly, peers who are further along the recovery path. It is helpful for young adults to share with them what is happening in their lives and any concerns they have so their family and friends can help them make the best decisions for themselves.

In this context, those who want to be helpful to young adults should not be in the business of asking young adults to avoid substances altogether. The paradox of using substances is that they do make everyone feel better in the short run, at least most of the time. At the same time they are likely to be causing harm to a young adult’s fragile brain in the long run—short-term symptom relief is usually associated with longer-term symptom rebound and worsening. Everyone has to go through their own decision making process and it is the job of young adult supporters not to preach but to partner with them in that process. We make recommendations for abstinence, but it is most important that young adult supporters help young adults figure out step-by-step what they want to do with recommendations they receive.

The biggest danger for young adults is that they will seek advice not from peers who are working on recovery but from peers who are themselves in big trouble. It is more helpful for young adults to “stick with the winners” to get the best advice. The second biggest danger is that young adults often feel that they cannot trust anyone they know to tell the truth about their substance use. If young adults are using drugs and alcohol, and not telling anyone who could help them think about their decisions, other than substance using peers, they are at greatest risk. It is a risk to ask for help, but it is a good risk to take.

It is all of our jobs to help young adults feel that sharing honest information is a good idea, for which they will get a round of applause, and not be punished.

5. What are effective approaches to treating a young adult living with co-occurring mental health and substance use disorders? What are the key factors that make these approaches effective?

The effective approach to helping anyone of any age who has co-occurring conditions is what is generically called “integrated treatment,” where clients engage in a relationship with an individual, a team, a program or a community of recovering peers and clinicians, and in the context of that relationship they work on addressing each of their issues, step-by-step over time, in order to achieve their recovery goals of a happy life.

The Integrated Dual Disorder Treatment (IDDT) Toolkit (available at www.mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/cooccurring/) is an evidence-based toolkit specifically designed for adults, including young adults, with serious mental health conditions and substance use issues. Although some systems have special IDD Treatment teams or programs, these “tools” can and should be applied to any type of program. In many county and state systems, all programs are working on becoming recovery oriented and co-occurring capable, so that people with co-occurring issues can get help anywhere. Key elements of successful co-occurring conditions care include these basic principles:

- Individuals with co-occurring conditions should be welcomed, including when they are actively using, and inspired with hope that they will get help to address all their issues to have a happy life. There should be welcoming “screening” so that it is easy for the client to share all of his or her issues, and have them documented and addressed.
- Relationships should be empathic, hopeful, integrated and strength based and address all problems as primary.
- Substance use issues, like other conditions, do not get “fixed,” so much as people are helped to build on their existing strengths and hopes to make step-by-step progress over time for all their issues in a process that is adequately supported, adequately rewarded (rounds of
ask the doctor

how much work they needed to be successful and help them figure out how to get one piece of additional help and support in order to do a little better the next time. If they are able to trust you enough so you become part of their support system, they may call you when they feel like using, or when they slip, and you can give them a round of applause for calling and help them through the next step.

7. What questions should a person ask about the treatment he or she is receiving to ensure it is effective?

As noted above, providers and systems are in different stages of development related to effective integrated co-occurring services. However, at this time, most providers recognize the importance of helping people with both mental health and substance use issues and most systems have some type of services available.

When seeking treatment, ask the following questions to ensure you are receiving an effective approach to treatment:

- I want help with both mental health and substance use issues. Can you help me? If not, where should I go?
- Do you welcome people who have both types of issues?
- Are your programs and staff working on being integrated and co-occurring?
- How would you help someone like me make progress one day at a time?
- Do you know how to do interventions that are matched to my “stage of change” for each issue?
- Can you help me learn some skills for dealing with substance use, building on what I am already doing right?
- If I tell you that I am using substances will you punish me or will you help me work on it?
- I do not want to be referred to a regular addiction program. I want help from my mental health team for both problems, can you do that?

It is important to note that some systems will say, “We have a dual diagnosis program but it is very small and there is a long waiting list.” If this happens, you should respond by asking, “What can you help me work on right now? I am willing to work with my team to make small steps of progress.”

8. In the co-occurring field, is there a focus on peer support and recovery-focused services? What role do psychosocial interventions play?

Peer support and recovery-oriented services are a critical component of all models of co-occurring services. Best practice models of integrated treatment, such as IDDT, have recognized that for people with co-occurring conditions to be engaging successfully in care, they need to be in a process that focuses on hope and recovery, not just on symptoms and disorders. In this process, peer support is a critical component.

More and more people living with mental illness are working in the field as peer specialists and the vast majority of peer specialists (in my experience, usually four out of five) are in dual recovery. There is a similar model emerging in the world of addiction treatment, called “peer recovery coaching,” that has been researched primarily at Chestnut Health Systems in Illinois by William White, Mike Boyle, David Loveland and others.

All treatment interventions for substance use conditions, whether abuse or dependence, are primarily psychosocial, whether or not the individual has a co-occurring mental health condition. The best practice of “integrated” care involves the best practice for an individual’s mental health condition combined with the best practice intervention for substance use, at the same time, within the same team.

This article continues on NAMI's Child and Adolescent Action Center website, visit www.nami.org/caac.

Editor’s Note: The questions included in this article were submitted by young adults interested in learning more about co-occurring conditions. NAMI greatly appreciates the time and expertise Dr. Minkoff provided for this article.
NAMI North Carolina’s Young Family Program: 20 Years Strong

by Jennifer K. Rothman, young family program director, NAMI North Carolina

Last year, NAMI North Carolina celebrated its 25th anniversary with an annual conference dedicated to looking back at our accomplishments. Much like many families, we have grown! We have seen the organization grow from primarily family members to include individuals living with mental illness. We went from only offering Family-to-Family to offering six NAMI education programs across the state. Best of all, we realized that our Young Family program has grown steadily since its start in 1989. NAMI North Carolina was always aware of the needs of families with children and adolescents living with mental illness and has worked hard to ensure these needs are addressed.

For the past 20 years, the Young Family program has been reaching out to families in need by creating supports and programs that are offered through our 35 local affiliates. We also keep parents of children and adolescents in mind when we plan for all of our events. We always make sure that informational exhibits addressing the needs of children and adolescents are available at all of our conferences.

NAMI North Carolina believes that we all need a stable support system and that is why Young Family Support Groups were developed—to make sure that there is support available for parents of children and adolescents. There are many groups for family members of adults, but they rarely touch on issues with schools, the juvenile justice system, medication and other topics specific to children. Our support groups give these parents a place to go where they are surrounded by other people who are going through the same thing—there is no better support than having someone who understands. We currently offer these groups in seven counties and are continuing to expand.

These families and those that work with children living with mental illness also need to be educated. Our educational presentations get the word out about NAMI while educating parents, schools and other professionals about serious mental illness in children. All of our presentations touch on major diagnoses, early recognition, home and school-based interventions and most importantly, what the child and the family are going through. We have worked hard to get into the school systems since teachers spend as much time with our children as families do, but most do not know how to accommodate a child or adolescent who has been diagnosed with a mental illness. This is where we come in.

Along with educating parents and professionals, NAMI North Carolina has been working to reach out to college students through the NAMI on Campus clubs. These clubs, run by students to help educate the campus about mental health, have worked hard to offer different educational events to help students better understand mental illness and where they can go for help—and that they are not alone! Some events that have been held, include movie viewings (A Beautiful Mind, Out of the Shadows and As Good as it Gets) with a professional panel discussion afterwards, suicide awareness workshops, movie viewings for children with mental illness and their families, stress fests with different de-stressing activities like coloring, playing with clay, getting a massage and more and countless other activities that help to bring awareness to the student population.

Our affiliates across the state have been supportive in reaching out to the younger population because they understand that this generation is our future and we need them to be educated and ready to advocate. We were thrilled when NAMI National released the NAMI Basics program. We held our first teacher training in April 2008. Since then, we have trained 50 teachers, have offered 10 classes and have reached 76 parents and caregivers. We have a highly motivated group of teachers who understand the importance of this curriculum and are doing everything they can to fill up their NAMI Basics classes, all while still keeping their own homes running smoothly.

NAMI North Carolina’s Young Family program is supported through the Division of Mental Health/Developmental Disabilities/Substance Abuse Services Federal Block Grant money. Without this funding, many of the young family activities would not be possible.

We are extremely proud of our Young Family program. We are making sure that all grounds are covered and that children and adolescents and those who care for them continue to be a high priority. We hope to continue to evolve and reach more young families in years to come so that they will one day be educating the next generation.

To learn more about NAMI North Carolina’s Young Families program, contact Jennifer K. Rothman at jrothman@naminc.org.
Educating High School Students One Club at a Time

by Kay Ashby, executive director, NAMI Virginia Beach

Voices of Change
Five years ago, my husband and I were introduced to the world of mental illness. Our 25-year-old daughter experienced a psychotic break. She had been hearing voices for over a year and a half. Unfortunately, we only learned of this at the hospital intake. I said, “Kim, you have not been hearing voices.” Her response, “Oh yes I have. I just did not want to tell anybody. They would think I was crazy.”

We have learned a great deal about mental illness in the five years since she was hospitalized. A NAMI Mutual Education Support and Advocacy (MESA) class opened our eyes through education and pushed us onto the path of advocacy. In 2008, after retiring from teaching, I became a MESA facilitator and took over the presidency of NAMI Virginia Beach.

NAMI Virginia Beach has been building its membership. As a former teacher, reaching out to the high school demographic seemed a natural progression. Not only would we reach a new and critical audience, but a passionate and energetic one as students are often willing to take on important and challenging causes. Fighting the stigma of mental illness and reducing the barriers to assist those in need is precisely such a cause. In October 2008, I began talking to Belinda Hutsenpiller, an AP Psychology teacher and former colleague, about the possibility of forming a mental health awareness club at Cox High School, based loosely on NAMI on Campus.

As serendipity would have it, at almost the same time, Kathleen Wakefield was also approaching Ms. Hutsenpiller about the possibility of forming a club. Ms. Wakefield has a different and much more poignant story. On July 25, 2001, in the space of a moment, Ms. Wakefield’s life changed forever when a police chaplain knocked on her door and informed her that her 21-year-old son, Jake, had died from a self-inflicted gunshot wound. Jake’s suicide gave Ms. Wakefield a new life goal: “It is my deepest desire to honor Jake’s life by educating teens and young adults about depression and suicide.” With this in mind, Ms. Wakefield established the foundation, I Need a Lighthouse (INAL), in 2001 to carry out her mission.

Getting Started
NAMI and INALs club goals mirrored each other, and fortunately, Ms. Hutsenpiller, along with Lisa Kopacz, another AP Psychology teacher at Cox High School, agreed to co-sponsor and form a club. Thus began the first Lighthouse Psychology Club in 2008. The first full meeting was held in February 2009 and more than 40 students showed up. Since that first meeting at Cox High School, three additional Lighthouse Psychology Clubs have been added at Bayside, First Colonial and Ocean Lakes High Schools.

A club’s success depends, in part, on limiting the additional work imposed on the sponsors. To this end, common practices have developed across the clubs, including:

• Students are responsible for getting to and from the events off school grounds;
• There are no dues;
• Teachers receive a small stipend from NAMI and INAL; and
• If the club members want food at a meeting, they bring it.

What We Have Done
Fighting the stigma of mental illness and raising awareness of the community resources available to assist those in need are the most pressing and immediate goals of the Lighthouse Psychology Clubs. This mission is principally met through the education of our members, whether it be broad, introductory surveys of the mental health issues and programs in the community or issue-specific training, such as suicide prevention.

Some of our best programs have taken place outside of the school. For example, the Virginia Beach Psychiatric Center (VBPC) hosted a meeting to discuss careers in the mental health field. The VBPC marketing director was able to provide the students with pertinent and specific career advice, as well as resume writing tips. In addition to the presentation, she arranged a visit to one of the psychiatric floors, which proved to be an eye-opening experience that the students still discuss.

However, we have found that presentations and training alone are not enough. In addition to regular programming, each club is required to engage in a community service project. Toward that goal, this year each club completed a project, including:

• After a presentation by Beach House, a mental health club house, Cox students chose to provide gifts for its members.
• Bayside students learned about The Harbors, an adult psycho-education program, and chose to collect donations for its members.
• First Colonial students sent cards to a senior citizens’ facility.
• Ocean Lakes adopted a family that had not celebrated a holiday or birthday for over two years.

The Virginia Beach School System has recognized NAMI Virginia Beach and INAL as Partners in Education. It is common to see Lighthouse Psychology Club members attending NAMI meetings and participating in NAMI advocacy efforts. Most importantly, an educational light has been has been focused on the facts and realities of mental illness, empowering Virginia Beach high school students to meet the associated challenges and prevent needless future tragedies.

Future Plans
As we marked the first year anniversary of the Lighthouse Psychology Clubs, we did so with our eyes set firmly on the future. Over the next two years, NAMI Virginia Beach and INAL have set the educational mission of forming a Lighthouse Psychology Club in all Virginia Beach high schools. Key information for forming a club, as well as general information regarding existing clubs, can be found on both the NAMI Virginia Beach website (www.namivb.org) and the INAL website (www.ineedalighthouse.org).

In the more near term, we look forward to continuing to develop and enrich our existing educational programming. We will visit Paul Aravich, Ph.D., a professor of neuroscience at Eastern Virginia Medical School whose passion is exploring the limitless possibilities of the brain. In his presentation, The Universe Between Your Ears, Dr. Aravich passes out gloves so that the audience may see and feel the brains he is discussing.

Tips for Getting Started with High School Clubs
Finding the right sponsor is the critical first step. It is worth remembering that:
• Psychology teachers meet regularly with students who have shown an interest in the field;
• Health and physical education teachers in Virginia Beach teach a unit on suicide education and prevention; and
• Guidance counselors deal with mental health issues on a regular basis.

So far, all of our sponsors have come from one of the above fields, with four psychology teachers, one health and physical education teacher and two guidance counselors. However, potential sponsors are certainly not limited to just these departments. An enthusiastic, well-liked teacher is key. While a co-sponsor is not necessary, it can lighten the sponsor’s load. Remember that each school system has its own requirements for starting a club and a teacher/sponsor is most likely best equipped to navigate these specific issues.

Finally, the clubs are meant to be educational and fun and are definitely not designed or equipped to serve as counseling sessions. While a representative from NAMI Virginia Beach or INAL attends each meeting, student officers run the meetings and with the sponsor(s), set the meetings’ tone and direction. Ultimately, it is the students’ club, and so the more the student members take ownership, the more rewarding and enriching the experience becomes for all of the members.

To learn more about Lighthouse Psychology Clubs, contact Kathleen Ashby, president, NAMI Virginia Beach, at mail@namivb.org or Kathleen Wakefield, founder and executive director, I Need a Lighthouse, Inc., at wakefield1@cox.net.

BOOK REVIEW

Turbo Max: A Story for Siblings and Friends of Children with Bipolar Disorder
by Tracy Anglada; Illustrated by Deirdre Baxendale

List Price: $9.95
Publisher: BPChildren

This colorfully illustrated book is a great companion for children, ages 8 to 12, with a sibling living with bipolar disorder. Through a series of Dear Diary entries, Rick, the book’s main character, reveals what life is like living with a sister who lives with bipolar disorder. Rick’s entries exhibit a wide range of emotions, including fear, embarrassment and confusion as he comes to terms with his sister’s illness.

Rick’s diary entries reveal that he longs to win a Turbo Max remote control car in a contest his community is hosting. However, his sister, Mandy, becomes hospitalized, so he is unable to participate in the contest. Fortunately, Rick learns he has a second chance to win the remote control car of his dreams, but he will need the help of his sister. With support from Mandy’s doctor, Rick learns how to work with his sister. He discovers that there are constructive steps he can take to make life easier for both of them. He comes to appreciate Mandy’s many talents and strengths. She helps him reach his dream and in the process recovers from her illness. Through Rick’s journey, children come to understand that bipolar disorder is treatable and that siblings can play a positive role in treatment and recovery. The book encourages siblings to attend support groups and to work with a mental health provider to develop coping skills and to overcome a host of challenges.

The author truly understands the impact that mental illness can have on siblings, especially children. She provides great coping strategies to take many of the bumps out of the road.
In June 2008, the Parent/Professional Advocacy League (PAL) released the research study, *Medications and Choices: The Perspective of Families and Youth*, which outlines the decision making process that families go through when deciding whether to use psychotropic medication to treat their child's mental health needs. The study includes survey data from 274 parents and more than 80 youth on the common experiences shared by the survey respondents. The following examples document some of those experiences:

- Parents reported high levels of satisfaction with the use of psychotropic medications because they worked more effectively than anything else available to them.
- Families described trying alternative forms of treatment for their children, often before and then in combination with psychiatric medications.
- Parents expressed concern about side effects and frustration with trying a succession of medications.
- Parents stressed their need for good communication with their child's prescriber.
- Families reported seeking out several avenues to gather information about medications.
- Parents frequently conveyed that their health insurance was more likely to cover medications than therapy for their child.

- Youth reported satisfaction with their medications, noting that medications made a positive impact on their lives.
- Youth conveyed a desire for privacy around both their diagnosis and prescription medications.
- Youth shared that they did not know what would happen if they mixed their medications with alcohol or drugs.
- Youth expressed that they were often more worried about side effects interfering with day-to-day life than long-term effects.
- Youth reported less ambivalence than their parents about medications. Parents often felt caught between their own experience of the effectiveness of medication and their concerns that medications may be stigmatizing or risky while youth focused on all the ways medications have helped them.

This survey report provides the family and youth perspective and voice in light of the recent national discussions about the rising use of psychiatric medications to treat children and adolescents.

PAL is a family-driven advocacy organization in Massachusetts that is affiliated with the National Federation of Families for Children's Mental Health. To access the survey, visit the PAL website at [www.ppal.net/default/](http://www.ppal.net/default/) (Click on “Publications”).