Spring 2012 • Issue 20

NAMI
National Alliance on Mental Illness

Beginnings

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

Reaching the Next Generation

Cognitive Behavior Therapy and Young Adults

Addressing Mental Health on College Campuses

Youth Voice • Ask the Doctor • Family Voice

NAMI Beginnings
National Alliance on Mental Illness

CONTENTS

NAMI Beginnings is published quarterly by NAMI, 3803 N. Fairfax Dr., Suite 100, Arlington, VA 22203-1701
Ph: (703) 524-7600 Fax: (703) 524-9094

Michael Fitzpatrick, *executive director*
Darcy E. Gruttadaro, J.D., *editor-in-chief*
Dana C. Markey, *managing editor*
Courtney Reyers, *copy editor*
Joe Barsin, *art director*

Guest Contributors:
Lynda Cutrell, M.B.A.
Kenneth J. Dudek, M.S.W.
Jonathan E. Goldberg, Ph.D.
Martha Monfried
Jennifer K. Rothman
Shalanda Shaw

Staff Contributors:
Darcy Gruttadaro and Dana Markey

NAMI, the National Alliance on Mental Illness, is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI advocates for access to services, treatment, supports and research and is steadfast in its commitment to raising awareness and building a community of hope for all those in need.

Stock photos used in this publication are not meant to indicate any particular attitude or opinion on the part of those whose images are being used and are not intended to indicate an endorsement by the subjects.

www.nami.org
Twitter: NAMICommunicate
Facebook: www.facebook.com/OfficialNAMI
NAMI HelpLine: (800) 950-6264

Capitol Hill and State House Watch

by Darcy Gruttadaro, J.D., director, NAMI Child and Adolescent Action Center

Ah, it is campaign season. Candidates are working hard to gain our support. Chances are they are not addressing mental health issues, whether they are running for president, Congress or state office or in local races. This is where we come in. As advocates, it is our job to raise the national consciousness about the impact of these serious health conditions.

Now is a great time to raise awareness about mental health issues. Getting a commitment from candidates allows us to later create "keep the promise" and similar initiatives based on the positions taken on the issues during the campaign.

Here are just a few of the ways to reach out to candidates:

- Visit candidate websites and ask a question about children's mental health.
- Attend town hall meetings and public forums to ask questions.
- Call-in to ask questions when candidates are on radio programs and participating in community events.

If you are not sure what questions to ask, you can try one of these:

- Half of all serious mental illness begins by age 14 and three-quarters by age 24, yet many youth do not have access to effective mental health services. What specifically will you do to improve access to effective mental health services for youth and young adults living with mental illness?
- Mental illness does not go away in bad economic times. In fact, more people than ever are seeking help from public mental health programs. What specifically will you do to strengthen public mental health services and supports?
- We have not made mental health care a priority in our nation, especially when it comes to children. What will you do to improve the mental health care system in our community, state and/or nation?

There are other ways to raise awareness on issues too, including by commenting on candidates' websites, Facebook pages or Twitter accounts. Here are a few examples of 140-characters-or-less statements that you can share:

- More than 50 percent of students living with mental illness over the age of 14 drop out of school. Early intervention can save lives.
- Three-quarters of serious mental illness occurs by age 24. Screening and early intervention improves lives and helps families.
- Early identification and intervention with effective mental health services is cost effective and saves lives.

These questions and statements are just some of the ways you can raise issues with candidates. Many of you likely have other excellent ideas. The key is to raise these issues. There is no better time than now when candidates are seeking our support.

NAMI recently launched a Mental Health Care Gets My Vote section of its website at www.nami.org/election. It includes valuable resources, ideas and tools to use in the fast approaching elections. Please visit the site and share the link with family and friends.

Act Now! Contact Your Congressional Members Today

The Keeping All Students Safe Act has been introduced in both the House (H.R. 1381) and Senate (S. 2020). This federal legislation will protect students from the harmful use of restraint and

seclusion in our nation's schools. No federal laws currently exist to protect students from the harmful use of restraint and seclusion in schools. Some state laws exist, however, many do not adequately protect children.

The consequences of not having a federal law to regulate restraint and seclusion in schools are well-documented. Reports issued by the U.S. Government Accountability Office (GAO), the National Disabilities Rights Network (NDRN) and numerous media stories from states across the country highlight case after case of children suffering serious injury, trauma and death as a result of the use of restraint and seclusion in schools.

Here are some talking points to share with federal legislators:

- The time is long overdue to pass federal legislation that protects students from the harmful use of restraint and seclusion in our nation's schools. These practices disproportionately impact students with disabilities, especially those with mental illness. We need your support to pass H.R. 1381 (in the House) and S. 2020 (in the Senate).
- A report issued by the U.S. Department of Education in March 2012 showed that restraint and seclusion is being used in alarmingly high numbers on students receiving special education services. National data shows that students with disabilities receiving special education services represented 12 percent of students in the data sample, but nearly 70 percent of the students who were physically restrained by adults in their schools. Students need to be protected from the harmful use of restraint and seclusion.
- There are evidence-based approaches to addressing the challenging behaviors of students, while at the same time promoting a more positive and safe school environment for students and school staff. These are addressed within this vitally important legislation.

Contact your House Representatives and Senators today and ask them to support moving this legislation forward. Call them by using the Capitol Switchboard at (202) 224-3121 and email them through NAMI's Legislative Advocacy Center at www.nami.org/advocacy.

Engaging Young Adults in Clubhouses

by Kenneth J. Dudek, M.S.W., president, Fountain House

Founded in 1948, Fountain House developed the first working community (often called a "clubhouse") to help alleviate the social isolation and stigma that often accompany mental illness. Every day, more than 300 members—people living with mental illness—come to Fountain House to contribute their talents, learn new skills, access opportunities and forge friendships.

Members and staff work as partners to operate successful employment, education, wellness and housing programs, perform all administrative and maintenance duties and prepare meals for the Fountain House community. Central to the Fountain House model is a strong culture of acceptance and inclusion as well as a collective responsibility for the work of the clubhouse. Our model has inspired similar programs in more than 400 locations in 30 countries and 32 states and currently serves more than 55,000 people living with mental illness worldwide.

Reaching Young Adults

In 1997, Fountain House implemented a youth initiative and since then, we have brought in 40 to 50 new members under the age of 25 each year. We created a Young Adult Program to address the specific needs of youth transitioning to adulthood, with the hope that early intervention would significantly enhance these young people's life trajectories.

The Young Adult Program is multi-generational. Young adults have weekly planning meetings and some dedicated social outings. However, for the most part, they are integrated throughout Fountain House and work alongside members and staff of various ages. Creating a vibrant space for youth has not meant developing a separate community with different expectations, but rather identifying and strengthening existing elements of our community that are appealing to young adults.

Engaging youth is a tricky business. We employ our most powerful tool—relationships—from the onset to engage them. Fountain House young adults take a lead role in our outreach to agencies and programs throughout New York City that serve children and adolescents. Potential young adult members identify with these presenters who speak about their life experiences and how Fountain House supports their goals. The advantages of this are two-fold: incoming members already know a few familiar faces and young adult members are engaged in the respected and confidence-building role

continued on page 4

continued from page 3

of ambassador for the organization. What truly attracts and engages youth are authentic relationships—both with other members and with staff.

Supported Education Programs

"The work of youth is education" is a familiar refrain at Fountain House. For young adults, education is age-appropriate. It is what most of their peers are doing and what many of our young adults desperately want to achieve. In 2004, with the help of the Sidney R. Baer, Jr. Foundation, we greatly expanded our supported education program to complement our successful supported employment program. Through our Education Unit, we offer assistance with admissions and financial aid applications, peer tutors, distance learning courses led by peer teachers and college liaisons who accompany students to campuses to connect them with their Disability Resource Office or to advocate for them. Our Supported Education Program provides critical ongoing and flexible support for our student members the entire time they are in school. We are thrilled that 80 percent of our student members complete their courses and last year, 14 Fountain House members graduated from postsecondary school.

One of our most successful initiatives has been our micro-grant for educational pursuits. Loosely based upon the Grameen Bank microloan program, we offer scholarships of up to 500 dollars for students pursuing GED or college study. This is a small sum in the context of financing an education, but it does motivate members to organize their plans for school. Applicants, accompanied by their staff workers, must appear before a committee composed of members, staff, board members and donors to discuss their past experiences, their full funding plans and their future aspirations. Semester after semester, students come back to the committee to talk about their progress and to receive advice and encouragement. Last year, Fountain House awarded over 60,000 dollars in scholarships and we have recently added two larger scholarships for graduate-level education.

Other Activities

Fountain House recently opened our newly renovated Lewis Wellness Center. This large, airy space has a beautiful gym and features programming such as meditation, yoga and therapeutic massage. Other opportunities offered through the Wellness Center include our Community Supported Kitchen, where members can prepare nutritious meals in a social setting. It also offers smoking cessation services, organized sports activities and free memberships to the YMCA and other community wellness organizations.

Young people seem to have a natural affinity for technology and Fountain House is expanding our multimedia area to take advantage of that. Young adults are engaged in filming and editing our weekly in-house news show, videos for our website and submissions for our annual film festival. They also work with older members who wish to improve their computer skills.

Lessons Learned

So, what have we learned in our efforts to appeal to and effectively integrate young adults? Young people experiencing mental health issues tend to use alcohol, marijuana or other drugs to self-medicate, preferring to be seen as a drug user before being seen as someone living with mental illness. In response, we have expanded our substance abuse support to include the traditional Alcohol Anonymous approach, Double Trouble groups and a harm reduction program. In addition, we have created partnerships with other programs in the community.

Secondly, we have identified housing as a great need for young adults. Whether they are ready to move out of their families' homes or they are aging out of children's programs, there is limited government assistance for young adults seeking supportive housing in the community, and for most, maintaining an independent apartment in New York City is cost-prohibitive. We can offer housing to some of our young adult members, but we want to develop more housing opportunities that respond to their unique needs.

The third thing we learned is that providers are leery to give a diagnosis of schizophrenia or bipolar disorder to young adults. Stigma runs deep, even among mental health professionals, and providers often feel that labeling someone so early in life will do more harm than good. To be fair, frequently the illnesses are not fully manifested, which makes proper diagnosis difficult. We believe that Fountain House is most effective for people living with schizophrenia, bipolar disorder and major depression. Hence, determining whether we are the best option for some of our young adult applicants when they do not have a diagnosis has been challenging.

It is in this vein that we are launching our newest initiative, Understanding, Networking and Integrating Transitional Youth (UNITY). UNITY is an eight-week targeted youth initiative for a cohort of 10 to 15 young people. Participants will meet at Fountain House three times a week, on evenings when our regular program is closed, to work together on one large project and to receive one-on-one mentoring, goal planning assistance and case management services. At the end of the program, UNITY participants may apply for membership to Fountain House or they may determine that there is another, more appropriate next step.

To learn more about Fountain House, visit www.fountainhouse.org.

What truly attracts and engages youth are authentic relationships—both with members and staff.

Supporting Students: Addressing Mental Health on College Campuses

by Dana C. Markey, program manager, NAMI Child and Adolescent Action Center

Dana C. Markey

There has never been a more critical time to address the mental health needs of college students than now. Colleges across the country are reporting large increases in enrollment.[1] At the same time, college counseling centers are observing an increase in the prevalence and severity of mental illness experienced by students.[2]

Many college students experience anxiety, depression and other mental health conditions. In an American College Health Association report released in 2011, students cited depression and anxiety as among the top impediments to academic performance, along with stress and sleep disturbances.[3] Of the more than 100,000 students surveyed, 31 percent reported they "felt so depressed it was difficult to function" during the past year, 6.4 percent reported that they had "seriously considered suicide" during the year and more than 11 percent reported experiencing some form of anxiety within the past school year.

Given these trends, the demand for mental health services and supports in colleges is expected to increase in the coming years. The increase in enrollment alone is justification for expanding and enhancing mental health services and supports available on college campuses and in surrounding communities. In order for colleges to meet these demands, it is essential that they understand the needs of these students and how best to support them.

In an effort to equip colleges with this important information, NAMI recently completed a national survey of young adults living with mental illness currently enrolled in school or who were enrolled in the past five years. The survey results provide significant insight into the lived experience of students living with mental illness and the services and supports they value most. Some preliminary highlights from the survey include:

- 63.8 percent of survey respondents who stopped attending college are no longer attending because of mental health related reasons.
- 72.7 percent of college respondents experienced a mental health crisis on campus. Yet, 34.2 percent reported that their college did not know about their crisis.
- A majority of survey respondents did not access accommodations through their college's disability resource center, often citing that they were unaware such services and supports existed or did not know how to access them.
- Stigma continues to be the number one barrier to accessing mental health services and supports for college students.

continued on page 6

There has never been a more critical time to address the mental health needs of college students than now.

[1] U.S. Census Bureau (2011). Statistical Abstract of the United States. Retrieved February 16, 2012 from http://www.census.gov/compendia/statab/2011/tables/11s0274.pdf.
[2] Gallagher, R.P. (2009). National Survey of Counseling Center Directors. Retrieved February 16, 2012 from http://www.education.pitt.edu/survey/nsccd/archive/2009/monograph.pdf.
[3] American College Health Association (2011). National College Health Assessment. Hanover, Md.: American College Health Association.

continued from page 5

- Survey respondents emphasized the critical need for the following services and supports to be available on campus:
  - Mental health training for faculty, staff and students
  - Suicide prevention programs
  - Peer-run, student mental health organizations
  - Mental health information during campus tours, orientation, health classes and other campus-wide events
  - Walk-in student health centers, 24-hour crisis hotlines, ongoing individual counseling services, screening and evaluation services and comprehensive referrals to off-campus services and supports

These survey results serve as a valuable reminder that the mental health needs of college students have not yet been met and more must be done to ensure they are aware of, have access to and benefit from mental health services and supports.

NAMI will use the information gathered from the national survey to develop recommended guidelines, activities and resources for colleges to use to address the mental health needs of all students. The data collected will also be used to develop an advocacy agenda that responds to the needs of college students living with mental illness. NAMI recognizes the importance of increasing national attention to the needs of college students. We look forward to ensuring all young adults have a chance at having successful, fulfilling and positive college experiences. A full survey report will be released soon, so stay tuned!

Tips for a Successful College Experience

Students living with mental illness can and do succeed in college, especially when they have the right services and supports. Here are some quick tips for ensuring a successful college experience.

1. **Do your research.** Find out what services and supports are offered through your college's disability resource center and student health center (including accommodations, therapy, medications and crisis services). Also research off-campus psychological and psychiatric services and hospitals. Oftentimes, colleges only offer short-term care so it is important to know what is available outside of campus.
2. **Understand policies.** Take time to review your college's policies and procedures that may impact you, including privacy/confidentiality rules, leave of absence guidelines and processes for responding to psychiatric crises.
3. **Create a support network.** There are many opportunities to connect with others on campus who can provide you with valuable support. Look for opportunities to join study groups, clubs, sports teams, mentoring programs or even peer-run mental health organizations.
4. **Set goals.** Identify specific goals to achieve during college and focus on one at a time to avoid getting overwhelmed. Consider hiring a life coach who can help you set and achieve your goals and develop specific skills. Coaches can often be found through your college's career center or by visiting the International Coach Directory website at www.findacoach.com.
5. **Create structure.** Establish a routine in college that sets time aside for homework, exercising, studying and socializing and positive, empowering activities. Keep a daily calendar to keep track of your commitments and budget your time accordingly.
6. **Think about disclosure.** Only you can decide whether you wish to tell others about your mental illness. However, it may be beneficial to tell a trusted friend, staff member, residential advisor or professor for support. You may also need to disclose your mental illness to receive accommodations if you are having trouble in school as a result of your mental illness. Understand the pros and cons of disclosure before you make the decision to share information about your mental illness.
7. **Understand medications.** If you are taking medication for your mental illness, make sure you know what to do if you miss a dose and where you can get a refill quickly. Also, understand the effects of mixing your medication with alcohol and other substances to avoid dangerous complications.
8. **Take care of your health.** Between academic responsibilities and social events, many students do not get anywhere near enough sleep. It is important to try and establish regular sleep patterns throughout the school year. Equally important is to try and eat healthy and exercise regularly.

For additional resources on these tips, check out **www.StrengthofUs.org**, NAMI's online resource center and social networking website for young adults. The site includes blogs, tip sheets and related media on these topics as well as strategies, advice and support from other college students living with mental illness.

An Emergence
What I Wish I Knew, What I Hope Will Happen Next

by Lynda Cutrell, M.B.A., NAMI Board of Directors

My story might just be your story too. I am a parent who faced dramatically changing behavior in my child. Changes that simply did not make sense. As my daughter started to enter young adulthood, things started to go wrong.

I watched as Daniella, my athletic, 5"11 daughter, who had always been surrounded by clusters of friends, began to isolate herself in her room. The charming junior assistant manager of our local bookstore, who woke at the crack of dawn to unload the morning newspaper deliveries, now needed 10 hours of sleep each night. Then 10 hours drifted to 14 hours and then to sleeping past noon. She was becoming easily exhausted and seemed to be ignoring routine requests. Her grades began slipping too. It seemed she could not concentrate long enough to read assignments, and with that, college prospects seemed to be slipping away.

Her weight began dropping. Routine media reporting, which exaggerated the possibility of toxic ingredients in foods, began to fuel a growing paranoia in her. The impact was clearly observable. At just under 6 feet, she reached a low of 115 pounds.

I assumed it was just a phase or maybe aggressive rebelliousness or possibly even drugs. What could it be?

I coaxed her to see our family doctor, followed by a social worker, then two more. Next was a psychologist. No one offered any clinical advice about what might be happening. Finally, Daniella refused any further examination. I got the label "hover mother" by her health care providers.

I could not blame Daniella for rejecting further counseling. I would not want to be subjected to observation of my mental state either. The frustration was high for both of us. Where was help? What was this?

Over the next six months, other symptoms presented. Daniella attempted self-medication, like so many young adults trying to find a way to relieve the bizarre and confused thinking associated with mental illness. She self-medicated with pot and it seemed to relieve her anxiety. With lowered anxiety, she reconnected with friends and seemed to be coming out again. Maybe it was a phase? I think every parent hopes things will resolve naturally.

> It took three years and for Daniella to reach the point of excessive psychosis before we found help.

By this time, frustration over not receiving answers and lack of help drove me to do daily research on what exactly was happening. My fears were layered by a history of family loss. I had lost my father by his own hand. I wondered if family genetics were at play (how did I not know there was a hereditary component to mental illness)?

I learned about psychiatric emergency rooms and the evaluation process. How might I get that opportunity? The situation presented itself within a few weeks. The police showed up at my door, Daniella had been stopped for a DUI. She was driving high in a highly agitated state and speaking paranoid nonsense. The police were young, concerned guys. They seemed to understand and were willing to offer her a choice: voluntary psychiatric evaluation or court.

We waited for four hours in the emergency room. She knew that there was something wrong too, but was too afraid of ending up in a psychiatric ward. After her medical clearance, there were two themes to her interview questions. Are you depressed? And have you ever heard voices? Daniella knew what answers would get her released so she calmed down enough to answer these questions and was released.

Over the next year, there were three more trips to the psychiatric emergency room. However, Daniella had passed the age of 18 and I had no authority to seek treatment for her. It did not matter when I described her deteriorating behaviors—breaking windows, punching holes in walls, breaking furniture, being unable to maintain hygiene—nothing yielded help for her due to the laws that are meant to protect individuals from involuntary treatment.

It took three years and for Daniella to reach the point of excessive psychosis before we found help. Beyond exhaustion, her father and I found a private group in Cambridge, Mass. that specialized in helping young people with psychosis. Within a few weeks of gaining her confidence and gently observing her symptoms, they knew what was happening. They shared with us some of the most important information about her illness, schizophrenia, including:

- It was not her fault
- It was fairly common
- It could be treated

continued on page 9

Stigma Must Stop

by Shalanda Shaw, age 23

Shalanda Shaw

Editor's Note: *Shalanda Shaw is a member of the Young Adult Expert Advisory Group that advises NAMI on the enhancement and expansion of StrengthofUs.org, an online resource center and social networking website for young adults. We applaud Shalanda for her tremendous accomplishments and for her contribution to StrengthofUs.org.*

Making a difference is an idea of some people, pursued by several and actually done by a few. I want to be among the few that remembers young adults with mental illness.

My name is Shalanda Shaw and I have been diagnosed with bipolar disorder. I was unexpectedly given this news at the age of 16. My world turned upside down. However, life was easier and walls were broken down because I was surrounded by understanding company during this time.

Yes, I was in the hospital for birthdays and even for holidays. I was depressed, suicidal, angry and stubborn. I attempted suicide, "knew better than everyone" and I had my own personal rollercoaster. I felt reduced from a straight-A student to a student who could not memorize five words and their definitions. I was silent and

"Me, Myself and I"

Sometimes I have to wonder
Why me?
What did I do to deserve such a disorder?
I have so many mood swings
I might as well build my own rollercoaster

Come aboard! I have plenty of words to describe myself
Can you read? Can you define them?
Here goes! Enjoy the ride!
And please do, do have a wonderful time
Maybe you will, Maybe you won't
Who knows? Ain't gonna know until you join the boat!

I am enlightened
I am confused

I am on top of the world, feeling the best
I am six feet below the earth, in distress

I have positive dreams of the future
I see a knife, some pills and a sharpened razor

With confidence I am built
I feel shame and guilt

I have magical powers to help others suffering
I pursue great ideas to kill myself
So that others won't have a burden

I can write good poems to exhilarate
I have better suicidal notes that will intimidate

Life is so great
It is a wonderful gift
I wish I wasn't born
Put me in the ditch

You are going up
You are going down
Isn't this ride profound?
Ready to get off?
Can't handle it anymore?
I know the feeling
Isn't bipolar disorder appealing?
Yet reeling?

Time to exit the ride
I won't torture you anymore
I wish I could do that
To my brain, forevermore

I have to say I am jealous
Yet joyous and jubilant
For I am a special
Yes, special little one

withdrawn and went from someone who loved using her imagination to watching television all the time. I went from sleeping seven hours or more to not sleeping at all. I was ostracized and called names. I met stigma. It was and still is uncool, vicious and limitless.

Stigma must stop.

I faced all of these obstacles and they were easier to overcome by hearing stories from my peers. In peer support groups, we related to each other and shared our fears, denials, acceptance and downhill and uphill battles with all signs of stigma, whether it is from our own family or an acquaintance. The bond, the common ground, was there. It broke us down to build us up. We also learned new information about coping and persevering.

Ages 18 to 24 are a pivotal time for many youth. They want to change, make a difference and improve. Education on ending stigma and changing the world for the better is a great way to help these young adults. Understanding from everyone on the issues impacting young adults living with mental illness and having positive thoughts about us is even better.

When I was younger, mood swings took over my life, my kindness to others and my drive to take life in hand and strive. Every hour, I had a different mood. I tried to be nice but if I was angry, I lashed out. If I was depressed, there was no talking to anyone. If I was manic, I could not shut up. So anger, depression and mania were three adjectives that made up, "Me, Myself and I." One of my coping skills is to write poems, so I wrote a poem about "Me, Myself and I." I hope this poem also helps to increase understanding of mental illness and helps to stop stigma.

continued from page 7

They got through to her and she willingly entered their residential program to begin an intensive, 10-month recovery and to learn about and treat her schizophrenia.

The effort it took to find and get treatment is not what anyone should encounter. A three-year delay in treatment would never be tolerated for any other illness. There were signposts everywhere, but the attitude was often to wait and see if she got sufficiently sick and her life became derailed.

I felt safe to talk about what had happened. I was joined by dozens of others who had shared similar experiences. Relief began in a unique community of understanding. I wanted to help others too.

That NAMI Cape Ann community is how I came to my own mission, which is to assemble the early warning signs of schizophrenia for national publication and distribution. I contacted a handful of providers in Boston and I asked: How is it possible that the number one cause of lifetime disability in this age group is so hidden and so difficult to get treatment for? One in 25 young adults will experience schizophrenia or bipolar disorder onset, would you not agree that an open appreciation for the experience of psychosis leads to earlier identification and treatment? The responses from the providers were positive and we began assembling the information.

Had I known the statistics, had I known something about the "age on onset," we could have dealt with her illness earlier.

Had I known there was such a thing as emerging psychosis or known how common this illness is or even known some of the warning signs, years of my daughter's life could have been saved. If guidance from just a single knowledgeable health care provider had been provided, we could have intervened earlier.

All the warning signs that I have now come to know were there. Yet, no one put it all together. Had I known the statistics, had I known something about the "age of onset," we could have dealt with her illness earlier.

The emotional crash from our struggle was like nothing we ever experienced. The only thing that brought me back was the love and support from the NAMI Cape Ann community. It took me two meetings before I could even speak about the pain.

Something was clear sitting around that little table at the YMCA where NAMI Cape Ann held its meetings: I was not alone. I saw several families that existed in happy, loving environments despite living with this illness. The biggest surprise was to see them laugh. Was that possible again? I had just spent the last six months crying, multiple times a day. I had lost many of my friends who did not know how to help.

NAMI's Child and Adolescent Action Center was the obvious place to launch change. We are now looking at what it would take to get this information about the early warning signs of mental illness into high school curriculums. It is a huge undertaking, but with broad education, we could be a nation that graduates a generation of folks that will understand and perhaps be willing to help someone experiencing psychosis and other signs and symptoms of mental illness.

Daniella is now 24 years old. She is living independently, is happy, is back to her charming self and is thinking about her future.

Cognitive Behavior Therapy and Young Adults: An Interview with a CBT-trained Provider

by Jonathan E. Goldberg, Ph.D., licensed psychologist, clinical instructor of psychiatry, Harvard Medical School

1. What is cognitive behavior therapy?
Cognitive behavior therapy (CBT) is an empirically validated form of therapy. This means it has been scientifically studied and found to be effective in addressing various mental illnesses that individuals experience. CBT focuses on the interaction of thoughts, feelings and behaviors and how these different components correspond to different mental illnesses (*e.g.*, anxiety and mood disorders).

With CBT, a provider works with an individual to understand how automatic, negative thoughts can contribute to emotional feelings as well as physical feelings and how the individual can engage in positive behaviors that help to manage these feelings. Behaviors can be adaptive or maladaptive, meaning behaviors can lead to healthier levels of functioning or can lead to detrimental levels of functioning.

When I talk about CBT, I describe it as a form of coaching. The provider is more like a coach who helps individuals practice thinking rationally, managing emotions effectively and developing healthy ways to cope with symptoms. CBT is a collaborative, two-person model so time is spent helping individuals feel comfortable talking about issues and helping them understand that these issues will be addressed collaboratively.

CBT is also a strength-based treatment so it does not focus on vulnerabilities or weaknesses but rather it offers the opportunity to develop strengths. The provider will talk about how to use the capacities individuals already have to address the issues they are facing.

2. How does CBT differ from traditional forms of psychotherapy?
People often assume, rightly or not, that therapy is about digging into unconscious conflicts that are responsible for symptoms. This is a very old way of looking at the therapeutic relationship.

The word I use most to describe CBT is collaborative. It is two individuals in a room who are working on a common goal. As a result, CBT-trained providers are usually engaging, interactive and instructive. They do not just empathetically listen. They are there to help problem-solve and address troublesome symptoms that are getting in the way of an individual's life.

CBT-trained providers focus on identifying practical strategies and adapting different behaviors to support recovery. They may talk about the dynamics behind symptoms, but this is not where they start. They typically start with the individual's goals.

This is different from what providers typically do in traditional forms of psychotherapies. They usually do a lot less talking and teaching and only focus on the specific mental illness that is present.

3. What mental illnesses does CBT treat?
CBT is used for a variety of illnesses. At first, CBT focused mostly on mood disorders and anxiety. However, now it is used with lots of different mental illnesses, including schizophrenia, psychotic disorders, substance use disorders and personality disorders.

Once an individual learns about the CBT model, in terms of how thoughts, feelings and behaviors correspond with each other, it can be used to address many different, diagnosable mental illnesses as well as normal changes in feelings and behaviors.

CBT is often manualized, which means protocols are published to help providers work with individuals in ways that are consistent with the standards for CBT. The manuals differ depending on what issues are being addressed, but the structure of CBT remains pretty similar across all mental illnesses.

4. What does a typical CBT session look like?
Oftentimes, CBT-trained providers will start the first session with an assessment of how well the individual is functioning and what specific issues he or she is there to address and how significant these issues are in his or her life.

There is a lot of initial talk about what the individual is experiencing and how his or her symptoms are impacting relationships, work, school, etc. Providers also take time to understand the onset of the issues the individual is experiencing and their clinical course. For example, they may ask questions like: When did you first start experiencing symptoms? How have they changed throughout your life? How have they impacted different areas of your life?

Most importantly, CBT-trained providers take time in the beginning to understand the individual's treatment goals. It is important from the onset that they understand what the individual is looking for from treatment.

5. How can young adults get the most out of CBT?
In order to get the most out of treatment, coming up with goals is very important. Young adults should have a personal understanding of what they would like from treatment. Much more than other types of psychotherapy, CBT is collaborative, so the provider is looking to understand what a young adult is looking to accomplish. This is going to direct the treatment itself. The provider is there to help the young adult meet his or her goals.

There are homework assignments with CBT. These assignments can include working on challenging automatic, negative thoughts, monitoring symptoms and finding new ways to cope with symptoms. Homework is important to get a sense of the progress being made between sessions. Young adults need to be motivated to work outside of the treatment sessions.

I tell the young adults I work with that a lot of the work does not occur during the 50-minute sessions, but outside of the sessions. I openly encourage discussion via email and phone calls to get a sense of how my young adults are doing when we are not meeting.

I recommend young adults use a notebook to jot down thoughts, particularly automatic, negative thoughts. This helps to get a sense of the anxiety or discomfort these thoughts create and how these thoughts are triggered in different situations (at home, in school, with friends, etc.).

6. How can parents and young adults locate CBT-trained providers?

Luckily, it is easier to locate appropriate providers now more than ever. The internet is a wonderful resource. Young adults can just go online and Google CBT and the state they live in to bring up providers. I had my practice advertised over the internet and most of my colleagues do this too.

Psychology Today (www.psychologytoday.com) provides a wonderful tool that allows people to type in a zip code and a list of providers and their specialties pop up. Young adults may also contact insurance providers. When I enrolled in BlueCross BlueShield, they asked me what my specialties were. Young adults can call their insurance provider to ask for a list of CBT-trained providers that work within their insurance network.

7. What questions should parents and young adults ask providers to ensure they are trained in CBT?

There are providers who advertise that they do CBT but they actually do more traditional psychotherapy. Here are some questions parents and young adults can ask to ensure what a provider is advertising is CBT:

- **Can you explain the difference between CBT and other types of psychotherapies?** If the provider is not able to give you a good sense of how CBT is different, they probably do not have a good understanding of CBT.
- **What additional training have you received in CBT?** I did a lot of training in CBT in my post-doctorate education so definitely ask what specialized training they have received.
- **How do you organize your time within sessions?** This will give a sense of how they spend time during sessions and if it sounds like CBT.
- **How collaborative is your therapy? How much interaction occurs between you and your clients?** CBT emphasizes collaboration and interaction much more than traditional psychotherapies so these are good questions to ask upfront.

Some institutes offer credentials for CBT but it is not common. The Beck Institute for Cognitive Behavior Therapy (www.beckinstitute.org) is a great resource for credentialing.

8. What are some strategies parents can use to engage young adults in treatment and keep them involved with treatment?

Young adults tend to be very self-conscious and do not like to be different. To get young adults engaged in treatment, it is important to normalize what they are experiencing so they feel comfortable seeking help. They need to know that therapy does not mean something is wrong with them. It is important to not identify them as a patient.

continued on page 12

continued from page 11

I encourage parents to normalize mental illness by talking about their own challenges with their children. Everyone experiences fluctuations in mood and anxiety. I tell parents to relate to what their young adult is going through. This helps make him or her less self-conscious when asking for help. Asking for help is a strength. Make it as easy as possible for young adults to ask for help.

Part of keeping young adults involved with treatment is working with their families to get involved too. My favorite families are the ones who show up with the young adult at the first session and talk about the family experience. It is rare that mental health issues are happening within a vacuum. Instead, it is happening within a family system and therefore, the family should be part of the treatment. Young adults feel more comfortable engaging in treatment when they know it is encompassing all of their experiences, which includes their experience within their family.

It is important for parents to be involved with treatment by doing homework exercises with their young adult, learning about the skills their young adult is learning, asking questions and being open to trying new things with their young adult, including doing deep breathing and challenging negative thoughts.

I always tell parents that there is no substitute for just listening and understanding what their young adult is going through. It is easy to become disconnected with what it really feels like to be a young adult and the stress that young adults are under academically, socially and emotionally. It is important for parents to understand these challenges and what their young adult is trying to communicate. Sometimes parents think they have all the answers before they really understand the question.

9. Are there any issues you feel are unique to the young adult population?

There are three top issues I often see in young adults:

- **Anxiety and mood disorders.** There is a lot of anxiety that comes with this stage of life. Self-consciousness and insecurity create intense anxiety symptoms, including panic attacks, obsessionality and compulsivity, in young adults. I also often see mood fluctuations. This often looks like irritability, isolation and withdrawal in young adults.
- **Sleep problems.** Sleep difficulty is one of the most common presenting symptoms for young adults. Their minds are racing at night, which prevents them from falling asleep. I work with them to shut down these thoughts or challenge those thoughts so they can sleep.
- **Bullying.** This is a huge issue and cyber bullying is an increasingly challenging issue. Social media websites are used to pick on young adults and find ways to reach them outside of school. This means young adults have no safe haven from bullying. They cannot be free from negative feedback. Bullying is an issue that needs to be addressed as soon as a young adult starts to feel isolated.

10. What books, websites or other resources do you recommend to families and young adults who want to learn more about CBT?

I recommend the following resources:

- The Beck Institute for Cognitive Behavior Therapy at www.beckinstitute.org

- The National Association of Cognitive-Behavioral Therapists at www.nacbt.org
- The Center for Anxiety and Related Disorders at www.bu.edu/card
- *Psychology Today* at www.psychologytoday.com

I always enjoy books by David Barlow. Another author, David Burns, does a lot of contemporary work with CBT and has several self-help books that include specific strategies people can use to address negative thoughts.

11. What strategies from CBT can young adults use in their everyday lives to address negative thoughts?

Strategies I recommend to young adults include:

- **Keeping a thought notebook.** It is always helpful to log thought processes throughout the day and week. It helps to make thoughts more concrete. It is also helpful to use a friend or family member to provide reality testing for the thoughts. They can ask questions about negative thoughts, look for evidence to support the negative thoughts and challenge the negative thoughts.
- **Thought-stopping techniques.** A lot of people do not realize that they can control their thoughts. There are techniques that can be used to do this. When negative thoughts occur, try saying "stop" out loud or internally or picture a stop sign or a police officer holding up his or her hand. Sometimes individuals wear a rubber band around their wrists and snap it when they have a negative thought. This helps to bring more awareness to these thoughts, which then allows them to challenge their thoughts. These techniques help reign in negative thoughts. CBT is designed to help people develop these techniques.
- **Relaxation techniques.** These techniques include deep breathing, progressive muscle relaxation, visual imaging and meditation. These approaches can help young adults deal with emotions that can come from negative thoughts.

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

NAMI North Carolina: Reaching the Next Generation through College Campuses

Jennifer K. Rothman, young families program director, NAMI North Carolina

Jennifer K. Rothman

NAMI North Carolina is not as diverse along the lifespan as we would like it to be. We have so few young people who are really involved in NAMI North Carolina. We need to work harder in bringing the mission of NAMI North Carolina to the younger generation. Children and adolescents are being diagnosed with mental illness earlier and more often than ever before. These illnesses will be with them through adulthood. Why wait to reach them until they are adults?

While we work tirelessly to educate and reach families and those who work with children and adolescents, we do not want to lose sight of these youth as they transition into college. This is a big step for any young adult, even more so for those living with a mental illness.

I had just graduated from North Carolina State University when I took the position of young families program director with NAMI North Carolina in May 2007. My first task was to develop NAMI on Campus clubs across the state, so it seemed that going back to my stomping grounds was the best bet in getting the first NAMI on Campus. I met with the counseling center at my alma mater, which showed interest, but I did not get a start until I found a faculty member in the Department of Social Work. By fall 2007, the first interest meeting was held and NAMI North Carolina State University was formed.

Currently, the NAMI North Carolina State University, run by Leslee Petersen, has close to 30 active members, including four officers, five permanent chairs and one temporary chair.

"I have gained so many skills as president of NAMI North Carolina State University and I am in the process of creating a stronger leadership tree within the group," Petersen said.

While most of the club's members are psychology and social work students, NAMI North Carolina State University is getting ready to implement a peer-led support group on campus to draw in a wider variety of students. NAMI North Carolina State University holds many events every semester but they consistently have movie nights, de-stress events, In Our Own Voice presentations and they have just added an annual suicide prevention vigil. They also try to have one training every semester. In the fall, they had suicide prevention training and this semester, they hope to have legislative advocacy training.

Since 2007, NAMI North Carolina has established NAMI on Campus clubs at eight universities and colleges across the state. In June 2011, NAMI North Carolina offered seven mini grants to NAMI Affiliates looking to improve the functioning of their affiliate, through the Silber Fund, which is designated for affiliate growth and development. Of these seven mini grantees, two chose to use their funds to develop NAMI on Campus clubs in their communities.

One of those affiliates, NAMI Pitt County, hit the ground running and developed NAMI East Carolina University. This could not have been possible without the hard work of Sandy Matthews, a NAMI Pitt member, who got the interest of students at East Carolina University through their stomachs and need for money by holding an exhibit on campus in September. She gave away free doughnuts and a chance to win a 50-dollar gift card if they were present at the first informational meeting!

Currently, NAMI East Carolina University is going through the process of getting sanctioned as an official East Carolina University organization. They are recruiting members, making contacts on campus and forming their constitution and bylaws. Their goal is to be completely "up and running" by the beginning of the fall semester.

"I would love to see our organization be the voice for those with mental illness on campus," Elana Zipkin, president, NAMI East Carolina University, said. "My hope is that through working with other organizations on campus, faculty and students, we can bring awareness and provide resources to those in need."

What are my suggestions for having successful campus-based clubs? Reach out to professors who have students in their classes who are interested in mental illness. NAMI on Campus is open to all majors, but your best bet would be to start with the psychology and social work departments. Once you are able to find a faculty member, set up an interest meeting (with free food) and have your faculty member send information about the event through his or her distribution lists. Students are always interested in becoming involved with campus activities and clubs. We all know that these are great resume boosters!

Once you have a group of motivated students, have them decide how they want to educate students and faculty about mental illness. Help them plan

continued on page 14

NAMI Eastside Young Adults Support Group Offers Peer Support and Advice

by Martha Monfried, co-president, NAMI Eastside, Wash.

When you are a young adult recovering from a psychotic event, where do you hang out with friends who understand? How do you cope with having to leave college because your brain is not working right and you fear you may never be able to return and get your degree? How do you get out of the house when you are bored out of your mind, but your illness has put you back living with your parents?

One safe place that offers peer support and advice is the NAMI Eastside Young Adults Support Group, which has met for more than two years on the second Thursday of every month at the Washington Cathedral Church in Redmond, Wash. Young men and women aged 18 to 30 years old always show up for the group, which was started by Vicky Walls in August 2009.

Teaching NAMI's Family-to-Family class for six years, Walls saw a need for the Young Adults Support Group from other parents in the classes who shared that their kids were lonely. However, the parents also worried that most of them would not come because they do not think anything is wrong with them.

"Young adults need to feel comfortable about their world," Walls said. "Those with mental illness have different social anxieties. They need to find others who know how they feel. They can learn from each other by sharing their experiences with psychotic episodes, hospitalizations and even jail."

At the support group, the young adults share their frustrations and tell their stories in a safe place where they find that no one is surprised.

"They have all been there," Walls said. "It makes them feel less alone and it reinforces that to get better they have to stick with treatment. That is just the way it is."

Many of the young adults do not want to take their medicine because "it does not feel good. You become an outsider to the world," Walls said. "It takes away their personality, who they are. At the support group, they realize that when they are unstable, they are also outsiders."

The group had only three young adults at first. Now it includes as many as 12 from the communities surrounding Redmond, including Seattle, Bellevue, Edmonds, Woodinville and Kenmore.

Walls lets the young adults run the meeting. "I try not to do too much, just make the new people feel comfortable and make sure everyone introduces themselves. They just talk—talk about their problems, fun things, life, how hard it is to live with a mental illness, where they went to school, what medication they are on and their frustrations about weight gain and side effects from medication. They also all share the same story about how they do not have friends, how they do not have a life, how they sit at home and watch TV and how they are very bored," she said.

The young adults hear about the support group from their parents, parole officers, doctors, psychiatrists, psychologists, social workers and counselors. According to Walls, many come when they are first out of treatment and are still in denial. The older young adults are more regular and give advice to and mentor the younger ones.

"At first the young ones do not believe it, but after a while they come back and listen to the older adults who are very wise and very in touch with their issues," Walls said. "The younger ones say, 'Yeah, you were right. What you said was exactly true.'"

The older adults are also role models. One, age 30, has become Wall's assistant. He is well along in his recovery and is taking a class at Edmonds Community College. Another young man, age 29, works part time at Safeway.

"It has been a blessing to me," Walls said. "I have learned a lot. The young adults are very proud. They need to feel that they are okay. They need friends and companionship. They want to feel and act like they are adults."

To learn more about NAMI Eastside's Young Adults Support Group, contact Martha Monfried at mmonfried@comcast.net.

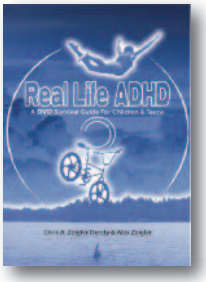
continued from page 13

events on campus where there is a lot of student traffic. Offering some funds to help purchase candy, doughnuts, hot chocolate and other goodies to pass out to students along with mental health statistics, information on the next NAMI on Campus meeting or information on what supports are available on campus, is a great way to find members. As the group grows, the outreach ideas start to flow!

NAMI North Carolina has also offered a share agreement with NAMI on Campus NAMIWalks teams. Each NAMI on Campus team gets half of the funds they raise for the NAMIWalks back in order to help fund events and outreach on their respective campuses.

I have truly enjoyed working with our NAMI Affiliates to develop NAMI on Campus clubs across North Carolina. More and more we see young people attending our events and this serves as a reminder that we always need to be thinking about the next generation of NAMI North Carolina and how we are going to continue our mission of support, education and advocacy.

To learn more about NAMI North Carolina's NAMI on Campus clubs, contact Jennifer Rothman at jrothman@naminc.org.



Real Life ADHD: A DVD Survival Guide for Children and Teens

by Chris Dendy and Alex Zeigler

List Price: $34.95
Real Time: 125 Minutes
Publisher: Chris A Zeigler Dendy Consulting LLC (2011)

Any child, teen or young adult living with attention deficit/hyperactivity disorder (ADHD) will discover that they are not alone in the information-packed DVD, *Real Life ADHD: A DVD Survival Guide for Children and Teens*, produced by Chris Dendy and Alex Zeigler.

The DVD opens up with insightful and humorous comments from Alex Zeigler, author and videographer, and his high school friend, Lewis Alston, a popular Atlanta Radio DJ/VJ. These charismatic young adults show by example that ADHD does not need to be a hurdle to living happy, successful lives. They set a fun, positive and hopeful tone that remains throughout the DVD.

The DVD is full of relatable teens and young adults who share their positive and negative experiences living with ADHD and provide helpful advice, recommendations and strategies for overcoming common challenges with ADHD, including:

- inattention
- disorganization
- forgetfulness
- impulsivity
- hyperactivity

Although some parts run a bit long, the personal stories and anecdotes provide powerful insights into the lived experience of ADHD and provide hope to others living with the disorder. The ten key scientific facts on ADHD and the expert information on medications included in the DVD also contain important information that everyone living with ADHD needs to know.

The DVD falls short in providing information on the value of behavioral interventions in addressing ADHD, especially from the expert perspective. Multimodal treatment, the combination of medication and psychosocial and behavioral interventions, has been shown through research to be the most effective treatment for ADHD. In addition, the DVD does not sufficiently distinguish between normal adolescent behavior and symptoms associated with ADHD, often focusing on issues that every teen experiences, whether diagnosed with ADHD or not.

Despite these minor issues, the DVD still provides great role models for youth living with ADHD and helpful information and, most certainly, viewers of the DVD will feel hopeful, empowered and comforted by the fact that they are not alone.

Save the Date for 2012 Training Institutes on Mental Health

The National Technical Assistance Center for Children's Mental Health at the Georgetown University Center for Child and Human Development is offering Training Institutes on improving mental health services for children and adolescents with or at risk for mental illness and their families.

The 2012 Training Institutes will focus on innovative approaches and how lessons learned from systems of care can guide efforts to improve children's mental health service delivery in a dramatically changing environment.

Participants can attend how-to training in a variety of sessions, including:

- Institutes, workshops, special forums and poster presentations
- General sessions with prominent featured speakers
- Native American services track
- Youth leadership track

There are also four optional, intensive pre-institutes training programs taking place on July 24 and 25 on cultural competence, leadership, health reform and effective residential treatment interventions.

The Training Institutes are designed for state, tribal, territorial and local policy makers, administrators, planners, providers, clinicians, care managers, families, youth, advocates, managed care organizations, educators, evaluators, technical assistance providers and others concerned with improving services for children, youth and young adults with or at risk for mental illness and their families.

Continuing education credits are available for all sessions.

To learn more about the Training Institutes, visit http://gucchd.georgetown.edu.

NAMI Beginnings
National Alliance on Mental Illness

3803 N. Fairfax Dr., Suite 100
Arlington, VA 22203-1701
(703) 524-7600
www.nami.org

Non-Profit Org.
U.S. Postage
PAID
PPCO
24506

This publication is supported by McNeil Pediatrics Division of Ortho-McNeil-Janssen Pharmaceuticals, Inc.
According to NAMI policy, acceptance of funds does not imply endorsement of any business practice or product.

12. What recommendations do you have for parents on addressing the mental health needs of their young adult?
It is important to understand what their needs are and not assume too much. Parents often go back to their own experiences and presume that young adults now are having the same experiences that they did. However, it is a different age and a different era now. Technological advances that have been made with social media and the pressures on young adults are not the same things parents may have experienced growing up.

It is also important for parents to get involved in their young adult's therapeutic, academic and social life. Understand who his or her friends are and how social challenges may contribute to anxiety and depression and what these challenges are. Be open to spending time with the young adult. This seems trite but parents are so busy these days that they often do not have an opportunity to sit down and talk about their young adult's experiences.

13. What recommendations do you have for schools on addressing the mental health needs of young adults?
A lot of issues young adults deal with occur in school. The most important thing schools can do when there is a problem is get the young adult's family involved immediately. Schools should be frank about the challenges they have observed the young adult having on campus. They should work with the young adult and his or her family to develop a plan of support that can be implemented during school. If need be, the plan should identify appropriate outside supports, including providers who can work with the young adult on campus.

Schools should also help the young adult and his or her family find services and supports. The young adult should know who to talk to on campus and that there are places to go to if he or she is having symptoms. It is important to develop a team approach to addressing the mental health issues the young adult is experiencing. The team should check in with the young adult and his or her family to discuss progress and if anything needs to be changed in the support plan to ensure the young adult is progressing.

14. Is there anything else you would like to add about CBT?
One thing I love about CBT is it is a very hopeful and optimistic, strength-based treatment. CBT-trained providers are using resources young adults already have to address the symptoms that are interfering with their functioning. Together, young adults and their providers can make a change. The provider is a supportive person that young adults can be genuine with and trust. CBT is all about working together on common goals.

Also, CBT aims to minimize the power dynamic so young adults do not feel like someone is telling them what to do. Young adults are often turned off by power dynamics so this is important.