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National Alliance on Mental Illness

# *Beginnings*

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

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**The Family  
Experience in  
Primary Care**

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# Capitol Hill Watch

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

## Federal Legislation Focused on Mental Health and Schools

**N**AMI is currently advocating for a number of federal bills that support school-based mental health services and supports. Students living with mental illness do not fare well in our nation's schools. These bills would all benefit from having you contact your U.S. Representatives and Senators to ask for their support and co-sponsorship of these bills.

A simple call to your Congressional members that states, "I am a constituent and would like my [Congressional Representative or Senator] to co-sponsor [bill number] because it will improve the academic and functional achievement of students living with mental illness," is of great value. Of course, it is always helpful to provide more detailed information about why a bill is important. The more we raise our collective voices in support of these bills, the more likely they will move through a committee and ultimately come up for a vote. Below is a summary of the three bills.

### Mental Health in Schools Act (H.R. 751)

In February 2011, U.S. Rep. Grace Napolitano (D-Calif.) introduced the Mental Health in Schools Act (House bill 751). This bill would provide much needed federal funding to create partnerships between schools, community mental health services and supports and other child-serving systems to help ensure that children and youth living with mental illness are identified early and linked with effective services.

This legislation would do the following:

- provide expanded federal funding for grant programs that provide access to comprehensive school-based mental health services and supports;

- provide comprehensive staff development for school and community child-serving systems to ensure that students are connected with effective mental health services and supports and that positive behavioral interventions and supports (PBIS) programs are implemented in schools; and
- provide comprehensive training for children with mental illness, their families and community members about the importance of early identification of mental illness, strategies to connect students with school and community-based services and supports and strategies that promote a schoolwide positive environment.

This model has already been implemented in 14 schools in Rep. Napolitano's district in southern California and has helped tremendously in improving the lives of students and their families. Please contact your U.S. House Representatives and ask them to co-sponsor the Mental Health in Schools Act (H.R. 751).

### Keeping All Students Safe Act (H.R. 1381)

In April 2011, Rep. George Miller (D-Calif.) introduced the Keeping All Students Safe Act (House bill 1381). The bill is designed to prevent and reduce the inappropriate use of restraint and seclusion in our nation's schools by establishing minimum safety standards similar to those already in place in hospitals and other community-based facilities.

There are currently no federal laws that regulate the use of restraint and seclusion in schools. The U.S. Government Accountability Office

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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 of those in need.

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# Advances in the Early Intervention of Psychosis

by **Michelle Friedman-Yakoobian, Ph.D.**, clinical team leader, Center for Early Detection, Assessment and Response to Risk (CEDAR)



*In the first month of starting college, Xavier\* was taken to the emergency room by the police after he was found wandering aimlessly around his university campus without shoes. He was muttering to himself about “mind tricks” being played on him by the government and university officials. To many people, this appeared to come out of the blue.*

*However, in reality, this moment had been years in the making. In ninth grade, Xavier experienced periods when he felt different—as if he was living in a dream. He started feeling overwhelmed at school and his grades slipped from As to Cs. By eleventh grade, he frequently caught himself getting confused about whether something he dreamed about had actually happened. He also found himself feeling like his friends were scheming against him and could somehow tell what he was thinking even though he knew that is not possible. He began spending less and less time with his friends. By his senior year, Xavier’s parents had to struggle with him daily to go to school. Xavier met with his school’s counselor who assumed he was depressed. However, she also had a sinking feeling that perhaps he was developing psychosis. She never discussed these concerns with Xavier or his family because she felt that mentioning psychosis when she was not sure about it would be unduly stigmatizing to him.*

## Prodrome to Psychosis

Contrary to popular belief, psychosis does not come out of the blue. Typically, a young adult will experience several months or years of milder symptoms that cause challenges with school and social functioning. This period of time is known as the

“prodrome to psychosis.” However, the signs of prodrome to psychosis are usually difficult to recognize and may be misunderstood as signs of depression, drug or alcohol abuse, late-onset attention deficit/hyperactivity disorder (ADHD) or even a normal phase of adolescence. It is not until a young person develops clear signs of a first psychotic break (such as in the story of Xavier above) that the symptoms are clearly recognized.

## Early Intervention Clinics

As studies find that developmentally-sensitive, specialized early interventions lead to better outcomes for young adults living with schizophrenia, a

**The idea is to provide early treatment to help young adults stay on track with their lives and to try to prevent full-blown psychosis from developing.**

movement toward even *earlier* intervention has evolved. That is, efforts have been made to identify young adults who are experiencing symptoms that may be part of the prodrome to psychosis. The idea is to provide early treatment to help young adults stay on track with their lives and to try to prevent full-blown psychosis from developing. This work was pioneered by Dr. Patrick McGorry and colleagues in Australia, then spread to the United Kingdom and some other countries and has now slowly become available in some areas of the United States—mostly in locations that are associated with academic medical centers (see the table, U.S. Clinics for Youth at Risk for Psychosis, on page 6 for a list of U.S. clinics).

In Boston, this has led to the development of the Center for Early Detection, Assessment and Response to Risk (CEDAR). CEDAR is affiliated with the Beth Israel Deaconess Medical Center and the Massachusetts Mental Health Center and is funded by the Sydney R. Baer Foundation and the Massachusetts Department of Mental Health. The goal of CEDAR is to connect with young adults like Xavier early on—when they are still able to recognize that their thinking is changing—rather than wait until symptoms become more fixed and disabling. In order to reach young people during this early stage, CEDAR provides free outreach trainings to community youth

agencies, including schools (middle school, high school and college), primary care settings, community clinics, emergency rooms and youth groups to get the word out about the CEDAR program. CEDAR staff members are available to provide expert consultation and evaluation on whether a young adult may be at risk for psychosis. Young adults who are identified as at-risk are offered supports, including family education, school/ work counseling and support, cognitive behavioral therapy and in some cases, low doses of medication to help them get back on track with their lives.

CEDAR is one of less than 20 programs in the United States that

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\* This story is a fictionalized account similar to the stories of a number of young adults who have experienced a first psychotic episode and who have been seen at the Center for Early Detection, Assessment and Response to Risk.

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specializes in identifying and treating young adults who are showing signs of risk for psychosis.

**Research on the Risk for Psychosis**

Currently, the largest study of risk for psychosis in North America is the North American Prodrome Longitudinal Study (NAPLS), which

includes eight sites across the United States and Canada. These sites work together to better understand what happens in the brain when psychosis begins. Another primary goal of the NAPLS study is to learn how to best distinguish individuals who are truly at risk for developing psychosis from those who are experiencing similar symptoms but are not going to develop

psychosis.

Some smaller studies in the United States and from around the world have also been investigating the treatments that may be most effective for helping young people at risk for psychosis. More research needs to be done before firm conclusions can be made about what treatments work. Although early studies have shown some support for

## Dos and Don'ts for Talking with Someone Who May Be at Risk for Psychosis

### Do...

1. **Spend time with the person and keep lines of communication open.** It is easiest to express your concerns in a helpful, non-threatening way when you maintain regular contact and communication. Even if the young adult has been withdrawing from you, continue to invite him or her to join you for dinner, go for a walk or talk on the phone, but also be willing to take no for an answer if the young adult is not up for it.
2. **Express your concerns.** Be open and honest as much as possible. In a gentle, non-judging way, let the young adult know that you have noticed that he or she seems to be going through a tough time or seems to be experiencing changes and that you are available to listen and help when he or she is ready to talk about it.
3. **Let the young adult know he or she is not alone.** Between 4-17 percent of young adults report experiencing sub-clinical (mild), psychotic-like symptoms. These experiences are not rare and there could be a number of reasons why they occur. Letting the young adult know that you are familiar with what he or she is going through and that he or she is not alone can be very reassuring.
4. **Let the person know that there is hope and practical help available.** Clarify what the young adult may want to gain from seeking help. Balance talking about what the young adult wants and what you

think would be helpful. Both medical and psychological therapies (for the individual and his/her family) can help to reduce symptoms, distress and daily difficulties associated with clinical risk.

5. **Be patient and avoid pushing too hard.** When you first express your concerns, the young adult may not want to talk about it. Let the young adult know that you respect his or her privacy—but are available to talk and share information about potentially helpful resources when he or she is ready. Then keep the lines of communication open with the young adult so he or she can warm up to the idea of talking with you about his or her concerns.

### Don't...

1. **Ignore changes in functioning or recurrent odd behavior as being “just a phase” or “teenagers being teenagers.”** Contrary to popular belief, research has found that it is not typical for adolescence to be a time of significant turmoil and distress. While increases in privacy concerns are common, it is not typical for teenagers to refuse contact with friends for long periods of time or to withdraw significantly from family relationships. If you know a young adult who has recently begun to withdraw from others, behave oddly and/or struggle at school and with friends, it is important to offer support and help. There can be a number of reasons why this can be happening. A careful assessment can help the

young adult (and you) better understand what is going on and what types of services and supports can help. Ignoring early warning signs delays early treatment, which has the best chance of being effective.

2. **Act as if you are giving dreadful news when talking about risk for psychosis.** There is a lot we now know about treating psychosis and there is much hope for recovery—especially when it is treated early. Talking with the young adult about risk can provide an important opportunity for the young adult to better understand what is happening to him or her and to get effective treatment that can prevent further distress and negative changes in functioning. If you are comfortable talking directly about the symptoms and daily difficulties as treatable, the young adult will often take your lead and feel reassured. Using everyday language such as “stress” and “changes in experiences or functioning” is also helpful in normalizing the young adult’s experiences.
3. **Push too hard or argue with the young adult if he or she denies that anything is wrong.** If the young adult denies experiencing challenges or refuses to talk with you about your concerns, respect his or her privacy and let him or her know that you are there to help if and when he or she wants to talk. You might gently describe some specific behavioral changes that you have noticed (e.g., “I have noticed that, since December, you


the following:

- cognitive behavioral therapy;
- omega-3 fatty acid supplements;
- intensive community care with family psychoeducation; and
- low-dose antipsychotic medications.

**Future Considerations**

Currently, individuals who are showing signs of risk for psychosis can have a

have been spending a lot of time in your room, your grades have gone down and you have been wearing sunglasses most of the time. I know that a lot of young adults can experience stress during their senior year of high school and sometimes it can help to talk to someone about it. I am here if you decide you want to talk”).

4. **Do not give up and do not forget to take care of yourself in the process.** The young adult may seem more interested in engaging in treatment at some points in time more than others. Steps forward may often be followed by steps backwards as well. To help a young adult get into treatment and stick with it, you may have to try several times and even enlist the help of other family members and friends. Keep a sense of priorities and avoid “sweating the small stuff.” Focus your efforts on the important activities and tasks that matter the most in the long run (e.g., school, well-being/safety and relationships) and not so much on the smaller things (e.g., keeping a room clean). Keep your perspective. The young adult did not choose to have these difficulties. Rather, he or she is currently being challenged by a significant change in functioning that may be due to a neurodevelopmental process or disorder. Lastly, maintain your own positive daily routines and keep in touch with your best supports to recharge your batteries. You cannot help the young adult if you are not caring for yourself first. 

hard time getting treatment because their symptoms may not meet criteria for any specific mental illness in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV). There is a proposal to add “psychosis risk syndrome” to the upcoming fifth edition of the manual, although it is not without some controversy. Those in favor note that this new category would lead to greater awareness about the early signs of psychosis,

would make it easier to justify reimbursement of treatment by insurance companies and would help to prevent the progression of mental illness. Those opposed have noted concerns about false diagnoses. That is, most people who are experiencing symptoms that would meet criteria for the psychosis risk syndrome may not go on to develop psychosis and could be unnecessarily exposed to stigma or medication side effects.

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(GAO) released a report that documented hundreds of cases in which the use of restraint and seclusion led to grave harm and in some cases death for students in public and private schools. Most of these cases involved students with disabilities, including those with mental illness. The media has also documented numerous cases of children living with mental illness being seriously harmed through the use of restraint and seclusion in schools.

This legislation would do the following:

- prevent and reduce the inappropriate use of restraint and seclusion by establishing minimum federal safety standards that schools must follow;
- require states to develop policies and procedures and monitoring and enforcement systems to meet the federal standards and to help keep children and school staff safe in our nation’s schools;
- encourage and create funding incentives for states to provide training and support to school staff to reduce and eliminate the use of restraint and seclusion in schools and create a more positive school environment; and
- increase transparency, oversight, enforcement and reporting requirements to prevent abuse and reduce and eliminate the use of restraint and seclusion in schools.


The time is long overdue to pass federal legislation to place restrictions

on the use of restraint and seclusion in our nation’s schools. Please call or email your U.S. House Representatives and ask them to co-sponsor the Keeping All Students Safe Act (H.R. 1381).

**Achievement through Prevention Act (S. 541)**

The Achievement through Prevention Act (Senate bill 541) would provide federal support for the expanded use of PBIS and early intervening services in schools to improve student academic achievement, create a more positive school climate and reduce student disciplinary referrals.

PBIS is an evidence-based, school program designed to improve school climate for all students, identify students with mental health needs and link these students with effective services and supports. To learn more about PBIS, visit [www.pbis.org](http://www.pbis.org), a U.S. Department of Education technical assistance center on PBIS. Please call or email your U.S. Senators and ask them to co-sponsor the Achievement through Prevention Act (S. 541).

Many thanks for all that you do for children, youth and their families in your communities. The more that we contact our federal representatives to ask for support of children’s mental health legislation, the more that they will act on the issues that are most important to us. 

## U.S. Clinics for Youth at Risk for Psychosis

LOCATION	NAME OF CLINIC	DETAILS
<b>California</b>		
Los Angeles	The Staglin Music Festival Center for the Assessment and Prevention of Prodromal States	Provides assessment and treatment for youth at risk or in first episode of psychosis aged 12-35.
Sacramento	Early Diagnosis and Preventative Treatment	Provides assessment and treatment for youth at risk or in first episode of psychosis aged 12-30.
San Diego	Cognitive Assessment and Risk Evaluation	Provides assessment and treatment for youth at risk aged 12-30.
San Francisco	Prodrome Assessment Research and Treatment Program	Provides assessment and treatment for youth at risk aged 12-35.
<b>Connecticut</b>		
New Haven/Hartford	Prevention Through Risk Identification Management and Education	Provides assessment and treatment for youth at risk aged 12-40.
<b>Georgia</b>		
Atlanta	Development and Mental Health Project	Provides research-based evaluations for youth at risk aged 13-30.
<b>Illinois</b>		
Chicago	First Episode Psychosis Program	Provides assessment and treatment for youth experiencing early stages of psychotic symptoms aged 15-40.
<b>Maine</b>		
Portland	Portland Identification and Early Referral Program	Provides assessment and clinical services for youth at risk aged 12-25.
<b>Massachusetts</b>		
Boston	Center for Early Detection, Assessment and Response to Risk	Provides assessment and treatment for youth at risk aged 14-30.
<b>Michigan</b>		
Detroit	Services for the Treatment in Early Psychoses	Provides assessment and treatment for youth at risk or in first episode of psychosis aged 12-50.
Ypsilanti	Michigan Prevents Prodromal Progression	Provides assessment and treatment for youth at risk aged 12-25.
<b>New Mexico</b>		
Bernalillo County	Early Assessment and Resource Linkage for Youth	Provides assessment and treatment for youth aged 12-25.
<b>New York</b>		
Manhattan	Center of Prevention and Evaluation	Provides assessment and treatment for youth at risk aged 12-35.
Long Island	Recognition and Prevention	Provides assessment and treatment for youth at risk aged 12-22.
<b>North Carolina</b>		
Chapel Hill	Outreach and Support Intervention Services	Provides assessment and treatment for youth at risk or experiencing early psychosis aged 16-36.
<b>Pennsylvania</b>		
Pittsburgh	Services for Treatment in Early Psychoses	Provides assessment and treatment for youth at risk and in first episode of psychosis aged 12-50.

# The Family Experience in Primary Care

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

Primary care physicians and staff are often the first point of contact for families when it comes to the health and well-being of their child. Mental health is no exception. As a result, they are in a unique and key position to identify mental health concerns early and to communicate these concerns with families.

There has been widespread support and calls for identifying mental health concerns in primary care.

- “Mass screening in primary care could help clinicians identify missed cases and increase the proportion of depressed children and adolescents who initiate appropriate treatment. It could also help clinicians to identify cases earlier in the course of disease” (U.S. Preventive Services Task Force, 2009).
- “One of the best indicators of risk for emergence of mental illness in the future is the presence of parental or caretaker concern about a particular child’s behavior. Primary care offices can screen for risk by routinely inquiring about parental concern. The prevention of mental illness and physical disorders and the promotion of mental health and physical health are inseparable” (Institute of Medicine, 2009).
- “The need for primary care clinicians to manage children with mental health concerns only will continue to increase in the future...Primary care clinicians are, and will continue to be, an important first resource for parents who are worried about their child’s behavioral problems” (American Academy of Pediatrics Task Force on Mental Health, 2010).

With this in mind, NAMI surveyed

more than 550 families in 40 states about their experiences in primary care. The survey revealed that 89 percent of families had discussed mental health concerns with their child’s primary care physician. Eighty-three percent responded that they believe primary care physicians should routinely talk about a child’s mental health with families even when there are no concerns. Yet, survey results also showed that:

- 35 percent of families believe that their child’s primary care physician was not comfortable talking about mental health and related issues;
- About 49 percent of families believe that their child’s primary care physician was not knowledgeable about mental illness; and
- Sixty-one percent of families believe that their child’s primary care physician was not knowledgeable about local mental health resources, services and supports.

To better understand how primary care physicians can meet the needs of families, we asked in the survey for families to recommend tips on how primary care physicians can create a welcoming office for discussing mental health concerns, encourage open communication with families about mental health and take action to support families who have a child living with mental illness. Some of what we learned from families is outlined below.

## Creating a Welcoming Setting

Families shared recommendations on what primary care physicians and staff can do to make their offices more welcoming and responsive to conversations about mental health. These tips include:

1. Display resources about children’s mental health, local services and supports and behavioral interventions.
2. Provide a private area to allow families to comfortably share information about their child’s mental health. Offer families the option to share information without their child being present.
3. Educate the office staff about mental health concerns, community resources and how to share these with families.
4. Create a safe zone for families to share concerns by actively listening and using positive language and nonjudgmental prompts to discuss concerns.
5. Provide mental health screening as part of routine clinical practice. Regularly asking families about mental health concerns gets the conversation started and makes mental health a part of a child’s overall health and well-being.

## Encouraging Open Communication

Effective communication is essential between families and primary care physicians. It promises to increase the likelihood of detecting ongoing mental health concerns early and intervening with services and supports.

Families responded in the survey that questions about a child’s mental health should be part of routine practice to help facilitate open communication with families about mental health. They suggested that primary care physicians ask these five questions:

1. Do you have any concerns about your child’s mental health?
2. How is your child behaving in school, at home, in the community and with peers?

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[www.nami.org/primarycare](http://www.nami.org/primarycare)

It is our hope that these resources will help empower primary care physicians and staff to respond to the calls for identifying mental health concerns in primary care practices and will equip them with the tools they need to openly communicate with families.

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3. Have you noticed any changes in your child's moods?
4. Is your child sleeping and eating well?
5. Is there a family history of mental illness?

They also suggested that primary care physicians make these five helpful comments when a child has a mental illness:

1. There is hope.
2. You are not alone.
3. It is not your fault.
4. I understand.
5. You and your child have many strengths.

**Taking Action to Support Families**


In the survey, we also asked about the role primary care physicians can play in addressing mental health concerns and supporting families with a child living with mental illness. Families suggested the following action steps that primary care physicians can take when mental health concerns are raised.

1. Ask questions to begin an interactive discussion about a child's mental health.
2. Screen within the primary care office to identify mental health issues early.
3. Evaluate for other physical conditions that can mimic mental illness and rule these out before making a diagnosis.
4. Discuss options for mental health services and supports, including psychosocial interventions, parent skills training and medications.
5. Suggest support groups, family education programs and other local resources.
6. Refer families to mental health providers for further evaluation and services.
7. Follow up with referrals to ensure help was received. Make appointments for families, if necessary.
8. Encourage families to seek treatment and to give it time to work.

9. Provide treatment when mental health providers are not available.
10. Check in with families to see if treatment is working. If not, re-evaluate treatment options and providers.

NAMI recently released a comprehensive survey report that summarizes the responses, thoughts and comments that we received from families. Their rich and robust survey responses also informed the development of a brochure for primary care providers that describes what families want from primary care. To access the survey report and brochure, visit [www.nami.org/primarycare](http://www.nami.org/primarycare).

We will continue to populate this new web section with valuable resources for primary care providers and families, including resources that can be displayed in primary care offices and shared directly with families.

It is our hope that these resources will help empower primary care physicians and staff to respond to the calls for identifying mental health concerns in primary care practices and will equip them with the tools they need to openly communicate with families. This promises to strengthen the interactions between families and primary care staff so youth with mental health needs are identified early and linked with effective services and supports before they experience the negative consequences of unidentified and untreated mental illness, including the development of a more-difficult-to-treat, chronic condition. 



# The Facts:

## Early and Periodic Screening, Diagnosis and Treatment

**T**he Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) service provides comprehensive health services for youth under age 21 enrolled in the Medicaid program. Medicaid is health insurance that helps many people who cannot afford medical care pay for some or all of their medical bills. EPSDT entitles children, by virtue of their eligibility for Medicaid and under federal law, to access a variety of health services. The following three main components make up the EPSDT mandate that states must follow:

- screening;
- treatment; and
- outreach.

These components are described in greater detail below.

### Screening

The screening part of EPSDT consists of a checkup that includes four separate components—medical, vision, hearing and dental. The medical screen requires states to screen for mental health concerns. The law requires that every time a child is screened, the screening includes the following mandatory components:

- comprehensive health and developmental history, including assessment of both physical and mental health development;
- physical exam;
- appropriate immunizations and lab tests, including mandatory lead tests at 12 and 24 months old; and
- health education, including anticipatory guidance.

Under separate screening schedules, set in consultation with the appropriate child experts, states must also ensure vision, hearing and dental screening and services.

These components should be provided to the child at “periodic intervals.” However, the periodic intervals used by states often do not reflect the most up-to-date guidance. For example, Bright Futures, a national health promotion initiative developed by the American Academy of Pediatrics and supported by the federal government, calls for annual adolescent screens that pay close attention to mental health and developmental needs. However, many states do not have schedules that call for annual adolescent screening.

When it comes to the mental health and developmental screen, the federal government has created a *State Medicaid Manual*, which provides guidance to states on this topic. All states are required to operate their Medicaid program consistent with this manual. The manual includes a list of what must be assessed in a screening, including:

- motor development;
- communication or language development;
- self-help/self-care skills;
- social and emotional development and cognitive skills;
- visual and motor integration;
- visual and spatial organization;
- virtual sequential memory;
- attention skills;
- auditory processing skills;
- auditory sequential memory; and
- adolescents should be closely screened on peer relations and psychological and psychiatric concerns.

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The screening part of EPSDT consists of a checkup that includes four separate components—medical, vision, hearing and dental. The medical screen requires states to screen for mental health concerns.

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**Treatment**

The EPSDT treatment requirements are broad. States must arrange directly or through referral the corrective treatment that a child needs as a result of health concerns identified during a screening. States are required to provide treatment as set forth in the federal law. The scope of benefits is set forth in the Medicaid Act and includes all of the services that states can or must cover for adults. There are a number of mandatory services that states must provide in the Medicaid program. The following are most relevant for children with mental health treatment needs:

- physician services;
- inpatient and outpatient hospital services;
- pediatric and family nurse practitioner services;
- rural health clinic services; and
- EPSDT.

Optional services include:

- prescription drugs;
- inpatient psychiatric services for persons under 21;
- emergency hospital services;
- private duty nursing;
- rehabilitation services;
- personal care services;
- case management services; and
- transportation services (this includes, when needed, lodging and costs for a caregiver).

In addition, there is a federal definition of medical necessity. This is important because states often try to use their own state definition of medical necessity and scope of treatment. The federal definition of medical necessity requires states to *cover treatment and services necessary to correct or ameliorate mental and physical conditions*. This standard is different than what private insurers may use and what states may use for adults. Ameliorate means to keep from getting worse, to improve. It does not mean to make the problem go away. That is a big difference when it comes to

covering rehabilitative services, therapy services or physical/speech therapy services that a child may need to improve and maintain function.

Also, when determining whether a treatment or service is needed to correct or ameliorate a problem, the treating provider should have the primary role in making the decision about what services are needed. Congress has declared that the physician is the key feature in determining the use of health services. It is the physician who decides about admission to a hospital, ordering tests, medications and other treatments and determining the length of stay.

For example, under these federal rules, if a state does not cover case management for adults but a child needs it to correct or ameliorate a problem, it must be covered for the child under EPSDT. If a state covers personal care services for adults but only covers seven hours a week, that quantitative limit cannot be placed on a child under EPSDT if more time is needed to correct or ameliorate a problem. If a state covers medical equipment for adults but caps it at a set dollar amount, that cap cannot be applied to a child eligible for EPSDT if the child needs the equipment to correct or ameliorate a problem.

**Outreach**

EPSDT requires states to use a combination of oral and written communication to inform Medicaid-eligible youth and their families about the benefits of preventative care and services that are available through EPSDT. States must also inform Medicaid-eligible youth and their families that these services are available without copayments and that support services, especially transportation and appointment scheduling assistance, are available on request. States are required to offer transportation and appointment scheduling assistance before each due date of a child's periodic screening. If a child has difficulty understanding English or has a sight or hearing impairment then this information must be conveyed in a format that can be understood.

The importance of reaching out to and informing Medicaid eligible youth and their families was really summed up well by the 7<sup>th</sup> Circuit Court of Appeals, which said *states cannot expect that children of needy parents will volunteer themselves or that their parents will voluntarily deliver them to the providers of health services for early medical screening and diagnosis. By the time a child is brought for treatment, it may be too late. EPSDT programs must be brought to the recipients, the recipients will not ordinarily go to the program until it is too late to accomplish its congressional purpose.*

**Improving EPSDT**

The National Health Law Program has identified and is targeting several top issues to improve EPSDT, including:

1. concern with states' periodicity schedules and the lack of annual adolescent screening;
2. the lack of mental health and developmental screening at every periodic visit. Research has shown that physicians who rely on their clinical judgment fail to identify 83 percent of children who have a diagnosable emotional or behavioral concern. Mental health and developmental screening needs to get more attention as part of EPSDT and needs to be acknowledged as an important part of this program. There also needs to be substance abuse screening for adolescents;
3. the need for flexibility in the form of payment so that states can use case rates, daily rates or other bundled rates to deliver effective and evidence-based practices that have multiple components. Right now many states are breaking these services apart and using the Medicaid list of services to decide what can and cannot be covered and how to pay for it. This happens with interventions like multisystemic therapy, treatment foster care, wraparound services and some in-home services that have multiple components that make them effective;

4. the need for recognition that interventions with families and caregivers are important and directly benefit a child. Services that focus on both the caregiver and child should be included as covered services. There also needs to be Medicaid coverage for the time that all members of a treatment team spend working with a child, particularly for children living with mental illness where a treatment team approach is needed; and
5. the need for guidance from the federal government so that states understand that they can reimburse local education agencies for activities such as outreach and Medicaid enrollment assistance.

**Advocacy**

There are several action steps that NAMI leaders and other advocates can take to support EPSDT, including:


- getting states and the federal government to continue to support the importance of EPSDT. The federal government and the Centers for Medicare and Medicaid Services (CMS), the federal agency that administers the Medicaid program, are committed to this but these are difficult budget times and programs are being looked at. While EPSDT has not come under a formal hatchet, there are activities at the state level that are undermining EPSDT. It is important to be advocates for not only the cost-saving aspects of EPSDT but the social value of EPSDT in allowing for less costly, in-home care versus institutional care, for early detection to avoid more chronic and costly conditions and for early detection and intervention to allow kids to go to school, to work and to be productive;
- working with providers to ensure that they understand the scope of coverage requests for EPSDT services, how to submit claims under EPSDT and the standards that states must apply for coverage; and
- providing input on the EPSDT program. The federal government

and CMS are committed to making EPSDT work and to improving EPSDT. They have recently established an EPSDT workgroup, which will be meeting to improve EPSDT and to focus on administrative activities that can be implemented and undertaken to make this program work better. The workgroup includes a subcommittee on mental health and behavioral health. To provide input to this subcommittee, please contact Jane Perkins, legal director, National Health Law Program, at [perkins@healthlaw.org](mailto:perkins@healthlaw.org).

**Resources**

There are a number of websites that offer information on EPSDT and mental health screening, including the following.

- The National Health Law Program [www.healthlaw.org](http://www.healthlaw.org)
- The Centers for Medicare and Medicaid Services [www.cms.gov](http://www.cms.gov)
- Health Resources and Services Administration [www.hrsa.gov/epsdt](http://www.hrsa.gov/epsdt)
- Rosie D.: Reforming the Mental Health System in Massachusetts [www.rosied.org](http://www.rosied.org)
- TeenScreen National Center for Mental Health Checkups at Columbia University [www.teenscreen.org](http://www.teenscreen.org)
- Center for Health Care Strategies [www.chcs.org](http://www.chcs.org)
- National Academy for State Health Policy [www.nashp.org](http://www.nashp.org)

*Editor’s Note: This information is adapted from a conference call that NAMI hosted with Jane Perkins, legal director of the National Health Law Program and leading national expert on the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Medicaid provision. A complete podcast of this conference call can be accessed at [www.nami.org/askthedoctor](http://www.nami.org/askthedoctor).* 

**Could Someone You Know Be at Risk for Psychosis?**

Some typical early signs of psychosis include:

- worrisome drop in grades;
- new trouble thinking clearly or concentrating;
- suspiciousness/uneasiness with others;
- decline in self-care or personal hygiene;
- spending a lot more time alone than usual;
- increased sensitivity to sights or sounds;
- mistaking noises for voices;
- unusual or overly intense new ideas; and
- strange new feelings or having no feelings at all.

These signs are particularly important when they are new or have worsened in the last year and if the young adult has a close relative who has experienced psychosis. To learn more about the risk for psychosis, visit the Center for Early Detection, Assessment and Response to Risk at [www.cedarclinic.org](http://www.cedarclinic.org).

# Team Work in Addressing ADHD

by Ann Bergeman, R.N

I adopted my son, Will, from Kazakhstan when he was two and a half years old. My first impression of him was that he was very bright, but active. I soon discovered that it was very important to have toys and tasks to keep him focused.

During Will's preschool years, I often heard from his teachers that he was extremely active. At his kindergarten parent/teacher conference, his teacher told me that Will was the class clown and that he often got distracted from his teaching because Will was so funny. In first grade, Will had difficulty staying on task and talked too much. His teacher initiated several parent meetings to discuss these issues but since they were not interfering with his academics, not much was done. In second grade, just a few weeks after the start of school, Will was called to the principal's office for disrupting class.

At this point it became clear to me that his behavioral issues were impacting his ability to learn. I had some coworkers who had sons living with attention deficit/hyperactivity disorder (ADHD) and thought this could be true for Will too. Even though I had been a psychiatric nurse for several years, I was not familiar with ADHD so I did some reading. I learned that the difficulties Will was having sounded like the symptoms of ADHD. I also learned that it was critical to identify ADHD and intervene with the appropriate services and supports early, so the child's self-esteem would not be affected.

## Partnering with My Son's Pediatrician

I called a meeting with Will's teacher and the school counselor to discuss my concerns. The teacher reviewed Will's behavior—talking too much, having a hard time sitting still and experiencing trouble focusing. When I discussed the possibility that Will might have ADHD with his teacher and the counselor, the counselor was taken aback because Will had high grades. She did not

believe that he needed any interventions except for reinforcing the existing classwide behavioral plan.

I still wanted to get Will assessed for ADHD, so I decided to discuss my concerns with his pediatrician. After expressing my concerns, Will's pediatrician gave me a form to rate Will's behavior. His teacher and I both filled it out. The pediatrician reviewed the form and then said to Will, "You and I both have trouble focusing and sitting still. I can see your leg shaking. I have a hard time sitting still too." The pediatrician then disclosed that he has ADHD too. This was extremely validating to Will and made him feel better about ADHD.

When I expressed concern about Will taking medication, his pediatrician took off his glasses and said, "How do you expect me to see without my glasses?" This was so helpful to understand the role medication can play in treatment along with behavioral interventions. Will was started on a small dose of medication. He had an immediate positive response. Sometimes, as a parent, I still struggle with giving Will his medication on weekends. His pediatrician told me that if Will had diabetes, he would take his medication seven days a week.

In fourth grade, Will started to experience irritability and anger so his pediatrician and I worked together to discuss increasing the dose of his current medication or trying a new medication. At one point, his pediatrician referred me to a psychiatrist to have Will evaluated for bipolar disorder, which shares some of the same symptoms as ADHD. The psychiatrist confirmed his ADHD diagnosis.

When Will started to experience anxiety, his pediatrician was once again very helpful. He let me know that anxiety is very common in kids living with ADHD. The pediatrician worked with Will and I to explore different options to address the anxiety. We decided together that Will would take valerian

root (an herbal supplement) when he felt anxious, which worked out well.

Will's pediatrician provided me with the support and information I needed to help Will access the services and supports he needed to succeed in school, in the community and at home.

## Partnering with My Son's School

Will's teachers were so helpful in alerting me to behaviors he was exhibiting in school. It is important to have a good rapport with teachers. At the beginning of each school year, I initiate a meeting with Will's teachers to discuss ADHD and ways in which they can be helpful and supportive.

I have found that I should not assume Will's teachers communicate with each other. One time, I received an email from his gym coach stating that, "Will does not focus like a fifth-grader." I had to let him know that Will has ADHD and that a symptom of his disability is having trouble focusing. I let him know that I would appreciate any support he could give Will to help him stay on task. After this incident, I discovered how important it is that all school personnel are aware of ADHD.

As a parent, I took a very active role in outlining what can help Will be successful in school. I find it is my role to educate others about ADHD. This is challenging since it is an invisible disability. Will's symptoms often manifest themselves in behaviors, which sometimes lead people to think he just needs to control himself better.

## Partnering with My Son

I also feel that it is so important to partner with Will to teach him about his symptoms and diagnosis. We work together to develop a routine and structure at home. Will has a lot of trouble waking up and getting ready for school so we set his clothes out the night before and I also work on giving him positive rewards if he gets up and ready on time. He has shared that he



needs this to help motivate him to get up. I also encourage Will to have a creative outlet.

I have also found that it is important to give kids positive feedback, especially if they are living with ADHD. Will has told me that it is hard for him because he feels like he gets in trouble all the time. Open and honest commu-

nication is important.

It takes so much energy to speak out. I think ADHD is still difficult to diagnose and address since it is often viewed as a behavioral issue. I feel very fortunate that his pediatrician and school intervened early to get him the services and supports he needed to succeed. Will has been such a blessing

to his dad and I. Will is in middle school now and is doing very well academically. I have been an active board member of the NAMI Rochester (N.Y.) Affiliate since 2006. I enjoy this role and having the opportunity to speak out to educate others about ADHD. **UB**

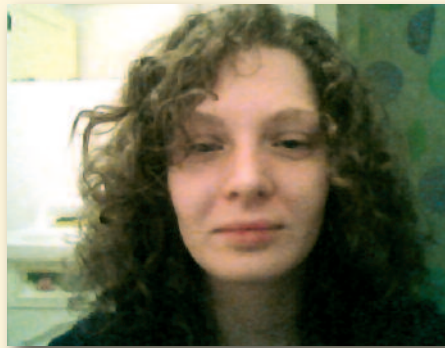
## YOUTH VOICE

## Finding a Healthy Life

by **Chrissy Peirsol**, age 24

I have this theory that anyone can be born with a pre-existing susceptibility to developing a mental illness, but that really does not mean much. In my opinion, if a child is raised in a loving and supportive home where coping skills are initiated at a young age, this child will have a greater chance of becoming an adult who does not live with mental illness. On the other hand, if that child has his or her early years filled with abuse and trauma, I believe they are more likely to encounter life-altering mental illness. I experienced abuse throughout my childhood. The traumas were great and many. As a little girl, I would fall asleep dreaming of Mr. Right to hold me tight and love me deeply. Now as an adult, I am my own Mr. Right and I hold myself tight and love myself deeply.

The first emotional breakdown that I can remember having was when I was 4 or 5 years old. I was begging my sister to help me clean our room so that we could eat dinner. She would not help me at all; I freaked out. I backed myself into a corner with my arms wrapped around my knees and started to rock myself, screaming and hyperventilating. I was such a different child. I guess what I am saying is that I can remember so many ways that I was different from other kids I have known. I had a vivid imagination. I had an imaginary friend who was a ghost from the cemetery up the street from my house.



*Chrissy Peirsol*

He used to tell me stories about angels and how children were saved just in time from evil creatures that came in the dead of night and the brightest of days.

The summer before I started seventh grade, my mother put me into the mental health system. It was the first time that she had private health insurance. She scheduled an appointment for me with a psychiatrist, which did not last very long. I left with a couple labels and a prescription for medications. By the age of 16, I was taking about 24 pills a day. My psychiatrist said that I was so out of control that to be an acceptable member of society I needed to be medically sedated. I hated being on so many different pills. I would sleep all the time or not at all. I could never eat because my stomach always hurt. The side effects were so painful and life altering.

I also remember the event that led me to get off my medication. My mother

handed me my pills then left the room like always. I could feel the weight of them in my hand. I told my hand to rise to take the pills, but my hand would not move. I tried over and over again to make my hand move to my mouth, but it was frozen. Then my hand tilted to the side, the pills falling to the ground. This was when my body took over. It said, "no more," and I stopped.

As a young adult I still struggle with my mental health. I am now battling depression. I use many different forms of therapy to treat it. I really like taking advantage of my community resources. I get massages and acupuncture as often as I can. I am also using my voice when working with my doctor on medication. The best tool I use to help me cope with my mental illness is to be an activist. I do a lot of volunteering. I volunteer with many nonprofits and grassroots organizations. If I can show my community that I am a strong, independent, successful woman then I can feel like I am a strong, independent, successful woman. I find great health and happiness in having courage and a strong voice that I can give to others who have not yet found their own. In fact, that is what I do now. I help other youth and young adults find their voice and move to a life that is more stable, successful and independent. Within this, I find my passion and my health. **UB**

# Smoothing Out the Bumpy Ride

by Amanda Costa, age 23

**M**y experiences with mental illness started during my sophomore year of high school. I started feeling constant waves of sadness and felt unmotivated. Typically a social butterfly, I began isolating myself from everyone and sleeping the days away. I was not myself and I knew I needed to do something before it got worse. I went to my family and friends and talked to them about how I was feeling. With their encouragement, I decided to see a therapist and was quickly diagnosed with depression. I began taking medication and going to therapy, both of which seemed to really help. Things were looking up and I did pretty well for the next few years.

However, during my senior year of high school, something changed. I began having trouble sleeping and started having excessive energy. I was running around all day, from one activity to the other, while only sleeping a few hours at a time. When I brought this to the attention of my therapist, she brushed it off as the normal excitement of senior year and not knowing any better, I agreed. Eventually, these feelings seemed to wear off on their own and I successfully graduated high school and moved on to attend college.

During my second semester of college, I started having trouble sleeping again. I would go out with friends until 5 a.m., barely sleep and then continue on to my classes. Halfway through the semester this started affecting my grades and I wound up failing all my classes. I also started spending money erratically and put myself \$3,000 in debt in a little under a month's time. After this, my mother was really concerned and suggested that I see a psychiatrist. During my first appointment, the psychiatrist diagnosed me with bipolar disorder and started me on two new medications. I left the appointment scared and confused. I had no idea what this diagnosis really meant and I was not given any resources to help me figure it out.




Amanda Costa

With the support of my family, I decided to take charge and educate myself about the diagnosis. I also found some bipolar disorder support groups. At these meetings, I learned about advocating for myself and was introduced to all the amazing resources out there for young adults living with mental health conditions.

I am blessed to have had the support of my family, friends and treatment team to help me get through the many battles I have faced on the road to recovery. Now that I am at a stable place in my life, I have begun to reflect on all the struggles I have endured to get to this point. I realize that there are a lot of things that could have been done differently to make this process smoother. Knowing what I do now, it is clear to me that during my high school years, I was exhibiting symptoms of bipolar disorder. I feel that a more open dialogue with my therapist could have led to an earlier diagnosis. If she took the time to really listen to how I was feeling and been more open to the possibility of a new diagnosis, I may have avoided a lot of struggles during college. I also feel that having a psychiatrist who was focused on helping me truly understand the diagnosis and the

medications and not just writing me a prescription and sending me on my way, could have made the transition a lot easier.

These experiences have sparked a passion within me to help other young adults on their journeys and to provide them with the resources and education they need to take charge of their own recovery. I have been lucky enough to be able to carry out this passion working at the Transitions Research and Training Center (RTC) at The UMass Medical School. The Transitions RTC is an organization focused on helping young adults living with mental health conditions positively navigate the transition into their adult lives. One focus of the RTC is a website that the young adult staff, including myself, has created, called Voices4Hope. Voices4Hope is a website for young adults with mental health conditions who want to connect with each other and gain access to information that will help them live happily and independently. Voices4Hope has made it possible for me to share the knowledge and resources with others that could have really helped me when I was struggling. I have finally come to a point in my life where I have accepted that things are not always easy and that I may have a bumpy journey ahead of me. However, I know now that there are others like me traveling down the same path and by sharing our knowledge and experiences with each other, it makes for a much easier ride.

To learn more about Voices4Hope, visit [www.voices4hope.wikispaces.com](http://www.voices4hope.wikispaces.com). NAMI has also developed a social networking website and online resource center for young adults living with mental illness. To check it out, visit [www.StrengthofUs.org](http://www.StrengthofUs.org). 

*Editor's Note: In addition to RTC's website, NAMI has also developed a social networking website and online resource center for young adults at [www.StrengthofUs.org](http://www.StrengthofUs.org).*

# Tips for Families: Talking with Your Pediatrician about Mental Health Concerns

by **Steve Kairys, M.D., M.P.H.**, chairman of pediatrics at the Jersey Shore University Medical Center and medical director of the Pediatric Council on Research and Education of the American Academy of Pediatrics New Jersey chapter

**M**any families see their pediatrician as someone who only cares about their child's physical concerns and well-child visits.

Many pediatricians, however, believe that their role is much broader—to help the whole child with all of his or her needs, including mental health. Just as pediatricians often get involved with educational problems, developmental concerns and family interactions, pediatricians also want to be helpful to families with concerns about their child's mental health and well-being. The reality is that more than 30 percent of family visits to a pediatrician usually involve an underlying mental health issue.

Most families do not routinely bring up mental health concerns with their pediatrician. Families either feel uncomfortable bringing up such concerns or they believe that their pediatrician would have asked about mental health if it was important to him or her. However, even pediatricians with a keen interest in mental health will fail to pick up on any issues unless a parent expresses concerns or a mental health screening tool is used.

As a general rule, any problem your child is having that is disrupting his or her life is definitely worth discussing with a pediatrician, particularly if your child is experiencing major difficulties in more than one area of his or her life—school, home or with friends. Here are some problems that could indicate a mental health issue.

- doing poorly in school, at home or with friends;
- acting very withdrawn, sad or overly anxious;

- having difficulty interacting with friends or siblings; and
- exhibiting behaviors that are aggressive or destructive.

Moreover, it is important to note that many mental health problems present as physical ailments, including headaches, chest pains or stomach pains. Any of these issues should be shared with your child's pediatrician.


Some pediatricians are prepared to address mental health concerns raised by families. These pediatricians will have you fill out a screening tool, such as the Pediatric Symptom Checklist, if there are any concerns. This is an easy-to-fill-out series of questions about how your child is feeling and functioning. The checklist is not meant to lead to a diagnosis, only to alert the pediatrician to potential issues that may need further assessment. The use of formal screening tools greatly increases the capacity of pediatricians to pick up potential mental health issues. There are also screening tools for attention deficit/hyperactivity disorder, autism, substance abuse and maternal depression (pediatricians are interested in the mental health of a parent because it is important for improving the health and development of the child).

After receiving the results of the screening tool, interviewing you and your child and doing a comprehensive physical examination, pediatricians should discuss next steps with you. These may include:

- following up with you to discuss the concerns further;
- encouraging school-based services and supports to help your child succeed in school;
- referring your child to a mental health or developmental specialist for an evaluation; or
- recommending specific mental health services and supports for your child.

For some mental health issues, medication may be part of the treatment plan recommended by your child's pediatrician. The key with the treatment plan is to mutually agree on goals for improvement and then to establish a care plan with your child's pediatrician based on these goals.

The American Academy of Pediatrics (AAP) has prioritized child mental health as a major priority. They have recently prepared a comprehensive mental health toolkit to provide information and specific tools to pediatricians

who need guidance on addressing mental health concerns and who may not be doing screening as part of routine care. Many states have also developed programs that allow child and adolescent psychiatrists to be available to pediatricians for support and guidance on specific child mental health concerns. To learn more about these initiatives, contact your AAP state chapter at [www.aap.org/member/chapters/chaplist.cfm](http://www.aap.org/member/chapters/chaplist.cfm) or visit the AAP mental health website at [www.aap.org/mentalhealth](http://www.aap.org/mentalhealth). 



Steve Kairys, M.D.,  
M.P.H.

# NAMI New Jersey's Role in Integrating Mental Health and Primary Care

by **Alicia Stevenson**, program coordinator and NAMI Basics national and statewide trainer, NAMI New Jersey and **Lorrie Agoratus**, coordinator, New Jersey Family Voices

## NAMI New Jersey Spotlight

*Editor's Note: NAMI New Jersey is involved in several initiatives aimed at the early identification and intervention of youth with mental health needs. These initiatives are outlined in the following three separate articles. Special thanks to Lorrie Agoratus, coordinator of New Jersey Family Voices, for her assistance in compiling these articles.*

*pull quote here*

**N**ew Jersey's Statewide Parent Advocacy Network (SPAN) has received two Integrated Community Systems of Care grants: one for children with special needs and another specifically for children with autism and other developmental disabilities. SPAN is an organization that empowers and supports families and informs and involves professionals and others interested in the healthy development and education of children and youth. It began "integrating systems of care" by creating the first parent center to house the Parent Training and Information Center (education), Family Voices/Family-to-Family Health Information Center (health), Federation of Families for Children's Mental Health (mental health) and Parent-to-Parent (support) at one site.

SPAN was awarded the grants from the U.S. Department of Health and Human Services Maternal and Child Health Bureau (MCBH) to collaborate with the New Jersey Departments of Health and Senior Services, Human Services and Children and Families, the New Jersey Pediatric Council on Research and Education and the New Jersey Chapter of the American Academy of Pediatrics to improve performance on MCHB's six core outcomes for children and youth with special health care needs and their families. These outcomes include:

1. families will be engaged as equal partners at all levels and will be satisfied with services;
2. every child will have access to early and continuous screening to identify special health care needs;
3. every child will have access to a medical home to coordinate all needed care;
4. every family will have access to community-based services that are easy to use;

5. every family will have adequate public and private insurance to pay for needed care; and
6. every youth with special health care needs will have access to services to support effective transition to adult systems of care.

Both of these new grants are based on the medical home model. The medical home is not a physical place but rather an idea of coordinated care, including mental health care, which is based on relationships and communication between health care providers. New Jersey now has several medical home pilot projects working with pediatric practices, Federally Qualified Health Centers and hospitals in five counties to support medical home training, collaboration with the "one-stop" parent center and linkage to care coordination and community-based resources. During the four years of the two grant projects, primary care practices in at least ten counties across the state will participate in learning collaboratives around medical home implementation and the other core outcomes.

NAMI New Jersey's participation in this initiative is essential. NAMI New Jersey wholeheartedly supports the concept of the medical home. Mental health must be considered of equal importance in the model. In fact, mental health has taken a back seat for far too long in the health arena and needs to come to the forefront of health care in general. Far more families struggle with mental health issues than any other single physical disorder and yet, there is far less support, understanding and knowledge about mental illness among the general population as well as health care providers. This has to change and the medical home model is the perfect place to start since it emphasizes the importance of



# Primary Care Psychiatry Collaborative

by **Gary Rosenberg, M.D.**, medical director, Behavior Health Services, Bergen Regional Medical Center and **Phil Lubitz**, associate director, NAMI New Jersey

recognizing and treating the whole person, body and mind.

New Jersey Family Voices receives approximately 2,000 contacts each month for assistance from families and professionals. In the past few years, there has been a tremendous increase in the number of calls received about children's mental health when before it was mostly physical conditions. But mental health is a key part of health. As a result, Lorrie Agoratus has attended various NAMI New Jersey and NAMI Mercer workshops and trainings to better assist parents and professionals in helping children living with mental illness.

We know that approximately 13 percent of youth live with mental illness but that only 20 percent of these youth access care. The Integrated Systems of Care grants will help children with special needs, including mental health, to have a medical home in New Jersey. NAMI New Jersey hopes to play an important role in the implementation of these grants to accomplish this.

To learn more about NAMI New Jersey's efforts, contact Alicia Stevenson at [aliciastevenson@comcast.net](mailto:aliciastevenson@comcast.net). To learn more about the medical home model, visit [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org). To learn more about SPAN, visit [www.spannj.org](http://www.spannj.org). 

Over the past several years NAMI New Jersey, the New Jersey Psychiatric Association (NJPA) and the American Academy of Child and Adolescent Psychiatry (AACAP) have collaborated to inform legislators and policymakers in New Jersey about children's mental health issues. In October 2010, NJPA formed a task force to develop a Primary Care Child Psychiatry Collaborative Program under the leadership of Gary Rosenberg, M.D. The task force developed a white paper, *Improving Access to Child and Adolescent Mental Health Care: Integrated Collaborative Care*, which makes the case for the collaborative program model.

Currently, there are 7,000 child and adolescent psychiatrists practicing in the United States, with a need at about 20,000. Insufficient access to child psychiatry is a problem in New Jersey. There are only 10.5 child psychiatrists for every 100,000 children in New Jersey. Waits of six to eight weeks for child psychiatry appointments are not uncommon. Waits can be up to three months long for first appointments.

As a result, many children with mental health needs and their families receive treatment from a primary care physician. As indicated in the task force white paper, the prevalence of mental illness in youth aged 13-18 is 22 percent, only one in five of them receive treatment and of these, at least 50 percent are treated by their primary care physician.


However, primary care physicians often feel overwhelmed and isolated in their efforts to treat youth with mental health treatment needs who often require the attention of a mental health care provider. The Primary Care Child Psychiatry Collaborative Program will

help to meet the needs of these youth and support primary care physicians by providing the following:

1. timely access to child psychiatry consultation services, including telephone consultations, for primary care physicians;
2. direct child psychiatric services;
3. care and care management for children and their families; and
4. education and training for primary care physicians.

The Primary Care Child Psychiatry Collaborative Program is an innovative strategy that marries existing strengths in the health care system to deliver unified treatment to families and their children. There are presently 15 states in the country that have developed a collaborative program to address the shortage of child psychiatrists and child mental health workers.

This initiative will help meet the needs of children living with mental illness when there are not enough mental health providers to meet their needs. It will be cost-effective and, more importantly, result in better outcomes for children in New Jersey.

To learn more about the Primary Care Child Psychiatry Collaborative Program, contact Phil Lubitz at [plubitz@naminj.org](mailto:plubitz@naminj.org). 

# Providing Professional Development and Resources for New Jersey Schools

by **Lorrie Baumann**, school education programs director, NAMI New Jersey

**N**AMI New Jersey's school education programs, Educating the Educators and Every Mind Matters, are educating children and adults throughout our state about mental health and mental illness. Educating the Educators is a three-hour professional development presentation done by three speakers, including a physician, educator and parent. The presentation provides school personnel with strategies, information and resources for helping students living with mental illness succeed in school. Its purpose is to inform educators about mental illness and present practical tools to help motivate children living with mental illness.

Educating the Educators has benefited from collaboration between NAMI New Jersey, the New Jersey Council of Child and Adolescent Psychiatry (NJCCAP) and the New Jersey Psychiatric Association (NJPA). Many of the physicians throughout our state have been helpful in the development of NAMI New Jersey's programs as reviewers and speakers. The educator presenters are experienced educators who are members of NAMI New Jersey and also family members. The parent speakers are NAMI New Jersey members who have participated in NAMI New Jersey's Family-to-Family and/or NAMI Basics classes. The success of Educating the Educators is a result of the dedication of the program's many speakers and volunteers.

In the first part of Educating the Educators, the physician talks about the biological basis of mental illness, the symptoms and treatments and how mental illness affects learning. In the second part, the educator provides strategies, accommodations and resources for working with students who exhibit the symptoms of mental illness. The last part of Educating the


Educators is called, "Walk in My Shoes." In this part, a parent describes to educators what it is like to have a child living with a mental illness and how educators can work with families to help their child succeed. Educating the Educators also provides participants with a resource packet that includes a strategies chart, lesson plans and a resource list for more information that includes NAMI websites. As a New Jersey Department of Education professional development provider, NAMI New Jersey can also issue a certificate for continuing education credit to participants.

Every Mind Matters consists of mental health/mental illness teaching resource kits for teachers to use with students in Grades 5-8 and Grades 9-12. Every Mind Matters is aligned with the New Jersey Core Curriculum Content Standards for Health. The resource kits include three lessons with an interactive PowerPoint presentation that a teacher can use to teach about mental health and mental illness. The kits also provide information on stigma busting, stress relief, brain health, anger management, anti-bullying and, for grades 9-12, suicide prevention. The kits contain interdisciplinary activities that can help teach language arts (poetry activities), math (graph activity), art (collage activity) and health and science (brain health activities).

The New Jersey Department of Education has a State Special Education Advisory Council (SSEAC). In 2010, the theme for the SSEAC was student mental health. NAMI New Jersey was invited to the SSEAC and presented overviews of both school education programs, Educating the Educators and Every Mind Matters. As a result of this presentation, NAMI New Jersey is presenting Educating the Educators this spring at the three

New Jersey Department of Education Learning Resource Centers in the north, central and south parts of the state. NAMI New Jersey has also presented Educating the Educators at the annual New Jersey Education Association Convention for the past four years to standing room only audiences and received excellent evaluations. To date, Educating the Educators has been presented to over 5,000 educators statewide.

The key to a better future depends on educating everyone, children and adults, about mental health and mental illness. Educating the Educators and Every Mind Matters provides that education.

Approximately 13 percent of youth aged 8-15 live with mental illness severe enough to cause significant impairment in their day-to-day lives, but unfortunately only one in five access treatment. Students living with mental illness also have the highest school dropout rate than students with other disabilities. Educating the Educators and Every Mind Matters programs seek to eliminate the stigma associated with mental illness and focus on wellness and recovery. By collaborating with education and the medical professions, NAMI New Jersey is improving outcomes for students. To learn more about NAMI New Jersey's school education programs, visit the NAMI New Jersey website at [www.naminj.org](http://www.naminj.org) (click on "education") or contact Lorrie Baumann at [schoolprograms@naminj.org](mailto:schoolprograms@naminj.org). 

# Reaching Teens and Families in Diverse Communities

by Evelyn Rivera-Mosquera, bilingual outreach coordinator, NAMI Greater Chicago

**N**AMI Greater Cleveland's Multicultural Outreach (MCO) program has been reaching out to Latino and African American populations in Cleveland for the past five years. We have slowly been developing strong relationships and making inroads with these populations. Our most recent initiatives focus on Latino and African American teens.

Latino and African American teens are at greater risk for engaging in risky behaviors than their peers.<sup>1</sup> Latino teens have the highest suicidal ideation rates and suicide attempt rates of any other racial/ethnic group. It is estimated that one in seven Latina teens will attempt suicide.<sup>2</sup> In addition, African American teens living with undiagnosed and untreated mental illness are disproportionately incarcerated in the juvenile justice system instead of referred to mental health services and supports.<sup>3</sup>

MCO has created a variety of programs specifically for inner-city churches and community-based organizations over the past few years. Our most recent initiative is a collaborative effort with the Cleveland Clinic, the Cleveland Metropolitan School District and the Epilepsy Association of Cleveland. The Cleveland Clinic was awarded a three-year grant from the U.S. Department of Health and Human Services to fund Project COPE, which facilitates access to mental health care for youth living with epilepsy and their parents. MCO will be responsible for developing educational workshops in English and Spanish for teens (ages 12-18) living with epilepsy and their parents. Research suggests that youth

living with epilepsy have higher rates of depression and anxiety and have higher rates of suicide if these conditions go untreated. The goal of our workshops is to educate the community about mental health to reduce the stigma these youth experience and to increase access to mental health services and supports. Three Project COPE seminars will be held each year from 2011 to 2013.

MCO has also developed a number of education programs targeting topics that are important to teens, including healthy versus toxic relationships and self-esteem. These specialized programs are developed and conducted by culturally competent psychologists and therapists in African American churches and the Latino Urban Minority



Evelyn Rivera-Mosquera

NAMI Greater Cleveland has also recently begun a monthly support group for teens living with attention deficit/hyperactivity disorder (ADHD) in Parma, Ohio that runs at the same time as our parent and caregiver support group. While Kari Kepic, Helpline assistant, and Terri Miller, consumer and family program coordinator,

run the parent group, James Stover, M.Ed., L.P.C., facilitates the ADHD Success Strategies for Teens group.


NAMI Greater Cleveland is excited about these initiatives and we plan to continue our work with teens in the future. We hope to one day see more funding specifically allocated to support the development and implementation of culturally competent

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Alcoholism and Drug Abuse Outreach Programs' youth center.

MCO's goal is to continue to build relationships with church youth groups and community-based organizations to bring the message of emotional wellness to our teens. The earlier we take the message of mental health wellness and prevention to youth, the more likely we can help children, teens and adults learn to integrate and nurture their mental health and not fear it.

mental health education and prevention programs at the national, state and local levels to combat the mental health disparity issues evident in racial/ethnic minority populations, especially with teens.

To learn more about NAMI Greater Chicago's efforts, contact Evelyn Rivera-Mosquera at [evelynrivera@sbcglobal.net](mailto:evelynrivera@sbcglobal.net). 

<sup>1</sup> Centers for Disease Control and Prevention (2005). Youth Risk Behavior Surveillance. Surveillance Summaries, MMWR; 55 (No. SS-5). Accessed at [www.cdc.gov/mmwr/PDF/SS/SS5505.pdf](http://www.cdc.gov/mmwr/PDF/SS/SS5505.pdf).

<sup>2</sup> Centers for Disease Control and Prevention (2009). Youth Risk Behavior Surveillance. Surveillance Summaries, MMWR; 59 (No. SS-5). Accessed at [www.cdc.gov/mmwr/pdf/ss/ss5905.pdf](http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf).

<sup>3</sup> National Council on Crime and Delinquency (2009). Racial and Ethnic Disparities in the U.S. Criminal Justice System. Accessed at [www.nccd-crc.issuelab.org/research/listing/created\\_equal\\_racial\\_and\\_ethnic\\_disparities\\_in\\_the\\_us\\_criminal\\_justice\\_system](http://www.nccd-crc.issuelab.org/research/listing/created_equal_racial_and_ethnic_disparities_in_the_us_criminal_justice_system).

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## American Academy of Pediatrics Resources on Mental Health and Primary Care



[www.aap.org/mentalhealth](http://www.aap.org/mentalhealth)

The American Academy of Pediatrics (AAP) Task Force on Mental Health has developed a wide array of materials to assist primary care physicians in addressing mental health concerns in primary care. These valuable resources include:

- *Addressing Mental Health Concerns in Primary Care: A Clinician's Toolkit*. This toolkit includes ready-to-use resources and tools for primary care physicians, including screening and assessment instruments, quick-reference care management advice, step-by-step care plans, time-saving documentation and referral tools, coding aids, billing and payment tips, parent handouts, community resource guides and much more.
- *Enhancing Pediatric Mental Health Care: Report From the American Academy of Pediatrics Task Force on Mental Health (Supplement Article)*. This report guides primary care physicians through the process of implementing mental health care into a pediatric practice.
- *Improving Mental Health Services in Primary Care: Reducing Administrative and Financial Barriers to Access and Collaboration*. This article outlines the barriers to providing collaborative mental health care.
- *Podcast: Children's Mental Health and the Medical Home*. This podcast provides an in-depth discussion of children's mental health and the medical home.

To learn more about this extremely important work, visit the AAP's Task Force on Mental Health website at [www.aap.org/mentalhealth](http://www.aap.org/mentalhealth). 