

 **nami** *Beginnings*  
National Alliance on Mental Illness

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

# Back to School

**Understanding Your  
Legal Rights Under  
Special Education Laws**

**Sowing the  
Seeds of Student  
Empowerment**

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# Capitol Hill Watch

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

## The Federal Government Focuses on Young Adults with Serious Mental Illnesses

**M**oving from the teen to young adult years represents a time of great change and challenges. It is also a time when many require effective mental health, housing, and employment services and supports to cope with the symptoms of mental illnesses and to pursue hopes and dreams.

Increasingly there is a focus on the lack of effective services and supports specifically designed to meet the unique needs of youth and young adults with mental illnesses. The availability of these services and supports can make the difference between young people living a life of dependence or independence. The right combination of services and supports has led to youth and young adults pursuing college and post-graduate degrees, achieving professional and personal success, and living productive and full lives in communities across the country. The lack of effective services and supports has led to social isolation, economic hardship, homelessness, incarceration, and death.

In June, the U.S. Government Accountability Office (GAO) released a report titled *Young Adults with Serious Mental Illness ~ Some States and Federal Agencies Are Taking Steps to Address their Transition Challenges*.

The GAO found that young adults with serious mental illnesses have great difficulty in finding and securing appropriate services as they straddle the child and adult systems. The mental health, employment, and housing services that are available are not tailored to their unique needs resulting in far too many of these young adults opting out of these services. The eligibility criteria for child and

adult systems are quite different resulting in wide-spread disruptions in services and discontinued care.

The report features a number of states that have taken innovative approaches to providing effective services to transition-age youth and young adults with mental illnesses, including Connecticut, Maryland, Massachusetts, and Mississippi. The states profiled have programs that integrate mental health treatment with employment and other supports. Services are coordinated across multiple state agencies, leveraging state and federal funding, and involving young adults and families in developing policies and services.

In 2007, the Substance Abuse Mental Health Services Administration (SAMHSA) completed a transition-age grant program, titled *Partnerships for Youth Transition*. Grants for this program were awarded to Maine, Minnesota, Pennsylvania, Utah and Washington state. The grants allowed these states to plan, design, and implement transition programs for youth with mental illnesses and their families. To learn more about this transition-age grant program and to view related resources developed by SAMHSA, visit [www.systemsofcare.samhsa.gov](http://www.systemsofcare.samhsa.gov) (click on *Programs* and then *Partnerships for Youth Transition*).

SAMHSA also recently announced that it will hold a Policy Academy in December 2008 focused on transition-age services and supports for youth and young adults with mental illnesses. States have applied to participate in the upcoming SAMHSA Policy Academy and those awarded a spot will be allowed to send a delegation of senior officials from systems designed to provide services to youth and young

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The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to improving the lives of individuals and families affected by mental illness. NAMI has over 1,100 affiliates in communities across the country that engage in advocacy, research, support, and education. Members of NAMI are families, friends, and people living with mental illnesses such as major depression, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD), and borderline personality disorder.

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

# Helping Parents Understand Their Rights in Special Education

## An Interview with a Legal Expert


by **Matthew D. Cohen, Esq.**, Co-founder of the Law Firm Monahan & Cohen, Chicago, IL

adults with mental illnesses. The state delegations will work to develop effective policies and strategies that will be implemented upon their return to their respective states. NAMI national has played an active role in planning for the upcoming Policy Academy and will participate in the academy in December. We will notify NAMI leaders in those states chosen to participate in the Policy Academy to work with state leaders upon their return in the implementation of effective transition-age mental health, employment, and housing services, and supports.

The release of the GAO report coincided with the introduction of *The Healthy Transition Act of 2008*, federal legislation that will provide planning and implementation grants to states to develop statewide coordination of services for youth and young adults with serious mental illnesses. The House and Senate bills (H.R. 6375/S. 3195) also call for the creation of a federal interagency task force to provide technical assistance to states as they design and implement plans to address the needs of transition-age youth and young adults.

*The Healthy Transition Act of 2008* was introduced by Senators Dodd and Smith in the Senate and Representative Pete Stark in the House. NAMI applauds their leadership in recognizing the critical need to address the needs of transition-age youth and young adults with serious mental illnesses who often struggle with education, employment, and housing. Stay tuned for updates on this and related legislation...

To review or order the GAO report, visit [www.gao.gov](http://www.gao.gov) (in the search area, include Report #GAO-08-678).

To review *The Healthy Transition Act of 2008*, visit [thomas.loc.gov](http://thomas.loc.gov) (search for the bills by using the bill numbers HR 6375 and S 3195). 

**Q: How can parents ensure that their child with a disability is learning reading, writing, math, and other subjects?**

**A:** The Individuals with Disabilities Education Act (IDEA) and No Child Left Behind (NCLB) both require that schools ensure children with disabilities receive an appropriate education and make educational progress. The two laws are different in how they define the standards for measuring progress.

IDEA, which is the federal special education law, requires the development of an Individualized Education Program (IEP) for students with disabilities. The IEP articulates standards and goals for students. By contrast, NCLB measures the academic progress of the school as a whole rather than for individual students. NCLB identified students with disabilities as one of the special subgroups that schools must evaluate and report on from year to year. NCLB has school-wide standards, including school-wide standards for children with disabilities, but does not require that there be any level of particular progress for individual students. In addition, NCLB allows schools to evaluate the students who have the most severe or profound disabilities using alternative assessments, so those students may be harder to compare in evaluating their progress.

Schools must review a student's IEP every year and develop annual goals that identify the progress that the student is expected to make in each of the areas identified as needing attention due to the student's disability. The areas of need can include academic subjects, including reading, writing, and math. They can also include social, behavioral, and emotional needs that directly impact how the student functions in school. This includes how the student functions socially, is able to comply with school rules, and gets along with others. The social, behavioral, and emotional needs of the student should be addressed in the annual goals in the IEP. IDEA leaves it up to the states to determine whether they will use short-term objectives in the IEP, along with annual goals. Although not required to, many states are continuing to use short-term objectives or benchmarks along with the annual goals.

When parents meet with the school to review an IEP, they should make sure that the IEP identifies their child's academic needs along with other needs in the areas of emotional growth, behavior, social skills, organizational skills, and related issues. Once these needs are identified, the school should include at least one goal to address each area of need and should have services to assist the student in accomplishing each goal. The goals are not legally binding, but

the school must develop goals that will lead to the student making meaningful progress. The key is to ensure that there is a balance between addressing the need for the student to achieve meaningful growth while remaining realistic about the student's ability. The IEP must have objective measurement procedures that allow for the student's progress to be regularly evaluated, at least quarterly, to assess whether the student is making sufficient progress. If it appears that the student is not making sufficient progress, then the school should adjust the program.

IDEA changed in 2004 to require the IEP evaluation and IEP process to address a student's academic, developmental, and functional needs. Schools must focus on how a student functions in all areas of school not just in academic performance. For a student with a mental disorder, this is important because he or she may do well academically but have major difficulties emotionally, behaviorally, and socially. The law now makes clear that these issues must be addressed by schools if they are interfering with the student's functioning in school. Section 504 of the Rehabilitation Act of 1973 can also be used to ensure the student receives an appropriate education. Section 504 has less detail than IDEA and focuses on services and accommodations without requiring schools to monitor student progress or to measure progress in achieving goals.

**Q: Many schools are willing to provide modifications and accommodations, but are not willing to provide remediation to get a student back to grade level, is this allowed? Do schools have to pay for private services needed to get a student to grade level?**

**A:** Public schools are required to provide instructional services, accommodations, remediation, modifications, and related services under IDEA and Section 504. They are not obligated to ensure that a student reaches grade level. Unfortunately, the nature of students' disabilities and the severity of those disabilities are such that the ability

to reach grade level varies by student. A student may have a disability that, with appropriate remediation, allows him or her to perform at grade level. Another student with a more severe disability may make progress but never achieve grade level. As a result, the law does not require schools to provide services that allow every student to reach grade level. Instead IDEA and Section 504 require schools to provide the services that allow a student to make reasonable or meaningful progress and to achieve progress toward independence as he or she reaches adulthood.

Schools have the right to identify assessment procedures they deem appropriate to address the nature of a student's disability. Parents have the right to request instruments that they believe are appropriate or to express concern if they believe the school's measurement or assessment procedure is inadequate. If there is a dispute about how the student's progress will be assessed, the parents may need to present information about why the school's proposed assessment is inappropriate or why theirs is more appropriate. This should be based on outside clinical consultation or research that is shared with the school.

Under IDEA, if there is a dispute related to a student's programming, including how the student should be evaluated or assessed, the parents may request a due process hearing. However, it is always better to attempt to work conflicts out informally or through mediation unless it is absolutely essential to initiate a due process hearing.

Parents always have the right to supplement services the school provides. However, the fact that the parents provide private supplementary services does not automatically mean that the school must pay for those services. When parents believe that the school's program is not appropriate and that private services are needed, they should give the school written notice

of their concerns. They should inform the school that they want supplementary services, whether it is tutoring, placement in a special education program in a private school, or some other service—and that they want the school to pay for the services. Parents should provide the school with notice at least ten business days before they start the private services. Providing the notice does not obligate the school to pay,

but failing to provide the notice may relieve the district of any obligation.

Sometimes parents believe that their child has a need for a particular methodology or intervention. Schools are not obligated to provide a particular program or methodology simply because the parents want it.

However, the IDEA 2004 amendments require for the first time that the program the school offers be based on peer reviewed research to the extent practicable. Schools must address methodology in the IEP to the extent that the methodology is necessary for the student to make progress. While parents do not have a right to pick an instructional method of study or skill building just because it is something they prefer, the school has an obligation to show that the program it is proposing is research based or has been studied and shown to be effective. At the same time, parents have a right to request a particular method if there is research to support it and the school's program is not working. For example, the parents of a child with autism might request that the school provide an Applied Behavioral Analysis method, also called the Lovaas method or Discrete Trial Training, which is a research-based approach designed to help students with autism.

**Q: How can parents get schools to do functional behavioral analyses and positive behavioral supports?**

**A:** Parents may request an evaluation at any time to assess their child's behavior within the school environment. When a functional behavioral assessment is



Matthew D. Cohen

done and it identifies problem behaviors, the school should convene an IEP meeting. This should lead to the development of instructional strategies, accommodations, and supports in the IEP, including the development of a behavioral intervention plan. If a student is having behavioral difficulties, a behavioral plan should be developed as part of the IEP process and should be included in the IEP. The behavioral plan may include intervention strategies. The IEP goals may address behaviors of concern and educational strategies. For example, if a student has trouble reading that involves acting out during reading time, it may be appropriate to use the functional behavioral analysis to develop some behavioral strategies to address the acting out during reading. It might also be appropriate to determine whether the student has a reading problem, which requires goals and reading interventions through the IEP. If a school is not responding to the parents' request for a functional behavioral analysis or a behavioral plan, and attempts at informal resolution or remediation are unsuccessful, parents may request a due process hearing.

IDEA requires schools to consider positive behavioral supports for a student with behavioral challenges. Many schools have implemented the Positive Behavioral Interventions and Supports (PBIS) program. With school-wide PBIS, there are levels or tiers of intervention in which the school promotes positive behavior as a general value and goal of the school and provides reinforcements for all students to engage in positive behavior. The program then has a hierarchy of more intensive interventions for students with behavioral difficulties that goes beyond the scope of the school-wide intervention strategies. When a student has an IEP, the student must be provided with interventions that address his or her behaviors that may be interfering with his or her ability to learn. The school should place an emphasis on positive approaches to address difficult behaviors rather than punishment, discipline, or other negative approaches. The student should not be subjected to losing privileges,

being excluded from lunch or recess, having detention, or suspension. The goal is to develop effective approaches that are meaningful for the student and that help him or her learn appropriate behaviors. Positive behavioral approaches reinforce appropriate behaviors and provide support that redirects a student to appropriate behaviors when he or she is struggling.

**Q: How should parents develop an IEP for their child living with bipolar disorder? What kind of services should be included?**

**A:** The starting point for any student with a disability is to identify how the disability impacts his or her functioning in school. Bipolar disorder is a particularly complicated disorder to address within a school framework because many school staff know very little about bipolar disorder. Bipolar disorder manifests itself in inconsistent ways depending on the circumstances and the student's emotional state. It tends to confuse school staff who may misinterpret the student's behavior. They often believe that the student is choosing to act out rather than that the misbehavior is related to a mood swing associated with a depressive or manic state. It is important to ensure that the evaluators and the implementers of the IEP have an understanding of bipolar disorder and how it impacts students.

Given that understanding, it is important to build into the IEP, strategies that address the different ways in which bipolar disorder may manifest itself. Rather than having one strategy based on one constellation of symptoms, there may need to be a series of strategies that are implemented when a student is displaying the different characteristics of bipolar disorder. It is important to prepare the school staff on how to recognize when a student is either in a highly depressed state or is beginning a manic state. This will help staff intervene quickly to help the student manage the challenging symptoms.

With a student with bipolar disorder, it is especially important to have mental health professionals involved as key

members of the IEP team. It is also important to have close coordination between the school and the family in tracking the student's progress and in monitoring symptoms. That way everyone is alert when the student is having a problem and is consistent and supportive in responding. The school should have a plan that recognizes that a student with bipolar disorder may need room to regroup and the ability to take a break in an environment where he or she can receive assistance outside of the classroom. A student should also have access to mental health professionals and his or her family to help de-escalate the complex symptoms that often accompany the disorder.

**Q: What are parents' rights in keeping their child in a previously agreed upon placement when the school is proposing a new placement?**

**A:** Parents should make sure that the IEP is being implemented as written. Some of the problems that students typically experience that lead to a proposed change of placement are based on a failure to sufficiently implement the IEP in the way that it was intended rather than a change in their condition or behavior. If the school is considering a change in placement for a student, parents should first verify that the IEP is being appropriately implemented.

Parents should also identify whether there are additional supports that would be appropriate for their child within the existing environment that would help to control or modify the behavioral concerns and that would alleviate the need for a change of placement.

Even if the school has been implementing the IEP as written, there may be other services that can be added to the IEP to improve progress and behaviors within the existing setting before considering a change of placement. Both IDEA and Section 504 require that a student be served in the least restrictive environment appropriate for the student's needs. Consequently, schools must consider whether there are additional supports

that would allow the student to remain in the current setting before the student is moved to a more restrictive environment.

Parents may also request that there be a functional behavioral analysis or a re-evaluation of their child's emotional and psychological functioning before making a determination on a change in placement. It may be that the functional analysis or the evaluation provides information on what can be done within the existing environment to support the student. One cautionary note, if a school conducts an evaluation, it may give the school ammunition to support the basis for a change in placement. While we generally expect that school evaluation teams will be objective, if there is already concern that a change of placement may be needed, an evaluation team sometimes may provide more ammunition in support of the proposed change. Parents might benefit from the involvement of outside mental health professionals, ideally to observe their child at school and help them understand whether things can be done in the current setting or whether a more intensive program or restrictive environment is needed.

If the school is recommending a change in placement, they must convene an IEP or 504 plan meeting. They must give parents notice of the proposed change, and under IDEA, if the parents request a due process hearing immediately, the student's placement is frozen in the last agreed upon placement until the due process procedure is resolved. The only exception exists if the school is suspending the student or makes an emergency placement in an *Interim Alternative Educational Setting*. The school is only allowed to do this under the following circumstances:

- The student is involved with drugs.
- The student is in possession of dangerous weapons.
- The student has injured another student.
- A hearing officer determines that the student is substantially likely to injure a student.

Other than those four circumstances, if the school proposes a change of

placement and the parents request a due process hearing, the school must maintain the student in the prior placement until the due process hearing is resolved.

**Q: What are the rights of students with disabilities to get the programs they need to succeed once they are out of high school?**

**A:** This question highlights a major change in IDEA 2004 in favor of much clearer school responsibility for transition planning for students aged 16 and older who are eligible for special education. Since the law was adopted in 1975, it has required schools to develop transition plans for students and to have those plans in place by age 16 to help prepare students for life beyond high school. Unfortunately, transition planning has been a low priority in the IEP process for many schools and students often either fail to have transition plans or the plans do not include meaningful services.

The IDEA 2004 amendments dramatically strengthened schools' obligations in evaluating a student's transition needs. Now the school and family must develop transition goals. Once those goals are developed, they help shape the creation of the student's annual goals. Schools must now focus more on what needs to be in place for the student when the student graduates. This substantially expands the school's responsibility in the services that must be provided.

This is made even more powerful because of the increased emphasis on a student's developmental and functional progress in addition to academic progress. For a student with a mental health disorder, he or she may be getting sufficient academic credit to progress from year to year, and may be doing well on achievement tests, but may be unable to function after graduation based on his or her emotional, behavioral, or social needs. The law now clearly requires schools to address those needs in a manner that takes into account the student's functioning in high school and what the student will need to function independently when he or she graduates from high school.

The transition planning language in IDEA also calls for schools to invite other community agencies to the IEP meetings if their services are needed for transition planning. The school also must reconvene the IEP meeting if those agencies fail to provide the needed services. Whenever an IEP includes a referral to another agency, parents should ask that the IEP also include a fairly short time frame for verifying that the other agency has agreed to provide the services. If the outside agency is not doing what the school requested, the school must hold a new IEP meeting to establish new approaches to address the student's needs.

IDEA 2004 also now requires the development of a *summary of performance* when a student either graduates or ages out of special education services. It is a document that identifies the student's needs to help when the student seeks services in the adult service system.

Even if a student has the credits to graduate at the end of senior year, the IEP team can determine that the student continues to have significant needs and therefore should continue to receive services and not graduate. Alternatively, the parents may object to the school's decision on graduation. In that case, if they request a due process hearing before graduation, the hearing will decide whether the student should graduate or continue to receive services. Obviously, whether or not to challenge graduation is an important decision and parents are advised to consult with a knowledgeable advocate or attorney before they decide whether to halt graduation and proceed with due process.

The IDEA 2004 amendments also make clear that when a student turns 18, the student becomes the decision maker about the special education services he or she receives rather than the parents, unless the parents have obtained legal guardianship or the state provides some mechanism that transfers authority from the student to the parents. In many states, a student assigns his or her parents the right to act as his or her advocate or spokesperson.

**Q: What if parents know that their child needs a certain type of service to ensure an appropriate education, however, the school district claims that they do not have the resources to provide that service? Does the school district have to find the resources to provide the service?**

**A:** A student is entitled to receive a free and appropriate education regardless of whether a particular service is affordable or available in a school district.

However, the challenge becomes how do you prove that a particular service, support, or resource is necessary for a student to ensure he or she receives a free and appropriate public education? If a school acknowledges that a service is necessary, but claims that it does not have the money to pay for it then the school must provide that service. If the parents or school cannot work out getting the service for the student and if the parents can prove that the school has acknowledged the need for the service but it has been denied because of cost, then the parents have a strong claim to pursue through due process.

Unfortunately, more often than not, if the school does not have the resources due to cost or lack of trained staff, the school will likely indicate that the service is not essential rather than admit that the service is needed but not available. When this is true, then the burden falls on the parents to show that the service that the school is offering is not appropriate and to identify the service that is needed for their child to make progress. These issues should be discussed at the IEP or 504 meeting. If the parents are unable to get the services they deem necessary, then they should consider mediation or due process to resolve the disagreement.

Parents can request a service or accommodation; however, they must have a clinical or educational basis for demonstrating why the service is needed.

The bottom line is that if the school acknowledges that a student needs a particular service, preferably in writing, then parents have a much stronger case to go after that service.

**Q: How do parents show a service is necessary for a free and appropriate education?**

**A:** There are two steps in approaching this question. First, if parents want a service that they are told is not available, they must show that the program the school is offering is not working. If the school is proposing something new that the parents do not want, it is harder because if the service has not been tried, then it is speculation to say that it will not work. But if the school has been providing a program and it has not worked, then the parents must take all the information the school has provided through report cards, progress reports, IEPs, achievement tests—and compare how the student is doing with how the student was expected to do. If the same goal statement is repeated year after year in the IEP it suggests that the student is not making progress. Also, if the student's level of performance is the same from year to year or is only going up a small amount, then it suggests that the program is not working.

The second step is to prove that a particular service is needed to help ensure progress. Proving that the school's program is not working does not automatically prove that the program or service requested is needed. Typically parents either have to find research that shows that the service is part of an accepted intervention to address their child's needs or they need to get outside educational or mental health professionals involved. These outside experts will help to show why the requested service is needed for the student to make progress.

**Q: How can parents hold their own in an IEP or 504 meeting if they cannot afford to hire an attorney or a special education specialist?**

**A:** It is important for parents to bring someone with them to an IEP meeting to provide moral support, to be an extra set of ears, and to take notes. Even if parents do not have a professional with them, one or more additional participants are important. If parents cannot afford to hire an

advocate or attorney, family advocacy organizations can often help identify individuals to go with the parents at no cost. Parents should not assume that the only option is to hire an attorney or advocate.

Parents should also do as much research as possible before the IEP or 504 meeting about how their child is doing and the school staff's perception of how their child is doing. It is often useful for parents to have conversations with key staff before the IEP meeting.

Parents should also research the programs and services that are available at the school. If there is more than one school in the district, parents should learn what is available in other schools in the district. This research is useful because schools do not always volunteer information on what is available. There may be things the student can benefit from that the parents may wish to discuss in the meeting. It is always easier to get services for the student when they are already available rather than requesting that the student receive a special program or new service.

It is also useful for parents to go into the meeting with a list of their child's concerns and needs to assure that they are addressed during the meeting. Sometimes meetings are terminated before a full discussion can occur. Parents always have the right to ask that the meeting be reconvened if they feel their issues have not been fully discussed.

Parents should also obtain a copy of the IEP or 504 plan either at the IEP meeting or as soon thereafter as possible. These documents should be received to ensure that they accurately reflect decisions made at the meeting. If not, parents should send a letter to the school asking for clarification on the issues.

The IEP should be as specific as possible in defining the services and accommodations that will be provided. It should address who, what, where, and when the services will be provided and how the services will be evaluated. One frequent concern is that an item discussed as a needed service may have qualifying language in the IEP, such as—counseling will be provided “as

needed” or time out will be provided “as needed” or a quiet room will be provided “if the student asks for it.” Parents should be aware of qualifying language because it may limit the use of the service. If it is essential, then it should be explicitly described as a required service.

Parents should also seek help from the Parent Training and Information Center (PTI) in their state, including training that is available on how to successfully participate in an IEP meeting. To find out about the training and related issues, visit [www.taalliance.org](http://www.taalliance.org) (click on the *Parent Center Map* on the homepage).

**Q: How can parents enforce a manifestation determination before suspension and prevent schools from using home instruction as an interim alternative placement?**

**A:** When a student is being considered for suspension for more than ten consecutive days or has been suspended for more than ten days in total for behaviors that are related or are close in time, the school must conduct a manifestation determination review to determine if the student’s behavior is caused by his or her disability.

The review includes two parts. First, the school must verify that the IEP has been appropriately implemented. If not, the behavior is automatically deemed to be related to the disability and the student may not be suspended long-term or expelled. If the IEP team determines that it has been appropriately implemented, it then must decide whether the behavior was directly caused by the student’s disability. If the student’s behavior was caused by his or her disability, then the school cannot proceed with a long-term suspension or expulsion but rather must explore ways to address the behavior within the school setting.

If the behavior was not related to the disability, then the school may impose a longer term suspension (more than ten days) or expulsion. However, under IDEA there is a *No Cessation of Services Rule*. This means that even if a student receives a long-term suspension

or is expelled, the student has the right to continue to receive some form of service that allows him or her to address his or her IEP goals and objectives, have access to the general curriculum, and receive support to address the behavior that got him or her into trouble.

**Q: How can parents get school districts to stop putting their child with a mental illness with other students with serious disruptive behavioral issues?**

**A:** Schools are required to serve a child in the least restrictive environment based on his or her individual needs, not based on his or her label. Many schools group students based either on their label or behavioral characteristics. They are allowed to do this if they can show that the program they are providing is appropriate to each student’s needs. Grouping students by label or behavior would violate the requirement of an individualized plan that is uniquely designed to meet the needs of each student.

For many students with mental

disorders, placement in these settings may contribute to a deterioration of their behavior. In these situations, it is also useful to consult mental health professionals for recommendations about the programming a student needs and the placements that should be avoided. For example, if the student is highly vulnerable, is unlikely to be able to protect himself or herself, maintain himself or herself safely, or to make emotional or educational progress in a setting with students who are noisy, disruptive, aggressive, or even predatory—it would be helpful for a mental health professional to provide a clinical opinion through a letter or report that includes the reasons why this type of placement is inappropriate and may cause the student to regress.

*Editors Note: The questions included in this article were submitted by families interested in learning more about special education services. NAMI greatly appreciates the time and expertise Matthew Cohen provided for this article.*

*This article continues on NAMI’s Child and Adolescent Action Center website, visit [www.nami.org/caac](http://www.nami.org/caac)*



**IDEA and Special Education Online Resources**



**The Council of Parent Attorneys and Advocates**  
[www.copaa.net](http://www.copaa.net)

**Department of Education – IDEA 2004 News, Information, and Resources**  
[idea.ed.gov](http://idea.ed.gov)

**Monahan & Cohen**  
[www.monahan-cohen.com](http://www.monahan-cohen.com)

**National Dissemination Center for Children and Youth with Disabilities**  
[www.nichcy.org](http://www.nichcy.org)



**National Technical Assistance Center on Positive Behavioral Interventions and Supports**  
[www.pbis.org](http://www.pbis.org)

**SchoolMentalHealth.org**  
[www.schoolmentalhealth.org](http://www.schoolmentalhealth.org)

**Technical Assistance Alliance for Parent Centers**  
[www.taalliance.org](http://www.taalliance.org)

**Wright’s Law on Special Education**  
[www.wrightslaw.com](http://www.wrightslaw.com)

# Do the Math!

## The School Psychologist's Role with Students with Mental Health Treatment Needs

by Loren M. Pearson, Psy.D., Certified School Psychologist, Philadelphia, PA

**T**here is little doubt that good grades in school add up to success in life...right? Therefore, educational achievement plus well rounded extra curricular activities minus poor instruction or curriculum equal positive personal and societal outcomes. What is the matter with this formula? Let us do the math. The National Advisory Mental Health Council's Workgroup Report found that one in ten children in the United States live with a diagnosable mental illness severe enough to significantly impair day-to-day functioning, including schoolwork. Yet most of these children are not receiving treatment or services. There has been a substantial decline in the number of child and adolescent community mental health providers in the last several decades. Research shows that 70% to 80% of children diagnosed with mental health conditions only receive support from their schools. Early intervention programs, guidance counselors, and special education services have been in operation for 30 years. School universal prevention programs and plans to address issues such as substance abuse, bullying awareness, and school violence are being employed at many schools. Yet, school psychologists continue to hear with alarming frequency from teachers—"I have tried everything but this student's behavior takes all my attention at the expense of my other students!"

Teachers are under considerable pressure to produce students who perform above average on high stakes tests and

classroom disruptors can have a huge impact. High numbers of challenging students are referred for evaluations to determine eligibility for special education services; however this process can take up to three months or almost a third of their school year and does not guarantee a change in placement. Special education programs do not have a therapeutic component and often do not address students' emotional needs. The bottom line is that school-based mental health professionals must be armed with strategies and techniques to intervene with this growing mental health responsibility.

School districts are rapidly accepting the need to institute "evidence-based practices" to produce positive student outcomes. School psychologists are well positioned to introduce research-based mental health interventions and practices that are effective for students struggling with behavioral and emotional issues. Cognitive Behavioral Therapy (CBT) is an evidence-based therapeutic approach that employs specific strategies and techniques that are easily incorporated into intervention plans for students struggling with mental illnesses. Mennuti, Freeman and Christner in their book, *Cognitive-Behavioral Interventions in Educational Settings*, demonstrate how well the CBT model works in the educational setting. CBT, like many educational services, is a short-term, highly collaborative approach that focuses on teaching and building skills that help students find lasting solutions for the challenges in their lives. Policy makers will appreci-

ate the cost and time effective benefits of the CBT model.


The CBT approach focuses on students' issues rather than on their diagnoses, making it feel less clinical. Additionally, CBT fits nicely with many existing educational practices. The school-based CBT practitioner can be a member of a special education Individual Educational Program (IEP) team and provide a related service that coordinates intervention goals with special education IEP goals. CBT in the school setting is also compatible with the Response to Intervention (RTI) model currently being implemented in many school districts. CBT practices provide useful applications and strategies across the continuum of school services from prevention activities for the general education instructional environments (e.g., group social skills curriculum), to early identification of students identified as potential risks (e.g., small group problem solving instruction), to direct interventions for students with diagnoses (e.g., psychoeducation, cognitive restructuring, relaxation training, and related services).

Schools provide the ideal environment to deliver evidence and research-based mental health interventions to children and adolescents. Students receiving treatment in schools are seen within a familiar and non-threatening setting. Common barriers to treatment such as scheduling, cost, and transportation issues are not factors in the school setting. In schools, students are provided with the opportunity to practice and receive support for

learning skills in the natural environment. While no single treatment approach offers a foolproof method for solving complex emotional and behavioral challenges facing students today, CBT research has demonstrated positive outcomes with children dealing with anxiety, depression, obsessive-compulsive disorder, post traumatic stress disorder, and autism spectrum

disorders. Many school psychologists are trained or have access to training using CBT approaches in the school setting and should be encouraged to use this effective approach with students with mental health treatment needs. Many school psychologists have strategies to improve instruction and achievement and to address the social and emotional challenges facing our

children. Providing CBT and other effective interventions through school psychological services promises to improve the young lives of students.

To learn more about the school psychologist's role with students with mental health treatment needs, contact Dr. Loren Pearson at [lpearson@kcsd.org](mailto:lpearson@kcsd.org). 

## Improving School Performance for Students with ADHD

**T**he school experience can be challenging for students with attention deficit hyperactivity disorder (ADHD). Students usually are identified only after consistently demonstrating a failure to understand or follow rules or complete required tasks. Several studies found that students with ADHD, compared to students without ADHD, had persistent academic difficulties that resulted in the following: lower average marks, more failed grades, more expulsions, increased dropout rates, and a lower rate of college undergraduate completion.

### Helpful Hints

There are a few evidence-based hints for addressing the specific learning needs of children with ADHD, including:

- Numerous studies have found that positive results occur when the major stakeholders in a student's education collaborate to address the child's ADHD. Common rewards, reinforcement strategies, and language help to promote consistency across settings. Parents and teachers can share information with one another and work together to plan behavioral and academic strategies for the student.
- If a child exhibits patterns of disruptive or aggressive behavior, best practice research indicates that the child may benefit from a positive behavioral intervention plan that clearly delineates expectations and includes positive supports. The process to develop an effective plan should be collaborative and involve the parents and other individuals who are most familiar with the child.
- A student can take some of the responsibility for his or her educational and behavioral accommodations. Student input helps to promote a sense of ownership and responsibility for the new strategies and accommodations.

The following are some suggestions for practices that may be helpful for parents and teachers working with a child with ADHD.

### Tips for Home

Caring for a child with ADHD may be challenging, but it is important to remember that the child can learn successfully. It is critical that parents remember that some of their child's disruptive behavior is a manifestation of the disability


and that the challenge is finding ways to help their child change the inappropriate behavior. The following are suggestions for parents:

- Focus on discrete rewards and consequences for appropriate and inappropriate behavior: such as tangible rewards and treats, movie night for a good week at school, removal of privileges, and time-out from reinforcing activities where the child is essentially removed from situations that foster inappropriate behavior;
- Set a daily routine and stick to it. Bedtime and preparation for school are much easier if there is a structure already in place;
- Have tangible reminders like charts for chores, an assignment pad to record homework, a specific folder to put work in upon completion, and gain the child's attention before speaking to him or her. Have the child repeat back directions for things that are really important; and
- Avoid the repeating patterns of inappropriate behavior followed by ineffective punishment, administering consequences without prior warning, or without the child understanding why he or she is receiving them, and avoid responding inconsistently to inappropriate behaviors.

### Tips for School

A student with ADHD can present unique challenges in the classroom. It is important for teachers to be aware of coexisting conditions such as learning disabilities, as well as reinforcing the importance of classroom and instructional structure. The following are tips for teachers:

- Work on the most difficult concepts early in the day;
- Give directions to one assignment at a time instead of directions to multiple tasks all at once;
- Vary the pace and type of activity to maximize the student's attention; and
- Structure the student's environment to accommodate his or her special needs. For example, the student can be seated away from potentially distracting areas (such as doors, windows, and computers) or seated near another student who is working on a shared assignment.

*These tips are reprinted from the U.S. Department of Education, Office of Special Education and Rehabilitative Services online resources accessed at [www.ed.gov](http://www.ed.gov).* 

# Quest for the Best IEP

by **Lisa R. Cook**, Family Advocate, NAMI North Carolina

*If women are from Venus,  
and Men are from Mars  
then the IEP process is from  
somewhere north of Uranus.*

**Y**es, with special education you enter a strange land of acronyms, assessments, anecdotal records, IQ ratings, and benchmarks, so you will need a personal guide to help you navigate. Hello, my name is Lisa Cook and I will be your tour guide today. As a veteran with six years under my belt in this strange land, I have learned to advocate for my daughter and have worked to advocate for others. Even with experience, I am still amazed at what I see and hear at Individualized Education Program (IEP) meetings.

Think of this as your road map with some detours that *LisaQuest* is unable to predict. You have to tailor your journey to suit your needs. At the end of the day, our desired destination is always the same, an IEP that will allow your child to be successful and feel supported as he or she embarks on his or her personal journey!

You have just received an invitation to attend an IEP meeting for your child. It may be the first or the fifty first, but for many parents the reaction is the same, a pit in their stomach followed by sweaty palms (okay maybe that was just me). For many parents, the process is daunting and overwhelming, so I have created a list of ten tips to help you on your journey.

**1. Keep your friends and family close.** IEP meetings often reveal things that you, as the parent, may not be aware of. I have attended at least four meetings where the teachers wrote in their notes that the youth mentioned thoughts of ending their lives, something the parents never knew and had not been informed about before the meeting. It is important to have someone there to provide support, offer a kind word, or just to listen. For some parents, the information shared—a low IQ, a



Lisa R. Cook

new special education classification, and more—can be devastating to hear. The IEP meeting is also a good time to bring service providers who can identify and communicate strategies and techniques that work and do not work for your child.

- 2. The meeting time must be convenient (within reason) for you and your support person.** You can decline the time offered by the school and provide other proposed times for the IEP team to consider. It is critical that you are proactive in the scheduling process because if you fail to respond, the school can hold the meeting without you.
- 3. Find a local advocacy group and see if they have representatives who can attend the IEP meeting with you.** NAMI often has family advocates that can assist you with the IEP. If at all possible, try to meet with the advocate before the IEP meeting to make sure that you are all on the same page. Be open-minded and take the advocate's experience and suggestions into consideration.
- 4. Know the school's position on consequences, special education services, and how they work with families.** Parents are often amazed when they read over their school's discipline policy and learn that a number of required interventions are not implemented and that students with disabilities are simply suspended.
- 5. Do your research. Go to your favorite search engine and review**

your state's Standard Course of Study or Grade-Level Curriculum. This is very important when the team develops benchmarks or goals for your child to reach. With this information, you can identify where your child currently is academically, according to grade level, and where your child should be.

- 6. Know who the key players are.** Identify each person in the IEP meeting and understand his or her role in the meeting. There are certain individuals who must be present during the IEP meeting. The U.S. Department of Education has many resources related to IEP meetings, which can be accessed online at [idea.ed.gov](http://idea.ed.gov).
- 7. NO BLAME, NO SHAME, NO ENEMIES!** Even though you may have experienced difficulty with your child's school, remember the ultimate goal is to work together to assist your child in reaching his or her goals, so try your best to use words that bring everyone together. Remember that after you leave the meeting, your child has to go back to that school.
- 8. Celebrate your child and his or her achievements.** IEP meetings often focus on deficits but this is a wonderful time to talk about what your child does well and improvements you have seen. This is especially true if your child is in the IEP meeting. Take a few minutes at the beginning of the meeting to go around the table and talk about your child's abilities and achievements. You will be amazed at how this will change the dynamics in the room! It also helps to start, and hopefully keep things, on a positive note.
- 9. Read and review before you sign the IEP.** This is a binding document that will be in effect for one year unless you meet again to make revisions. It is important to be assertive and voice any concerns or questions. Make

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# Peer Corps and the Seeds of Student Empowerment

by **Caroline Kulczuga**, student at Northwestern University, *Peer Corps* Coordinator, NAMI Greater Chicago

I first became acutely aware of the lack of mental health resources for college students in the spring of 2007. I also became aware of the misinformation out there about mental illnesses. I learned of my ability to do something about it.

My first two years of college were largely a personal journey. I was seeking to find and be comfortable with myself. Although I had heard stories of students experiencing trying times, not knowing where to look for help, and more, I had not really grasped the big picture. However, as time went on, I met more people, expanded my social networks, and was privileged to learn about many personal stories of hardship, triumph, and tragedy. I began to form an impression of what was truly going on in many university settings. The conclusion I reached—college-aged students deal with an incredible array of mental, social, and physical issues. These include anxieties that are compounded by an unfamiliar new environment and the lack of information about the resources available to students. There are also many students disillusioned with the mental health system they encounter or flat-out do not believe that things can change for the better.

In spring 2007, I became an intern for NAMI Greater Chicago (NAMI-GC), and began to work almost exclusively on their *College Outreach Program* (NCCOP). I learned an incredible

amount about mental health and why an adequate mental health system is such a critical component of college life. The vast majority of mental illnesses have onset during the college-age years. Yet despite its prevalence, the stigma of mental illness pervades almost every echelon of society. College-age students are the most likely age group to develop a mental illness and yet are often away from their traditional support networks, are uninformed, or afraid to ask for help.

To tackle this problem, Isabelle Burtan, NAMI-GC Project Director, and I developed the NCCOP initiative—*Peer Corps*. Based on a thirty-plus year successful peer counseling program at Harvard University, *Peer Corps* is a student-run, peer counseling and training program. It can be implemented at any university. Our program is rooted in two concepts—empathy and education.

The *Peer Corps* training model teaches non-judgmental and non-directive listening skills. Instead of being solution-oriented, we are trained to reflect students' emotions and to be with them in the moment. *Peer Corps* counselors do not give advice, diagnose, or pass judgment. They are well-informed about the resources available on campus and in the surrounding community and are trained in referral skills. With this program, we hope to create a safer, healthier, more informed, and supportive



Caroline  
Kulczuga


campus community.

We work *with* the university mental health system and compliment their services—to allow more students to be helped and educated while also allowing them to take charge of their mental health to become more active and educated members of the community.

Through the incredible guidance of Isabelle, and a lot of hard work, *Peer Corps* is being launched at Northwestern University. Word about the program is spreading to other Chicago-area colleges and universities. We have a group of students at Northwestern who are trained in the program. The training model includes forty-plus hours of training. Implementation of the program has included conducting training sessions, holding supervisory meetings, developing budgets, developing materials, and contacting university administration.

Despite the immense work and commitment that has gone into launching this initiative, the most difficult part is gaining administrative support. In the wake of tragedies like Virginia Tech and Northern Illinois University, we believed that the need for programs like ours would be crystallized. But changing the system has been a challenge.

Nonetheless, the seeds of student empowerment have been planted, and the motivation and commitment of students is truly inspiring. I am a senior now, and will soon leave college life behind. Yet I leave confident in the strength of our peer-support message and in the knowledge that it is expanding and taking hold.

To learn more about *Peer Corps*, contact NAMI Greater Chicago at [info@namigc.org](mailto:info@namigc.org). 


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sure you get a copy and read the IEP before signing it.

**10.DOCUMENT, DOCUMENT, DOCUMENT!**

Always remember that if it is not written down, then it did not happen.

And most of all, remember that the IEP is there to help your child, so use it for your child's benefit and think positively. Happy trails!

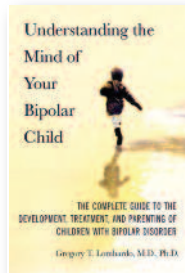
To contact your local NAMI to inquire about a family advocate to help with the IEP process, visit NAMI at [www.nami.org](http://www.nami.org) (click on *State and Local NAMIs*). 

# Getting an Accurate Diagnosis of Bipolar Disorder

by Gregory Lombardo, M.D., Ph.D., Child Psychiatrist, New York

**T**he diagnosis of bipolar disorder, especially in children, has become problematic for several reasons. The criterion for diagnosis is based on an earlier concept of manic depression in which there were clear shifts between manic and depressive states or between hypo-manic and depressive states. With the wider use of several kinds of medications—antidepressants, stimulants, mood stabilizers, and atypical anti-psychotics—characteristic responses to these medications (positive and negative) have come to be seen as signs of bipolar disorder. The use of these medications has also led to the recognition of subtler forms of the disorder characterized by mood states not previously recognized as signs of bipolar disorder such as a mixed state and extreme irritability. Diagnosis of bipolar disorder in children has also drawn attention to a cluster of traits that can sometimes be seen as earlier signs of the condition. These include marked oppositional behavior, frequent nightmares, excessive silliness, high anxiety, daily or seasonal mood cycles, and a mixed state.

There is a *spectrum of symptoms* that can appear in bipolar disorder, including elevated mood, depression, irritability, anxiety (social anxiety, panic attacks, and generalized anxiety), sleep disorders (difficulty getting to or staying asleep, excessive sleep, nightmares, and night terrors), hypersensitivity to sound or light, decreased sensitivity to temperature (especially cold), cognitive problems (sometimes arising from poor coordination of the left and right hemispheres



of the brain affecting visual tracking and fine motor coordination), and problems with executive function. This spectrum of symptoms can also occur in varying intensities and can have onset at different ages. As these complexities have been better understood, the diagnosis

of bipolar disorder (especially in children) has become more frequent,<sup>1</sup> leading to increased confusion and skepticism about the term bipolar.<sup>2,3</sup>

Another challenge in diagnosing bipolar disorder, one present in psychiatry as a whole, is that because of the staggering complexity of the central nervous system, the exact physiology underlying the diagnosis is not known and differs from person to person. We know this because people with similar symptoms can react differently to the same medication. In other areas of medicine, diagnosis is accompanied by an understanding of the condition at the cellular and even the molecular level. Often there are definitive radiological, microscopic, or chemical tests that confirm the diagnosis. Psychiatric diagnoses are more properly understood as *syndromes*—collections of symptoms that are seen together, but which do not necessarily have the same underlying biologic causes. Indeed, the criteria for psychiatric diagnoses given in the DSM-IV are purely based on signs and symptoms. Diagnosis based on symptoms alone would now not be acceptable in the treatment of infectious diseases, cancer, or heart disease—and one day will not be adequate in psychiatry.

In my opinion, diagnosis on the basis of symptoms is already unacceptable when it comes to bipolar disorder. In

my experience, the following three sets of criteria must be used for diagnosis:

- a person's present condition (symptoms and unusual strengths);
- developmental history; and
- family history.

For example, depression occurring first at age seven may be crucially different than depression beginning at age twenty or forty—it may appear different, it may need to be treated differently, and it is more likely to be a harbinger of bipolar disorder appearing more fully at a later age. Similarly, frequently recurring depressions signify something different than a depression that is more or less isolated. Attention deficit hyperactivity disorder (ADHD) in a child is likely to be a symptom of bipolar disorder if it is accompanied by depressive symptoms, a sleep disturbance, marked irritability, severe oppositional behavior, or onset in adolescence. ADHD should also be regarded more cautiously in a child with a family history of bipolar disorder or a family history of other traits within the syndrome, including depression, marked anxiety, panic attacks, substance abuse, emotional or physical abuse, marked creativity, charismatic personality, or extreme productivity. These traits may also be scattered among different relatives.

In the case of a young child and in some adults, the diagnosis of bipolar disorder should be made over time and should not be arrived at with a single evaluation.

The value of a bipolar diagnosis is its ability to predict a person's future vulnerability and to guide clinicians in the use of medication. Earlier detection and treatment can help lessen the

<sup>1</sup> Boris Birmaher M.D., "Longitudinal Course of Pediatric Bipolar Disorder," *Am J Psychiatry* 164:537-539, April 2007, <http://ajp.psychiatryonline.org/cgi/content/full/164/4/537>.

<sup>2</sup> Jerome Groopman, MD, "What's Normal? The difficulty of diagnosing bipolar

disorder in children," 04/9/07, <http://www.jeromegroopman.com/articles/whats-normal.html>.

<sup>3</sup> Gregory T. Lombardo, MD, PhD, "Accumulating Evidence," [www.understandingthemindofyourbipolarchild.com](http://www.understandingthemindofyourbipolarchild.com).

long-term severity of the disorder. The course of the condition, if untreated, is to become more severe over time. I have seen young patients under my care *improve* year by year with mood swings becoming less and less severe and the level of social, academic, and professional functioning improving steadily.

For example, Grace, a woman I featured in my book, *Understanding the Mind of Your Bipolar Child*, was first diagnosed at age 13 with Bipolar II. Initially she struggled with mood, behavior, substance abuse, and academic problems. However, her mood changes became less and less severe over the years, her substance abuse ceased, her academic functioning improved, and her relationship with her parents improved dramatically. Now in her twenties, her mood is stable, she is professionally successful,

she has a stable marriage, and she is the competent parent of a young daughter.

Recent concerns that bipolar disorder is being over diagnosed in children exist in part because diagnostic criteria for children were developed from clinical experience with adults. The criteria did not recognize a spectrum of symptoms and intensities that can vary over the course of development. In my experience, it is much more common for a diagnosis to be missed than it is to be made inappropriately.

Once a diagnosis is made, treatment should be comprehensive and should include the following:

- medication;
- psychotherapy;
- attention to medical complications, especially for obesity;
- assessment of cognitive function;
- school consultation;

- attention to family dynamics and needs; and
- attention to peer relationships.

My own clinical experience shows that early diagnosis and comprehensive treatment can make the difference between a declining course with increasing developmental problems or one of increasing progress with mood and development from year to year. The most difficult cases are those of adults whose diagnosis was missed and who now experience more serious mood, professional, and personal problems.

To learn more about early-onset bipolar disorder and to contact Dr. Gregory Lombardo, visit his website at [www.understandingthemindofyourbipolarchild.com](http://www.understandingthemindofyourbipolarchild.com). 

## STATE NEWS

# Families as Advocates— Coming Together for Kids

by **Cindi Keele**, Executive Director, NAMI Missouri

In October 2007, NAMI Missouri was awarded a SAMHSA Family Network Grant. The parent organization that had previously held this grant went under in 2006.

Because we had been serving parents of children with mental illnesses for more than a decade, we believed we stood a chance at keeping the funding in Missouri. While these grants rarely go to NAMI organizations, we knew we had to try.

The sad state of Missouri's mental health treatment and service system fueled this imperative. Our governor's 2005 Medicaid cuts left more than 100,000 citizens without healthcare and many of them were children. Mental health treatment and services were slashed, leaving us with a system that was severely rationed. In March

2006, NAMI's *Grading the States* Report described Missouri as a state in which "the legislature has pounded the public mental healthcare system with budget cuts. At some point cuts mean more than trimming the fat or saving money; instead, they become harms, translating into needless suffering and early deaths."

Since that time, parent advocates in the developmental disability (DD) community managed to get some cuts restored. Autism services and treatment got significant increases, while children with serious emotional disturbances (SED) were all but ignored. We could not allow this to continue.

Most will admit children with SED face more stigma and public ignorance than a child with Down Syndrome. In Missouri, this translates into a marked

imbalance in access to adequate care. That said, we also realized the DD community had built a first class advocacy network.

Missouri's children with SED have never had a network. The SAMHSA Family Network Grant had been used to build a single organization, but not to engage the many factions and family organizations that had been fostered by the SAMHSA System of Care effort. The creation of this network became the basis for our proposal and the development of *Families as Advocates—Coming Together for Kids*.

We are extremely busy and have begun to see results in the early stages of our grant. Recently, our network was granted a voting seat on Missouri's System of Care steering committee. We held two statewide network meetings

involving more than 18 parent organizations and child advocacy groups.

In early January, *Families as Advocates* provided testimony to a House budget committee on child mental health funding. We hosted an advocacy workshop and a legislative breakfast in the Capitol Building in March and trained new *Visions for Tomorrow* teachers in May.

My advice to state organizations interested in submitting a SAMHSA Family Network Grant proposal is to do lots of preparation. Contact and share your plans with as many parent and child advocacy organizations as you can find. Get their feedback and foster their partnership. We could not have done this without a groundswell of support from many, many partners. One partner in particular, *Family*


*Bridges* in Springfield, MO, led us in new directions. They ultimately became our official consultant agency for the proposal. We also conducted a statewide parent survey to assess parents' needs and to lend added credibility to our proposed grant activities.

NAMI organizations interested in the SAMHSA Family Network Grant will likely have to form a separate board composed of at least 51% parents of children and young people receiving mental health services to qualify to apply for the grant. Our Board is closer to 75% parents with children in the service system and we also have teen and young adults represented, thanks to our *Family Bridges* partners.

You should allow a minimum of eight weeks to prepare the grant. These grant proposals are no walk in the park

and require strong research and writing abilities.

Despite the time commitment, the effort is well worth it. While the grant funding is not significant, it is enough to have staff dedicated to child and adolescent issues and to focus energy on getting appropriate care to children and their families. Over time, it can be leveraged into making early screening, treatment, and transformation a reality in your children's mental health system.

For more information about NAMI Missouri's grant activities, contact Cindi Keele, NAMI Missouri Executive Director, at [namimockj@yahoo.com](mailto:namimockj@yahoo.com). For more information about SAMHSA Family Network Grants, visit [www.samhsa.gov/grants](http://www.samhsa.gov/grants). 

## AFFILIATE NEWS

# Focusing on Families— The Parent Matching Program

by Wendy Brennan, NAMI-NYC Metro Executive Director and Tod Severance, NAMI-NYC Metro Communication's Coordinator.

**E**ven under the best of circumstances, raising children can be a challenge. Yet for many parents, finding support to deal with the common trials of parenthood requires no more than a phone call to friends or family. But, as Mary Lee Gupta, NAMI-NYC Metro Services Coordinator notes, “when you have a child with mental health issues, major mental illness, or behavioral issues, you often feel very much alone.” Hoping to improve this isolation, Gupta began *The Parent Matching Program*. The mission of the program is to match parents with other parents who have had experience with the same issues, or as Gupta put it—“a parent who has been there.”

*The Parent Matching Program* began in 2005 and is modeled after the *Parent-to-Parent Program* at Family TIES of Massachusetts, a project of the Federation for Children with Special

Needs. Built from established evidence-based practices for parents with children with a broad range of disabilities, the parent-to-parent support model has been successfully used across the country for many years. Research has shown that this support model increases parents' acceptance of their child's disability, enhances their coping ability, decreases isolation, and improves their ability to address problems as they arise.

After receiving permission from Family TIES, Gupta used their model as the basis for a parent matching program for parents of children with mental illnesses. Recognizing that it would be difficult for parents who care for children to regularly attend support groups, *The*



Mary Lee Gupta



Mary Ann Cerón

*Parent Matching Program* enables parents to connect on a regular basis by phone. As Gupta explains, “it was clear from the beginning that for this program to be successful, it would have to be easily accessible for parents. The phone model allows us to bring the support these parents need to them and at a time that is convenient for them.”

To staff *The Parent Matching Program*, NAMI-NYC Metro seeks out parents of older children, adolescents, and young adults with mental illnesses who have dealt with their child's illness for several years and have developed positive coping skills. These volunteers are asked to give a small amount of time to act as support parents for parents,

caregivers, and foster parents who are facing challenges stemming from their child's mental illness. After completing a three-hour training session, support parents are matched with a parent in need, and together they schedule four calls over a two month period to provide the needed support. Matches are based on diagnosis, age of the child, experiences in the treatment and service system, developmental challenges, and other issues that arise.

NAMI-NYC Metro now has a diverse group of more than 30 trained support parents. In 2006, with generous support from the New York Community Trust Foundation, they expanded the program and developed a full complement of services for parents and caregivers with children under 18 years of age in the mental health system. This included the development of Helpline resources for children and adolescents across New York City, two monthly conference calls (one in English and one in Spanish), and the hiring of a parent advocate to support parents and to engage in outreach in the Latino community.

Mary Ann Cerón calls being a NAMI-NYC Metro Parent Advocate her dream job. She finds great reward in helping other parents. Mary Ann first

heard about NAMI-NYC Metro in 2004 from another parent. Having a difficult time coping with bipolar disorder, Mary Ann was looking for a support group for herself and her children, who also have mental illnesses. After a call to the Helpline, she got a referral for a support group. Following four hospitalizations and an ongoing struggle to find the right medications, she decided she needed to understand more about mental illness and thought that volunteering at NAMI-NYC Metro would help her acquire the knowledge she wanted.


After applying for a volunteer position, Mary Ann trained to work on the NAMI-NYC Metro Helpline, where she learned a lot about available mental health resources in New York City. She also took the NAMI Peer-to-Peer class—an experiential learning program that promotes wellness and recovery. The class taught her valuable tools to help her take care of herself and her children. Eventually, Mary Ann trained to become a volunteer support parent for *The Parent Matching Program*.

In addition to her personal commitment to *The Parent Matching Program*, the fact that Mary Ann is Latina is extremely beneficial for NAMI-NYC

Metro's outreach in the Latino community. Like many of New York's diverse racial and ethnic communities, the Latino community faces strong challenges in overcoming the stigma surrounding mental illness. Mary Ann believes that stigma is the reason her mother did not get help with her own mental illness. She acknowledges that it is a fight to knock down many of the walls that currently exist.

Many parents become more involved in NAMI after participating in *The Parent Matching Program*. They may participate in a support group, become a support parent themselves, assist with outreach efforts, or start their own support group for parents in their community.

As word spreads about *The Parent Matching Program*, NAMI-NYC Metro is poised to help many more caregivers advocate for themselves. The program also supports and sustains parents who provide help. Mary Ann smiles when she says "I am so happy that after sharing with another parent, I can hear hope and relief."

To learn more about *The Parent Matching Program*, contact Wendy Brennan, NAMI-NYC Executive Director, at [wbrennan@naminyc.org](mailto:w Brennan@naminyc.org). 

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