

Helping Parents Understand Their Rights in Special Education —

An Interview with a Legal Expert

Darcy Gruttadaro, Director of the NAMI National Child & Adolescent Action Center, recently interviewed Matthew D. Cohen on issues related to The Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act.

Mr. Cohen is a founding partner of Monahan and Cohen, a Chicago law firm specializing in special education, disability rights and human service law. Mr. Cohen has represented thousands of children with disabilities, lectures frequently on special education law around the country, and has written numerous articles on special education issues. He is an adjunct faculty member at the Loyola Law School. He is also a past president of Children and Adults with Attention Deficit Hyperactivity Disorders (CHADD), and helped organize the Children's Behavioral Alliance (CBA). The CBA issued a briefing paper, "In the Best Interests of All," which addressed the educational and mental health needs of children with social, emotional and behavioral challenges. NAMI was a member of the CBA.

Darcy Gruttadaro (DG): Please briefly describe the eligibility criteria under both IDEA and Section 504 – and specifically as it relates to students with mental illnesses.

Matthew Cohen (MC): IDEA and Section 504 have very different criteria for eligibility and it is important to understand the general differences in these federal laws to understand how they relate to students with mental illnesses. IDEA requires that a student meet the eligibility criteria in one of the thirteen categories of disability. Emotional disturbance (ED) is one of

the thirteen categories, and includes children with mental illnesses and behavioral disorders, if the problems are severe and adversely effect school functioning.

Section 504 does not use categories of disabilities and does not specifically identify any disability as being covered or not covered. Instead, Section 504 refers to any physical or mental impairment. Therefore, at the outset, both laws provide for the potential protection of students with mental illness but do so in very different ways.

The second thing that differentiates IDEA from Section 504 is that IDEA requires a showing that a student's disability has an adverse effect on their school performance as a result of the disability. By contrast, under Section 504, there is a requirement that the identified physical or mental impairment substantially limits a major life activity. Both learning and thinking are considered major life activities. Therefore, the language of the two laws is very different in how they describe disability and how the disability impacts functioning. Section 504 is much broader in the range of functioning that it covers.

The third area of difference between IDEA and Section 504 is that the criteria for eligibility under IDEA require that once you have met one of the thirteen categories and there has been some indication of an adverse effect on educational performance, the student still has to demonstrate that he or she requires special education. By contrast, under Section 504, once it is determined that the student has a physical or mental impairment and that it sub-

stantially limits a major life activity, the student qualifies for protection under the law if they need special education,

related services, or accommodations. The critical difference here is that to be eligible for special education, the student must need special education instruction. To qualify for 504 protection, a student may be in need of related services or accommodations without special education instruction. Typically, that protection under Section 504 is understood to include

social services, counseling, occupational therapy, speech or physical therapy or may include accommodations for timing in testing or preferential seating. It may also include specialized instruction, if that is necessary to address the impact of the disability. Thus, there are some situations where the student is eligible for Section 504 but not eligible under IDEA.

What is interesting about the ED category under IDEA is that it is not based on a diagnosis of mental illness, although the law does reference schizophrenia. Rather eligibility is based on the presence of behavior that fits into several prescribed categories. Therefore, a student's eligibility relates more to what people observe in the behavior of the student than it is based on a determination of a mental health professional that the student has a mental illness. The behavioral characteristics that are used under the ED category in IDEA include inappropriate behavior or feelings under normal circumstances, inappropriate relationships or difficulty developing relationships with peers or adults, indicators that suggest the child has a school related



Matthew D. Cohen, J.D.

phobia, and others.

Because the IDEA eligibility criteria for the ED category is behavior-based, there is a frequent disconnect between how the parents and private evaluators view the child's needs and how the child is viewed by providers and school professionals. This is one of the sources of disputes between parents and schools because the existence of a clinical diagnosis of mental illness does not by itself determine whether a child is eligible under either IDEA or Section 504. Instead, schools focus on behavior and particularly on behavior that is exhibited in the school.

IDEA and Section 504 not only work differently for eligibility, but they also have different implications for

“It is important to note that the purpose of both of these laws (IDEA and 504) is not to ensure that the students have a positive school experience.”

schools. IDEA is a funding statute. If a student is eligible for IDEA services, the school then qualifies for reimbursement from the state and federal government for a portion of the services that they provide. However, in return for that funding, the school district is expected to follow detailed procedures in evaluating the student, developing an IEP, reporting to and involving parents, following the child's progress and addressing the student's behavioral needs. By contrast, Section 504 is not a funding statute. It is a civil rights statute and provides no funding for Section 504 services. As a result, schools are often more willing to use Section 504 when a student does not require a lot of services because Section 504 does not have the same level of regulatory requirements. When a student requires more expensive and extensive services, then the school may be more motivated to provide IDEA services because the school is more likely to qualify for reimbursement.

DG: Parents often express concern that schools tell them that their child with a mental illness is not eligible

for special education services under IDEA because the child is doing well academically. However, the child is clearly struggling in school in other areas. What can parents do?

MC: Many schools assume that a student's eligibility under IDEA exists only if the student's disability results in a measurable impact on the child's academic performance. The schools often take this a step further and evaluate educational performance based on whether the student receives passing grades and makes progress on school-wide achievement tests. While passing grades and achievement test scores are relevant in assessing whether a child is making adequate progress in school,

they should never be the only factors in determining whether a student may be experiencing an adverse effect on their performance as a result of their mental illness under IDEA or a substantial limitation in their academic performance in school under section 504.

Both laws require that the school district evaluate the child's performance holistically on the following factors:

- The child's functioning in school, including an assessment of the child's behavior;
- The child's social relationships;
- The child's ability to participate successfully in class;
- The ability to complete work and perform acceptably on tests;
- The child's ability to conform to school rules and classroom expectations; and
- The child's ability to access education in a way that is productive given their capabilities.

Schools also need to measure the child's communication ability, self-help ability to develop vocational skills,

development of motor skills and more. There are a wide range of different skills that impact a child's ability to participate in and benefit from education that need to be assessed in determining a child's need for special education services under IDEA or Section 504 protection.

It is important to note that the purpose of both of these laws (IDEA and 504) is not to ensure that the students have a positive school experience. The purpose is to assist students in developing skills that will promote their ability to be independent functioning citizens in adulthood. If the only measures for IDEA or 504 eligibility were higher test score, then these laws would fail to address many of the skill areas that the laws recognize as necessary to accomplish the goal of promoting independence and self sufficiency in adulthood.

Schools often fail to recognize the significance of these other life domains in determining whether a child with a disability is eligible under IDEA or 504. It is entirely possible that a child with a mental illness could receive passing grades and even high test scores while spending most of their time in a disciplinary status in the principal's office or withdrawn with no meaningful participation in class with peers. Those are examples of situations in which schools might fail to appropriately apply the eligibility criteria for IDEA and 504 by focusing solely on grades and achievement test scores, and deciding that the child is not eligible for services on that basis alone, despite the fact that the child's behavior in school shows clear evidence of the child's overall struggle in functioning.

One of the useful pieces of data that parents should review in preparing for the evaluation for special education services or Section 504 protection, is report cards and progress reports for their child. Most schools' report cards include not only grades for academic performance but a rating system or comment section for behavior. It is often the case that the student may be receiving passing grades but the comment section for behavior lists a variety

of problematic behaviors. Clearly, this type of information documents the school's recognition that the student is experiencing social or behavioral problems.

The most important data that parents can use to establish the basis for their child's eligibility for special education is information from the child's educational record, although sometimes a parent may need outside clinical evaluation data. It is important that parents keep all records that they get from the schools, including report cards, progress reports, notes from teachers, informal reports, disciplinary reports, and others. The school district often has information in a student's record that shows ongoing social or behavioral concerns about the child, but which has not lead to either a decline in achievement scores or poor grades.

DG: What do you recommend that parents do to prepare for the initial evaluation for special education services and during the evaluation process? If their child is found ineligible, what should parents do if they believe that their child is eligible for special education services?

MC: Parents need to keep all records for their child including school records, report cards, progress reports, notes from teachers, informal reports, disciplinary reports, and other related documents.

One of the disabilities that is frequently misunderstood and at times addressed incorrectly by schools is attention deficit/hyperactivity disorder (ADHD). Many children with ADHD do not require special education services or even the protection of Section 504. But for children with ADHD who do require special education services, the IDEA regulations provide that the child may be covered under the category called Other Health Impairment, if they meet the criteria for that category. If a child's ADHD results in the student having a limited ability to attend to educational tasks by virtue of their being excessively occupied with or

attentive to other things in the environment, then the child qualifies for special education services. Students with AD/HD may also be covered under Section 504, particularly if they only need accommodations or related services, such as nursing service to administer medication.

Under the law, a student's needs are supposed to be met regardless of which labels that the child is given. However, in some situations the label drives the service rather than getting services to meet the needs of the child. Consequently, there may be circumstances where an educational label the school is choosing to categorize the child may not be the most appropriate or desirable label for the child. It is important for parents to be aware of the impact of these labels and to make informed choices about which label they believe will most appropriately address the needs of the child.

If a child is already involved with a private mental health professional, it is important for parents to obtain information from that mental health professional (preferably in writing) indicating the professional's assessment of how the student's emotional condition is affecting their functioning in school. It is equally important that parents obtain from that professional any recommendations about the types of interventions, support, or services that the child needs in school to address the emotional disorder and its resulting symptoms. It is particularly useful for the outside professional to be specific about the type and amount of services, any things that should be avoided, and the type of positive behavioral interventions the child would benefit from.

DG: What do you recommend that parents do to best prepare for the Individualized Education Program (IEP) meeting and how do they ensure that their child has the most appropriate IEP to meet his or her needs?

MC: The single most important step for parents preparing for the IEP meeting is to have as much information

Online Resources on IDEA and Special Education

- Council for Exceptional Children – www.cec.sped.org.



- NICHCY – National Dissemination Center for Children with Disabilities – www.nichcy.org.

- Technical Assistance Alliance for Parent Centers – www.taalliance.org.



- Department of Education – Office of Special Education Programs – www.ed.gov (click on “About Ed” and “Offices” and “Office of Special Education and Rehabilitative Services”).
- National Association of State Directors of Special Education – www.nasdse.org.
- Wright's Law on Special Education – www.wrightslaw.com.

as possible about their child's needs, about their child's functioning at school, and about solutions that they think will be helpful for the child to function successfully at school.

Parents need to arrive at the IEP meeting as informed consumers with the necessary information to advocate for their child's needs. They also need to assess whether the proposals offered by the school are adequate and responsive to the child's needs. There also may be options available within the school system that the particular team is either unaware of or disinclined to offer and unless the parent has information about what is available, it will be harder to access those services.

Although the IEP process is intended to develop a program in response to a child's individual needs, it is always easier to obtain services that are already available than to have the school provide new services that it has not previously offered. In addition, it is important for parents to focus on services that are necessary for the child as opposed to services that are ideal or optimal because schools are only required to provide those services that are necessary to ensure that a child receives an appropriate education.

It is also important for parents to think about the type of communication that will be necessary for them to understand how their child is progressing on the IEP plan and to be adequately informed about whether the plan is working. In some instances the child may have a mental illness that is unfamiliar to the school staff and in these cases parents should share information with the school about the child's disorder and how it affects the child's functioning in school. Mental illnesses are sometimes hidden disorders and the symptoms of these disorders do not manifest themselves in the same way throughout the school day or the school term. School staff that do not understand these disorders may misinterpret the variability of the symptoms as misbehavior or a lack of motivation rather than understanding that the behavior is a symptom of the illness. Parents need to explain to the school staff why the behaviors or

symptoms may vary to help them take seriously the impact of the illness. Parents should also be familiar with the school's disciplinary guidelines and the classroom's disciplinary standards to determine whether there may be any modifications necessary for their child.

Parents should also be aware that their child's IEP should include goals to address areas of need, which may include academic or behavioral needs. The law requires schools to address not only the direct consequences of the child's disability but also any collateral effects. As a result children with mental illness may need support not only for the behaviors or symptoms associated with the illness, but may also need goals that address their academic functioning because of any adverse effects that their illness may have on their actual academic performance.

DG: Parents frequently express concern that they have worked with the school to develop an appropriate IEP for their child, however the school is not following the IEP. What can parents do in these circumstances to ensure compliance with the IEP?

MC: The first step in addressing a failure to properly implement the IEP is for the parents to ensure they have adequate documentation of what the school is or is not doing that is required in the IEP. Parents often respond to implementation problems with anecdotal reports that become battles of each party denying the position of the other without evidence. Behavioral reports, phone calls, communication, progress sheets, reports of meetings and other documentation are all important to establish patterns of the failure to properly implement the IEP. In the case of a school failing to implement the IEP, parents should carefully move up the hierarchy of authority within the school district, starting with the individuals who are supposed to be implementing the IEP but are not doing so.

When a school fails to properly implement the IEP, it creates an impossible dilemma for many parents in which their complaints of non-compli-

ance lead to deterioration in their relationship with the school staff. As much as possible, parents should try to solve the problem within the school before moving up to complain to the school district. However, there are a number of vehicles available to parents if they have been unsuccessful in attempting to resolve the IEP non-compliance issue. These include—complaints to the Director of Special Education, the Superintendent and the School Board. Parents may also decide to file a complaint with the State Education Agency, or to submit a complaint to the Office of Civil Rights within the US Department of Education. Parents may also request a due process hearing under either IDEA or Section 504. In addition, parents may request mediation either before requesting a due process hearing or as a first step after requesting the due process hearing. However, it is always preferable to resolve disputes with the school district in a voluntary and cooperative manner rather than through the adversarial process.

DG: Can schools use the argument that they lack the funding necessary to provide services to ensure that the child eligible for services under IDEA receives an appropriate education?

MC: No. Neither IDEA nor Section 504 allows cost to be the determining factor in whether a service is provided to students with disabilities. While cost may be considered as one of many factors, it may not be the sole or controlling factor. It is important for parents to recognize that under IDEA the school district receives substantial financial support from the state so that the cost of any service is not paid exclusively by the school district. It is also important for the parents and school to recognize that the failure to provide needed services may well lead to the need for more expensive services at a later time. However it is equally important that the parents be reasonable in their requests and strategic about asking the schools for things that are essential as opposed to seeking from the school district any possible service that could

be documented regardless of whether it is critical to the student's ability to function and learn at school. In addition, it should be recognized that if a school truly does not have the resources, they may reject the request even though they recognize the necessity. While the parent may ultimately prevail in a due process hearing against the school district, it will be less expensive for a parent to obtain a particular service on their own than it would be for them to enter into a legal battle with the school district over it.

DG: What has your experience been with securing "related services" outside of the school building (e.g. home and community-based services) for children with mental illnesses?

MC: School districts generally do not have well developed cooperative relationships with community mental health providers, although IDEA calls for the existence of interagency relationships that will provide coordinated

services. Parents may request outside services at the district's expense if the school district is unable to provide a service that is demonstrated to be necessary within the schools. However, schools are reluctant to agree to pay for private services even when they do not have the specific service available within the system because of the potential for escalating costs.

The parents will need to justify or probe the need for an outside service by documenting both that the service is essential to the child's ability to be successfully educated and that the service is unavailable within the public school system. Parents should be careful in requesting outside services because of its impact on school finances but should recognize that school districts have an obligation to provide all services that are necessary to meet the child's needs other than medical services.

Schools may sometimes refer a child to an outside mental health professional for evaluation. If this is being done in order to determine eligibility for

special education or Section 504 protection, it is supposed to be done at no cost to the parents.

DG: Recognizing that it is crucial that parents develop an "individualized" plan for their child, do you have any specific recommendations about what parents may wish to consider requesting in their child's IEP given that their child has a mental illness?

MC: Mental illnesses are highly variable in their impact on each child, as are the interventions that are appropriate to address them. However, parents can seek a number of interventions to address their child's needs. Since some schools are unaware of these mental illnesses and their impact on children, parents can request that information about their child's illness be shared with school staff. This is critical to promote sensitivity and appropriate judgment on the part of schools in working with the child. When schools lack staff

continued on page 15

NAMI's Child & Adolescent Action Center Participates in Duke University's CAPTN

Darcy Gruttadaro, the Director of NAMI's Child & Adolescent Action Center, has been selected to serve as a Steering Committee member for the Child and Adolescent Psychiatry Trials Network (CAPTN), a collaborative effort of the Duke Clinical Research Institute and the American Academy of Child and Adolescent Psychiatry (AACAP).

CAPTN is designed to conduct large, simple, practical trials that provide answers to important clinical questions in child psychiatry. As many families know, the current research base in child psychiatry is inadequate. Many of the psychiatric treatments that are used for children have been studied in adults, but not thoroughly studied in children. The overall goal of CAPTN is to evaluate the effectiveness and safety of treatments delivered by child and adoles-

cent psychiatrists under usual clinical conditions (in their community practice settings) to children and adolescents with mental illnesses. CAPTN holds real promise in helping to promote evidence-based medicine (EBM – the idea of EBM is that physicians have systematic research available to help guide their decisions about the treatment provided) in child psychiatry and in markedly increasing the research capacity in this area.

Here's how it works: CAPTN is currently recruiting child and adolescent psychiatrists to participate in practical clinical trials. This research will be done in clinician's offices rather than in controlled academic settings, so the findings are likely to have much broader application. Child and adolescent psychiatrists who join the CAPTN network benefit

by learning more about existing treatment and clinical research, by improving the care of youth they see in their practice, by receiving recognition in peer-reviewed journals, and by receiving clinical research and human subjects protection training.

Please consider asking your child's psychiatrist to participate in CAPTN. Both you and your child's psychiatrist can learn more about CAPTN by visiting their Web site at www.captn.org. The NAMI Child and Adolescent Action Center will continue to send updates about CAPTN through our e-mail group. If you would like to be added to our e-mail group, please e-mail Belen Assusa at belen@nami.org. We will also post updates about CAPTN on the child and adolescent section of the NAMI Web site, www.nami.org.