



AFC'S GUIDE TO

Autism Spectrum Disorders & Education

December 2012



Advocates for Children of New York
Protecting every child's right to learn

This guide to Autism Spectrum Disorders (ASD) is for parents, caregivers, and advocates of children with ASD in New York City. We hope this guide will help readers recognize signs of ASD, know where to go for help, and know their rights in the education system. It is for informational purposes only.

TABLE OF CONTENTS

What is Autism?	3
Signs of Autism Spectrum Disorders.....	4
Diagnosing Autism Spectrum Disorders	5
Evaluations for Educational Services.....	6
Early Intervention.....	8
Preschool Special Education	9
School-Aged Special Education	10
Behavioral Supports.....	12
Related Services and Supports.....	13
Assistive Technology.....	14
Instructional Practices.....	15
Private Schools	16
Mediation & Impartial Hearings	17
Additional Support Services	18
Safety Issues	19
Recreational & Social Activities	20
Programs for Adults.....	21
Parent to Parent Tips.....	23
Parent Information & Support Groups	25
Advocacy Tips & Organizations.....	26
Web Sites of Interest.....	27
Glossary of Acronyms	28
Contact Information.....	29
About Advocates for Children/Contact Us.....	32

This guide does not constitute legal advice. This guide attempts to summarize existing policies or laws without stating the opinion of AFC. If you have a legal problem, please contact an attorney or advocate.

WHAT IS AUTISM? WHAT ARE AUTISM SPECTRUM DISORDERS?

Autism Spectrum Disorders (ASD) are a group of developmental disabilities that can cause impairments in social interactions, communication, and behavior. The Centers for Disease Control and Prevention estimates that 1 in 110 children in the United States has an ASD.

Continuum of Autism Spectrum Disorders:

- **Autism:** also known as “classic autism” – the individual presents with significant challenges in social interaction, language and communication, and behavior, and may also have an intellectual disability
- **Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS):** the individual’s symptoms may be milder than those with a diagnosis of autism
- **Asperger Syndrome:** the individual may have social challenges and unusual interests or behaviors, but usually has no difficulty with language or intellectual ability
- **Rett’s Disorder:** children have typical development followed by a slowing of development, especially in the areas of language development, gross motor, and hand skills. This disorder affects mostly females.
- **Childhood Disintegrative Disorder:** Usually, this disorder is seen in 3- and 4-year-olds who have had typical development and then show a loss of language, motor, social, and other skills that they had already learned.



The criteria for each of these conditions can be found at:
<http://www.cdc.gov/ncbddd/autism/hcp-dsm.html>

SIGNS OF AUTISM SPECTRUM DISORDERS

Signs That A Child May Have ASD:

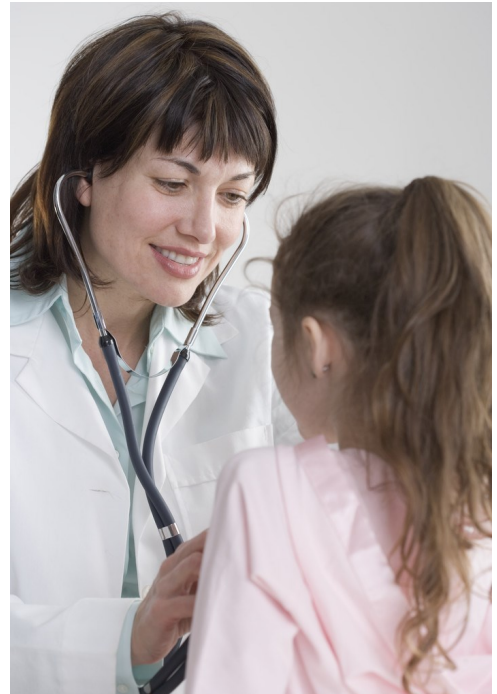
- Does not respond consistently when name is called
- Makes little or no eye contact
- Does not use gestures such as pointing or nodding head “yes”
- Does not show interest in other children
- Does not play with toys appropriately (e.g., may spin wheels on a toy car repetitively)
- Becomes very upset if plans or routines change

Your child’s pediatrician should be watching for any early signs of ASD. He/she should be screening for “developmental milestones” — things a child typically does at certain ages. For example, at 3 months old, a child has a social smile, watches faces, and follows moving objects with his/her eyes. Ask your pediatrician for a copy of a milestones checklist.

You can also get information from the Centers for Disease Control and Prevention about children’s typical developmental milestones starting at 3 months of age. This can be found at: <http://www.cdc.gov/ncbddd/actearly/milestones/index.html>.

Note:

A child with ASD may not show ALL of these symptoms, and this is not a complete list of the signs of ASD. If your child shows some of these signs or if you are concerned about your child’s development, please speak with your pediatrician.



DIAGNOSING AUTISM SPECTRUM DISORDERS

How Are Autism Spectrum Disorders Diagnosed?

There is currently no medical test for autism. Autism spectrum disorders are diagnosed by observation of behavior and communication by an experienced professional. Since some behavior linked with autism is shared by other disorders, it is important for a clinician to rule out other possible disabilities. Early diagnosis is very important because early intervention can result in positive outcomes for children with autism spectrum disorders.

The first step is to tell your child's pediatrician that you are concerned about your child's development and ask for a developmental screening. Be as specific as you can when describing your concerns: your child's behavior, language, eye contact, play skills, etc. If the initial screening indicates delays or concerns, a more comprehensive developmental evaluation should be done.

There are a number of tools to diagnose autism spectrum disorders that include screenings of your child's social, behavioral, and communication skills. A list of some of these may be found at: <http://www.cdc.gov/ncbddd/autism/hcp-screening.html>. The screenings include the:

- Autism Screening Questionnaire (ASQ)
- Modified Checklist for Autism in Toddlers (M-CHAT)

A positive result on a screening should then be followed by a more thorough evaluation such as the:

- Autism Diagnosis Interview
- Autism Diagnostic Observation Schedule (ADOS)



Tip:

If your child is non-verbal, be sure to ask that the evaluation is given using a non-verbal testing tool. Your child may have knowledge that he/she cannot express verbally.

EVALUATIONS FOR EDUCATIONAL SERVICES

If a parent or professional suspects that a child may have a delay or disability, including autism, evaluations to determine what educational services may be appropriate may be obtained from:

- **Early Intervention (EI)**, provided by the NYC Department of Health and Mental Hygiene, for children from birth to 3 years of age. See page 8.
- **The Committee on Preschool Special Education (CPSE)**, which is a part of the NYC Department of Education (DOE), for children from 3 to 5 years of age. See pages 9 and 29.
- **The Committee on Special Education (CSE)**, which is a part of the NYC Department of Education (DOE), or your child's public school, for children 5 years of age and older. See pages 10 and 29.
- **Medical and Other Professionals** — Many insurance companies, including Medicaid, cover educational, psychological, psychiatric, neurological, neuropsychological, and other evaluations as medical expenses. EI and the DOE will sometimes accept an independent evaluation in place of their own; however, even if they conduct their own evaluation, they should consider the results of the independent evaluation. For a list of evaluation sites, please contact Advocates for Children's Education Helpline at 866-427-6033.

Types Of Evaluations

When a child is referred for EI or special education services, the child must be evaluated in all areas of suspected disability. It is important to obtain as extensive an evaluation as possible to ensure that a child's needs have been correctly identified.

Evaluations performed through EI or the DOE include:

- Social History
- Psycho-educational
- Speech/Language
- Occupational Therapy (OT)
- Physical Therapy (PT)
- Classroom Observation
- Review of Health Records
- Functional Behavioral Assessment (see p. 12)
- Assistive Technology Evaluation (see p. 14)

Note:

Evaluations performed through EI or the DOE are for the purpose of eligibility for educational services.

Note:

If you tell EI or the DOE that you think your child may have autism, they should also do a screening for autism (see page 5). If a doctor has already diagnosed your child with autism, you should give EI or the DOE a copy of the diagnosis.

Other evaluations a parent may want to consider are:

- **Neuropsychological** — an evaluation that provides information about a child’s cognitive, behavioral, language, and organization skills. It can lead to or confirm a diagnosis.
- **Psychiatric** — an evaluation to diagnose emotional, behavioral, or developmental disorders.
- **Audiological** — an evaluation that assesses a child’s hearing and possible hearing sensitivities.
- **Assessment for Allergies** — a medical screening to determine if a child has underlying food or environmental allergies. Children with limited ability to speak and express themselves may communicate through acting out behaviors when they have physical discomfort.



Parents’ Rights In The Evaluation Process

For evaluations through Early Intervention or the Department of Education:

- A parent has the right to consent or refuse to consent to special education evaluations and services.
- A parent has the right to a copy of all of his/her child’s evaluations.
- A parent whose main language is not English has the right to a written copy of the evaluation report in his/her preferred language or to an oral translation.
- Once a child is receiving special education services, a re-evaluation should be done *at least* every three years. This is called the triennial evaluation. A parent does not have to wait three years before requesting a new evaluation. A parent may request a re-evaluation every year. For example, a parent may want to request an evaluation when a parent thinks that a child is not making progress.
- For EI and CPSE, a parent has the right to choose an evaluation agency. A parent can request a second evaluation if the parent disagrees with the evaluation.
- For school-aged students, a parent has the right to request independent evaluations from the DOE if he/she feels that the evaluations conducted by the DOE are inadequate.

EARLY INTERVENTION

What Is Early Intervention (EI)?

EI is a family-centered program, run by the NYC Department of Health and Mental Hygiene, that provides evaluations and services for children from birth to 3 years of age who have developmental delays or disabilities, and for their families. EI services are free to families and may be provided at a child's home or child care center, or at an EI agency.

Why Is Early Intervention Important?

The earlier a child's delays or disabilities are identified and addressed, the easier it is to maximize his/her growth and development.



ASK YOUR DOCTOR:

Your child's pediatrician should be watching for early signs of ASD. See page 4.

How Do I Refer My Child For EI Services?

If you think your child (ages 0-3) has ASD or another disability or delay, call 311 to refer your child for EI evaluations. You can also contact the **Early Childhood Direction Center (ECDC)** or your pediatrician for help. See page 30.

What Happens If My Child Is Eligible For EI Services?

If your child is found eligible for EI based on evaluations, an **Individualized Family Service Plan (IFSP)** is developed. An IFSP is a written plan that states the services EI will provide and the goals of these services. The IFSP team, which develops this plan, includes the parent, the service coordinator, the early intervention official, the evaluator, a language interpreter if needed, and anyone else you invite. The IFSP is reviewed every 6 months and re-evaluated every year by the IFSP team.

Advocacy Tip:

Keeping consistent services is essential. Stay on top of important dates to ensure a smooth transition.

What Services Are Available Through Early Intervention?

EI services may include: special instruction, speech therapy, occupational therapy, physical therapy, Applied Behavioral Analysis (ABA) or other methods for working with children with autism (see p. 15), family training, assistive technology, nutrition services, and respite care.

Where Do I Get More Information?

Two helpful guidebooks are *Advocates for Children's Guide to Early Intervention*, available at http://www.advocatesforchildren.org/get_help/guides_and_resources, and *New York State's Early Intervention Program: A Parent's Guide*, available at <http://www.health.ny.gov/publications/0532/index.htm>.

What Happens After Early Intervention?

Most children with ASD will need preschool special education services when EI services end. See the next section of this guide for more information.

PRESCHOOL SPECIAL EDUCATION

What Is The Committee On Preschool Special Education (CPSE)?

CPSE, run by the NYC Department of Education, provides evaluations and services for children from 3-5 years of age who have developmental delays or disabilities. CPSE services are free to families and may be provided at a child's home, child care center, or preschool, or at a CPSE program.

How Do I Refer My Child For Preschool Special Education Services?

If you think your child (ages 3-5) may need special education services, you must write a letter asking the CPSE to evaluate your child. You can address your letter to the Chairperson of the Committee on Special Education (CSE). See page 29. If your child is receiving EI services, you can ask your EI service coordinator for help.

What Happens If My Child Is Eligible For Preschool Special Education Services?

If your child is found eligible for CPSE services based on evaluations, an **Individualized Education Program (IEP)** is developed. An IEP is a written plan that states the services the CPSE will provide and the goals of these services. The IEP team, which develops this plan, includes the parent, the CPSE administrator, the evaluator, your child's special education teacher or provider, a parent member (another parent of a child with a disability), a language interpreter if needed, and anyone else you invite.

What Services Are Available Through The CPSE?

- **Related Services:** The CPSE provides "related services" (see p. 13), either at the child's home, child care center, preschool, or at a service provider's office. A preschooler may receive "related services only" or may receive related services and one of the programs below.
- **Special Education Itinerant Teacher (SEIT):** A SEIT is a special education teacher who works one-on-one with the child in his/her preschool or child care setting or at the child's home. The SEIT may provide a service such as ABA behavioral therapy or another method for working with children with autism. See page 15.
- **Integrated Class:** A class with typically developing preschoolers and preschoolers with special needs. An integrated class can be half-day or full-day depending on the child's needs.
- **Special Class:** The child is in a half-day or full-day small, special education class.
- **Home Program:** Sometimes a child with autism may need a home-based educational program after school in addition to a special class during the day. This is called a "dual recommendation." The SEIT and/or related services providers come to the house to provide ABA behavioral therapy or other services to a child.

Note: A child should be educated in the least restrictive environment appropriate. See page 11.

SCHOOL-AGED SPECIAL EDUCATION

What is School-Aged Special Education?

The NYC Department of Education provides evaluations and services for children from 5-21 years of age who have a disability that impacts their education. Evaluations and services are free to families and are typically provided at school.

Whom Do I Contact If I Think My School-Aged Child Has A Disability?

If you think your child (ages 5-21) may need special education services, you should write a letter asking your child's public school to evaluate your child and send a copy of your letter to the Chair of the Committee on Special Education (CSE). See page 29. If your child is receiving CPSE services during preschool, the CPSE should refer your child to the CSE the year before your child enters kindergarten.

Who Is Eligible For School-Aged Special Education Services?

To be eligible for school-aged special education services, a child must meet one of 13 classifications of disability under the law. Each eligible child receives one classification of disability, even if more than one classification would be appropriate. One of the classifications is "autism." This is an educational classification that can be used for any child on the ASD spectrum. Some children on the ASD spectrum have a different classification of disability such as "speech or language impairment."

What Happens If My Child Is Eligible For School-Aged Special Education Services?

If your child is found eligible for services based on evaluations, an **Individualized Education Program (IEP)** is developed. An IEP is a written plan that states the services the DOE will provide and the goals of these services. The IEP team, which develops this plan, includes the parent, a district representative (someone familiar with the programs available in the district), a school psychologist, your child's special education teacher or provider, a general education teacher if general education is being considered for your child, a language interpreter if needed, and anyone else you invite.

Note:

Remember that a classification of "autism" on a child's IEP does NOT mean that a child must receive a specific class or program. The child should be placed and receive services based on his/her functioning levels—NOT his/her classification. Like all children with special needs, a child with ASD should be placed with his/her typical peers to the extent possible. See page 11.

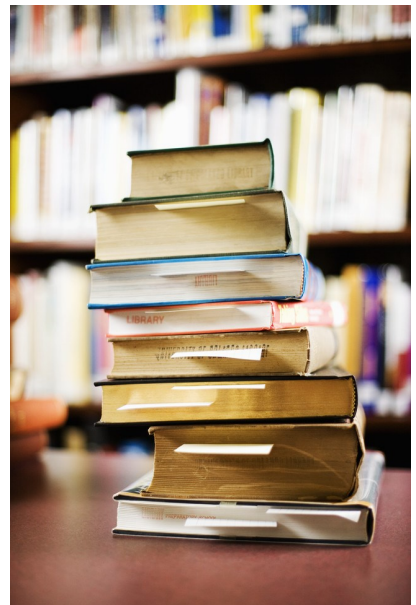
School-aged students with ASD can be placed in a range of programs/classes depending on their cognitive levels, social-emotional abilities, and other skills and needs.

Every child has the right to attend school in the **least restrictive environment (LRE)** in which the child can make meaningful progress. This means that a child should be educated in the setting most similar to his/her typically developing peers. The DOE should recommend a small, special education class only if a child could not make progress in a large class even with supports and services.



- **General Education with Related Services:** The student is in a general education class and receives “related services.” See page 13 for a list of related services.
- **Special Education Teacher Support Services (SETSS):** A special education teacher works with a student individually or in a small group of students for part of the day.
- **Integrated Co-Teaching (ICT, formerly CTT):** General education students and students with disabilities are educated together in a regular-sized class with a full-time general education teacher and a full-time special education teacher.
- **Special Class:** The student is in a small, special education class in a community school.
- **Special Class in a Specialized School (District 75):** A separate school district, District 75, runs special classes. Sometimes, these classes are located in buildings with general education classes. Other times, the buildings consist only of District 75 special classes. For children with severe autism, the DOE often recommends a six student class in a specialized school (i.e., 6:1:1 = 6 students, 1 teacher, 1 paraprofessional). However, children with autism may be in larger classes depending on their needs.
- **District 75’s Inclusion Program:** High functioning students with ASD may attend general education classes with supports from District 75, such as a paraprofessional and special education teacher who work with the student for parts of the day and help change the classroom curriculum for the student. For more information, go to <http://schools.nyc.gov/Offices/District75/Departments/InclusiveEducation/default.htm>.
- **ASD NEST and Horizon Programs:** These programs both serve higher functioning students with ASD. ASD NEST is an integrated program. NEST classes have two teachers and usually serve four children with ASD and eight typically developing children. The ASD Horizon program offers six-student classes in community schools for children with ASD, and is based on the principles of Applied Behavioral Analysis (ABA). **Both programs have a specific evaluation process and a limited number of spots.** For more information, visit <https://www.schools.nyc.gov/learning/special-education/school-settings/specialized-programs>.

- **Non-Public Schools:** A student whose educational needs cannot be met in a public school program may be placed in a state-approved non-public school at no cost to the family. There are several non-public schools that serve children with ASD. See page 16 for some important notes about non-public schools. A list of state-approved non-public schools is available online at <http://www.p12.nysed.gov/specialed/privateschools/home.html>.
- **Residential Placements:** A student with severe needs who requires comprehensive services on a 24-hour basis may be eligible for placement in a residential program.
- **Home and Hospital Instruction:** A student who is unable to attend school temporarily may receive instruction and services at home or in the hospital.
- **Home-Based Programs:** Sometimes a child may need home-based services, in addition to services at school, in order to make educational progress. For example, some children with autism need Applied Behavioral Analysis (ABA) therapy (see p. 15) at home after school to make meaningful educational progress. If you think your child needs a home-based program, you should bring documentation of this need to the IEP meeting. If the DOE refuses to give home-based services to your child and your child needs these services, you can request an impartial hearing. See page 17.



BEHAVIORAL SUPPORTS

Many children with ASDs have behaviors that interfere with their learning. Your child's CPSE/CSE/school should conduct a **Functional Behavioral Assessment (FBA)** to determine when, why, and under what circumstances a child shows behaviors. For example, some children with ASDs have difficulty with transitions and some show behaviors when they are having difficulty communicating their needs.


After an FBA is conducted, the CPSE, CSE, or school should work with the parent and the IEP team to develop a **Behavior Intervention Plan (BIP)**. A BIP has strategies for how to address and change the child's behaviors.

Your child may also be eligible for behavioral supports such as an individual behavior management paraprofessional or counseling. See page 13.

RELATED SERVICES AND SUPPORTS

Students with disabilities (ages 3-21) may receive a wide range of related services and supports. These include:

- **Assistive Technology:** Equipment and services to help your child move or communicate. Your child is entitled to and may need assistive technology even though it is not always discussed at IEP meetings. See page 14 for more information.
- **Counseling:** to help manage your child's behavior and help develop skills such as play and expressing feelings.
- **Hearing and Vision Education Services:** specific modifications, techniques, and equipment for children with hearing or vision loss.
- **Occupational Therapy (OT):** to develop skills such as fine motor, visual perception, and sensory processing.
- **Paraprofessional:** An individual assistant to help your child with serious behavior management or health needs. Some children also need paraprofessionals on the school bus.
- **Parent Training and Counseling:** This service teaches parents how to help their children make academic progress and address their children's educational needs. The DOE must offer parent training to parents of children with autism.
- **Physical Therapy (PT):** to develop skills such as gross motor, strength, and range of motion.
- **School Health Services:** such as a nurse.
- **Speech Therapy:** to develop receptive and expressive language and articulation.
- **Transportation:** If your child needs special transportation accommodations such as an air-conditioned bus, limited travel time, or an individual paraprofessional for the bus, you will need a note from your child's doctor.



Note: For school-aged children, related services are generally provided at school. If your child's school is not able to provide the related services on your child's IEP, the DOE must arrange for an outside agency to provide the services or issue a Related Services Authorization (RSA), a form that allows your child to get the services outside of school from an approved provider. A list of providers is available at <http://schools.nyc.gov/Academics/SpecialEducation/ParentResources/Related+Services+Information.htm>.

ASSISTIVE TECHNOLOGY

What Is Assistive Technology?

Assistive technology includes equipment, devices, and services that help students with disabilities participate in school; for example, the device may help the student communicate with others. Assistive technology can also include training for parents, professionals, and students on how to use the device. Generally, the device belongs to the DOE, and the IEP should state that it will be used in school, at home, and/or in the community to help the child meet IEP goals. To get assistive technology for your child, write a letter to your child's IEP team requesting an assistive technology evaluation. The DOE's Center for Assistive Technology conducts evaluations for students who are not in District 75 programs.

For more information, refer to AFC's Guide to Assistive Technology, at http://www.advocatesforchildren.org/sites/default/files/library/assistive_technology_guide.pdf.

What Are Examples Of Assistive Technology?

- A computer or computer adaptations (e.g., large print keyboards)
- Computer devices such as *Dynavox* or *Chat PC* that assist with communication
- Picture Exchange Communication System (PECS) and communication boards
- Word boards or devices that speak (alternative communication devices)
- Blind and low vision materials or devices that help provide access to the general environment, reading materials, computer, etc. (e.g., Braille)
- Classroom adaptations to assist with hearing related problems
- Environmental controls and devices that provide general access to the environment (e.g., remote control devices, special switches) and may assist with activities of daily living

Assistive Technology Resources:

United Cerebral Palsy Technology Resource Center

(877) 827-2666

http://www.ucpnyc.org/site/c.bu1WVjcNSKnL6G/b.6561427/k.48DE/Assistive_Technology_Resources.htm

Provides information, evaluations, and devices

The CogniTech Cafe

(987) 586-8000

<http://www.cognitechcafe.com>

Provides information and consultations

D75 Technology Solutions

(212) 802-1597

<http://schools.nyc.gov/Offices/District75/Departments/Technology/default.htm?>

For students in District 75 programs only



Advocacy Tip:

Although students have the right to an assistive technology evaluation, the system can move slowly; getting an assistive technology evaluation outside of the DOE may speed up the process.

INSTRUCTIONAL PRACTICES

The law requires that a child's IEP include the special education, supports, and services that the child will receive "based on peer-reviewed research to the extent practicable." Parents can ask for a student's IFSP or IEP to include one or more research-based instructional practices. However, the DOE often refuses to include a specific method on the IEP. The DOE must provide the child with an appropriate educational program that allows the child to make progress. Here are a few examples of instructional practices commonly used for children with autism. More information about some methodologies can be found at <http://www.autismweb.com/>.

ABA (Applied Behavioral Analysis): ABA uses the science of behavior analysis to teach skills. ABA is typically provided on an individual basis, with a teacher working one-to-one with a child. ABA may include:

- Task Analysis: teaching a skill by breaking it down into small steps
- Discrete Trial: teaching one step at a time
- Positive Reinforcement: giving a reward for a correct response
- Verbal Behavior: using ABA to teach and reinforce speech

TEACCH (Treatment and Education of Autistic and Communication related Handicapped Children): A TEACCH classroom emphasizes structure, with separate areas for each task, and visual learning. For more information, visit <http://www.teacch.com/>. In NYC, many 6:1:1 classes use TEACCH.

DIR Method (Developmental Individual-Difference Relationship-Based Model) also known as **Floor Time** or **Greenspan Method**: DIR focuses on the interaction between people to teach skills and has been described as being similar to play therapy. The emphasis is on the emotional development of the child. For more information, visit <http://www.icdl.com/dirFloortime/overview/index.shtml>.

Miller: Miller builds skills using adaptive equipment. Children's actions are narrated to them "while they are elevated 2.5 feet above the ground on an Elevated Square and similar challenging structures." For more information, visit <http://www.millermethod.org/what.html>.

RDI – Relationship Development Intervention: RDI is a clinical intervention that tries to address the social issues related to autism.

Sensory Integration: This intervention addresses unusual responses to hearing, sight, odor, touch, and/or movement.

PRIVATE SCHOOLS

There are **three ways** the NYC Department of Education (DOE) may pay for non-public (or private) school when it has not provided an appropriate public school placement for a student with a disability. Some schools are on a list of special education state-approved non-public schools and may be recommended by the DOE. Other schools are not state-approved, and parents must file an impartial hearing to get tuition funding. For more information on schools outside of the DOE that serve children with ASD, refer to AFC's fact sheet at http://www.advocatesforchildren.org/sites/default/files/library/schools_serving_children_ASD.pdf.

Non-Public School (NPS) Recommendation On A Student's IEP

The DOE may decide that the public school system has no appropriate public school program for your school-aged child. In this case, the DOE will make an IEP program recommendation called **“defer to the Central Based Support Team” (CBST)**. The CBST is an office that matches *state-approved* non-public schools with students. Its general number is (718) 758-7713. When a child's case is sent to the CBST, a case worker is assigned to search for schools. You may also want to contact schools from the state-approved list yourself to speed up the process. A list of state-approved non-public schools is available at http://www.p12.nysed.gov/specialed/privateschools/privschol_dis.html.

Nickerson (or PI) Letter

The DOE must provide the parent with a Nickerson letter when a student's IEP recommends a special class and the DOE has failed to offer a placement within the mandatory timelines. A Nickerson letter requires the DOE to pay tuition for the school year at a state-approved non-public school. To use your Nickerson letter, you must find an appropriate school on the state-approved list that will accept your child. Due to the limited number of non-public schools, getting this letter does not guarantee you will be able to find a school for your child. More information on Nickerson letters is included in AFC's Guide to Special Education, available at http://www.advocatesforchildren.org/get_help/guides_and_resources.

Payment Through an Impartial Hearing

If you can prove at a hearing that the DOE failed to provide your child with a **“free appropriate public education” (FAPE)**, you may be able to win payment for tuition at a private day or residential school. You will also have to prove that the school you have chosen is appropriate to address your child's special education needs. An impartial hearing is the *only* way to have the DOE pay for a private school that is not on the list of state-approved non-public schools. Parents must request a hearing every school year they want their child to attend a non-approved school.

MEDIATION & IMPARTIAL HEARINGS

The law gives parents certain rights during the special education process if the DOE fails to provide an appropriate education to their child. Below are brief descriptions of several ways parents can resolve disputes with the DOE.

Mediation is a meeting between the parent, a DOE representative, and an outside neutral mediator to try to resolve disagreements. The mediator is not a judge, but is to help the parties reach an agreement about their dispute. To request mediation, give your written request to the local mediation center and to the school or CSE. A list of local mediation centers is available at <http://www.p12.nysed.gov/specialed/publications/policy/mediationbook.htm#cdrc>. Both sides must agree to participate in mediation. If both sides reach an agreement at mediation, the DOE and the parent must honor the agreement.



An **Impartial Hearing** is held before an Impartial Hearing Officer who acts as a judge for your case. The hearing officer is an independent decision-maker who is not a DOE employee. He/she has the authority to decide what solution is appropriate after hearing testimony and receiving evidence from both the parent and the school district. Because a hearing is a formal process, parents often bring an advocate or an attorney to represent them. A hearing officer's decision must be followed by both the DOE and the parent, unless either side appeals to the State Review Officer. For more information, refer to AFC's Guide to Impartial Hearings, available at http://www.advocatesforchildren.org/get_help/guides_and_resources/by_type.

To file a **Complaint with the DOE**, call 311 and ask for the Special Education Call Center, which is responsible for investigating and responding to special education complaints in NYC.

You also have the right to file a **State Complaint** with the New York State Education Department regarding any violations of special education law. For a sample state complaint form, go to: <http://www.p12.nysed.gov/specialed/publications/policy/covercomplaint.htm>.

For disputes about Early Intervention, you can file a complaint, mediation, or hearing with the Department of Health. For more information, see AFC's Guide to Early Intervention.

ADDITIONAL SUPPORT SERVICES

In addition to educational services provided by Early Intervention or the Department of Education, children with ASD may be eligible for services through other programs.

Medicaid is an income-based, government-funded program. With Medicaid, a person with ASD can get coverage for all medical services and service coordination. **There are 4 ways a child with ASD can obtain Medicaid:**

1. If a child qualifies for **SSI (Supplemental Security Income)**, then he/she automatically qualifies for Medicaid. To qualify, the child's parent must meet income criteria.
2. If a parent receives **public assistance**, then a child can receive Medicaid.
3. A person with ASD who is older than 18 may qualify for SSI if he/she is unable to earn money due to his/her disability. If he/she qualifies for SSI, then he/she automatically qualifies for Medicaid.
4. If a child is younger than 18 and the parent does not meet the income guidelines for SSI, the child may qualify for Medicaid through the **Medicaid Waiver Program**. To apply for the Medicaid Waiver Program, contact the **Developmental Disabilities Service Organization (DDSO)** in the appropriate borough for a list of agencies that can help you enroll. If the child has a service coordinator, he/she can help apply for the program. See page 31 for information on how to contact your local DDSO.

The **Medicaid Waiver Program**, also known as the **Home - and Community-Based Services (HCBS)** waiver program, provides Medicaid and other services to a person with disabilities regardless of the family's income. Services can include:

- Community habilitation
- Respite care
- Day habilitation (21 and older)
- Individualized Residential Alternative (IRA), a group home for adolescents and adults with disabilities.

See pages 21-22 for more information about these programs.



TIP:

There is often a waiting list of several years for the Medicaid Waiver Program, so a parent should apply as soon as possible.


Put your child's name on multiple agency waiting lists to increase the chances of getting services more quickly.

Family Reimbursement Programs

Some of the agencies providing services for persons with autism receive funding for Family Reimbursement Programs. Families can apply to the individual agencies for financial assistance for emergencies, or some costs related to camp, needed furniture, or clothing. Some medical-related expenses—such as surgeries and medical equipment—are covered as well, so long as accurate records and receipts are provided. Each agency will have its own application process and criteria. For a list of agencies providing Family Reimbursement Programs, contact your local DDSO (see p. 31) or the OPWDD Information Line: (866) 946-9733.

SAFETY ISSUES

Because individuals with ASD often lack a sense of danger in their home or community, caretakers must consider several issues when addressing their safety. Individuals with ASD may engage in many behaviors that could be unsafe, such as throwing or breaking things, climbing out of windows, or mouthing/eating items that are not meant to be eaten. Children that engage in these behaviors do not understand the consequences of their actions.



Caregivers should take precautions in the home and make safety modifications to prevent unsafe behaviors. One common example is to use locks on doors and cabinets to limit access to dangerous substances like medications or cleaning products, or to prevent the individual from leaving the home.

For information on other safety products such as special locks or identification bracelets, visit <http://www.autismspeaks.org/family-services/resource-library/safety-products>.

The National Autism Society has an initiative called **Safe and Sound** that provides information for families, law enforcement, and emergency first responders who may need to interact with persons with ASD.

Information about this initiative can be found at:

<http://www.autism-society.org/living-with-autism/how-we-can-help/safe-and-sound/>.



RECREATIONAL & SOCIAL ACTIVITIES

Many organizations offer recreational and social programs for children with autism and their families. Below are just a few of these organizations.

- **Achilles International:** <http://www.achillesinternational.org>
- **Horseback Riding:** <http://www.autismspeaks.org/community/fsdb/category.php?%20sid=37&cid=115>
- **Kids Enjoy Exercise Now (KEEN):** <http://www.keennewyork.org>
- **Metropolitan Museum of Art:** <http://www.metmuseum.org/events/visitorsdisabilities>
- **Mommy Poppins:** <http://mommypoppins.com/newyorkcitykids/special-needs-programs-and-classes-for-all-new-york-city-kids>
- **New York Families for Autistic Children (NYFAC):** <http://nyfac.org/programs>
- **New York Metro Parents:** <http://www.nymetroparents.com/article/The-Benefits-of-Sports-for-Children-with-Special-Needs>
- **Local Police Athletic League**
- **Project HAPPY:** <http://www.project-happy.org>
- **Special Needs Activity for Kids (SNACK) and Friends:** <http://snacknyc.com>
- **Special Olympics:** <http://www.specialolympicsny.org>
- **Local YMCAs**

SUMMER CAMP

Resources for Children with Special Needs holds a Camp Fair every January, where you can get copies of their updated Camp Guide. For more information, call 212-677-4650 or go to <http://www.resourcesnyc.org>.



PROGRAMS FOR ADULTS

Transition to Adulthood

It is important to plan ahead for a child's future. Do not wait until a child is aging out to investigate and apply for available transition resources. Beginning at age 15, a student's IEP must include a transition plan. A parent should contact the service coordinator (if the child has one), the school district Transition Coordinator, the school, and/or the CSE to:

- (1) learn about program options, timelines, and when to put a student on waiting lists and
- (2) develop a transition plan.

A wide range of programs and services for people with ASD aged 21 and over is provided by the **Office of Persons with Developmental Disabilities (OPWDD)**. Parents can apply for their services at any time, but should apply at least 2 years before their children transition out of the school system.

Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCESS-VR), formerly VESID, coordinates adult vocational rehabilitation and related services to help individuals successfully achieve employment. Once again, it is important to make the contact and obtain information on the process two years before transitioning out of the school system.

For more information, contact OPWDD at (866) 946-9733, <http://www.opwdd.ny.gov> or ACCESS-VR at (800) 222-5627, <http://www.access.ny.gov/vr>.

Adult Programs Include:

- **Day Habilitation:** typically, a 5 day per week, center-based program that assists persons with developmental disabilities to learn, retain, or improve self-help, communication, socialization, and community integration skills. Individuals may "volunteer" at various job sites in the community. An Individualized Service Plan is developed establishing the goals to be addressed for each individual.

Advocacy Tip:

Be sure to keep up to date with information on different programs for persons with ASD, especially when transitioning into adulthood. OPWDD will at times offer trial programs that might be of interest for your child.



- **Community Habilitation** (formerly known as Residential Habilitation): services are typically offered in an individual's home and an Individualized Service Plan (ISP) is developed to address self-help skills, behavioral needs, communication, and social skills at home and in the community.
- **Day Treatment:** a day program, including clinical behavioral services, that addresses the individualized needs of people with autism who have more intensive needs. The availability of this type of program is limited.
- **Respite Services:** provides temporary relief for caregivers of individuals with autism so that they may take care of other personal and family needs. Services are usually provided in the home.
- **Residential Services:** group homes of 6 to 8 individuals with staff 24 hours per day for 7 days per week. The individuals live in a family type setting with staff who assist and guide them in preparing meals, caring for their home, and transporting them to and from day habilitation programs, job sites, medical visits, and recreational trips.
- **Sheltered Work and Supported Employment Programs:** programs offering employment for persons with autism with the additional support of a job coach.



A list of agencies offering day programs or employment assistance for people with disabilities can be found at: <http://www.autismspeaks.org>.

Guardianship

Generally, at age 18, a person can make his/her own decisions about health, education, and other legal matters. However, for an individual with autism who is not able to make decisions about personal needs, property, and finance, a parent (or other individual) must become the legal guardian of the person in order to gain the right to make decisions on his/her behalf. Parents must petition a court to gain guardianship, and should begin the process well before a child turns 18 so that guardianship is in place before he or she turns 18. For more information about the guardianship process, call New York Lawyers for the Public Interest (NYLPI) at (212) 244-4664.

Advocacy Tip:

It is important that parents complete a Developmental Disabilities Profile (DDP-4) form for their child. This form will help the parent and government agencies plan for future services. Call the DDSO in your borough for more information (see page 31 for a list).

PARENT-TO-PARENT TIPS

Parents of children with ASD share 15 things that parents should know:

1. Be confident! You, the parent, know your child better than anyone else.
2. Learn how your child learns best – by seeing, hearing, touching, or imitating– and give this information to your child’s teachers. You can learn effective strategies from your child’s teachers too.
3. Keep in close contact with teachers and therapists to be sure progress is being made and, if it is not, speak with them and ask why.
4. If your child does not speak or only uses a few words, make sure he/she is evaluated with a non-verbal assessment.
5. Start some type of communication system with your child (for example, sign language or a picture board) as early as possible. Don’t wait! Make sure it is used both at home and at school.
6. Speak to your child even though he/she may not respond or appear to be listening. Often children with ASD receive and understand more information than they can express.
7. Don’t assume that a child with ASD doesn’t know or can’t do something until you have tried to teach them in several different ways.
8. ALWAYS PRAISE your child for learning or for good behavior.
9. Look for schools that have strong programs for children with ASD.
10. Observe your child’s behaviors at different times of day, in different settings, and during different seasons. Behaviors may be a way of communicating needs or feelings, such as fear, excitement, frustration, or discomfort. Keep a notebook and write about what you see. This can help you set up a behavior plan or discover needs for medical care. Food and seasonal allergies can sometimes cause “acting out” behaviors.
11. If you begin to see difficult behaviors (such as aggressive or self-injurious behaviors), tell your child’s teachers and therapists and, together, create and use a behavior plan to address the behaviors right away.

12. Look for a doctor who understands and treats children with ASD and who is keeping up with the latest medical findings for the disorders. Some behaviors can be caused by medical problems. Behaviors may be a child's way to cope with a pain they cannot express. Don't assume all behaviors are due to ASD.
13. Before starting any intervention, evaluation, or medication, be sure you understand what it is, what it is supposed to do, and any possible side effects. Then, watch your child's behavior and take notes. It is usually best to try only one intervention at a time so you know what is or is not helping.
14. Don't forget to stop and acknowledge the progress your child makes. Celebrate their successes and the person he or she is.
15. When preparing for the future, consider a Special Needs Trust. This allows funds to be set aside for an individual with a disability without affecting their right to entitlements such as Medicaid. These trusts should be developed with the assistance of an attorney who is experienced in setting up such trusts.



PARENT INFORMATION & SUPPORT GROUPS

AHRC NYC

(212) 780-2500

<http://www.ahrcnyc.org>

Asperger Syndrome and High Functioning Autism Association

(888) 918-9198

<http://www.ahany.org/index.htm>

Autism Society of America (ASA) Chapters

(800) 328-8476

<http://www.autism-society.org>

Autism Speaks

(212) 252-8584

<http://www.autismspeaks.org>

Center for Autism & Related Disorders (CARD)

(855) 345-2273

<http://www.centerforautism.com>

Grace Foundation

(718) 983-3800

<http://www.graceofny.org>

GRASP (Global and Regional Asperger Syndrome Partnership)

(888) 474-7277

<http://www.grasp.org>

Heartshare Human Services

(718) 422-4200

<http://www.heartshare.org>

New York Families for Autistic Children (NYFAC)

(718) 641-3441

<http://nyfac.org>

Parent to Parent

(800) 405-8818

(718) 494-4872

<http://www.parenttoparentnys.org>

Parents of Angels of the Bronx

(718) 931-0515

<http://www.meetup.com/bxangels>

Quality Services for the Autism Community (QSAC)

(718) 7-AUTISM

<http://www.qsac.com>

Spectrum Support Group

(212) 219-1195

<http://www.spectrumparent.blogspot.com>

YAI Network

(212) 273-6182

<http://www.yai.org>

ADVOCACY TIPS & ORGANIZATIONS

Advocacy Tips for Parents

- Get copies of all school records and documents, read them carefully, and make sure you understand what they mean
- Keep an organized file of all of your child's records so that you can refer to them later
- Keep copies of all the forms you complete for your child, including a record of the agency or individual to whom you sent them
- Put your requests in writing and get confirmation they were received
- Don't sign anything that has not been explained to you or that you don't understand or agree with
- Take notes
- Don't be afraid to ask questions
- Ask for an interpreter at meetings
- Request written translation of evaluations and IEPs in your native language

The following organizations offer education advocacy to parents of children with special education needs, including children with ASD.

Advocates for Children of New York, Inc.

Jill Chaifetz Education Helpline

(866) 427-6033

Monday - Thursday

10AM - 4PM

info@advocatesforchildren.org

<http://www.advocatesforchildren.org>

AHRC

(212) 780-2534

<http://www.ahrcnyc.org>

New York Lawyers for the Public Interest (NYLPI)

(212) 244-4664

<http://www.nylpi.org>

Parent to Parent of New York, Inc.

(718) 494-4872

<http://www.parenttoparentnys.org>

Resources for Children with Special Needs (RCSN)

(212) 677-4650

<http://www.resourcesnyc.org>

Sinergia

(212) 643-2840

<http://www.sinergiany.org>

United We Stand

(718) 302-4313

<http://www.uwsofny.org>

WEBSITES OF INTEREST

Asperger Syndrome and High Functioning Autism Association:

<http://www.ahany.org>

Autism Links:

<http://www.healing-arts.org/children/autism-links.htm>

Autism Research Institute:

<http://www.autism.com/>

Autism Speaks:

<http://www.autismspeaks.org>

Autism Society of America:

<http://www.autism-society.org>

Autism United:

<http://www.autismunited.org>

Autism Web—A Parent's Guide to Autism and PDD:

<http://www.autismweb.com/resources.htm>

Centers for Disease Control and Prevention:

<http://www.cdc.gov>

Institute for Community Inclusion:

<http://www.communityinclusion.org>

Global and Regional Asperger Syndrome Partnership:

<http://www.grasp.org>

LOVAAS Institute:

<http://www.lovaas.com>

National Autism Hotline:

(304) 525-8014

<http://www.autismservicescenter.org>

National Institute of Mental Health:

<http://www.nimh.nih.gov/publicat/autism.cfm>

NYC Department of Education:

<http://schools.nyc.gov/Offices/District75/Departments/Autism/default.htm>

New York State Department of Health:

http://www.health.state.ny.us/community/infants_children/early_intervention/autism/

New York State Education Department:

<http://www.p12.nysed.gov/specialed/autism/>

PACER (Parent Advocacy Coalition for Educational Rights):

<http://www.pacer.org>

Rethink Autism:

<http://www.rethinkautism.com/>

University at Albany College of Arts and Sciences—Center for Autism and Related Disabilities:

<http://www.albany.edu/psy/autism/autism.html>

Wrights Law:

<http://www.wrightslaw.com>

Yale Child Study Center:

<http://medicine.yale.edu/childstudy/autism/>

Zero to Three:

<http://www.zerotothree.org>

Note: In addition to these websites, there are also a number of listservs that can be found online for information and support.

GLOSSARY OF ACRONYMS

Below is a list of the acronyms used in this guide,
along with what the acronyms stand for.

ABA:	Applied Behavioral Analysis
ASD:	Autism Spectrum Disorder
BIP:	Behavior Intervention Plan
CBST:	Central Based Support Team
CPSE:	Committee on Preschool Special Education
CSE:	Committee on Special Education
DDP-4:	Developmental Disabilities Profile form
DDSO:	Developmental Disabilities Service Organization
DOE:	Department of Education
EI:	Early Intervention
FBA:	Functional Behavioral Assessment
HCBS:	Home- and Community-Based Services Waiver Program
ICT:	Integrated Co-Teaching
IDEA:	Individuals with Disabilities Education Act
IEP:	Individualized Education Program
IFSP:	Individualized Family Services Plan
LRE:	Least Restrictive Environment
OPWDD:	Office for People With Developmental Disabilities (formerly OMRDD)
OT:	Occupational Therapy
PDD-NOS:	Pervasive Developmental Disorder - Not Otherwise Specified
PECS:	Picture Exchange Communication System
PT:	Physical Therapy
RSA:	Related Services Authorization
SBST:	School Based Support Team (IEP Team at a school)
SEIT:	Special Education Itinerant Teacher
SETSS:	Special Education Teacher Support Services
SSI:	Supplemental Security Income
TEACCH:	Treatment and Education of Autistic and related Communication Handicapped Children



CONTACT INFORMATION: Committees on Special Education (CSEs)

Region	Chairperson	Districts	Address	Phone #
1	Rosetta BrownLee	7, 9, 10	One Fordham Plaza Bronx, NY 10458	(718) 329-8001
2	Michele Beatty	8, 11, 12	3450 E. Tremont Ave., 2 nd Fl. Bronx, NY 10465	(718) 794-7429 (718) 794-7490
3	Esther Morell	25, 26	30-48 Linden Pl. Flushing, NY 11354	(718) 281-3461
		28, 29	90-27 Sutphin Blvd. Jamaica, NY 11435	(718) 557-2553
4	Chris Cinicola	24, 30	28-11 Queens Plaza North, 5 th Fl. Long Island City, NY 11101	(718) 391-8405
		27	Satellite Office 82-01 Rockaway Blvd., 2 nd Fl. Ozone Park, NY 11416	(718) 642-5715
5	Mariama Sandi	19, 23, 32	1665 St. Marks Pl. Brooklyn, NY 11233	(718) 240-3558
6	Arlene Rosenstock	17, 18, 22	5619 Flatlands Ave. Brooklyn, NY 11234	(718) 968-6200
7	Amine Haddad	31	715 Ocean Terrace, Bldg. A Staten Island, NY 10301	(718) 759-4983
		20, 21	415 89 th St. Brooklyn, NY 11209	(718) 420-5758
8	Deborah Cuffey-Jackson	13, 14, 15, 16	131 Livingston St., 4 th Fl. Brooklyn, NY 11201	(718) 935-4900
9	Jennifer Lozano	1, 2, 4	333 7th Ave., 4 th Fl. New York, NY 10001	(917) 339-1600
10	Mark Jacoby	3, 5, 6	388 W. 125 th St. New York, NY 10027	(212) 342-8300

CONTACT INFORMATION: Early Childhood Direction Centers (ECDCs)

Early Childhood Direction Centers (ECDCs) provide information about services for young children, ages birth through five, who have developmental delays or disabilities.

Bronx

Ana Cecilia Hernandez,
Director
2488 Grand Concourse, #337
Bronx, NY 10458
Phone: (718) 584-0658
Fax: (718) 584-0859

Brooklyn

Karen Samet, Director
160 Lawrence Avenue
Brooklyn, NY 11230
Phone: (718) 437-3794
Fax: (718) 907-3195

Manhattan

Marilyn Rubinstein, Director
New York Presbyterian
Hospital
435 East 70th Street, Suite 2A
New York, NY 10021
Phone: (212) 746-6175
Fax: (212) 746-8895

Queens

Catherine Warkala, Director
Queens Centers for Progress
82-25 164th Street
Jamaica, NY 11432
Phone: (718) 374-0002, ext. 465
Fax: (718) 969-9149

Staten Island

Laura Kennedy, Director
Staten Island University Hospital
242 Mason Avenue, 1st Floor
Staten Island, NY 10305
Phone: (718) 226-6670
Fax: (718) 226-6385



CONTACT INFORMATION: ACCESS-VR & OPWDD

Local District ACCESS-VR Offices

Bronx District Office

1215 Zerega Avenue
Bronx, NY 10462
Phone: (718) 931-3500
Fax: (718) 931-4299

Brooklyn District Office

55 Hanson Place
Brooklyn, NY 11217
Phone: (718) 722-6700
Fax: (718) 722-6714

Manhattan District Office

116 West 32nd Street, 6th Floor
New York, NY 10001
Phone: (212) 630-2300
Fax: (212) 630-2365

Queens District Office

1 Lefrak City Plaza
59-17 Junction Blvd., 20th Fl.
Corona, NY 11368
Phone: (347) 510-3100
Fax: (718) 760-9554

Staten Island Satellite Office

2071 Clove Road, Suite 302
Staten Island, NY 10304
Phone: (718) 816-4800
Fax: (718) 448-4843

Harlem Satellite Office

163 West 125th Street,
7th Floor — Room 713
Adam Clayton Powell Jr.
State Office Building
New York, NY 10027
Phone: (212) 961-4420
Fax: (212) 961-4423

Local Developmental Disabilities Services Offices (DDSOs)

Metro NY DDSO (Manhattan & Bronx)

Stanley J. Butkus, Director
75 Morton Street
New York, NY 10014
Phone: (212) 229-3000
Fax: (212) 924-0580

Brooklyn DDSO

Donna Limiti, Director
888 Fountain Avenue
Brooklyn, NY 11208
Phone: (718) 642-6000 day
Phone: (718) 642-6054 evening
Fax: (718) 642-6282

Bernard M. Fineson DDSO (Queens)

Frank Parisi, Director
80-45 Winchester Boulevard
Admin. Building 80-00
Queens Village, NY 11427
Phone: (718) 217-4242
Fax: (718) 217-4724

Staten Island DDSO

Richard Monck, Director
1150 Forest Hill Road
Staten Island, NY 10314
Phone: (718) 983-5200
Fax: (718) 983-9768

Institute for Basic Research in Developmental Disabilities

W. Ted Brown, Director
1050 Forest Hill Road
Staten Island, NY 10314
Phone: (718) 494-0600 & (718) 494-5117
Fax: (718) 698-0833



Our Mission

AFC promotes access to the best education New York can provide for all students, especially students of color and students from low-income backgrounds. We use uniquely integrated strategies to advance systemic reform, empower families and communities, and advocate for the educational rights of individual students.

Still have more questions?

Please Call

The Jill Chaifetz Education Helpline

Monday through Thursday

10AM to 4PM

866-427-6033 (toll free)

Advocates for Children of New York, Inc.

151 West 30th Street, 5th Floor

New York, NY 10001

Phone (212) 947-9779

Fax (212) 947-9790

info@advocatesforchildren.org

www.advocatesforchildren.org