AFC'S GUIDE TO

Guide to Autism Spectrum Disorder and Education

May 2024



Advocates for Children of New York

Protecting every child's right to learn

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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.

This guide to Autism Spectrum Disorder (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.

WHAT IS AUTISM SPECTRUM DISORDER (ASD)?

Autism Spectrum Disorder ("ASD" or "Autism") is a developmental disability that affects social interactions, communication, and behavior. Autism is common: up to I in 36 children in the United States has an ASD. It is called a "spectrum" disorder because there is a wide range in autistic characteristics or traits.

SIGNS OF AUTISM SPECTRUM DISORDER

Your child's pediatrician should be watching for any early signs of ASD. They 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 their 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 developmental milestones starting at 2 months of age.

DIAGNOSING AUTISM SPECTRUM DISORDER

There is currently no medical test for autism. An experienced professional can diagnose autism by watching your child's behavior and communication. 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 and awareness can result in positive outcomes for children with autism.

The first step is to tell your child's pediatrician if you are worried 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.

There are a number of screening tools for autism. A list of some of these may be found on the <u>CDC's website</u>.



TIP:

If your child is non-verbal (doesn't talk), be sure to ask that the **evaluation** includes non-verbal testing tools. Your child may have knowledge that he/she cannot express through words.

EVALUATIONS FOR SERVICES

If you think that your child may have a delay or disability, including autism, you can ask these agencies for an evaluation about services:

Early Intervention (EI):

El is for children from birth to 3 years of age, and is run by the NYC Department of Health and Mental Hygiene. See page 6.

<u>The Department of Education</u> (DOE) or New York City <u>Public Schools ("NYCPS"):</u>

NOTE:

El and the DOE will sometimes take an independent evaluation instead of doing their own evaluation. However, even if El and the DOE do their own evaluations, they should always consider any independent evaluations that are given to them.

For children 3-5 The Committee on Preschool Special Education (CPSE), run by the NYC Department of Education (DOE). See pages 9 and 29.

For children 5-21 or until they receive a High School diploma: Your child's public school, or, if your child is not enrolled in a public school, the Committee on Special Education (CSE).

Public and Private Insurance:

Many insurance companies, including Medicaid, cover evaluations as medical expenses. "Article 16" clinics will provide free evaluations as part of the process to determine if a child would qualify for services through the Office of People with Developmental Disabilities ("OPWDD").

Types Of Evaluations

When a child is referred for evaluations, El or the DOE must evaluate the child in all areas of concern. It is important to get a thorough evaluation to make sure that your child's needs have been correctly identified. Evaluations done through El or the DOE can include:

- Social History (a history of your family and your child)
- Psycho-educational (measures IQ, or cognitive ability, and academic levels)
- Speech/Language
- Occupational Therapy (OT)
- Physical Therapy (PT)
- Classroom Observation
- Review of Health Records
- Functional Behavioral Assessment (FBA)
- Assistive Technology Evaluation

Other evaluations you may want to have done are:

NOTE:

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

- Neuropsychological: an evaluation 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 disorder.
- 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:

- ✓ You have the right to consent or refuse to consent to special education evaluations and services.
- ✓ You have the right to a copy of all of your child's evaluations.
- ✓ If you speak a language other than English you have a right to ask for evaluations to be translated in your preferred language in writing or orally.
- ✓ Once your child starts getting special education services, a reevaluation should be done at least every three years. This is called the "triennial" evaluation. You do not have to wait three years before asking for a new evaluation. You can ask for a re-evaluation up to once a year. You may want to ask for an evaluation if your child is not making progress.
- ✓ You have the right to ask for independent evaluations from the
 DOE if you think that the DOE evaluations are not correct or if
 the DOE hasn't done an evaluation.

EARLY INTERVENTION

What Is Early Intervention (EI)?

El is a family-centered program, run by the NYC Department of Health and Mental Hygiene, that evaluates and serves children from birth to 3 years of age who have developmental delays or disabilities. El services are free and may be provided at your home, a child care center, or an El agency. While services should be provided

in person, families may also be offered services by telehealth (by video on a phone, tablet, or computer).

Why Is Early Intervention Important?

The earlier a child's delays or disabilities are identified and addressed, the better the outcome.

How Do I Refer My Child for El Services?

If you think your child (ages 0-3) has ASD or another disability or delay, call 311 to refer your child for El evaluations.

What Happens If My Child Is Eligible for El Services?

If evaluations show that your child is eligible for El, an Individualized Family Service Plan (IFSP) is created. An IFSP is a written plan that states the services El will provide and the goals of these services. The IFSP is created by a team that includes you (the parent), the service coordinator, the early intervention official, the evaluator, an interpreter who speaks your language if you need one, and anyone else you invite. The IFSP is reviewed every 6 months and re-evaluated every year by the IFSP team.



What Services Can My Child Get Through El?

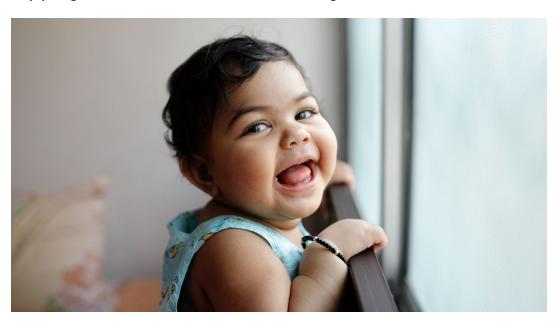
El services may include: special instruction, speech therapy, occupational therapy, physical therapy, Applied Behavioral Analysis (ABA) or other methods for working with children with autism (see page 13), family training, assistive technology, nutrition services, and respite care (short term care to give parents a break).

Where Do I Get More Information?

Two helpful guidebooks are <u>Advocates for Children's Guide to Early Intervention</u> and <u>New York State's Early Intervention Program: A Parent's Guide</u>.

What Happens After Early Intervention?

Most children with ASD will need preschool special education services when El services end. Your service coordinator should discuss this transition process and help you get started. 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 evaluates and serves children from 3-5 years of age who have disabilities. CPSE services are free and may be provided at your home, a child care center, preschool, or 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 should send a letter or an email to the CPSE Support Inbox asking the CPSE to evaluate your child. If your child is receiving El services, you can ask your El service coordinator for help.

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

If evaluations show that your child is eligible for CPSE services, 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 is created by a team that includes you (the parent), the CPSE administrator, the evaluator, your child's special education teacher or provider, an interpreter who speaks your language if you need one, and anyone else you invite.

What Services Are Available Through The CPSE?

Related Services: The CPSE provides "related services" (see page 12), either at your 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 your child in a preschool or child care setting or at your home.

Integrated Class: A class with preschoolers with and without disabilities.

Special Class: A small, special education class usually consisting of 6, 8, or 12 students, a special education teacher, and two teaching assistants.

Home Program: Sometimes a child with autism needs 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 your home to provide therapy or other services to your child.

NOTE:

A child should be educated in the "least restrictive environment" that works for them. See page 14 for more.

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 usually provided at school.

Who 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. If your child is not enrolled in a public school or is in a charter school, you should write to the

Chair of the Committee on Special Education (CSE). If your child is receiving CPSE services, 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 student must have a disability that impacts their ability to learn and will be classified as having one of the 13 different classifications of disability under federal law. One of the classifications is "autism." 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.

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.

- **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, your child's doctor will need to fill out forms explaining why the accommodations are needed.

RELATED SERVICES AND SUPPORTS

The law requires that the special education, supports, and services on a child's IEP be "based on peer-reviewed research to the extent practicable." Parents can ask for a student's IFSP or IEP to include research-based instructional practices. However, the DOE sometimes 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.

INSTRUCTIONAL METHODOLOGIES

There are many different theories of instruction and therapy for autistic people, and you should speak with your child's experts and do research to determine what will work best for your child. There are many different organizations set up to support people with autism and their families.

Below are some instructional methodologies, listed alphabetically, that are used for people with autism:

ABA (Applied Behavioral Analysis): ABA uses 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

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.

Miller Method: 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."

RDI (Relationship Development Intervention):

RDI is a clinical intervention that tries to address the social concerns related to autism.

Sensory Integration: This

intervention addresses unusual responses to hearing, sight, odor, touch, and/or movement.

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



PROGRAMS IN NYC PUBLIC SCHOOLS FOR STUDENTS WITH AUTISM

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. The DOE should recommend a small, special education class only if a child could not make progress in a larger class even with supports and services.

General Education with Related Services: The student is in a general education class and receives "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): 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 neighborhood 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 who need a lot of support, 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 AIMS Program: AIMS (Acquisition, Integrated Services, Meaningful Communication, and Social Skills) is a special education program in select District 75 schools that teaches small groups of students using ABA or Verbal Behavior (VB). AIMS has a specific evaluation process and a limited number of spots.

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.

ASD NEST and Horizon Programs: These programs serve students with ASD who benefit from more grade level instruction and inclusion. ASD NEST is an integrated program, meaning there are students with and without disabilities, and there are two teachers, one special education teacher and one general education teacher. The ASD Horizon program has self-contained, small classes in neighborhood schools for children with ASD. Both programs have a specific evaluation process and a limited number of spots.

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. 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 ask for an impartial hearing.

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 such as OPWDD (Office of People with Disabilities). See AFC's guide on Applying for OPWDD, or learn more on OPWDD's website.

Important services can include community rehabilitation, classes and the right to self-direct services (e.g., to hire whomever you want to work with your child).

PRIVATE SCHOOLS

Sometimes there are no public school options that work for a student with a disability. There are three ways the NYC Department of Education (DOE) can 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.

Non-Public School (NPS) Recommendation on A Student's <u>IEP</u> (state approved schools only)

The DOE may decide that the public school system cannot meet your child's needs. 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 to speed up the process.

2 P-I (or Nickerson) Letter (state approved schools only)

The DOE must provide the parent with a P-I letter when a student's IEP recommends a special class but the DOE doesn't offer a placement within the mandatory timelines. A P-I letter requires the DOE to pay tuition for one school year at a state-approved non-public school (after March 15, the P-I will also cover the next school year). To use a P-I letter, you must find an appropriate school on the state-approved list that will accept your child and that can provide the program on your child's IEP. 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.

Payment Through an Impartial Hearing (either state approved or non-approved private schools)

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 school, whether or not it's "state-approved". 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 <u>list of state-approved non-public schools</u>. Parents must ask for a hearing every school year they want their child to attend a non-approved school.

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. You should contact the service coordinator (if your child has one), the school district Transition Coordinator, the school, and/or the CSE to:

TIP:

It is important to start the process at least two years before transitioning out of the school system

- (I) 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 any may be eligible

for supports for their school age child 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.

For more information, contact OPWDD (<u>www.opwdd.ny.gov</u>, (866) 946-9733) or ACCESS-VR (<u>www.acces.nysed.gov/vr</u>, (800) 222-5627).

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

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

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)

SCIS: Special Class in an Integrated Setting (preschool)

SEIT: Special Education Itinerant Teacher (preschool)

SETSS: Special Education Teacher Support Services

SSI: Supplemental Security Income

ST: Speech Therapy

TEACCH: Treatment and Education of Autistic and related

Communication Handicapped Children

PARENT-TO-PARENT TIPS

Parents of children with ASD share things other parents should know:

- ★ Be confident! You, the parent, know your child better than anyone else.
- ★ Keep copies of everything! Ask for all evaluations, teacher reports and IEPs. Read them carefully and if you don't understand something, ask! Also, keep copies of all letters and forms you fill out and give to the DOE and other agencies.
- ★ Make your requests for help in writing or email and keep copies.
- ★ 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.
- ★ If you need one, ask for an interpreter at meetings and for written translation of evaluations and IEPs in your native language.
- ★ 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.
- ★ 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.
- ★ If your child does not speak or only uses a few words, make sure he/she is evaluated with a non-verbal assessment.
- ★ 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.
- ★ 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.

- → 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.
- * ALWAYS PRAISE your child for learning or for good behavior.
- ★ Look for schools that have strong programs for children with ASD.
- ★ 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.
- ★ 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.
- ★ Look for a doctor who understands and treats children with ASD and who is keeping up with the latest medical findings for the disorder. 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.
- ★ 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.
- ★ Don't forget to stop and acknowledge the progress your child makes. Celebrate their successes and the person they are.
- ★ Connect with other parents! You can often find information about supports and programs from other parents. There are many parent support groups and listservs.

Our Mission

Advocates for Children of New York (AFC)'s mission is to ensure a high- quality education for New York students who face barriers to academic success, focusing on students from low-income backgrounds. AFC achieves this through four integrated strategies:

- Free advice and legal representation for families of students;
- Free trainings and workshops for parents, communities, and educators and other professionals, to equip them to advocate on behalf of students:
- Policy advocacy to effect change in the education system and improve education outcomes; and
- Impact litigation to protect the right to quality education and to compel needed education reform.

Still have more questions? Please call the Jill Chaifetz Education Helpline:

Monday through Thursday 10 am to 4 pm 866-427-6033 (toll free)

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