

SUNY Downstate Autism Network*

Resource Guide – Bringing Together Brooklyn Autism Resources



Families dealing with Autism and Autism Spectrum Disorder (ASD) face many challenges. The idea of the SUNY Downstate Autism Network is to bring together families and professionals to provide support and help link families with the best ASD services, programs and supports in the Brooklyn area. The Network:

- Is **based in SUNY Downstate** – building on the resources of the Department of Pediatrics, the Brooklyn Leadership Education in Neurodevelopmental Disabilities (LEND), the School of Health Professions, the Department of Family & Community Medicine, the Departments of Neurology and Psychiatry, and student groups including SDCID, COTAD and SOTA.
- Builds **linkages to quality ASD programs and services** available to families in Brooklyn.
- LEND's **Family Support Project** provides monthly parent support groups and an Advocacy Training Series

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To receive a digital version of this Resource Guide (that will let you use the internet links to find further information):

1) scan this Q-R code.



2) or – use this link:

<https://drive.google.com/file/d/10t5OWAA5LqMHA0m0gi8yF96o2RZMte-K/view?usp=sharing>

Introduction –

What is autism / Autism Spectrum Disorder (ASD)? Children and adults with Autism Spectrum Disorder have in common difficulties with:

- Language – ranging from not speaking at all, to speaking a lot ... but not being able to carry on a back-and-forth conversation
- Social communication – including giving inconsistent eye contact, awkward or lack of gestures, difficulty picking up ‘social cues’ and ‘reading the room’
- Social interaction – ranging from not being interested in others at all - to interacting but only when it’s about something the individual wants or is interested in – to wanting to make friends, but not knowing how
- Narrow interests – for example, being totally fascinated with trains, or dinosaurs, or particular cartoon shows ... and little else. Children and adults with ASD may have repetitive behaviors including handflapping, finger twirling, repeating certain actions compulsively, or have to have the same routines all the time and will be very upset with any change
- Sensory issues – either being overly sensitive to (and bothered by) certain noises, or textures of clothing or foods, or being drawn to certain sensory inputs, like spinning objects
- Children and adults with ASD often have problems with inattention, distractibility and hyperactivity – and meet the criteria for ADHD. They may also have problems with clumsiness and motor coordination

ASD covers a very broad range – including more severe “high needs” autism in which the individual appear to be completely in their own world and oblivious to others, has little understandable language, and may flap their hands or move in unusual ways – to milder, “low-needs” autism, formerly called “Asperger Syndrome”, in which the individual may talk a great deal, and at an advanced level, but in a self-absorbed way often unaware whether others are interested, have difficulty connecting to others and even though the individual may want to have friends, has difficulty making and keeping friendships. Note that ASD may look somewhat different in girls than boys (and go unrecognized).

What causes autism / ASD? We don’t know exactly. We are sure that it has to do with how the brain is wired (and it isn’t caused by bad parenting!) We also know that it runs in families, and it is very much related to genes and inheritance – but it’s not simple how it’s inherited and probably involves many gene effects combining together – as well as the influence of the environment. Note that there is absolutely no truth to the idea that vaccines cause autism.

Introduction (cont'd)

The nature of the ASD “spectrum” – in fact, now we talk about “*the autisms*” rather than just autism. We recognize that there are many different causes that lead to autism, and it can take many different forms. The different elements of ASD - including language and social communication, compulsiveness and rigidity, anxiety, and attention and hyperactivity – will contribute in different ways and degrees to how the person develops. What this means is that there is a very wide range – not just from very severe to very mild, but other factors (for example, the person’s basic personality, or how much anxiety, or inattention or interest in social engagement they have) which vary greatly in shaping the picture of the person. Therefore, there are many different combinations and ways that children and adults can be on the ASD spectrum. It is important to realize that **children and adults with ASD are not all alike** – each is unique and their own person!

What is the long-term outlook for your child with autism / ASD? It is difficult to say. A person’s autism picture will change over time – usually moving toward progress in language and social engagement – so that it is hard to predict how a given individual with autism will look as they get older. For some young children, even those who appear to have severe autism and who aren’t talking or relating to others at all in their preschool years, there can be great improvement over the years, they may do well in school, and in some cases as they grow up will attend college or be able to work and live independently. For other children and youth, improvement is much slower, and they may continue to have severe disabilities, social impairments and high support needs into adulthood.

What can be done to treat / improve outcomes? Early identification and starting intervention services as soon as possible are key. Speech Therapy, Occupational Therapy, Physical Therapy and behavioral services like Applied Behavioral Analysis (ABA – see below) can lead to major improvements in children’s language, ability to relate to others, and to learn academic and life skills. Finding the right preschool and school program is also crucial. See the following sections on EI, Preschool, and School-Age programs, as well as other supports and resource programs.

Neurodiversity – is the recognition that *all of us* have brains that are somewhat different. Many in the ASD community regard autism as a form of ‘neurodiversity’ that should be seen as a positive part of the human experience... and argue that we should stop using words that imply that autism is an impairment or a disorder. While for many individuals with ‘high needs’ autism and their families, it certainly *is* a disorder and calls for treatment – for others with ‘low needs’ and special abilities (“it’s my ‘superpower’ ”), neurodiversity is a valuable perspective.

Clinical services –

Why is a diagnosis helpful? There are two reasons:

1. When a child or adult gets a diagnosis of “autism” or “Autism Spectrum Disorder” (ASD), it can help you better understand them, the challenges they face, and why they may have difficulty with certain things or act in certain ways. Even though all individuals with autism are different, and some on the ASD spectrum will have some autism characteristics much more than others, there are certain common features and understanding these can be helpful to you, your family, and the community, schools and programs in supporting them.
2. Having an ASD diagnosis will help individuals get the right services and supports. Some services, such as Applied Behavioral Analysis (ABA) are only available to individuals with an ASD diagnosis. Also, school programs that are designed for children on the ASD spectrum – both high and low needs – will only be available if they have a formal ASD diagnosis.

How do I get my child evaluated for autism? It should be along two tracks: 1) a general developmental / educational evaluation, and 2) a specific evaluation for ASD.

For the general evaluation of child’s overall development, learning and behavior, it depends on the child’s age:

- For children 0-3 year old, it will be through the Early Intervention Program
- For 3-5 year olds, it’ll be through the Committee on Preschool Special Education (CPSE)
- For school age children, it will be through the Committee on Special Education (CSE).

See the following sections for details on each of these. The EI, CPSE or CSE evaluations provide key information on your child’s abilities and challenges and may include findings that suggest the possibility of ASD, but usually (with the exception of EI), *won’t* include an ASD diagnosis.

It is therefore important to also get a specific diagnostic evaluation for ASD if you, your doctor, or your child’s teachers are concerned. This will include a thorough interview with you about your child’s development and history, and use of specific tests such as the Childhood Autism Rating Scale (CARS-2) or Autism Diagnostic Observation Schedule (ADOS-2). Typically this is done by Psychologists, Developmental Pediatricians, Child Neurologists or Child Psychiatrists.

Where can I get a diagnostic evaluation for ASD? Sites in Brooklyn or NYC that provide ASD evaluations (may or may not be covered by health insurance, often long wait times) include:

- SUNY Downstate Child Development Clinic (718) 270-2272
- Kings County Developmental Evaluation Clinic (718) 245-2743
- Health Care Choices / Dr. Nancy Wetzel (718) 234-0073
- Mekor Services (for OPWDD eligibility) Cynthia Winograd (718) 853-9700
- Ridge Psychological Testing (917) 921-0704
- Dr. Sylvie Goldman, Developmental Psychologist (646) 426-3876
- Dr. Jennifer Bain, Child Neurology (646) 426-3876

Diagnostic ASD evaluation sites (cont'd):

- Dr. Gabriella Hort Paskin, Developmental Pediatrician [\(212\) 304-5800](tel:2123045800)
- Dr. Nechama Kramer , Psychologist (917) 692-7192
- Dr. Asher Lipner, Psychologist 347-535-7863
- Agencies including AHRC, Adapt, YAI, INCLUDE NYC, and Sinergia do psychological testing, but have a very long wait.

Where can I get medical care for ASD? In addition to your child's regular primary care pediatrician or family medicine doctor, it is sometimes helpful to have your child seen and followed by a medical doctor who is expert in ASD – such as a Developmental Pediatrician, Neurologist or Psychiatrist. Besides evaluating for ASD, they can both assess behavioral and medical problems (such as feeding, sleeping, behavior problems, or seizures) that can occur in children with ASD, help you with behavioral approaches, link you with needed services or specialists, and, as appropriate, prescribe medication.

Clinics and providers in Brooklyn who provide care for children with ASD include:

- SUNY Downstate Child Development Clinic (718) 270-2272
- SUNY Downstate Child Neurology Clinic (718) 888-7869
- Henry Hasson MD (718) 785-9828

Early Intervention (EI) services –

What EI services are available for 0-3 year olds? Basic EI services (for children with speech or motor or other developmental delays) include Speech Therapy to help promote a child's language development – and sometimes help with feeding problems, Occupational Therapy is very important both for fine motor development and coordination, as well as helping with sensory-motor coordination, feeding issues, and socialization skills, Physical Therapy is important to address gross motor delays, motor planning problems, and coordination and Special Instruction will help with problem-solving and cognitive delays. An Individual Family Service Plan (IFSP) is the document setting out the evaluation, goals and approved services.

Children 0-3 in EI can be evaluated and diagnosed with ASD when their assessment includes a Psychological Evaluation – if you or your child's therapists or doctors are concerned about possible ASD, make sure to communicate with your child's EI service coordinator that you want a Psychological eval done. When a child is diagnosed with ASD in EI, one of the most important EI services is Applied Behavioral Analysis (ABA). ABA is a behavioral intervention that can make a huge difference for children on the ASD spectrum. ABA therapists work to shape the child's behavior using positive reinforcement – e.g. to gradually give better eye contact and to establish joint attention and social engagement. ABA services typically total 10 or 20 hours per week. Usually at the beginning they are given at home (which gives you the chance to interact with the ABA therapists and observe), later they may be integrated into center-based programs.

Early Intervention (cont'd)

A center-based program tailored for children with ASD may be recommended if your child is 2 years or older. Center-based programs are especially helpful in helping your child with social skills and following group routines. These include language-based programs with small class sizes, consistent daily routines and are highly structured. Being with other children will help to improve your child's play skills and social interactions with others. The staff at these programs should have training and experience working with children with ASD.

To learn about EI services in New York City, go to:

(<https://www.nyc.gov/site/doh/health/health-topics/early-intervention.page>)

<https://www.nyc.gov/assets/doh/downloads/pdf/earlyint/early-help-matters-brochure.pdf>

<https://www.nyc.gov/site/doh/providers/resources/public-health-action-kits-early-intervention.page>

To make a referral to EI, call 311 and ask for Early Intervention or complete this form:

"<https://www.nyc.gov/assets/doh/downloads/pdf/earlyint/ei-referral-form.pdf>" and fax it to: (347) 396-8801

3–5 years and Committee on Preschool Special Education (CPSE) services

For children on the ASD spectrum, CPSE services are almost always center-based and should be provided for 12 months per year. Programs may be either in public preschools, or CPSE-approved private schools, and may be self-contained (just children with special ed needs) or integrated (a mix with typically-developing children). An Individualized Education Plan (IEP) summarizes the evaluation, goals and classroom type and services approved for the child.

Whether or not they are specifically designated as ASD programs, these programs provide small classrooms, much structure and routines for the child, and emphasize language, social skills, and engagement with others. Speech Therapy (ST), Occupational Therapy (OT) and counseling services may be provided either as separate, one-on-one ("pull-out") services during the course of the child's day at the center or be integrated into the classroom itself ("push-in") where the therapist works with the teacher to include ST or OT approaches within the group.

Transportation services (a small yellow school, with a matron on board) are usually provided. For children in an integrated setting or placed in a mainstream, general education classroom but requiring additional services such as ST or OT, an additional service is a Special Education Itinerant Teacher (SEIT) who works with the child either one-on-one or in groups of 2 or 3 (which may be advantageous to promote the child's social interaction skills).

CPSE programs are organized by local CPSE school district. Call 311 to find your local district's contact numbers for more information. The EI to Preschool transition is described here:

<https://infohub.nyced.org/docs/default-source/default-document-library/doe-guide-to-the-ei-to-preschool-transition---second-edition.pdf>

3–5 years and CPSE (cont'd)

An important point about the transition from EI to CPSE is that while CPSE may have good programs suited to the range of children on the ASD spectrum, they do NOT include ABA services, and often children who were making good progress while receiving ABA through EI, stop progressing as they reach 3 years and move to CPSE. However home-based ABA services are covered through a child's health insurance, whether Medicaid or third-party (through parents' employment). It is therefore essential for families to explore securing insurance-covered ABA services at home to combine with the child's school program. Families should reach out to their insurance plan, learn which ABA agencies are covered, and then apply to those agencies. Required are a formal diagnostic evaluation (including a CARS or ADOS), and an "ABA prescription" from a specialist provider documenting the diagnosis and need for ABA.

While ABA is the most proven ("evidence-based") approach, not all ABA providers are of equal quality – some may be overly rigid and unable to connect well with a given child. Other approaches to ASD have also received attention – for example the DIR or Floortime model which uses a more 'democratic' approach to reach out to and connect with the child. Other programs follow the Denver model, utilizing a combination of both of these approaches.

School age / Committee on Special Education (CSE) services –

CSE services starting with kindergarten and extending through high school (the upper age for children with disabilities is now 22 years) vary widely. They include related services such as Speech Therapy or Occupational Therapy or counseling services. CSE classrooms may be self-contained (just children with special education needs) and inclusion (integrated classes with a mix of children with disabilities and typically-developing children). Also students with milder disabilities may simply attend general education classes, while receiving related services to address their particular needs. An Individualized Education Plan (IEP) summarizes the evaluation, the goals and the approved type classroom and services approved for the child. "Turning 5" is the NYCDOE process of transitioning children from CPSE to CSE. The overall process is described here: <https://www.schools.nyc.gov/learning/special-education/preschool-to-age-21/moving-to-kindergarten>. InsideSchools offers quality reviews of public schools in NYC and additional resources for families on understanding their child's rights and navigating the educational system. <https://insideschools.org/>

What are the types of services available through the public sector / CSE?

District 75 – In New York City, District 75 is the category of Committee on Special Education (CSE) schools for children with more severe learning disabilities, intellectual disability or behavior problems who require specialized, self-contained classrooms (i.e. no 'inclusion' with general education students) and smaller classrooms (6:1, 8:1 and 12:1 student to teacher ratios,

School age and CSE (cont'd)

along with teacher assistants and in some cases paraprofessionals or para's). District 75 schools are distributed throughout the different geographic school districts across the five NYC boroughs, and are usually co-located within a community school. For general information on District 75 see: [District 75 \(nyc.gov\)](https://www.nyc.gov/district75)

District 75 classes for ASD students are generally geared toward children with higher needs / more severe autism. They can vary widely in approach and quality. Some embrace an 'ABA approach' or philosophy, but they do *not* specifically provide ABA services. One exception is a new program for ASD within District 75 called the AIMS program (for Acquisition, Integration, Meaningful Communication and Social Skills) with 6:1:1 classes each with a teacher, a speech therapist, and a para who are supervised by an ABA specialist. The AIMS program remains small, with few schools having AIMS classes.

Community School Special Education programs – for students with a range of learning disabilities, ADHD and / or milder behavioral issues. CSE programs in community schools are generally not specialized for children on the ASD spectrum (with the exception of the ASD Nest and Horizon programs described below), nonetheless many children with ASD are steered into them at the "Turning 5" process as they move from preschool to kindergarten. For students with ASD, services should be provided 12 months per year (to avoid regression in learning over the 2 month summer break), but often aren't.

The smallest community school CSE classes are self-contained 12:1:1 classes with 12 students, one special education teacher and one assistant teacher, and follow common-core learning standards, but at a somewhat slower pace. While many children with a range of ASD severity are placed in 12:1:1 classes, they are not designed for the learning, social and behavioral needs of ASD students, and there is little chance for individualized teaching.

Integrated Co-teaching (ICT) are inclusion classes with about 25-30 students – half special education students with IEP's, half general ed students and two teachers – a special education and a general education teacher. These classes do follow common core general education curricula, but with a student to teacher ratio of about 12 to 1 offer more possibility of breaking into smaller learning groups for special education students with mild learning challenges.

As a parent, the idea sounds appealing of having your child in an inclusion class rather than a self-contained class with just special education children, and in some cases students with low needs, milder ASD may do well in an ICT class. However, the teachers are not specifically trained to teach children on the ASD spectrum, and often won't have the time to pay enough individual attention to the child with ASD. For many children with ASD they are simply too big and overwhelming. Also, community CSE programs last for just 10 months / year, not 12 months. Your child may therefore lose the gains over the 2 month summer break that he or she made with the classroom structure and continuity during the regular school year.

ASD Nest programs are a good option for low needs children with mild ASD who are able to perform at grade level academically but may have social interaction challenges. ASD Nest is an inclusion approach in which 5-6 eligible children with ASD are placed in an integrated classroom with grade level curriculum, as in ICT classes, but with both a general education teacher and a special education teacher who are trained to work with ASD students, and with specialized supports such as Social Development Intervention (social skills training), Speech Therapy and Occupational Therapy. These may be provided in pull-out sessions or within the classroom, as well as parent training and counseling. The culture of the ASD Nest class is one of tolerance, and bullying shouldn't be occurring. The CSE notes that Nest students graduate from high school with a 95% graduation rate (above the citywide average). To be eligible for an ASD Nest program, your child must be able to perform at or above grade level, not have significant disruptive behavior, and have an official diagnosis of ASD. Classes follow the regular 10-month schedule, with additional summer services. From a small pilot project as a collaboration with NYU, the ASD Nest program has grown over recent years, but classrooms and openings are still limited. Information and applications for ASD Nest are available at the NYC DOE website: <https://www.schools.nyc.gov/learning/special-education/school-settings/specialized-programs>. For a listing of schools with ASD Nest see: <https://steinhardt.nyu.edu/metrocenter/nest/nyc-public-schools-asd-nest-program>

Horizon programs are an intermediate option for children with ASD who are able to participate and learn at grade level "with appropriate autism supports" (per the DOE website). Typically, students eligible for Horizon will test at the below average to average range on intelligence tests, have mild to moderate delays in language / communication, and have only moderate behavioral issues (not aggressive, self-injurious, or prone to eloping / wandering off). Horizon classes are self-contained, with up to 8 students, one special education teacher and one para. They emphasize a curriculum to promote social communication, and provide instruction, social and behavioral support "based on the principle of Applied Behavioral Analysis - ABA)," although not ABA services per se. Like the Nest program, Horizon classes follow the regular 10-month school schedule, with additional summer services. Information and applications for Horizon are available at the NYC DOE website: <https://www.schools.nyc.gov/learning/special-education/school-settings/specialized-programs>

What are the non-public (private school) options? There are many private schools which offer classes specializing in teaching children on the ASD spectrum or communication problems or 'learning differences'. These classes are usually self-contained – typically the children in these classes have ASD or learning or social difficulties or intellectual disabilities (usually children are grouped by disability type). They generally offer 12 months program. Some incorporate ABA principles, while others include specific ABA services during the school day. Classes are often small, highly structured, while at the same time offering individualized instruction appropriate to the child's academic level. They also include specialized services such as Speech Therapy,

Non-public (private school) options (cont'd):

Occupational Therapy, Physical Therapy and counseling as either pull-out or push-in services embedded into the classroom. Staff are trained to work with children with ASD. These 'non-public' specialized schools may be appropriate for low-needs children with milder ASD who would tend to be overwhelmed in a boisterous public school classroom (such as an ICT class). They also may be the best fit for high-needs children with more severe ASD who will benefit from a very structured environment, ABA services and individualized teaching.

These non-public schools have limited openings and are very expensive. For most children who attend them, the tuition is paid by the Department of Education / CSE. The process of arranging this is complicated. As a parent, you have to be able to make the case that you've looked at the public school options, and that the public school system does not have an acceptable classroom setting and program for your child. The process is often difficult and lengthy, and it is helpful to get the guidance of an educational advocate or lawyer. In some cases, if you win the case with the Board of Education, they pay the legal bills.

To get guidance on non-public options and support including help locating legal services, contact:

- SUNY Downstate Child Mental Health Clinic (718) 270-2036
- INCLUDEnyc – (212) 677-4660
- New York Lawyers in the Public Interest (NYLPI) – (212) 244-4664
- See also "Legal Assistance Groups" information in the **Additional Resources** on page 17.

Transition to Adulthood¹

Individuals with ASD (and their families) face many challenges as they transition to adulthood. Leaving the supports, safety and predictability of school and childhood for possible college, the workplace or a degree of independent living can be daunting. Transition planning should be a collaborative process between the young person, their family, the Department of Education, and other appropriate agencies. It should have the goal of maximizing the individual's level of self-determination, utilizing person-centered planning, and build the individual's (and family's) capacity for self-advocacy – their ability to speak and act on their own behalf. The central elements of transition involve post-secondary education (college or vocational school), employment, independent living, and community participation.

In New York, the supports and services provided through the Department of Education will have a hard stop at age 22, and after that, public services will be provided only through the Office of People with Developmental Disabilities (OPWDD). Therefore, a crucial part of transition planning and continuing key support services into adulthood is enrollment in OPWDD well beforehand.

The following is a brief overview of different elements of transition. Sources of further information are provided at the end of this booklet.

Department of Education / IEP transition planning is required by Federal and NYS law to begin by age 15 years, with the aim of identifying the student's (and family's) long term goals for living, working and learning as an adult. The process should include interviewing the student (e.g. "what kind of job do you think you'd like to do when you graduate?" "what do you have to do to prepare for this kind of work?"), and input from the family. The planning should be based on age-appropriate transition assessments, set up measurable, achievable and relevant goals, and institute a coordinated set of transition activities including instruction, vocational trainings, related services (e.g. OT, PT, ST, counseling), community experiences and building daily living skills to reach those goals.

High school graduation options include Regents diploma (academic diploma currently requiring passing 4 NYS Regents exams), Local diploma (for students with disabilities who pass Regents exams with the Safety Net), and non-diploma options (formerly "IEP diplomas") including Career Development and Occupational Studies (CDOS – a certificate showing readiness for entry-level jobs), and Skills and Achievement Commencement Credential Certificate (SACCC – for students with significant disabilities who take the NYS Alternate Assessment). Note that CDOS and SACCC are not actual high school diplomas and can't be used for application to college, military or trade schools. AHRC's Melissa Riggio program supports individuals with intellectual or developmental disabilities attend colleges in NYC:

<https://www.ahrcnyc.org/services/school/college/>

¹ This section is based on a Family Support Project / LEND presentation by Emily Bakaj, and an AHRC webinar by Trudy Pines

Department of Education (cont'd)

ACCES-VR (Adult Career & Continuing Education Services – Vocational Rehabilitation) is a NYS Education Department-funded program to “assist individuals with disabilities to achieve and maintain employment and to support independent living” (<https://www.acces.nysed.gov/vr>). 14-23 year olds with a documented disability can apply to ACCESS-VR, and if eligible, will be supported in developing an “individualized plan for employment” (IPE), and receive services such as job counseling, job placement, vocational training, driver training and coaching, and supported employment.

OPWDD and covered services, self-direction – OPWDD is the New York State umbrella program that funds a wide range of disability services (<https://opwdd.ny.gov/contact-us>). It itself is funded through Medicaid, and requires securing Medicaid / Waiver for the individual applying (https://www.health.ny.gov/health_care/medicaid/redesign/medicaid_waiver_1115.htm). The first step in enrollment is the Front Door process (calling 866 946-9733, and watching informational videos [Front Door Videos | Office for People With Developmental Disabilities \(ny.gov\)](https://www.health.ny.gov/health_care/medicaid/redesign/medicaid_waiver_1115.htm)). Once enrolled, the individual is assigned to a Care Coordination organization. The three who cover NYC and Brooklyn are: Care Design NY, Advance Care Alliance, and Tri County Care (Tri County provides excellent service, but is currently ‘on-hold’ for new enrollment). A Care Manager at that organization then serves as a guide through the process, establishing a person-centered plan and arranging services.

OPWDD-covered services include:

Family Support Services (FSS), including Respite, Behavioral Support, Social Skills training, Recreation and specialized Summer Camps, and Parent and Sibling Support Groups.

Home and Community Based Services (HCBS) including Community Habilitation (Com-Hab – services to support skills to live safely and independently, make friends, participate in the community – these are often based in the home), Day Habilitation (Day-Hab – services outside the home, either in a certified site, or in the community “Day Hab without Walls”), Employment Supports, and Housing supports.

Self-Direction is an option within OPWDD in which the individual and their family choose, arrange and supervise the services, with their own budget approved budget from OPWDD. A “Self-Direction Support Broker” and “Fiscal Intermediary” are required. See: [Front Door Videos | Office for People With Developmental Disabilities \(ny.gov\)](https://www.health.ny.gov/health_care/medicaid/redesign/medicaid_waiver_1115.htm)

Independent living and group home options – besides living with one’s family with supports, OPWDD supports a range of housing options (<https://opwdd.ny.gov/types-services/housing>): Independent living with housing cost subsidies, live-in caregivers, “paid neighbors” and, if needed, environmental modification (“e-mods”) – physical changes to the home to support safety and community access.

Family care – living with a family who has been certified and reimbursed by OPWDD

Group homes – living with a small group of people in a household certified by OPWDD with staff to help meet the individual’s needs – includes Individual Residential Alternatives (IRA’s).

Guardianship and alternatives - Legal custody / guardianship arrangements are important to consider as children transition to adulthood, otherwise they will be expected to make medical / legal decisions for themselves, and parents / family will have no right to either be involved in medical decision-making nor access their medical information, nor be part of financial or legal decisions. In New York State, 17A guardianship can be pursued without a lawyer and costs \$20 to apply ([Guardianship 17A Petition - DIY Forms | NY CourtHelp \(nycourts.gov\)](https://www.nycourts.gov/17a-guardianship/)). However 17A guardianship is the most restrictive and not always the best option – it entirely removes the individual’s rights and self-determination, and other arrangements should be considered first:

Supported Decision-Making – a less formal set of arrangements and agreement to support an individual with a disability’s making and communicating their own decisions – working with a facilitator to develop a voluntary supported decision-making agreement (SDMA) which covers what types and how decisions will be made (see www.sdmny.org)

Article 81 guardianship – a less restrictive form with more rights for the individual

Representative payee – appointed to help manage social security benefits and finances

HIPAA release and Healthcare proxy to support healthcare information access and medical decision-making

Transition of Healthcare – the “process of moving from child/family-centered health care model to an adult / patient-centered model” (<https://www.gotttransition.org/six-core-elements/>) with the goal of improving the individual’s ability to manage their own health care and effectively use health services. At a practical level, this will involve locating adult health providers who understand autism and care of patients with neurodisabilities (and who accept your health insurance) – both primary care providers and specialists such as neurologists and psychiatrists. Mental health providers will be especially important to address the anxiety, stress, depression, and sometime outright mental breakdowns that can occur during transition years. Such adult health providers are often difficult to find – and it is important to start the process of identifying and connecting with them well ahead of time.

Safety issues

Children and adults with autism are at increased risk of abuse, injury and death. Elopement, or wandering off, may occur in about half of children with autism – with the risk of the child getting into dangerous situations. Drowning is the leading cause of death among children and youth who wander.

The “Big Red Safety Box” program (<https://nationalautismassociation.org/big-red-safety-box/>) offered at no charge by the National Autism Association includes a safety kit, and a Caregiver booklet with checklist and guidance on prevention measures:

- Securing the front door, outdoor gates and garage doors
- Identifying ‘triggers’ – does the child wander off because of particular fascinations? Sensory overload? Anxiety-provoking situations? – and how to address these
- Teaching safety and communication
- Swimming lessons
- Wrist ID’s and/or locator GPS devices
- Alerting relatives, schools, neighbors, local first responders
- Creating an emergency plan

Additional resources²

Family Support and Advocacy organization resources

Advocates for Children of New York is an educational advocacy organization that works to protect every child's right to appropriate education. <https://www.advocatesforchildren.org/>

AHRC provides a wide range of community, home and school services and programs as well as education, advocacy and informational webinars. <https://www.ahrcnyc.org/>

IncludeNYC provides resources to enhance quality of life for those with disabilities and their families. <https://includenyc.org>

Sinergia provides advocacy, support, workshops and services to culturally and linguistically diverse individuals with developmental disabilities in NYC. <https://www.sinergiany.org/>

Brooklyn Center for the Independence of the Disabled is dedicated to improve the quality of life of Brooklyn residents with disabilities. <https://www.bcid.org/>

Brooklyn LEND’s Family Support Project has established a Parent Support Group which provides guidance, advocacy training, and support for families with children diagnosed with ASD via virtual meetings. Email us at lendparents@gmail.com to receive a flyer with more information and schedule of ZOOM meetings.

² This section is based on a LEND capstone project by Sade Afolabi

Legal Assistance Groups

The Legal Aid society defends the rights of New Yorkers who need legal support. They help people with disabilities obtain and maintain the benefits to which they are entitled.

<https://legalaidnyc.org>

The New York Legal Assistance Group (NYLAG) offers comprehensive free civil legal services to individuals and families who in crisis or facing legal challenges. They help families who need guidance navigating the legal complexities of the special education system. <https://nylag.org>

Summer Camps

DOE NYC Summer Rising is the city's free summer program for students in K-8th grade, including those with disabilities. <https://www.schools.nyc.gov/enrollment/summer/grades-k-8>

Hebrew Educational Society (HES) Summer Camp offers summer camps with specialized support. <https://www.thehes.org/summer-camp/>

Mommy Poppins provides information about specialized summer camps for children with disabilities. <https://mommypoppins.com/newyorkcitykids/nyc-summer-camps-autism-special-needs-aspergers-adhd-sensory>

New York Family provides information about children with special needs.

<https://www.newyorkfamily.com/camps-for-kids-with-special-needs/>

Very Special Camps is a directory of summer camps and programs for individuals with special needs. <https://www.verspecialcamps.com/>

American Camp Association of NY and Nj is an organization dedicated to preserving, promoting, and enhancing the quality of the summer camp experience. <https://www.acanynj.org/>

Culture, Leisure & Recreation

Subway Sleuths New York Transit Museum offers a 10-week afterschool program, for students with autism. <https://www.nytransitmuseum.org/learn/subwaysleuths/>

New York City Ballet Access Program offers visitors with different abilities the opportunity to experience the art of ballet. <https://www.nycballet.com/educate/access-programs>

Lincoln Center offers accessibility for audiences with autism and other developmental disabilities. <https://www.lincolncenter.org/series/accessibility-at-lincoln-center>

MoMA Accessibility Program offers workshops about creating arts for individuals with intellectual disabilities and their families. <https://www.moma.org/visit/accessibility/>

Whitney Museum of American Art welcomes disabled and non-disabled visitors to experience the richness of American art. <https://whitney.org/education/access>

Intrepid Museum Access Program offers monthly programs for individuals with developmental disabilities and their families. <https://www.intrepidmuseum.org/education/access-family-programs>

Culture, Leisure & Recreation (cont'd)

New York Hall of Science Accessibility Program offers unique STEM learning opportunities for individuals with developmental disabilities. <https://nysci.org/autism-access-initiative>

Queens Museum provides assistive services such as tours, ASL interpreters, large print resources, and Art Access programs for both children and adults with disabilities. <https://queensmuseum.org/event/art-access-museum-explorers-for-children-with-disabilities/>

The American Museum of Natural History offers assistive services such as tours, ASL interpreters and large print resources. Service animals welcome. <https://www.amnh.org/plan-your-visit/accessibility-language-assistance>

Culture Pass is a collaboration among all branches of the City's library system. It allows a library cardholder to reserve one free day pass per institution per year. <https://www.culturepass.nyc>

IDNYC is a free government-issued photo ID card for people 10 and older who live in NYC. It can help you get City services, museum memberships, and more.

<https://www.nyc.gov/site/idnyc/benefits/museums-and-cultural-institutions.page>

Mental Health Resources for individuals with developmental disabilities

Young Adult Institute offers mental health services specifically for people with intellectual and developmental disabilities, their partners, and caregivers.

<https://www.yai.org/clinical-services/mental-health>

JCCA Com pass Program offers mental health services for teens and Young Adults with disabilities. <https://www.jccany.org/our-programs/jewish-programs/compass/>
<https://www.jccany.org/our-programs/behavioral-health-and-wellness/psychology-services/>
<https://www.jccany.org/our-programs/behavioral-health-and-wellness/>

JCCA Health Home offers mental health services for those NOT enrolled in OPWDD.

<https://www.jccany.org/our-programs/behavioral-health-and-wellness/health-homes/>

Mental Health Resources for caregivers and family members

NYC Well offers free confidential counseling, mental health support and referrals.

<https://nycwell.cityofnewyork.us/en/>

Information about free or low-cost mental health services to asylum seekers and other vulnerable persons in the NYC area.

<https://humanrights.weill.cornell.edu/resources/mental-health-resources-nyc>

Child Mind Institute is a non-profit organization offering mental health services to children.

<https://childmind.org/>

National Alliance on Mental Health is a mental health organization offering mental health resources. <https://nami.org/>

Home On Our Sleeves provides mental health resources for children.

<https://www.onoursleeves.org/>

New York Psychotherapy and Counseling Center is a non-profit community mental health organization offering mental health services to their communities. <https://nypcc.org/>

Financial Assistance Resources & Family Reimbursement Programs

Supplemental Security Income (SSI) is a monthly subsidy from the government to help provide the needs of children with disabilities. A child may be eligible even if you are working. You can apply to find out if your child is eligible.

<https://www.ssa.gov/ssi/>

<https://www.ssa.gov/apply>

Access HRA is an online benefits portal and mobile app for New York City residents.

HRA provides New Yorkers with a variety of critical services including, but not limited to, food and cash assistance, emergency rental assistance, services for individuals with disabilities or those living HIV/AIDS, and emergency shelter for survivors of domestic violence.

<https://a069-access.nyc.gov/accesshra/>

ADAPT Community Network provides financial support to eligible individuals with disabilities and their families.

<https://adaptcommunitynetwork.org/service-options/family-support/family-reimbursement/>

Manhattan DD Council provides reimbursement for the cost of goods or services that are not covered by current programs, entitlements, or insurance. You must contact one of the agencies to apply. <https://www.manhattanddcouncil.org/wp-content/uploads/Directory-Reimbursement-Programs.pdf>

Transportation Resources

Metropolitan Transportation Authority (MTA) Access-A-Ride Paratransit Program is a door to door special needs transportation service. <https://new.mta.info/accessibility/paratransit>

The MTA Reduced Fare program for people with disabilities allows eligible customers to pay half the transportation fare. <https://new.mta.info/sites/default/files/2018-07/disabled.pdf>

NYC DOE School bus provides door to door transportation to Students with Disabilities (SWD) <https://www.schools.nyc.gov/school-life/transportation/bus-eligibility>

Brooklyn Family Support Services Guide 2023-2024

This directory lists services available to Brooklyn individuals with a developmental disability and/or their families. In order to use many of these services, the person with a developmental disability must live with his or her family in Brooklyn. Developmental disabilities include intellectual disability, autism, cerebral palsy, neurological impairment, global delays, and epilepsy, etc. <https://bkddcouncil.org/wp-content/uploads/2024/01/brooklyn24-fss-guide.pdf>