

Autism: Start Here

What Families Need to Know

4th Edition





Our Mission

Autism New Jersey is a nonprofit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families, and the professionals who support them. Through awareness, credible information, education, and public policy initiatives, Autism New Jersey leads the way to lifelong individualized services provided with skill and compassion. We recognize the autism community's many contributions to society and work to enhance their resilience, abilities and quality of life.

Our Vision

We are GROUNDED in science, STRENGTHENED by knowledge and DEVOTED to creating a society of compassion and inclusion for all those touched by autism.

GLOSSARY

This list is a quick reference for acronyms used within this publication.

AAP	American Academy of Pediatrics
ABA	Applied Behavior Analysis
ADI-R	Autism Diagnostic Interview-Revised
ADOS-2	Autism Diagnostic Observation Scale
ASD	Autism Spectrum Disorder
BCBA	Board Certified Behavior Analyst
CARS-2	Childhood Autism Rating Scale, Second Edition
CDC	Centers for Disease Control and Prevention
CSOC	Children's System of Care
DCF	Department of Children and Families
DDD	Division of Developmental Disabilities
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
EEG	Electroencephalograph
EIS (or NJEIS)	Early Intervention System (NJEIS in New Jersey)
ESY	Extended School Year
FAPE	Free Appropriate Public Education
FBA	Functional Behavior Assessment
IDEA	Individuals with Disabilities Education Act
IDEIA	Individuals with Disabilities Education Improvement Act (re-authorization of IDEA in 2004)
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan
LRE	Least Restrictive Environment
M-CHAT-R/F	Modified Checklist for Autism in Toddlers, Revised with Follow Up
NJAC	New Jersey Administrative Code
OSE	Office of Special Education
OT	Occupational Therapist/Therapy
PBS	Positive Behavior Supports
PRISE	Parental Rights in Special Education
PT	Physical Therapist/Therapy
ST	Speech Therapist/Therapy

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What is Autism and How is it Diagnosed?

Autism Spectrum Disorder | Developmental Milestones |
Autism Screening | Characteristics of Autism |
Diagnostic Evaluations | Medical Tests | Causes | Prevalence |



What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) or autism is a developmental disorder that affects a person's social communication and interaction. Individuals with ASD also have restricted and repetitive behavior, interests and activities. These characteristics fall across a "spectrum" ranging from mild to severe. While one person may have symptoms that impair his or her ability to perform daily activities, another may have only mildly noticeable differences and have few, if any, functional impairments.

In order for an individual to qualify for a diagnosis of Autism Spectrum Disorder, they must meet the criteria outlined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychological Association, 2013). The DSM-5 requires an individual to meet a specific number of criteria from two major categories. To be diagnosed with ASD, a person must have difficulty with social communication and interaction, and display restricted repetitive behaviors, interests and activities. The diagnostician will rank the characteristics based on level of severity and describe the support the individual needs. For individuals who were diagnosed with ASD prior to 2013, the DSM-5 advises that "individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder."

The complete DSM-5 criteria for Autism Spectrum Disorder is available to download at www.autismnj.org/diagnosis

How do I know if my child is developing typically?

While there are general trends in how children develop, all children grow and learn differently. Many factors affect a child's progress toward developmental milestones, and it may be difficult for parents to determine whether their child is on track due to individual differences. If delays are present, early intervention can have a significant and lasting impact. Therefore, it is important to become familiar with child development and discuss any questions with your child's healthcare providers.

How is ASD first identified?

Pediatricians are often the first contact when parents become concerned about their child's development. During office visits, the physician may ask questions about the child's development, and parents often share their concerns at that time.

The American Academy of Pediatrics (AAP) recommends that pediatricians screen for ASD during well checks at 18 and 24 months and at any time a parent raises a concern. Pediatricians will ask the parent questions to assess their child's progress toward typical milestones. They may utilize one of the commonly used screening instruments, such as the Modified Checklist for Autism in Toddlers Revised with Follow-Up (M-CHAT-R/F) or

Some developmental milestones include the following:

By 12 months, most children will:

- Imitate simple actions like clapping
- Use basic gestures like waving and pointing
- Respond when their name is called or when they're told "no"

By 24 months, most children will:

- Enjoy playing with other children
- Identify many different objects
- Use 2- to 4-word phrases, such as "want juice"

By 36 months, most children will:

- Play imaginatively with a variety of toys
- Follow complex instructions
- Speak in 4- to 5-word sentences

The Centers for Disease Control and Prevention (CDC) provides detailed information about milestones from birth through age 5 at www.cdc.gov/actearly. In addition, parents can download a free app to track milestones at www.cdc.gov/milestonetracker

the Childhood Autism Rating Scale Second Edition (CARS™ 2). Careful consideration of parents' responses on the screening instrument allows the pediatrician to determine if there is cause for concern and referral. If the screening indicates a number of red flags, the pediatrician may recommend that the child participate in a multidisciplinary evaluation. Although the initial screening does not result in a diagnosis, it provides valuable information for the parents so they can begin treatment while waiting for an appointment with a full evaluation team. The creators of the M-CHAT-R/F offer the screening tool as a free download at www.mchatscreen.com and provide translations into numerous languages.

What red flags may indicate the presence of autism?

The Centers for Disease Control and Prevention (CDC) lists a number of possible red flags that parents or caregivers may notice including:

- **Not respond to their name by 12 months of age**
- **Not point at objects to show interest (point at an airplane flying over) by 14 months**
- **Not play "pretend" games (pretend to "feed" a doll) by 18 months**
- **Avoid eye contact and want to be alone**
- **Have trouble understanding other people's feelings or talking about their own feelings**
- **Have delayed speech and language skills**
- **Repeat words or phrases over and over (echolalia)**
- **Give unrelated answers to questions**
- **Get upset by minor changes**
- **Have obsessive interests**
- **Flap their hands, rock their body, or spin in circles**
- **Have unusual reactions to the way things sound, smell, taste, look, or feel**

Source: www.cdc.gov/ncbddd/autism/signs.html for additional examples

What do these concerns actually look like?

The major characteristics common to autism are deficits in social communication and interaction, and restrictive, repetitive behaviors, interests and activities. These traits fall along a continuum from mild to severe and vary from person to person.

Difficulty with social interactions

Some individuals with autism do not spontaneously reach out to others to share information or feelings. While some may not seem to notice other people at all, others may strongly desire to interact with others but are not sure how to appropriately initiate interactions with others, or may become overwhelmed in social situations due to deficits in social skills. With effective treatment, many people with autism learn social skills and come to enjoy spending time with others.

Difficulty with communication

Many individuals with autism have delays in or do not develop spoken language. Some may only communicate using single-word utterances or simple sentences. Other speech abnormalities include echolalia (immediate or delayed repeating of information), unconventional word use, and unusual tone, pitch and inflection. Others have complex vocabulary and can speak at length and in depth about topics that interest them, but they may have poor conversational skills. They may also have difficulty understanding common nonverbal cues such as body language, facial expressions and eye contact.

Individuals with autism who do not develop functional speech can use augmentative means of communication, such as sign language, picture boards and technological devices. Autism-specific apps can help them to communicate their needs and feelings, as well as to gain independence in their daily activities.

Unusual behaviors

Individuals with autism have restrictive, repetitive behavior, interests and activities. For example, a child with autism may play with only one toy or watch the same video repeatedly. People with autism may engage in peculiar, sustained play activities such as spinning the wheels of a toy car instead of pretending to drive it, or dangling an object in front of their eyes for long periods of time. Other repetitive behaviors may include motor movements, such as hand flapping, spinning or jumping. Some people with autism may focus intensely on a particular topic, such as dinosaurs or vacuum cleaners, to the exclusion of any other interests. Individuals with autism can be very reliant on specific routines and resistant to changes. Even a minor change in their routine or environment could be a great upset to a child or adult with autism.



During evaluations, the child and parents may meet with a number of specialists, including a pediatric neurologist or developmental pediatrician, psychologist, speech-language pathologist, and occupational or physical therapist.

What can parents expect at a diagnostic evaluation?

If autism is suspected, an evaluation by a physician or psychologist should be conducted as soon as possible. Sometimes, a variety of professionals also conduct evaluations. During these evaluations, the child and parents may meet with a number of specialists, including a pediatric neurologist or developmental pediatrician, psychologist, speech-language pathologist, and occupational or physical therapist. Ideally, each professional summarizes his/her findings in a written report. Ultimately, the child must meet the criteria outlined by the DSM-5 to qualify for an official diagnosis by a physician or psychologist.

The evaluation may consist of the following components:

- 1. Medical and developmental history:** Parents/caregivers will be interviewed to collect information about the pregnancy, birth, health, and medical history of the child. They will also report any behavioral concerns and the progress the child has made toward developmental milestones. Social and development questionnaires may be requested to assess the child's behavior both at home and at school, daycare, or other childcare settings.
- 2. Autism testing:** Observations should include both structured and unstructured observations of the child. Information about the child's development is assessed through the Autism Diagnostic Observation Schedule ADOS[®]-2, a series of tasks that assess an individual's social and communication skills, play, behavior, and restricted interests. To capture as much information as possible about the child's life, the team interviews the people who know him best: the parents. Thus, parents may be asked to complete a structured interview such as the Autism Diagnostic Interview ADI[®]-R and a Vineland Adaptive Behavior Scale (Vineland[™]-II) to provide an assessment of the child's communication, socialization, daily living skills, and motor skills. These assessments, in addition to other standardized measures that may be used, will provide a basis for determining if the child has ASD.
- 3. Psychological testing:** A psychologist will administer developmental and intelligence testing. These tests yield important information related to the child's abilities, limitations, and overall level of functioning compared to other children the same age.
- 4. Speech-language assessment:** A speech therapist will assess the child's communicative abilities, including the ability to understand and use language, articulate clearly, use language for different functions, and engage in conversations. The speech therapist's evaluation should result in specific treatment recommendations for improving the child's speech and communication.
- 5. Occupational or physical therapy assessment:** An occupational therapist will assess the child's fine motor and self-help skills to determine if the child is able to complete age-appropriate activities such as getting dressed,

using utensils, brushing teeth, or writing. The physical therapist will evaluate the child's gross motor skills and coordination (e.g., running, biking, throwing, catching). These evaluations should result in recommendations to improve the child's ability to complete daily living skills.

Once each component of the evaluation is completed, the team reviews the findings with each other and then with the family. The team provides a written report to the family which specifies the diagnosis, if any, and the amount and type of services recommended. Parents can then begin to schedule appointments with individual treatment providers.

Are any medical tests used to diagnose autism?

Although there is no diagnostic laboratory test for ASD, tests are often recommended for the following reasons: 1) to search for a cause, 2) to find out if there are other medical problems that might look like autism (e.g., hearing loss), and 3) to detect additional medical problems that might be co-existing with autism.

Audiologic testing is recommended for any child with delayed language or at risk for autism. A child who does not speak or respond to others' speech may have autism, a hearing problem, or some other condition which interferes with speech.

Neuroimaging, the process of capturing images of the brain, may be needed if there is an abnormal neurologic examination not explained by the diagnosis of autism (e.g., non-symmetrical motor examination, cranial nerve abnormalities, microcephaly). Hypopigmented or hyperpigmented skin lesions, in which the skin appears lighter or darker, may be examined by a Woods Lamp. Electroencephalograph (EEG), a test that measures the electrical activity of the brain, may be recommended if the child is demonstrating signs of seizure activity or language regression. Routine clinical neuroimaging, such as Magnetic Resonance Imaging (MRI), is not recommended as part of the diagnostic evaluation of autism at the present time.

Metabolic testing (a blood test) should be considered when there is a history of lethargy, cyclic vomiting, early seizures, intellectual disability, or unusual facial features. Untreated phenylketonuria (PKU) is an example of a metabolic disorder.

“Autism New Jersey gave us hope, allowed us to cry, encouraged our dreams and provided us with the information we’d need to forge ahead.”

Gino, father of a son with autism

Additional blood tests may be recommended. Lead testing is recommended for children with pica (eating substances other than food). Individuals may also have their ferritin level checked if there are concerns of anemia (a lower than normal amount of red blood cells).

Genetic testing may be used to rule out Fragile X Syndrome or other genetic disorders. Girls who fail to progress and lose skills

following typical development may be tested for a mutation in the MECP2 gene, indicating the presence of Rett's Disorder. Physicians may also consider other genetic tests such as CGH (microarray).

Further medical tests may be recommended by the team. Individual recommendations are based on the child's medical history and symptoms.

What causes autism?

Currently, there is no known cause of ASD. Research suggests that autism is caused by genetic factors, which may be triggered by environmental causes. Exposure to environmental causes may occur in the womb or during or after birth. Ongoing studies are primarily focused on genetic and environmental causes, such as maternal illnesses during pregnancy, conditions during childbirth, and chemical exposures in the individual's environment. ASD is not linked to parenting skills or psychological issues. Given the many similarities and differences between individuals with ASD, many researchers suggest that there is likely to be more than one cause of autism. Autism Speaks provides regular updates on the latest findings in autism research at www.autismspeaks.org.

How common is autism?

According to the Centers for Disease Control and Prevention (CDC, 2020), autism affects 1 in 54 individuals nationally and 1 in 32 in New Jersey. The number of children identified with autism has been growing steadily in the last few decades. Some of this increase can be explained by:

- **more comprehensive research methods (e.g., casting a wider net in health and educational settings and seeking out those who do not have a diagnosis)**
- **accounting for the full spectrum from mild to severe**
- **improved parent and professional awareness**
- **advanced parental age**

Researchers from the fields of genetics and environmental toxicology continue to investigate other possible reasons why the rate of autism has increased so significantly. Visit www.autismnj.org/prevalence-rates for the most recent prevalence information.

What can a diagnostic evaluation not tell me?

Diagnostic evaluations provide a wealth of information about an individual's abilities and limitations. However, even after numerous assessments and medical tests, the cause and prognosis will likely still be unclear. There is considerable variation in the abilities of people with ASD. Some individuals may need extensive, lifelong support to function in home, vocational, and community settings, while others may need intermittent support in fewer areas. While effective and early intervention can greatly improve an individual's prognosis, as of now, there is no definitive way to know what a person's level of functioning will be in the future. Thus, the diagnostic evaluation should provide families with the information they need to seek appropriate treatments to address current deficits and teach new skills. Such skills are likely to have a substantial impact on the person's ability to interact with others and his/her quality of life. With a lot of hard work, individuals with ASD can make tremendous progress.

Resources

Management of children with autism spectrum disorders by American Academy of Pediatrics, available at www.pediatrics.org

Learn the signs. Act early. by Centers for Disease Control and Prevention, available at www.cdc.gov/actearly

Community report from the Autism and Developmental Disabilities Monitoring (ADDM) network. www.cdc.gov

Special thanks to **Dr. Audrey Mars** who provided input for this section. Dr. Mars is a neurodevelopmental pediatrician at Hunterdon Health Care and a long-time member of Autism New Jersey's Professional Advisory Board.

Who's Who in Autism Services



To find referrals for a service provider in your area, visit www.autismnj.org/referral or contact Autism New Jersey at **800.4.AUTISM**

Board Certified Behavior Analyst (BCBA)

Board Certified Behavior Analysts are professionals who use behavioral assessments to design, implement, and evaluate procedures to help individuals learn new skills and reduce challenging behaviors. BCBAs are certified at different levels based on educational and experience requirements. BCBAs work in a variety of settings, such as homes, schools, in the community, and private practice.

For more information: www.bacb.com

Case Manager

Case Managers serve as the primary contact and coordinator of services for a child receiving special education. Case manager is a general term that is used across different service systems, such as early intervention, public school and state agencies. For example, school Case Managers help to coordinate communication between school and home, and they are responsible for scheduling Individualized Education Program (IEP) meetings. **For more information:** www.state.nj.us/education/specialed/

Developmental Pediatrician

Developmental Pediatricians are medical doctors who receive specialty training in developmental behavioral pediatrics after completing a residency in pediatrics. Developmental pediatricians participate in multidisciplinary teams to evaluate an individual for a suspected diagnosis. They provide medical and behavioral oversight as a child ages and transitions between educational settings.

For more information: www.abp.org



Director/Supervisor of Special Education

Directors of Special Education supervise a school district's special education services. They manage the child study team, supervise the development of IEPs, and help to ensure service provision is consistent with the NJ Administrative Code. **For more information:** www.state.nj.us/education/specialed/

Neurologist

Neurologists are physicians who specialize in the diagnosis and treatment of neurological disorders, such as epilepsy and autism. Neurologists participate in multidisciplinary teams to evaluate an individual for a suspected diagnosis. They conduct brain imaging tests and provide medical recommendations for various neurological conditions.

For more information: www.aan.com

Occupational Therapist (OT)

Occupational Therapists help individuals improve their fine motor skills such as writing and cutting, and they also teach daily living skills to increase independence and active participation in life. OTs work in a variety of settings, including homes, schools, in the community, and private practice.

For more information: www.nbcot.org

Pediatrician

Pediatricians are physicians who specialize in treating children. Pediatricians oversee an individual's physical, behavioral, and developmental health from birth through adolescence. Pediatricians may screen for autism spectrum disorder during well checks and refer a patient for a multidisciplinary diagnostic evaluation if necessary.

For more information: www.aap.org

Physical Therapist (PT)

Physical Therapists help individuals to improve muscle strength, balance, coordination and gross motor skills. PTs work in a variety of settings, including schools, homes, outpatient rehabilitation clinics, and private practice.

For more information: www.apta.org

Psychiatrist

Psychiatrists are physicians who specialize in treating mental health disorders. They have training in diagnosis, medical care, and psychotherapy. Psychiatrists may be involved in the prescription and oversight of certain medications. Psychiatrists work in hospital settings and private practice.

For more information: www.abpn.com

Psychologist

Psychologists are clinicians who treat a variety of common problems. Clinical psychologists are doctoral-level professionals who treat a variety of mental health symptoms such as depression, anxiety, anger, and stress. They may provide parent training and support, as well as assist in addressing the needs of a family. School psychologists are typically masters-level professionals who specialize in psychology as it relates to education, and they help children both academically and behaviorally. School psychologists often conduct educational assessments. Psychologists work in school settings, hospitals, and private practice.

For more information: www.apa.org

Speech Language Pathologist (SLP)

Speech Language Pathologists evaluate, diagnose, and treat speech, language, communication, and swallowing disorders. Speech therapists help individuals improve their articulation, understanding and use of language, conversation, and social skills. They may also assist in the selection and development of augmentative and alternative communication devices. SLPs work in a variety of settings, including schools, homes, hospitals, and private practice. **For more information:** www.asha.org

Introduction to State & Local Services

Early Intervention | Special Education |
Parent-Professional Collaboration within Early
Intervention & Special Education |
New Jersey Department of Children and Families |



EARLY INTERVENTION: BIRTH to THREE

Early Intervention | Eligibility |
 Accessing Early Intervention Services |
 Services | Transition to Preschool |
 Financial Contribution |

Early Intervention

The New Jersey Early Intervention System (NJEIS) under the Department of Health implements New Jersey's statewide system of services for infants and toddlers, birth to age 3, with developmental delays or disabilities and their families. State Early Intervention programs are governed by Part C of the Individuals with Disabilities Education Act (IDEA).



Eligibility

Early Intervention services are provided for eligible children until the age of 3. In New Jersey, children are evaluated using a standardized assessment tool and are eligible for NJEIS when:

- (a) two or more areas of development are delayed below the average of other children; *OR*
- (b) when one area of development shows a significant delay.

In technical terms, children are considered eligible when they are experiencing a developmental delay that meets these criteria:

- (a) 1.5 standard deviation below the mean in each of two functional developmental areas (scored below approximately 90% of children their age); *OR*
- (b) 2.0 standard deviation below the mean in one functional developmental area (scored below approximately 98% of children their age); *OR*
- (c) Diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

Children are evaluated in the following developmental areas:

- Physical development
- Cognitive development
- Communication development
- Social and emotional development
- Adaptive functioning

Children with a documented diagnosis of autism spectrum disorder are determined eligible for the NJEIS.

Accessing Early Intervention Services

A parent who is interested in accessing NJEIS services should contact the toll free number **888.653.4463**. A service coordinator will talk with families about their concerns. If the family consents, the service coordinator will work with the family to schedule an evaluation of their child's developmental levels and needs. Children who have a diagnosis prior to their referral to NJEIS will also have an assessment conducted by a NJEIS team to determine developmental levels and needs. Evaluation and assessment services are provided at public expense with no cost to families.

Services

Following the evaluation process, an Individualized Family Service Plan (IFSP) is written at a meeting with the family, the service coordinator, at least one member of the evaluation team and anyone else the family wishes to include. The IFSP is a written document that identifies services and supports needed for the child and family. It is based on information collected from the family, as well as from the evaluation and assessment.

In order for the child to receive services, the parent must consent to the plan. Parents have the right to withdraw consent at any time. Out of the services offered, parents can reject some services and accept others. The plan is reviewed every six months, or more frequently as appropriate to make sure it continues to meet the needs of the child and family. At least once a year, parents participate in a meeting to review their child's outcomes and IFSP services for any changes needed. The meeting must be held at a time and location that is agreeable to the family and in the language or method of communication that is used in their home.

Early intervention may include the following services:

- Assistive technology
- Nursing services
- Transportation
- Audiology services
- Nutrition services
- Vision services
- Family training, counseling, and home visits
- Occupational therapy
- Special instruction (New Jersey uses the term *Developmental Intervention*)
- Health services
- Physical therapy
- Psychological services
- Medical services
- Speech therapy
- Service coordination services
- Social work

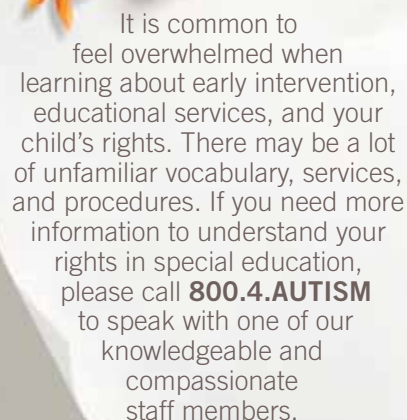
Transition to Preschool

An important part of early intervention services is assisting children and families to make the move from the early intervention program to school services as smooth as possible. This process is called *transition*. When a child is approximately 2.5 years old, a transition information meeting will be held with the parents, service coordinator, and others who have worked with the child and family to begin planning for services and supports that might be needed when the child turns 3. As in other meetings about a child's needs and progress, it is essential that parents are part of the planning. As a child approaches 3 years of age, the service coordinator will help with transition from early intervention to a preschool program which may be provided by their local school district, and/or other service providers, based on the child's needs.

Financial Contribution

The Department of Health has set up a Family Cost Participation system to determine each family's ability to contribute toward NJEIS services. Based on family size and household income, NJEIS determines the per hour co-pay for a family. This amount cannot exceed the actual cost of service and will not be more than 5% of the family's monthly income. Families with an annual income at or above 300% of the federal poverty level will be required to participate in the costs of NJEIS services provided. Families must agree to provide required income documentation to determine family cost participation for services.

For more information see www.nj.gov/health/fhs/eis/.



It is common to feel overwhelmed when learning about early intervention, educational services, and your child's rights. There may be a lot of unfamiliar vocabulary, services, and procedures. If you need more information to understand your rights in special education, please call **800.4.AUTISM** to speak with one of our knowledgeable and compassionate staff members.

SPECIAL EDUCATION: THREE to TWENTY-ONE

Special Education | Eligibility | Accessing Special Education Services | Services

Special Education

Special education rights in New Jersey are derived from the federal law commonly known as IDEA (Individuals with Disabilities Education Act). The New Jersey Administrative Code (NJAC) 6A:14 are the state's regulations based upon IDEA. NJAC 6A:14 explains the rights of the children determined eligible for special education and related services as well as policies and procedures the school districts must adhere to in order to comply with the law. Additionally, it illustrates procedural safeguards in case a school district and parent do not agree on a particular issue. The New Jersey Administrative Code (NJAC) 6A:14 is available from Autism New Jersey, directly from your school district, or from the New Jersey Department of Education's Office of Special Education (OSE) at **609.292.0147** or www.nj.gov/education/specialed/.

Eligibility

A student is eligible for special education and related services when it is determined that the student has a defined disability that affects his/her educational performance and requires special education and related services. The disability categories are: "auditorily impaired, autistic, cognitively impaired, communication impaired, emotionally disturbed, multiply disabled, deaf/blindness, orthopedically impaired, other health impaired, preschool child with a disability, social maladjustment, specific learning disability, traumatic brain injury, or visually impaired."

Accessing Special Education Services

When appropriate, parents are encouraged to contact the local school district's Special Services department and request an evaluation to determine eligibility for Special Education services. Parents may call to request the evaluation: however, putting the request in writing and sending it by certified mail ensures that the school district has received the information and will respond. A meeting may be held to determine if an evaluation is warranted as well as which evaluations would need to be conducted.



THREE TO TWENTY-ONE

Services

The New Jersey Administrative Code states that parents are a part of the Individualized Education Program (IEP) team. This means that parents are members of the IEP team and have the right to provide input into the development and implementation of the IEP as well as placement considerations. The New Jersey Administrative Code also addresses issues such as class size, Extended School Year (ESY), discipline, the 17 required components of the IEP, and the 11 items to be considered when developing the IEP.

Based on federal law, children who are eligible for special education services have the right to a Free Appropriate Public Education in the Least Restrictive Environment (LRE). The essence of FAPE is an “appropriate” education. Yet, the term “appropriate” is different for every child and based upon a number of factors. The IEP team makes decisions about educational placement following consideration of the nature and severity of the child’s disability, different types of educational settings, and the child’s present levels of performance.

The IEP is a document that lists all of the educational services that are to be provided to the child receiving special education. It should describe the child’s special education program in detail. It should also describe how the child currently performs and his or her specific instructional needs across all academic and functional areas. Additionally, the IEP must include measurable annual goals and short-term objectives or benchmarks. It is important that the parents collaborate with school staff to ensure that any services the parents deem necessary are included to allow their child to benefit from their education as appropriate. The IEP is a legal and binding contract between the school district and the parents.

School districts are responsible for the education of a child with autism from the age of 3 to 21 if appropriate. They are also responsible for any related services the child may need to benefit from their special education. Once parents provide consent to begin the initial evaluation process, a 90-day time-line begins. Within that 90-day period, the school district conducts the educational evaluation of the child, develops the IEP with parent input and begins implementation of the IEP. Reevaluations will be conducted at least every 3 years (unless waived) and the IEP will be reviewed and updated annually.

Available Services

Related services include, but may not be limited to, the following:

- Counseling
- Medical services
- Occupational therapy
- Physical therapy
- Recreation
- School nurse services
- Social work services
- Speech-language services
- Transportation

If a parent does not agree with the school district’s evaluation, they have the right to request that an independent evaluation be performed at public expense. An independent education evaluation is an assessment of a child that is conducted by a qualified person or persons not employed by the child’s school district. School districts may make referrals for providers, or individuals can call **800.4.AUTISM** to find an appropriate evaluator.

The school district will also provide the parents with a copy of a booklet called *Parental Rights in Special Education* (PRISE). PRISE is a condensed version of the New Jersey Administrative Code and comes complete with sample forms for requesting emergency relief hearings, complaint investigations, mediation, and due process hearings. This booklet must be provided by the school district one time per year, such as when a child is referred for an initial evaluation, when a reevaluation is conducted, and when a request for a due process hearing is submitted to the Department of Education. At other instances, the school district must provide parents with a statement explaining that parents have rights under the special education law, how parents can obtain a copy of PRISE, and sources they may contact for assistance in understanding special education rules.

PARENT-PROFESSIONAL COLLABORATION within EARLY INTERVENTION & SPECIAL EDUCATION

Children with autism spectrum disorder benefit considerably when parents and professionals work cooperatively to plan for and meet their needs. It is common for multiple service providers to be involved in the child's care and treatment. Parents, family members, and service providers each bring their own perspectives, expertise, and experience with the individual. Therefore, members of the child's treatment team should regularly share information with each other as they all work toward the goal of achieving the best outcome for the child. Parents should always be considered equal members of this team.

Collaboration means working together in an equally reciprocal relationship to achieve a common goal. Effective collaboration begins with consistent and open communication. Parents and professionals can form a successful partnership by focusing on the child's goals and working on them together.

A collaborative relationship can be cultivated in a number of ways. For parents, participating in activities such as volunteering at school or joining a parent advisory council or parent teacher organization may be fulfilling, educational, and provide networking opportunities. Parents may also wish to share their ideas for new goals and objectives for their child with professionals. For professionals, sensitivity is crucial when working with a family to establish educational goals for a student with ASD. Although it is important to share their expertise, professionals should be considerate of the difficult issues facing the family.

Like any other relationship, the parent-professional one takes work. Despite the best of intentions, there may be times when parents and professionals do not see eye-to-eye about recommendations or services for a child. As challenging as that may be, it is often in the child's best interest to continue to negotiate and advocate informally. Clear, open, honest, and written communication with the members of the IFSP or IEP team can often resolve issues before more formal procedures are needed. Even if the team seems to be working effectively together, communication and trust may break down. If this occurs, there are procedural safeguards in place that allow parents to request a facilitated IEP meeting, file a formal complaint, or begin mediation or due process.

COLLABORATION



Helpful Hints for Receiving Appropriate Early Intervention Services

The service coordinator should fully understand the child's and family's needs. Similarly, parents should become familiar with NJEIS terminology and what the system does and does not offer. For example, in NJEIS, one of the services is called "Developmental Intervention," and it takes many forms based on the child's needs. Methods based on the principles and practices of applied behavior analysis (ABA) fall under the category of Developmental Intervention. Thus, if a parent would like to request ABA services, they can do so within the discussion of what type of Developmental Intervention they see as the best fit for their child and family. See page 22 for an in-depth discussion of ABA.

If a family cannot come to an agreement with the service coordinator about the child's services, or feels that the child's service coordinator is not providing the services in the IFSP, there are specific steps to take. These procedures are described in the New Jersey Early Intervention System *Family Rights Handbook*, which can be accessed at: www.nj.gov/health/fhs/eis/for-families/safeguards-familyrights.

Helpful Hints for Receiving Appropriate Special Education Services

Similarly, the IEP team should fully understand the child's needs. If a family cannot come to an agreement with the other members of the IEP team about the child's services, or feels that the team is not providing the services in the IEP, assistance is available. These procedures are outlined in detail in the *Parental Rights in Special Education (PRISE)* booklet that is available from your local school district or the New Jersey Department of Education at: www.state.nj.us/education/specialed/form/prise/prise.pdf.



New Jersey

Department of Children and Families

Children's System of Care

The New Jersey Department of Children and Families' Division of Children's System of Care (CSOC) administers the publicly-funded developmental disability service system for children and youth up to age 21.

PerformCare is the administrative services organization and the single point of entry for all requests for eligibility and services through CSOC. PerformCare arranges needs assessments and facilitates the delivery of family support services. PerformCare's services include funding for respite and camp, in-home behavioral support, assistive technology devices, and home and vehicle modifications. In addition, placement in residential treatment or group homes may be provided when a child's needs cannot be met in the community.

Application materials, a list of frequently asked questions, fact sheets about Family Support Services and other information can be downloaded at www.performcarenj.org/families/disability/index.aspx. For new applications, or to request services for an eligible individual, contact PerformCare at 877.652.7624. PerformCare is available 24 hours a day, 7 days a week. Applications on behalf of individuals who are 18 years or older must be submitted to the Department of Human Services (DHS) Division of Developmental Disabilities (DDD). CSOC will honor determinations of eligibility and provide developmentally disability services made by DDD for individuals between the ages of 18 and 21.

If your child has an unmet need, contact PerformCare to apply for eligibility or to request a specific support service. Families should keep in mind that services provided through CSOC are based on eligibility and availability of funding.

Supports for Adults 21 and Over

The New Jersey Division of Developmental Disabilities (DDD) provides supports and services for individuals with developmental disabilities age 21 and over. For detailed information about DDD, visit www.autismnj.org or the Division's website: www.state.nj.us/humanservices/ddd/home/index.html



Autism New Jersey can assist parents in navigating service systems for their loved one via phone, email or workshops.

Evaluating Potential Treatments for Autism



When a child receives a diagnosis of autism, parents are immediately faced with many important decisions. Choosing a treatment for your child can be a confusing and overwhelming process. While you can easily find information about a variety of treatment approaches, sometimes the extensive amount of information available makes it more difficult to navigate the decision process.

As you learn about different interventions, you may come across many promising options. Various treatment providers may claim that their methods provide the greatest potential for improving your child's outcome. You may also learn about the concept of "evidence-based treatment." So how do you sift through all of this information and go about making the right decision for your child and family?

Choosing a treatment approach for your child with autism is similar to choosing a treatment for any medical condition—ideally you will use an approach that has been thoroughly researched and proven to work. Treatment outcomes should provide evidence that the intervention helped participants learn new skills or reduce levels of challenging behavior, and that minimal or no side effects were observed as a result of the treatment. These outcomes should reflect meaningful and positive changes in the individual's life.

To date, there has been substantial research demonstrating the effectiveness of certain treatments. Unfortunately, however, many treatments marketed to the autism community do not demonstrate any scientific evidence of effectiveness, yet they often receive more attention in the media and the community. While it is certainly important to be optimistic and open to promising treatments, parents should also be cautious of treatments that have not been tested. It is therefore essential for parents to review all of the options carefully in order to make informed treatment decisions for their child. These decisions will have a direct impact on the quality of treatment the child receives and may ultimately save the family valuable time that could be lost when pursuing ineffective treatments.

Given the complexity of reviewing the research to make these decisions, the National Autism Center recently assembled a large group of researchers to evaluate the existing studies on autism treatment. The findings were widely disseminated through the *National Standards Project Phase I* (2009) and *Phase II* (2015). In Phase I, Researchers carefully examined 775 studies of various treatment options, resulting in the classification of treatments into the following categories: established (significant research supports the effectiveness of these treatments), emerging (some research supports the effectiveness, although further research is warranted), and unestablished (no sound evidence of effectiveness exists). Phase II provides an update to the literature for interventions for those under age 22, and also included studies evaluating interventions for adults (22+). This categorization provides a structure from which parents can make informed treatment decisions. Autism New Jersey utilizes a similar classification system, which is outlined in the agency's *Position Statement on Treatment Recommendations*. This classification system uses a traffic light as an analogy for understanding treatment recommendations: green light interventions are recommended, yellow light interventions should only be used cautiously, and red light interventions should be avoided due to proven ineffectiveness.

The *National Standards Project* concluded that interventions derived from applied behavior analysis (ABA) demonstrated the most consistent and positive results for individuals with ASD. ABA is an umbrella term for a number of techniques and treatment packages. ABA treatment is individualized and adapted for the learner, and the intensity of treatment is matched to the person's need. There is an emphasis on using a person's motivations to make therapy fun and engaging, while teaching the individual new skills. ABA has also been proven effective in reducing challenging behaviors. *For more detailed information about ABA, see page 22.*

Full reports from the National Standards Project are available to download at www.nationalautismcenter.org

Furthermore, the Association for Science in Autism Treatment (ASAT) provides descriptions of autism interventions and the current state of research supporting or failing to support these interventions on their website: www.asatonline.org.



Ultimately, it is suggested that families choose the intervention that has the highest likelihood of success for their child and is a good match for the family.

Treatment recommendations

Green light (shown through research to be effective)

Applied behavior analysis (ABA)

**includes a variety of evidence-based practices; see website*

Medications to treat ASD-related irritability: Risperdal and Abilify

Yellow light (have not been studied enough)

More research needed

Animal therapies

Art therapy

Developmental therapies
(DIR/Floortime, RDI, ESDM)

Medical marijuana

Music therapy

Oral Motor therapy (PROMPT/Kaufman)

Project TEACCH

Vitamins (most)

Preliminary evidence suggests ineffectiveness

Craniosacral therapy

Dietary changes

Sensory integration

Vitamin B6 with magnesium

Red light (shown through research to be ineffective or harmful)

Auditory integration training

Chelation and clay baths

Facilitated communication

Hyperbaric oxygen therapy

Psychoanalysis

Rapid Prompting Method

Secretin

For more information and an expanded list, please visit the Treatment section of our website.

It is recommended that evidence-based treatments (e.g., ABA), which are those known to be effective, be considered first. Parents should also take other important variables into consideration, such as: the family's time and monetary resources, the availability of providers, and the clinical recommendations of professionals who know the child. Additionally, families may wish to consider beginning only one treatment at a time. When multiple treatments are provided concurrently, it is very difficult to detect which treatment contributed to any resulting behavior change. Finally, when using any treatment, it is highly recommended that objective data be collected and analyzed to determine if the treatment works for that individual. Objective data describe observable and measurable behaviors rather than relying on subjective reports or people's impressions. Examples include the number of words a child uses per day, the length of time it takes for a child to follow an instruction, or the duration of sitting in circle time. A greater amount of objectivity will help you decide if a treatment approach is effective and should be continued.

"Autism New Jersey provided me with a clear sense of what to do in a way that the many confusing and conflicting voices on the internet could not."

Mary Beth, mother of a son with autism

Individuals with ASD deserve state-of-the-art interventions to help reduce the core symptoms of the disorder. While decisions about treatment approaches are certainly difficult, Autism New Jersey can provide you with resources to help you navigate the process. As you begin to investigate treatments and interview providers, it is suggested that you consider and ask providers the questions on page 32.

Resources

Evidence-Based Practices for Children, Youth and Young Adults with Autism Spectrum Disorder
Connie Wong, Samuel L. Odom, et. al., available at www.cidd.unc.edu

National Standards Report, Phase I and Phase II by the National Autism Center, available at www.nationalautismcenter.org

Making Sense of Autism Treatments: Weighing the Evidence by Association for Science in Autism Treatment, available at www.asatonline.org

A Parent's Guide to Evidence-based Practice and Autism by the National Autism Center, available at www.nationalautismcenter.org

Position Statement on Treatment Recommendations by Autism New Jersey available for download at www.autismnj.org/publications or by calling **800.4.AUTISM**



Autism New Jersey maintains many resources on choosing interventions. If you need assistance call **800.4.AUTISM**.



It is essential for parents to review all of the options carefully in order to make informed treatment decisions for their child.



If you'd like to learn more about applied behavior analysis, see the Suggested Reading List included in this publication.

You may also wish to order the following booklet on the enclosed Autism New Jersey publication order form: *Applied Behavior Analysis and Autism: An Introduction* by Dr. Suzanne Buchanan & Dr. Mary Jane Weiss

Applied Behavior Analysis



Applied behavior analysis (ABA) has become widely known as an effective treatment for autism. It is a compelling approach because it has been studied extensively and has shown consistent, positive results in improving the lives of individuals with ASD.

ABA can be used to teach skills from many domains, including language and communication, self-help, academic, play/leisure, and social skills. ABA strategies can be used to help individuals with autism in specific ways: to increase or teach new behaviors, to decrease challenging behaviors, and to generalize behaviors from one context to another. These strategies can be used with learners of any age. The treatment approach is very dynamic; that is, professionals overseeing ABA programs are constantly engaged with the learner to determine which intervention, strategy, prompt, and reward are best for the learner in the moment. ABA methods can be tailored both to the learner and to the skill being taught, thereby making ABA a practical approach for treating the core symptoms of ASD. Parent participation in understanding and using the treatment strategies is highly encouraged to help maximize the individual's progress.

ABA involves breaking down complex skills into simple parts, making them easier to learn. Goals are selected based on the results of ongoing assessments as well as the family's priorities, and objective data are collected and used to monitor progress. Teaching procedures are clearly written to give both teachers and family members consistent information about the learner's goals and the ways they can help him/her work toward greater independence. Learners are given the opportunity to practice skills many times, in various settings (e.g., home, school, work, community), and with different people (e.g., parents, teachers, peers). These opportunities allow the individual to learn skills that are functional and durable over time. ABA services are sometimes provided to teach a specific skill or address a particular challenging behavior, and other times ABA is used as the basis for a comprehensive treatment program. Although treatment often involves many hours, there is a strong emphasis on making learning fun and engaging.

One of the primary components of ABA is that treatment continually emphasizes the individual's motivations and regularly rewards the learner for working toward his/her goals, a concept known as *positive reinforcement*. Individuals participating in ABA services are working hard to learn new skills, and effective use of individualized reinforcers contributes to making treatment enjoyable for the learner.

Many different concepts and teaching procedures are utilized within a comprehensive ABA program. People sometimes mistakenly equate ABA with Discrete Trial Instruction, yet ABA has always been much broader than one teaching technique. Research and advancements in the field have resulted in the discovery of many effective teaching strategies.

More than four decades of research and hundreds of scientific studies have proven that ABA is an effective treatment for individuals with ASD. Several large agencies and task forces have evaluated the numerous treatment options available to individuals with autism and consistently recommend ABA as the treatment of choice for treating ASD.

Some of the concepts and procedures within ABA include, but are not limited to, the following:

- Reinforcement
- Shaping
- Prompting
- Task Analysis & Chaining
- Discrete Trial Instruction
- Activity Schedules
- Verbal Behavior
- Pivotal Response Training
- Natural Environment Training
- Incidental Teaching
- Token Economy
- Generalization
- Maintenance
- Functional Behavior Assessment & Intervention

Here are some simple snapshots of ABA in action.

These examples are for illustration purposes only and would involve considerably more detail when put into practice.

Shaping

- Instead of waiting until a new skill is done perfectly, it is important to provide reinforcement (preferred consequences) for closer and closer approximations of the skill. The target skill is defined and broken down into smaller steps. Reinforcement is provided when the individual demonstrates the skill at the highest level learned, and it is no longer provided for previous steps.

This is an example of shaping communication skills:

Currently, your child takes your hand and leads you to the refrigerator when he's hungry. He places your hand on the item he wants. This is reinforced by giving him the food he desires. Through teaching, the child learns to point to the item he desires. Pointing to the desired food is now reinforced, whereas taking your hand and placing it on the item is no longer reinforced. The child is working towards more independent choice-making and requesting skills.

Task Analysis

- A complex task is broken down into the component steps and then taught one step at a time, ultimately resulting in a “chain” of appropriate steps to complete the task. The task analysis is created based on the individual's current skill level for a specific task.

This is an example of a task analysis for brushing teeth:

- | | | |
|-----------------------|---------------------------------|------------------------|
| 1. Pick up toothbrush | 4. Put toothpaste on toothbrush | 7. Brush tops of teeth |
| 2. Turn on water | 5. Brush front of teeth | 8. Rinse |
| 3. Wet toothbrush | 6. Brush inside teeth | 9. Spit |
| | | 10. Turn off water |

Reinforcement is provided after each step is demonstrated by the individual, and it is gradually faded as the individual becomes more independent.

Discrete Trial Instruction (DTI)

- In DTI, a specific instruction or cue is provided, the teacher prompts the individual (as necessary), the individual responds, and the instructor or parent provides a positive or neutral consequence. This sequence is repeated and intermixed with other objectives until the individual can respond independently. Some skills may be learned quickly, and others may require many repetitions over several days.

This is an example of discrete trial instruction for teaching a child early toy play skills:

Instruction: “Do this.” Instructor pushes a toy train through a tunnel.

Response: The child pushes the train through the tunnel (with instructor guidance).

Consequence: “Wow—the train went through the tunnel!” (Instructor may also present a tangible reward.)

The child learns how to play with the train set appropriately, through steps that are first taught individually and then combined. After some practice, the instructor may work with the child and a sibling to learn how to play with the toy together.

Functional Behavior Assessment

- Before treating challenging behaviors, it is important to determine the “function” of the behavior or why it “works” for the learner. In ABA programs, the challenging behavior is observed, as well as what happens before and after the behavior, commonly referred to as the ABC's (Antecedent-Behavior-Consequence). Repeated observations can show patterns of behavior and give us ideas for more effective ways to respond. This information is used in the development of a behavior plan.

This is an example of assessing challenging behavior:

The teacher says, “It's time to turn off the computer.” (Antecedent)

The student gets up, knocks over the chair, and falls to the floor. (Behavior)

The teacher repeats the request and prompts the student to pick up the chair and turn off the computer. (Consequence)

This example shows only one episode of a challenging behavior. Behavior analysts review multiple episodes to look for any patterns in the A-B-C sequence to determine the function of the behavior for the individual. This information is used in the development of an appropriate behavior plan.

What to Look for in a Behavior Analyst

Applied behavior analysis (ABA) programs have much to offer individuals with autism, if they are delivered by knowledgeable and compassionate behavior analysts. But, how do you know if you have found someone who is ethical, competent and effective? Here are a few ideas to consider when trying to identify and work with behavior analysts.

Professionals in this field are responsible for knowing how to successfully implement a wide range of assessment, intervention, and quality assurance methods. To do so requires extensive training including academic coursework, hands-on experience, and supervision. Years ago, parents and professionals had little guidance when trying to determine who was qualified to provide behavior analytic services. Fortunately, since 1999, the Behavior Analyst Certification Board™ (BACB) has been administering a voluntary certification program designed to ensure a minimum level of knowledge for those who practice ABA. The BACB offers 3 levels of certification for those with doctoral, masters, and baccalaureate degrees.

- Board Certified Behavior Analyst – Doctoral (BCBA-D)
- Board Certified Behavior Analyst (BCBA)
- Board Certified Assistant Behavior Analyst (BCaBA)

Additionally, the BACB has developed standards for the Registered Behavior Technician (RBT) designation, which establishes training standards for behavior technicians, the paraprofessionals who implement behavior plans directly with clients.

This certification is a major advancement for the profession and consumers of ABA services and has become increasingly important in the ABA marketplace. For example, many state insurance mandates use the BACB credentials as evidence of qualifications to be eligible for insurance reimbursement. Here in New Jersey, the Department of Banking and Insurance has followed suit, stating that a BCBA-D or BCBA must administer or supervise reimbursable services.

In 2020, the Applied Behavior Analyst Licensing Act was signed into law. In addition to establishing the Board of Applied Behavior Analyst Examiners, this law will soon require all who practice behavior analysis to hold a license or fall into an exempt category. As of this writing, this requirement is not yet in effect, and the Board is drafting regulations that will govern the profession and the application process.

The criteria for this certification offer guidelines for consumers when choosing a behavior analyst. Here is a brief list of items to look for in a behavior analyst. (The term, “learner,” is used as an umbrella term for child, adult, student, client, etc.)

A behavior analyst should:

1. Spend time with the learner and those who play a role in his programming (parents, teachers, staff, etc.) to directly observe and gain an appreciation of the learner’s preferences and skills as well as the team’s values and goals.
2. Observe the learner on multiple occasions to become familiar with what the learner can do with and without intervention.
3. Conduct objective assessments that capture a true picture of the learner’s behavior.
4. Implement (or train others to implement) an intervention that:
 - Makes a meaningful difference in the learner’s life while minimizing risks
 - Is individualized
 - Is a good fit for the team implementing the procedures
5. Collect and analyze data to describe the learner’s progress and ensure service accountability.
6. Overall, act in accordance with the BACB’s Professional and Ethical Compliance Code for Behavior Analysts.
www.bacb.com/wp-content/bacb-compliance-code

Resources

Behavior Analyst Certification Board (BACB) www.bacb.com. Website includes information for consumers and professionals regarding eligibility requirements, examination content, and professional ethics code.

For more information, visit the licensure board’s webpage:

<https://www.njconsumeraffairs.gov/abae/Pages/default.aspx> or contact them at 973.273.8070 or email appliedbehavior@dca.njoag.gov.

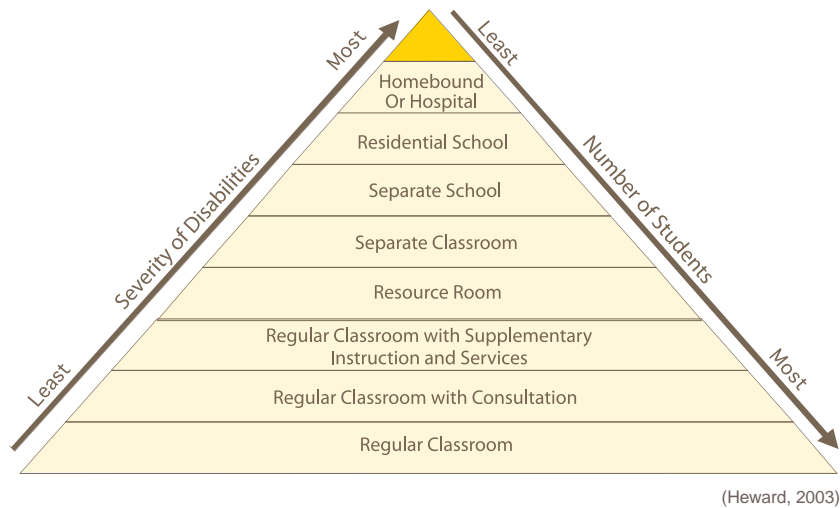
What to Look for in a Special Education Program



If you have questions about special education programs or your child's IEP, call **800.4.AUTISM** to speak with one of our staff members.



Students with autism require a well planned educational program that includes proper supports to maximize progress. School districts may have a number of different classroom placement options, as depicted in this diagram:



Sometimes it is difficult to determine the type of educational program that will best meet an individual student's educational needs. Many learners with ASD can benefit from participation in special education programs with a high staff-to-student ratio and the systematic use of behavioral teaching methods; yet others may be successful in general education classes with additional supports. Additionally, the intensity of the program may vary in the number of hours provided as well as the amount

of one-to-one and group instruction. Although differences exist across educational programs, each should emphasize skill development across language and communication, social interaction, daily living, and appropriate behavior. Instruction in each of these areas should be well planned and allow the student opportunities for repeated practice. Generalization of newly acquired skills and maintenance of previously learned skills should also be promoted through effective instruction.

Since no one placement is appropriate for all learners, parents and educators should carefully consider specific program characteristics that will help the student make the most of academic and social opportunities. Decisions about placement are made as part of the Individualized Education Program (IEP) process. Parents, as contributing members of the IEP team, can provide input on placement decisions and are therefore encouraged to learn about the different types of classes. It may be helpful for parents to visit some of the classes to see the alternatives first-hand. The form on page 28 provides a structure from which to evaluate program options.

Resources

Advice for Parents on Selecting Appropriate Treatments by the Cambridge Center for Behavioral Studies available at www.behavior.org/treatment-advice

Autism Program Quality Indicators (APQI) by New Jersey Department of Education, available at www.state.nj.us/education/specialed/info/autism.pdf

Educating Children with Autism by the National Research Council, available at www.nap.edu

Exceptional children: An introduction to special education by William L. Heward

What to Look for in a Special Education Program Interview Questions

General Program Considerations

1. Can the components of your child's IEP be implemented in this environment
2. At preschool age, is the program operated on a full-day basis?
3. Is an extended school year (ESY) program available, if needed?
4. What instructional methods are used? Are they evidence-based?
5. Is there at least 1 teacher or aide for every 3 students in the room?
6. In special education programs, are there no more than 6 students in an elementary classroom or no more than 9 students in a secondary classroom?
7. Is one-to-one instruction and support available, if needed?

Classroom Environment

1. Does the classroom appear safe for your child?
2. Is there a bathroom nearby? Do the teachers ensure privacy when meeting hygienic needs?
3. Are there a variety of materials available?
4. Is there a space designated for one-to-one teaching, if needed?
5. Are visual supports evident throughout the classroom?
6. Are there opportunities for planned and supported interaction with typical peers?
7. Are there opportunities for community-based instruction?

Instructional Procedures

1. Does the teacher seem to have a good rapport with the students?
2. Are the classroom activities well organized?
3. Are rewards used to motivate students? Are the students' preferences assessed on a regular basis?
Do the students choose the rewards?
4. Do the students respond when the teacher gives a direction? Are the students oriented to the ongoing lesson?
5. Are the activities appropriate to the child's age?
6. Are the activities designed to lead to more advanced skills?
7. How is generalization planned for and assessed?

Staff Training and Development

1. Is staff trained in the diagnostic criteria and characteristics of ASD?
2. Do staff participate in ongoing trainings or consultations on issues related to autism and evidence-based strategies for teaching new skills?
3. Does staff have experience in developing IEP goals to meet individual student needs?
4. Is staff knowledgeable in functional assessment and positive behavior support?
Crisis intervention? CPR and safety?
5. How are staff monitored and supervised?
6. Does the district have staff or utilize a consultant with expertise in ASD and evidence-based strategies to supervise the program?

Progress Evaluation

1. Are objective data which assess the progress of each student obtained for both teaching new skills and addressing challenging behaviors?
2. Are programming decisions made based on objective data?
3. Is there a systematic way of determining when an educational objective has been met and what the next step will be?
4. Is there regular communication between school and home regarding a student's progress? What is the form and frequency of communication?

Collaboration

1. Does the classroom teacher encourage parent observations? What are the policies for observations?
2. Are parent training opportunities available?
3. Does the school have a parent support group or other opportunities for meeting with parents?

Challenging Behaviors

1. How are inappropriate, aggressive, and other challenging behaviors addressed?
2. Are there thorough and well-monitored procedures in place?
Is a functional assessment completed prior to developing interventions?
3. Who is responsible for assessing challenging behaviors and designing behavior plans?
4. How are parents involved in the process of developing and implementing behavior plans?
5. Are interventions monitored for effectiveness with objective data?
6. Are incident reports used to document accidents, injuries, and property destruction?
Are parents notified?

Related Services

1. Are related services such as speech therapy, physical therapy, and occupational therapy available for the student when indicated? Are objective data which assess the progress of each student obtained for each of these therapies?
2. How are specific transportation needs met?
3. Is in-home programming available if needed?

Personal Notes about the Program

1. How did you feel about the program?
2. Did you feel welcomed and comfortable?
3. Is the program's philosophy one that fosters parental involvement?
4. Did you feel that your questions were well answered?
5. Does it seem reasonable that the student's needs will be met within this placement?

Following is a list of books with practical information for family members and professionals. Written by experts in the field, these resources are frequently recommended for the compelling, inspiring and state-of-the-art content.

This reading list is designed to give readers initial suggestions for learning more about ASD and effective treatment. For additional suggestions on these and other topics, call 800.4.AUTISM.

Advocacy And Law

- *What Do I Do When... The Answer Book on Special Education Law* (5th ed.) by John Norlin
- *Wrightslaw: The Special Education Survival Guide: From Emotions to Advocacy* (2nd ed.) by Pam Wright & Pete Wright
- *Wrightslaw: All About IEPs* by Pam Wright, Pete Wright & Sandra Webb O'Connor

Autism

- *Asperger's from the Inside Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome* by Michael John Carley
- *Essential First Steps for Parents of Children with Autism* by Lara Delmolino, Ph.D. & Sandra Harris, Ph.D.
- *OASIS Guide to Asperger Syndrome: Advice, Support, Insight, and Inspiration* by Patricia Romanowski Bashe & Barbara Kirby
- *Toolkits* by Autism Speaks. Current titles available at <http://www.autismspeaks.org/family-services/tool-kits>
- *The Complete Guide to Asperger's Syndrome* by Tony Attwood

Challenging Behaviors

- *Functional Behavior Assessment for People with Autism: Making Sense of Seemingly Senseless Behavior* by Beth Glasberg
- *Stop that Seemingly Senseless Behavior: FBA-based Interventions for People with Autism* by Beth Glasberg

Communication

- *A Picture's Worth: PECS and Other Visual Communication Strategies in Autism* by Andy Bondy & Lori Frost
- *Teaching Conversation to Children with Autism: Scripts and Script Fading* by Lynn McClannahan & Patricia Krantz
- *Teaching Language to Children with Autism or Other Developmental Disabilities* by Mark Sundberg & James Partington

Family

- *Let Me Hear Your Voice: A Family's Triumph over Autism* by Catherine Maurice
- *Voices from the Spectrum: Parents, Grandparents, Siblings, Friends, Helpers, and People with Autism Tell their Stories* edited by Cindy Ariel & Robert Naseef

Healthcare

- *Healthcare for Children on the Autism Spectrum* by Fred Volkmar & Lisa Wiesner
- *Sleep Better! A Guide to Improving Sleep for Children with Special Needs* by V. Mark Durand

Life Skills

- *Self-Help Skills for People with Autism: A Systematic Teaching Approach* by Stephen Anderson, Amy Jablonski, Marcus Thomeer & Vicki Knapp
- *Steps to Independence: Teaching Everyday Skills to Children with Special Needs* (4th ed.) by Bruce Baker & Alan Brightman
- *Toilet Training for Individuals with Autism and Related Disorders* (2nd ed.) by Maria Wheeler

School

- *Autism for Public School Administrators: What You Need to Know* by Autism New Jersey

Siblings

- *Siblings of Children with Autism* (2nd ed.) by Sandra Harris & Beth Glasberg

Social Skills

- *Crafting Connections: Contemporary Applied Behavior Analysis for Enriching the Social Lives of Persons with Autism Spectrum Disorder* by Mitchell Taubman, Ron Leaf & John McEachin
- *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations* by Brenda Smith Myles, Melissa Trautman, & Ronda Schelvan
- *Reaching Out, Joining In: Teaching Social Skills to Young Children with Autism* by Mary Jane Weiss & Sandra Harris
- *Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communication Problems* by Jed Baker

Teaching and Treatment Interventions

- *Activity Schedules for Children with Autism: Teaching Independent Behavior* (2nd ed.) by Lynn McClannahan & Patricia Krantz
- *Applied Behavior Analysis and Autism: An Introduction* by Suzanne Buchanan & Mary Jane Weiss
- *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals* edited by Catherine Maurice, Gina Green & Stephen Luce
- *The Complete Guide to Autism Treatments. A parent's handbook: make sure your child gets what works!* by Sabrina K. Freeman, Ph.D.
- *Incentives for Change: Motivating People with Autism Spectrum Disorders to Learn and Gain Independence* by Lara Delmolino & Sandra Harris
- *Making a Difference: Behavioral Intervention for Autism* edited by Catherine Maurice, Gina Green & Richard Foxx
- *Pivotal Response Treatments for Autism: Communication, Social, and Academic Development* by Robert Koegel & Lynn Kern Koegel
- *Right from the Start: Behavioral Intervention for Young Children with Autism* (2nd ed.) by Sandra Harris & Mary Jane Weiss
- *Teaching Individuals with Developmental Delays: Basic Intervention Techniques* by O. Ivar Lovaas
- *A Work in Progress: Behavior Management Strategies and a Curriculum for Intensive Treatment of Autism* edited by Ron Leaf & John McEachin

Treatment Guidelines

- *Educating Children with Autism* by the National Research Council
- *National Standards Project: Addressing the Need for Evidence-based Practice Guidelines for Autism Spectrum Disorders* published by the National Autism Center

These questions were adapted from an article, *The Road Less Traveled: Charting a Clear Course for Autism Treatment*, by Dr. David Celiberti and colleagues.

Evaluating Potential Treatments for Autism Interview Questions

Treatment Approach

1. What research exists to support the effectiveness of this approach?
2. If there is no published research supporting the treatment approach, who is promoting the approach and on what basis?
3. Has this approach been used with other children that have characteristics similar to my child?
4. How much and in what observable ways can my child benefit from this approach?
5. Where can I learn more about this treatment?
6. Are there any side effects of this approach?
7. How will you assess my child and develop a treatment plan?

Specific Service Provider

1. What are the professional credentials for practicing this treatment approach?
2. What is your professional background (education, supervised work experience, experience with children similar to my own)? Can you provide a copy of your resume?
3. How will you individualize this treatment for my child?
4. Are you willing to collaborate with other professionals involved with my child?
5. How often will you see my child?
6. Will there be other professionals (e.g., instructors) working with my child? If so, how do you supervise them?
7. What is the role of parents and family members?
8. What are the costs of treatment and your agency's billing practices?
9. Will I be able to receive insurance reimbursement for this treatment?
10. With permission, will I be able to speak with another family to whom you provided treatment?

Ongoing Monitoring of Treatment Effectiveness

1. How do you determine if my child is making progress?
2. How often will you re-evaluate my child?
3. How long will my child need to participate in this treatment?
4. How often should you and I communicate, and how?
5. How can I (as a parent) support the work you will do with my child?



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