

Autism Then and Now

Expanding understanding for a
lifetime of support

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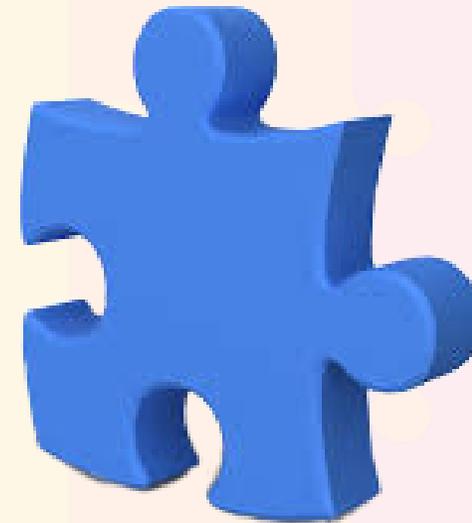
What Is Autism?

- Autism spectrum disorder (ASD) is a developmental disorder that affects communication and behavior.
- Symptoms generally appear in the first two years of life.
- About 1 in 54 children is diagnosed with ASD.
- ASD is more than 4 times more common among boys than among girls.
- Autism is known as a “spectrum” disorder because there is wide variation in the type and severity of symptoms people experience.
- ASD is a lifelong disorder.
- Treatments and services can improve a person’s symptoms and ability to function.



In The Beginning

- "Autism" comes from the Greek word "autos", which means "self".
- It describes conditions in which person is removed from social interaction and becomes an "isolated self".
- In 1911, Eugen Bleuler, a Swiss psychiatrist, was the first person to use the word "autism".
- In 1943, Dr. Leo Kanner, a Ukrainian-Austrian-American psychiatrist, published the first systematic description of early infantile autism. He concluded that this was a neurodevelopmental disorder and that 'these children have come into the world with an innate inability to form the usual, biologically provided contact with people'.



Symptoms

- Difficulty with communication and interaction with other people
- Restricted interests and repetitive behaviors
- Problems with back-and-forth communication that may include difficulty with conversation, body language, eye contact, and/or facial expressions.
- Difficulty in developing and maintaining relationships, often due to difficulty with imaginative play, making friends, or sharing interests.



Diagnosis

- Diagnosing autism spectrum disorder (ASD) can be difficult because there is no medical test, like a blood test, to diagnose the disorder.
- Doctors look at the child's developmental history and behavior to make a diagnosis.
- Many children do not receive a final diagnosis until much older.
- Some people are not diagnosed until they are adolescents or adults.
- A delayed diagnosis means that children with ASD might not get the early help they need.



Early intervention

Applied Behavior Analysis (ABA)

- By looking at the person's behavior, doctors can usually diagnose Autism Spectrum Disorder by the age of two
- It is important to seek out an assessment as soon as possible so that a diagnosis can be made, and treatment can begin.
- As children with ASD become adolescents and young adults, they might have difficulties developing and maintaining friendships, communicating with peers and adults, or understanding what behaviors are expected in school or on the job.
- Adults with ASD may also come to the attention of healthcare providers because they have co-occurring conditions such as attention-deficit/hyperactivity disorder, obsessive compulsive disorder, anxiety or depression, or conduct disorder.



Treatments and Therapies

- Currently, no treatment has been shown to cure ASD, but several interventions have been developed and studied for use with young children.
- **Applied Behavior Analysis (ABA)** is the science based on understanding behavior and making socially meaningful and positive changes to behavior. Progress is tracked and measured.
- **Medication** - There are no medications that can cure ASD or treat the core symptoms. However, there are medications that can help some people with ASD function better. For example, medication might help manage high energy levels, inability to focus, anxiety and depression, behavioral reactivity, self-injury, or seizures.
- **Occupational Therapy**
Occupational therapy teaches skills that help the person live as independently as possible. Skills may include dressing, eating, bathing, and relating to people.
- **Social Skills Training**
Social skills training teaches children the skills they need to interact with others, including conversation and problem-solving skills



Birth to Preschool

- **Early Intervention** with individuals at risk for, or in the early stages of mental, physical, learning, or other disorders refers to efforts targeted at young children (infancy through 5th grade), sometimes including prenatal care.
- **Preschool Evaluations** are important in determining the best learning environment and methodologies for an individual.
- **Special Education Itinerant Teacher (SEIT)** usually works one-on-one with a student in need. They work with the child in the classroom and sometimes at home to build necessary academic, social, and behavioral skills, adjusting their teaching to the individual needs of each student.



School-age Services

Services for children with autism spectrum disorders are available for children and young adults between the ages of 0 and 21.

Individuals with Disabilities Education Act (IDEA) outlines the kinds of services and supports children with disabilities may be eligible to receive. The services your child actually receives will be determined by an Individualized Education Program (IEP) for each individual .

Services Include:

- Specialized School Programs
- After School Programs
- Recreational Services for the Weekend
- Summer Camp
- Respite Services
- Special Education Teacher Support Service (SETSS) Program
- Social Skills Groups
- Community Habilitation (In-Home Supports)



Transitioning from School to Adult Services

- As a child reaches adolescence, the family and school district will work jointly to develop a plan for the transition to adulthood
- It is important to start early.
- Preparation for the transition process happens in school. Students with autism have the right to receive comprehensive transition services. Under IDEA, school districts are responsible for providing the support they need to meet their goals for after high school to the best of their abilities.
- By age 16, each student's Individual Education Program (IEP) process must include transition planning services for all special education students. Ideally, this process should begin when the student is between 12 and 14 years old.

Services Include:

- Work-Based Learning for Students
- Job Exploration Counseling
- Post-Secondary Counseling
- Work and Self-Advocacy Skills Training



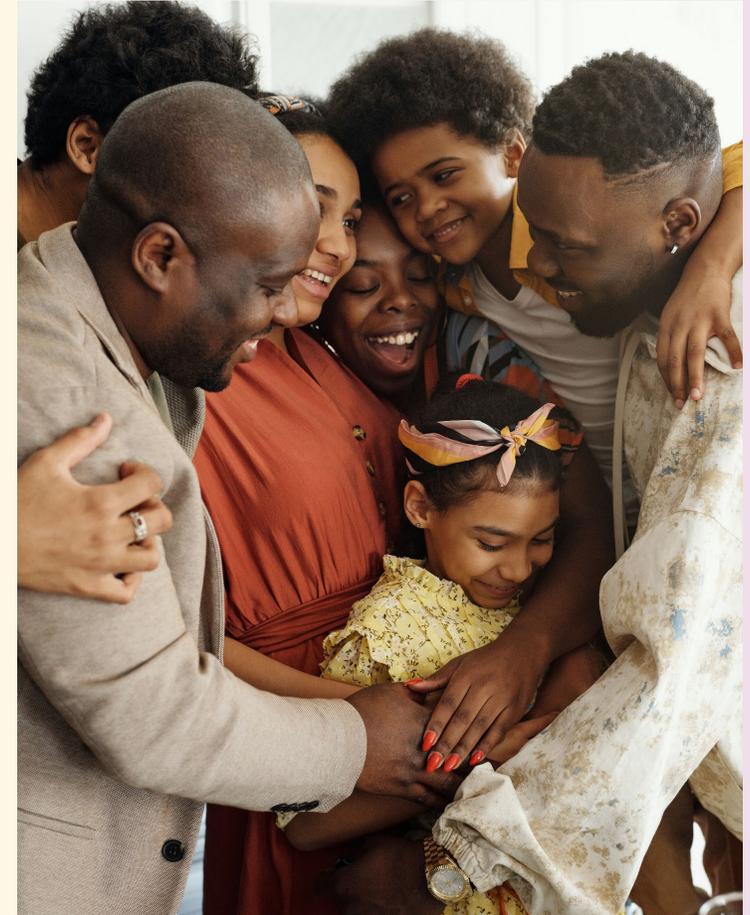
Adult Services

- Moving out of the family home is one of the biggest decisions in a person's life. For a person on the autism spectrum, finding and securing a house and caregiving supports can be complicated.
- Non-profit agencies can make this planning easier through tools and resources to guide each student and family through the process.
- Adult Services
 - Residential Services
 - Day Programs to Promote Independent Living
 - Community Habilitation (In-Home Supports)
 - Job Club and Self-Advocacy Groups
 - Specialized Case Management for Older Adults with Autism



Family Impact

- Having a child with Autism affects various aspects of family living, including housekeeping, finances, emotional and mental health of parents and marital relationships.
- Autism can limit the response to the needs of other children within the family, create poor sibling relationships and affect relationships with extended family, friends and neighbors.
- Parental stress is an important predictor for intervention outcomes in children with ASD.
- Such stress can result in lower levels of developmental improvement and in decreased development of language, communication and other adaptive behaviors



Advocacy

- NYC Family Advocacy Information Resource (<http://www.nycfamilyadvocacyinformationresource.org/>)
- Parents for Inclusive Education (<http://www.parentsforinclusiveeducation.com/>)
- Self-Advocacy Association of New York State (<https://sanys.org/>)
- NYC Family Advocacy Information Resource (<http://www.nycfamilyadvocacyinformationresource.org/>)
- The Queens Developmental Disabilities Council (QCDD) can be found online at www.qcddny.org.
- Support Advocates for Children at www.advocatesforchildren.org Include NYC at www.includenyc.org
- Connect with the Mayor's Office for People with Disabilities (MOPD) at www.1.nyc.gov/site/mopd/index.page



Autism and Covid-19

- For some people on the spectrum, life in lockdown is aggravating anxiety and other autism traits
- Many public health measures can be very challenging for people with autism, depending on each individual's challenges and support needs, as evidenced by reported difficulty wearing masks and social distancing.
- In addition to school and work closures, many children and adults with autism have been unable to get the medical care, behavioral therapies and education services they need to reach their full potential.
- Many autism diagnosis appointments have been delayed, potentially impacting getting therapies and services to children when they are most effective.
- Direct service providers and health care personnel who assist people with autism have encountered shortages of personal protective equipment and have had to cope with increased stress.
- Further, a recent [survey by Autism Speaks](#) found that more than 9 percent of white families and more than 17 percent of minority families did not receive any distance learning supports during the pandemic.



Encounter Groups

- Encounter / Therapy Groups are key tools in helping parents/siblings of individuals on the autism spectrum communicate and share with others in similar situations
- Social Skills Groups for ages 7-11 and 12-18
- P.E.E.R.S. Certified trainers – Groups for kids/teens with (in person or online) Parents attend a separate group, learning to coach their kids to make and keep friends. Weekly classes.
- For information on the above, click on this link: [BIPS Homepage](#)



Autism – Living In The Community

- Non-profit agencies offer a variety of person-centered services for adults with autism spectrum disorders - from day habilitation, community habilitation and residential services to vocational services and emergency respite for caregivers,
- Programs foster independence, provide excellence in care, and give support and guidance to individuals and their families.
- The goal of programs is to help all caregivers improve the independence and quality of life of their loved ones.
- In addition to a sibling support group and parent training group, agencies also offer various workshops and training for those who care for or live with individuals with autism.



For information on the above, click on the link: www.qsac.org

Education/Training

According to the Americans with Disabilities Act ADA, individuals with autism are entitled to training and education, specifically targeted to their needs.

Below are links to some methodologies used in the Education / Training of individuals on the autism spectrum

- ["Discovery: Using Alternatives to Traditional Vocational Assessment" PDF](#)
Article by Michael Callahan
- ["Discovery Questions"](#)
Article by Michael Callahan
- ["Documenting Discovery: Developing a Descriptive Profile to Guide Employment Plans Pathways to Employment Resource Center \(PERC\) Curriculum" PDF](#)
Article by Michael Callahan
- Parents for Inclusive Education
(<http://www.parentsforinclusiveeducation.com/>)



Agencies and Non-Profit Organizations Serving the Community

The following is a list of agencies and non-profit organizations that provide services and offer resources in New York City:

- Quality Services for the Autism Community (QSAC) <https://www.qsac.com/>
- The Arc *Autism Now* <https://autismnow.org/>
- Office for People With Developmental Disabilities (OPWDD) <https://opwdd.ny.gov/>
- CPC Queens Services <https://www.cpc-nyc.org/programs/family-support/services-families-special-needs-queens>
- YAI https://www.yai.org/find-a-service?f%5B0%5D=field_service_region%3AQueens
- Queens Council on Developmental Disabilities (QCDD) <https://www.qcddny.org/>
- Innovative Resources for Independence, Inc. <https://www.in-res.org/>
- Life's WORC <https://lifesworc.org/>
- Unique Peoples Services, Inc <https://www.uniquepeopleservices.org/>

In the Workplace

- April is Autism Awareness Month, a time for us all to recognize the contributions of America's workers with disabilities, including autism spectrum disorders (ASD). It is also a time to talk about the obstacles that continue to hold back far too many qualified job seekers from entering the workforce.
- Most of us aspire to be competitively employed in a job that we find both appealing and challenging; one that suitably matches our interests and abilities. People with autism are no different.
- Research from Drexel University and elsewhere tells us that they are less likely than other disability groups to be employed or pursue postsecondary education. In fact, young adults with ASDs have the highest risk of being completely disengaged from any kind of postsecondary education or employment after high school.



Americans with Disabilities Act (ADA)

- **The Americans with Disabilities Act (ADA)** became law in 1990
- The ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.
- The purpose of the law is to make sure that people with disabilities have the same rights and opportunities as everyone else.
- In 2008, the Americans with Disabilities Act Amendments Act (ADAAA) was signed into law and became effective on January 1, 2009. The ADAAA made a number of significant changes to the definition of “disability” related to employment practices of private employers, state and local governments, employment agencies and joint management labor committees.



Diversity in the Community

- Culture plays a large part in the treatments and learning processes of individuals diagnosed with autism. It is important to maintain cultural and socioeconomic diversity among the provider agencies in order to meet the needs of individuals with Autism and their families in every community.
- Effectively serving students with autism spectrum disorders (ASDs) requires professionals to possess specialized knowledge, skills, and understanding. When students with ASDs are from culturally or linguistically diverse families, the professionals assessing and providing services to the students need the additional dimension of how cultural and linguistic differences may affect identification, assessment, and treatment strategies.



Port Authority Abilities Network

The mission of the Port Authority Abilities Network (PAAN) is to establish a diverse and inclusive work environment that values, respects, and embraces employees for their abilities. PAAN aims to build awareness, maximize potential, and empower members with and without disabilities. PAAN is dedicated to increasing the level of awareness across the agency about the talents and contributions of people with disabilities while fostering opportunities for our members to reach their highest potential.

- **Objectives:**
- Provide members with networking, mentoring, and career development opportunities
- Serve as a resource for disability-related matters
- Promote and brand the Port Authority as an employer of choice for people with disabilities
- Partner with other Employee Business Resource Groups to develop and implement initiatives that foster diversity within the agency
- For additional information please contact the Abilities Network at paabilitiesnetwork@panynj.gov



Citations

- Slide #1 & 2 – AutismSpeaks, a non-profit organization dedicated to promoting solutions through advocacy and support - www.autismspeaks.org
- Slide #3
 - "How Autism Became Autism", by Bonnie Evans, July 26, 2013, SAGE History of the Human Sciences - <https://journals.sagepub.com/doi/full/10.1177/0952695113484320>
 - "Leo Kanner and Autism: A 75-year Perspective", April 18, 2018; National Library of Medicine - <https://pubmed.ncbi.nlm.nih.gov/29667863/>
- Slide 6# - Early Intervention Applied Behavior Analysis (ABA) - www.opwdd.ny.gov
- Slide #7 - "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning and appropriate social behavior." – the United States Surgeon General.
- Slide # 8 -11 - Quality Services for the Autism Community (QSAC) <https://www.qsac.com/>
- Slide #19 – "Helpful Resources for Drexel Students with Disabilities" – <https://www.law.cornell.edu/uscode/text/42/ties> – Undergraduate Life at Drexel (2021) – www.Drexel.edu/undergrad/life-at-drexel
- Slide # 20 Americans with Disabilities Act (ADA) - <https://www.law.cornell.edu/uscode/text/42>