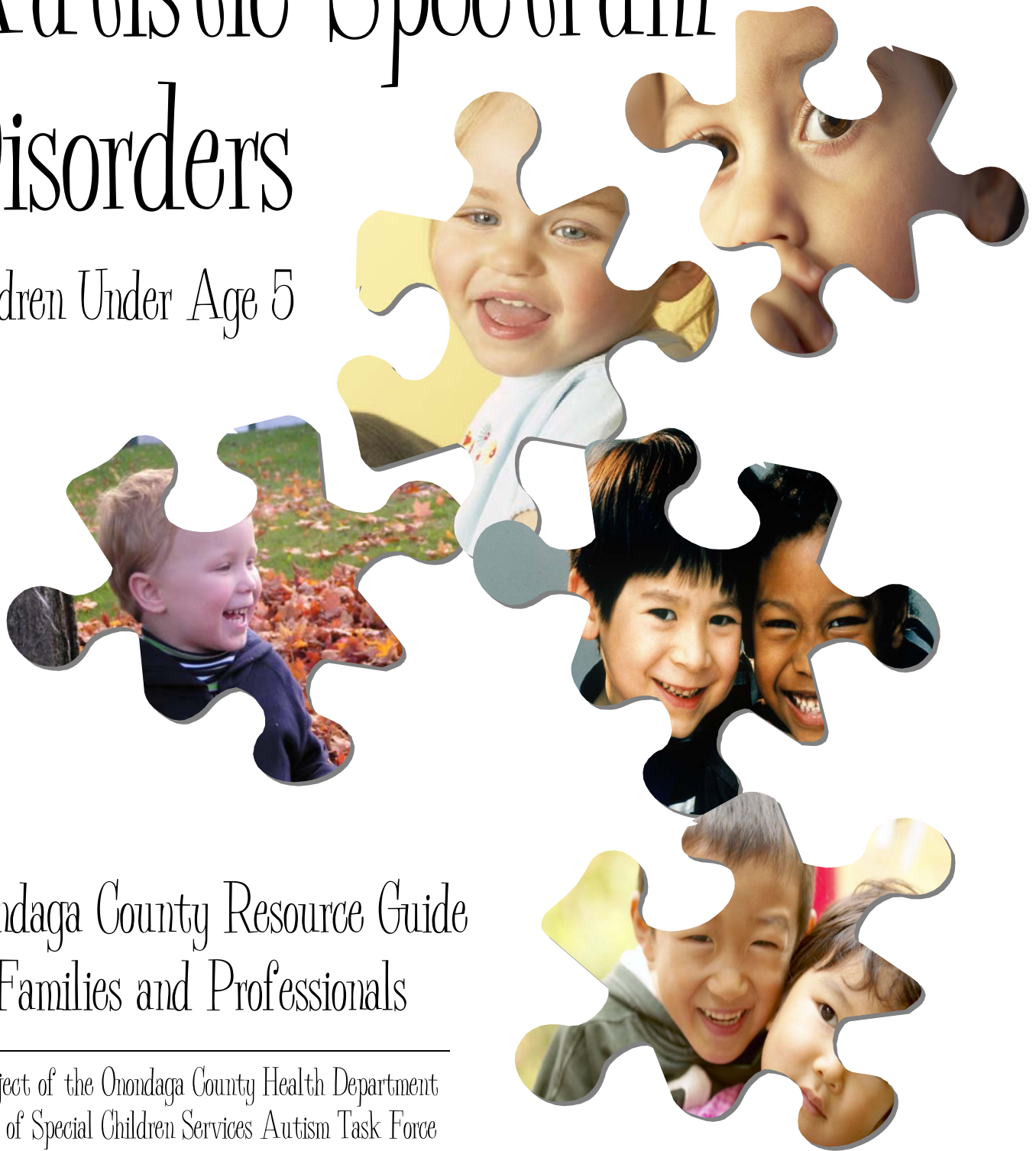


Autistic Spectrum Disorders

Children Under Age 5



Onondaga County Resource Guide for Families and Professionals

A Project of the Onondaga County Health Department
Bureau of Special Children Services Autism Task Force

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Onondaga County Autism Task Force, 2006

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Introduction

Whether this resource manual finds you in the beginning of your journey or well along the way, we welcome you to the collaborative spirit we have attempted to create in the pages that follow. In these pages, you will find general information about Autistic Spectrum Disorder as well as information on support groups, programs and services, and more resources in Onondaga County. Hopefully, this manual will serve as the starting point for connections that build new dreams and provide hope. Our children are extraordinary. As parents and professionals in this journey we are given the opportunity to see life from their unique perspective. Together we can establish a partnership that creates positive support and successful futures for children and families living with autism spectrum disorders.

One of the biggest challenges we face as advocates is identifying reliable, current, and reputable information. In order to be successful in this role, we must tackle the daunting task of understanding how to navigate the system. Being discriminative about how we gather and use information is a key part of this task. This manual will hopefully ease the burden of identifying useful information and provide guidance on local options. However, this manual does not need to be read cover to cover. Do not feel overwhelmed by new or unfamiliar information. Ask more questions when you are uncertain about any information. Your Early Intervention Service Coordinator or local parent groups are good places to start. Use this resource manual as a starting point.

To keep the scope of this document from being too overwhelming, an emphasis has been placed on services for younger children. However, some of these services and resources can continue to be utilized through adolescence. Also, this guide primarily covers services accessible in Onondaga County. Located at the end of this guide is a comprehensive glossary of common acronyms and definitions. Please make sure to check listed websites for the most current information regarding research and changes in laws, policies, and procedures.

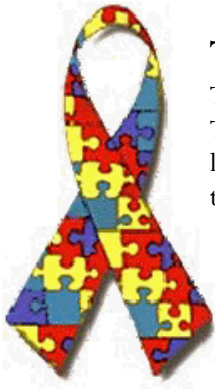
Most importantly, make sure you remember to believe in yourself and in our beautiful children. We have the opportunity to build dreams and foster hope. Accurate and reliable information provides us with the building blocks to do so.

Welcome to this partnership.

The Onondaga County Health Department Autism Task Force

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The Autism Awareness Ribbon

The puzzle pattern of this ribbon reflects the mystery and complexity of autism. The different colors and shapes represent the diversity of people and families living with this disorder. The brightness of the ribbon signals hope—hope through research and increasing awareness in people like you.

What is Autism? The Clinical Perspective

Autistic Disorder is one part of a clinical spectrum of disorders known as Pervasive Developmental Disorders (PDD). Autism is defined by the Individuals with Disabilities Education Act (IDEA) as “a developmental disability significantly affecting verbal and nonverbal communication and social interaction, usually evident before age three, which adversely affects the child’s educational performance. Other characteristics associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change in daily routines, and unusual responses to sensory experiences.” Autism affects social skill development, sensory processing, language development, and behavior.

Common Characteristics of Autism

Three core symptoms are expressed by children with autism. These core symptoms are described by the DSM-IV as impairment of social relatedness, delays and disorders of communication (both verbal and non-verbal), and behavior patterns that are more restricted, repetitive, and stereotyped. Variation of these symptoms depends on the severity of the disorder. It should be noted that not all symptoms of autism fit easily into the core symptoms. Autism is known as a spectrum disorder. Cases of autism can be placed on a continuum ranging from mild to severe. The severity of the case is based on the level of functional skills in the areas of communication, cognitive abilities, and social interaction.

Some medical conditions or genetic syndromes in children have a higher-than-expected occurrence of autism. These include Down Syndrome, Fragile-X Syndrome, Rett Syndrome, tuberous sclerosis, phenylketonuria, Joubert Syndrome, Moebius Syndrome, chromosome 15q11-13 duplication, congenital rubella syndrome, prenatal exposure to thalidomide and valproic acid, and hypoxic-ischemic encephalopathy in the term newborn. Children with autism have a higher-than-expected occurrence of conditions such as mental retardation, macrocephaly (large head), seizures, gastrointestinal upset, allergies, attention deficit hyperactivity disorder, problems with sleep, obsessive-compulsive disorder, depression and anxiety disorders.

Diagnostic Criteria

The current criteria for diagnosing Autistic Disorder and other types of pervasive developmental disorders (PDD) in the United States is provided by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)* (provided in shaded area below).

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
 1. qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - b. failure to develop peer relationships appropriate to developmental level
 - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. lack of social or emotional reciprocity
 2. qualitative impairments in communication as manifested by at least one of the following:
 - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c. stereotyped and repetitive use of language or idiosyncratic language
 - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - d. persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

What Causes Autism?

The cause of most autism is unknown. Scientists believe that both genetic and environmental factors may play a role. Studies are still being planned and executed to determine the cause. While the causes of autism continue to be researched, it is known that parental actions *do not* cause autism. Current and past research findings can be found through some of the websites listed at the end of this guide. ¹

¹*Clinical Practice Guideline: The Guideline Technical Report. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years).* (1999) New York State Department of Health

How Common is Autism?

Based on the current criteria for diagnosing autism and Autistic Spectrum Disorders (ASD), studies have found the prevalence rates to be between 2 and 6 per 1,000 individuals. This equates to 1 in 166 having an ASD. It is estimated that 4 million children are born in the United States every year. According to the prevalence rates, of these children, approximately 24,000 will at some point be diagnosed with an ASD. Assuming consistency in the prevalence rates, it can be estimated that there may be as many as 500,000 individuals between the ages of 0 and 21 that have an ASD. In a study conducted by the Centers for Disease Control and Prevention, the Metropolitan Atlanta Developmental Disabilities Surveillance Program, the rate of autism between the ages of 3 and 10 was compared with rates of other child disabilities. It was discovered that while rates of mental retardation were the highest, autism rates were higher than rates of cerebral palsy, hearing loss, and vision impairment.³

In 1991, autism was added as a special education classification. Currently, it is now the 6th most commonly classified disability in the United States. It was estimated that in 2003 141,022 children were served with special education services under the “Autism” classification. However, it should be noted that the education data is an underestimate of the true prevalence of ASDs; not all children with ASD receive special education services under that classification.³

What is Asperger Syndrome?²

Asperger Syndrome or Asperger’s Disorder is classified as a pervasive developmental disorder at the more functional end of the autism spectrum. Asperger Syndrome is characterized by sustained impairment in social interaction. The development of restricted, repetitive patterns of interests, behaviors, and activities are also characteristics of Asperger Syndrome. While there may be subtle impairments in language, what distinguishes Asperger Syndrome from autism is the absence of delays in language or cognitive development, or in age-appropriate adaptive behaviors and self-help skills. There remains considerable debate concerning whether there should be a differentiation between Asperger Syndrome and high functioning autism.

Facts About Autism^{3 4 5}

- Autism is a neurologically based disorder of development. It is not considered to be a mental illness.
- Although mental retardation coexists with autism, not all children with autism are mentally retarded.
- Certain aggressive behaviors may be seen in children with autism. There may be many reasons why these children demonstrate disruptive behaviors. These reasons include but are not limited to: frustration, confusion due to language deficits, sensory sensitivities, high anxiety, and low tolerance for change. Nevertheless, these behaviors are generally not “chosen” by the child.
- There is no credible evidence that autism can be caused by deficient or improper parenting, contrary to what may have been once believed in the past.
- Autism has varying degrees from severe to mild.

² www.albany.edu/psy/autism/fact%20sheet%205.doc

³ *Clinical Practice Guideline: The Guideline Technical Report. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years).* (1999) New York State Department of Health

⁴ www.momsonamissionforautism.org/index/Autism_Myths

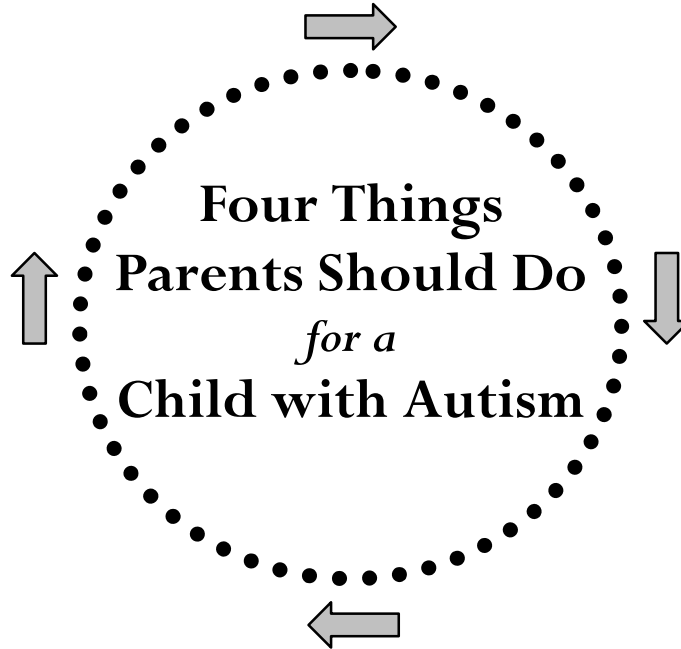
⁵ *Services for Young Children with Autism in Monroe County: A Guide for Families.* (2003) Monroe Early Intervention Program.

1. Get an Official Diagnosis

- Get a diagnosis by a Developmental Pediatrician, Clinical Psychologist, Neurologist, or a team of diagnostic professionals.
- Educate yourself on the diagnosis. Review both its clinical definition and parent stories.
- Get your child reevaluated yearly and continue to remain educated on the diagnosis. Save all your evaluations to track progress.

4. Believe in yourself and your child

- Know that you are among many who feel overwhelmed, devastated and bewildered at times.
- Get busy! Your child needs a good intervention program designed by the people who know him/her best.



2. Develop & Maintain a Support System

- Find a Parent Support Group.
- Get a Service Coordinator, Social Worker or other professional that can help you understand and navigate the system.
- Prepare family and friends with an explanation of your child's diagnosis.

3. Develop & Maintain an Action Plan

- Research your Intervention and Education options.
NY State Dept of Health
http://www.health.state.ny.us/community/infants_children/early_intervention/
- Visit many local programs before making a decision on placement.
- Call a parent support group for references and/or to ask questions on options available.
- Choose a program and a methodology- if appropriate.
- Make sure the program allows for your involvement and partnership.

Treatment Options

The two most widely used approaches by providers and families in Onondaga County are Applied Behavioral Analysis (ABA) and Development, Individual Difference, Relationship Model (DIR). No single methodology is a “perfect fit” for every child and family. Sometimes a combination of approaches works well with a child.

The following recommendations and information on treatment options were adopted from *The Clinical Practice Guideline: The Guideline Technical Report*, New York State Department of Health, 1999. Further information is available in this report providing recommendations for treatment options with positive outcomes. Studies are also provided in the report that gives empirical evidence supporting recommendations for treatment options.

Any quality intervention program should focus on developing increased attention to social stimuli, imitation skills, communication and language, symbolic play, and social relationships. A comprehensive intervention program should include:

- Opportunities for family involvement
- A highly structured and supportive teaching environment
- A functional approach to dealing with problem behavior
- A high degree of predictability and routine
- Strategies for generalization of skills to less restrictive settings
- Strategies for transition between daily activities
- Long-term strategies for transitions between intervention settings
- Parent, caregiver and staff training that emphasize the individual child’s needs

[See Dawson, G. & Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches. In Guralnick (Ed.) *The effectiveness of early intervention: Second generation research*. (pp. 307-326) Baltimore: Brookes.]

The information below is intended to provide a brief introduction to different methods. It is in no way intended to be an endorsement of any particular methodology. Choices about what intervention strategy to choose should be based on child and family priorities, needs and preferences.

For more information about treatments, please refer to the 1999 New York State Department of Health, Early Intervention Program publication, *Clinical Practice Guidelines: Autism/pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3years)*.

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

Applied Behavioral Analysis (ABA)

Behavioral and educational interventions are currently the predominant approach for treating children and adults with autism. Some of these interventions use an intensive, systematic approach known as applied behavioral analysis (ABA). ABA is a data-driven, evidence based strategy. Many educational

interventions for young children, including some current forms of speech and language therapy, are also based on behavioral principles.

Behavioral therapies such as ABA consist of specific approaches designed to help individuals acquire or change behaviors. A functional assessment which evaluates the possible antecedents and consequences of the behaviors, as well as potential reinforcers, is conducted as part of an initial assessment. Reducing behaviors that interfere with a child's ability to function and interact is often the first target of ABA interventions. As these behavior problems are controlled, the targets of the intervention shift to other aspects of autism, such as improvement in communication and social interaction. As children learn new skills, these skills are then applied to a variety of situations; this is called generalization of skills. For children with autism spectrum disorders, generalization of skills is an important learning objective.

Developmental, Individual Difference, Relationship Model (DIR)

The Developmental, Individual Difference, Relationship Model (DIR) is a conceptual framework that incorporates a variety of approaches tailored to the child's developmental level as opposed to a single, specific intervention. The model was developed as the basis for a comprehensive intervention approach that emphasizes the child's relationships, developmental abilities and individual differences in the following areas: motor development, sensory integration, affective learning, cognitive development and language functioning. The model is based on a theory that the symptoms of autism may be related to underlying biologically based processing difficulties causing the child to have problems with relationships and affective interactions.

The DIR intervention strategy is sometimes referred to as "floor time." This strategy is coined "floor time" because it involves a component that encourages both the parent and the therapist to spend a large portion of time interacting with the child on the floor. These sessions use the child's individual differences and developmental levels as a starting point. The floor time model is intended to develop the child's emerging developmental capacities and through affective intervention, cognitive and emotional growth is developed. Other interventions may be incorporated depending on the child's needs, including behavioral and educational approaches.

TEACCH

Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) is a program model founded in North Carolina at the University of North Carolina at Chapel Hill. This program focuses on the person with autism and then develops a program around this person's skills, interests and needs. It uses structured teaching and visual materials to organize the child's physical environment, to develop schedules and work systems, and to make expectations clear and explicit. Outcomes for children include independent work skills, improved communication, and better social and leisure skills.

Sensory Integration Therapy

The purpose of sensory integration therapy is to facilitate the development of the nervous system's ability to process sensory input in a more normal way. This therapy is based on the theory that the brain in a

normal individual integrates various sensory messages in order to form coherent information upon which to act. These integrated sensory messages may come from smell, touch, taste, hearing, sight, sense of position, and various others. According to this theory, the process of normal integration may be malfunctioning or missing in some individuals, especially those with autism. Children are evaluated for sensory processing difficulties and are then provided with appropriate sensory activities based on their responsiveness to specific forms of sensory stimuli. Sensory experiences, including goal oriented play, are then used to assist children in responding more easily to the world around them.

Complementary and Alternative Treatments

Several well designed studies have shown that secretin is not effective in improving the signs and symptoms associated with autism. Chelation therapy to remove heavy metals has been used. Thus far, no studies have documented its effectiveness and several deaths have been reported in children receiving this therapy. Other novel treatments that have been used include the following: gluten-free, casein-free diet; intravenous immunoglobulin; digestive enzymes; vitamins and minerals; enzymes and other nutritional supplements; anti-fungal agents; antibiotics; and hormonal treatment. There currently is not enough published information to determine if these treatments are effective or ineffective, and if they carry any risk for the children using them.

Educational and Therapeutic Services and Supports in Onondaga County

Acronyms:

SCIS-Special Class in an Integrated Setting; **SEIT**-Special Education Itinerant Teacher; **ABA**-Applied Behavioral Analysis; **DIR**- Developmental, Individual Difference, Relationship Model; **PECS**-Picture Exchange Communication; **TEACCH**- Treatment and Education of Autistic and Communication Handicapped Children

🗣️ se habla Español

<i>Program</i>	<i>Services</i>	<i>Intervention Method</i>	<i>Service Providers</i>	<i>Locations</i>
ARISE Child & Family Service 635 James Street Syracuse, NY 13203 (315) 472-3171	<ul style="list-style-type: none"> ▪ Advocacy ▪ Arise at the Farm/ Therapeutic Horseback Riding ▪ Assistive Technology & Equipment ▪ Counseling ▪ Financial Assistance ▪ Information & Referrals ▪ Recreation ▪ Service Coordination ▪ Support Services 		<ul style="list-style-type: none"> ▪ Service Coordinator 	
Arc of Onondaga (ARC) 600 South Wilbur Avenue Syracuse, NY 13204 (315) 476-7441 www.arcon.org	<ul style="list-style-type: none"> ▪ Advocacy ▪ EI/Preschool Programs ▪ Financial Assistance ▪ Recreation ▪ Service Coordination 		<ul style="list-style-type: none"> ▪ Service Coordinator 	
Center for Neurodevelopmental Pediatrics 550 Harrison Street, Suite 100 Syracuse, NY 13210 1-866-543-KIDS	<ul style="list-style-type: none"> ▪ Evaluations ▪ Ongoing medical care 			<ul style="list-style-type: none"> ▪ On-site

<i>Program</i>	<i>Services</i>	<i>Intervention Method</i>	<i>Service Providers</i>	<i>Locations</i>
Childcare Solutions 6724 Thompson Road Syracuse, NY 13221 (315) 446-1220 www.childcaresyracuse.org	<ul style="list-style-type: none"> ▪ Consultation with childcare facilities ▪ Information & Referrals ▪ Parenting Seminars 			<ul style="list-style-type: none"> ▪ On-Site
Children First 725 Erie Blvd, West Syracuse, NY 13204 (315) 472-7094	<ul style="list-style-type: none"> ▪ Evaluations 	<ul style="list-style-type: none"> ▪ DIR/Floor time ▪ Sensory Integration 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapy ▪ Special Educator ▪ Speech Therapy 	<ul style="list-style-type: none"> ▪ Home ▪ Child care settings
Children's Therapy Network (CTN) 171 Intrepid Lane Syracuse, NY 13205 (315) 437-4689 📞	<ul style="list-style-type: none"> ▪ SEIT ▪ Toddler Groups 	<ul style="list-style-type: none"> ▪ ABA ▪ DIR/Floor time ▪ Sensory Integration 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapy ▪ Special Educator ▪ Speech Therapy ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ Community ▪ Facility-Group ▪ Facility-Individual ▪ Home
CNY Autism Society of America (CNY ASA) (315) 447-4466 www.cnyasa.org	<ul style="list-style-type: none"> ▪ Family Support Group 		<ul style="list-style-type: none"> ▪ Support Group 	<ul style="list-style-type: none"> ▪ Jowonio School
Connections Family-Centered Therapies 1744 W. Genesee St. Syracuse, NY 13204 (315) 468-3414 connections@connectionstx.com	<ul style="list-style-type: none"> ▪ Related Services-Itinerant 	<ul style="list-style-type: none"> ▪ DIR/Floor time ▪ PECS ▪ Sensory Integration 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapy ▪ Special Educator ▪ Speech/Language Therapy 	<ul style="list-style-type: none"> ▪ Community ▪ Facility-Individual ▪ Home

Program	Services	Intervention Method	Service Providers	Locations
Developmental Disabilities Services Organization (DDSO) 800 South Wilbur Avenue Syracuse, NY (315) 473-5050 www.omr.state.ny.us	<ul style="list-style-type: none"> ▪ Equipment ▪ Family Support ▪ Financial Assistance ▪ Service Coordination ▪ Medicaid Waiver 		<ul style="list-style-type: none"> ▪ Service Coordinator 	<ul style="list-style-type: none"> ▪ Facility ▪ Community
Early Childhood Direction Center 805 South Crouse Avenue Syracuse, NY 13224 (315) 443-444 http://ecdc.syr.edu	<ul style="list-style-type: none"> ▪ Advocacy ▪ Family Support ▪ Information & Referrals ▪ Linking with community Resources 			<ul style="list-style-type: none"> ▪ Facility
ENABLE Community-Based Pre-School 1603 Court Street Syracuse, NY 13208 (315) 455-7591 www.enablecny.org	<ul style="list-style-type: none"> ▪ Assistive Technology ▪ Counseling ▪ Diagnostic Evaluations ▪ Financial Assistance ▪ SCIS Full-Day ▪ SEIT ▪ Service Coordination ▪ Social Skills Groups ▪ Therapy 	<ul style="list-style-type: none"> ▪ ABA ▪ Sensory Integration ▪ DIR ▪ PECS ▪ Auditory Listening Program ▪ Functional Behavioral Assessments 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapy ▪ Special Educator ▪ Speech Therapy ▪ Social Work ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ Facility-Individual ▪ Facility-Group ▪ Westside Nursery School ▪ Exploring Your World ▪ Northside CYO ▪ Shining Starts Daycare Center
Exceptional Family Resources 1065 James Street, Suite 220 Syracuse, NY 13203 (315) 478-1462 www.contactefr.org	<ul style="list-style-type: none"> ▪ CSHCN ▪ Educational Advocacy ▪ Financial Assistance ▪ Information & referrals ▪ Parent to Parent ▪ Recreation ▪ Respite ▪ Resource Manual ▪ Service Coordination 		<ul style="list-style-type: none"> ▪ Service Coordinator ▪ Respite provider ▪ Educational Advocates 	<ul style="list-style-type: none"> ▪ Home ▪ Community ▪ Facility

Program	Services	Intervention Method	Service Providers	Locations
Familycapped, Inc. 228 Lafayette Road Syracuse, NY 13205 (315) 469-9931 www.familycapped.com/	<ul style="list-style-type: none"> ▪ Family Support Group ▪ Information & Referrals ▪ Recreation ▪ Service Coordination 		<ul style="list-style-type: none"> ▪ Service Coordinator 	<ul style="list-style-type: none"> ▪ Casey's Place
Families for Effective Autism Treatment (FEAT) (315) 638-4058 www.featofcny.org	<ul style="list-style-type: none"> ▪ Family Support Group ▪ Play Group ▪ Recreation ▪ Parent Training 	<ul style="list-style-type: none"> ▪ ABA 	<ul style="list-style-type: none"> ▪ Support Group 	<ul style="list-style-type: none"> ▪ Baldwinsville United Methodist Church
High Peaks 100 Intrepid Lane Syracuse, NY 13205 (315) 492-8319 www.highpeaksrehab.com	<ul style="list-style-type: none"> ▪ SEIT ▪ Auditory Processing Evaluations 	<ul style="list-style-type: none"> ▪ ABA ▪ DIR/Floor time ▪ Sensory Integration 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapy ▪ Special Education ▪ Speech Therapy 	<ul style="list-style-type: none"> ▪ Home ▪ Community ▪ Facility-Individual ▪ Child care settings
InterActive Therapy Group (ITG) 500 East Brighton St., #200 Syracuse, NY 13210 (315) 469-1189 www.interactivetherapygroup.com	<ul style="list-style-type: none"> ▪ SCIS Half-Day ▪ SEIT ▪ Evaluations 	<ul style="list-style-type: none"> ▪ DIR/Floor time ▪ Sensory Integration 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Para-Professional ▪ Physical Therapy ▪ Psychologist ▪ Special Educator ▪ Speech Therapy ▪ Social Work 	<ul style="list-style-type: none"> ▪ Home ▪ Community ▪ Facility-Individual ▪ Facility-Group Developmental
Jowonio 3049 East Genesee Street Syracuse NY 13224 (315) 445-4010 www.jowonio.org	<ul style="list-style-type: none"> ▪ SCIS Full-Day ▪ SCIS Extended-Day ▪ SCIS Half-Day ▪ SEIT ▪ Evaluations 	<ul style="list-style-type: none"> ▪ DIR/Floor time ▪ PECS ▪ Sensory Integration ▪ TEACCH ▪ Child Directive Therapy ▪ Sign Language 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapy ▪ Special Educator ▪ Speech Therapy ▪ Psychologist ▪ Social Worker ▪ Nurse ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ Home ▪ Facility-Individual ▪ Facility-Group ▪ Syracuse University Day Care ▪ Bernice Wright & Bellevue Heights Nursery Schools

Program	Services	Intervention Method	Service Providers	Locations
Little Lukes 5820 Heritage Landing Drive East Syracuse, NY 13057 (315) 701-1107	<ul style="list-style-type: none"> ▪ Evaluations ▪ Early Intervention (home and community) ▪ Early Intervention groups ▪ Preschool related services ▪ SCIS –half-day and full day (Fall 2006) 	<ul style="list-style-type: none"> ▪ ABA ▪ DIR/ Floortime ▪ PECS ▪ Sensory Integration ▪ Combination approaches tailored to individual family needs 	<ul style="list-style-type: none"> ▪ Occupational therapy ▪ Physical therapy ▪ Special Educator ▪ Speech therapy ▪ Psychologist 	<ul style="list-style-type: none"> ▪ On-site ▪ Child care settings ▪ Home/community
Liverpool Early Education Program (LEEP) 500 Hickory Street Liverpool, NY 13088 (315) 622-7161	<ul style="list-style-type: none"> ▪ SCIS Half-Day ▪ SEIT ▪ Evaluations 	<ul style="list-style-type: none"> ▪ PECS ▪ Occupational Therapy ▪ Physical Therapy ▪ Speech/Language Therapy 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapy ▪ Special Educator ▪ Speech Therapy ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ Donlin Drive Elementary ▪ Liverpool Elementary
MLW Developmental Evaluation Center (DEC) 215 Bassett Street Syracuse, NY 13210 (315) 472-4404	<ul style="list-style-type: none"> ▪ Evaluations ▪ Consultation 	<ul style="list-style-type: none"> ▪ ABA ▪ DIR/Floor time ▪ PECS ▪ Sensory Integration ▪ TEACCH 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapy ▪ Special Educator ▪ Speech Therapy ▪ Psychologist 	<ul style="list-style-type: none"> ▪ Home ▪ Community ▪ Facility-Individual
North Syracuse Early Education Program 205 South Main Street NorthSyracuse, NY 13212 (315) 452-3021 ☎ www.mainstreet25.com	<ul style="list-style-type: none"> ▪ SCIS Full-Day ▪ SCIS Half-Day ▪ SEIT ▪ Evaluations 	<ul style="list-style-type: none"> ▪ ABA ▪ DIR/Floor time ▪ PECS ▪ Sensory Integration ▪ TEACCH 	<ul style="list-style-type: none"> ▪ Occupational therapy ▪ Physical therapy ▪ Special Educator ▪ Speech therapy ▪ Psychologist ▪ Social Worker ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ Home ▪ Community ▪ Facility-Individual ▪ Facility-Group

Program	Services	Intervention Method	Service Providers	Locations
OCM BOCES Children's Village Park Hill Elementary School 303 Roby Avenue East Syracuse, NY 13057 (315) 437-0289 www.cnyfreshschoolcoalition.org/cv.htm	<ul style="list-style-type: none"> ▪ SCIS Half-Day ▪ Deaf and Hearing Impaired ▪ Evaluations 	<ul style="list-style-type: none"> ▪ DIR/Floor time ▪ PECS ▪ Sensory Integration ▪ TEACCH 	<ul style="list-style-type: none"> ▪ Occupational therapy ▪ Physical therapy ▪ Special Educator ▪ Speech Therapist ▪ Psychologist ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ Facility-Individual ▪ Facility-Group ▪ Park Hill Preschool
Onondaga Central Preschool 208 Rockwell Road Nedrow, NY 13120 (315) 469-6926	<ul style="list-style-type: none"> ▪ SCIS Half-Day ▪ Evaluations 		<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical Therapisy ▪ Special Educator ▪ Speech Therapist 	<ul style="list-style-type: none"> ▪ Rockwell Elementary
Parkside Children's Services 301 Valley Drive Syracuse, NY 13207 (315) 468-1632 www.arcon.org/childservices.cfm?method=view&id=12	<ul style="list-style-type: none"> ▪ SCIS Half-Day ▪ SEIT ▪ Evaluations ▪ Parent Groups 	<ul style="list-style-type: none"> ▪ Sensory Integration 	<ul style="list-style-type: none"> ▪ Occupational therapy ▪ Physical therapy ▪ Special Educator ▪ Speech therapy ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ Facility-Individual ▪ Facility-Group ▪ Merrick Head Start ▪ St. Brigids ▪ Sumner Child Care ▪ Child care settings
SPICE/ Elmcrest Children's Center 960 Salt Springs Road Syracuse, NY 13224 (315) 446-3220	<ul style="list-style-type: none"> ▪ Evaluations ▪ SCIS Full-Day ▪ SEIT ▪ Counseling ▪ Parent Groups 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ PECS ▪ Physical Therapy ▪ Play therapy ▪ Sensory Integration ▪ Social Work ▪ Speech/Language Therapy ▪ Combination of various other methods ▪ ABA 	<ul style="list-style-type: none"> ▪ Occupational Therapist ▪ Physical Therapist ▪ Special Educator ▪ Speech/Language Therapy ▪ Psychologist ▪ Social Worker ▪ Play Therapist ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ Home ▪ Community ▪ Facility-Individual ▪ Facility-Group ▪ Small Wonders Day Care

<i>Program</i>	<i>Services</i>	<i>Intervention Method</i>	<i>Service Providers</i>	<i>Locations</i>
Syracuse City School District Early Childhood Program 220 West Kennedy Street Syracuse, NY 13205 (315) 435-4267 📞	<ul style="list-style-type: none"> ▪ Itinerant ▪ Related Services ▪ SCIS Half-Day ▪ SEIT ▪ Evaluations ▪ Parent Groups 	<ul style="list-style-type: none"> ▪ Behavioral Teaching Techniques ▪ Wilbarger Brushing Program ▪ DIR/Floor time ▪ LEAP ▪ Oral motor, feeding ▪ Sensory Integration ▪ TEACCH 	<ul style="list-style-type: none"> ▪ Occupational Therapy ▪ Physical therapy ▪ Special Educator ▪ Speech Therapy ▪ Psychologist ▪ Para-Professional 	<ul style="list-style-type: none"> ▪ All Syracuse City School Pre-K programs ▪ Merrick Head Start ▪ St. Brigid's, Calvary & Sumner Head Start ▪ Early Childhood Centers citywide, nursery schools & childcare centers
Transitional Living Services (TLS) 420 East Genesee Street Syracuse, NY 13202 (315) 478-4151 www.tls-onondaga.org	<ul style="list-style-type: none"> ▪ Financial Assistance ▪ Recreation Support ▪ Referrals ▪ Service Coordination ▪ Support Services 		<ul style="list-style-type: none"> ▪ Service Coordinator 	<ul style="list-style-type: none"> ▪ Community ▪ Facility

Out of County Resources

Program	Services	Intervention Method	Service Providers	Locations
Gavras Center 182 North Street Auburn, NY 13021 (315) 255-2746	<ul style="list-style-type: none"> ▪ SEIT ▪ Supplemental Evaluations ▪ Other 	Other	Other	<ul style="list-style-type: none"> ▪ Home ▪ Community ▪ Facility-Individual ▪ Facility-Group
Franziska Racker Center 882 Route 13 Cortland, NY 13045 (607) 753-9375	<ul style="list-style-type: none"> ▪ Evaluations ▪ Other 	Other	<ul style="list-style-type: none"> ▪ Occupational Therapist ▪ Physical Therapist ▪ Social Worker ▪ Special Educator ▪ Speech Therapist 	<ul style="list-style-type: none"> ▪ Community ▪ Facility-Individual ▪ Facility-Group ▪ Head Start
Little Lukes-Oswego 10 Burkle Street Oswego, NY 13126 (315) 342-4600	<ul style="list-style-type: none"> ▪ Service coordination ▪ Evaluations ▪ Early Intervention Home and community ▪ SCIS Full-Day ▪ SCIS Half-Day ▪ Preschool related services 	<ul style="list-style-type: none"> ▪ ABA ▪ DIR/Floor time ▪ PECS ▪ Sensory Integration ▪ Combination of approaches tailored to child/family needs 	<ul style="list-style-type: none"> ▪ Occupational Therapist ▪ Physical Therapist ▪ Special Educator ▪ Speech Therapist ▪ Psychologist 	<ul style="list-style-type: none"> ▪ On-site ▪ Child care settings ▪ Home/community
Strong Memorial Autism Spectrum Disorders Program Strong Center for Developmental Disabilities Golisano Children's Hospital at Strong 601 Elmwood Avenue, Box 671 Rochester, NY 14642	<ul style="list-style-type: none"> ▪ Evaluations 	<ul style="list-style-type: none"> ▪ ABA ▪ Educational Consultations ▪ Functional Behavior Assessment ▪ Inclusion Consultations 	<ul style="list-style-type: none"> ▪ Other 	<ul style="list-style-type: none"> ▪ Home ▪ Community ▪ Facility-Individual

Resources for Diagnosis, Evaluations, and Other Medical Services

The following resources can be utilized for diagnoses of autism spectrum disorders. While services are available for various developmental disabilities, each center provides services specifically addressing autism.

Center for Neurodevelopmental Pediatrics

550 Harrison Street
Suite 100-Pediatrics
Syracuse, NY 13210
Phone: 1-866-543-KIDS
*All ages

Enable

1603 Court Street
Syracuse, NY 13208
Phone: (315) 475-1382
*6 months- 12 years

MLW Developmental Evaluation Center

215 Bassett Street
Suite 113
Syracuse, NY 13210
Phone: (315) 472-4404
E-mail: grantc@upstate.edu
*18 months-6 years

Autism Spectrum Disorders Program

Strong Center for Developmental Disabilities
Golisano Children's Hospital at Strong
601 Elmwood Avenue, Box 671
Rochester, NY 14642
Phone: (315) 275-6605
*All ages

Questions for Families to Ask Providers

When considering service providers, here are several questions to keep in mind. These questions will provide pertinent information to contemplate when choosing the best service and provider for your child. These questions were adopted from the Clinical Practice Guideline: The Technical Report.

- What kinds of interventions, therapies, and services do you provide?
- Do you have a particular philosophy on working with children with autism/PDD?
- Please describe a typical day or session.
- What experience do the teachers and/or therapists have in working with children with autism?
- What experience does the person who supervises the program have?
- How closely does the program supervisor work with the therapists, teachers, and parents?
- What kinds of ongoing training do your full- and part-time staffs participate in?
- Are parents involved with planning as part of the intervention team?
- Do you provide a parent training program?
- How much and what kinds of involvement are expected of parents and family members?
- Are parents welcome to participate in or observe therapy and/or group sessions?
- What techniques do you use to manage difficult behaviors?
- Do you ever use physical aversives or any physically intrusive procedures? If yes, please describe them.
- Please describe your program strategies for communication and language development.
- Are there opportunities for inclusion with typical children?
- How do you evaluate the child's progress, and how often?
- How do you keep parents informed of the child's progress?

Support Groups and Additional Resources

ARC of Onondaga

600 South Wilbur Avenue
Syracuse, NY 13204
Phone: (315) 476-7441
Website: www.arcon.org

NYS ABA

119 Washington Avenue
Albany, NY 12210
Phone: (518) 694-4288
<http://www.nysaba.org>

FEAT of CNY (Families for Effective Autism Treatment)

Bobbi Rogers – Phone: (315) 638-4058
51 Carousel Lane
Baldwinsville, NY 13027
Website: www.featofcny.org

Parent to Parent Network

Dru Nordmark, Parent to Parent Coordinator
Exceptional Family Resources
1065 James Street
Syracuse, NY 13203
Phone: (315) 478-1462 ext. 322
Phone: 1-800-305-8815

Autism Society of America (ASA)

7910 Woodmont Avenue
Bethesda, MD 20814
Phone: 1-800-3AUTISM
Website: <http://www.autism-society.org/>

Local Chapter:

CNYASA
4465 East Genesee Street
PMB 252
DeWitt, NY 13214-2242
Phone: (315) 447-4466
E-mail: cnyasa@yahoo.com
Website: <http://www.cnyasa.org>

New York Autism Network (NYAN)

Regional Offices

- New York City and Hudson Valley Regional Center
Phone: (914) 493-NYAN
- Long Island Regional Center
Phone: (516) 366-2960
- Western New York Regional Center
Phone: (716) 275-6605
- Eastern New York Regional Center
Phone: (518) 442-5132

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

Current Information and Resources on Autism

References

Clinical Practice Guidelines: Report of the Recommendations: Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years) (1999) New York State Department of Health Early Intervention Program. www.health.ny.us

Clinical Practice Guidelines: Quick Reference Guide: Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years) (1999) New York State Department of Health Early Intervention Program. www.health.ny.us

Clinical Practice Guidelines: The Guideline Technical Report: Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years) (1999) New York State Department of Health Early Intervention Program. www.health.ny.us

To order, contact the Bureau of Special Children Services at (315) 435-3230, or:

Publications
New York State Department of Health
P.O. Box 2000
Albany, New York 12220

Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment, California Department of Developmental Services, 2002. www.ddhealthinfo.org/pdf/ASD_Best_Practice.pdf

Websites

- Asperger Syndrome Coalition of the U.S. www.asperger.org/index_asc
- Asperger Syndrome Education Network (ASPEN) www.aspennj.org
- Autism Society of America www.autism-society.org/site/PagerServer
- Centers for Disease Control and Prevention—Autism Information Center www.cdc.gov/ncbddd/dd/aic/about/default
- Families for Early Autism Treatment (FEAT) www.featofcny.org
- National Institute of Child Health and Human Development www.nichd.nih.gov
- National Alliance for Autism Research www.naar.org
- Center for Autism and Related Disabilities (CARD) <http://www.albany.edu/psy/autism/autism>
- The Cure Autism Now Foundation www.cureautismnow.org
- Autism Resources www.autism-info.com
- Autism Biomedical Information Network www.autism-biomed.org

Additional Websites

- www.autism-society.org
- www.autismspeaks.org
- www.autismwebsite.com
- www.cureautismnow.org
- www.floortime.org
- www.nysaba.com
- www.cnycoalition.org
- www.contractefr.org
- www.familycapped.com
- www.familyvillage.wisc.edu/
- www.devdelay.org

Suggested Reading

General information

- [A Parent's Guide to Autism](#), Charles Hart , Future Horizons Press
- [The Child with Special Needs](#), Stanley I. Greenspan, Perseus books
- [Children with Autism a Parents Guide](#), Michael Powers, Woodbine House
- [Aspergers Syndrome: A Guide for Educators and Parents](#), Brenda Smith Myles and Richard.L. Simpson, Autism Asperger's Press
- [Siblings of Children with Autism: A Guide for Families](#), Sandra Harris, Woodbine House

Parent and Personal Perspective

- [A Thorn in My Pocket](#), Eustacia Cutler, Future Horizons
- [Let Me Hear Your Voice](#), Catherine Maurice, Pro-Ed
- [The Boy Who Loved Windows](#), Pat Stacey, DaCapo Press
- [There's a Boy in Here: Emerging from the Bonds of Autism](#), Judy and Sean Barron,
- [Thinking in Pictures](#), Temple Grandin, Doubleday Press

Treatment Strategies

- [Building Bridges Through Sensory Integration](#), Yack, Sutton and Aquilla, Sensory Resources
- [Sensational Kids: Hope and Help for the Sensory Processing Disorder](#), Lucy Jane Miller, Putman Press
- [Comic Book Conversations](#), Carol Gray, Future Horizons Press
- [For Parents by Parents: A Resource Guide](#), Published by the ICDL, Bethesda MD
- [Social Stories](#), Carol Gray, Future Horizons Press
- [Visual Strategies for Improving Communication](#), Linda Hodgdon, Quirk Roberts Press
- [Solving Behavior Problems in Autism](#), Linda Hodgdon, Quirk Roberts Press
- [Aspergers . . . What does it mean to Me](#), Catherine Faherty, Future Horizons Press
- [Visual Support: Work in the Home and Community: Strategies for Individuals with Autism and Asperger Syndrome](#), Jennifer Savner and Brenda Smith Myles, Autism Aspergers Press

- Asperger's Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns, Brenda Smith Myles and Jack Southwick, Autism Aspergers Press
- Activity Schedules for Children with Autism: Teaching Independent Behavior, Lynn Mc Clannahan and Patricia Krantz, Woodbine House
- Right From the Start: Behavior Intervention for Young Children with Autism: A Guide for Parents and Professionals, Harris and Weiss, Woodbine House
- Teaching Children with Autism, Kathleen Quill, Delmar Publishers
- A Treasure Chest of Behavioral Strategies for Individuals with Autism, B. Fouse and M. Wheeler , Future Horizons
- Learning Language and Loving it: A Guide to Promoting Children's Social, Language, an Literacy Development in Early Childhood Settings, The Hanen Program
- Engaging Autism: Helping Children Relate, Communicate and Think with the DIR Floortime Approach, Stanley I. Greenspan, DaCapo Lifelong Books

School-Age Resources

- Creating a Win-Win IEP for Students with Autism, Beth Fouse, Future Horizons
- You're Going to Love This Kid, Paula Kluth , Future Horizons
- Navigating the Social World, Jeanette McAfee, Future Horizons
- How to Be a Para Pro: A Comprehensive Manual for Paraprofessionals, Diane Twachtman-Cullen, Starfish Press

Definitions and Acronyms

(commonly encountered related to children with ASD)

- **ABA:** Applied Behavioral Analysis, a structured approach that involves discrete trial training: skills, or lessons, are broken down into small, measurable tasks.
- **ADA:** Americans with Disabilities Act of 1990
- **ADD:** Attention Deficit Disorder
- **ADHD:** Attention Deficit Hyperactivity Disorder
- **AIT:** Auditory Integration Training
- **APE:** Adapted Physical Education, provides instruction to meet individual student needs in the development of motor skills, physical fitness and self-image
- **ASA:** Autism Society of America
- **ASD:** Autistic Spectrum Disorder
- **Adaptive Development:** Development of the child in comparison to other children the same age. This might include the child's ability to dress self, feed self, toilet train, play with other children, understand dangers in crossing the street, behavior, etc.
- **Advocate:** someone who takes action to help another
- **CA:** Chronological Age
- **CARS:** Childhood Autism Rating Scale (diagnostic tool)
- **CGI:** Clinical Global Improvement (rating scale)
- **CHAT:** Checklist for Autism in Toddlers (diagnostic tool)
- **Cognitive development:** A term that describes the mental process people use for remembering, reasoning, understanding and using judgment
- **DD:** Developmental Disability
- **DOH:** Department of Health
- **DSM IV:** Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition (American Psychiatric Association)
- **Due Process:** Legal principles and practices to ensure that each child is guaranteed his/her rights to equal education opportunities

- **ED:** Emotional Disorder
- **EI:** Early Intervention services or program services designed to identify and treat a developmental problem as early as possible, usually before the age of 3
- **FAPE:** Free Appropriate Public Education; one of the key requirements of IDEA requires that an educational program be provided for all school aged children without cost to their family (regardless of their disability)
- **FC:** Facilitated Communication
- **FERPA:** Family Education Rights and Privacy Act: Governs the privacy of a student's school records
- **Fine motor development:** In physical development, the use of the small muscles of the body, especially the hands and fingers
- **Fragile X:** a genetic condition of the X chromosome affecting cognitive, physical and sensory development
- **Floor Time:** A method for actively engaging children and families in a process that fosters social-emotional and cognitive development, using a child's natural motivations and emotions to fuel development and relationships, using motor and sensory play, symbolic play and language
- **Gross motor development:** In physical development, the use of the large muscles of the body for activities such as running, climbing, throwing and jumping
- **IEP:** Individualized Education Program; the IEP outlines your child's unique education plan by defining broad goals and specific objectives for the school year, the services needed to implement those goals and objectives and a method of evaluating your child's progress.
- **IFSP:** Individualized Family Service Plan; is a written plan for providing early intervention services to eligible children and their families. It must include a statement of the infant or toddler's present levels of development. The IFSP must include a statement of the specific early intervention services necessary to meet the unique needs of the child and family to achieve identified goals.
- **IQ:** Intelligence quotient
- **Inclusion:** The placement of students with disabilities in classrooms with typically developing students of the same age.
- **LD:** Learning Disability
- **Least Restrictive Environment (LRE)** – placement or program which can best meet the individual student's needs and which does so with a minimum loss of contact with regular education programs.
- **MH:** Mental Health

- **MR:** Mental Retardation
- **Mainstreaming:** Placement of a child with a disability in a classroom with non-disabled peers
Multidisciplinary: a team approach involving specialists from more than one discipline, such as speech therapist, physical therapist, child development specialist and others as needed
- **OCD:** Obsessive Compulsive Disorder
- **OT:** Occupational Therapy
- **Occupational Therapy:** a therapy or treatment provided by an occupational therapist that helps individual development or physical skills that will aid in daily living. It focuses on sensory integration, coordination of movement, fine-motor and self-help skills.
- **PDD:** Pervasive Developmental Disorder
- **PDD-NOS:** Pervasive Developmental Disorder-Not Otherwise Specified
- **PECS:** Picture Exchange Communication System
- **PT:** Physical Therapy
- **Part B:** Part B of IDEA, addresses special education services, ages three (3) through twenty-one (21)
- **Part C:** Part C is infant/toddler part of IDEA and addresses the priorities and concerns of families of children from birth to age three.
- **P.L. 99-457:** Public Law 99-457; an amendment to P.L. 94-142 (Education for All Handicapped Children Act of 1975) passed in 1986, which requires states to provide a “free and appropriate public education” to all children ages 3-5 and provides funds for states to offer programs and services to infants and children (ages birth through 2 yrs.) with disabilities.
- **Receptive Language:** language that is spoken or written by others and received by the individual. The receptive language skills are listening and reading.
- **Related Services:** transportation and developmental, corrective and other support services that a child with a disability needs to benefit from education. Examples include speech/language therapy, psychological services, physical and occupational therapy, counseling services, recreation, interpreters, medical services, and assistive technology
- **Respite:** Temporary relief from caregiving responsibilities, intended to provide support to families or other caregivers who may otherwise be overwhelmed by the intensity and constancy of caregiving responsibilities that may be necessary for a child with special needs.
- **Reverse Mainstreaming:** non-handicapped children are placed in classes which are primarily for children with disabilities

- **SD:** Standard Deviation
- **SI:** Can be used to refer to Speech Impairment, Sensory Integration, Special Instruction
- **SLP:** Speech Language Pathologist
- **SSI:** Social Security Income
- **Sensory Integration:** term applied to the combination of the input of sensation and the output of motor activity.
- **Service Coordinator:** someone who acts as a coordinator of a child's services, working in partnership with the family and providers of special programs
- **Social Stories** – are personalized, short stories developed and written by teachers, therapists or family members. Social stories utilize the strength as a visual learner that many persons with autism exhibit. Social stories demonstrate strategies with which to practice and approach the complex social skills development.
- **Speech/Language Therapy:** a planned program to improve and/or correct communication problems
- **Stimming:** The informal term for self-stimulation
- **TEACCH:** Treatment and Education of Autistic and Communication-Handicapped Children.