

# AUTISM

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**Disclaimer:** While many people have reviewed this packet for accuracy, policies, procedures and information such as websites, agency names, mailing addresses and phone numbers can change at any time. It is always a good idea to request copies of current policies and rules from the agencies with whom you are working.

### Additional Packets Available

Additional disability information packets and guides are available. Many are also available in Spanish and Chinese.

They include:

- ADHD
- Behavior
- Cerebral Palsy
- Down syndrome
- Learning Disabilities
- Mental Health
- Medical Home
- Transition from Early Intervention to Preschool

To request another packet or for more information please contact:

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# Section 1: Fact Sheets and Diagnosis

*General Information*





The National Institute of Mental Health: <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>

# Autism Spectrum Disorder

## What Is Autism Spectrum Disorder?

Autism spectrum disorder (ASD) is characterized by:

- Persistent deficits in social communication and social interaction across multiple contexts; Restricted, repetitive patterns of behavior, interests, or activities;
- Symptoms must be present in the early developmental period (typically recognized in the first two years of life); and,
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

The term “spectrum” refers to the wide range of symptoms, skills, and levels of impairment or disability that children with ASD can have. Some children are mildly impaired by their symptoms, while others are severely disabled. The latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) no longer includes Asperger’s syndrome; the characteristics of Asperger’s syndrome are included within the broader category of ASD.

Information on ASD can also be found on the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development [website](#) and the Centers for Disease Control and Prevention [website](#).

## Causes

Scientists don't know the exact causes of autism spectrum disorder (ASD), but research suggests that both genes and environment play important roles.

### Genetic factors

In identical twins who share the exact same genetic code, if one has ASD, the other twin also has ASD in nearly 9 out of 10 cases. If one sibling has ASD, the other siblings have 35 times the normal risk of also developing the disorder. Researchers are starting to identify particular genes that may increase the risk for ASD.

Still, scientists have only had some success in finding exactly which genes are involved. For more information about such cases, see the information below about Fragile X syndrome and tuberous sclerosis.

Most people who develop ASD have no reported family history of autism, suggesting that random, rare, and possibly many gene mutations are likely to affect a person's risk. Any change to normal genetic information is called a mutation. Mutations can be inherited, but some arise for no reason. Mutations can be helpful, harmful, or have no effect.

Having increased genetic risk does not mean a child will definitely develop ASD. Many researchers are focusing on how various genes interact with each other and environmental factors to better understand how they increase the risk of this disorder.

### Environmental factors

In medicine, "environment" refers to anything outside of the body that can affect health. This includes the air we breathe, the water we drink and bathe in, the food we eat, the medicines we take, and many other things that our bodies may come in contact with. Environment also includes our surroundings in the womb, when our mother's health directly affects our growth and earliest development.

Researchers are studying many environmental factors such as family medical conditions, parental age and other demographic factors, exposure to toxins, and complications during birth or pregnancy.

As with genes, it's likely that more than one environmental factor is involved in increasing risk for ASD. And, like genes, any one of these risk factors raises the risk by only a small amount. Most people who have been exposed to environmental risk factors do not develop ASD. The National Institute of Environmental Health Sciences is also conducting research in this area. More information is available on their [website](#).

Scientists are studying how certain environmental factors may affect certain genes—turning them on or off, or increasing or decreasing their normal activity. This process is called epigenetics and is providing researchers with many new ways to study how disorders like ASD develop and possibly change over time.

### **ASD and vaccines**

Health experts recommend that children receive a number of vaccines early in life to protect against dangerous, infectious diseases, such as measles. Since pediatricians in the United States started giving these vaccines during regular checkups, the number of children getting sick, becoming disabled, or dying from these diseases has dropped to almost zero.

Children in the United States receive several vaccines during their first 2 years of life, around the same age that ASD symptoms often appear or become noticeable. A minority of parents suspect that vaccines are somehow related to their child's disorder. Some may be concerned about these vaccines due to the unproven theory that ASD may be caused by thimerosal. Thimerosal is a mercury-based chemical once added to some, but not all, vaccines to help extend their shelf life. However, except for some flu vaccines, no vaccine routinely given to preschool aged children in the United States has contained thimerosal since 2001. Despite this change, the rate of children diagnosed with ASD has continued to rise.

Other parents believe their child's illness might be linked to vaccines designed to protect against more than one disease, such as the measles-mumps-rubella (MMR) vaccine, which never contained thimerosal.

Many studies have been conducted to try to determine if vaccines are a possible cause of autism. As of 2010, none of the studies has linked autism and vaccines.

Following extensive hearings, a special court of Federal judges ruled against several test cases that tried to prove that vaccines containing thimerosal, either by themselves or combined with the MMR vaccine, caused autism. More information about these hearings is available on the U.S. Court of Federal Claims' [website](#).

The latest information about research on autism and vaccines is available from the [Centers for Disease Control and Prevention](#). This website provides information from the Federal Government and independent organizations.

## **Early Signs & Symptoms**

Symptoms of autism spectrum disorder (ASD) vary from one child to the next, but in general, they fall into two areas:

- Social impairment, including difficulties with social communication
- Repetitive and stereotyped behaviors.

Children with ASD do not follow typical patterns when developing social and communication skills. Parents are usually the first to notice unusual behaviors in their child. Often, certain behaviors become more noticeable when comparing children of the same age.

In some cases, babies with ASD may seem different very early in their development. Even before their first birthday, some babies become overly focused on certain objects, rarely make eye contact, and fail to engage in typical back-and-forth play and babbling with their parents. Other children may develop normally until the second or even third year of life, but then start to lose interest in others and become silent, withdrawn, or indifferent to social signals. Loss or reversal of normal development is called regression and occurs in some



children with ASD.

## Social impairment

Most children with ASD have trouble engaging in everyday social interactions. For example, some children with ASD may:

- Make little eye contact
- Tend to look and listen less to people in their environment or fail to respond to other people
- Rarely seek to share their enjoyment of toys or activities by pointing or showing things to others
- Respond unusually when others show anger, distress, or affection.

Recent research suggests that children with ASD do not respond to emotional cues in human social interactions because they may not pay attention to the social cues that others typically notice. For example, one study found that children with ASD focus on the mouth of the person speaking to them instead of on the eyes, which is where children with typical development tend to focus. A related study showed that children with ASD appear to be drawn to repetitive movements linked to a sound, such as hand-clapping during a game of pat-a-cake. More research is needed to confirm these findings, but such studies suggest that children with ASD may misread or not notice subtle social cues—a smile, a wink, or a grimace—that could help them understand social relationships and interactions. For these children, a question such as, "Can you wait a minute?" always means the same thing, whether the speaker is joking, asking a real question, or issuing a firm request. Without the ability to interpret another person's tone of voice as well as gestures, facial expressions, and other nonverbal communications, children with ASD may not properly respond.

Likewise, it can be hard for others to understand the body language of children with ASD. Their facial expressions, movements, and gestures are often vague or do not match what they are saying. Their tone of voice may not reflect their actual feelings either. Many older children with ASD speak with an unusual tone of voice and may sound sing-song or flat and robotlike.

Children with ASD also may have trouble understanding another person's point of view. For example, by school age, most children understand that other people have different information, feelings, and goals than they have. Children with ASD may lack this understanding, leaving them unable to predict or understand other people's actions.

## Communication issues

According to the American Academy of Pediatrics' developmental milestones, by the first birthday, typical toddlers can say one or two words, turn when they hear their name, and point when they want a toy. When offered something they do not want, toddlers make it clear with words, gestures, or facial expressions that the answer is "no."

For children with ASD, reaching such milestones may not be so straightforward. For example, some children with autism may:

- Fail or be slow to respond to their name or other verbal attempts to gain their attention
- Fail or be slow to develop gestures, such as pointing and showing things to others
- Coo and babble in the first year of life, but then stop doing so
- Develop language at a delayed pace
- Learn to communicate using pictures or their own sign language
- Speak only in single words or repeat certain phrases over and over, seeming unable to combine words into meaningful sentences
- Repeat words or phrases that they hear, a condition called echolalia
- Use words that seem odd, out of place, or have a special meaning known only to those familiar with the child's way of communicating.

Even children with ASD who have relatively good language skills often have difficulties with the back and forth of conversations. For example, because they find it difficult to understand and react to social cues, some highly verbal children with ASD often talk at length about a favorite subject, but they won't allow anyone else a chance to respond or notice when others react indifferently.

Children with ASD who have not yet developed meaningful gestures or language may simply scream or grab or otherwise act out until they are taught better ways to express their needs. As these children grow up, they can become aware of their difficulty in understanding others and in being understood. This awareness may cause them to become anxious or depressed.

### **Repetitive and stereotyped behaviors**

Children with ASD often have repetitive motions or unusual behaviors. These behaviors may be extreme and very noticeable, or they can be mild and discreet. For example, some children may repeatedly flap their arms or walk in specific patterns, while others may subtly move their fingers by their eyes in what looks to be a gesture. These repetitive actions are sometimes called "stereotypy" or "stereotyped behaviors."

Children with ASD also tend to have overly focused interests. Children with ASD may become fascinated with moving objects or parts of objects, like the wheels on a moving car. They might spend a long time lining up toys in a certain way, rather than playing with them. They may also become very upset if someone accidentally moves one of the toys. Repetitive behavior can also take the form of a persistent, intense preoccupation. For example, they might be obsessed with learning all about vacuum cleaners, train schedules, or lighthouses. Children with ASD often have great interest in numbers, symbols, or science topics.

While children with ASD often do best with routine in their daily activities and surroundings, inflexibility may often be extreme and cause serious difficulties. They may insist on eating the same exact meals every day or taking the same exact route to school. A slight change in a specific routine can be extremely upsetting. Some children may even have emotional outbursts, especially when feeling angry or frustrated or when placed in a new or stimulating environment.

No two children express exactly the same types and severity of symptoms. In fact, many typically developing children occasionally display some of the behaviors common to children with ASD. However, if you notice your child has several ASD-related symptoms, have your child screened and evaluated by a health professional experienced with ASD.

## **Who Is At Risk?**

Studies measuring autism spectrum disorder (ASD) prevalence—the number of children affected by ASD over a given time period—have reported varying results, depending on when and where the studies were conducted and how the studies defined ASD.

A survey by the Centers for Disease Control and Prevention (CDC) of health and school records of 8-year-olds in 11 communities throughout the country found that in 2010, the rate of ASD was higher than in past U.S. studies, around 1 in 68 children. Boys face about four to five times higher risk than girls.

Experts disagree about whether this shows a true increase in ASD prevalence. Since the earlier studies were completed, guidelines for diagnosis have changed. Also, many more parents and doctors now know about ASD, so parents are more likely to take their children to be diagnosed, and more doctors are able to properly diagnose ASD. These and other changes may help explain some differences in prevalence numbers. Even so, the CDC report confirms other recent studies showing that more children are being diagnosed with ASD than ever before. For more information, please visit the autism section of the CDC website.

## **Diagnosis**

Autism spectrum disorder (ASD) diagnosis is often a two-stage process. The first stage involves general developmental screening during well-child checkups with a pediatrician or an early childhood health care provider. Children who show some developmental problems are referred for additional evaluation. The second stage involves a thorough evaluation by a team of doctors and other health professionals with a wide range of specialties. At this stage, a child may be diagnosed as having ASD or another developmental disorder.

Children with ASD can usually be reliably diagnosed by age 2, though research suggests that some screening tests can be helpful at 18 months or even younger. Many people—including pediatricians, family doctors, teachers, and parents—may minimize signs of ASD at first, believing that children will "catch up" with their peers. While you may be concerned about labeling your young child with ASD, the earlier the disorder is diagnosed, the sooner specific interventions may begin. Early intervention can reduce or prevent the more severe disabilities associated with ASD. Early intervention may also improve your child's IQ, language, and everyday functional skills, also called adaptive behavior.

## Screening

A well-child checkup should include a developmental screening test, with specific ASD screening at 18 and 24 months as recommended by the American Academy of Pediatrics. Screening for ASD is not the same as diagnosing ASD. Screening instruments are used as a first step to tell the doctor whether a child needs more testing. If your child's pediatrician does not routinely screen your child for ASD, ask that it be done.

For parents, your own experiences and concerns about your child's development will be very important in the screening process. Keep your own notes about your child's development and look through family videos, photos, and baby albums to help you remember when you first noticed each behavior and when your child reached certain developmental milestones.

## Types of ASD screening instruments

Sometimes the doctor will ask parents questions about the child's symptoms to screen for ASD. Other screening instruments combine information from parents with the doctor's own observations of the child. Examples of screening instruments for toddlers and preschoolers include:

- Checklist of Autism in Toddlers (CHAT)
- Modified Checklist for Autism in Toddlers (M-CHAT)
- Screening Tool for Autism in Two-Year-Olds (STAT) Social Communication Questionnaire (SCQ)
- Communication and Symbolic Behavior Scales (CSBS).

To screen for mild ASD in older children, the doctor may rely on different screening instruments, such as:

- Autism Spectrum Screening Questionnaire (ASSQ)
- Australian Scale for Asperger's Syndrome (ASAS)
- Childhood Asperger Syndrome Test (CAST).

Some helpful resources on ASD screening include the Center for Disease Control and Prevention's General Developmental Screening tools and ASD Specific Screening tools on their [website](#).

## Comprehensive diagnostic evaluation

The second stage of diagnosis must be thorough in order to find whether other conditions may be causing your child's symptoms.

A team that includes a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals experienced in diagnosing ASD may do this evaluation. The evaluation may assess the child's cognitive level (thinking skills), language level, and adaptive behavior (age appropriate skills needed to complete daily activities independently, for example eating, dressing, and toileting).

Because ASD is a complex disorder that sometimes occurs along with other illnesses or learning disorders, the comprehensive evaluation may include brain imaging and gene tests, along with in-depth memory, problem-solving, and language testing. Children with any delayed development should also get a hearing test as part of the comprehensive evaluation.

Although children can lose their hearing along with developing ASD, common ASD symptoms (such as not turning to face a person calling their name) can also make it seem that children cannot hear when in fact they can. If a child is not responding to speech, especially to his or her name, it's important for the doctor to test

whether a child has hearing loss.

The evaluation process is a good time for parents and caregivers to ask questions and get advice from the whole evaluation team. The outcome of the evaluation will help plan for treatment and interventions to help your child. Be sure to ask who you can contact with follow-up questions.

### ***What are some other conditions that children with ASD may have?***

#### **Sensory problems**

Children with autism spectrum disorder (ASD) either overreact or underreact to certain sights, sounds, smells, textures, and tastes. For example, some may:

- Dislike or show discomfort from a light touch or the feel of clothes on their skin
- Experience pain from certain sounds, like a vacuum cleaner, a ringing telephone, or a sudden storm; sometimes they will cover their ears and scream
- Have no reaction to intense cold or pain.

Researchers are trying to determine if these unusual reactions are related to differences in integrating multiple types of information from the senses.

#### **Sleep problems**

Children with ASD tend to have problems falling asleep or staying asleep, or have other sleep problems. These problems make it harder for them to pay attention, reduce their ability to function, and lead to poor behavior. In addition, parents of children with ASD and sleep problems tend to report greater family stress and poorer overall health among themselves.

Fortunately, sleep problems can often be treated with changes in behavior, such as following a sleep schedule or creating a bedtime routine. Some children may sleep better using medications such as melatonin, which is a hormone that helps regulate the body's sleep-wake cycle. Like any medication, melatonin can have unwanted side effects. Talk to your child's doctor about possible risks and benefits before giving your child melatonin. Treating sleep problems in children with ASD may improve the child's overall behavior and functioning, as well as relieve family stress.

#### **Intellectual disability**

Many children with ASD have some degree of intellectual disability. When tested, some areas of ability may be normal, while others—especially cognitive (thinking) and language abilities—may be relatively weak. For example, a child with ASD may do well on tasks related to sight (such as putting a puzzle together) but may not do as well on language-based problem-solving tasks. Some children with ASD (such as those formerly diagnosed with Asperger's syndrome) often have average or above-average language skills and do not show delays in cognitive ability or speech.

#### **Seizures**

One in four children with ASD has seizures, often starting either in early childhood or during the teen years. Seizures, caused by abnormal electrical activity in the brain, can result in

- A short-term loss of consciousness, or a blackout
- Convulsions, which are uncontrollable shaking of the whole body, or unusual movements
- Staring spells.

Sometimes lack of sleep or a high fever can trigger a seizure. An electroencephalogram (EEG), a nonsurgical test that records electrical activity in the brain, can help confirm whether a child is having seizures. However, some children with ASD have abnormal EEGs even if they are not having seizures.

Seizures can be treated with medicines called anticonvulsants. Some seizure medicines affect behavior; changes in behavior should be closely watched in children with ASD. In most cases, a doctor will use the

lowest dose of medicine that works for the child. Anticonvulsants usually reduce the number of seizures but may not prevent all of them.

For more information about medications, see the [NIMH online booklet](#), "Mental Health Medications". None of these medications have been approved by the FDA to specifically treat symptoms of ASD.

### **Fragile X syndrome**

Fragile X syndrome is a genetic disorder and is the most common form of inherited intellectual disability, causing symptoms similar to ASD. The name refers to one part of the X chromosome that has a defective piece that appears pinched and fragile when viewed with a microscope. Fragile X syndrome results from a change, called a mutation, on a single gene. This mutation, in effect, turns off the gene. Some people may have only a small mutation and not show any symptoms, while others have a larger mutation and more severe symptoms.

Around 1 in 3 children who have Fragile X syndrome also meet the diagnostic criteria for ASD, and about 1 in 25 children diagnosed with ASD have the mutation that causes Fragile X syndrome. Because this disorder is inherited, children with ASD should be checked for Fragile X, especially if the parents want to have more children. Other family members who are planning to have children may also want to be checked for Fragile X syndrome. For more information on Fragile X, see the Eunice Kennedy Shriver National Institute of Child Health and Human Development [website](#).

### **Tuberous sclerosis**

Tuberous sclerosis is a rare genetic disorder that causes noncancerous tumors to grow in the brain and other vital organs. Tuberous sclerosis occurs in 1 to 4 percent of people with ASD. A genetic mutation causes the disorder, which has also been linked to intellectual disability, epilepsy, and many other physical and mental health problems. There is no cure for tuberous sclerosis, but many symptoms can be treated.

### **Gastrointestinal problems**

Some parents of children with ASD report that their child has frequent gastrointestinal (GI) or digestion problems, including stomach pain, diarrhea, constipation, acid reflux, vomiting, or bloating. Food allergies may also cause problems for children with ASD. It's unclear whether children with ASD are more likely to have GI problems than typically developing children. If your child has GI problems, a doctor who specializes in GI problems, called a gastroenterologist, can help find the cause and suggest appropriate treatment.

Some studies have reported that children with ASD seem to have more GI symptoms, but these findings may not apply to all children with ASD. For example, a recent study found that children with ASD in Minnesota were more likely to have physical and behavioral difficulties related to diet (for example, lactose intolerance or insisting on certain foods), as well as constipation, than children without ASD. The researchers suggested that children with ASD may not have underlying GI problems, but that their behavior may create GI symptoms—for example, a child who insists on eating only certain foods may not get enough fiber or fluids in his or her diet, which leads to constipation.

Some parents may try to put their child on a special diet to control ASD or GI symptoms. While some children may benefit from limiting certain foods, there is no strong evidence that these special diets reduce ASD symptoms. If you want to try a special diet, first talk with a doctor or a nutrition expert to make sure your child's nutritional needs are being met.

### **Co-occurring mental disorders**

Children with ASD can also develop mental disorders such as anxiety disorders, attention deficit hyperactivity disorder (ADHD), or depression. Research shows that people with ASD are at higher risk for some mental disorders than people without ASD. Managing these co-occurring conditions with medications or behavioral therapy, which teaches children how to control their behavior, can reduce symptoms that appear to worsen a child's ASD symptoms. Controlling these conditions will allow children with ASD to focus more on managing the ASD.

## Related Disorders

Rett syndrome is another developmental disorder which includes a regression in development. Only 1 of every 10,000 to 22,000 girls has Rett syndrome.

Unlike ASD, Rett syndrome mostly affects girls. In general, children with Rett syndrome develop normally for 6–18 months before regression and autism-like symptoms begin to appear. Children with Rett syndrome may also have difficulties with coordination, movement, and speech. Physical, occupational, and speech therapy can help, but no specific treatment for Rett syndrome is available yet.

With funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development, scientists have discovered that a mutation in the sequence of a single gene is linked to most cases of Rett syndrome. This discovery may help scientists find ways to slow or stop the progress of the disorder. It may also improve doctors' ability to diagnose and treat children with Rett syndrome earlier, improving their overall quality of life.

## Treatments

While there's no proven cure yet for autism spectrum disorder (ASD), treating ASD early, using school-based programs, and getting proper medical care can greatly reduce ASD symptoms and increase your child's ability to grow and learn new skills.

### Early intervention

Research has shown that intensive behavioral therapy during the toddler or preschool years can significantly improve cognitive and language skills in young children with ASD. There is no single best treatment for all children with ASD, but the American Academy of Pediatrics recently noted common features of effective early intervention programs. These include:

- Starting as soon as a child has been diagnosed with ASD
- Providing focused and challenging learning activities at the proper developmental level for the child for at least 25 hours per week and 12 months per year
- Having small classes to allow each child to have one-on-one time with the therapist or teacher and small group learning activities
- Having special training for parents and family
- Encouraging activities that include typically developing children, as long as such activities help meet a specific learning goal
- Measuring and recording each child's progress and adjusting the intervention program as needed
- Providing a high degree of structure, routine, and visual cues, such as posted activity schedules and clearly defined boundaries, to reduce distractions
- Guiding the child in adapting learned skills to new situations and settings and maintaining learned skills Using a curriculum that focuses on
  - Language and communication
  - Social skills, such as joint attention (looking at other people to draw attention to something interesting and share in experiencing it)
  - Self-help and daily living skills, such as dressing and grooming
  - Research-based methods to reduce challenging behaviors, such as aggression and tantrums
  - Cognitive skills, such as pretend play or seeing someone else's point of view
  - Typical school-readiness skills, such as letter recognition and counting.

One type of a widely accepted treatment is applied behavior analysis (ABA). The goals of ABA are to shape and reinforce new behaviors, such as learning to speak and play, and reduce undesirable ones. ABA, which can involve intensive, one-on-one child-teacher interaction for up to 40 hours a week, has inspired the development of other, similar interventions that aim to help those with ASD reach their full potential. ABA-based interventions include:

- **Verbal Behavior**—focuses on teaching language using a sequenced curriculum that guides children from simple verbal behaviors (echoing) to more functional communication skills through techniques such as errorless teaching

and prompting

- **Pivotal Response Training**—aims at identifying pivotal skills, such as initiation and self-management, that affect a broad range of behavioral responses. This intervention incorporates parent and family education aimed at providing skills that enable the child to function in inclusive settings.

Other types of early interventions include:

- **Developmental, Individual Difference, Relationship-based(DIR)/Floortime Model**—aims to build healthy and meaningful relationships and abilities by following the natural emotions and interests of the child. One particular example is the Early Start Denver Model, which fosters improvements in communication, thinking, language, and other social skills and seeks to reduce atypical behaviors. Using developmental and relationship-based approaches, this therapy can be delivered in natural settings such as the home or pre-school.
- **TEACCH (Treatment and Education of Autistic and related Communication handicapped Children)**—emphasizes adapting the child's physical environment and using visual cues (for example, having classroom materials clearly marked and located so that students can access them independently). Using individualized plans for each student, TEACCH builds on the child's strengths and emerging skills.
- **Interpersonal Synchrony**—targets social development and imitation skills, and focuses on teaching children how to establish and maintain engagement with others.

For children younger than age 3, these interventions usually take place at home or in a child care center. Because parents are a child's earliest teachers, more programs are beginning to train parents to continue the therapy at home.

Students with ASD may benefit from some type of social skills training program. While these programs need more research, they generally seek to increase and improve skills necessary for creating positive social interactions and avoiding negative responses. For example, Children's Friendship Training focuses on improving children's conversation and interaction skills and teaches them how to make friends, be a good sport, and respond appropriately to teasing.

### Working with your child's school

Start by speaking with your child's teacher, school counselor, or the school's student support team to begin an evaluation. Each state has a Parent Training and Information Center and a Protection and Advocacy Agency that can help you get an evaluation. A team of professionals conducts the evaluation using a variety of tools and measures. The evaluation will look at all areas related to your child's abilities and needs.

Once your child has been evaluated, he or she has several options, depending on the specific needs. If your child needs special education services and is eligible under the Individuals with Disabilities Education Act (IDEA), the school district (or the government agency administering the program) must develop an individualized education plan, or IEP specifically for your child within 30 days.

IDEA provides free screenings and early intervention services to children from birth to age 3. IDEA also provides special education and related services from ages 3 to 21. Information is available from the [U.S. Department of Education](#).

If your child is not eligible for special education services—not all children with ASD are eligible—he or she can still get free public education suited to his or her needs, which is available to all public-school children with disabilities under Section 504 of the Rehabilitation Act of 1973, regardless of the type or severity of the disability.

The U.S. Department of Education's Office for Civil Rights enforces Section 504 in programs and activities that receive Federal education funds. More information on Section 504 is available on the Department of Education [website](#).

More information about U.S. Department of Education programs for children with disabilities is available on their [website](#).

During middle and high school years, your child's teachers will begin to discuss practical issues such as work, living away from a parent or caregiver's home, and hobbies. These lessons should include gaining work

experience, using public transportation, and learning skills that will be important in community living.

## Medications

Some medications can help reduce symptoms that cause problems for your child in school or at home. Many other medications may be prescribed off-label, meaning they have not been approved by the U.S. Food and Drug Administration (FDA) for a certain use or for certain people. Doctors may prescribe medications off-label if they have been approved to treat other disorders that have similar symptoms to ASD, or if they have been effective in treating adults or older children with ASD. Doctors prescribe medications off-label to try to help the youngest patients, but more research is needed to be sure that these medicines are safe and effective for children and teens with ASD.

At this time, the only medications approved by the FDA to treat aspects of ASD are the antipsychotics risperidone (Risperdal) and aripiprazole (Abilify). These medications can help reduce irritability—meaning aggression, self-harming acts, or temper tantrums—in children ages 5 to 16 who have ASD.

Some medications that may be prescribed off-label for children with ASD include the following:

- **Antipsychotic medications** are more commonly used to treat serious mental illnesses such as schizophrenia. These medicines may help reduce aggression and other serious behavioral problems in children, including children with ASD. They may also help reduce repetitive behaviors, hyperactivity, and attention problems.
- **Antidepressant medications**, such as fluoxetine (Prozac) or sertraline (Zoloft), are usually prescribed to treat depression and anxiety but are sometimes prescribed to reduce repetitive behaviors. Some antidepressants may also help control aggression and anxiety in children with ASD. However, researchers still are not sure if these medications are useful; a recent [study](#) suggested that the antidepressant citalopram (Celexa) was no more effective than a placebo (sugar pill) at reducing repetitive behaviors in children with ASD.
- **Stimulant medications**, such as methylphenidate (Ritalin), are safe and effective in treating people with attention deficit hyperactivity disorder (ADHD). Methylphenidate has been shown to effectively treat hyperactivity in children with ASD as well. But not as many children with ASD respond to treatment, and those who do have shown more side effects than children with ADHD and not ASD.

All medications carry a risk of side effects. For details on the side effects of common psychiatric medications, see the [NIMH website](#) on "Mental Health Medications".

### FDA warning about antidepressants

Antidepressants are safe and popular, but some studies have suggested that they may have unintended effects on some people, especially in teens and young adults. The FDA warning says that patients of all ages taking antidepressants should be watched closely, especially during the first few weeks of treatment. Possible side effects to look for are depression that gets worse, suicidal thinking or behavior, or any unusual changes in behavior such as trouble sleeping, agitation, or withdrawal from normal social situations. Families and caregivers should report any changes to the doctor. The latest information is available on the [FDA website](#).

A child with ASD may not respond in the same way to medications as typically developing children. You should work with a doctor who has experience treating children with ASD. The doctor will usually start your child on the lowest dose that helps control problem symptoms. Ask the doctor about any side effects of the medication and keep a record of how your child reacts to the medication. The doctor should regularly check your child's response to the treatment.

You have many options for treating your child's ASD. However, not all of them have been proven to work through scientific studies. Read the patient information that comes with your child's medication. Some people keep these patient inserts along with their other notes for easy reference. This is most useful when dealing with several different prescription medications. You should get all the facts about possible risks and benefits and talk to more than one expert when possible before trying a new treatment on your child.

## Living With

After your child is diagnosed with autism spectrum disorder (ASD), you may feel unprepared or unable to



provide your child with the necessary care and education. Know that there are many treatment options, social services and programs, and other resources that can help.

Some tips that can help you and your child are:

- Keep a record of conversations, meetings with health care providers and teachers, and other sources of information. This will help you remember the different treatment options and decide which would help your child most.
- Keep a record of the doctors' reports and your child's evaluation. This information may help your child qualify for special programs.
- Contact your local health department or autism advocacy groups to learn about the special programs available in your state and local community.
- Talk with your child's pediatrician, school system, or an autism support group to find an autism expert in your area who can help you develop an intervention plan and find other local resources.

## Understanding teens with ASD

The teen years can be a time of stress and confusion for any growing child, including teenagers with autism spectrum disorder (ASD).

During the teenage years, adolescents become more aware of other people and their relationships with them. While most teenagers are concerned with acne, popularity, grades, and dates, teens with ASD may become painfully aware that they are different from their peers. For some, this awareness may encourage them to learn new behaviors and try to improve their social skills. For others, hurt feelings and problems connecting with others may lead to depression, anxiety, or other mental disorders. One way that some teens with ASD may express the tension and confusion that can occur during adolescence is through increased autistic or aggressive behavior. Teens with ASD will also need support to help them understand the physical changes and sexual maturation they experience during adolescence.

If your teen seems to have trouble coping, talk with his or her doctor about possible co-occurring mental disorders and what you can do. Behavioral therapies and medications often help.

## Preparing for your child's transition to adulthood

The public schools' responsibility for providing services ends when a child with ASD reaches the age of 22. At that time, some families may struggle to find jobs to match their adult child's needs. If your family cannot continue caring for an adult child at home, you may need to look for other living arrangements. For more information, see the section, "Living arrangements for adults with ASD."

Long before your child finishes school, you should search for the best programs and facilities for young adults with ASD. If you know other parents of adults with ASD, ask them about the services available in your community. Local support and advocacy groups may be able to help you find programs and services that your child is eligible to receive as an adult.

Another important part of this transition is teaching youth with ASD to self-advocate. This means that they start to take on more responsibility for their education, employment, health care, and living arrangements. Adults with ASD or other disabilities must self-advocate for their rights under the Americans with Disabilities Act at work, in higher education, in the community, and elsewhere.

## Living arrangements for adults with ASD

There are many options for adults living with ASD. Helping your adult child choose the right one will largely depend on what is available in your state and local community, as well as your child's skills and symptoms. Below are some examples of living arrangements you may want to consider:

- **Independent living.** Some adults with ASD are able to live on their own. Others can live in their own home or apartment if they get help dealing with major issues, such as managing personal finances, obtaining necessary health care, and interacting with government or social service agencies. Family members, professional agencies, or other types of providers can offer this assistance.
- **Living at home.** Government funds are available for families who choose to have their adult child with ASD live at

home. These programs include Supplemental Security Income, Social Security Disability Insurance, and Medicaid waivers. Information about these programs and others is available from the Social Security Administration (SSA). Make an appointment with your local SSA office to find out which programs would be right for your adult child.

- **Other home alternatives.** Some families open their homes to provide long-term care to adults with disabilities who are not related to them. If the home teaches self-care and housekeeping skills and arranges leisure activities, it is called a "skill-development" home.
  - **Supervised group living.** People with disabilities often live in group homes or apartments staffed by professionals who help with basic needs. These needs often include meal preparation, housekeeping, and personal care. People who are more independent may be able to live in a home or apartment where staff only visit a few times a week.
  - Such residents generally prepare their own meals, go to work, and conduct other daily activities on their own.
- Long-term care facilities.** This alternative is available for those with ASD who need intensive, constant supervision.

## Clinical Trials

Many recent research studies have focused on finding the earliest signs of autism spectrum disorder (ASD). These studies aim to help doctors diagnose children at a younger age so they can get needed interventions as quickly as possible.

For example, one early sign of ASD may be increased head size or rapid head growth. Brain imaging studies have shown that abnormal brain development beginning in an infant's first months may have a role in ASD. This theory suggests that genetic defects in growth factors, which direct proper brain development, cause the brain abnormalities seen in autism. It's possible that an infant's sudden, rapid head growth may be an early warning signal, which could help in early diagnosis and treatment or possible prevention of ASD. Current studies on ASD treatment are exploring many approaches, such as:

- A computer-based training program designed to teach children with ASD how to create and respond to facial expressions appropriately
- A medication that may help improve functioning in children with Fragile X syndrome
- New social interventions that can be used in the classroom or other "everyday" settings
- An intervention parents can follow to reduce and prevent ASD-related disability in children at high risk for the disorder.

More information about clinical trials on ASD funded by the National Institute of Mental Health is available on the [website](#).

You can read about future research plans on the Interagency Autism Coordinating Committee's (IACC's) [website](#). The IACC is made up of representatives of Federal agencies and members of the public and coordinates efforts within the U.S. Department of Health and Human Services concerning ASD.

NIMH supports research studies on mental health and disorders. See also: [A Participant's Guide to Mental Health Clinical Research](#).

Participate, refer a patient or learn about results of studies in [ClinicalTrials.gov](#), the NIH/National Library of Medicine's registry of federally and privately funded clinical trials for all disease.

Find NIH-funded studies currently recruiting participants with [ASD](#).



### What to Ask the Specialist Who Diagnoses Your Child

Hearing a diagnosis of autism can be emotionally blind-siding. Even though you may want to take the results home and crawl into bed, you can't. You must use this office visit as an opportunity to get started on helping your child.

Because hearing a diagnosis will no doubt be troubling, be sure to take notes so that you can more fully understand the implication of the diagnosis and how you can get your child help.

Here are questions you can print out and bring with you to your doctor or specialist:

**What exactly does the diagnosis mean?** You may hear a lot of technical jargon that you don't understand. Ask for explanations. If you're told your child has PDD-NOS, ask what this means and ask if PDD means autism. Ask more questions until you fully understand the diagnosis, such as: What symptoms indicate that my child has this diagnosis? What other symptoms does he have that indicates autism?

**What do the test results mean?** Ask specific questions about the evaluations. Again, there will be lots of confusing terms that your specialist can explain. For example: What does it mean that he has "low tone"? or How was his IQ determined? or What do you mean by perseverations? The more you understand, the better you can help your child.

**Where is my child on the autism spectrum?** The spectrum of ASD ranges from mild to severe. Sometimes, specialists will refer to a child as having "high-functioning autism" or "low-functioning autism." Find out your doctor's impressions of where your child is on the spectrum. This information can help you get the necessary treatment for your child.

**Should I seek out another expert opinion?** If you disagree with the initial diagnosis, then you should seek out the help of another specialist, such as a developmental pediatrician, child psychologist, child psychiatrist, or autism specialist. Even if you do agree with the diagnosis, depending on your child's needs, you may need to seek out another opinion. For example, if your child has significant behavioral issues, you will need to see a certified behavior analyst. Ask the evaluator for recommendations for other specialists who can be helpful. Your child may also be able to be assessed by an entire team of specialists through your Early Intervention program or school district, at no cost to you.

**What services do you think my child will need? How many hours?** Ask for specific recommendations for your child's educational and treatment services. For example: Do you think my child should be in a special school for autism or a mainstream school? If the specialist recommends a specific treatment such as ABA, ask how many hours per week. Make sure you get these recommendations in writing. This letter can help you in the future when you are trying to get services for your child. If the evaluator does not know, ask for a referral to someone who can answer these questions.

**What can I do to help while we're waiting for treatment to begin?** Ask for specific suggestions on how to help your child right now. Your evaluator may be able to offer advice on how to reduce certain self-stimulatory behaviors or tips on how to increase certain skills. If your evaluator does not offer any recommendations, ask for a referral to someone who can.

**Can I have a copy of all of this in writing?** Make sure to get copies of the evaluations and recommendations. These can be used to help you make your case for services with various government agencies.

**When can I come back for a follow up visit?** Make the appointment for your follow-up visit now. There are often long waiting lists for specialists.

**Who do I call now to start treatment?** Ask for specific referrals for treatment providers so that you can act quickly to start treatment.

### What About a Prognosis

Even though you might want to ask, "Will my child get better?" or "Will he go to a regular school?", no specialist has a crystal ball, and no one can predict your child's future. Focus more on what you and your specialist can do to help your child now. There are effective treatments out there, so have hope. Your optimism and perseverance will mean more to your child than any doctor's prognosis.



# Neurodiversity and autistic people

*by Autistic Self Advocacy Network*

Neurological diversity (or neurodiversity) is the idea that we are all neurologically different—that individuals on the autism spectrum do not have a disease but rather a difference to be recognized. Autistic people have a unique set of characteristics, which can manifest as difference, disability, or gifts/skills, from person to person and within the same person. These differences provide Autistics with many rewards and challenges, not unlike our non-Autistic peers. The neurodiversity movement works toward equal rights for those of all neurological configurations—the rights to accommodations and support services so that we all might lead fulfilling and productive lives.

The concept of neurodiversity does not support one neurological type over another. ASAN believes in the same human rights for all people regardless of neurology. We consider non-Autistics to be neither superior nor inferior to Autistic people. Likewise, we do not consider “high-functioning” autistics (including people labeled with Asperger’s Syndrome) to be either superior or inferior to “low-functioning” autistics. We are generally against the use of functioning labels, which lead to the false idea that people function at the same level across all areas. In reality, each person (on and off the autism spectrum) has a unique set of skills and challenges. Functioning labels significantly downplay the uniqueness of each individual, and lead to artificial and inaccurate categorization.

Neurodiversity is not against the idea of therapy and education for autism-related difficulties, as long as this therapy is geared toward improving quality of life and not toward eliminating non-normative differences. (Cure-based approaches seek to eradicate non-normative differences.) Moreover, the therapy and education must be appropriate for the individual’s needs and must not involve practices that are considered extreme among the general population.

Neurodiversity supports the right for all people to live as independently as possible. We are against forced institutionalization and are for community choice. In other words, no person should be forced into an inappropriate living situation, just as no person should be forced to endure inappropriate treatment. Moreover, neurodiversity focuses on providing everyone with the skills needed to live independently. These skills include self-care, education, employment skills, transition, and self-advocacy.

# Presuming competence

by Self-Advocates Becoming Empowered



A really important concern while interacting with persons with disabilities is what we call “presuming competence.” You might think a person can’t do things, but do not assume that. This is important because while persons with disabilities need support at times, they want to have the opportunity to accomplish things in their lives. Everybody wants to feel confident when it comes to solving problems.

For example, it may be easy for someone to assume that people who have limited speech don’t put much thought into the world. But using other ways to communicate, such as Facilitated or Augmentative Communication, can bust that myth. That person may appear to not understand by first impression when in reality; they are expressing themselves in a different way.

Keep this in mind when you interact with persons with disabilities. When it comes to being intelligent, everybody is in their own way. One reason kids with disabilities are not included is because people make false assumptions about their abilities to learn and grow. Doug Biklen said, “The question is no longer who can be included or who can learn, but how can we achieve inclusive education. We begin by presuming competence.”



## Comments by Kyle Moriarty

*I would say that having people see me as smart is hugely important and works to calm my anxiety. I feel that if you are treated as a person with intelligence you are hope magnified and you will respond in positive ways. I know that being treated like I was unintelligent or illogical was not helpful and caused me a great deal of anxiety. That didn't work!*

*I want you to know that I am intelligent and have something to say but I was not able to let people know until I was introduced to typing, Facilitated Communication (FC). Erratic times before typing my thoughts, I was seen as not literate, not very likely*

*to be included in regular classes or go to college. Without FC I was expected to rely on broken, habitual speech that was not relevant to anything I really wanted to say. It made me feel like I was not smart. I dealt with a lot of anxiety. Many years past with me taking in information and not being able to share what I knew. I could think and read but no one understood that.*

*The point here is to label jars not people and to believe in their intelligence. My*



*friend, Tracy Thresher, says to presume competence and not limit children to life without hope or purpose. I want more than anything to support others to go with a voice. In having a voice they are able to have a future. Please understand we are all individuals and each one has needs that are as individual as we each are. We need to have options to fit our needs not the other way around.*

### **Story by Tracy Thresher**

*I am Tracy Thresher. I have been using Facilitated Communication (FC) and having a voice since 1990. Not being able to express myself was like being in a world of silence. I couldn't tell people what I liked and didn't like. People thought that I didn't understand what was being said to me. It was frustrating and made me angry and I withdrew.*

*The experience of the world looks different from my experience. Most people take their ability to talk for granted and I take my inability to talk quite seriously. I live with it every day – it is always there each time someone wants to read my thoughts.*

*The impact of learning to speak up and have a voice has been quite meaningful for me. I have typed life goals and dreams that have actually come true. This would never have happened without FC.*

*Hope is essential for dealing out success. When I first met Kyle I felt his despair and anguish with time lost - he did not have hope. He came to a FC workshop I was helping to teach. Kyle could not enter the room that first day and stayed downstairs the whole time. On the next workshop he came in the room but stood in the back the whole time and on the third day he sat with his team.*



*The next year Kyle hit the road running. Thoughts that had been trapped inside for years had a place to go. Letting out lost thoughts is moving out of despair into life and fulfilling life's hope. With a strong voice you can move from anguish and lost time darkness into a world of fun and life.*



## **Tips For Presuming Competence**

1. Always ask before giving assistance and let the person tell you what you may do to be helpful.
2. Treat adults as adults. Use a typical tone of voice, just as if speaking with a friend or co-worker.
3. In general do not assume a person can't read, but also don't assume they can.
4. Speak to the person directly, not the support person or companion.
5. Don't assume a person who has limited or no speech cannot understand what is being said. People usually understand more than they can express.
6. Never pretend you understand what is said when you don't! Ask the person to tell you again what was said. Repeat what you understand.
7. Do not try to finish a person's sentence, or cut them off. Listen until they have finished talking, even if you think you know what they might say.
8. You might not be able to see someone's disability. There are many disabilities that are hidden within a person.
9. Avoid using stereotypes in your thinking. We all have different personalities and our own ways of doing things. To find out what a person prefers, ask them directly.
10. Offer compliments but avoid giving a lot of praise when people with disabilities do typical things.
11. Most people with disabilities want to help others, as well as be supported, and enjoy making a difference in someone's life.
12. Look for something that indicates a person understands. Respond to any attempt the person makes to communicate.
13. Avoid speaking for others. Encourage a person to speak on their own behalf. If you must restate something, be careful not to change the meaning.

14. Because some people like to please others, it is important to be mindful of your body language, tone of voice, and other gestures that may influence a person's decision.
15. Have your support of the person be low-key, almost "invisible" to others. Don't "over-support."
16. Let a person make their own decisions. Don't take over and make decisions for them. It can be difficult for some of us to make quick decisions. Be patient and allow the person to take their time.
17. Focus on what a person can do. All people want a chance to live a typical life, just like everyone else.
18. Find ways to include a person in a conversation. Do not talk about the person to others as if they're not there.

**"If you want to see competence, it helps if you look for it."**

**–Douglas Biklen**

## Section 2: Strategies for Home and School

*Different management approaches for the specific disability  
from various sources*







# Communication-Building Tips for Parents of Children with Autism Spectrum Disorder

Adapted from the Hanen guidebook *More Than Words*®.

The following tips are for parents of children who haven't started talking yet or who have started to say a few words to ask for what they want (e.g., "Milk" or "Mommy, up!")

## 1. Have fun

The first step in helping your child communicate is to show him how much fun you are to play with so he'll want to interact with you. Observe what he likes to do and then join him in his play. Remember – sometimes a tickle on his tummy is all that's needed to help your child pay attention to you. If you wait after giving a tickle, maybe your child will let you know he wants another one by looking at you or making a sound.

## 2. Be face to face

Sometimes your child might find it hard to look at you and that means he's missing out on seeing your facial expressions. It will be easier for your child to look at you if you are face to face with him. By being face to face with your child, you can see what he's looking at. Then you can give him words to match his interests. If your child finds being face to face overwhelming, start by being at the same physical level. That might mean lying beside him on the floor or crouching down if he's sitting on his little chair.

## 3. Imitate what your child does

One of the best ways to get an interaction started with your child is to copy his actions and sounds. For example, if your child is moving a toy train across the floor, get your own train and move it beside his across the floor, too. If your child is making a sound ("choo choo"), make the same sound. If your child notices you and repeats the action or sound, imitate him again. In this way, you and your child might find yourselves having many back-and-forth turns, just like in a real conversation.

## 4. Sing songs together

Some children learn their first words in songs. That's because most children's songs, such as the "Eensy Weensy Spider" and "Head and Shoulders" have repetitive melodies, words and actions that make it easy for your child to join in. Your child will need to hear you sing the whole song a few times before he's ready to do or say something on his own. When he's familiar with the song, try pausing before the last word in a line to give your child a chance to sing that word.

## 5. Use real objects to help your child see what's going to happen next

Some children get upset when they have to change activities. You can prepare your child for changes by showing him objects to help him anticipate what is going to happen. For example, hold up his pajamas to let him know that it's bedtime or show him his rubber duckie to signal bath time. Sometimes, letting your child hold the object in his hand will make it easier for him to move from one activity to another.



# Communication and Play Tips for Parents of Verbal Children with Autism Spectrum Disorder

*Adapted from the Hanen guidebook *More Than Words*<sup>®</sup>.*

These tips are for parents of children who can speak in sentences but who need help including you and other children in their conversations and play.

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## 1. Do something unexpected... then WAIT

Children notice when things don't happen the way they usually do. When something unexpected happens, children often have something to say about what's going on. So, try changing your voice by talking softly or very loudly and wait to see how your child responds. Or, do something silly and then wait. For example, hand him your shoes to wear when he's getting dressed.

## 2. Talk about different points of view

Help your child take an interest in what someone else thinks by talking about the differences between him and others. For example, at the grocery store, emphasize the different kinds of foods each family member likes (e.g., "You like Cheerios, but Daddy likes oatmeal. He likes a different cereal") or when you are giving him a treat, compare what he likes to what you like (e.g., "You like chocolate ice cream and I like vanilla.")

## 3. Encourage pretending

Walk into any preschool classroom and you'll see children playing "house," "school," "doctor," or pretending to be their favourite action heroes. Give your child a jump start on pretending by providing some pretend play toys, toy dishes, doctor's kit or grocery cart with pretend food and then join in the play. Let your child lead the play and avoid directing him. Build on what he's already doing by adding a new idea to his play. If he resists your idea, be persistent, but stay playful. Remember that the other children won't always want to play the same way your child does.

## 4. Involve your child in activities that require teamwork

The best activities for getting your child to play and talk to another child are the ones that require teamwork, where each child has something specific to do in order to reach an end goal. Here are some ideas for teamwork activities: baking (one child can put the icing on the cupcakes and the other one can then shake the sprinkles on); building a fort together out of blocks or pillows; and making chocolate milk (one child can pour the milk and the other can then put the chocolate in the cup).

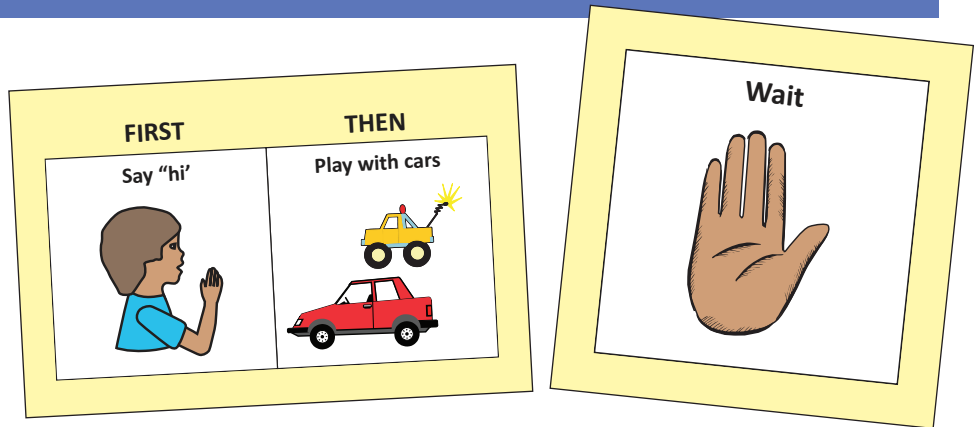
## 5. Focus on the positive

Problems are bound to come up when your child plays with you or with another child. You'll have better results with his behavior if you let your child know when he's doing something right rather than just correcting him when he's doing something wrong. So instead of saying, "I don't like it when you don't take turns," try complimenting your child when he does co-operate: "I like it when you take turns with me."

# Visual Supports and Autism Spectrum Disorders

## Introduction

**What are visual supports?** A visual support refers to using a picture or other visual item to communicate with a child who has difficulty understanding or using language. Visual supports can be photographs, drawings, objects, written words, or lists. Research has shown that visual supports work well as a way to communicate.



Visual supports are used with children who have autism spectrum disorders (ASD) for two main purposes. They help parents communicate better with their child, and they help their child communicate better with others.

This brochure introduces parents, caregivers, and professionals to visual supports and provides instruction on how to use them effectively. Visual supports can be used with persons of any age, although this brochure refers to children. Also, visual supports can be used by caregivers other than parents.

**Why are visual supports important?** The main features of ASD are challenges in interacting socially, using language, and having limited interests or repetitive behaviors. Visual supports help in all three areas.

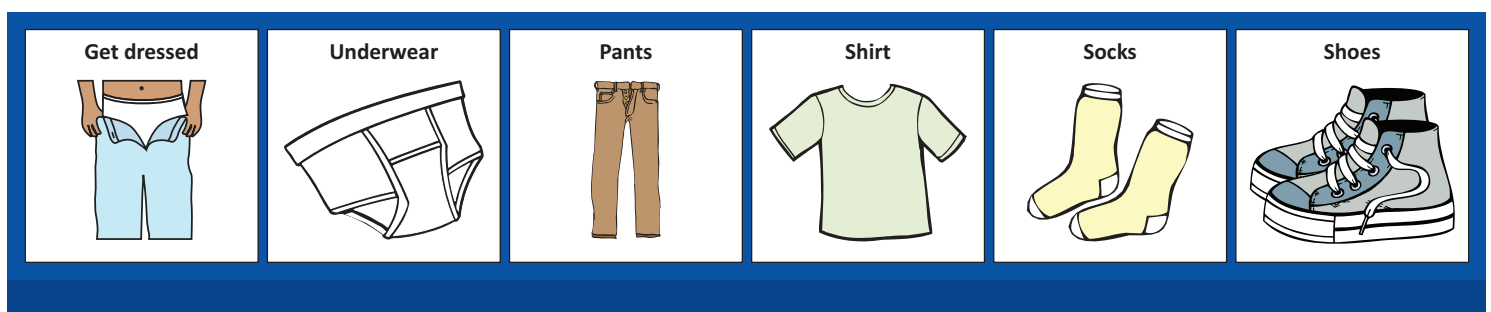
First, children with ASD may not understand social cues as they interact with others in daily activities. They may not grasp social

expectations, like how to start a conversation, how to respond when others make social approaches, or how to change behavior based on unspoken social rules. Visual supports can help teach social skills and help children with ASD use them on their own in social situations.

Second, children with ASD often find it difficult to understand and follow spoken instructions. They may not be able to express well what they want or need. Visuals can help parents communicate what they expect. This decreases frustration and may help decrease problem behaviors that result from difficulty communicating. Visuals can promote appropriate, positive ways to communicate.

Finally, some children with ASD are anxious or act out when their routines change or they are in unfamiliar situations. Visuals can help them understand what to expect and will happen next and also reduce anxiety. Visuals can help them pay attention to important details and help them cope with change.

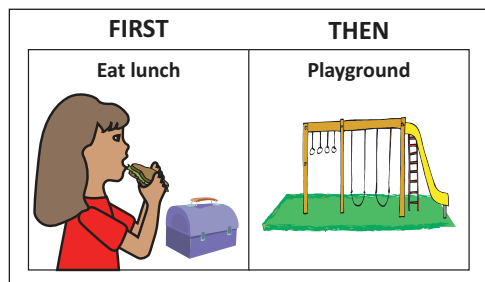
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## First – Then Board

### ❑ What is it?

A First-Then Board is a visual display of something your child prefers that will happen after completing a task that is less preferred.



### ❑ When is it helpful?

A First-Then Board is helpful in teaching children with ASD to follow directions and learn new skills. A First-Then Board motivates them to do activities that they do not like and clarifies when they can do what they like. A First-Then Board lays the language foundation needed to complete multi-step directions and activities and to use more complex visual systems.

### ❑ How do I teach it and use it?

Decide what task you want your child to complete first (what goes in the “first” box) and the preferred item or activity (what goes in the “then” box) that your child can have immediately after the “first” task is done. This preferred item/activity should be motivating enough to increase the likelihood that your child will follow your direction.

Put the visuals on the board (e.g., photos, drawings, written words) that represent the activity you identified. Present the board to the child with a brief, verbal instruction. Try to use the least amount of words possible. For example, before beginning the “first” task, say, “First, put on shoes, then swing.” If needed, refer to the board while your child is doing the task. For example, say “One more shoe, then swing” when your child is almost done.

When the “first” task is completed, refer back to the board. For example, say “All done putting on shoes, now swing!” and immediately provide the preferred, reinforcing item or activity.

In order to teach children with ASD the value of the First-Then Board, you must give them the reinforcing activity or item after they complete the “first” task. Otherwise, your child may not trust the board the next time you use it.

### ❑ What if challenging behaviors occur?

If challenging behaviors occur, continue by physically prompting your child to complete the “first” task. Keep your focus on the task rather than on the challenging behavior. Then it is important to still provide the reinforcing item or activity, since the focus of the board

is on completing the “first” task, and not on addressing challenging behaviors.

If you think challenging behaviors may happen, begin by introducing the First-Then Board for a task that your child usually completes willingly and successfully. If challenging behaviors become more difficult to control, it may be appropriate to consider behavioral consultation with a professional to address these behaviors directly.

## Visual Schedule

### ❑ What is it?

A visual schedule is a visual representation of what is going to happen throughout the day or within a task or activity.

### ❑ When is it helpful?

A visual schedule is helpful for breaking down a task that has multiple steps to ensure the teaching and compliance of those steps. It is also helpful in decreasing anxiety and rigidity surrounding transitions by communicating when certain activities will occur throughout the day or part of the day.

### ❑ How do I teach it and use it?

After your child understands the concept of sequencing activities through the use of a First-Then Board, you can develop a more complex schedule for a series of activities during the day.

Decide the activities that you will picture in the schedule. Choose activities that really will happen in that particular order. Try to mix in preferred activities with non-preferred ones.

Put on the schedule the visuals (e.g., photos, drawings, written words) that show the activities that you have identified. The schedule can be portable, for example, on a binder or clipboard, or it can be fixed to a permanent place, like a refrigerator or wall. Your child should be able to see the schedule before beginning the first activity on the schedule. It should continue to be visible to your child during the rest of the activities.

When it is time for an activity on the schedule to occur, cue your child with a brief, verbal instruction. For example, say “Check the schedule.” This helps your child pay attention as the next activity begins. At first, you may need to physically guide your child to check the schedule (e.g., gently guide by shoulders and prompt your child to point to the next activity on the schedule). You can gradually decrease physical prompts as your child begins to use the schedule more independently.

When a task is completed, cue your child to check the schedule again, using the procedure described above, and transition to the next activity.





Provide praise and/or other positive reinforcement to your child for following the schedule and for transitioning to and completing activities on the schedule. It may be helpful to use a timer that your child can hear to make transition times clear to your child.

Mix variability into the schedule by introducing a symbol that represents an unknown activity (e.g., “oops” or “surprise activity”). Begin to teach this concept by pairing this with a positive activity or surprise. Gradually use this for unexpected changes in the schedule.

### ❑ What if challenging behaviors occur?

If challenging behaviors occur, continue by physically prompting your child to complete the task that is occurring. Keep your focus on the task rather than on the challenging behavior. Then transition to the next activity as communicated by the schedule and still provide the reinforcing item or activities indicated on the schedule, since the focus of the schedule is on completing the tasks, and not on addressing challenging behaviors.

If you think challenging behaviors may happen, begin by introducing the visual schedule during tasks that your child usually completes willingly and successfully. If challenging behaviors become more difficult to control, it may be appropriate to consider behavioral consultation with a professional to address these behaviors directly.

## Visually Setting Parameters

### ❑ What is it?

Setting parameters involves using visuals to set clear boundaries around items or activities and to communicate basic expected behaviors, like waiting.

### ❑ When is it helpful?

Visually setting parameters is helpful in communicating limits that are part of an activity and that may seem unclear to your child. Some examples of situations where this might be useful follow. Communicate physical boundaries of an area or activity, for example, use a “stop” sign to mark where to stop in the backyard. Or show how much of an item or activity is available before it is gone. For example, place a “not available” picture on the computer when it is not time to play on the computer. Or place pictures of 3 juice boxes on the refrigerator and remove or cover one each time

juice is given. Show the need to wait for something that is delayed but will be available soon, for example, by providing a “wait” card paired with a timer.



### ❑ How do I teach it and use it?

Begin to teach the use of these visuals in situations that have clear, defined, brief parameters. As your child understands these visuals better, gradually increase their use in more long-term activities and with more abstract parameters.

### ❑ Examples:

**Physical boundaries:** Place the visual on physical boundaries that already are defined (e.g., a door) and refer to it when the rule is followed. For example, when your child stops at the door, point to the stop sign and say, “Stop.” Give praise or reinforcement for complying with this parameter. After you have taught the concept, use the same visual during other activities or in other settings where the same boundary is needed but is not as clear, such as a “Stop” sign on the playground.

**Limited availability:** Decide the number of times or length of time that the item or activity is available. Indicate that through the visual, for example, 3 pictures of a juice box on the refrigerator to indicate that 3 juice boxes are allowed that day. After the item or activity has been used or done, show the change by using the visual, for example, cross out or remove one of the juice box pictures. When the item is no longer available, use the visual to show this. For example, show your child that there are no more pictures of juice on the refrigerator after they have used them all.

**Wait:** Begin by presenting the symbol for “wait” for a very brief amount of time before your child can have a preferred item or activity. It may help to pair the use of the “wait” symbol with a timer. Have your child trade the “wait” card for the item or activity. For example, when your child asks for a snack, hand your child the “wait” card, set the timer for 10 seconds, and then praise your child’s waiting and trade the snack for the “wait” card.

As your child learns to use visuals for setting parameters, gradually increase the length of time or the number of situations in which your child is expected to wait for items or activities.

#### ❑ **What if challenging behaviors occur?**

If you think that challenging behaviors may occur, introduce these parameters during less difficult situations or begin with simple expectations.

If problem behaviors occur, be consistent with the parameters you have set. Focus on praising any aspects of the parameters that are being followed, rather than shifting your focus to the challenging behaviors.

Using visual supports can help you and your child with ASD communicate and manage everyday activities in positive ways.

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KENNEDY CENTER**

## Resources for Using Visual Supports:

- ❑ [www.do2learn.com](http://www.do2learn.com)
- ❑ [card.ufl.edu/content/visual.html](http://card.ufl.edu/content/visual.html)
- ❑ [www.kidaccess.com/index.html](http://www.kidaccess.com/index.html)
- ❑ Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks Galore for the Real World*. Raleigh, NC: Tasks Galore.

## Resources on Autism Spectrum Disorders:

- ❑ **Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)**, Vanderbilt Kennedy Center, is dedicated to improving assessment and treatment services for children with autism spectrum disorders and their families, while advancing knowledge and training. For information on TRIAD and Vanderbilt autism services and resources:

### Vanderbilt Autism Resource Line

Local (615) 322-7565

Toll free (1-877) ASD-VUMC [273-8862]

Email: [autismresources@vanderbilt.edu](mailto:autismresources@vanderbilt.edu)

### TRIAD Outreach and Training

(615) 936-1705

Web: [triad.vanderbilt.edu](http://triad.vanderbilt.edu)

- ❑ **Tennessee Disability Pathfinder**, a free information and referral service for all types of disabilities, all ages, provides information on autism resources external to Vanderbilt. Local (615) 322-8529, (1-800) 640-4636. Web: [www.familypathfinder.org](http://www.familypathfinder.org)
- ❑ Local chapters of the **Autism Society of America (ASA)** ([www.autism-society.org](http://www.autism-society.org)) provide information, support, and advocacy for individuals with ASD and their families.

### Autism Society of Middle Tennessee

Phone: (615) 385-2077, (866) 508-4987

Email: [asmt@tnautism.org](mailto:asmt@tnautism.org)

Web: [www.tnautism.org](http://www.tnautism.org)

### Autism Society of the Mid South

Phone: (901) 542-2767

Email: [autismsocietymidsouth@yahoo.com](mailto:autismsocietymidsouth@yahoo.com)

Web: [www.autismsocietymidsouth.org](http://www.autismsocietymidsouth.org)

### Autism Society of East Tennessee

Phone: (865) 247-5082

Email: [asaetc@gmail.com](mailto:asaetc@gmail.com)

- ❑ **Autism Speaks** ([www.autismspeaks.org](http://www.autismspeaks.org)) provides resources and support for individuals with ASD and their families.

## Autism Q&A: Positive Behavior Support

Autism spectrum disorder (ASD) impacts people in many ways. ASD may impact a person's ability to socially interact, communicate effectively, learn new skills, and process sensory information. The pervasiveness of ASD and the array of challenges may result in the individual exhibiting interfering behaviors such as hitting, screaming, running away, or inflicting injury to himself.

All behavior is functional; it serves a purpose for the person. If professionals, parents, and friends can understand why individuals demonstrate a specific challenging behavior and what causes or triggers it, then positive behavior supports can be used to help individuals participate at home, in school, and in communities. Positive behavior supports can prevent a behavior from occurring or teach the individual a new functional skill to replace it.

**Question: What is positive behavior support?**

**ANSWER**

Positive behavior support is an all-encompassing system of behavior management. Behavior is supported through a structured plan that positively addresses the person's behavior as well as his or her quality of life. Positive behavior support is based in the principles of applied behavior analysis (ABA) and involves understanding factors that impact behavior including antecedents and consequences. Further, it is embedded in the values of person centered planning. Person centered values require intervention and support tailor-made to meet the individual's needs and unique goals and movement towards community and social involvement and personal choice.

The fundamental philosophy of positive behavior support is that most behavior, problem or adaptive, serves a specific function or purpose in the individual's life. In order to change that behavior we must assess the function of the problem behavior and replace it with a functional skill, such as a communication or social skill, that will have the same outcome. With this view, it is important to understand that problem behavior is not something that has to be suppressed; instead, problem behavior is a form of communication that has a function in the life of the person who displays it.

**Question: What is meant by function of a behavior?**

**ANSWER**

Individuals with ASD may communicate many different messages with their behaviors. Those who support them may find it overwhelming to consider all the possible messages that a person is trying to communicate. However, it is possible using applied behavior analysis to understand the messages that a person is saying with his or her behavior.

The messages that a person is communicating usually can be narrowed down to five basic messages or purposes. Those messages are: a) seeking attention from others; b) seeking something tangible like an item, activity, or food; c) seeking sensory input from the action itself; d) avoiding a person, task, item, or environment; or e) demonstrating medical discomfort.

Behavior, therefore, has purpose and is established as a way of 'communicating' one of these five basic messages. In order for the problem behavior to be replaced with a different behavior, support personnel must figure out which of the basic functions are relevant for a particular behavior and teach the individual a new positive behavior to replace the challenging one.

**Question: Doesn't all interfering behavior have the same functions?**

**ANSWER**

The critical thing to remember is that the function of a behavior is individual. The same behavior may not serve the same function for two different individuals with ASD. It is critical to determine what the specific function is for each person.

A behavior may have multiple functions for a person or the person may display different behaviors for the same reason or purpose. The educator, parent, or support person must take the time to fully understand why the behavior occurs and to be as specific as possible. For example, Juan may hit himself, and the team may determine that he does so to gain access to something. Determining what he wants access to and when he wants access will help create an effective plan for Juan.

**Question: Please describe what is meant by consequences and antecedents of a behavior.**

**ANSWER**

As noted previously, principles of ABA are used when implementing positive behavior supports. There are two primary principles impacting behavior -- the antecedents and the consequences.

Consequences, also known as reinforcement, strengthen behavior. Often, a person's problem behavior has been reinforced unknowingly. Behavior that is reinforced is maintained and continues. The behavior becomes established as a way of 'requesting' something specific. In order to replace that behavior with a different behavior, support personnel have to figure out what is reinforcing the person's specific behavior. In other words, what is the individual getting or avoiding when the behavior is exhibited? What can be taught to the individual as a new way to request for that consequence?

In addition to understanding the consequences present after a behavior has occurred, the events that come before the behavior (that trigger its occurrence) need to be understood. These events, called antecedents, will help identify the functions that the person is requesting with the problem behavior. For example, if Juan's problem behavior mostly happens after he is left alone; his parent might guess that he is seeking attention. If his problem behavior usually happens after he is given a task that he does not like, then his teacher might guess that he is avoiding the task.

There are two types of triggers that may impact the presence of a problem behavior. The ones described above, antecedents,

act like fast triggers. In other words, problem behaviors follow them immediately. The other types of triggers are called setting events. Setting events are slow triggers to the behavior. They are conditions that set up the possibility a behavior may occur, but do not set off the behavior at that moment. In Juan's case, imagine if his problem behavior occurred after he was left alone. We might hypothesize that Juan was seeking attention. What if the only time he displayed the behavior was when he was left alone in school and his schedule had changed? What if he does not display problem behavior when he is left alone at school and his schedule has not changed? We might then hypothesize that changes in his schedule seem to make it more likely that Juan will display problem behavior, but only if his schedule changed and he is left alone. Examples of setting events are illness, pain, fatigue, having had an undesirable event occur, or a change in schedule.

**Question:** What is the positive behavior support process.

### ANSWER

The positive behavior support process involves multiple steps and includes activities that help determine the function of the behavior as well as development of a behavior support plan. These steps are:

- 1. Determine the definition of the interfering behavior.** The first step in identifying the function of problem behavior is to concretely define the behavior in question. This definition should describe the behavior specifically and all individuals involved should be able to identify the occurrence of the behavior.
- 2. Determine the function of the behavior.** Sometimes the function of the behavior will be obvious. For example, Shauna cries when the television is turned off. This function is clear as is the driving antecedent. Shauna wants access to the television! Other times, in order to identify the function of behaviors, a functional behavior assessment (FBA) will need to be completed. When doing an FBA, gather information and collect data through observations and interviews to understand the function, the driving triggers, and maintaining consequences of the behavior.  
  
To identify the function of the behavior, a summary of findings from the information and data gathered should be used to formulate a hypothesis outlining the belief as to why and when the problem behavior occurs. The hypothesis should identify the setting event, antecedent, consequence, and function for each behavior.
- 3. Develop a positive behavior support plan.** Once you have an understanding of the function of the interfering behavior, develop a plan that explicitly outlines what to do to proactively prevent the behavior and/or identify the skills to be taught to replace the behavior. With a positive behavior support plan, when appropriate, be proactive and avert the problem behavior through antecedent and environmental supports. For example, if Shauna demonstrates problem behavior after the television is turned off, outline steps in her plan to prepare her for the termination of this activity. Additionally, the plan should identify how to replace the behavior with an adaptive behavior that will result in the same outcome. For example, if the function of Juan's behavior is to gain attention, then the new behavior should result in the same outcome. Therefore, teaching that functional skill, requesting attention and access to a person, will be a major part of Juan's PBS plan. Finally, his plan will include specific instructions for team members to reinforce the new behavior and respond if the problem behavior occurs again. For Shauna, the plan will outline how to reinforce her when appropriate behavior is demonstrated when the television is turned off, and will also outline what to do if she cries.

- 4. Implement the plan.** Now that a plan is developed, team members will need to implement the plan across environments. It is important that anyone who provides support to the person be familiar with the plan and implement each step consistently. This may require some training of team members.
- 5. Monitor and evaluate.** To determine whether the plan is working, data should be collected and analyzed. Data helps determine if the person is developing new, positive skills and can be taken on the problem behavior occurrence and/or on new behaviors being taught. Juan's teacher makes a tally mark each time he asks for attention while Shauna's mother makes a check each time she cries when the television is turned off. Team members analyze the data frequently to ensure the plan is effective and the person is being supported. If positive behaviors are not being learned, the team will need to make changes to the plan.

### SUMMARY

Individuals with ASD may demonstrate problem behavior for a myriad of reasons. Positive behavior supports may be implemented to help a person reduce the occurrence of such behaviors and participate in the home, community, and school. All behavior is functional. Thus, it is critical that teams who support students with challenging behavior assess the function of the behavior and determine what causes it to occur. Based on this information, positive behavior supports are identified that explicitly outline what to do to proactively prevent the behavior and/or identify the skills to be taught to replace the behavior. Positive behavior supports teach functional behaviors that will result in long term behavior change and assist individuals in their future success.

### ADDITIONAL INFORMATION AND RESOURCES

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For additional information on ACE please go to our website: [www.vcuautismcenter.org](http://www.vcuautismcenter.org)

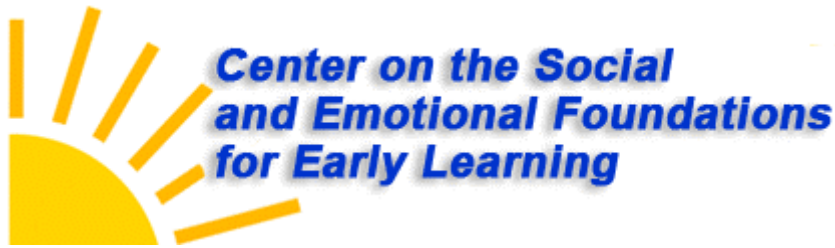
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## SCRIPTED STORIES FOR SOCIAL SITUATIONS– TIP SHEET

The rules or expectations of social interactions are typically learned by example. Children with communication difficulties and/or behavior challenges often do not learn these interactions incidentally, but may need more explicit instructions through a scripted description of the social situation.

Scripted stories for social situations help children understand social interactions, situations, expectations, social cues, the script of unfamiliar activities, and/or social rules. As the title implies, they are brief descriptive stories that provide information regarding a social situation. When children are given information that helps them understand the expectations of a situation, their problem behavior within that situation is reduced or minimized. Parents, teachers and caregivers can use these simple stories as a tool to prepare the child for a new situation, to address challenging behavior within a setting or situation, or to teach new skills. The following is an example of a scripted story explaining when it's appropriate to run.

### **RUNNING**

**I like to run. It is fun to go fast.  
It's okay to run when I am playing outside.  
I can run when I am on the playground.  
Sometimes I feel like running, but it is dangerous to run when I am inside.  
Running inside could hurt me or other people.  
When people are inside, they walk.  
Walking inside is safe.  
I will try to walk inside and only run when I am outside on the playground.  
My teachers and parents like it when I remember to walk inside.**

### **WRITING A SCRIPTED STORY**

***Begin by observing the child in the situation you are addressing. Try to take on the child's perspective and include aspects of his or her feelings or views in the story. Also, include usual occurrences in the social situation, clear "expectations", and the perspective of others, along with considering possible variations.***

There are three types of sentences used in writing Scripted Story:

1. **Descriptive sentences:** objectively define anticipated events where a situation occurs, who is involved, what they are doing and why. (e.g., When people are inside, they walk.)
2. **Perspective sentences:** describe the internal status of the person or persons involved, their thoughts, feelings, or moods. (e.g., Running inside could hurt me or other people.)
3. **Directive sentences:** are individualized statements of desired responses stated in a positive manner. They may begin "I can try..." or "I will work on..." Try to avoid sentences starting with "Do not" or definitive statements. (e.g., I will try to walk in inside.)

A Scripted Story should have 3 to 5 descriptive and perspective sentences for each directive sentence. Avoid using too many directive sentences.

Write in first person and on the child's developmental skill level. Also remember to use pictures that fit within the child's developmental skill level to supplement text.



# Supporting Communication in High School



There are numerous approaches you can use to support and encourage comprehension, expressive communication, and/or interaction in the high school environment. Some of these key strategies and examples include:

## 1 Priming

Provide information about tasks or activities ahead of time to support comprehension and expressive communication in the classroom.

- Provide an outline of class notes or written directions.
- Offer a list of questions to student before the beginning of class so they can formulate answers ahead of time.

## 2 Additional Processing Time

Build in extra time for support in processing and responding to directions or questions presented to the class.

- Warn the student that you will be asking them to respond to the question next.
- Have the class think about or write down answers for 15–30 seconds before raising their hands.

## 3 Modeling

Demonstrate and identify appropriate use of communication and social skills.

- Model target communication skills and social skills in class to the student.
- Model appropriate ways for peers to interact with and respond to the student with ASD.
- Show a video of another person or the student appropriately performing the target skill(s).

## 4 Peer Supports

Encourage and coach peers to provide supports (e.g., prompts to participate in discussions) to the student in class.

- Intentionally seat the student near peers who you have coached to provide support.
- Give the student specific roles within small group activities that challenge the student with ASD to practice target skills (e.g., group leader for a student who needs practice initiating).
- Give the student a list of topics or questions to use when initiating conversation.

## 5 Social Connections

Help students to connect with peers in and out of class.

- Point out commonalities or shared interests with peers in the class.
- Sponsor a club around a student's interest.
- Offer your classroom as a meeting place and arrange a lunch group once a week.

## 5 Key Strategies for Supporting Communication

**Autism at-a-Glance** is a publication of the Center on Secondary Education for Students with ASD (CSESA)

If you serve students with more significant communication needs, please see our *Autism at-a-Glance* titled *Supporting Functional Communication in High School*.



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## Important Reminders

### Slow Down, Support, and Simplify

Remember, high school environments are fast-paced and complex which often makes comprehension, communication and conversations more difficult for students with ASD. Think of strategies to slow the pace, minimize confusion, and reduce complexities in conversations, activities, and other situations.

- Use a subtle signal that the student knows to indicate when you are joking or using sarcasm or when the student is drifting off topic.
- Pair visual supports with verbal instruction in order to maximize comprehension and capitalize on strengths and preferences for visual modalities.

### Provide Specific Positive and Constructive Feedback

Offer specific feedback to the student (and others in the class) about their communication skills. General feedback, such as “good job” or “nice work in class”, does not provide enough information to reinforce specific target skills.

- “Nice job focusing on the main idea. Next time try to look up at the class when you talk.”
- “I like how you are facing me while you listen. It might be helpful to give some other clues that you are listening—maybe nodding your head or saying ‘uh-huh’.”

## Resources

American Speech-Language Hearing Association  
<http://www.asha.org/slp/clinical/autism-resources/>

*Understanding Autism: A Guide for Secondary School Teachers*

#### DVD

<http://www.researchautism.org/resources/teachersdvd.asp>

#### Brochure

<http://csesa.fpg.unc.edu/resources/understanding-autism-guide-secondary-school-teachers>

*Recommendations for Students with High Functioning Autism*

<http://teacch.com/educational-approaches/recommendations-for-students-with-high-functioning-autism-kerry-hogan>

*Understanding the Student with Asperger's Syndrome: Guidelines for Teachers*

<http://www.aspergersyndrome.org/Articles/Understanding-the-Student-With-Asperger-s-Syndrome.aspx>



# Supporting Functional Communication in High School

(for students with more significant communication needs)



There are numerous approaches you can use to support and encourage comprehension, expressive communication, and/or interaction in the high school environment. Some of these key strategies and examples include:

## 1 Visual Supports

Provide objects, gestures, pictures, or written cues to support comprehension and expressive communication in the classroom

- Use pictures or writing with verbal directions and questions to support understanding.
- Give cards with conversation starters, topics, or jokes to promote interaction during lunch or other times during the day.

## 2 Additional Processing Time

Build in extra time for support in processing and responding to directions or questions presented to the class.

- Make sure to pause for at least 5 seconds after giving a direction or asking a question

## 3 Opportunities for Communication

Arrange the environment in a way that encourages, and even necessitates communication

- On occasion, put away materials that are necessary for a familiar routine (e.g., worksheet) so the student has to communicate in order to get the materials.
- Embed times for casual conversation during the day, just as you would see students doing during the day, similar to what you may see during passing time between classes.
- Use topics of interest to the student during class to increase interactions.
- Offer students the opportunity to communicate a choice whenever possible.

## 4 Modeling

Demonstrate and identify appropriate use of communication and social skills

- Take short videos of other high school students (or your student) modeling appropriate communication and social skills and show the videos to your student.
- Use classroom staff or peers to model skills live (e.g., turn taking in conversation, initiating an interaction)

## 5 Peer Supports and Social Connections

Find other high school students that may be able to support the student with communication and social connections in class or around school

- Find clubs or sports teams for the student to join that align with his/her interests
- Arrange a lunch group with other high school students
- Start peer programs or have high school student interns in your classroom

# 5 Key Strategies for Supporting Communication

Feb 2014

**Autism at-a-Glance** is a publication of the Center on Secondary Education for Students with ASD (CSESA)

If you serve students who are able to communicate conversationally, please see our *Autism at-a-Glance* titled *Supporting Communication in High School*.



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## Important Reminders

### Slow Down, Support, and Simplify

Remember, high school environments are fast-paced and complex which often makes comprehension, communication and conversations more difficult for students on the autism spectrum. Think of strategies to slow the pace, minimize confusion, and reduce complexities in conversations, activities, and other situations.

- Provide information in small chunks – one step of a series of directions or one question at a time
- Think of ways to embed visual supports around the school environment—in the cafeteria, the media center, the gym, and more.

### Provide Specific Positive and Constructive Feedback

Offer specific feedback to the student about their communication skills. General feedback, such as “good job” or “nice work in class,” does not provide enough information to reinforce specific target skills.

- “Nice job giving an answer to the question David asked you.”
- “I like how you said ‘hi’ to other students in the library.”

## Resources

American Speech-Language Hearing Association

<http://www.asha.org/slp/clinical/autism-resources/>

Augmentative and Alternative Communication Resources

<http://www.asha.org/slp/clinical/aac/>

Communication Bill of Rights

[http://www.asha.org/NJC/bill\\_of\\_rights.htm](http://www.asha.org/NJC/bill_of_rights.htm)

*Understanding Autism: A Guide for Secondary School Teachers*

**DVD**

<http://www.researchautism.org/resources/teachersdvd.asp>

**Brochure**

<http://csefa.fpg.unc.edu/resources/understanding-autism-guide-secondary-school-teachers>

State Assistive Technology Resources

<http://resnaprojects.org/allcontacts/statewidecontacts.html>

## \*A Note About Augmentative and Alternative Communication (AAC)

Augmentative and alternative communication (AAC) is a field that focuses on helping individuals augment or compensate for significant challenges in the area of communication using various systems or aids. The goal of AAC is to maximize effective communication for an individual. AAC systems/aids may be high-tech (e.g., applications on an iPad, speech-generating devices) or low-tech (e.g., picture symbols, communication boards, sign language). When considering different systems/aids, it is important to include someone with expertise in AAC.

School districts may have a person or team of people who are able to evaluate and support students who have limited verbal abilities and need alternative methods for communication. This team may consist of special educators, speech language pathologists, occupational therapists, physical therapists, or others. If you have a student who may benefit from AAC or uses some form of AAC, look for contacts in your district or in your local area to help support these students in maximizing their communication.

# Assistive Technology 101



## What Is Assistive Technology?

Assistive technology is any kind of technology that can be used to enhance the functional independence of a person with a disability. Often, for people with disabilities, accomplishing daily tasks such as talking with friends, going to school and work, or participating in recreational activities is a challenge. Assistive Technology (AT) devices are tools to help to overcome those challenges and enable people living with disabilities to enhance their quality of life and lead more independent lives.

Assistive technology can be anything from a simple (low-tech) device such as a magnifying glass, to a complex (high-tech) device, such as a computerized communication system. It can be big — an automated van lift for a wheelchair — or small — a Velcro attached grip attached to a pen or fork for example, for eating and writing. Assistive technology can also be a substitute — such as an augmentative communication device that provides vocal output for a child who cannot communicate with her voice.

## Meeting Challenges with Assistive Technology

Assistive technology helps to level the playing field for individuals with disabilities by providing them a way to fully engage in life's activities. An individual may use assistive technology to travel about, participate in recreational and social activities, learn, work, communicate with others, and much more.

Here are several examples of AT that enables people with disabilities to enter into the community and interact with others.

- For greater independence with mobility and travel, people with physical disabilities may utilize mobility aids, such as wheelchairs, scooters, and walkers. Adapted car seats and vehicle wheelchair restraints promote safe travel.
- Hand-held GPS devices help persons with visual impairments navigate busy city streets and utilize public transportation.
- Building modifications at work sites, such as ramps, automatic door openers, grab bars, and wider doorways mean fewer barriers to employment, businesses, and community spaces, such as libraries, churches, and shopping malls.
- Special computer software and hardware, such as voice recognition programs and screen enlargement programs, enable persons with mobility and sensory impairments to carry out educational or work-related tasks.
- Education and work aids such as automatic page turners, book holders, and adapted pencil grips enable children to participate in classroom activities.
- Bowling balls with hand-grips and one-handed fishing reels are a few examples of how technology can be adapted for sporting activities. Light-weight wheelchairs have been designed for organized sports, such as basketball, tennis, and racing.
- Adaptive switches make it possible for a child with limited motor skills to play with toys and games.
- Accessibly designed movie theaters provide closed captioning and audio description for moviegoers with hearing and visual difficulties.
- Devices to assist a person with daily living tasks, such as cooking, dressing, and grooming, are available for people with special needs. For example, a medication dispenser with an alarm can be set to remind a person with memory loss to take daily medication. A person with use of only one hand can use a one-handed cutting board and a cabinet mounted can opener to cook meals with improved independence and safety.



## Choosing the Right Assistive Technology Device(s) for Your Child

To determine the assistive technology needs of a child, an AT assessment should be conducted. The assessment can be conducted by the school, an independent agency, or an individual consultant. This assessment should take place in a child's customary environments -- home, school, and community.

It is important that the assessment address the child's strengths as well as his/her weaknesses. It is key, when discussing how the child participates in his/her world, to hear the perspectives of teachers, parents and siblings, as well as that of the child. The discussion should not be limited merely to what skills the child possesses but should include the ways in which a child communicates, what he likes and dislikes, and what kind of strategies and interventions are helpful in interacting with the child. Consideration must be taken on how a child's need for AT might change depending on the environment, for example on the playground, the classroom, a friend's house or in a public place like a mall or library. This type of input will provide clues as to what technology might work and how well your child will respond to it.

The end result of an assessment is a recommendation for specific devices and services. Once it is agreed that assistive technology would benefit a child, issues related to design and selection of the device, as well as maintenance, repair, and replacement of devices should be considered. Training (to use the device) and ongoing technical assistance is necessary not only for the child, but also for family members, teachers, service providers, and other people who are significantly involved in a student's life. It is also important to integrate and coordinate any assistive technology with therapies, interventions, or services provided by education and rehabilitation plans and programs.

Acquiring assistive technology does not just happen once in a lifetime. The type of devices your child needs may change depending on the child's age, abilities, physical status, and features of the immediate environment. Change in your child's life may necessitate a re-assessment of his or her assistive technology needs.

## Learning More about Assistive Technology

Parents can help to identify potential AT for their child if they learn about the choices that are available. A good place to start is often with speech-Language therapists, occupational therapists and school professionals. There are many organizations that provide AT information and training to consumers and families such as parent training and Information centers (PTI's), community technology centers, state assistive technology programs and rehabilitation centers. If possible you should visit an AT center with your child to see and try out various devices and equipment. Some AT centers offer lending programs that allow families to borrow devices for a trial period.

The Family Center on Technology and Disability (FCTD) offers a wide range of assistive technology resources for disability organizations, AT providers, educators and families of children with disabilities. Families are always welcome to visit the FCTD web site ([www.fctd.info](http://www.fctd.info)) to find other AT and disability organizations and to learn more about assistive technology.

The following list includes several organizations that offer a various resources on AT.

Abledata - [www.abledata.com](http://www.abledata.com)

Assistivetech.net - [www.assistivetech.net](http://www.assistivetech.net)

AbilityHub - [www.abilityhub.com](http://www.abilityhub.com)

PACER Center - Simon Technology Center - <http://www.pacer.org/stc/>

Technical Assistance Alliance for Parent Centers - [www.taalliance.org](http://www.taalliance.org)

Association of State Technology Act Programs - [www.ataporg.org/stateatprojects.asp](http://www.ataporg.org/stateatprojects.asp)



# Autism Technology Fast Facts



*Autism Center  
for Excellence*

## Apple Apps Resource Guide

This Guide was created by Lindsey Aftel, Mary Freeman, Jessica Lynn and Whitney Mercer, Students at VCU's Occupational Therapy Program.

In order to purchase any of these applications, go to Apple App Store on the Internet or on your iPhone, iPad, or iTouch, type the name of the application in the Search Box, and click on the App to purchase it.

App	Function	\$US
<b>Communication</b>		
Voice4U	<ul style="list-style-type: none"> <li>▶ Includes a library of picture &amp; voice prompts (for individuals with speech difficulties)</li> <li>▶ Allows download of your own photos and audio prompts</li> </ul>	\$29.99
Proloquo2Go	<ul style="list-style-type: none"> <li>▶ Full-feature augmentative and alternative communication solution (full AAC solution)</li> <li>▶ Provides natural sounding, text-to-speech voices, up-to-date symbols, automatic conjunctions, and a default vocabulary of over 7,000 items</li> </ul>	\$189.99
iCommunicate	<ul style="list-style-type: none"> <li>▶ Offers pre-loaded pictures and storyboards/routines (e.g., schedule) that facilitate language comprehension</li> </ul>	\$34.99
Speak it!	<ul style="list-style-type: none"> <li>▶ Copy or type text for text-to-speech</li> <li>▶ Uses natural sounding voices</li> </ul>	\$1.99
My Choice Board	<ul style="list-style-type: none"> <li>▶ Presents a visual display of "choices" for those with limited communication skills</li> <li>▶ Choice boards can be customized</li> </ul>	\$9.99
<b>Behavior</b>		
iReward	<ul style="list-style-type: none"> <li>▶ Behavioral management reward system</li> <li>▶ Allows you to post a picture of a reward and give stars for behaviors that will win the reward</li> </ul>	\$4.99
ABC Data	<ul style="list-style-type: none"> <li>▶ Data collection tool for counting behavior by simple tallies or percentages, recording session duration, and emailing the data</li> <li>▶ Tracks ABC data, frequency and duration, and high frequency data</li> </ul>	\$4.99
BehaviorTrackerPro	<ul style="list-style-type: none"> <li>▶ Graphs all of the data (by frequency, duration, or rate)</li> </ul>	\$29.99
<b>Aids for Daily Living</b>		
Picture Scheduler	<ul style="list-style-type: none"> <li>▶ Task organizer- attach photo, video, or audio to reminder message</li> <li>▶ Ability to sort tasks into categories</li> <li>▶ Aids in recall of details- record notes (audio or video) to accompany a photo in a listed schedule</li> </ul>	\$2.99
First Then Visual Schedule	<ul style="list-style-type: none"> <li>▶ Audio-visual prompting tool for scheduling daily events or steps to complete an activity</li> <li>▶ Visual schedules provide positive behavioral supports</li> <li>▶ Completely customizable (e.g. record their own voice, add their own images)</li> </ul>	\$9.99
Sleep Cycle	<ul style="list-style-type: none"> <li>▶ Uses accelerometer to record movement during sleep</li> <li>▶ Tracks sleep quality and rhythms</li> </ul>	\$9.99
Grocery IQ	<ul style="list-style-type: none"> <li>▶ Make shopping lists, aisle-by-aisle, mini-lists for usual and unusual purchases</li> <li>▶ Ability to scan bar codes (with mobile camera) or use the predictive search feature</li> </ul>	\$9.99
iPrompts	<ul style="list-style-type: none"> <li>▶ Create picture-and-text task sequences for multi-step activities, create choice sets and activity schedules</li> </ul>	\$49.99
My Med Schedule	<ul style="list-style-type: none"> <li>▶ Web-based application that sends text alarms as reminders for taking medications</li> </ul>	free
iDress for Weather	<ul style="list-style-type: none"> <li>▶ Provides images of clothing and weather conditions daily</li> <li>▶ Clearly displays the daily temperature (daily highs and lows)</li> <li>▶ Ability to customize the closet using personalized images or photos</li> </ul>	\$1.99
Visules	<ul style="list-style-type: none"> <li>▶ Communicates checklists and individual cues using text, images, and color</li> </ul>	\$4.99

<b>School</b>		
Stories2lear	▶ Create personalized social stories using photos, texts, and audio messages	\$13.99
Math Magic	▶ Addition, subtraction, multiplication and division with visual supports, solution choices, reinforcers and rewards (star system) ▶ Levels can be adjusted to customize for the child; can also activate a timer ▶ Has a very simple design and vibrant colors	\$ .99
myHomework	▶ Allows one to keep track of their homework, classes, projects and tests ▶ Design of application resembles day to day notebook separated by colorful sticky pads that mark the pages ▶ Notifies you when you have upcoming assignments by numbering them on your application icon ▶ Can transfer homework or class entries to friends and email work reminders	free
Awesomenote	▶ Note taking application and to-do manager ▶ Able to customize with themes with different folder icons, colors, fonts, and paper backgrounds ▶ Can send notes with photo attachments as emails, Post-it styled notes, as well as synchronization with Google Docs and Evernote	\$3.99
Dragon Dictation	▶ Speak into a microphone and have it type what you say ▶ Voice recognition to speak, see and edit text ▶ Can share on clipboard, text and email ▶ Can also dictate status updates to social networks (Facebook and Twitter)	free
Evernote	▶ Create text, photo and audio notes that synchronize with your computer ▶ Add, sync, access, and share files (PDF, Word, Excel, PowerPoint, etc)	free
<b>Visual</b>		
Big Names	▶ With large, high-contrast text, it's easier to select and call a person from your contact list ▶ Supports both portrait and landscape orientation ▶ Has English, German, Japanese and French language support	\$1.99
iBraille	▶ Application translates English to Braille and vice-versa	free
Eyeglasses	▶ Ideal application for individuals who are farsighted, those who have reading glasses, bifocals, or for anyone who needs to see more clearly ▶ Uses an autofocus camera to clearly display text or imagery ▶ Can choose between 2x, 4x, 6x or 8x magnification and hold iPad (as well as iPod touch or iPhone) about 5 inches away from object that needs to be magnified	\$2.99
<b>Hearing</b>		
iHear Dialer	▶ Dial phone numbers without looking at the keypad ▶ Move fingers over keypad to hear phone number digits, then select digit by releasing ▶ Able to choose between two voices (Alex and Jules) ▶ Can dial last 6 previous numbers (history)	\$1.99
Voice Controls	▶ After holding down your home button, speak voice controls to your iPad to make calls, play music, etc.	
<b>Other</b>		
EpDetect	▶ For Windows mobile phones with accelerometers and SMS texting ▶ Detects seizure activity and sends text alarm to caregiver	free
Instamapper	▶ GPS tracker with mapping- allows you to track a cellphone route and send your location to another phone or PC	free
Nav4All	▶ Navigation system for driving or walking (mobile phone navigation) ▶ Has a tracking and tracing feature available (allows viewing of vehicle movements)	free
iVideoCamera	▶ Allows recording of video ▶ Includes 20 live effects to record video with	\$0.99
iCounselor: OCD	▶ Provided by iCounselor to help to resist obsessions and learn skills ▶ Rate the frequency and strength of the OCD (obsessive compulsive disorder) thoughts on a color coded scale with 0 being none and 10 being continual, very difficult to resist ▶ Can then choose 1/10 calming activities then select 1/10 ways to change those thoughts ▶ Then can select one method for avoiding and resisting those obsessions/rituals ▶ iCounselor is also available for Anger, Eating Disorders, Anxiety and Depression	\$0.99

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## Managing Wandering for People With Autism

*Author Irene van der Zande has been featured as a child safety expert by USA Today, CNN, Today Moms, and The Wall Street Journal. She is the author of [Bullying: What Adults Need to Know and Do to Keep Kids Safe](#), the [Kidpower Safety Comics](#) series, and [The Kidpower Book for Caring Adults: Personal Safety, Self-Protection, Confidence, and Advocacy for Young People](#). She is also the executive director and founder of [Kidpower Teenpower Fullpower International](#), a non-profit organization established in 1989 that has protected over two million people of all ages and abilities from bullying, sexual abuse, abduction, and other violence through workshops, consultation, and educational resources.*

The following article provides suggestions for parents from both Kidpower and Autism Speaks about how to protect their children with autism who are prone to wander or to suddenly put themselves in harm's way. Most parents can empathize with the rush of terror that one feels for any threat to their child's safety. This anxiety is compounded many times over when you have a child with autism.

As one worried mother said, "My son is a persistent escape artist. Once he had opened the window and was getting ready to jump out. His father caught him mid-air in the nick of time—he runs headlong towards streets and he is so fast!"

The overwhelming fear when your child disappears or abruptly becomes dangerously out of your reach can be heart stopping. We see the potential hazards but often people with autism and young children don't see the world the same way we do. And our priorities are different. Their safety and well-being are the most important things in our lives. Unless they have learned differently, acting on their impulses is usually what is most important to them in the moment.

For their safety and our peace of mind, understanding the causes of wandering, making safety plans, and teaching skills can be a tremendous help in managing wandering for people with autism.

### Findings from the Wandering Study

The [Wandering Study](#) conducted by researchers for Autism Speaks provides important analysis and documentation of the issues caused by wandering for families with autism.

The study found that the belief that children with autism wander off because of inattentive parenting is a myth. Siblings of kids with autism were found to be far less likely to wander after the age of four. Also wandering was found to increase with autism severity and to happen from many different places. Children with autism wandered from their own homes, homes they were visiting, school, and stores.

Motivations for wandering were found to include:

- heading to a favorite place
- the joy of running or exploring,
- seeing something interesting,
- escaping an anxious situation,
- getting away from uncomfortable sensory stimuli, or
- pursuing a special interest.

Finally, the study documented the tremendous anxiety caused by wandering. Over half the parents (56% reported that this was their child's most stressful behavior, and yet half the parents said that they had

received no training or guidance about how to address this problem.

Knowing what to do is important because wandering increases risks to a child of being hit by a car, drowning, or being harmed by a person.

### **Teaching Safety Rules and Skills to Help Prevent Wandering**

People with autism tend to think in concrete, literal terms. Consistent definitions and ongoing practice of concrete, specific safety rules and skills can help them to develop an understanding about how we want them to act in different situations.

“See the boundary”, “Wait”, “Check First”, “Stop”, “Turn around”, and “Stay Together” are concepts and skills that can help to prevent wandering. You can help your child to develop safety habits for using these skills by:

- Defining physical boundaries and the rules that go with these boundaries as concretely and consistently such as the door, the room, the house, the sidewalk, the driveway, the yard, and the street.
- Teaching safety skills as soon as possible.
- Practicing and rehearsing the skills and reinforcing the boundaries by role-playing common problems.
- Reviewing the plan using the skills before you go anywhere.
- Providing constant reminders of when to use these skills with rewards for doing so.

For those who relate to books or stories, we recommend creating personal books with a social story. These can be as simple as four pieces of paper stapled together with stick figure drawings with one sentence on each page following this plot:

- A neutral statement of the situation - “Darla likes to run down the sidewalk.”
- The problem - “Darla’s mom gets worried and upset.”
- The solution - “Darla will Check First before she runs – and Wait at the corner.”
- The happy ending - “Everyone is safe and has fun.”

One common problem is that family members, teachers, and professionals will often use highly varying words and ideas to explain about safety, which can be confusing for anyone who is learning something new or changing unsafe habits, especially someone with autism or other literal thinkers.

Our [Kidpower Safety Signs](#) were originally created as a tool for showing core safety concepts in a very simple form so that everyone who is responsible for the safety of a person with autism can work together to help this individual develop skills more effectively. They are memorable that many of the signs are now being used in all our programs both for the general public and people with special needs. These Safety Signs create a common language that makes it easy and fun for everyone, everywhere, to use the same words, gestures, and ideas about staying safe with people.

Whether you use our Safety Signs or other symbols or gestures that work for your family, school, or organization, Kidpower’s four keys to teaching safety skills are Simplicity, Consistency, Repetition, and Relevance. This means:

1. Make it simple – because simple things are easier to remember.
2. Be consistent – because consistent messages make more sense.
3. Repeat the rules and practices a lot– because successful behavior makes understanding and skills stronger and turns them into habits.
4. Make it relevant – because people learn a skill faster when it seems useful and familiar.

As one parent wrote, “With our son, we go over the rules every day. Now it’s to a point where he’s saying the rules back to us. When we go out, he’s right by my side at all times.”



## Learning How to “Wait”

Remembering to “Wait” can keep your child from leaving a place unexpectedly.

To teach how to “Wait”, you can use any concrete symbol that makes where your child needs to “wait” very clear, including:

- Red tape across doors or floors.
- A big red Wait or Stop Sign by the door.
- Making a “No Circle” – a circle with a diagonal line through it – for anywhere that it is not okay to go without holding a known adult’s hand –the front door, the classroom door, the back yard gate, etc.

By understanding your own child, you can create strategies that work because they are relevant and used consistently.

- “My son LOVES duct tape. We finally realized that he treats red duct tape like a stop sign. So, we put tape lines on the sidewalk and he won’t cross them.”
- “From home? We kept his shoes where he couldn’t get to them, because he wouldn’t leave without them.”
- “I look at things from my child’s sneakiest perspective.”
- “We use the term ‘safe spot’. That meant waiting on the front porch to start (when we were leaving the house). Then it became anywhere we were...so when at the grocery ‘safe spot’ was the grocery cart...‘Hand on the safe spot’ or if we went to the water park ‘The blue steps are the safe spot’”.

Extra locks and alarms are also sometimes necessary to ensure that a child with autism does not go outside so parents can get some sleep or relax:

- “We installed double-bolt locks on all exterior doors.”
- “Chain locks up high and out of reach.”
- “Alarms on the doors and windows of our house

## Learning How To “Stay Together”

When a child knows to “Stay Together” with you, getting separated through wandering becomes far less likely. To teach how to “Stay Together” when you go out, you can:

- Make a plan that you are going to “Stay Together” before you leave and review each time before you go out.
- Play games where you move in different directions and your child sticks to your side like glue.
- Teach the Kidpower Safety Sign for “Stay Together” or create your own sign and practice using with examples of places where temptations might be likely such as the mall or Farmer’s Market.
- Practice calling the child’s name and having her or him answer, “I am here.”
- Practice calling, “Come here, \_\_\_\_\_” and have the child come to you immediately to get a small reward.
- Play games like “Red Light/Green Light” using the words, “Stop. Walk. Run” instead, getting rewards for following the commands.

Other “Stay Together” solutions parents have found include:

- “During any nighttime event, I hang a glow stick around his neck so I can see him and hang one around my neck too so that he can see me too.”

- “I put him on a leash in a store, never mind the dirty looks.”
- “Our OT worked on defining boundaries: room, house, yard, block, neighborhood, etc. We worked a lot on when to ‘stop’ and ‘turn around’ as my son stimmed on running down sidewalks in only one direction.”

### Learning How to “Check First” Before Changing the Plan

When we go out in the world, especially as children become more independent, keeping track of them can be challenging. Kids are safest if we know where they are, who is with them, and what they are doing. Learning to follow the Kidpower safety rule of “Check First Before You Change Your Plan” can help to prevent wandering or other unsafe behavior but often leads to disappointment. Be sure to reward your child each time she or he Checks First with you.

To teach how to “Check First”, you can:

- Teach the Kidpower Safety Sign for “Check First” or create your own sign and practice using with role-plays of common temptations, such as seeing a puppy or a favorite game.
- Give lots of relevant examples using pictures or actual situations or stories of when to Check First – someone you don’t know calls your name, you see a funny puppet,
- Make signs by the door with reminders and drawings: “STOP! Did you ask to go outside?”

Figuring out how to balance your child’s independence with safety often requires step-by-step solutions that depend on your child’s abilities, ages, and skills.

- "Gotta start young. From the beginning I have taught my girl to stay right by me at all times. I also walk away from her in the store to see how she reacts. She always looks for me and stays where she's at because she knows I'll come right back."
- "We made simple maps for our son and brought him around the neighborhood to show him where he could go. We also bought a set of good walkie talkies and taught him to press the button and talk. Next he got a bike and the boundaries were expanded still checking in on the walkie talkies. Now he has a cell. We encourage him to text us a picture so we can see where he is but mostly he stays within 5 blocks."

The article [A Five Step Plan For Preparing Your Child for More Independence](#) describes a realistic process for deciding when to let your child go somewhere without adult protection.

### When a Child Wanders: Getting Help And Getting Found

If our child does wander off, we want this child to get help and be found as quickly as possible, before any problems occur.

Sometimes electronic solutions are the best answer:

- “I take a pic on my phone of her every day in her outfit and every night as soon as she puts her pjs on. If she is lost outside of the house, it will be the best resource for those helping to search.”
- “We use a GPS tracker. It's small enough to attach to a belt loop and gives us real time updates on our phones. It gives me big peace of mind that I can find him if he does wander.”
- “Project Lifesaver. As a fireman/paramedic that has had to respond on numerous urban searches, both with and without the equipment, it is hands down the best. As long as Indianapolis has had it, we have ALWAYS been able to find the wanderer.
- “There is a GPS device sold at radio shack and other electronic retailers that can be sewn into clothing or otherwise attached to your child. You can then set a boundary, for example, the inside of your home or your yard. If your child wanders out of the boundary, you will receive a text message alerting you to his/her whereabouts.”

For families where this works, a dog can be a useful member of the protection team surrounding your child.

- “We broke down and bought a German shepherd and trained him to locate our son anytime he wandered off. It took several games of hide and seek, but 4 years later our furry puppy still likes to play hide and seek with our son. We usually have him found within minutes.”
- “We got my son a service dog and it was the best decision we ever made.”

Enlisting help from the community by giving information is also important.

- “When we moved to a new neighborhood the first thing we did was go door to door with a flyer with a picture of our guy and our number on it. The message we put out was "if you see this boy unaccompanied please contact us as soon as possible". The response from our new neighbors was good, most were interested in knowing more about autism and happy to help if they could. We were very lucky to have such wonderful neighbors.
- “I am working on a special flyer (as recommended by autism orgs I have researched) which I will keep in his backpack and will share it with the police & fire departments so they are aware of his behaviors, capabilities and challenges...in case he wanders away.”
- “My son wears a charm bracelet on his ankle for summer with my cell & his med on the other side. I also had puzzle piece key chains engraved with the same. One is hooked to his back pack & one goes on his coat.”

The most effective plans often require a variety of steps. As one parent wrote, “My little one wandered once and scared the hell out of me. So, I ordered the Big Red Safety Box from the NAA. Also, installed locks on the tops of the doors, put his name in his undies, did the smart phone decals on his shirts, put an ID inside his helmet, notified all my neighbors, and held a meet and greet with the local Fire Department and Police Department so they know my son and the risk of living with autism now!”

Finally, children who can understand that they are lost can learn what to do to get help. This article describes how to make a safety plan and practice skills, [“What If I get Lost?”](#)

### **Managing Your Own Feelings**

It’s normal for most parents to worry about their kids – and especially likely if you have a child with autism or other special needs – and even more likely if your child has a tendency to wander.

Anxiety and worry only make you miserable without making your child safer. Instead of worrying, give yourself the gift of peace of mind. Use these ideas and find your own solutions so you can:

- Take reasonable actions to prevent wandering.
- Teach your child what to do and not do as much as possible.
- Enlist the help of others in protecting your child.

And then take care of yourself. Try to be safe in your imagination by reminding yourself of the steps you have taken.

There are no guarantees. Sometimes no matter what you do, your child might wander off or get hurt. This does not mean you are a bad parent – it just means that you had some bad luck.

Be kind to yourself – and get emotional support from family, friends, and wonderful organizations like Autism Speaks.

Remember that your child will be safe most of the time because of your preparation, protection, and love.

## I HAVE MEDI-CAL – HOW DO I GET TREATMENT FOR AUTISM?

### Medi-Cal to Cover Behavioral Health Treatment for Autism Starting September 15, 2014

**Who is eligible?** Any individual age 0-21 who has Medi-Cal as primary or secondary insurance. We hope to get the benefit extended above age 21 in the future.

**What kind of treatment can I get?** The benefit includes “Behavioral Health Treatment (BHT), including applied behavior analysis and other evidence-based behavior intervention programs that develop, or restore, to the maximum extent practicable, the functioning of an individual with a diagnosis of Autism Spectrum Disorder (ASD). Treatment includes the development of a treatment plan at the expense of the Managed Care Plan. Speech, occupational and physical therapy are also covered benefits through Medi-Cal as well as psychology, psychiatry and counseling services

**How do I get treatment?** Contact your Medi-Cal Managed Care Plan (e.g., Kaiser, Anthem BlueCross, LACares, Health Plan of San Mateo) . The number is on the back of your insurance card. Ask the plan what is necessary to get behavioral health treatment. Also contact your primary care physician and ask for a referral for behavioral health treatment.

**What if I don’t have a Medi-Cal Managed Care Plan but have a fee for service plan instead or don’t know what kind of Medi-Cal plan I have?** Call the number on the back of your insurance card and ask how to access treatment. Ask your primary Care physician how to access treatment. E-mail [ABAInfo@dmhc.ca.gov](mailto:ABAInfo@dmhc.ca.gov) for help.

**How long will it take to get treatment?** Managed Care Plans must provide timely access to care which for mental health services is 10 calendar days. The creation of this benefit is fast, so all plans may not have provider networks established on day one and some patience may be required at first. However plans are still obligated to provide timely treatment even if they need to arrange care through a non-network provider.

**What if I don’t have a diagnosis?** Ask your managed care plan and primary care for a referral for an autism evaluation. Again waiting lists are not permissible longer than 10 days. Your child should be able to start treatment without a comprehensive diagnostic evaluation if an evaluation is not immediately available. If you have any problems, file a complaint as described below.

**What if my child is already getting treatment through the regional center?** At this time your child will continue to be able to receive treatment through the regional center for the foreseeable future. If you are not receiving adequate treatment from the regional center, contact your managed care plan and request treatment.

**What if my child is already getting treatment from another source?** Your child will be entitled to continuity of care up to 12 months. You should request to keep your same provider.

**What do I do if I am put on a waiting list, told treatment is not available or have any other problem?**

1. File a written grievance with your health plan, send by certified mail and save a copy. If you can’t do that, call and file a grievance and get a reference number. If you do not file a grievance there is no evidence you are dissatisfied. You are much more likely to get treatment if you file a complaint. The health plan cannot retaliate.
2. Send an e-mail to the Department of Health Care Services ([ABAInfo@DHCS.CA.GOV](mailto:ABAInfo@DHCS.CA.GOV)) and register a complaint
3. Please CC the advocates ([MediCalAutismBenefit@yahoo.com](mailto:MediCalAutismBenefit@yahoo.com)) on the e-mail to DHCS so we can track the issues families encounter and develop solutions.
4. Call the Department of Managed Health Care (DMHC) at 888- 466-2219 and register a complaint. It is important that you do all the above steps because it will not be clear which agency regulates your plan’s provider network.

## **Section 3: How to Work with Professionals**

*Articles about the service providers associated with the specific disability*





## *How is Autism Treated?*

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Treatment for autism is usually a very intensive, comprehensive undertaking that involves the child's entire family and a team of professionals. Some programs may take place in your home. These may be based in your home with professional specialists and trained therapists or may include training for you to serve as a therapist for your child under supervision of a professional. Some programs are delivered in a specialized center, classroom or preschool. It is not unusual for a family to choose to combine more than one treatment method.

*The terms “treatment” and “therapy” may be used interchangeably. The word “intervention” may also be used to describe a treatment or therapy.*

We've provided an overview of many different treatment methods for autism in this section of your kit. The descriptions are meant to give you general information. Your pediatrician, developmental pediatrician, or a social worker who specializes in the treatment of children with autism, can make suggestions or help you prioritize therapies based on your child's comprehensive evaluation. Once you have narrowed down some choices of appropriate therapies for your child, you will want to explore more comprehensive information before making a commitment to one. For many children, autism is complicated by medical conditions, biological issues and symptoms that are not exclusive to autism. Children with other disorders, such as Articulation Disorder, **Apraxia, Seizures, GI problems**, etc. might require some of the same therapies.

Examples of these treatments are **Speech & Language Therapy, Occupational Therapy**, or the care of a **Neurologist** or **Gastroenterologist**. For this reason, we've included information here to explain the treatments for the core symptoms of autism and the treatments for associated symptoms and biological and medical conditions. Intensive treatments for autism's core symptoms address the social, communication and behavioral issues at the heart of autism. Treatments for associated symptoms address challenges commonly associated with autism, but not specific to the disorder. If your child has biological or medical conditions, such as allergies, food intolerances, gastrointestinal issues or sleep disturbances, these will need to be treated too. Treatment programs may combine therapies for both core symptoms and associated symptoms. Your child's treatment program will depend on his needs and strengths. Some of these therapies may be used together. For example, if medical causes for sleep disturbances are ruled out, a behavioral intervention might be used to address them. Occupational Therapy or Speech & Language Therapy are often integrated into one of the intensive therapy programs described here as core symptom therapies. Many children benefit from receiving multiple therapies provided in the same learning format. The National Research Council recommends that, during the preschool period, children with autism should receive approximately 25 hours of structured intervention per week. Intervention can include time spent in a developmental program, speech-language therapy, occupational therapy, one-on-one or small group intervention, and parent-delivered intervention.



*Therapies include a wide range of tools, services and teaching methods you may choose to use to help your child reach his or her potential. The recommended number of hours of structured intervention is 25 hours per week during the preschool period.*

*For school-age children the therapy may be provided during the school day and if necessary, there may be additional therapy provided outside of the school day. The type of services (i.e. Speech and Language Therapy), the duration of the service (i.e. 45 minutes), the frequency of the service (i.e. 3 days/week), as well as the location (in school) will be provided as part of your child's Individual Education Program*

Many of the therapy methods described here are very complex and will require more research on your part before you get started. Whenever possible, observe the therapies in action. Talk to experienced parents and make sure you have a thorough understanding of what is involved before beginning any therapy for your child.





# Treatment for the Core Symptoms of Autism

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Most families use one type of intensive intervention that best meets the needs of their child and their parenting style. The intensive interventions described here require multiple hours per week of therapy, and address behavioral, developmental, and/or educational goals. They are developed specifically to treat autism. During the course of treatment, it may be necessary to reevaluate which method is best for your child.

*Therapies are not always delivered in a “pure format.” Some intervention providers who work primarily in one format may use successful techniques from another format.*

Before we get into the types of therapies available, it is helpful to take a step back and look at the bigger picture. Although research and experience have revealed many of the mysteries surrounding autism, it remains a complex disorder that impacts each child differently. However, many children with autism have made remarkable breakthroughs with the right combination of therapies and interventions. Most parents would welcome a cure for their child, or a therapy that would alleviate all of the symptoms and challenges that make life difficult for them. Just as your child’s challenges can’t be summed up in one word, they can’t be remedied with one therapy. Each challenge must be addressed with an appropriate therapy. No single therapy works for every child. What works for one child may not work for another. What works for one child for a period of time may stop working. Some therapies are supported by research showing their efficacy, while others are not. The skill, experience, and style of the therapist are critical to the effectiveness of the intervention.

Before you choose an intervention, you will need to investigate the claims of each therapy so that you understand the possible risks and benefits for your child. At first, all of these techniques, ABA, VB, PRT, DTT, ESDM, among others, may seem like alphabet soup to you. You may be confused now, but you will be surprised at how quickly you become “fluent” in the terminology of autism therapies.

*For information on different treatment options, turn to the glossary in this kit, or visit [www.AutismSpeaks.org](http://www.AutismSpeaks.org) and view the National Standards Project produced by the National Autism Center at [www.nationalautismcenter.org/about.national.php](http://www.nationalautismcenter.org/about.national.php)*

*You should also see your pediatrician for more information, so that you can be confident you are making informed choices as you begin to narrow down your options.*

Behavior analysis was originally described by B.F. Skinner in the 1930’s. You may have learned about Skinner and “operant conditioning” when you studied science in school. The principles and methods of behavior analysis have been applied effectively in many circumstances to develop a wide range of skills in learners with and without disabilities.



# *What is Applied Behavioral Analysis?*

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Since the early 1960's, applied behavior analysis, or ABA, has been used by hundreds of therapists to teach communication, play, social, academic, self-care, work and community living skills, and to reduce problem behaviors in learners with autism. There is a great deal of research literature that has demonstrated that ABA is effective for improving children's outcomes, especially their cognitive and language abilities. Over the past several decades, different models using ABA have emerged, all of which use behavioral teaching. They all use strategies that are based on Skinner's work. ABA is often difficult to understand until you see it in action. It may be helpful to start by describing what all of the different methods of ABA have in common. ABA methods use the following three step process to teach:

- An **antecedent**, which is a verbal or physical stimulus such as a command or request. This may come from the environment or from another person, or be internal to the subject;
- A resulting **behavior**, which is the subject's (or in this case, the child's) response or lack of response to the antecedent;
- A **consequence**, which depends on the behavior. The consequence can include positive reinforcement of the desired behavior or no reaction for incorrect responses. ABA targets the learning of skills and the reduction of challenging behaviors. Most ABA programs are highly-structured. Targeted skills and behaviors are based on an established curriculum. Each skill is broken down into small steps, and taught using prompts, which are gradually eliminated as the steps are mastered. The child is given repeated opportunities to learn and practice each step in a variety of settings. Each time the child achieves the desired result, he receives positive reinforcement, such as verbal praise, or something else that the child finds to be highly motivating, like a small piece of candy. ABA programs often include support for the child in a school setting with a one-on-one aide to target the systemic transfer of skills to a typical school environment. Skills are broken down into manageable pieces and built upon so that a child learns how to learn in a natural environment. Facilitated play with peers is often part of the intervention. Success is measured by direct observation and data collection and analysis – all critical components of ABA. If the child isn't making satisfactory progress, adjustments are made.

One type of ABA intervention is Discrete Trial Teaching (also referred to as DTT, "traditional ABA" or the Lovaas Model, for its pioneer, Dr. Ivar Lovaas). DTT involves teaching individual skills one at a time using several repeated teaching trials and reinforcers that may or may not be intrinsically related to the skill that is being taught.

## *Who provides traditional ABA or DTT?*

A board certified behavior analyst specializing in autism will write, implement and monitor the child's individualized program. Individual therapists, often called "trainers," (not necessarily board certified) will work directly with the child on a day-to-day basis.



## *What is a typical ABA therapy session like?*

■ Sessions are typically 2 to 3 hours long, consisting of short periods of structured time devoted to a task, usually lasting 3 to 5 minutes. 10 to 15 minute breaks are often taken at the end of every hour. Free play and breaks are used for incidental teaching or practicing skills in new environments. Done correctly, ABA intervention for autism is not a "one size fits all" approach consisting of a "canned" set of programs or drills. On the contrary, every aspect of intervention is customized to each learner's skills, needs, interests, preferences, and family situation. For those reasons, an ABA program for one learner might look somewhat different than a program for another learner. An ABA program will also change as the needs and functioning of the learner change.

## *What is the intensity of most ABA programs?*

■ 25 to 40 hours per week. Families are also encouraged to use ABA principals in their daily lives.

*To find more information on ABA go to  
The Association for Behavior Analysis International  
[www.ABAinternational.org](http://www.ABAinternational.org)  
Behavior Analyst Certification Board  
[www.BACB.com](http://www.BACB.com)*

## *What is the difference between Traditional ABA and other interventions that involve ABA, such as Verbal Behavior, Pivotal Response Treatment, and the Early Start Denver Model?*

■ Verbal Behavior and Pivotal Response Treatment therapies use the methods of ABA, but with different emphasis and techniques. All of these methods use the three step process described above.

## *What is Pivotal Response Treatment?*

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■ **Pivotal Response Treatment, or PRT,** was developed by Dr. Robert L. Koegel, Dr. Lynn Kern Koegel and Dr. Laura Shreibman, at the University of California, Santa Barbara. Pivotal Response Treatment was previously called the Natural Language Paradigm (NLP), which has been in development since the 1970s. It is a behavioral intervention model based on the principles of ABA.

PRT is used to teach language, decrease disruptive/self-stimulatory behaviors, and increase social, communication, and academic skills by focusing on critical, or "pivotal," behaviors that affect a wide range of behaviors. The primary pivotal behaviors are motivation and initiation of communications with others. The goal of PRT is to produce



positive changes in the pivotal behaviors, leading to improvement in communication skills, play skills, social behaviors and the child's ability to monitor his or her own behavior. Unlike the Discrete Trial Teaching (DTT) method of teaching, which targets individual behaviors based on an established curriculum, PRT is child-directed. Motivational strategies are used throughout intervention as often as possible. These include varying tasks, revisiting mastered tasks to ensure the child retains acquired skills, rewarding attempts, and using direct and natural reinforcement. The child plays a crucial role in determining the activities and objects that will be used in the PRT exchange. For example, a child's purposeful attempts at functional communication are rewarded with reinforcement related to their effort to communicate (e.g. if a child attempts a request for a stuffed animal, the child receives the animal).

### *Who provides PRT?*

■ Some psychologists, special education teachers, speech therapists and other providers specifically are trained in PRT. The Koegel Autism Center offers a PRT Certification program.

### *What is a typical PRT therapy session like?*

■ Each program is tailored to meet the goals and needs of the child, and also to fit into the family routines. A session typically involves six segments during which language, play, and social skills are targeted in structured and unstructured formats. Sessions change to accommodate more advanced goals and the changing needs as the child develops.

### *What is the intensity of a PRT program?*

■ PRT programs usually involve 25 or more hours per week. Everyone involved in the child's life is encouraged to use PRT methods consistently in every part of the child's life. PRT has been described as a lifestyle adopted by the affected family.

*Where can I find more information on PRT?*

*UCSB Koegel Autism Center*

[www.education.ucsb.edu/autism](http://www.education.ucsb.edu/autism)

*UCSD Autism Research Program*

<http://psy3.ucsd.edu/~autism/prttraining.html>

## *What is Verbal Behavior?*

■ Another behavioral (based on the principles of ABA) therapy method with a different approach to the acquisition and function of language is **Verbal Behavior** (VB) therapy. In his 1957 book, "Verbal Behavior," B.F. Skinner (see previous section on ABA) detailed a functional analysis of language. He described all of the parts of language as a system. Verbal Behavior uses Skinner's analysis as a basis for teaching language and shaping behavior.



Skinner theorized that all language could be grouped into a set of units, which he called operants. Each operant he identified serves a different function. He listed echoics, mands, tacts and intraverbals as the most important of these operants. The function of a “mand” is to request or obtain what is wanted. For example, the child learns to say the word “cookie” when he is interested in obtaining a cookie. When the child is given the cookie, the word is reinforced and will be used again in the same context. In a VB program, the child is taught to ask for the cookie any way he can (vocally, sign language, etc.). If the child can echo the word, he will be motivated to do so in order to obtain the desired object. The operant for labeling an object is called a “tact.” For example, the child says the word “cookie” when seeing a picture and is thus labeling the item. In VB, more importance is placed on the mand than on the tact, theorizing that “using language” is different from “knowing language.” An “intraverbal” describes conversational or social, language. Intraverbals allow children to discuss something that isn’t present. For example, the child finishes the sentence, “I’m baking...” with the intraverbal fill-in “Cookies.” Intraverbals also include responses to questions from another person, usually answers to “wh-” questions (Who? What? When? Where? Why?). Intraverbals are strengthened with social reinforcement.

VB and classic ABA use similar behavioral formats to work with children. VB is designed to motivate a child to learn language by developing a connection between a word and its value. VB may be used as an extension of the communication section of an ABA program.

### *Who provides VB?*

- VB therapy is provided by VB-trained psychologists, special education teachers, speech therapists and other providers.

### *What is the intensity of most VB programs?*

- VB programs usually involve 30 or more hours per week of scheduled therapy.
- Families are encouraged to use VB principals in their daily lives.

*For Information on VB go to  
Cambridge Center for Behavioral Studies  
[www.behavior.org/vb](http://www.behavior.org/vb)*

## *What is the Early Start Denver Model (ESDM)?*

■ The Early Start Denver Model (ESDM) is a developmental, relationship-based intervention approach that utilizes teaching techniques consistent with applied behavior analysis (ABA). The goals are to foster social gains – communicative, cognitive, and language – in young children with autism, and to reduce atypical behaviors associated with autism. ESDM is appropriate for children with autism or autism symptoms who are as young as 12 months of age, through preschool age. The



content of intervention for each child comes from assessment using a comprehensive ESDM Curriculum Checklist which covers all domains of early development: Cognitive Skills, Language, Social Behavior, Imitation, Fine and Gross Motor Skills, Self-help Skills and Adaptive Behavior. Adults delivering ESDM focus on behaviors involved in capturing and holding children's attention, fostering their motivation for social interaction through highly enjoyable routines, using joint play activities as the medium for treatment, developing nonverbal and verbal communication, imitation, and joint attention, and using reciprocal, turn-taking exchanges inside joint activity routines to foster social learning. Based on a NIH-funded clinical trial, ESDM has been shown to be effective for increasing IQ, language, social skills, and adaptive behavior when delivered for at least one year.

### *Who provides ESDM?*

■ ESDM can be provided by ESDM-trained behavior analysts, special education teachers, speech therapists and other providers. Parents can also be taught to use ESDM strategies.

### *What is the intensity of most ESDM programs?*

■ ESDM programs usually involve 20-25 or more hours per week of scheduled therapy. Families are encouraged to use ESDM strategies in their daily lives.

### *What is a typical ESDM session like?*

■ ESDM is designed to be highly engaging and enjoyable for the child, while skills are systematically taught within a naturalistic, play-based interaction. Some skills are taught on the floor during interactive play while others are taught at the table, focusing on more structured activities. As the child develops social skills, peers or siblings are included in the therapy session to promote peer relationships. ESDM can be delivered in the home, the clinic, or a birth-to-three or developmental preschool setting.

*To find more information on ESDM:*

*ESDM Manual: Rogers, SJ., & Dawson, G. (2009). Play and Engagement in Early Autism: The Early Start Denver Model. New York: Guilford.*

*ESDM curriculum checklist: Rogers, SJ and Dawson, G. (2009) The ESDM Curriculum Checklist.*

*Information about training in the ESDM model can be found at this website:*

[www.ucdmc.ucdavis.edu/edsl/esdm/training.html](http://www.ucdmc.ucdavis.edu/edsl/esdm/training.html)

## *What is Floortime (DIR)?*

■ **Floortime** is a specific therapeutic technique based on the **Developmental Individual Difference Relationship Model (DIR)** developed in the 1980s by Dr. Stanley Greenspan. The premise of Floortime is that an adult can help a child expand his circles of communication by meeting him at his developmental level and



building on his strengths. Therapy is often incorporated into play activities – on the floor. The goal of Floortime is to help the child reach six developmental milestones that contribute to emotional and intellectual growth:

- *Self regulation and interest in the world*
- *Intimacy or a special love for the world of human relations*
  - *Two-way communication*
  - *Complex communication*
    - *Emotional ideas*
    - *Emotional thinking*

In Floortime, the therapist or parent engages the child at a level the child currently enjoys, enters the child's activities, and follows the child's lead. From a mutually shared engagement, the parent is instructed how to move the child toward more increasingly complex interactions, a process known as "opening and closing circles of communication."

Floortime does not separate and focus on speech, motor, or cognitive skills but rather addresses these areas through a synthesized emphasis on emotional development. The intervention is called Floortime because the parent gets down on the floor with the child to engage him at his level. Floortime is considered an alternative to and is sometimes delivered in combination with ABA therapies.

### *Who provides Floortime?*

■ Parents and caregivers are trained to implement the approach. Floortime-trained psychologists, special education teachers, speech therapists, occupational therapists may also use Floortime techniques.

### *What is a typical Floortime therapy session like?*

■ In Floortime, the parent or provider joins in the child's activities and follows the child's lead. The parent or provider then engages the child in increasingly complex interactions. During the preschool program, Floortime includes integration with typically developing peers.

### *What is the intensity of most Floortime programs?*

■ Floortime is usually delivered in a low stimulus environment, ranging from two to five hours a day. Families are encouraged to use the principals of Floortime in their day to day lifestyle.

*To find more information on Floortime go to:*

*Floortime Foundation*

[www.Floortime.org](http://www.Floortime.org)

*Stanley Greenspan*

[www.StanleyGreenspan.com](http://www.StanleyGreenspan.com)

*Interdisciplinary Council on Developmental and*



## *What is Relationship Development Intervention (RDI)?*

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Like other therapies described in this handbook, RDI is a system of behavior modification through positive reinforcement. RDI was developed by Dr. Steven Gutstein as a parent-based treatment using dynamic intelligence. The goal of RDI is to improve the long-term quality of life of individuals with autism by helping them improve their social skills, adaptability and self-awareness. The six objectives of RDI are:

- **Emotional Referencing:** The ability to use an emotional feedback system to learn from the subjective experiences of others.
- **Social Coordination:** The ability to observe and continually regulate one's behavior in order to participate in spontaneous relationships involving collaboration and exchange of emotions.
- **Declarative Language:** The ability to use language and non-verbal communication to express curiosity, invite others to interact, share perceptions and feelings and coordinate your actions with others.
- **Flexible Thinking:** The ability to rapidly adapt, change strategies and alter plans based upon changing circumstances.
- **Relational Information Processing:** The ability to obtain meaning based upon the larger context; Solving problems that have no "right-and wrong" solutions.
- **Foresight and Hindsight:** The ability to reflect on past experiences and anticipate potential future scenarios in a productive manner.

The program involves a systematic approach to working on building motivation and teaching skills, focusing on the child's current developmental level of functioning. Children begin work in a one-on-one setting with a parent. When they are ready, they are matched with a peer at a similar level of relationship development to form a "dyad." Gradually, additional children are added to the group, as well as the number of settings in which children practice, in order to help the child form and maintain relationships in different contexts.

### *Who provides RDI?*

Parents, teachers and other professionals can be trained to provide RDI. Parents may choose to work together with an RDI-certified consultant. RDI is somewhat unique because it is designed to be implemented by parents. Parents learn the program through training seminars, books and other materials and can collaborate with an RDI-certified consultant. Some specialized schools offer RDI in a private school setting.

### *What is a typical RDI therapy session like?*

In RDI, the parent or provider uses a comprehensive set of step-by-step, developmentally appropriate objectives in everyday life situations, based on





different levels, or stages, of ability. Spoken language may be limited in order to encourage eye contact and non-verbal communication. RDI may also be delivered in a specialized school setting.

### *What is the intensity of most RDI programs?*

- Families most often use the principles of RDI in their day to day lifestyle. Each family will make choices based on their child.

*Where can I find more information on RDI?*

*Connections Center*

[www.RDIconnect.com](http://www.RDIconnect.com)

## *What is Training and Education of Autistic and Related Communication Handicapped Children (TEACCH)?*

■ TEACCH is a special education program, developed by Eric Schopler, PhD and his colleagues at the University of North Carolina in the early 1970s. TEACCH's intervention approach is called "Structured Teaching." Structured Teaching is based on what TEACCH calls the "Culture of Autism." The Culture of Autism refers to the relative strengths and difficulties shared by people with autism that are relevant to how they learn. Structured Teaching is designed to capitalize on the relative strengths and preferences for processing information visually, while taking into account the recognized difficulties. Children with autism are assessed in order to identify emerging skills, and work then focuses on these skills to enhance them. In Structured Teaching, an individualized plan is developed for each student. The plan creates a highly structured environment to help the individual map out activities. The physical and social environment is organized using visual supports so that the child can more easily predict and understand daily activities and as a result, respond in appropriate ways. Visual supports are also used to make individual tasks understandable.

### *What does TEACCH look like?*

■ TEACCH programs are usually conducted in a classroom setting. TEACCH-based home programs are also available and are sometimes used in conjunction with a TEACCH-based classroom program. Parents work with professionals as co-therapists for their children so that TEACCH techniques can be continued in the home.

### *Who provides TEACCH?*

■ TEACCH is available at the TEACCH centers in North Carolina, and through TEACCH-trained psychologists, special education teachers, speech therapists and other providers in other areas of the country.



To find more information on TEACCH go to: *TEACCH Autism Program*  
[www.TEACCH.com](http://www.TEACCH.com)

## *What is Social Communication/ Emotional Regulation/ Transactional Support (SCERTS)?*

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SCERTS is an educational model developed by Barry Prizant, PhD, Amy Wetherby, PhD, Emily Rubin and Amy Laurant. SCERTS uses practices from other approaches including ABA (in the form of PRT), TEACCH, Floortime and RDI. The SCERTS Model differs most notably from the focus of “traditional” ABA by promoting child-initiated communication in everyday activities. SCERTS is most concerned with helping children with autism to achieve “Authentic Progress,” which is defined as the ability to learn and spontaneously apply functional and relevant skills in a variety of settings and with a variety of partners. The acronym “SCERTS” refers to the focus on:

- “SC” Social Communication - Development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults.
- “ER” Emotional Regulation - Development of the ability to maintain a well-regulated emotional state to cope with everyday stress, and to be most available for learning and interacting.
- “TS” Transactional Support - Development and implementation of supports to help partners respond to the child’s needs and interests, modify and adapt the environment, and provide tools to enhance learning (e.g., picture communication, written schedules, and sensory supports). Specific plans are also developed to provide educational and emotional support to families, and to foster teamwork among professionals.

### *What does a SCERTS session look like?*

The SCERTS Model favors having children learn with and from other children who provide good social and language models in inclusive settings, as much as possible. SCERTS is implemented using transactional supports put in place by a team, such as environmental accommodations, and learning supports, like schedules or visual organizers.

### *Who provides SCERTS?*

SCERTS is usually provided in a school setting by SCERTS-trained special education teachers or speech therapists.

*Where can I find more information on SCERTS?*

*SCERTS*

[www.SCERTS.com](http://www.SCERTS.com)



## *Treatment for Biological & Medical Conditions Associated with Autism*

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■ The next section of this handbook covers a number of what are frequently called “related services.” These services are therapies that address symptoms commonly associated with autism, but not specific to the disorder.

### *Speech-Language Therapy (SLT)*

■ Speech-Language Therapy (SLT) encompasses a variety of techniques and addresses a range of challenges for children with autism. For instance, some individuals with autism are unable to speak. Others seem to love to talk. They may have difficulty understanding information, or they may struggle to express themselves. SLT is designed to coordinate the mechanics of speech and the meaning and social value of language. An SLT program begins with an individual evaluation by a speech-language pathologist. The therapy may then be conducted one-on-one, in a small group, or in a classroom setting. The therapy may have different goals for different children. Depending on the verbal aptitude of the individual, the goal might be to master spoken language or it might be to learn signs or gestures to communicate. In each case, the aim is to help the individual learn useful and functional communication. SLT is provided by Speech-Language Pathologists who specialize in children with autism. Most intensive therapy programs address speech-language therapy as well.

### *Occupational Therapy (OT)*

■ Occupational Therapy (OT) brings together cognitive, physical and motor skills. The aim of OT is to enable the individual to gain independence and participate more fully in life. For a child with autism, the focus may be on appropriate play, learning, and basic life skills. An occupational therapist will evaluate the child's development as well as the psychological, social and environmental factors that may be involved. The therapist will then prepare strategies and tactics for learning key tasks to practice at home, in school, and other settings. Occupational therapy is usually delivered in 30 minute to one hour sessions with the frequency determined by the needs of the child. Goals of an OT program might include independent dressing, feeding, grooming, and use of the toilet, as well as improved social, fine motor and visual perceptual skills. OT is provided by Certified Occupational Therapists.

### *Sensory Integration (SI)*

■ Sensory Integration (SI) therapy is designed to identify disruptions in the way the individual's brain processes movement, touch, smell, sight and sound, and help he or she process these senses in a more productive way. It is sometimes used alone, but is often part of an occupational therapy program. It is believed that SI does not teach higher-level skills, but rather enhances sensory processing abilities, allowing the child to be more available to acquire higher-level skills. Sensory Integration therapy might be



used to help calm your child, to help reinforce a desired behavior, or to help with transitions between activities. Therapists begin with an individual evaluation to determine your child's sensitivities. The therapist then plans an individualized program for the child, matching sensory stimulation with physical movement, to improve the way the brain processes and organizes sensory information. SI therapy often includes equipment such as swings, trampolines and slides. Certified Occupational and Physical Therapists provide Sensory Integration Therapy.

## *Physical Therapy (PT)*

■ Physical Therapy (PT) is focused on any problems with movement that cause functional limitations. Children with autism frequently have challenges with motor skills such as sitting, walking, running or jumping. PT can address poor muscle tone, balance and coordination. A physical therapist will start by evaluating the developmental level and abilities of the child. Once they identify the individual's challenges, the physical therapists design activities that target those areas. PT might include assisted movement, various forms of exercise, and orthopedic equipment. Physical therapy is usually delivered in 30 minute to one hour sessions by a Certified Physical Therapist, with the frequency determined by the needs of the child.

## *Social Skills*

■ Individuals with autism have a great deal of difficulty with social interactions. In recent years, social skills training, in both one-on-one and peer group settings, has become a very common treatment for facing this particular challenge. Social skills taught during training sessions range from simple skills like eye contact, to more difficult skills like inviting a peer for a play date. Studies have shown that this type of intervention program can significantly improve social competence and social skill development. Though social skills training is not an official or certified form of therapy, professionals like social workers, speech therapists, and psychologists often focus largely on improving social skills when treating both children and adults with autism. In addition, parents, family members, and other caregivers can be taught effective ways to help improve the social skills of their loved ones with autism inside and outside the home on a regular basis.

## *Picture Exchange Communication System*

■ Picture Exchange Communication System (PECS) is a learning system that allows children with little or no verbal ability to communicate using pictures. PECS can be used at home, in the classroom or in a variety of other settings. A therapist, teacher or parent helps the child to build a vocabulary, and to articulate desires, observations or feelings by using pictures consistently. The PECS program starts by teaching the child how to exchange a picture for an object. Eventually, the individual is shown how to distinguish between pictures and symbols and use them to form sentences. Although PECS is based on visual tools, verbal reinforcement is a major component, and verbal communication is encouraged. Standard PECS pictures can be purchased as a part of a manual, or pictures can be gathered from photos, newspapers, magazines, or other books.

## *Auditory Integration Therapy*

■ Auditory Integration Therapy (AIT), sometimes called Sound Therapy, is sometimes



used to treat children with difficulties in auditory processing or sound sensitivity. Treatment with AIT involves the patient listening to electronically modified music through headphones during multiple sessions. There are different methods of AIT, including the Tomatis and Berard methods. While some individuals have reported improvements in auditory processing as a result of AIT, there are no credible studies that demonstrate its effectiveness or support its use.

## *Gluten Free, Casein Free Diet (GFCF)*

■ Many families of children with autism are interested in dietary and nutritional interventions that might help some of their children's symptoms. Anecdotal evidence suggests that removal of gluten (a protein found in barley, rye, and wheat, and in oats through cross contamination) and casein (a protein found in dairy products) from an individual's can be helpful for reducing some symptoms of autism. The theory behind this diet is that proteins are absorbed differently in some children. Children who benefit from the GFCF diet experience physical and behavioral symptoms when consuming gluten or casein, rather than an allergic reaction. While there have not yet been sufficient scientific studies to support the effectiveness of the GFCF diet for reducing symptoms of autism, many families report that dietary elimination of gluten and casein has helped regulate bowel habits, sleep activity, habitual behaviors, and contributed to the overall progress of their children. Because no specific laboratory tests can predict which children will benefit from dietary intervention, many families choose to try the diet with careful observation by the family and the intervention team.

Families choosing a trial of dietary restriction should make sure their child is receiving adequate nutrition by consulting their pediatrician or a nutrition specialist. Dairy products are the most common source of calcium and Vitamin D for young children in the United States. Many young children depend on dairy products for a balanced, regular protein intake. Alternative sources of these nutrients require the substitution of other food and beverage products, with attention given to the nutritional content. Substitution of gluten free products requires attention to the overall fiber and vitamin content of a child's diet. Vitamin supplements may have both benefits and side effects. Consultation with a dietician or physician is recommended for the healthy application of a GFCF diet. This may be especially true for children who are picky eaters.

## *What about Other Medical Interventions?*

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■ Right now you are eager to do everything possible to help your child. Many parents in your position are eager to try new treatments, even those treatments that have not yet been scientifically proven to be effective. Your hopes for a cure for your child may make you more vulnerable to the lure of untested treatments. It is important to remember that just as each child with autism is different, so is each child's response to treatments. It may be helpful to collect information about a therapy that you are interested in trying, and speak with your pediatrician, as well as your intervention team members, in order to discuss the potential risks/benefits and establish measurable outcomes as well as baseline data. If you talk to the parents of older children with autism, they can provide you with a history of therapies and biomedical interventions that have been promised to be cures for autism over the years. Some of them may have been helpful to a small number of children. Upon further study, none of them, so far, has



turned out to be a cure for the vast majority. We do know that many children get better with intensive behavioral therapy. There is a large body of scientific evidence to support this theory. It makes sense to focus on getting your child engaged in an intensive behavioral program before looking at other interventions.

## *Is There A Cure?*

Is recovery possible? You may have heard about children who have recovered from autism. Although relatively rare, it is estimated that approximately 10% of children lose their diagnosis of autism. The factors that predict which children lose their diagnosis are unknown. Children initially diagnosed with autism who lose their diagnosis often have residual difficulties in the areas of hyperactivity, anxiety, and depressive symptoms. Recovery from autism is usually reported in connection with intensive early intervention, but it is unknown how much or which type of intervention works best, or whether the recovery can be fully credited to the intervention. You may also hear about children who reach “best outcome” status, which means they score normally on tests for IQ, language, adaptive functioning, school placement, and personality, but have mild symptoms on some personality and diagnostic tests. Recent epidemiology studies estimate that approximately 60% of children with autism have IQ’s above 70 by age 8 (70 is the cut-off point for developmental delay). Presently, there is no reliable way of predicting which children will have the best outcomes. In the absence of a cure or even an accurate prognosis of your child’s future, do not be afraid to believe in your child’s potential. All children with autism will benefit from intervention. All will make very significant, meaningful progress.

## *How Do I Choose the Right Intervention?*

The two articles that follow may provide helpful information for you as you choose between methods of therapies for your child.

### **Alleviate Stress by Actively Pursuing the Right Intervention**

*From Overcoming Autism by Lynn Kern Koegel, PhD and Claire LaZebnik*

*It’s scary to have to question your own child’s potential, but the best way to relieve your fears is to take action with productive interventions. The first step is to be informed. Talk to people you trust – parents who’ve been there, experts in the field, doctors you have a relationship with, and so on. There are a lot of fly-by-night procedures that prey on distraught parents who will do anything for their child. Make sure that the interventions you’re using are scientifically sound and well documented. Make sure they’ve been tested with many children with autism and that they’ve been replicated by other experts and clinics. Also, make sure you understand their limitations – some interventions only work on a small number of symptoms or on a small subgroup of children with autism. If you’re going to spend time and money for interventions, be informed about the degree and extent of the change they may bring about.*



## Understanding Your Child's Learning Style

*From Does My Child Have Autism? by Wendy Stone, PhD, & Theresa Foy DiGeronimo, M.Ed*

*Finding the right intervention program begins with an understanding of your child's learning style – which is quite different from the learning style of other children. You probably realize this as you've tried to get your child with autism to wave bye-bye using the same teaching strategies you used with your other children – that is, demonstrating the action, providing a verbal prompt by saying "wave bye-bye" and even moving his or her hand to demonstrate what to do. But when that approach didn't seem to be working, you probably started to think that your child was being stubborn or uncooperative. After all, you're teaching simple skills using methods that worked very well for your other children. But the reality is that your child isn't being bad; he or she just has a different learning style from your other children. This difference in learning styles isn't apparent only when you try to teach children with autism; it's also evident in the way they learn (or don't learn) on their own. There are lots of things that children without autism seem to learn effortlessly, without being taught, but that children with autism don't pick up on as easily. For example, young children without autism somehow learn, without explicit teaching, how to use a pointing gesture to let you know what they want or to indicate where they want you to look. They learn to follow your point or eye gaze to figure out what you're looking at or what you're interested in. They figure out on their own how to use eye contact and facial expressions to convey their feelings—as well as to understand the meaning of your facial expressions and tone of voice. Social-communicative behaviors and skills like these just don't come as naturally to young children with autism and often need to be taught explicitly.*









## Questions to Ask Marketers of Autism Interventions

Written by Daniel Mruzek, PhD, BCBA-D

Families with a member with autism know that there is a vast selection of potential treatment options. Some of these treatments are purported to address one or more of the core features of autism (e.g., a pill that supposedly improves spoken communication), while others are marketed as treatments for other difficulties commonly experienced by individuals with autism (e.g., exercises to reduce tantrums). Many of these interventions are expensive and time-consuming, and some are potentially dangerous (e.g., hyperbaric chamber). Like other “purchasing” decisions, families need to consider treatment options carefully.

How does one investigate these options? One way is to ask a trusted expert (e.g., a physician, psychologist, behavior analyst). Another way is to reference science-based “quick reference” guides, such as ASAT’s web-based [Summaries of Scientific Research on Interventions on Autism](#). A third way to investigate the soundness of a potential autism treatment is to ask the marketer or practitioner polite, but direct questions about the treatment that they recommend. Below, we have eight questions that you can ask the marketer of an autism intervention that might be helpful as you make treatment decisions.

Family members might be a little apprehensive about asking marketers of purported autism interventions direct questions about the state-of-the-science of their interventions; however, a legitimate interventionist will appreciate good questions and the resultant opportunities to partner with the family in the development of effective treatments. This process of direct questioning is one way we can practice scientific skepticism – a quality of the scientific process that makes it such a powerful means of positive change. Also, this process increases the likelihood that hard-earned family income is spent wisely in maximizing the independence of their member with autism.

Additional information on selecting treatments for your family member is found in an article entitled, *The Road Less Traveled: Charting a Clear Course for Autism Treatment*, authored by David Celiberti and colleagues and found [here](#).

Question	Notes
1 “What is the rationale or theory underlying this intervention?”	The marketer’s description of the rationale should sound reasonable. Be aware of scientific-sounding explanations that sound impressive but, upon consideration, are not plausible, logical or realistic.
2 “Do any scientific papers (e.g., peer-reviewed journal articles) indicate that the proposed treatment is effective?”	Watch out for references to testimonials, opinion pieces, case studies and “articles” that have been posted without scientific peer review. They can provide an illusion of legitimacy and effectiveness when, in fact, no scientific evidence may exist.
3 “What should the benefits of the intervention look like, and how will we monitor/measure these?”	The practitioner or marketer should be able to offer specific and observable potential benefits and an objective method of measuring for gains for your family member.
4 “Do you have (de-identified) data sets from your practice that suggests that this treatment	If the practitioner cannot point to scientific studies supporting their proposed intervention, ask to see treatment data for other individuals with whom they have worked in the past. The practitioner should not provide you with the name or

- works?”
- other identifiers of the individual they treated- just a good description of what they did and data that demonstrate functional improvement for the individual.
- 5 “What are the possible side effects, and how will we monitor/measure these?”
- Many interventions have potential unintended consequences that should be considered beforehand and, if concerning, monitored for during implementation.
- 6 “How much time does it take, and when will it be done?”
- Even a brief intervention (such as a 10-minute exercise during the school day) adds up to substantial time lost for other, possibly important activities (e.g., skill building); therefore, one question to consider is what will not be done during implementation of the proposed intervention?
- 7 “How will we monitor treatment data for my family member?”
- Watch for the use of objective (i.e., measurable) data to assess for possible treatment effectiveness. And, of course, objective data are of no use if the intervention team is not regularly reviewing these data and incorporating these data into treatment decisions. Will the data “pile up” in a folder or drawer, or will the intervention team maintain a schedule of ongoing review?
- 8 “How difficult is it to implement this treatment correctly?”
- Beware of proposed interventions that require that they be implemented “just right” in order to be helpful. This quality can be an excuse that marketers use when unwary consumers question a lack of progress. Usually, an effective intervention is helpful even if not implemented with perfect fidelity.

## Section 4: Resources

*Where to go for further information*







## Autism Spectrum Disorders Key Terms and Acronyms

### 504 Plans

See Academic adjustments

### ABA

See applied behavior analysis

### A-B-C Cycle of Behavior

Understanding of antecedents, behaviors and consequences provides three points of intervention – antecedent interventions (preventive), behavior interventions – (teaching a skill) and consequence interventions – (reinforcement of new skills).

### ABC Antecedent, Behavior, Consequence

What happens before, during and after the behavior (ABC), specifying setting(s).

### Academic adjustments

Such modifications to the academic requirements as are necessary to ensure that such requirements do not discriminate or have the effect of discriminating, on the basis of [disability] against a qualified ... applicant or student [with a disability]. Modifications may include changes in the length of time permitted for the completion of degree requirements, substitution of specific courses required for the completion of degree requirements, and adaptation of the manner in which specific courses are conducted. [34 C.F.R. § 104.44(a) Section 504 of the Rehabilitation Act]

### Academic content standards

Statements of what all students should know and be able to do in subject areas; No Child Left Behind Act requires academic content standards specify what all students are expected to know and be able to do, contain coherent and rigorous content, and encourage the teaching of advanced skills

### Accommodations

Alterations to the environment, equipment, or format of a curriculum to allow equal access to the content; accommodations do not alter the actual content of the material being taught

### Adaptive behavior

An individual's manner of dealing with the demands of daily life, including self-care skills, organizational skills, basic interpersonal skills, and conformance to community standards (obeying rules, taking responsibility, etc)

### Adult services

Services needed for people when they reach adulthood; often including, but not limited to, assistance in finding a job, assistance in the home, assistance at work, employment-related supports such as housing and transportation, and provision of various therapies or medications

### Age-appropriate transition assessment

Ongoing process of collecting data on the individual's needs, preferences, and interests as they relate to the demands of current and future work, education, living, and personal and social environments

### Aggression

Refers to a range of behaviors that can result in both physical and psychological harm to oneself, other or objects in the environment. The expression of aggression can occur in a number of ways, including verbally, mentally and physically.

### Aging out

Term applying to a student who is nearing the end of his/her school career based on chronological age

### Americans with Disabilities Act (ADA) (Americans with Disabilities Amendment Act 2008)

Federal disability antidiscrimination legislation passed in 1990 to guarantee basic civil rights to people with disabilities; similar to those provided to individuals on the basis of race, sex, national origin and religion; guarantees equal opportunities for individuals with disabilities in areas of employment, transportation, government services, telecommunications, etc.

### Antecedent:

An event or activity that immediately precedes a behavior

### Applied behavior analysis (ABA)

Based on behavioral theory, a prescribed set of interventions designed to improve socially relevant behaviors and skills

### ASD Nest Model

A public school program that has (a) a curriculum that includes instruction in necessary and meaningful areas (common core included); (b) administrators who support and advocate for their staff and students; (c) highly qualified professionals who value collaboration and have the skills and support to develop meaningful instructional programs; (d) families who are valued and informed; and (e) a system whose goal is "SUCCESS FOR ALL".



## **Assistive technology**

Means any device or service that is used to increase, maintain, or improve the functional capabilities of a child with a disability

## **Assistive technology (AT) service**

As defined by the IDEA, any service that directly assists a learner with a disability in the selection, acquisition, or use of an assistive technology device

## **Attention**

The ability to concentrate as needed

## **Attention-deficit/hyperactivity disorder (ADHD)**

Any of a range of behavioral disorders in children that are characterized by symptoms that includes poor concentration, an inability to focus on tasks, difficulty in paying attention, and impulsivity. A person can be predominantly inattentive (often referred to as ADD), predominantly hyperactive-impulsive, or a combination of these two.

## **Attribution**

The ability to connect cause and effect, and to understand why things happen to us

## **Auditory processing**

How the brain processes and interprets what is heard through the ear

## **Authentic environment**

Authentic environments provide a realistic context to an authentic task; is the actual environment in which a task is performed

## **Autism Spectrum Disorders (ASD)**

ASD is a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a "spectrum disorder" that affects individuals differently and to varying degrees. There is no known single cause for autism. *ASD is a lifelong disorder with no single cause.*

## **Baseline**

Data collected prior to starting an intervention

## **Behavior Intervention Plan (BIP)**

A plan that defines how a setting will be changed to improve a learner's behavioral success

## **Body language**

Information about a person's thoughts or feelings that is unconsciously conveyed through physical mannerisms

## **Brain Stem**

"Body brain": breathing, heart rate, digestion, muscle tension

## **Career and technical education**

Sequence of courses that provide opportunities for students to become proficient in relevant technical knowledge and skills as well as the core academic standards

## **Career / Vocational assessment**

Global term used to designate any and all types of evaluation or measurement of vocational functioning; may include both formal and informal methodologies

## **Cartooning**

Cartooning is a method that takes an abstract social situation and makes it into a concrete visual representation. When a student is involved in social circumstances that didn't go as expected, drawing it out as a cartoon with speech and thought bubbles can help the student "see" what happened. The cartooning allows the student to better understand the interactions, gain perspective on what others were thinking, and identify the hidden rules that were involved

## **Cause and effect**

The ability to connect how a certain action leads to a certain reaction

## **Center for Applied Special Technology (CAST)**

An educational research & development organization that works to expand learning opportunities for all individuals through Universal Design for Learning

## **Central Coherence**

The ability to see the big picture from a collective set of details



**Child with a disability**

IDEIA TITLE I / A / 602 / 3

(3) Child with a disability.--

(A) In general.--The term 'child with a disability' means a child--

(i) with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this title as 'emotional disturbance'), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and (ii) who, by reason thereof, needs special education and related services.

**Cognition**

Conscious mental activity, including thinking, perceiving, reasoning, and learning

**Collaboration**

Working together for a common goal

**Common Core's Curriculum Maps**

Curriculum planning documents that teachers can use as a resource for making their own more detailed curricula and lesson plans. They translate the new Common Core State Standards for Kindergarten through 12th grade into unit maps that teachers can use:

- to plan their year,
- craft their own more detailed curriculum,
- and create lesson plans.

**Common Core State Standards**

These standards define the knowledge and skills students should have within their K-12 education careers so that they will graduate high school able to succeed in entry-level, credit-bearing academic college courses and in workforce training programs. The standards:

- Are aligned with college and work expectations;
- Are clear, understandable and consistent;
- Include rigorous content and application of knowledge through high-order skills;
- Build upon strengths and lessons of current state standards;
- Are informed by other top performing countries, so that all students are prepared to succeed in our global economy and society; and
- Are evidence-based.

**Common Core Standards Initiative**

A state-led effort coordinated by the National Governors Association Center for Best Practices (NGA Center) and the Council of Chief State School Officers (CCSSO). The Common Core State Standards provide a consistent, clear understanding of what students are expected to learn, so teachers and parents know what they need to do to help them. The standards are designed to be robust and relevant to the real world, reflecting the knowledge and skills that our young people need for success in college and careers

**Common triggers**

The events or situations that precede an inappropriate response to that situation

**Communication**

The deliberate conveying of information to another person

**Communication disorder**

Stuttering, impaired articulation, language or voice impairment that adversely affects a child's educational performance

**Community-based instruction**

Integrating students into their community as part of their educational curriculum and instruction

**Community-based services**

Services provided in a community setting; preferably in the individual's home community

**Community of Practice (CoP)**

Concept referring to the process of social learning that occurs when people who have a common interest in some subject or problem collaborate over an extended period to share ideas, find solutions, and build innovations. This work is meant to expand knowledge and/or improve practice

**Competitive employment**

Working either full- or part-time, for at least minimum wage or an equivalent payment after leaving high school in:

- a) an integrated competitive employment setting
- b) the military
- c) a community-based supported employment setting
- d) family business (e.g., farm)
- e) self-employment



### **Connecting cause and effect**

Although students with autism may be able to repeat a rule or a consequence about a social situation, they may not connect how the rule or consequence can apply to them personally. A universal support for all students is teaching why a social behavior can result in a given effect. This can be done using a social situation that has happened, or when teaching subject matter in language arts or history, or by using video clips of social situations and discussing what was the cause and effect. Embedding the teaching of cause and effect as it applies to social situations naturally makes it an ongoing experience, rather than a separate topic to teach.

### **Consequence**

The response (positive or negative) to a behavior

### **Consequence interventions**

Strategies that address the stimuli (i.e. a verbal response, the acquisition of a reinforcing item or an activity) that contingently follow a behavior. Two strategies can be used when problem behavior occurs more frequently than appropriate behavior: increase reinforcement for appropriate behavior, and decrease reinforcement received for engaging in problem behavior.

### **Contextual factors**

Those factors in the learning environment that determine whether or not the student can be successful. Information regarding those factors collected both indirectly and directly, allows school personnel to predict the circumstances under which the problem behavior is likely and not likely to occur. For instance, if the student acts out when given a worksheet, it may not be the worksheet that caused the acting-out, but the fact that the student does not know what is required and thus anticipates failure or ridicule

### **Contingency**

Something that occurs as a result of another factor

### **Cortex**

“Thinking brain”: reasoning, logic, impulse control, following plans

### **Counseling**

Advice or guidance provided by a trained, licensed professional such as a psychiatrist, psychologist, or a social worker; e.g., rehabilitative counseling, career counseling, guidance counseling, mental health counseling, peer counseling

### **Courses of study**

A multi-year description of coursework necessary to achieve the student’s desired post-school goals, from the student’s current to anticipated exit year

### **Crisis Behavior**

Crisis behavior occurs when a student in distress loses the ability to exert self-control and an outburst or meltdown occurs. Crisis behavior is:

- 1) The disruption of classroom activities requiring the immediate intervention on the part of the teacher, or
- 2) Behavior that escalates to present an imminent danger to the student or others

### **Crisis Management**

Set of procedures applied in handling, containment, and resolution of an emergency in planned and coordinated steps

### **Data**

A well-developed assessment plan and a properly executed functional behavioral assessment should identify the contextual factors that contribute to behavior. Determining the specific contextual factors for a behavior is accomplished by collecting information on the various conditions under which a student is most and least likely to be a successful learner. Information collected both indirectly and directly, allows school personnel to predict the circumstances under which the problem behavior is likely and not likely to occur. This information collection becomes the data upon which decisions can be based

### **Data based decision-making**

Instructional decisions based on student performance data

### **Data collection**

Any method of recording behavioral data for subsequent analysis

### **Dialogue Guides**

Tools for building shared understanding and shared implementation efforts through conducting interactive discussions that seek common ground and encourage application

### **Disability**

... a physical or mental impairment that substantially limits one or more of the major life activities of such individual; a record of such an impairment; or being regarded as having such impairment [Americans with Disabilities Act Sec. 12102(2)]; forms the basis of civil rights





of people with disabilities and is used as the core definition of disability for all federal government legal and regulatory compliance responsibilities as it relates to both physical and programmatic access

### **Division on Career Development and Transition**

A Division of the Council for Exceptional Children (CEC), the Division on Career Development and Transition (DCDT) focuses on the career development of individuals with disabilities and/or who are gifted and their transition from school to adult life

### **Duration**

How long a behavior last

### **Dynamic Learning Maps Alternative Assessment System Consortium (DLMAASC)**

A consortium of 13 states that are focused on:

- Common Core Essential Elements (CCEE) and achievement level descriptors (ALD) of levels of demonstration of the common core
- Learning maps
- Inclusion of instructionally-relevant tasks; do more than test concepts; they also model good instruction.
- Dynamic assessment
- Universal design
- Evidence-centered design including cognitive labs
- Structured scaffolding
- Professional development to understand learning maps and choose appropriate tasks for students

### **Echolalia**

The repetition of sounds, words, or phrases heard in the environment

### **ELA**

English Language Arts

### **Emotional regulation**

Control of emotions, stabilization, ability to recognize your emotional state and make changes as necessary

### **Empathy**

The ability to understand how another person feels or what he/she may be thinking; sometimes referred to as “putting yourself in another person’s shoes.” Sometimes referred to as theory of mind

### **Empirically supportive intervention**

Educational practices/instructional strategies supported by relevant scientific research studies or research-based “best practice”

### **Employment**

See competitive employment

### **Essential Elements**

The characteristics that define an entity, practice or program and are fundamental and necessary. Community of Practice on Transition Essential Elements is a document that describes the characteristics that define a community of practice (CoP) on Secondary Transition.

### **Evidence-based practice**

Educational practices/instructional strategies supported by relevant scientific research studies or research-based “best practice”

### **Executive Functioning**

A collection of brain processes which are responsible for planning, flexibility, abstract thinking, rule acquisition, initiating appropriate actions and inhibiting inappropriate actions, and selecting relevant sensory information

### **Externship**

An externship is an opportunity for a student to engage in practice based learning, by actively participating in a field of interest. It is very similar to an internship, but is generally of a shorter duration and focuses on giving someone a taste of a potential career. Unlike an internship, there is less focus on job training. Students may or may not receive academic credit for an externship, depending on the institution they attend.

### **Fading**

Decreasing the level of assistance needed to complete a task or activity

### **Fair Labor Standards Act (FSLA)**

Applies to employees engaged in interstate commerce or employed by an enterprise engaged in commerce or in the production of goods for commerce, unless the employer can claim an exemption from coverage; established a national minimum wage, guaranteed time and a half for overtime in certain jobs, and prohibited most employment of minors



### **Free Appropriate Public Education (FAPE)**

Special education and related services that – (a) Are provided at public expense, under public supervision and direction, and without charge; (b) Meet the standards of the SEA, including the requirements of this part; (c) Include an appropriate preschool, elementary school, or secondary school education in the State involved; and (d) Are provided in conformity with an individualized education program (IEP) that meets the requirements of §§ 300.320 through 300.324. [IDEA 2004 Part B Regulations, §3

### **Fidelity of implementation**

Implementation of an intervention, program, or curriculum according to research findings and/or on developers' specifications

### **Flourishing**

Positive mental health

### **Fluency**

A stage of learning, during which a person can perform an activity with little to no thought

### **Formative Assessment/Evaluation**

Classroom/curriculum measures of student progress; monitors progress made towards achieving learning outcomes; informs instructional decision-making

### **Frequency**

How often a behavior occurs during a set period of time

### **Functional Behavior Assessment (FBA)**

A comprehensive and individualized strategy designed to:

- Identify why a behavior occurs and the context in which it occurs
- Develop and implement a plan to modify variables that maintain the behavior
- Teach new behaviors that serve the same function using positive interventions

### **Functional communication**

The ability to receive or to convey a message, regardless of the mode, to communicate effectively and independently in a given environment

### **Functional life skills**

Skills required for participation in typical life spaces of adults in our society: vocational, educational (post-secondary educational environments), domestic, recreational, and community environments

### **Functional performance**

A term that is generally understood to refer to skills and activities that are not considered academic, i.e. routine activities of everyday living

### **Functional vocational assessment**

Assessment to determine a student's strengths, abilities, and needs in an actual or simulated work setting or in real work sample experiences; process should occur over time with repeated measures using situational assessments

### **Function of the behavior**

The function of the behavior may usually be described as an effort to "get something", or to "avoid and/or escape something"

### **Generalization**

Transferring a skill/behavior into other environments

### **Graphic organizer**

Strategy for graphically representing concepts and providing links among concepts.

### **Grounding assumptions**

The Grounding Assumptions of the Community of Practice on Secondary Transition describes the fundamental assumptions that ground the implementation of the Secondary Transition requirements in federal law (NCLB SEC. 1001 (2)) and IDEA 2004 [34 CFR 300.1 (a)] [20 U.S.C. 1400(d)(1)(A)]

### **Guiding principles**

The unifying beliefs that are the foundation for the collaborative efforts of the Community of Practice on Secondary Transition

### **Hidden curriculum**

A term used to describe the unwritten social rules and expectations of behavior that we all seem to know, but were never taught



## High Quality Professional Development

A coordinated set of learning experiences designed to improve student outcomes through evidence-based and standards-based instruction.



### Hypothesis

An educated guess based on data collected.

### IDEA – Individuals with Disabilities Education Improvement Act of 2004

Original passage in 1975; latest reauthorization 2004; federal statute relative to education and services to students with disabilities ages 3 through 21

### IDEA Part B

Generally serves children who have an identified disability and are eligible for special education services (ages 3 and older)

### IDEA Part C

Generally serves infants and toddlers who are eligible to receive early intervention services (Birth through age 2)

### IDEA Partnership

IDEA Part D federal grant; collaboration of 55 plus national organizations, technical assistance providers, and State and local organizations and agencies, together with the Office of Special Education Programs (OSEP)

### Incredible 5-Point Scale

The Incredible 5-Point Scale was developed by Kari Dunn Buron and Mitzi Curtis. The scale is a visual representation using numbers, words, and/or pictures to represent levels of a social behavior and can include supports to help at each level. The process works well with students with Asperger Syndrome/High Functioning Autism, but can work with students on the more classic end of the spectrum also

### Independent living skills

Skills or tasks that contribute to the successful independent functioning of an individual in adulthood; may address leisure recreation, home maintenance and personal care, and community participation

### Individualized education program (IEP)

A written plan developed by a specified group of people who know the child, including parents, that specifies the services and accommodations the school will provide to a child with a disability

### Individualized education program (IEP) team

... group of individuals ... responsible for developing, reviewing, or revising an IEP for a child with a disability. [IDEA 2004 Part B Regulations, §300.23(a)]

**Individualized family service plan (IFSP) –** Individualized family service plan or IFSP means a written plan for providing early intervention services to an infant or toddler with a disability under this part and the infant's or toddler's family that—

- a) Is based on the evaluation and assessment;
- b) Includes the content;
- c) Is implemented as soon as possible once parental consent for the early intervention services in the IFSP is obtained; and
- d) Is developed in accordance with the IFSP procedures.

### Individual Transition Plan (ITP)

A transition plan developed for every child transitioning from the Early Intervention Program to programs under Education Law, Section 4410, and/or to other early childhood services. The transition plan shall include procedures to prepare the child and family for changes in service delivery.

### Individualized plan for employment (IPE)

Legal document outlining a plan leading a person with a disability to competitive employment; utilized by Vocational Rehabilitation

### Integrated play groups

Based on the work of Pamela Wolfberg, Ph.D., an Integrated Play Group places children with autism and peer partners who have demonstrated capable play experience in a play situation guided by an adult facilitator to teach how to play and socialize with each other

### Interest inventory

Self-assessment tool used in career planning that matches a person's interests, likes, and dislikes with activities and possible career options

### Internship

Expanding and connecting classroom learning in a full-time/part-time supervised work-based setting

Specialized activities that target students' individual needs to develop their knowledge or skills in their area of weakness

### **Intervention strategies**

See Intervention

### **Job analysis**

Identification of the specific tasks and subtasks involved in completing a specific job

### **Job coach**

Person providing assistance to an individual to learn or maintain a job; can include training and support at the job site

### **Job shadowing**

Exploring different occupations and types of work environments by following and watching people actually performing the jobs

### **Joint attention**

Consciously focusing one's attention on the same event or object as another person

### **Least Restrictive Environment (LRE)**

A student who has a disability should have the opportunity to be educated with non-disabled peers, to the greatest extent possible

### **LEA– Local Education Agency**

Refers to a specific school district or a group of school districts in a cooperative or regional configuration

### **Limbic System**

“Feeling brain”: emotions, feeling safe, memory

### **Linguistic**

Related to language

### **Medicaid**

Federal health program for individuals and families with low incomes and resources; an entitlement program jointly funded by the states and federal government, managed by the states; low-income parents, children, seniors, and people with disabilities may be served

### **Medicare**

Federal health insurance program mainly for persons aged 65 or older; some limited benefits for younger persons eligible for Social Security disability benefits for more than two years

### **Mental health**

“a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with people, and the ability to adapt to change and cope with adversity” (U.S. Department of Health and Human Services, 1999, p. 4). Mental health is not merely the absence of mental illness but the presence of something positive

### **Mentoring**

A supportive relationship between a youth or young adult and someone more senior in age and experience, who offers support, guidance, and concrete assistance

### **“Mindblindness”**

Another term for weak Theory of Mind which is difficulty “putting oneself in another person’s shoes” (Baron-Cohen, 1995)

### **Mobility skills**

Ability to travel safely and efficiently from one location to another; any means an individual with a motor impairment ambulates; e.g., walking, wheelchair, using a cane

### **Modification**

Service or support related to a child’s disability that helps him or her to access subject matter and demonstrate knowledge; modifications fundamentally alter the standard or expectation of the task

### **Motivation**

Wanting to partake of an object or activity. Intrinsic desire within one’s self.

### **National Center and State Collaborative Partnership (NCSC)**

A collaboration of 13 states that are focused on:

- Alternate assessments based on alternate achievement standards (AA-AAS)



- To evaluate performance of students who are unable to participate in general state assessments even with accommodations
- Provide mechanism for students with the most significant cognitive disabilities to be included in an educational accountability system
- Based on the grade-level content covered by the general assessment
- Different achievement expectations that are appropriately challenging for students with significant cognitive disabilities
- Curriculum, instruction, and professional development will be made available throughout the project
- Final product to be a summative assessment for students in grades 3 through high school

**National Collaborative on Workforce and Disability for Youth, (NCWD-Y)** The National Collaborative on Workforce and Disability for Youth (NCWD-Y) is a comprehensive technical assistance resource to assist the workforce development community to address issues affecting the employment of youth with disabilities

**Natural reinforcers**

Reinforcers that are logically related to the task at hand For example, if the student points at a book and says “book,” handing him the book is the natural reinforcer. Consequences that increase the likelihood of the reoccurrence of the behavior

**Next Generation Learners Initiative**

An initiative of the Council of Chief State School Officers to create a system of supports that engages each child—from birth through early adulthood, in the totality of his or her circumstance—in learning so they are prepared for life, meaningful work, and citizenship. Concentrates on the elements of education that have direct bearing on students and their learning experiences and focuses on learners and learning, rather than on schools and schooling.

**Nonverbal behaviors**

Deliberate behaviors other than speech/vocalizing

**Nonverbal communication**

Facial expression, gestures, body language, and distance you keep from other people when talking to them. There are some estimates that say as much of 90% of our communication messages come from the nonverbal elements of our communication

**Nonverbal cues**

Facial expression, gestures, and body language that indicate another person’s thoughts, feelings, intentions and beliefs

**Obsessive-compulsive disorder (OCD)**

A chronic anxiety disorder most commonly characterized by obsessive, distressing, repetitive thoughts and related compulsions

**Office of Civil Rights (OCR)**

The Office for Civil Rights ensures equal access to education and to promote educational excellence throughout the nation

**On-the-job-training**

Knowledge and skills a person acquires while in the workplace, doing some activities related to an existing position description

**Operational definition**

Describes a behavior in observable and measurable terms such that any person may identify the behavior when it occurs

**Overt behaviors**

Behaviors that can be observed

**P-16**

A P-16 system integrates a student’s education beginning in preschool (as early as 3 years old) through a four-year college degree

**Paraprofessional (Paraeducator, Instructional assistant)**

Paraprofessionals assist special education teachers with providing special education and related services to students with disabilities

**Partnership for Assessment of Readiness for College and Careers (PARCC)**

A consortium of 25 states and the District of Columbia that are focused on the development of:

- More Meaningful Standards - assessment system will be anchored in the CCSS which are consistent across states, clear to the public, and provide an on-ramp to college and careers
- Higher Quality Tests - will include sophisticated items and performance tasks to measure critical thinking, strategic problem solving, research and writing
- Through-Course Testing - parts of the assessment will be administered at key times during the school year
- Maximize Technology - assessments at most grades will be computer based
- Cross-State Comparability – with adopt common assessments and common performance standards

**Patterns of Behavior**

As data is analyzed, it is often helpful to determine if there are any patterns of behavior, e.g., “when Trish doesn’t get her way, she reacts by hitting someone”

A group of peers that includes an individual with ASD and is structured around a specific purpose such as tutoring or play

### **Performance-based learning**

Performance-based learning puts students at the center of the learning process by enabling demonstration of mastery based on clear and commonly-shared expectations

### **Person-centered planning**

Person-centered Planning (PCP) is a process that assists people with disabilities and their families to plan for the future to enable the individual with a disability to be active and contributing members of the community through structured exercises focusing on the individual's strengths and preferences

### **Personal care assistant**

Provides personal health care related needs to individuals with disabilities, including promoting self-care, independent living, personal health, mobility, and personal finance skills

### **Portfolio**

Collection of evidence representing a person's academic and/or work performance; e.g., papers, pictures, descriptions, recommendations, summary of performance

### **Positive Behavior Supports (PBS)**

Evidence-based practices embedded in the school curriculum/culture/expectations that have prevention focus; teaching, practice, and demonstration of pro-social behaviors. A decision making framework that guides the selection, integration, and implementation of the best evidence practices for improving important academic and behavior outcomes for all students. Services are often organized within a three-tiered approach including universal, targeted and tertiary prevention

### **Positive psychology**

The study of processes and conditions that promote optimal functioning in people including positive affect, positive character strengths, and positive institutions (Seligman & Csikszentmihalyi, 2000)

### **Positive reinforcement**

Presentation of something immediately following a behavior that makes that behavior more likely to occur in the future

### **Positive Youth Development**

Building and improving assets that enable youth to grow and flourish throughout life (Larson, 2000)

### **Postsecondary education/training**

*In-school years:* type of instruction, related service, community experience, development of employment and other post-school adult living objectives, and if appropriate, acquisition of daily living skills, and provision of a functional vocational evaluation, listed in association with meeting the post-secondary goal(s)

*Post-school years:* enrolled full- or part-time for at least 1 complete term or training program at any time since leaving high school in:

- a) post-high school completion program (e.g., GED) or adult basic education program (e.g., independent living training)
- b) short-term education or employment training program (e.g., WIA, Job Corps, certificate program)
- c) vocational-technical school
- d) community college
- e) college/university

### **Postsecondary goal**

...generally understood to refer to those goals that a child hopes to achieve after leaving secondary school; i.e., high school [IDEA 2004 Part B Regulations, §300.320(b), discussion of Final Rule p. 46,668]; a postsecondary goal must have a related annual goal for a student 16 years of age or older, or younger if the state has determined

### **Postsecondary outcomes**

Participation in postsecondary education or competitive employment one year after exiting high school

### **Pre-service training**

Initial teacher training in higher education

### **Pre-vocational**

Preparation for a job; includes teaching job-related skills

### **Present level of academic achievement and functional performance**

Description of current levels of student performance in academic and functional skill areas utilized in developing the individualized education program

See rehearsal below

### **Proactive strategies**

Approach that focuses on ways to eliminate a problem behavior before it becomes a problem

### **Promising practice**

Promising practices have a limited degree of success, but not yet evidence-based. Educators should use with caution and following the literature to ensure the practices develop into research-based or evidence-based

### **Prompts**

Supplemental support to elicit the target behavior

### **Psychological evaluation**

Evaluation of performance and capabilities which uses psychological assessments to guide the establishment of appropriate interventions

### **Psycho-social evaluation**

Assessment of an individual's thoughts, emotions, and interactions with others

### **Punishment**

Events that follow a behavior and decrease the likelihood of the behavior reoccurring

### **Reciprocal interactions/conversation**

Social situations that involve give-and-take or back-and-forth exchanges

### **Referral**

Sending a youth or young adult to another source or provider for advice, treatment, support services, etc.

### **Regression**

A child appears to develop typically but then begins to lose speech and social skills, typically between the ages of 15 and 30 months, and is subsequently diagnosed with autism

### **Rehabilitation Act of 1973**

The federal act that ensures rehabilitation services [see 504 Plan]

### **Rehabilitation counselors**

Rehabilitation counselors work with various state departments and community programs to provide (a) services to persons with disabilities, (b) information to employers about the Americans with Disabilities Act, and (c) collaborate with adult service agencies to provide employment for persons with disabilities

### **Rehearsal/Priming**

Acting out a situation in order to practice skills in a structured, positive environment

### **Reinforcement**

A term used to refer to anything that increases the likelihood that a response will occur. Note that reinforcement is defined by the effect that it has on behavior - it increases or strengthens the behavior

### **Related services**

...transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education [IDEA 2004 Part B Regulations, §300.34(a)]

### **Replacement behavior**

A more acceptable behavior that serves the same purpose as the behavior in question. For example, if the IEP team determines through a functional behavioral assessment that a student is seeking attention by acting-out, they can develop a plan to teach the student more appropriate ways to gain attention, thereby filling the student's need for attention with a replacement behavior that serves the same function as the inappropriate behavior

### **Replacement Skills**

Some student problems are so severe they require direct instruction of new skills to replace the problem behaviors. For example, if the student finds it difficult to control his or her anger, she or he may need to be taught certain skills, such as recognizing the physical signs of anger, using relaxation skills, applying problem-solving skills, and practicing communication skills

### **Research-based practice**

Research-based practice refers to applying research to guide program development and implementation. Practices based on published/peer reviewed research supporting effectiveness of specific strategies



### **Response to Intervention/Response to Instruction/Responsiveness to Intervention (RTI)**

Practice of providing high quality instruction and interventions matched to student need, monitoring progress frequently to make changes in instruction or goals and applying child response data to important educational decisions

### **Rituals/Compulsive Mannerisms**

A repetitive or ritualistic movement, posture, or utterance. Stereotypies may be simple movements such as body rocking, or complex, such as self-caressing, crossing and uncrossing of legs, and marching in place.

### **Role-playing**

Acting out a situation in order to practice skills in a structured, positive environment

### **Scaffolding**

Adjusting the level of support provided based on the child's level of comfort and competence. This can include supports in the form of modeling, prompts, direct explanations, and targeted questions

### **School to Work Opportunities Act (1994)**

Federal act that provides funding for systemic change; includes work-based, school-based and connecting activities to create quality opportunities for all students

### **Screen**

Quick, inexpensive assessment/evaluation to determine if further investigation is needed

### **SEA – State Education Agency**

Refers to the Department of Education at the state level

### **Secondary schools redesign (High school redesign)**

Secondary school redesign is based on the concept that providing students with rigorous and relevant instruction can reduce student achievement gaps, increase graduation rates, decrease drop-out rates, and improve post-school outcomes for students with disabilities

### **Section 504 (Sec. 504)**

[See Rehabilitation Act of 1973]

### **Self-advocacy**

Speaking up for oneself-- asking for what one needs

### **Self-advocacy strategies**

Assist the individual in being able to articulate needed supports and to advocate for them

### **Self-awareness**

The ability to monitor, assess, and modify one's own behavior

### **Self-determination**

Deciding one's own fate/future

### **Self-Injury/Abuse**

The act of deliberately harming your own body. Self-injury is an unhealthy way to cope with emotional pain, intense anger and frustration.

### **Self-monitoring**

Recording data about one's own behavior

### **Self-regulation**

In sensory processing, an individual's method of responding to sensory input

### **Self-stimulatory behaviors**

Repetitive, apparently non-functional behaviors that provide some sensory input (e.g., finger flicking or rocking); also known as "stereotypies"

### **Semantic mapping**

Incorporates visual strategies to help students stay on a selected topic

### **Sensory integration**

The organization of sensory input for use. The use may be a perception of the body or world, an adaptive response or learning process

### **Sensory processing**

A person's way of noticing & responding to sensory messages from their body and the environment. A complex set of actions that enable the brain to understand what is going on both inside your own body and in the world around you. Individuals with disabilities may respond





to sensory input in more extreme ways. For example, persons with autism may be more sensitive to sounds and touch. Two major patterns of sensory processing:

- Over-responsive to sensory input (hypersensitive) - Responds to sensory input more intensely, more quickly, &/or for a longer period of time. The person may display patterns of sensory avoidance or hyper-reactivity to sensory input.
- Under-responsive to sensory input (hyposensitive) - Responds less to sensory input. Person misses stimuli that others notice easily; system needs stronger input to activate. (Dunn, 2007)

**Service Coordinator**

Designated individual to assist and support youth and families in accessing available service systems in an integrated way

**Setting Event**

Conditions or events that influence behavior by temporarily changing the value or effectiveness of reinforcers

**Severity**

Intensity of a behavior

**Shaping**

Development of a new target behavior by the reinforcement of closer approximations the target behavior (e.g. target behavior placing utensils appropriately in a place-setting, reinforcement initially occurs for getting utensils to table, then placing utensils at each place-setting and then finally for placing the fork on the left and the spoon and knife on the right)

**Shared leadership**

Shared leadership refers to a group functioning more effectively when all members accept responsibility as a group, including administrators, teachers, families, service providers, and students willing to work together and take equal responsibility

**Sheltered employment**

Sheltered employment refers to “an accredited occupationally-oriented facility, including a work activities center, operated by a private nonprofit agency, which, except for its administrative and support staff, employs disabled persons certified under special provisions of federal minimum wage laws by the Wage and Hour Division, U.S. Department of Labor” (65 Del. Laws, c. 74, § 1.).

**SLA - State Lead Agency**

The state agency designated to provide oversight for IDEA Part C Program

**Smarter Balanced Assessment Consortium (SBAC)**

A consortium of 35 states that are focused on the development of:

- State-of-the-art adaptive online exams, using “open source” technology
- Online system will provide assessment information to teachers and others on the progress of all students
- Required summative exams; offered twice each school year
- Optional formative, or benchmark exams
- Variety of tools, processes and practices that teachers may use in planning and implementing informal, ongoing assessment

**SOCSS (Situation, Options, Consequences, Choices, Strategies, Simulation)** SOCCSS is another technique that provides a framework for tackling many situations. In this problem solving method, first the SITUATION is discussed using Wh- type questions (who, what, where, when, why). Next, OPTIONS for the problem are identified and then CONSEQUENCES for each option. Following that, the options are prioritized and the best one is selected. Then, STRATEGIES are developed so the student knows how to handle the situation next time. The final step is SIMULATION, which allows the student to practice the chosen strategies to prepare for the next time the situation occurs. A student with autism is going to need guidance and support to move through these steps, as perspective taking and flexible thinking is required to think of more than one solution or what the consequences might be

**Social cognition/social thinking**

How a person processes and interprets information about other people and their interactions

**Social communication**

The reciprocal use or exchange of information that has a deliberate effect on another person’s concentration, thought processes, or emotions

**Social Emotional Learning (SEL)**

Social emotional learning is the process of teaching children and youth skills needed to handle ourselves effectively in everyday life and establish meaningful relationships. These skills include recognizing and managing emotions, developing caring and positive relationships, making responsible decisions and handling life challenges effectively. (www.casel.org )

**Social interaction**

Dynamic, changing sequence of social actions between individuals or groups who modify their behavior in response to one another.

**Social learning**

Learning to understand others’ perspectives and to behave in ways that others will consider socially appropriate



### **Social Narratives**

Social narratives are phrases, sentences, or stories that help explain a social behavior or situation to an individual with autism. There are a variety of types, such as Power Cards, Social Stories™, social scripts, or cartooning, to choose from based on the student's needs. Most of the narratives include the following steps: (1) Identify the target behavior; (2) Collect data to determine baseline; (3) Write the narrative based on the student's abilities; (4) Teach the narrative and review as determined by need; (5) Continue to collect data and evaluate the effect of the narrative (based on Texas Autism Resource Guide for Effective Teaching)

### **Social Security Disability Income (SSDI)**

Benefits to workers or certain members of a worker's family, who may qualify, based on an impairment severe enough to prevent working for a year or more, or which is expected to result in death; benefits continue as long as the person is medically disabled and not engaged in substantial gainful employment

### **Socialization/Social skills**

Socially acceptable learned behaviors that enable a person to interact with others in ways that elicit positive responses and assist in avoiding negative responses

### **Social Skills Groups**

Gathering groups of students who are challenged with gaining social competence can allow for teaching and practicing positive social behaviors. The groups can be school based, agency based, or community based with a focus on social skills, social frameworks, or recreation and leisure skills

### **Social translator**

Used to help interpret the person's behavior in the context of their characteristics, and helps to interpret situations and the behavior of others to the student with ASD

### **Social validity**

The extent to which the people directly involved with social skills programming believe it is valuable for the child or adolescent with ASD and, therefore, are likely to be enthusiastic about supporting and implementing it

### **SODA (Stop, Observe, Deliberate, Act)**

SODA is a framework for approaching social situations. For instance, if I were going to lunch with a group of friends, first I would STOP before entering the situation. Next, I would OBSERVE what people are doing and saying. Then, I would DELIBERATE about how I can fit into the situation. And last, I would ACT on what I decided during the deliberation phase. SODA gives a method for approaching many social situations rather than a breakdown of each and every skill

### **Special Education**

Specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability, including instruction conducted in the classrooms, homes, hospitals, institutions, and in other settings; to ensure that all children with disabilities have ... special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living [IDEA 2004 Part B Regulations, §300.1(a)]

### **Specially designed instruction**

Specially designed instruction means adapting, as appropriate to the needs of an eligible child under this part, the content, methodology, or delivery of instruction-to address the unique needs of the child that result from the child's disability; and to ensure access of the child to the general curriculum, so that the child can meet the educational standards within the jurisdiction of the public agency that apply to all children (20 U.S.C. § 1401 sec. 300 [39]).

### **Stakeholder**

Anyone affected by or invested in the implementation and outcomes of a process or activity. For example, teachers, students, administrators, and families are all stakeholders in education

### **Stress Thermometers**

Stress thermometers are a visual support that can show students with autism how their emotions affect their levels of stress and what supports can be helpful for each level. Using a picture of a thermometer, the student shares what is least stressful to most stressful and those are written on the left side of the red line rising on the thermometer. On the right side, supports for each stressor are added. The visual is reviewed and taught to the student

### **Structured leisure participation**

Participation in organized activities that possess the following characteristics: regular participation schedules, rule-guided interaction, direction by one or more adult leaders, an emphasis on skill development that increases in complexity and challenge, and performance that requires sustained active attention and the feedback (Mahoney et al., 2005). Participation in structured leisure is associated with both personal and interpersonal development

### **Study skills**

Techniques of scheduling time, finding a quiet place, remembering, reviewing, deciding what material is important, and taking notes

### **Summative Assessment/Evaluation**

Comprehensive in nature, provides accountability and is used to check the level of learning at the point of expected mastery; measures growth in relation to a specific set of criteria or standard/expectation

### **Supplemental Security Income (SSI)**

Monthly disability income for those who meet social security rules for disability and who have limited income and resources

### **Supported employment**

Competitive work in integrated work settings, or employment in integrated work settings in which individuals are working toward competitive work, consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individuals, for individuals with the most significant disabilities for whom competitive employment has not traditionally occurred; or for whom competitive employment has been interrupted or intermittent as a result of a significant disability; and who, because of the nature and severity of their disability, need intensive supported employment services [Rehabilitation Act of 1973 Section 7(35)(a)]

### **Symbol**

An abstract representation that communicates an idea; symbols can range from pictures to written and spoken language

### **Symbolic communication**

Use of symbols of any sort to communicate meaning

### **Taxonomy (Kohler's Taxonomy for Transition Programming)**

Kohler's Taxonomy for Transition Programming is a model for planning, organizing, and evaluating secondary transition programs for students with disabilities. The model includes 5 areas related to transition planning, which are student-focused planning, student development, family involvement, program structure, and interagency collaboration

### **Theory of mind**

The ability to recognize and understand the thoughts, feelings, beliefs, and intentions of other people

### **Through-Course Testing**

Students will take parts of the assessment at key times during the school year, closer to when they learn the material.

### **Token**

An item that may be earned for displaying an appropriate behavior and redeemed later for a reinforcer Examples include stickers, points, fake coins

### **Transition**

Any environmental change, such as a change of location, activity, or support personnel 1) Transitions can be minor, such as changing activities within the classroom, or major, such as moving from elementary school to middle school. 2) The change from school to post-school life

### **Transition (IDEA 2004)**

A coordinated set of activities for a child with a disability that is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation (20 U.S.C. § 1401 sec. 602 [34]).

### **Transition assessment (see Age-Appropriate Transition Assessment)**

### **Transition services**

A coordinated set of activities for a student with a disability that:

1. is designed to be within a results-oriented process, focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education; vocational education; integrated employment (including supported employment); continuing and adult education; adult services; independent living or community participation;
2. is based on the individual child's needs, taking into account their strengths, preferences, and interests;
3. includes *instruction, related services, community experiences*, the development of *employment and other post-school adult living objectives* and, when appropriate, acquisition of *daily living skills* and *functional vocational evaluation*.

[Individuals with Disabilities Education Improvement Act of 2004, Public Law No. 108-446, 20 U. S. C. 1400, H. R. 1350]

### **Underlying Characteristics**

Characteristics across a number of domains associated with ASD



### **Universal Design for Learning (UDL)**

Process of designing instruction that is accessible by all students; UDL includes multiple means of representation, multiple means of expression, and multiple means of engagement; the focus in creation of UDL curricula is on technology and materials

### **Visual schedule**

A visual schedule will tell the student what activities will occur and in what sequence. Schedules can be object-based (e.g. a shopping bag means student is going shopping), photograph/picture symbol (e.g. a picture of the grocery store) or traditional orthography

### **Visual supports**

Tools that are used to increase the understanding of language, environmental expectations, and to provide structure and support. For example a photograph of the staff member with whom the child will be working or a skittles candy wrapper that is handed-over to request a skittle snack

### **Vocational/career assessment (revisit within context of career development)**

Systematic collection of information about the student's vocational aptitudes, abilities, expressed interests, and occupational awareness used in planning a transition from secondary school to competitive employment or postsecondary education

### **Vocational Rehabilitation (VR) Services Program**

Program to assist States in operating a comprehensive, coordinated, effective, efficient, and accountable program of vocational rehabilitation that is an integral part of a statewide workforce investment system; and designed to assess, plan, develop, and provide vocational rehabilitation services for individuals with disabilities, consistent with their strengths resources, priorities, concerns, abilities, and capabilities, interests and informed choice, so that individuals may prepare for and engage in gainful employment. [Rehabilitation Act of 1973 Title I Section 100(a)(2)]

### **Vocational evaluation**

Comprehensive and systematic process that uses work (real or simulated) to assess the vocational potential of individuals; incorporates other data such as a test score, medical data, information on education and work experience and the needs and interests of the individual in setting vocational goal and service requirements

### **Work-based learning**

Meaningful and engaging educational opportunities connecting classroom learning to learning on job sites in the community; support youth to make career decisions, network with potential employers, select courses of study, and develop job skills relevant to future employment

### **Work-Readiness Skills**

Ability to make the educational and vocational decisions and perform the kinds of educational and vocational tasks that are expected by school and the workplace; include soft skills, computer literacy, and job seeking skills

### **Wrap-around services**

Wrap-around services are individualized, community-based mental health services for children that support them at home and in school (Furman & Jackson, 2002)

### **Youth**

Period in life between childhood and maturity, known as adolescence; given different program requirements, the age range for youth is between 14 and 25; may extend as low as 12 and as high as 29; youth can be both in and out of school.

### **Youth development**

Youth development is the on-going growth process that involves transition into adult life ensuring that youth are engaged in opportunities to meet personal and social needs while building skills and competencies to become engaged and contributing members in their daily lives (Center for Youth Development and Policy, 2009).

### **Youth leadership**

Empowering youth with meaningful opportunities to effect change within their community and within any institutions or systems that concern them; requires skill development in the form of communication, advocacy, and awareness; requires that institutions make a sustained commitment to creating meaningful leadership opportunities for youth

## Websites, Organizations, and Other Resources – Autism

### **Autism-Specific**

#### **Autism Deserves Equal Coverage**

[www.autismdeserveequalcoverage.com](http://www.autismdeserveequalcoverage.com)

We advocate and work with providers, families, therapists, ABA agencies, Regional Centers and other organizations in securing insurance to cover medically necessary treatments for autism.

#### **Autism Health Insurance Project**

[www.autismhealthinsurance.org](http://www.autismhealthinsurance.org)

Supports families in their journey through the insurance maze, so that families can be treated fairly through this process, and that children can get the coverage for interventions that they need.

#### **autism NOW: The National Autism Resource and Information Center**

[www.autismnow.org](http://www.autismnow.org)

Autism NOW is a central point of quality resources and information for individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities, their families, and other targeted key stakeholders.

#### **Autism Society of America**

[www.autism-society.org](http://www.autism-society.org)

ASA's Autism Info section is an invaluable introduction to autism and its issues. The site connects to local and state resources as well.

#### **Autism Speaks**

[www.autismspeaks.org](http://www.autismspeaks.org)

Autism Speaks is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, and treatments for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

#### **Autistic Self Advocacy Network (ASAN)**

[www.autisticadvocacy.org](http://www.autisticadvocacy.org)

ASAN seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens.

#### **Ellen Notbohm**

[www.ellennotbohm.com](http://www.ellennotbohm.com)

Her website includes a valuable e-newsletter with tips, articles, and more for parents and professionals of children and youth with autism.

#### **The Interactive Autism Network (IAN)**

[www.ianproject.org](http://www.ianproject.org)

IAN is an innovative online project bringing together tens of thousands of people nationwide affected by autism spectrum disorders (ASD) and hundreds of researchers in a search for answer.

#### **A Thinking Person's Guide to Autism (TPGA)**

[www.thinkingautismguide.com](http://www.thinkingautismguide.com)

TPGA is the resource we wish we'd had when autism first became part of our lives: a one-stop source for carefully curated, evidence-based information from autism parents, autistics, and autism professionals.

#### **Treatment and Research Institute for Autism Spectrum Disorders (TRIAD): Vanderbilt Kennedy Center for Excellence in Developmental Disabilities**

[vkc.mc.vanderbilt.edu](http://vkc.mc.vanderbilt.edu)

TRIAD is dedicated to improving assessment and treatment services for children with autism spectrum disorders and their families while advancing knowledge and training.

## **Developmental and/or Intellectual Disabilities**

### **Best Buddies**

[www.bestbuddies.org](http://www.bestbuddies.org)

Best Buddies is a nonprofit organization dedicated to improving the quality of life for individuals with intellectual disabilities by creating opportunities for one-to-one friendships and integrated employment.

### **Developmental Disabilities Resources for Healthcare Providers**

[www.DDHealthinfo.org](http://www.DDHealthinfo.org)

A collection of information and programs on developmental disabilities, from California Department of Developmental Services (DDS) and UC San Diego's School of Medicine.

### **Exceptional Parent Magazine**

800-247-8080, [www.eparent.com](http://www.eparent.com)

Provides support and information to families of children and adults with disabilities and special healthcare needs as well as to health professionals and education professionals.

### **The Presidents Committee for People with Intellectual Disabilities (PCPID)**

[www.acf.hhs.gov/programs/pcpid/](http://www.acf.hhs.gov/programs/pcpid/)

Dedicated to improving the lives of individuals with intellectual disabilities. Website contains its history, its goals, facts and research about Intellectual Disabilities.

### **SF State & Support for Families Website on Speech and Language Development**

[www.speechlanguageinfo.myefolio.com/main/home](http://www.speechlanguageinfo.myefolio.com/main/home) (English)

Parent resource website on speech and language development in multiple languages.

### **Special Olympics**

[www.specialolympics.org](http://www.specialolympics.org)

Through year-round sports training and competition, it endeavors to empower those with intellectual disabilities around the world.

### **Woodbine House**

[www.woodbinehouse.com](http://www.woodbinehouse.com)

Publisher specializing in quality books, DVDs, children's books kits, etc. about children with special needs.

### **Special Education**

#### **Building the Legacy: IDEA 2004**

[idea.ed.gov](http://idea.ed.gov)

Major topics covered by IDEA 2004. It has excellent sections on Early Intervening Services/RTI, IEPs, Discipline, Highly Qualified Teachers, Procedural Safeguards, and other important topics.

### **Community Alliance for Special Education (CASE) and Disability Rights California**

#### ***Special Education Rights and Responsibilities Handbook***

[www.disabilityrightsca.org/pubs/PublicationsSERREnglish.htm](http://www.disabilityrightsca.org/pubs/PublicationsSERREnglish.htm)

Covers basic rights, evaluations and assessments, eligibility, and more in a Q&A format. Based on special education laws and court decisions in effect at the time of publication.

### **Division of Early Childhood (DEC)**

[www.dec-sped.org](http://www.dec-sped.org)

Promotes evidence-based practices that support families and professionals to enhance the development of young children who have or are at risk for developmental delays and disabilities.

## **The Education Resources Information Center (ERIC) Digests**

[www.eric.ed.gov](http://www.eric.ed.gov)

ERIC Digests are secondary research articles that synthesize research in specific topics of education.

## **Office for Civil Rights (OCR), U.S. Department of Education**

### ***Frequently Asked Questions about Section 504***

[www2.ed.gov/about/offices/list/ocr/504faq.html](http://www2.ed.gov/about/offices/list/ocr/504faq.html)

OCR serves student populations facing discrimination as well as the advocates and institutions promoting systemic solutions to civil rights problems.

## **Resources for Early Childhood project, Ohio Resource Center**

[www.rec.ohiorc.org/InclusiveClassroom](http://www.rec.ohiorc.org/InclusiveClassroom)

Early childhood educators and parents can learn how to make inclusion happen, including the Learning Experiences, Planning Options and Universal Design for Learning pages.

## **U.S. Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education Programs**

1-877-433-7827, [edpubs.ed.gov](http://edpubs.ed.gov)

Website has U.S. Department of Education publications and other products. May also order paper copies. All publications are provided at no cost.

## **Wrightslaw Special Education Law and Education**

Provides accurate, reliable information about special education law, education law, and advocacy for children with disabilities. Fantastic resource.

## **Parent to Parent**

### **Center for Parent Information and Resources (CPIR)**

[www.parentcenterhub.org](http://www.parentcenterhub.org)

Central resource of information to the community of Parent Training Information (PTI) Centers and Community Parent Resource Centers (CPRCs). *Find parent center(s) in your state here.*

## **San Francisco/California Region**

### **The Arc San Francisco**

[www.thearcsf.org](http://www.thearcsf.org)

Nonprofit service, education, and career center for adults with developmental disabilities and their families.

### **California Foundation for Independent Living Centers**

[www.cfilc.org/find-ilc/](http://www.cfilc.org/find-ilc/)

[www.ilrcsf.org](http://www.ilrcsf.org) (San Francisco ILRC)

Independent Living Centers provide direct services to youth and adults with disabilities in order to help them live independently. Go to the CFILC website to find the center in your county.

### **Autism Society of the Bay Area**

[www.sfautismsociety.org](http://www.sfautismsociety.org)

The Autism Society of the San Francisco Bay Area is an all-volunteer, grassroots organization currently focusing on expanding the limited lifespan care options for the dramatically increasing numbers of adults with autism.

### **Family Resource Center Network of California (FRCNCA)**

[www.frcnca.org](http://www.frcnca.org)

A coalition of California's 47 Family Resource Centers. Early Start Family Resource Centers (ESFRC) provide parent to parent support, outreach, information and referral services to families of children with disabilities and the professionals who serve them.

### **Golden Gate Regional Center**

1535 Market St, Suite 220, San Francisco CA 94103

415-546-9222; Intake Line 888-339-3305; intake@ggrc.org

[www.ggrc.org](http://www.ggrc.org)

State-funded organization that helps individuals with developmental disabilities in Marin, San Francisco and San Mateo counties access services. *For the regional center in your county, go to the CA Department of Developmental Services ([www.dds.ca.gov](http://www.dds.ca.gov), 916-654-1690).*

### **San Francisco Unified School District (SFUSD)**

#### ***Early Childhood Special Education Services***

1520 Oakdale Ave, San Francisco, CA 94124; Tel: 415-401-2525; Fax: 415-920-5075

#### ***Special Education Central Office***

3045 Santiago St, San Francisco, CA 94116; Tel: 415-759-2222; Fax: 415-242-2528

[www.sfusd.edu/en/programs-and-services/special-education/overview.html](http://www.sfusd.edu/en/programs-and-services/special-education/overview.html)

### **SFUSD Community Advisory Committee for Special Education (CAC)**

[www.cacspedsf.org](http://www.cacspedsf.org)

Champions effective special education programs and services and advises the Board of Education on priorities in the Special Education Local Plan Area (SELPA). The State Education Code mandates that each SELPA have a CAC and that a majority of CAC members are parents. *If you are not in SF, ask your local school for information about your local CAC.*

### **State Council on Developmental Disabilities**

[www.scdd.ca.gov](http://www.scdd.ca.gov)

Established by state and federal law as an independent state agency to ensure that people with developmental disabilities and their families receive the services and supports they need.

### **Support for Families (SFCD)**

1663 Mission St, 7th Floor, San Francisco, CA 94103

415-920-5040, info@supportforfamilies.org

[www.supportforfamilies.org](http://www.supportforfamilies.org)

The family resource center and parent training information center in San Francisco. Provides information, education, and support for families and professionals of children with disabilities, concerns, or special health care needs.





Since 1982, Support for Families has offered information, education, and parent-to-parent support free of charge to families and professionals of children with any kind of disability, concern, or special health care need in San Francisco.

All services are free of charge:

- Phonenumber & Drop-In Center
- Resource Library with Computer and Internet Access
- Support Groups
- Educational Workshops
- Family Special Events
- Parent Mentor Program
- Short-term Counseling
- Community Outreach & Satellites
- Information & Resources



**SUPPORT FOR FAMILIES  
OF CHILDREN WITH DISABILITIES**

1663 Mission St, 7<sup>th</sup> Floor  
San Francisco, CA 94103  
415-282-7494 (Office)  
415-920-5040 (Phonenumber)  
[info@supportforfamilies.org](mailto:info@supportforfamilies.org)  
[www.supportforfamilies.org](http://www.supportforfamilies.org)

**HOURS**

MWF 9:30am – 4:30pm  
TTH 12:30pm – 8:30pm

**PUBLIC TRANSIT**

BART: 16<sup>th</sup> St Mission (3 blocks to 13<sup>th</sup>)  
MUNI: 14 Mission, 49 Van Ness, Van Ness Metro Station



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**PLACE  
STAMP  
HERE**



**SUPPORT FOR FAMILIES OF**  
CHILDREN WITH DISABILITIES  
1663 Mission St., 7th Floor  
San Francisco, CA 94103



INFORMATION PACKET  
EVALUATION

FOLD

TAPE TO SEAL

Are you a:    **parent**                      **professional** (circle one)

## AUTISM INFORMATION PACKET EVALUATION

<i><b>This packet</b></i>	Strongly Agree 	Agree	Neutral	Disagree	Strongly Disagree 	N/A
Has increased my knowledge about my child's needs or disability/ the needs of children with disabilities and their families	5	4	3	2	1	N/A
Helped increase my feelings of support	5	4	3	2	1	N/A
Helped increase my knowledge of resources or services	5	4	3	2	1	N/A
Helped provide strategies to advocate for children and families/my child and participate in the decision-making process	5	4	3	2	1	N/A
Helped increase my ability to communicate with professionals/families	5	4	3	2	1	N/A
Helped increase my knowledge of parent participation activities at the school as well as school reform.	5	4	3	2	1	N/A
Helped increase my knowledge of family-centered care	5	4	3	2	1	N/A

1. On a scale of 1 to 5, with 5 being the best, how would you rate the value of this packet?

Great Value   5     4     3     2     1  Little Value  
Comments:

2. On a scale of 1 to 5, with 5 being the best, how would you rate the quality of this packet?

Great Value   5     4     3     2     1  Little Value  
Comments:

3. Would you recommend this packet to others?     Yes     No

4. What did you find **most** useful?

5. What did you find **least** useful?

6. Any other articles or information you would like to see?

7. Has the information you received today made it more likely that special education issues can be resolved without having to go to Fair Hearing?     Yes     No     Not Applicable  
If not, why not?

**(Optional Information) Name:**

**Phone Number:**

*Evaluations help us improve our services and report back to our funders, which allows us to continue to provide our services - including these packets - free of charge. **Please complete and return this evaluation in one of four ways:***

1. Mail this evaluation to our office by folding this sheet of paper into thirds (see other side of page).
2. Scan or take a photo of this evaluation and email it to [newsletter@supportforfamilies.org](mailto:newsletter@supportforfamilies.org)
3. Fax this evaluation to 415-282-1226
4. Or fill out the evaluation online: [www.surveymonkey.com/s/sfcd-info-packet](http://www.surveymonkey.com/s/sfcd-info-packet)

**THANK YOU!**