



# Ohio's Parent Guide to Autism Spectrum Disorders

SECOND EDITION

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Developed by Ohio parents, for Ohio parents





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Developed by Ohio parents, for Ohio parents



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Columbus, Ohio 43214  
[www.ocali.org](http://www.ocali.org)

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**This guide was developed and written by parents of individuals with autism spectrum disorders. The examples provided are from their experiences. The information included in this manual is a result of their answer to the question:**

When your child was first diagnosed, what information did you need most?

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# I Suspect My Child Has Autism:

## A Four-Step Guide for Ohio Parents on What to Do Next

When parents have concerns about their child's development, there is almost always a valid reason for their concerns. Research supports that parents are accurate reporters of early signs of developmental delays or autism. A short encounter or interaction between your child and a physician may not be enough time for the physician to accurately observe the collection of symptoms that you see day in and day out. Parents need to be prepared with a list of specific observations, including times, places, and frequency, to paint an accurate picture of their worries. In the past, 80 percent of physicians told parents to "wait and see".<sup>1</sup> Early intervention works. Act now!

### 1) Medical/Clinical Evaluations

<sup>1</sup>Autism Society. Retrieved March 1, 2009.

## STEP 1 Asking for Evaluation *There are three types of evaluations.*

- Talk to your child's doctor; be specific about your concerns.
- Ask your doctor to evaluate your child for autism or make a referral to a professional who can (developmental psychologist, developmental pediatrician, pediatric neurologist). It's okay to ask that action be taken immediately.
- To pay for the evaluation, check these sources:
  1. **Private insurance:** Check your whole insurance plan to see if it pays for a medical/clinical evaluation for developmental disabilities or autism.
  2. **Bureau for Children with Medical Handicaps (BCMh):** BCMh is a part of the Ohio Department of Health that provides funding for evaluations through their approved providers. To find out what is covered, call the state office toll free at (800) 755-4769 or visit [www.odh.ohio.gov](http://www.odh.ohio.gov) and search for BCMh.

#### Early medical signs:

- Problems with communication
- Resistant to change
- Difficulty playing with peers
- Little or no eye contact
- Unusual reaction to noises, lights, touch, smell, and taste
- Handflapping, rocking, walking on toes
- Frequent or extreme tantrums (meltdowns)

#### Websites to check your child's development:

- [www.concernedaboutdevelopment.org](http://www.concernedaboutdevelopment.org)
- [www.firstsigns.org](http://www.firstsigns.org)
- [www.cdc.gov](http://www.cdc.gov) (Learn the Signs, Act Early)

3. **Medicaid:** Check with your county's Jobs and Family Services (JFS) agency to see if your child is eligible for funding for an evaluation through a Medicaid provider. Find your county's JFS by calling toll free (877) 852-0010 or visit [jfs.ohio.gov/county/cntydir.stm](http://jfs.ohio.gov/county/cntydir.stm).

4. **County Board of Developmental Disability Services (CBDDS):** Some county boards pay for a medical/clinical evaluation. Check with your county board to see if they will provide funding for a medical/clinical evaluation. Find your county board contact information toll free at (877) 464-7633 or visit <http://dodd.ohio.gov/CountyBoards/Pages/default.aspx>.
5. **County Board of Mental Health:** Some mental health boards subsidize the cost of an evaluation. Check with your County Board of Mental Health for a referral for a medical/clinical evaluation. Contact them toll free (877) 275-6364 or visit <http://mha.ohio.gov>.

## 2) Education Evaluations

- If your child is approaching age 3 or older and you would like services for him in school, you need to get an educational evaluation.
- A medical/clinical evaluation does not necessarily qualify a child for special educational services. For this, an educational evaluation is needed.
  1. **Contact your local school district special education office in writing** to request an initial Multi-Factored Evaluation (MFE). Districts are required by law to respond within 30 days.
  2. **You will be asked to attend a meeting to plan the evaluation** if the district agrees to evaluate your child. Parents should request assessments in all of the following areas: communication, social, motor, sensory, emotional, behavioral, functional and academic performance. If your request for an evaluation is denied, consult Appendix C or call Autism Society of Ohio at (614) 487-4726.
  3. **Review the Evaluation Team Report (ETR)** to see if your child qualifies for services. If so, the team will then write an Individual Education Program (IEP) for him. (To learn more about the special education process, read Chapter 5 of Ohio's Parent Guide to Autism Spectrum Disorders).

### School-Age Signs

- Lack of appropriate eye contact
- Behavioral problems, meltdowns
- Lack of friends
- Difficulty with changes in schedule
- Problems completing work
- Poor motor skills, poor handwriting
- Anxious and inflexible

## 3) Evaluation for Additional Services

1. **County Board of Developmental Disability Services:** This agency provides funding and services for individuals with developmental disabilities, including autism. (For a description of those services, see pages 124-125) The evaluation process will vary depending on the age of your child.
  - **0-3 years of age** – The county board will do play-based assessment to see if your child is eligible for services.
  - **3-16** – Request your child be evaluated to determine eligibility for county board funding and services. This evaluation is called the Children's Ohio Eligibility Determination Instrument (COEDI).

- **16 and up** – Request your child be evaluated to determine eligibility for county board funding and services. This evaluation is called the Ohio Eligibility Determination Instrument (OEDI).

You can call toll free (877) 464-7633 or visit <http://dodd.ohio.gov/IndividualFamilies/Pages/default.aspx> to find your county board’s phone number.

1. **Help Me Grow:** If your child is younger than 3 years old, check your local *Help Me Grow* program to determine if he or she is eligible for *Help Me Grow* services. For a description of this program, see pages 11-12, 121. To find your local office, call toll free (800) 755-4769 or visit [www.ohiohelpmegrow.org](http://www.ohiohelpmegrow.org).

For more information about evaluation see Chapter 2.

**Learn more about autism spectrum disorders** and how you can support your child while the evaluation process is being completed.

## STEP 2 Educating Yourself

**The Ohio’s Parent Guide to Autism Spectrum Disorders** which was developed by parents for parents, is a great place to start.

If you’re feeling overwhelmed and need support, the following websites can provide information that

will help and connect you to local autism groups and resources in your area:

- Autism Society [www.autism-society.org](http://www.autism-society.org)
- Autism Society of Ohio [www.autismohio.org](http://www.autismohio.org)
- Your local Autism Society Chapter (linked from the Autism Society of Ohio website)

For additional information about autism, check these websites:

- Organization for Autism Research [www.researchautism.org](http://www.researchautism.org)
- Autism Speaks [www.autismspeaks.org](http://www.autismspeaks.org)

### Remember . . .

- Don’t feel pressured.
- The services you choose must meet the needs of your child and family.
- Be mindful of programs that promise a cure.
- Check out available options before making a decision.
- Network with professionals and other parents to gather information.

## STEP 3 Getting Services

Getting services is an ongoing process as your child develops and matures. Various service providers will interact with your child throughout his/her life. Your child's team may consist of your child's teachers and other school personnel, doctors, psychologists, therapists, behavioral consultants, neurologists, etc.

Each individual with autism is "uniquely autistic." There is no "one-size-fits-all" treatment. The job of determining what will work best falls on the family and the professionals who work with them. However, the National Academy of Sciences recommends early and intensive intervention of at least 25 hours per week and year-round interventions for young children with autism. See Chapter 4 for more information on types of interventions.

Your child may be eligible for the following range of services, including, but not limited to:

1. Case management/service coordination
2. Behavioral intervention services
3. Speech, occupational and physical therapies
4. Respite, summer programs
5. Waiver services
6. Medical and medication management services
7. Social work services
8. Psychology services
9. Counseling
10. Nutritional services

## STEP 4 Record Management

These services may be provided by state or local agencies or private providers through the child's insurance plan. For more information on these services and which agencies may provide them, see Chapters 5 and 6.

You will be gathering a lot of information that you will want to keep handy. (There are sample forms in Appendix B that will help.) Here's how to do it:

- **Create a filing system that you can maintain** and update. For example, use a 3-ring binder, an expandable file folder, a filing cabinet or box.
- **Keep records of the following:**
  1. Business cards of the various agencies and professionals you are in contact with.
  2. A phone log that documents the person, the agency, and one sentence describing the topic and results of the discussion.
  3. Reports such as medical records, evaluation reports, service plans, educational records, home-school communication forms, and travel records of trips to doctors and therapies.
  4. Articles and autism information, etc.
- **Collect ongoing data of your child's progress.** This can be done by keeping a video log, samples of school work, therapy notes, grade cards, progress notes, behavior plan notes, etc.
- **Set aside a time to maintain your file on a regular basis.**



CHAPTER 1

# What is an Autism Spectrum Disorder?

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“ On April 23, 1995, I came back from a diagnostic appointment at the university with Coty in tow. I just found out that my baby boy, my sweet, precious little one, has autism. I am supposed to get the diagnosis confirmed by a pediatric neurologist. I am devastated, confused and uncertain of “our” future. ”

# What Is an Autism Spectrum Disorder?

Autism Spectrum Disorder refers to a developmental disability with a neurological basis that affects an individual's verbal and nonverbal communication and social interaction. Each individual with ASD has unique abilities, symptoms and challenges.

ASD is a spectrum disorder and the symptoms and characteristics of ASD can range from mild to severe. Individuals may exhibit any combination of characteristics in any degree of severity. This means that two children with the same diagnosis can act very differently from one another and has varying skills and needs. Children with a diagnosis of ASD can be either nonverbal or verbal.

Every person with ASD has a unique personality and combination of characteristics. Some individuals with mild ASD exhibit only slight delays in language, but greater challenges with social interactions. For example, they may have difficulty initiating and/or maintaining a conversation. Individuals with ASD are often described as talking at others instead of with others (e.g., they may monologue on a favorite subject despite attempts by others to interject comments).

You can review the entire DSM 5 Diagnostic criteria required for a clinical diagnosis of ASD in Appendix A.

There is also an educational definition of ASD. The educational definition was designed to identify children eligible for services under the Individuals with Disabilities Education Act (IDEA). This identification is made by the child's evaluation team which is convened by the school district. Parents are included as members of this team. This evaluation takes into consideration whether the child's symptoms adversely affect her educational performance. (See Chapter 5). A clinical diagnosis is not required for an educational identification of ASD, nor does it automatically guarantee identification under IDEA.





*ASD does not discriminate according to social, economic status, or race. There is no proven cause of ASD.*

## Possible Signs of an ASD

*"If you've met one child with autism, you've met one child with autism."  
(Stephen Shore, adult with ASD)*

In general, ASD impacts communication and social interaction, as well as an individual's ability to develop and maintain relationships and adjust behavior to a variety of social situations. Behaviors and function can vary widely within and across individuals with ASD.

Because of the complexity of ASD, the clinical diagnosis has several components. In order for a child to receive a clinical diagnosis of ASD, two core symptoms must be present:

- (1) Persistent deficits in social communication and social interaction across multiple contexts, and
- (2) Restricted, repetitive patterns of behavior, interests or activities.

Each of these symptoms must be qualified with a rating of their level of severity, either:

- (1) Requiring support,
- (2) Requiring substantial support, or
- (3) Requiring very substantial support.

Further, the identified symptoms must:

- Be present in the early developmental period (although they may not become fully manifest until social demands exceed the capacity of the individual),
- Cause clinically significant impairment in social occupational or other important areas of current functioning,
- Cannot be better explained by an intellectual disability or a global developmental delay

And finally, because ASD can often co-occur with an intellectual disability and language impairments can occur separate from ASD, the clinical diagnosis must also specify if the ASD is:

- With or without accompanying intellectual impairment,
- With or without accompanying language impairment, and
- With or without a known medical genetic condition or environmental factor.

(To review the complete DSM-5 Diagnostic Criteria, see Appendix A.)

Here are descriptions of two individuals with ASD:

*John is a 7-year-old boy who received a clinical diagnosis of ASD when he was 3 years old. He does not speak, but uses gestures to make his needs known. When he is not understood, he shows frustration by squealing, throwing himself on the floor and crying. In school, he receives full-day instruction in a classroom for children with ASD. He can complete simple puzzles and match blocks by color when asked and supervised directly. John does not interact with his peers. He prefers playing alone and does not play with toys in the way they were intended.*

*Gracie is an 8-year-old girl who was identified by her school evaluation team under the category of autism. After her identification at school, her parents took her to a children's hospital for evaluation where she was diagnosed with a high functioning form of ASD. Gracie is very verbal and attends a regular second grade classroom. While she can read words at a sixth grade level, her comprehension skills are at a first-grade level. Her teachers report that Gracie has difficulty interacting with her classmates. She loves to talk about spiders and bugs and has begun her own bug collection. She continually tries to dominate conversations with her peers around the topic of bugs. Gracie does not realize that her peers are not interested when they walk away while she is talking.*

While both of these students have ASD, certainly, their characteristics in the areas of communication, behavior, and socialization vary greatly.

The following is a list of some common behaviors or characteristics you might observe in your child.

## **Language and Communication**

- Difficulty in expressing needs (use of gestures or pointing instead of words)
- Delayed speech or no speech
- Immediate or delayed repetition of the words of another person (family member, peers, TB character, singer, etc.) instead of typical, responsive language
- Has difficulty processing language (may not understand and/or may take longer to respond)
- Literal interpretation of language
- Difficulty in understanding nonverbal cues, including facial expressions
- Not responsive to verbal cues (acting as if deaf although hearing tests in normal range)
- Does not use joint attention—showing or sharing something with another person: this is typically demonstrated by using eye gaze and gestures, particularly pointing, for social interaction

## ***Social***

- Lack of social interaction; may prefer to be alone
- Difficulty interacting with other children
- Difficulty initiating conversation or play with others
- Little or no eye contact
- Acts or speaks in socially inappropriate manner (such as spaking too loudly or for too long)
- Emotional responses that do not match situations (e.g., over- or under-reaction)

## ***Unique Behaviors***

- Insistence on sameness; resistance to change
- Tantrums/meltdowns
- Sustained odd play
- Special interests or inappropriate attachment to objects (e.g., spins or lines up objects)
- Limited food choices and/or textures
- Frequently walks on tiptoes (toe-walking)
- Stereotyped behaviors, including hand flapping, whole-body rocking, clapping, etc.
- Self-injurious behaviors

## ***Emotional***

- Lack of awareness of own and others' feelings
- No real fear of danger
- Anxious or easily stressed

## ***Sensory and Motor Skills***

- Over- or under-sensitivity related to one or more sensory processing systems, including touch, balance, body awareness, sight, hearing, taste, smell
- Impaired gross or fine-motor skills
- Odd posture or gait
- Noticeable physical over-activity or extreme under-activity

## **Causes of ASD**

There is no known single cause of ASD, but it is generally accepted that it is caused by abnormalities in brain structure or function. For example, brain scans show differences in the shape and structure of the brains of children with ASD. Researchers are investigating a number of theories, including the links between heredity, genetics, and medical problems such as tuberous sclerosis, or epilepsy. In many families, there appears to be a pattern of ASD or related disabilities, further supporting a genetic basis to the disorder. It also appears that some children are born with a susceptibility to ASD, but researchers have not yet identified a single "trigger" that causes ASD to develop.

# Occurrence of Autism Spectrum Disorder

In 2014, CDC's National Center on Birth Defects and Developmental Disabilities released a report confirming that the rate of ASD continues to rise. Research in 2010 targeting 8 year old children living in 11 communities indicated a rate of 1 in 68 children were currently diagnosed with ASD. This new estimate is 30% higher than the estimated 1 in 88 children in 2008, 60% higher than the estimates of 1 in 110 reported in 2006, and 120% higher than the estimates for 2002 and 2000 (1 in 150). ASD is more common than childhood cancer, Down Syndrome, and juvenile diabetes.

## Genetics Research and Autism

As mentioned, there is currently no known cause of ASD. During the past decade, scientists have made significant breakthroughs in understanding the genetics of ASD. Researchers are now focusing on specific chromosomal regions that may contain autism-related genes. This has been accomplished by studying chromosomal abnormalities in individuals with ASD and by screening each chromosome for evidence of genes associated with ASD.

Current theory among autism genetics researchers supports the idea of "complex" inheritance. This means that multiple genetic factors are likely to be involved and may predispose an individual to develop autism. This theory also includes a role for environmental factors. That is, in addition to having a certain combination of autism-related genes, exposure to specific environmental factors may be necessary for autism to develop in some individuals.

For instance, if one version of a gene makes a person susceptible to a particular chemical, exposure to that chemical could trigger autism to develop. By focusing on the study of genetic factors and determining their underlying mechanisms, researchers may be better able to pinpoint environmental factors that contribute to autism.

Much of current research is based on the Human Genome Project, a 13-year scientific study to identify and analyze all the genes in human DNA. If you have questions about a possible genetic link regarding autism in your family,

it is recommended that you consult a geneticist.

### Resources

Autism Speaks: [www.autismspeaks.com](http://www.autismspeaks.com)

Autism Society of America: [www.autism-society.org](http://www.autism-society.org)

AUCD: [www.aucd.org](http://www.aucd.org)

Collaborative on Health and the Environment: [http://healthandenvironment.org/resources/practice\\_prevention](http://healthandenvironment.org/resources/practice_prevention)

HelpGuide.org: <http://www.helpguide.org/articles/autism/autism-spectrum-disorders.htm>

Human Genome Project: [www.ornl.gov](http://www.ornl.gov); [www.genome.gov](http://www.genome.gov)



# Screening and Diagnosis

“

*It was 11:32 p.m. I was changing my 4-month-old daughter's diaper when I noticed her characteristic movements. I knew that look, the expression of a blank stare, wrists and ankles circling as arms and legs flapped. Parents of kids with autism know it as self-stimulating behavior or "stimming."*

”

*I called our pediatrician and voiced my concerns as I tried to manage my emotions. That red flag was all too familiar. My son, who was 8 years older than his sister, had been diagnosed with autism five years earlier (two years and several specialists after the first signs were detected). The pediatrician told me that there was nothing he could do, for there was no known testing or screening for my daughter until she was at least 18 months of age. I was dumbfounded, since I knew how important early intervention was.*

*continued...*

continued...

*Nevertheless, I couldn't make an appointment until my daughter was 18 months, and then it took an additional 4 months for her to be seen by the diagnostic team at the local hospital.*

*Developmental delay was her first diagnosis. Even though all the signs of autism were present, the main evaluator did not believe that autism ran in families or that it could be shared by siblings. My daughter was only mimicking my son, it was suggested. After checking further, she was diagnosed with PDD-NOS. She still exhibits self-stimulating behavior seven and a half years later. The difference is that now I am not the only one to notice it. Others see it too.*

There is no blood test to determine if a child has an autism spectrum disorder. The diagnosis is referred to as a *descriptive diagnosis*, meaning the diagnosis is based on observation of the child's behavior. This chapter covers early signs that parents might notice and screening and diagnostic instruments that professionals may use to make the diagnosis of autism spectrum disorder.

## Early Signs

The characteristic behaviors of ASD may or may not be obvious in infancy (12-18 months), but usually becomes more apparent during early childhood (18 months to 6 years). Children with high functioning ASD may not be identified until much later because they often show no delay in the development of fundamental language skills.

## "Red Flags" of Autism

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his own by 24 months
- May lose language or social skills after having acquired them



## “Red Flags” of High Functioning ASD

Sometimes children with High Functioning ASD may not be diagnosed until after the age of 5 and parents may notice some of the following symptoms.

- Clumsy
- Hyperactive
- Language processing speed (may be slow to understand and respond to requests or may not be able to say what she needs)
- Social skills (may make inappropriate comments, may talk to everyone about a topic of interest)
- Early reading and math skills (may read early but not comprehend what’s read, or acquire math skills long before same-age peers)

Demonstrating more than one of these red flags does not necessarily mean your child has an ASD. However, it does indicate a need for further evaluation. Many of the behaviors associated with ASD are shaped by other disorders, such as intellectual disabilities or behavioral disorders. Various assessments may be necessary to rule out or identify other possible explanations for symptoms being exhibited. It is important to distinguish ASD from other conditions, since an accurate diagnosis and early identification provide the basis for building an appropriate and effective program.

## Where to Turn for an Evaluation

If you’re concerned about your child’s development, talk to your child’s pediatrician. He or she may be able to refer you for further evaluation. If your pediatrician does not share your concerns, consider seeking a second opinion from a professional who specializes in ASD.

If your child is in preschool or elementary school, talk to his teacher. If your child is not yet in school, you may still contact your local school district. The school district is responsible for identifying all children with disabilities.

If your child is under 3 years of age, you may also contact Ohio’s early intervention program called *Help Me Grow*. The program is designed for parents of newborns, infants, and toddlers, and it provides both health and developmental services. *Help Me Grow* connects families with the resources they need, including assessment services. Call (800) 755-GROW (4769).

For further information on the process of determining eligibility for special education services, see Appendix E.

*Help Me Grow* is Ohio's federally mandated early intervention program. It provides services to children birth through age 3 who have identified disabilities or are at risk for developmental delays. It ensures that children with developmental delays and disabilities have access to and receive needed intervention services.

Any family, regardless of income level, with a concern about the development of their infant or toddler, is entitled to an evaluation and assessment to determine eligibility for services. Any child under the age of 3 who has a specified developmental delay or medical condition that is likely to result in a delay is eligible for *Help Me Grow* services.

*Help Me Grow* brings together parents and health, education, and social service professionals. This team writes an Individualized Family Service Plan (IFSP) based on the family's priorities and the child's developmental needs. The IFSP becomes the road map for the services the family and their young child will receive.

An evaluation can also be obtained at a children's hospital or clinic with a developmental psychiatrist or psychologist, or other appropriate, licensed professional.

An ASD is diagnosed by observation of the child's communication, behavior, and developmental levels. A brief observation in a single setting cannot present a true picture of the child's abilities and behaviors. Parental (and other caregivers' and/or teachers') input and the child's developmental history are important components in making an accurate diagnosis. See Appendix A for the Diagnostic Criteria for ASD from the DSM 5.

Ideally, an evaluation is completed by a team of professionals from various backgrounds, which may include a combination of any of the following:

- **Developmental pediatrician** – Treats health problems of children with developmental delays or handicaps. (A pediatric neurologist may be used in place of, or in addition to, a developmental pediatrician.)
- **Child psychiatrist** – A medical doctor who can prescribe medication and provide help in behavior, emotional adjustment, and social relationships.
- **Clinical psychologist** – Specializes in understanding the nature and impact of developmental disabilities, including ASD. May perform psychological and assessment tests, as well as help with behavior modification and social skills training.
- **Occupational therapist** – Focuses on practical, self-help skills that will aid in daily living, such as dressing and eating. May also work on sensory integration, coordination of movement, and fine-motor skills.
- **Physical therapist** – Helps to improve the use of bones, muscles, joints, and nerves to develop muscle strength, coordination, and motor skills.
- **Speech/language pathologist** – Involved in the improvement of communication skills, including speech and language.

- **Social worker** – May provide counseling services or act as case manager helping to arrange services and treatments.

The evaluation process may include a variety of assessment tools, such as:

- Childhood Autism Rating Scale (CARS)
- The Modified Checklist for Autism in Toddlers (M-CHAT)
- The Social Communication Questionnaire (SCQ)
- The Autism Diagnostic Observation Schedule (ADOS)
- The Autism Diagnostic Interview – Revised (ADI-R)
- Gilliam Autism Rating Scale (GARS)
- Psychoeducational Profile, 3<sup>rd</sup> Edition (PEP-III)
- Parent Interviews for Autism (PIA)

According to the Individuals with Disabilities Education Act (IDEA), if a child has a disability, the child is entitled to a free and appropriate public education (FAPE). FAPE means an individualized educational program (IEP) that is designed to meet the child's unique needs. FAPE includes special education and related services that are provided for the child's educational benefit. In Ohio, the medical diagnosis of autism is not required for a child to be identified under the category of autism by the school team and to receive special education services. For more information about educational identification and accessing special education services, see Chapter 5.

Seek out other parents and discuss your child's situation with them. Learn about their experiences. Often other parents are one of your best sources of information. In addition, remember that you are allowed to invite any individual (e.g., extended family member, friend, or neighbor) to participate in your child's IEP meeting. Bring people who can help develop an IEP for your child.

## What Will Happen During the Diagnostic Assessment Process?

You will very likely have to wait some time, from several weeks to several months, to obtain an appointment at an autism clinic or with a professional who performs autism assessments. Each diagnostic process will differ based on the practices of the professionals involved and the assessment(s) they are using.

When you make the appointment, be sure to ask the following:

- How long is the waiting period to obtain an assessment?
- What professionals will be involved?
- What assessments will be performed?
- What records will be required from you?
- What will you need to do to prepare for the appointment?
- How many adults will be in the room with your child during the appointment?
- What will happen with your child during the appointment?
- Will you accompany your child during the assessment process?
- How long will the assessment process take?
- How long will it be until you will hear the results of the assessment?
- How long will it be until you have a written report?

## Dealing with Professionals

*When the doctor told me that my son had autism, I was devastated. "Will he end up living at Bittersweet Farms (a residential facility for adults with autism)?" I asked. The doctor looked at the social worker and rolled her eyes. "No way," she said. I was about to breathe a sigh of relief when she added with a laugh, "They have 100 people on their waiting list. There's no way he'll ever get in!" I had just been told that my second child, like my first, had autism. I completely shut down, grabbed my child and ran out to my car. I was reeling from the news. Do you think anyone from the doctor's office called me? Well, actually, the social worker did, but only to tell me that I had better get my son involved in a home program. Not a word was said to address how I was feeling.*

As soon as your child is diagnosed with autism, and possibly before, you will most likely begin dealing with a number of professionals.

The following are some of the professionals you may encounter:

- **Medical professionals** – pediatrician, developmental-behavioral pediatrician, neurologist
- **Mental health professionals** – psychiatrist, psychologist, neuropsychologist, social worker, caseworker
- **School personnel** – special education teacher, general education teacher, school psychologist, counselor, special education director, school principal
- **Therapists** – behavioral therapist, speech therapist, occupational therapist, physical therapist, play therapist, music therapist
- **Service coordinators** – early interventionist, DODD (developmental disabilities) service and support specialist, Family and Children First Council (FCFC) specialist

It can be intimidating to have to deal with so many different professionals. Professionals often speak in their discipline's "jargon", which helps them speak shorthand to each other. It can also serve to distance them from their patients/clients. This distance can sometimes seem like arrogance and insensitivity, and can seem particularly painful the first time a family is told their child has autism. Families remember this moment for the rest of their lives. Many have horror stories, like the ones in the vignette above, about remarks and behaviors of professionals at these meetings.

It is not that the professionals are uncaring; after all, they chose careers helping children. It is usually because they do not have the training (or the time) to help families process their feelings about the information they are receiving. It is unrealistic to think families will not have strong reactions to receiving a diagnosis of ASD for their child.

## Suggestions for Dealing with Professionals

- First, allow yourself to have the feelings you experience. It is not necessarily a bad thing to show emotion in front of professionals. It will help them develop empathy and a better understanding of what you are going through.
- Communicate your level of stress by sharing actual examples of what you are going through. For example, let the IEP team know that your child is locking himself in the bathroom for three hours every night to avoid doing his homework or that your child (and you) are only sleeping three hours a night.

- Do not be intimidated by the expertise of professionals. They are the “experts” in their field, but remember that you are the expert on your child. You have information that is just as valuable and you deserve to be treated with respect.
- If possible, both parents should attend meetings. Even if you are a single parent, it is in your child’s best interest for parents to work together. Each parent may request a separate parent teacher conference, but schools are only required to conduct one set of Multi-Factored Evaluation (MFE) or IEP meetings. Both parents should have access to information about their child unless the court has prohibited one or the other parent from being involved.
- Everyone filters out some information, especially information that arouses intense feelings. Bring a friend or advocate to meetings to help you hear and remember what is being said.
- Make a list of questions when you think of them. Bring the list with you to appointments. Write down the answers as soon as you can or have a friend take notes.
- Ask professionals to explain what they have said in plain English until you understand it.
- If there is not time for them to explain everything to your satisfaction, ask to schedule another meeting.
- Find out how you can communicate with a professional if you have questions later on.
- Clarify early on what (services) you can expect from the professional. For example, find out if the particular doctor provides diagnosis or assessments for the disability you suspect. Some pediatricians cannot or will not diagnose ASD.
- Communicate often.
- Keep communication open. Discuss problems as soon as they arise. Be honest. Give the professional a chance to address any problems.
- Be prepared. Professionals have limited time. Appointments will go more smoothly if you have done your homework and are ready with questions.
- Keep appointments or call if you can’t keep them.
- Put everything in writing. Keep notes of every appointment and phone call. (See Parent Record-Keeping Worksheet in Appendix B.)
- View professionals as resources in their fields. Continue to ask questions until you understand their position. Sometimes the professional does not have the most current information. Parents of children with autism are often in a position of knowing more than the professional.
- Remember that everyone has biases. Ask and understand what they are. For example, a surgeon’s solution to a medical problem is usually to cut. A medical doctor’s may be to use medication. Ask for data to support their recommendations.
- Don’t assume that professionals are only interested in what is best for your child. They may have competing interests. For example, a school system is only required to provide your child an “appropriate program,” not necessarily the best program. They are trying to use their dollars most efficiently for many children. You want the best program for your child.
- Learn your rights.

- Be a good consumer. To advocate for a particular treatment method or service, do your homework and bring the research with you.
- Figure out what you really want for your child and state it as a goal. Instead of demanding a particular treatment or service, ask the professionals how they propose to help your child to achieve the goal. Then ask if what they propose is going to work and how they know that.
- Demand accountability. Professionals should have data and research to show what works.
- Ask for periodic reports so you can monitor your child's progress.
- Ask for a meeting to discuss if a treatment or therapy is not working.
- Remember it is okay, and you have the right, to disagree with professionals and, ultimately, to decide what is right for your child and family.
- Be respectful, even if you disagree. Explain your point of view in a calm, courteous way.
- If a relationship with a professional breaks down and is beyond repair or you just don't feel comfortable, you have the right to leave.
- Beware if you are continually jumping from one professional to another. Ask yourself if you have some unresolved feelings you need to deal address.
- Nurture and cultivate relationships with professionals, especially those who are working directly with your child. Your child will need all the advocates he can get.
- Consider bringing brownies to a meeting. Chocolate makes everyone feel better.
- Thank professionals in writing when they have helped you. Also write to their supervisors about how they have helped your child.

*You and your child will most likely be dealing with a host of professionals for his entire life. You will get more help for your child if you can learn to build strong relationships with those who are in a position to help him. This will start with you believing that you are an equal partner in parent-professional collaborations and continue as you nurture those relationships.*

## Dual Diagnosis or Comorbidity

*Little by little we began to ask everyone who knew him if they thought there was something else going on with Peter Ben. Didn't some of the things he did look autistic? Was this possible? Down Syndrome I knew really well. I had lived and worked with many people with Down Syndrome, both children and adults. My son Peter Ben wasn't behaving like any I had known. Could it be autism? Autism I didn't know.*

*Our wonderful pediatrician confessed he didn't see the purpose in adding more labels to our son, but he too was very surprised that Peter Ben's language had almost stopped. No one from school wished to commit to the possibilities of a second diagnosis, but many characteristics our son had were so telling after a while.*

*It was the other parents who tipped our hand for us. There was the mom who saw us struggling with Peter Ben at a school function and asked, "How come I haven't seen you at the Autism Society meetings?" Another woman said, "I know he has Down Syndrome. What else is going on with him?" Finally, we got an appointment at Children's Hospital with a psychologist who was able to evaluate Peter Ben. Yep. He met the criteria by several counts. He had autism.*

People with ASD can have two or more separate diagnoses, including mental health, medical conditions, or other developmental disabilities. This is referred to as *dual diagnosis*, *comorbidity*, or *co-existing conditions*.



## ... With Specific Developmental Disabilities

It can be difficult to identify and diagnose symptoms and traits of ASD as distinct from other developmental disabilities that can cause speech and communication delays, low muscle tone, sensitivities to/unawareness of light, sound, or different kinds of touch, or demonstration of repetitive movements. It is important to understand the difference between symptoms in children who only have other conditions and those who also have ASD, because it could impact the treatment and services a child receives.

It is well documented that ASD can co-exist with many other conditions. Each year more parents are getting accurate diagnoses of ASD among their children who also have:

- Fragile X syndrome
- Epilepsy and seizure disorders
- Visual impairment/blindness
- Hearing impairment/deafness
- Down Syndrome
- Tuberous sclerosis
- Cerebral palsy
- Angelman's Syndrome
- Eating disorders
- William's Syndrome
- Prader-Willi Syndrome
- Fetal alcohol syndrome or effect

It is not the intent to describe each condition in detail here. However, if you suspect autistic behaviors or traits in your child who has another developmental disability, please pursue an evaluation from a qualified professional. Having an accurate diagnosis of ASD for a child with a co-existing disability can help make important decisions for treatment and education.

(For example, behaviors may be misinterpreted without a proper diagnosis. Sometimes an adult may declare that a child is "choosing" to ignore verbal directions, when that child is, in fact, too overwhelmed by environmental noises as a result of her ASD. In such a case, using pictures or written words instead of verbal directions is recommended, but such interventions are often not considered for a child who has normal hearing and can say some words.)

Some disability support organizations, such as those for Fragile X, Down Syndrome, and sensory impairments (visually impaired, hearing impaired) offer specific resources and support for the dual diagnosis that includes ASD. These include organizations like the Upside of Downs, the National Association of the Deaf, National Federation for the Blind, and Disability Solutions.

*If anyone from whom you are seeking help says “there is no such thing as a dual diagnosis, you’re just in denial about your child,” seek another opinion!*

## ... With Other Diagnoses – Common Disorders That Occur with ASD

Just as a child with epilepsy can suffer from anxiety, depression, motor difficulties, speech delays, or any other condition, an individual with ASD can suffer from other symptoms or disorders. Though these conditions can and should be treated, their treatment does not address the distinctive symptoms of ASD, such as impairment in social interaction, restricted repetitive and stereotyped patterns of behavior or interests, and so on, and thus the primary diagnosis of ASD should not be ignored.

Examples of co-occurring/dual diagnoses include the following:

### ***Mental Health***

- Bipolar disorder
- Generalized anxiety
- Obsessive compulsive disorder
- Oppositional-defiant disorder
- Depression
- Schizophrenia
- Mood disorder

### ***Neurological***

- Seizure disorder (estimated at up to 25 percent of individuals with ASD)
- Tourette’s Syndrome
- Sleep disorders
- Learning disabilities
- Attention deficit disorder (ADD or ADHD)
- Sensory integration disorder
- Executive functioning disorder

## Physical

- Cerebral palsy
- Muscular dystrophy
- Abnormal gait
- Poor coordination

## Medical

- Diabetes
- Asthma
- Heart conditions
- Vision loss
- Hearing loss
- Allergies
- Gastrointestinal conditions
- Hypoglycemia

In addition to the specific diagnoses above, unusual responses to sensory stimuli, sleep problems, and low muscle tone can occur in individuals with ASD.

*While generalized anxiety or panic disorders are frequently co-occurring disorders in their own right, anxiety is also an inevitable outcome for individuals on the spectrum who try to fit into neurotypical society (Gutstein, 2004). Other symptoms of living with ASD may also look like a separate disorder, although they are an expression of ASD.*

### Resources

#### **Autism Spectrum Disorders:**

Autism Society of America: <http://www.autism-society.org>

Holtz, K., Ziegert, A., & Baker, C. (2004). Life journey through autism: An educator's guide. Silver Springs, MD: Organization for Autism Research, Danya International. Also available at [www.autismresearch.org](http://www.autismresearch.org).

**Dual Diagnosis:**

Riverbend Down Syndrome: <http://www.riverbendds.org/index.htm?page=home.html>

**Deafness and Autism:**

About.com: [deafness.about.com/cs/multiplendisab/a/autism.htm](http://deafness.about.com/cs/multiplendisab/a/autism.htm)

**Visual Impairment and Autism:**

Texas School for the Blind: <http://www.tsbvi.edu/143-mivi-general/965-autism-and-visual-impairment>

**Fragile X and ASD:**

National Fragile X Foundation: <https://fragilex.org/fragile-x-associated-disorders/fragile-x-syndrome/autism-and-fragile-x-syndrome/>

**Autism and Epilepsy:**

Autism Research Institute: [http://www.autism.com/symptoms\\_seizures](http://www.autism.com/symptoms_seizures)

Epilepsy Foundation: <http://www.epilepsy.com>

**Down Syndrome and Autism:**

Chromosomal abnormalities and autism: <http://www.medicalnewstoday.com/releases/63408.php>

National Down Syndrome Society: <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Dual-Diagnosis-of-Down-Syndrome--Autism/>

Down syndrome & autistic spectrum disorder. *Disability Solutions*, 3 (5 & 6).

International Rett Syndrome Association: [www.rettssyndrome.org](http://www.rettssyndrome.org)

Riverbend Down Syndrome: [www.riverbendds.org/index.htm?page=autism.html](http://www.riverbendds.org/index.htm?page=autism.html)

This Yahoo group (an electronic mailing list) provides more information on autism and Down Syndrome: [groups.yahoo.com/group/ds-autism](http://groups.yahoo.com/group/ds-autism) click on "Join this Group"

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CHAPTER 3

# Living with ASD

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*I remember thinking it can't be autism. He has such good eye contact and is so affectionate. Our doctor had reassured us that we did not need to worry. He is a boy and boys talk later, we were told. I still worried. I knew something was different, and I began to learn to trust myself as a parent. I didn't know that ASD could be so different for each child, but I knew that my son needed help.*

”

## You Are Not Alone

This chapter provides parents of children with ASD practical strategies and suggestions for how to handle situations that may arise when living with a child/ren with ASD, relating to such topics as toileting, family outings, physician appointments, family issues, finances, etc.

Upon receiving a diagnosis of ASD, parents experience a host of strong emotions. Few forget the day when they realized that their child had a developmental disability and that their journey of parenting might be quite different from what they had imagined. In an article entitled *You Are Not Alone*, Patricia McGill Smith tells of a parent describing it as if a “black sack” was being pulled down over her head, and she could not hear, see, or think in normal ways.

Each person may react differently to the news, but there are some common reactions that are shared by many. Parents grieve the loss of the “typical” child that they expected to have. You may experience some or all of the following:

- **Shock or denial.** You may think, “How can this be happening to me?” or want to make the disability go away.
- **Anger.** You may be angry at yourself or others for “causing” ASD, you may be angry at God, at medical personnel, at your spouse, or even your child.
- **Guilt.** You may think there was something you could have done that would have prevented the diagnosis.
- **Rejection.** Some parents even report having a “death wish” for their child.
- **Confusion.** Confusion is very common for families trying to sort through all the information about ASD and make choices about treatment.
- **Fear.** You may fear the worst or have memories of other children and/or adults with disabilities and wonder if your child will have a similar life.
- **Isolation.** Because of the unique communication, social and behavioral issues presented by children with ASD, you may feel very alone. Eating out, doing things as a family, or finding time alone with your spouse or spending time with your friends becomes a challenge.
- **Envy.** Seeing other parents with their typical children may make you feel envious and resentful.
- **Relief.** Some parents report they are glad to know that their child’s behavior is not caused by poor parenting.

As extreme as some of these feelings may seem, they are normal. One of the ways you can take care of yourself is to realize that you, your spouse, or family members are not bad people for feeling angry or having other negative feelings – you are human. These are common feelings parents and families have reported as they go through the process of adjusting to a child’s diagnosis. You may find yourself feeling waves of grief throughout the lifespan at different times. Events like birthdays, school transitions, holidays, and other big events can trigger feelings of loss. If you get stuck working through the stress and grief of having a child with ASD, seek help and support.



## **Signs That Indicate That You Need Help**

- Trouble sleeping or sleeping all the time
- Feeling tired all the time
- Loss of appetite
- Headaches, or other frequent pains
- Loss of interest in sex
- Thoughts of hurting yourself or others

*See a health care provider and/or counselor for help.*

## **You Can Do This!**

Although at times it may seem almost impossible to handle the challenges that you are facing, you can do this! Remember, your child is not defined by her ASD. You will be able to parent your child successfully if you try to:

- Appreciate the uniqueness of your child. Don't compare her to others.
- Focus on your child's strengths. All children have things they do well.
- Show unconditional love. If you find yourself taking anger out on your child or someone else, get help.
- Get informed. Learn about your child's educational and other rights as well as programs that can help you and your family. Ask lots of questions!
- Don't be overprotective. Let your child do things for herself as much as possible.
- Have fun!! Find things you both enjoy and do them a lot.

## Taking Care of Yourself and Your Family

The demands and challenges of raising a child with ASD can be overwhelming. According to the Autism Society of America, research indicates that parents of children with ASD experience greater stress than parents of children with intellectual disability and Down Syndrome. The best way to help your child is to deal with your own stress.

*Having support can make a big difference, but you must take the initiative. You cannot expect others to come to you.*

- **Share your feelings with your spouse/ partner if you have one.** Reaching out helps both of you.
- **Enlist the help of friends and relatives.** While they can help, be aware they may also be experiencing some of the same feelings of loss and confusion. Talk openly with them about your child and how they can help.
- **Involve your faith community.** Some parents find comfort in their spirituality. See Issues of Faith later in this chapter.
- **See a counselor for individual or marital counseling if needed.** Check with your doctor, mental health agency, or leader of your faith community for possible counselors. Ask if they have experience with special needs families.
- **Find other parents who understand the challenges of raising a child with ASD.**

*I cannot overemphasize the importance of parent-to-parent support. I thought no one else could be experiencing the stress and chaos that I was having when my son was first showing signs of autism. I thought no one else had a child that behaved like mine. I was wrong. I met Sheryn and Darlene and they both talked openly about their children and their families. Their honesty brought great relief to me. We soon began laughing about the many times our boys would take their clothes off and the endless hours of trying to guess what they were saying because they did not have words yet. Our kids were similar, but yet unique. Years later, we still laugh, cry, and support one another. I am thankful I met them early in my journey and for the others that have come since and those I am yet to meet. They make all the difference.*

The importance of parent-to-parent support cannot be overstated. Other parents of children with disabilities can identify with your feelings of loss and frustration, help you find programs and funding for therapies, laugh with you, and possibly even cry with you. Many enjoy the company of another parent because there is no judgment, but a true understanding of how hard parenting can be.

Talking with another parent is a great place to find practical everyday help for issues that may be hard for you right now. You can find support informally by meeting for a cup of coffee, joining an online support group, or locating local organized support groups for parents like local chapters of the Autism Society of America. In Ohio you can call (614) 487-4726 to find out about parent support groups near you.

Parents report that they often learn as much from talking with other parents as they do from professionals and books. Parents before you have learned to negotiate education, funding and other service systems, and they can give you many helpful pointers on how to access services.

## **Online Support**

In this age of technology, many people turn to their computers before going to the library or bookstore when researching information about ASD. The Internet can also be a place of refuge for parents who are hesitant to talk about their personal lives in the more public forum of a support group meeting. There are electronic (online) groups that are organized around the topic of ASD so that individuals can exchange information about topics of common interest. They can also serve an important support function for people who are strapped for time to attend meetings in person or are geographically isolated.

While it is important to have an understanding network of family and friends to count on when the going gets rough, your existing circle of friends may not be able to understand your changing needs and their support may not be adequate. An electronic mailing group can be like having an autism help hotline available 24/7.

For example, on a recent electronic mailing group for parents of children with ASD, a parent reported that his child began having sleep problems again after months of sleeping through the night. The list member soon received responses from several parents who had similar experiences and who suggested strategies they used to deal with the problem. Parents may use the list to locate competent caregivers for their children.

These Internet communities are commonly referred to as **listservs** (the copyrighted name for electronic mailing list or email list). They are also referred to as “**Internet groups**” or just plain “**lists.**” Both Yahoo and Google (two major Internet browsers) have “Groups” under their listings. Yahoo and Google both have thousands of these listservs grouped by categories.

“**Blogs**” (short for web logs) are also increasing in popularity. They are a kind of online journal created by an individual, but made public on the Internet so anyone interested can read about their experiences. Like the listservs, they can link people with common interests.

**Chat rooms** are roundtable discussions in real time where several people who are online at the same time can send messages to one another and discuss particular topics.

**Electronic mailing groups or listservs** are the safest to participate in. Particularly helpful are those that are moderated, meaning that you must ask permission to join and someone reviews the postings to ensure that they are appropriate. There can be varying degrees of restrictions for membership, depending on how the groups were created.

Listservs will have archives of old postings. In order to search the archives of a group, or list, you must be a member. In other words, you cannot just open up a website and begin to participate. This extra level of security means that members can reduce the risk of “spamming.” Further, moderated groups have the ability to “unsubscribe” people who do not abide by the rules set up for the group.

Here are some examples you may wish to try out.

**ASO Website:** [www.autismohio.org](http://www.autismohio.org) Click on Autism Links. From there, click on Mailing Lists. Several will come up that you can explore. Follow the online instructions to join.

**Yahoo Groups:** [groups.yahoo.com/search?query=autism+Ohio](http://groups.yahoo.com/search?query=autism+Ohio) (found by inputting “autism Ohio” into the search function for “Yahoo Groups”): 23 groups for Ohio are listed. Just follow the directions; you can select the areas that interest you.

**Google Groups:** [groups.google.com/](http://groups.google.com/) Search for autism. Then click on “groups matching autism” – 75 different groups are listed.

It may feel overwhelming to narrow down your search. One way of doing this is to begin with those listed on [www.autismohio.org/](http://www.autismohio.org/) since it was established for parents, family members and professionals interested in autism spectrum disorders in Ohio.

## Time for Yourself

Most parents of children with an ASD feel they do not have the time to do anything for themselves, but even a few minutes a day can help relieve stress. When we are stressed, our brains are working overtime and our judgment can be impaired. Sometimes we think we cannot stop out of guilt because we might not be helping our family enough. We continue to work harder and harder while getting more frustrated and possibly making mistakes.

Simple things like taking a short walk, listening to music, or cooking a favorite meal can help you to feel better. Take time to think about your unique abilities and interests that are separate from your role as a parent. It is O.K. to take a break from your child now and then. Taking a break is good both for you and for your child. In fairness to all family members, it is O.K. for your family to occasionally engage in activities without your child with ASD. Take an extended break if you are able. If it seems impossible to do, start small and gradually extend the time.

You may have to learn to relax and let go. Here are some tips that may help.

- Set an alarm or timer to remind yourself to take breaks throughout the day.
- Schedule extended breaks (a few hours a week or whatever you can manage) on your calendar instead of waiting until you think you can fit it in. If it is not scheduled, it usually doesn't happen.

Other ways to consider to reduce stress include:

- Prayer/meditation
- Exercise/walking/stretching
- Deep breathing/relaxation exercises
- Keeping a journal
- Setting realistic expectations, but have a "to-do" list to guide your activities
- Advocating for others; that is, helping another parent take an action or say what they want or get what they need. (See Chapter 7 on Advocacy and Disability Awareness.)

## **Time for You and Your Spouse**

Parenting a typical child can place stress on a marriage. Parenting a child with special needs can be especially challenging. Couples need to have open discussions about their feelings, but they also need opportunities to stay connected and talk about things other than the children. Listening to and respecting your spouse's feelings can go a long way to remaining close. Recognize that your spouse may handle grief differently than you and allow your spouse to do it in his or her way.

*After some time passed, I remember being grateful that my husband and I grieved differently. When I was in the depths of depression, he was still in shock. At first, I felt angry that he was not as sad as I was, but later I realized it was a gift. If we had both been at that level of sadness, it would not have been good for our son. My husband was able to laugh more and interact more while I was working through my emotions.*

## Single Parenting

Many parents face parenting without a spouse or significant other because of death, divorce, or separation. We know that families with children with ASD have higher rates of divorce, some report it as high as 75 to 80 percent. Divorce and death/loss are two of the most stressful events for any family.

When experiencing and living after the divorce, remember to plan for the following:

- Incorporate a visitation schedule into your child's visual or written schedule.
- Help children identify their emotions, even if it makes you or them uncomfortable. This is very important because negative behaviors may occur when children do not acknowledge their emotions.
- Give the child time to adjust to the change in routine.
- Use pictures/video of the different homes the child will be going to help explain the change in living arrangements.
- Try to keep the rules and rewards the same in managing difficult behavior.
- If possible, keep the noncustodial parent involved in child's development and education.

Single parenting may require you to ask for help more often than if you had a live-in spouse or partner. This can be hard, but it is an important part of keeping yourself healthy. Being a single parent, you may find yourself concerned with how you are going to handle all the expenses of raising a child with ASD alone. You may also question how you will be able to date or have a serious relationship with someone in the future, knowing that you have a child with ASD. These are legitimate concerns. Remember, these questions have gone through the minds of many other parents of children with ASD. Other parents can be your best resource. Seek the support of those who have experienced similar circumstances.

For more information on parent reactions and stress, you can check the following websites. If you don't have access to a computer, call OCALI toll free at (866) 886-2254 and ask for a copy of the information.

**Dan Coulter website**

This is a father of two children with significant disabilities. Dan puts into words the questions that many parents have and he gives some good advice.

<http://www.coultervideo.com>

**Autism Society of America: Living with Autism website**

This area of the website addresses daily family and parenting issues

<http://www.autism-society.org/?s=living+with+autism>

**CIPR**

This federally funded program is a clearinghouse that provides a wealth of information for parents of children with disabilities. This article focuses on parenting a child with a disability

[www.kidsource.com/NICHCY/parenting.disab.all.4.3.html](http://www.kidsource.com/NICHCY/parenting.disab.all.4.3.html)

## Siblings

*Siblings will be in the life of a person with ASD longer than anyone else.*

The sibling relationship can have a large impact on the future of both your typical children and your child with ASD. In other words, the way a typical child reacts to having a sibling with ASD will affect the relationship that they have in the future. Again, it is helpful to hear others' experiences. Many see having a brother or sister with special needs as something positive that teaches them to accept others as they are. Siblings can be the strongest protectors and loudest cheerleaders. In contrast, some siblings feel jealous, neglected, or rejected because of the time and energy they see being invested in the child with special needs. Typical siblings may worry about the future of their brother or sister and their future role in care giving. They may be concerned about how peers will react to their sibling with ASD and they may feel embarrassed. Some typical siblings become targets of aggressive behaviors. These can be difficult issues for parents.

## What do siblings need?

- **Information/communication** – Siblings need regular discussions that are suitable for their level of understanding about ASD. They need to be able to ask questions and share their concerns. A young child may be concerned about “catching” autism while older siblings may be more concerned about what is expected of them in future care giving. Try to make no subject “out of bounds” to discuss.
- **Support** – Just like parents, siblings need support. They need a place to talk to other siblings about what it is like to have a brother or sister with ASD. Look for support groups, sibshops, or other programs for siblings in your area. There are also online support groups and listservs for siblings. (See the resources at end of the section.) If there is no formal group in your area, arrange some informal play dates with brothers and sisters of children with ASD that you know to give them the opportunity to interact with each other.
- **Respect and consideration for their uniqueness** – Celebrate even “expected” milestones for siblings. Allow them to have choices about how involved they want to be with their sister or brother.
- **Safety** – Siblings need to have a safe place for themselves and their belongings. Help them to learn to communicate with you and their brother or sister with ASD when they need space and time away. Be sure they know it is O.K. to ask for help.
- **Individual time and attention** – Plan to spend regularly scheduled time alone with your typical children. They need to count on a specific time that is devoted just to them.
- **Acceptance of typical sibling behavior** – Sibling conflict is normal in most households. Expect conflict and know this may help prepare the child with ASD for real-life situations. Don’t always expect the typical sibling to compromise or “know better.”
- **Opportunities to have a “normal” life** – Give yourself permission to take a trip without the child with ASD. Try to find respite resources so siblings can fully experience things they choose. Both siblings and the child with ASD need chores and responsibilities equal to their abilities. Don’t assume that because a child has ASD she does not have the ability to help around the house.
- **Strategies for dealing with their sibling, peers, and their own emotions** – Siblings need to know how to deal with the unusual behaviors that are often exhibited by their sibling/s with ASD. They also need some guidance in how to deal with questions from peers and the general public. Siblings need to know that it is O.K. to feel embarrassed about their sibling or to worry about them. If you think your typical child could use the assistance of a professional counselor, that is O.K. too.
- **Positive parents** – Probably the greatest impact will be the attitude of the parent(s). Being positive will help them meet the challenge. How we choose to deal with our own emotions and attitudes will impact their experience.



## Sibling Resources

Feiges, L. S., & Weiss, M. J. (2004). *Sibling stories: Reflections on life with a brother or sister on the autism spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Harris, S., & Glasberg, B. A. (1994). *Siblings of children with autism: A guide for families*. Bethesda, MD: Woodbine House.

### **The Sibling Support Project website**

This project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns. [www.siblingsupport.org/](http://www.siblingsupport.org/)

## Grandparents and Other Family Members

Like parents, grandparents grieve the loss of the “typical” grandchild they had hoped for and are concerned for their own children in the process. They, too, will need information, open communication, and recognition that they are grieving. Many well-meaning family members offer advice on behavioral issues. However, parents can become frustrated and perceive a lack of support when grandparents do not agree with the parents on how to handle difficult situations with their child with ASD. Open communication and information can help enhance your support and allow family members the opportunity to learn about your child.

There are books and organizations that address the needs of grandparents of children with ASD. The Autism Society of America is one such organization. Listed below are examples of books for grandparents of children with ASD.

### Books

Martin, E. P. (2004). *Dear Charlie, A grandfather's love letter to his grandson with autism*. Arlington, TX: Future Horizons.

Thomas, K. R. (2006). *Grandparenting a child with autism: A search for help and hope*. Louisville, KY: Harmony House Publishers.

### Websites

Autism Society of America: *Life with autism*: <http://www.autism-society.org/?s=living+with+autism>

Center for Parent Information and Resources (CPIR) - The Unplanned Journey: <http://www.parentcenterhub.org/repository/journey/>

## Family/Social Gatherings

Holidays, family reunions, birthdays, visiting relatives, and other special celebrations can be especially stressful for a child with ASD. These activities may bring about unexpected events as well as excessive amounts of sensory input. Such situations can contribute to anxiety, and the child can soon feel overwhelmed.

Writing a letter before family visits can help make the event more enjoyable. Share the things that will help your child feel comfortable, activities that he enjoys, foods he likes, and how family members can expect your child to respond when situations may be too much for him. Bring special toys, videos, games, or other comfort items. Be sure to plan frequent breaks when traveling. Finding a place where your child can take a break from the crowd will help the visit be more enjoyable for everyone.

Holidays bring lots of change and increased social demands. Consider keeping the decorations simple and safe. Make sure your decorations will not choke or harm your child if she were to touch them or place them in her mouth. Send a list of preferred gifts to family members to help everyone feel more fulfilled, that way your child will receive a gift he prefers and the family member may get to witness him enjoying the gift. Prepare your family for the possibility that your child may not want to participate in opening gifts or consider setting a limit on the number of gifts he is expected to open. At home, you may allow your child to open a gift a day so he is not overwhelmed on the actual holiday. Consider using a social narrative to describe what will happen at holidays or birthdays or other special events.

If you plan to attend a family reunion or other large gathering, showing your child pictures of the unfamiliar people and places ahead of time may help ease anxiety. Preparing both your child and your family through open communication is always helpful. For other ideas see the book *Finding Our Way* by Kristi Sakai ([www.aapcpublishing.net](http://www.aapcpublishing.net)).

# Day-to-Day Issues in Living with ASD

This section is a broad overview with suggestions for navigating the many situations and decisions parents face as they negotiate their daily lives and support their child with ASD. It covers friendships, finances, approaching therapy and education decisions, creating a workable daily home schedule, dealing with doctor appointments, and even discusses issues of faith.

## Balancing Life on the Spectrum

*I remember crying at my ultrasound when our doctor told us we were having another boy. I am sure he thought they were tears of joy, but in reality, I was crying because I knew my chances of having another child with ASD could be greater. Ultimately, I came to terms with the thought that I would love our second son no matter what, ASD or not. Our second son does not have ASD, and he has helped my older son in ways I could never have imagined.*

It is easy to feel overwhelmed by all the decisions that you will be making while living with ASD. It can be challenging to find time and ways to help everyone feel valued and get their needs met, not to mention having your own needs met, as discussed earlier. If everything in your family revolves around the child with ASD, other family members can become resentful. Do you define your family as a special needs family or a family with a special needs child? Finding a balance in your decision making and making choices that fit your family will help ease the stress of day-to-day living.

You may be wondering ...

- Should I/we have another child, knowing there is an increased risk for having another with ASD?
- Should we move or sell possessions to get better services?
- How many assessments and therapies are necessary for my child?

Evaluate your decisions carefully and try to keep some balance in your everyday life. Consider how decisions will impact your whole family and not just the child with an ASD. Unfortunately, there are people who take advantage of families that are desperate to help their child. Research carefully the services and/or treatments that are being offered to you and your child with ASD and select them according to what best meets the needs of your child and family. While searching for answers, you will find opinions that may differ even among the “experts.” Take one day at a time and try to keep your routines as normal as possible. It will help provide some consistency when things are hectic.

## Your Changing Circle of Friends

One of the most difficult and surprising aspects of learning that your child has a diagnosis of ASD is discovering that your circle of friends will change. Your friends and close family members can be a true source of support and encouragement. Unfortunately, when we need our friends and family the most, sometimes they are not as supportive as we had hoped. As a result, you may find yourself confiding in total strangers at a support group meeting or seeking comfort in the listening ear of a coworker when you used to share *everything* with your sister, or your best friend.

Individuals are just that – *individuals*. The people who have been closest to you may react to your child’s diagnosis in a variety of ways, just as parents themselves react in a variety of ways. Some may be in denial while others may express a genuine sadness. Keep in mind, though, that your closest friends and family members love and care about you *and* your child. Their concern is for your well-being as much as it is for your child’s.

When an adult friend or relative has experienced a life-changing event, many people do not know how to react. Some friends are uncomfortable in the presence of people with intellectual disability or developmental disabilities. Others withdraw in fear that they would say or do the wrong thing. This may be true if your child has challenging behavior or has yet to attain functional communication. In an effort to be supportive, people may say all the wrong things:

“My cousin’s son didn’t talk until he was 4, and now he’s a sophomore in college.”

“Einstein was autistic, you know.”

“Well at least he can walk.”

“I saw a lady on TV whose son’s autism was cured with (fill in the blank).”

### Others may be blunt:

“That kid just needs a spanking now and then!”

“Get over it!”

You will no doubt hear statements that will hurt your feelings or cause anger. It is difficult enough to ignore a stranger, but we expect much more from those close to us. Parents are vulnerable, especially when new to the diagnosis. If you are having difficulty with feelings of depression or anger, consult a professional counselor who has experience in working with parents of children with chronic disorders. A chaplain at the nearest children's hospital may be able to provide appropriate resources or referrals.

Consider also that, although we have crossed into the 21<sup>st</sup> century, many adults today did not grow up with much exposure to people with cognitive disabilities. And certainly, most adults did not attend school with children with disabilities. So the reactions of your friends and family members, especially the older ones, may simply be due to a lack of knowledge.

The best way to react to these situations is to share information about ASD, and to encourage friends and relatives to spend time with your child. Invite them to your support group meetings or ask them to accompany you on a doctor visit. Explain to them that you not only need their moral support, but you also could use a little respite from time to time. The better they know your child, the more willing they may be to help.

Make a mental note every time someone offers to help, however generic the offer may be. If you are experiencing a particularly difficult week, ask someone to run errands for you, help with laundry, or pick up your children after school. If you are affiliated with a church or a social club, fellow members may be willing to assist in some way on a regular basis. Be comfortable in asking for help when there is a need. Many people are happy to help. You will be supported, and your child will be exposed to a variety of people and personalities in the process.

Your daily routines have probably changed since your child's diagnosis. Much time is now spent with therapists, teachers, medical specialists, and other providers who understand and accept your child. It may be easy to consider these new adults in your life as your new friends. You may look forward to the brief encounters with

professionals who truly understand. Certainly, they may be friendly people, and they can be a tremendous source of support to you; however, your *real* friends should not be forgotten. Include them as much as possible in your new routines. Think outside the box when planning visits with your friends. While your life may have changed, your friends' lives probably have not, so try not to let autism be the topic of every conversation.

*During our engagement, my (then) fiancé and I agreed not to talk about wedding plans on every date. Now that we live with autism in our family, we know how important it is to not let autism dominate every conversation.*

### 10 Things I Want My Friends to Know

1. My life has changed, but I still want you to be my friend. We may need to be creative in thinking of new ways to spend time together.
2. Listen. I want you to know about my child and about how his life is affected by ASD. I may have days when I just need to “vent”.
3. Keep what I say confidential. As my friend, you may occasionally be my sounding board. Please respect the privacy of my family by not repeating what I say.
4. Don't judge my child or me. Ask questions if you have concerns about the choices we have made for our child.
5. Respect my feelings. My feelings may run the gamut from desperation to hopefulness and will change largely based on what kind of day my child is having.
6. Encourage and support me. I need to hear positive feedback. Be my guest at a support group meeting, or offer to keep my child while I go.
7. I really am happy for the milestones that your children are reaching. Don't exclude me from your celebrations; however, please understand if I am not always able to attend.
8. Ask questions. I'll be happy that you are interested.
9. Communicate with me. Please let me know if you can or cannot help with my child. It is OK to tell me if you are uncomfortable. I need to know how you feel.
10. Be my advocate. Other friends or acquaintances may not understand or may be judgmental. You may be able to keep them abreast of my child's progress and our family's needs.

*Parents, grandparents, and siblings largely report that support groups have been very helpful. However, others are uncomfortable with the candid expressions of feelings and vulnerability displayed at support group meetings. Attending casual gatherings or informal activities sponsored by autism groups may be an easier way for some parents to meet new friends. Some areas in Ohio have successfully started support groups and other activities just for dads, grandparents, or siblings of kids with autism. These provide opportunities for the attendees to meet other people who share similar experiences.*

You can check the Autism Society of Ohio website at [www.autismohio.org](http://www.autismohio.org) to find out what autism support groups are meeting in your area. If you do not have computer, call OCALI's toll-free number (866) 886-2254 to ask about support groups in your area.

## **Finances**

Having a child with ASD can be a drain on a family's resources due to the cost of expensive evaluations, home programs, and therapies. Besides, one family member may have to give up his or her job because of the care-giving demands of raising a child with autism, and the financial pressures may increase as a result. Because of the challenging behaviors often present in children with ASD, many parents find the need to seek out jobs with flexible hours or work different shifts so one parent is at home all the time. Some have developed their own home-based businesses, and still others rely on some form of government assistance to manage.

Networking with other parents, getting involved with local support groups or chapters of ASA will keep you informed of the latest sources of funding and other supports that could help. It may be difficult for you to ask for help, but there may be untapped resources out there. (See Chapter 6 for more information on Ohio's service systems.)

### **Things to Consider Related to Finances and Funding Services**

- If insurance denies a claim, appeal it.
- Parents in the same insurance company can band together. One company planned to drop coverage for speech therapy, but after several parents called and wrote letters, the benefit was reinstated.

- Ask providers if they have fees based on income.
- Use college students to help. They are more affordable and often are able to earn course credit.
- Use volunteers from your community if you are doing a home-based program.
- Ask that money be given for services to help your child instead of extravagant toys and gifts.
- Consider hosting your own fundraisers.
- Explore possible tax deductions with your tax advisor.

## ***Daily Functioning at Home***

In addition to dealing with friends and finances, parents often find that they must create a daily home schedule that supports the child with ASD and the family as well. Families engage in daily routines within the household that are executed with little thought or planning, and certain activities continue to occur without question over and over again. They are a part of living, a part of being in the household. These includes activities such as:

Bedtime	Going to the grocery store/errands
Bath time	Household chores
Meals	Getting ready for school
Play time	Having other children visit the home
Nap or quiet time	Toileting/self-care

Although a variety of strategies could be suggested here for each activity to help a child with ASD cope more easily, it is important to focus on the underlying characteristics and environmental factors of each child and each home situation as you think about these routines. As you encourage your child with ASD to participate in these routines and gain adaptive skills, consider the following.

### **1. Understand that your child's age may not equal his developmental level.**

It is important to remember that children with ASD often vary in developmental levels across areas. For example, a child may be on level with neurotypical peers in communication skills, but lower in social interactions. Even within one area, a child's skill level can vary, such as being comfortable entering into a conversation, but unable to maintain the conversation. With daily living skills, a child may be able to set the table with utensils for dinner, but may become overwhelmed when asked to clear the table and put away leftover food and dishes.



## **2. Create realistic expectations.**

As expectations are being created for the child, make sure they are appropriate for her ability level. Utilize skills that the child has mastered to build confidence and encourage the use of new, emerging skills. Take time to teach a task in small increments so that if a problem arises, the problem step can be retaught and supported. Look for ways to break down complex tasks into smaller pieces so the child will be successful. For example, if a child is 18 years old, but developmentally 7 years old, do not expect her to do a full load of laundry alone. Expect parts of the skills – gathering the dirty clothes, sorting by color and whites, or putting away the clothes when the laundry is complete. As the child masters one skill, add a step to build the child's ability to complete the entire task.

## **3. Understand the difference between schedule versus routine.**

Maintaining routine is different from keeping a schedule. For example, a bedtime routine may be flexible in the schedule because it is not always precisely at the same hour. However, the bedtime routine stays structured in that the child always gets to have one book read, is tucked in by a parent, and goes to sleep with his teddy bear. This allows for flexibility within the schedule while maintaining a routine.

For more detailed information on intervention strategies for a specific routine, refer to *Everyday Solutions: A Practical Guide for Families of Children with Autism Spectrum Disorders* by Mindy Small and Lisa Kontente ([www.autismohio.org](http://www.autismohio.org)).

## **Hygiene**

Hygiene can pose challenges for individuals with ASD in multiple areas. Most hygiene tasks involve lots of sensory information that can be overwhelming. Self-care usually involves many steps and as well as motor planning. Socially, many with ASD miss the importance of good hygiene and the unwritten rules that go with visiting public restrooms and other social situations that relate to care of their bodies. The seemingly obvious, such as bathing regularly or wearing clean clothes, may not be important to children with ASD since they may not understand their significance. This understanding and the skills related to hygiene will need to be taught.

## The Unwritten Rules

There are many unwritten social rules related to self-care. Early on, we may be worried about just teaching the tasks, but as children get older and more self-aware, it is important to teach them the social behaviors that many of us take for granted. The following are just a few examples of the “hidden curriculum” that must be directly taught to children with ASD.

### Public vs. Private Behavior

- Teach proper urinal behavior for boys such as not lowering pants fully to the ground or looking at others’ body parts while toileting.
- Make it clear that scratching or adjusting one’s private parts or underwear is not to be done in public.
- Teach that it is not appropriate to pick one’s nose in public.

### For Teenagers

- Help them learn what is “in” and what is “out.”
- Help them understand how much first impressions count.
- Help them see how hygiene can affect relationships and even employment.

## Resources

### Books

Crump, M. (2005). *No B.O.: The head-to-toe book of hygiene for preteens*. Minneapolis, MN: Free Spirit.

Myles, B. S., Trautman, M. L., & Schelvan, R. L. (2004). *The hidden curriculum: Practical solutions for understanding unstated rules in social situations*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Schaefer, V., & Bendell, N. (1998). *The care and keeping of you: The body book for girls* (American Girl Library). Middleton WI: American Girl.

Although challenging, teaching children to take proper care of themselves is a huge step towards independence. Many of the tools used to help in other areas are equally helpful when it comes to personal hygiene. For example, visual/written schedules, social narratives, desensitization, and gradual exposure to a task can all be used to help individuals with ASD learn new tasks. (See Chapter 4 for a list of current interventions and strategies used to teach and treat individuals with ASD.)

## ***Haircuts, Hair Combing, and Nail Trimming***

Consider the sensory issues that are involved with these tasks. Hands and heads are some of our most sensitive areas. Select among the following options for making this a less traumatic experience for your child with ASD.

- If your child is a sound sleeper, trim hair and/or nails at night.
- Find a hair stylist who will come to your house.
- Play relaxing music or find a distracting toy, video game, or favorite show to occupy the child while the haircut or nail trim is occurring.
- If going to a stylist, visit the shop several times before actually going for a haircut. Use pictures or video to illustrate what is going to happen.
- Pick a time when the shop is not so busy.
- Go frequently, even for just a small trim, rather than wait a long time between haircuts.
- Experiment to determine whether clippers or scissors are better. Some children like clippers because they can make the cutting go faster, but they can also sound louder.
- Consider combing hair more than once a day to get used to the sensation.
- For nail trimming, do a finger at a time with breaks in between until more tolerable.
- Put hygiene checks in schedules. Remember: If it is not seen, many do not think about it. Simply reminding them to look in the mirror may be enough.

## ***Hand and Body Washing***

Preferences are important for motivation. Consider the following:

- Does your child prefer aromas or textures for soap? Consider foam vs. bar vs. liquid.
- Does your child prefer a certain water temperature?
- Does your child like soft or rough washcloths and towels?
- Does your child prefer a schedule or list of tasks to be performed while washing?
- Is hand-over-hand support provided to help the motor planning and memory?

## **Toileting**

Becoming toilet trained is one of the most important skills that your child will need to learn, and it is not easy. It takes real commitment from parents and caregivers, but it can be achieved with a systematic approach. This text is only a brief outline of one method. Refer to the resources after this section for more information on toileting.

To begin the process, your child should be able to:

- Follow simple directions.
- Sit in a chair for 5 minutes.
- Stay dry for 1-1/2 hours.

### ***Skills Involved in Toileting***

Initially, focus on just teaching the child to eliminate in the toilet. Later, teach the other skills needed to be completely toilet trained, including:

1. Recognizing when he has to go
2. Waiting to eliminate
3. Entering the bathroom
4. Pulling pants down
5. Sitting on the toilet
6. Eliminating in the toilet
7. Using toilet paper correctly
8. Pulling pants back up
9. Flushing the toilet
10. Washing hands
11. Drying hands

## Elimination Records

About two weeks before you are ready to start toilet training, start recording when your child urinates and has a bowel movement to establish her elimination pattern – the times of each day when she is most likely to wet and/or soil her pants.

Elimination Record														
	Sunday		Monday		Tuesday		Wednesday		Thursday		Friday		Saturday	
Time	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet
7:00														
8:00														
9:00														
10:00														
11:00														
12:00														
1:00														
2:00														
3:00														
4:00														
5:00														
6:00														
7:00														
8:00														
9:00														
10:00														
11:00														

In the Pants column, you will record every hour:

D=dry

U=Urinated in pants

BM=Bowel movement

U/BM=Both

If you are putting the child on the toilet, record the results in the Toilet column in the same way. Do not begin the toilet training process while collecting these data.

D=Did not eliminate in toilet

U=Urinated in toilet

BM=Bowel movement

U/BM= Both

During these two weeks, there is no failure or success. You are only trying to see what your child's elimination pattern is so that you can set up a toileting schedule that makes sense for her.

### ***Determining a Toileting Schedule***

Carefully analyze the Elimination Record. At this point, decide whether you will focus on urine or bowel training. For this example, we focus on urine training.

1. Circle all the U's on the forms and add them up.
2. There will be a greater number of times for urination. Select four or eight times during the day when your child is most likely to eliminate. No two times should be closer than 1-1/2 hours.
3. Arrange the toileting schedule so that your already established toileting times for bowel training become a part of it.
4. Take the child to the toilet at all the schedule times.

### ***Putting the Child on the Toilet***

The bathroom routine should be:

1. Bring your child to the bathroom on schedule or when she signals. Pull her pants down to below the knees, encouraging her to do the rest.
2. Have her sit on the toilet for 5 minutes. Stay with her, praise her, and explain what is expected in a straightforward, non-demanding way.
3. If she eliminates, praise her and give her a reward.
4. If she does not eliminate, remove her from the toilet, and take her out of the bathroom for 10 minutes. Return to the bathroom for another 5-minute sitting.

In the beginning, going to the toilet should be a casual matter with little required on the child's part other than to sit. In a 20-minute period, give your child two 5-minute chances to eliminate with a 10-minute break in between.

## ***Using Visual Cues***

You may create visual cues, consisting of photographs or pictures, to support the toilet-training process. A good aid to use during toilet training is a visual schedule to help the child through the toileting procedure. See an example of a visual schedule at the end of this section.

In addition, a special visual prop can be helpful in setting the tone and in alerting your child to the activity. An example is to give the child a rubber duck when you want him to use the bathroom. Parents of nonverbal children may also consider incorporating sign language into the routine and teaching the child the sign for toilet so the child will learn to indicate when he needs to use the restroom.

## ***Intensive Training***

Another method is called “intensive training” or “weekend training.” It consists of spending the entire day in the bathroom focused entirely on toilet training. This approach also uses the Elimination Record to record times when the child was placed on the toilet.

Using this method, the child is dressed in only a shirt and remains on the toilet until he eliminates. Once the child eliminates, he is given a 5- to 10-minute break, then placed on the toilet again. The child is given plenty of fluids and salty snacks to encourage elimination. Parents use favorite toys in the bathroom to occupy the child.

## ***Sensory Issues***

Parents face some consistent problems relating to sensory dysfunction when trying to toilet train a child with ASD. Many children on the spectrum are sensitive to such things as the feel of the water splashing from the toilet, the texture of the toilet paper, the sound of the flushing, the feel of the toilet seat, and the list goes on. It is not uncommon to see the following demonstrated by some children with ASD:

- Flushing or playing with water in the toilet
- Playing with toilet paper
- Smearing feces
- Being “addicted” to diapers
- Refusing to wash hands
- Refusing to eliminate in toilet
- Afraid of flushing
- Refusing to sit on toilet

## ***Set the Stage for Success***

*Be consistent:* Keep the toileting routine as consistent as possible so that your child will come to expect it and be at ease with it.

*Use a regular toilet from the beginning:* If your child is too small, place a smaller seat on top of the regular toilet.

*Avoid distracting toys and people:* It is important for your child to learn that the bathroom is not a playroom; he is there for one reason only, to eliminate in the toilet.

*Avoid distracting talk:* Talk to your child about what he is supposed to be doing and what the toilet is for. Avoid talking about unrelated matters.

### **Resources**

Azrin, N., & Foxx, R. M. (1988). Toilet training in less than a day. New York: Pocket Books.

Baker, B. L., Brightman, A. J., Blacher, J. B., & Heifetz, L. J. (2003). Steps to independence: Teaching everyday skills to children with special needs. Baltimore: Brookes.


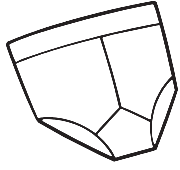

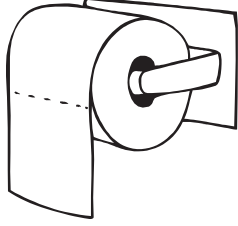
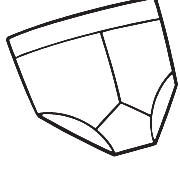

Coucovanis, J.A. (2008). The Potty Journey, Guide to Toilet Training Children With Special Needs, Including Autism and Related Disorders. Shawnee Mission, KS: Autism Asperger Publishing Company.

Dalrymple, N. J. (1991). Toileting: Functional programming for people with autism. Indianapolis: Indiana Resource Center for Autism.

Wheeler, M. (1998). Toilet training for individuals with autism and related disorders: A comprehensive guide for parents and teachers. Arlington, TX: Future Horizons.



# Toilet Training Visual Schedule

	<p><b>Pull down pants</b></p>
	<p><b>Pull down underwear</b></p>
	<p><b>Sit on toilet</b></p>
	<p><b>Use toilet paper</b></p>
	<p><b>Pull up underwear</b></p>
	<p><b>Pull up pants</b></p>

## Human Sexuality

When children become teenagers, their bodies start to dramatically change. They begin to grow pubic and underarm hair. They start to break out with acne. Girls begin to menstruate. Boys' voices change. For teenagers with ASD, these changes to their bodies may be frightening if they are not forewarned and prepared.

Parents need to decide the best way to talk with their teenagers with ASD about human sexuality based on their beliefs and traditions. Basic introductions should address the following topics:

1. Describe the basic physical changes that occur on the outside of the body during puberty.
2. Describe the basic physical changes that occur inside of the body during puberty.
3. Describe the basic emotional changes that occur during puberty.
4. Identify ways to manage or handle these changes.

Puberty can be an exciting time in a young adult's life. It's the time when the body makes many changes – both physical and emotional – to prepare for adulthood. It is a good opportunity to teach teenagers with ASD about their bodies and how they work.

### Puberty

#### **Typical Changes**

- Increased attention to physical appearance
- Interest in romantic love
- Increased need for independence
- Masturbation
- Unpredictable changes in mood
- Desire to be accepted and liked by your peer group
- Pubic and underarm hair

#### **Changes in Girls**

- Growing breasts
- Beginning periods
- Premenstrual syndrome

#### **Changes in Boys**

- Erections
- Wet dreams

## Elopement or Wandering

Have you ever found yourself worrying about your child wandering off and getting lost? All parents are concerned about their child's safety – whether the child has special needs or not. However, the concern of parents of children with ASD is often heightened due to the child's deficits in communication and socialization.

You can use direct instruction to teach your child that wandering away is not appropriate. You can use stories to explain that it is dangerous for your child to leave your house or yard. Still, some children and adolescents with ASD have an overwhelming desire and talent for leaving their homes and wandering unattended. This does not only happen at home. Children often wander away from a parent at a busy store or at the park. This is very dangerous because most children with ASD do not understand or obey the rules of the road or private property.

Neighbors can be very helpful in keeping an eye out for your child. Talk to them and explain what to do and how to approach your child if they should see him out alone. You can also inform neighborhood children and teenagers about what to do if they see your child out alone.

Make sure to contact your local police and fire department to alert them about your child and his tendency to wander. They should be able to “red flag” your telephone number and home if you ever call 911. This specific information may be embedded in the 911 database, so that the dispatcher will be able to tell the police and fire department about your child before they arrive.

If wandering is a typical problem for your child, you can install extra locks on all exterior doors high enough so the child cannot reach them, even when standing on a chair. Many parents have installed sliding bolt locks on the top frame of the door. There are also bed and door alarms available to signal when a child or adolescent is out of bed or opens a door or window. You can even get an alarm that plays a recorded message when a door is open, like “Jack! Do not leave the house!” and then sounds a siren to alert the parent. Children or adolescents can also wear bracelets that trigger an alarm once they pass through a protected doorway.

A very helpful precaution is to have a medical identification tag for your child to wear that lists name, diagnosis and contact information. These can be ordered at a drug store or online from MedicAlert. These medical emblems can be worn on the wrist, around the neck, or laced into a shoelace.

To be prepared, parents can create an emergency handout about their child for the time when they do wander off (see box).

### **Sample Autism Emergency Contact Handout**

If your child is a habitual wanderer, keep a copy of this handout at home, at school, in the car and on the child in case of an emergency. The sheet should include the following information:

- Name of child
- Current photograph and physical description, including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers, and emergency contact persons
- Sensory, medical, or dietary issues and requirements
- Inclination for wandering and any atypical behaviors that may attract attention
- Favorite attractions and locations where child may be found
- Likes, dislikes – approach and de-escalation techniques
- Method of communication. If nonverbal – sign language, picture boards, written word
- ID jewelry, tags on clothes, printed handout card
- Map and address guide to nearby properties with water sources and dangerous locations highlighted

## **Out in the Community**

As parents of a child with ASD, we are familiar with our son's or daughter's behavior, but others may not be accustomed to this disorder. Most of our children appear normal to others. It is only when they start to exhibit bizarre or out-of-control behavior that they come to the attention of others. Outings in the community can be a great challenge for most parents.

### **Tips for Successful Outings**

- Keep outings short.
- Do what you say you will do in the order you say you will do it.
- Decide on the optimal number of stops.
- Do the most important things first.
- Prepare a visual schedule for your child.
- Offer a reward at the end of the outing for good behavior.

## ***Shopping Trips***

One of the biggest challenges a family faces is the weekly shopping trip. Sometimes it is considered more trouble than it is worth. However, shopping is a basic skill that needs to be learned by children with ASD. Indeed, shopping trips are a good opportunity to teach your child to become more independent.

1. Create a visual shopping list using visual symbols with the list on one side and a completed list on the other side that may be used during the shopping trip (see example at the end of this chapter).
2. Involve the child in the selection process. For example, if you are buying a dozen apples, have the child select them. Point out if one has a bruise so he can learn.
3. Bring handheld toys or action figures to occupy the child.
4. Allow the child to help push the cart once she is older and no longer fits in the cart.

## ***Issues of Faith***

For many families, attending religious services is an important part of family life. It is intended to be a time of worship and quiet reflection, but when a child with ASD attends, it can be anything but quiet.

Nevertheless, a family's place of worship can be a source of comfort and support. While some families are established within a faith community, others may be new to religious life, having turned (or returned) to their faith as a source of strength upon the diagnosis of their child. Dedicated members of your faith community may be able to assist your family in various ways, from offering a listening ear to providing assistance in your home. A faith community may provide a comfortable setting for companionship and support.

Including a family member with ASD in religious services and activities may require some creative planning. Many religious bodies have programs for people with disabilities within their religious communities (see Resources at the end of this section). While not autism-specific, these programs may provide a blueprint for personalizing a program for your child.

It may be beneficial to request a meeting with the appropriate leader(s) in the faith community to discuss options for including your loved one in religious activities. Ask a teacher or service provider who may be of the same religious affiliation to accompany you and provide information about the kind of structure and support your child needs. This "team" can be a valuable resource.

Consider all the sensory stimulation during a service, including music, singing, stained glass windows, candles, flowers, and incense, which all together may be a lot for your child with ASD to handle. Here are some ideas to help entertain your child:

1. Personal stereo with headphones to block out extraneous sounds
2. Coloring books and washable crayons/markers
3. Picture books
4. Stuffed animal or another comfort item

Some have questioned whether or not it is wise to teach religion to a person on the spectrum, the argument being that religion is too abstract to grasp. If your faith is an important part of your family tradition, do not be discouraged from seeking an appropriate environment for religious training and fellowship. If you are not looking for an in-depth religious program, it may still be wise to teach your child about the various religions and denominations to which he may be exposed. In her adult life, she may receive services from a faith-based organization and should be respectful of the caregivers' beliefs. Likewise, it may be necessary to teach your child strategies for politely declining unwanted invitations from religious organizations she (or you) do not wish to be affiliated with.

## Resources

**Autism Society of America** includes two articles on religion and autism  
<http://www.autism-society.org/living-with-autism/community-inclusion/autism-and-faith/>

**Bethesda Lutheran Homes and Services, Inc.**, is dedicated to sharing Christ's love and providing services and benefits to individuals with developmental disabilities, their families, and others who support them. [www.blhs.org](http://www.blhs.org)

**Council for Jews with Special Needs** works to provide the necessary supports and resources for individuals with disabilities to participate in the Jewish Community. [www.cjsn.org](http://www.cjsn.org)

**Friendship Ministries** is a not-for-profit organization that helps churches and organizations share God's love with people who have cognitive impairments. [www.friendship.org](http://www.friendship.org)

**Jewish Council for Disabilities** is an organization dedicated to enhancing the life opportunities of individuals with special needs insuring their participation in the full spectrum of Jewish life. [www.njcd.org](http://www.njcd.org)

**National Apostolate for Inclusion Ministry** has joined forces with the National Catholic Partnership on Disability (NCPD): supports the inclusion of persons with intellectual disability in the Catholic Church. <http://www.ncpd.org>

**National Organization on Disability** has a section of their website devoted to religious participation. It includes a variety of interfaith resources and information. [www.nod.org](http://www.nod.org) (link on left of page for religious participation)

## **Restaurants**

Eating out can be a fun family excursion as long as you keep some basic strategies in mind. Don't let autism keep you from the activities and places you and your family enjoy.

1. Sit in a booth with the child with ASD on the inside to prevent bolting.
2. Have plenty of napkins available.
3. Remove all condiments and drinks from the child's reach.
4. Have a snack or activity ready for the child when you sit down to occupy her until the food arrives.
5. Take walks to the bathroom or arcade games to allow the child to explore the restaurant under your supervision.

## **Vacations**

Family vacations – no matter how longed for – can pose difficult issues. The most important thing to remember is to maintain as much of a routine as possible for a child with ASD. For example, have the child awake at his normal time, followed by breakfast and maybe watching television as a way to start the day. It is also important to keep the child's sleep schedule the same.

Creating a travel book may be a good planning device for your child. It can include pictures of the kind of transportation you will be using, who you are going to visit, where you will sleep, and what you will do or see at your destination. Also, remember to pack some of his smaller toys that will occupy him and remind him of home.

Use your vacation destination as a way to experience new sensory activities, without overlooking your child's fragile nervous system. Textures, sounds, sights, colors, and music are just some examples of sensory experiences. Here are some ideas for guiding sensory experiences on vacation.

1. Going to the beach and playing with sand.
2. Walking through a forest and feeling the different leaves.
3. Exploring a museum, identifying colors and shapes.

Make sure to take a lot of photographs of the places you visit to make a special memory scrapbook once you return home. Collect items from your trip like brochures, postcards, rocks, leaves, and other mementos to use in the scrapbook (remember to bring an empty coffee can or ziploc bags to store the nature items).

## ***Preventing Meltdowns in a Public Place***

As any parent knows, when your child (typical or ASD) has a meltdown in public, it can be embarrassing and frustrating for you and other family members. Prepare ahead of time for going out in public. You can do this by creating a schedule of events, including pictures or drawings to illustrate what will occur and review it with the child before the trip. Sometimes you can even prepare a basic schedule on a napkin or a piece of paper to help your child understand what is going to happen. You can also bring an object that your child finds comfort in, or read a social narrative about the event ahead of time to prepare for the outing. These are just a few suggestions on how you can provide some predictability for your child before going into the community.

## ***Handling a Meltdown in a Public Place***

Always remember that your child with ASD does not want to have a meltdown, so be patient and compassionate. However, when a meltdown does occur, the child is usually in extreme distress and may lose control of her raging emotions. When a meltdown does occur, try to remember the following:

1. **Only move the child if there is an immediate safety concern.** Moving the child while he is having a full-blown meltdown can be dangerous for you and the child, because he is unable to process what is happening.
2. **Do not try to give your child whatever he was asking for before the meltdown to stop it.** This advice is not to say you should not give in and let the child have his way. It is because during the meltdown he is unlikely to be able to respond to the object or even process the fact that he has it.
3. **Step back and do not intervene unless your child asks you to.** At this point, your job is not to try and calm him down; it is to wait. A child can rarely express his immediate needs during a meltdown.
4. **If there are others close by, move them.** Well-meaning people may try to help, but tell them very clearly to stay back because their presence will only escalate the situation. This is when the autism awareness cards may be helpful (see box).
5. **Make sure your own reactions don't escalate.** Try to step back and disconnect enough so that you are not caught up in your child's intense emotions and try to think rationally.
6. **Try not to take it personally.** It hurts when our children are angry and lash out at us, but try thinking of it as a symptom of something your child *has*, not who he *is*.
7. **Take this opportunity to step back to observe your child carefully.** Pay attention to his environment to determine if there are triggers – lighting, noise level, etc.
8. **Do NOT restrain your child.** However tempting, restraints may reinforce future meltdowns because some children find deep pressure relaxing. It is not only potentially dangerous for you and the child, in the long term, restraining is ineffective. THE ONLY EXCEPTION is when your child is hurting himself or others, or is in danger.



## Resource

Myles, B. S., & Southwick, J. (2005). *Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns* (2<sup>nd</sup> ed.). Shawnee Mission, KS: Autism Asperger Publishing Company.

## ***When the Child Hits the Parent***

There may come a time when your child hits you. First and foremost, do not take it personally. Your child is trying to communicate with you and may not be able to do so in a functional manner when in a state of distress. The following are important things to keep in mind.

1. Your child may not remember she did it.
2. Determine if he purposely hit you, or if he was flailing and randomly and accidentally hit you.
3. Review what you might have done to inadvertently contribute to the child physically acting out toward you during a meltdown.
4. Decide whether to bring up the hitting after the incident.
5. Make sure your child knows that you forgive her when she makes a mistake, whether intentional or not.
6. Call on your support group to get emotional support and to discharge some of the emotions you are feeling if necessary.
7. When you are of a clear and rested mind, you will need to ask some questions – is this an ongoing pattern and do I need to seek help from a behavior professional?

The following are some examples of cards that may be carried by people with autism or their caregivers to briefly explain autism to strangers. You can make these cards yourself or purchase them from local Ohio Autism Society chapters. You may also call OCALI at (866) 886-2254 to ask for the address of the Autism Society Chapter nearest you.

If you want to make your own autism awareness cards, here is the copy you can put on each side of the card.

### **Examples of Autism Awareness Cards**

#### **Side One**

If you are puzzled by my child's behavior? It is not boldness or lack of discipline!  
My child has autism ...

#### **Side Two**

*Autism is a life-long neurological disorder that prevents the person from understanding what he sees, hears, or otherwise senses. People with autism often become confused and respond inappropriately in social situations. Autism strikes out of every 68 people.*

*You can also make a card with the following messages:*

*Our son has autism, a severe language and behavioral disorder. He sometimes becomes confused, disoriented, or upset and may throw temper tantrums or scream. We are committed to teaching him how to function in the community and would appreciate your patience and understanding. If you would like to learn more about autism, please feel free to contact us or the American Autism society (1-800-3Autism).*

*This young person has autism/Asperger Syndrome. It is a developmental disability that affects social and communication skills. People with autism tend to behave in an odd and unpredictable way as a result of their disability. Please help us by being understanding and showing tolerance.*

### **Resources**

#### **Books**

Sakai, K. (2005). *Finding our way: Practical Solutions for Creating a Supportive Home and Community for the Asperger Syndrome Family*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Sicile-Kira, C. (2004). *Autism spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder and Other ASDs*. New York: Perigee.

Tilton, A. J. (2004). *The Everything Parent's Guide to Children with Autism: Know What to Expect, Find the Help you Need, and Get Through the Day*. Avon, MA: Adams Media Corporation.

## ***Preparing Your Child for a Medical Appointment***

Not unlike most children, children with ASD are not particularly fond of going to doctors. The experience can be traumatic because there are many sounds, sights, and smells that can seem frightening to them. It is extremely important that before going to a physician's appointment, the child is prepared and provided with an understanding of what will take place at the appointment.

## ***Preparing the Medical Environment***

When initially setting up the appointment, whether for a routine pediatric visit, a dental appointment, or a visit to the hospital, mention your child's diagnosis to be sure it is added to the chart, if it is not already included. Ask that it is noted in a prominent spot so that all involved will be aware prior to meeting your child. This is meant to benefit your child. With proper information, even the initial interaction with the nurse or receptionist can set a positive tone for your child's visit.

Three to four days prior to your child's visit, call the office to touch base again. Ask what the routine and wait time will most likely be for your child's appointment. They should be able to tell you about transitions and specific steps (such as being weighed, measured for height) that will be included in the routine. Confirm that they are aware of your child's diagnosis. Explain the specific characteristics of your child and express any stress triggers that might bother him. Suggest adaptations that could be made to ensure that the transition and actual appointment will proceed quickly and smoothly for everyone. Suggestions may include the following:

- With medical professionals, reviewing the environment with the child in mind
- Limiting the number of people who will be involved in the child's care
- Designating a medical team member as the child's procedure coach
- Providing sensory items to help the child self-regulate
- Preparing the child for surgery or a physician's appointment according to the child's developmental level, not the child's chronological level
- Using visuals to help the child understand what will occur
- Providing simple, step-by-step information
- Developing coping techniques that are specific to your child, such as talking about the visit ahead of time and looking at pictures of the physician's office and equipment

If the visit to the hospital is an emergency and advance notice was not given, be sure to let the medical team know about your child's characteristics, needs, stress triggers, and sensory preferences as soon as possible. Putting these items in writing prior to arrival and bringing them with you will make it easier to convey the child's needs to the medical staff as well as give them a framework for how best to interact with your child in this emergency situation.

## ***Preparing Your Child for the Medical Environment***

Tell your child she will be making a visit to the doctor or dentist. Do not surprise her with this information upon arrival. All children are nervous about a medical visit, but giving them information in advance allows them to process, anticipate, and better absorb the reality of what will occur around them. It allows them to predict what will occur so they are not caught off guard by the flood of new sights and sounds around them – a major consideration for children with ASD.

### ***Giving Information***

Information should be given on your child's level, in the amount and manner in which your child can best understand it. If you are able to obtain pictures of the actual office, use them. Often major children's hospitals have online virtual tours, with photos describing a visit to the hospital, or they allow you to visit the hospital for a tour prior to your actual visit. If these options are not available, consult children's books that depict a visit to the doctor, dentist, or hospital. It is important to familiarize your child with titles of people, equipment that might be used, the routine of the environment, and steps of the actual procedure, if at all possible.

Create a story specific to your child's visit. Include details such as:

- Steps in the routine
- Making transitions to different rooms
- Waiting in certain areas
- Wearing special pajamas during the visit
- People your child will meet
- Equipment your child will see
- Sights, smells, and sounds that your child will encounter

Add details that make your child's trip unique such as:

- Who will accompany him
- What he can bring with him
- What he will do when the visit is over

Ask your child open-ended questions about what he is feeling and which steps seem hard or easy. Help him make a plan to be successful, and remind him that it is okay to ask questions if something comes up he does not understand. Create a portable, step-by-step visual, such as a photo flipbook or a written schedule of each step. Make sure the schedule outlines the details you have discussed and the coping techniques chosen by your child to help him with the visit. This predictability will give your child a sense of control as he ventures into an often unsettling encounter.

## ***Medical Play***

In addition to specific information about the encounter, allow your child to play through the medical experience. Refer back to the children's books and provide your child with a medical doctor's kit. Encourage your child to be both the doctor and the patient during various play series. Do not interrupt your child even if she engages in hostile or aggressive play, unless it is endangering her own or others' safety. Sit back and observe what your child is expressing through words and actions. After the play sequence is finished and your child is in a state of attention, talk with her about what you observed and directly answer all the questions you can. Give honest information, using soft language so as to not frighten your child, but provide accurate information.

## ***Use a Transitional Item***

Plan a transitional item that your child can bring to accompany him on his journey. This may be a favorite stuffed animal, a blanket, or some special treasure. This item allows

the child to cling to something he is familiar with in the midst of an unfamiliar and invasive environment. Create a plan with the child as to who will hold the item during various steps in the procedure. The object may have to be out of the child's hands at times, and it is better if this is discussed prior to the moment when the child is being asked to release the item. If a plan is in place, the child can be reminded that the item will only be out of his hands for a few moments and returned during the next step.

### ***During the Medical Encounter***

In addition to all the advance preparation, your child will need you as a coach during the actual medical encounter. Encourage him to bring along the portable visual you created to support him through his visit. Be sure to leave space for flexibility, as the medical environment often entails emergencies or unforeseen delays.

As each step takes place, indicate to your child that it is over by crossing it off or turning the page of her special book or visual. Reiterate the lessening number of steps left. Remind your child that she successfully completed previous steps and then guide her through the step that is next. For example, "Great job getting weighed. You have already finished three steps. You arrived at the doctor's office, waited in the waiting room, and got measured and weighed by the nurse. Now we are waiting for the doctor to come in."

You can also review previously chosen coping techniques or offer new choices on the spot. In the midst of the medical encounter, provide your child with limited choices. For example, "While we wait for the doctor to come in, do you want to play 'I Spy,' read your book, or talk about *Star Wars*?" Be sure to only offer choices that are available. Coping choices may change for different steps because of restrictions of body movement, room changes, or the effect of medication.

### **Resources**

Hudson, J. (2006). *Prescription for success: Supporting children with autism spectrum disorders in the medical environment*. Shawnee Mission, KS: Autism Asperger Publishing Company.

"Your Next Patient Has Autism," North Shore Long Island Jewish Health System:  
<https://www.northshorelij.com>

## ***Leisure Activities***

Leisure activities are something everyone enjoys and looks forward to. To the extent possible, children with ASD should participate in leisure activities as individuals, in groups of peers, and with their families. By using your child's interests and strengths, encouraging skill building in small steps, and creating a fun and well-supported environment, leisure activities can be enjoyed by all.

### **Sample Community Activities to Consider for Your Child**

Playing on a sports team	Playing outdoors
Visiting the library	Visiting a museum
Scouts	Reading
Religious groups	Playing board games
Going to a birthday party	Watching a parade, event or sport
Camps	

The following are some ways to adapt activities and build in support to create success for your child, given her special needs.

### ***Provide a Framework***

Prime your child in advance with information that will create a visual for him and prepare him for the overall experience. In your description, review items such as:

#### **The overall environment**

- Sounds
- Sights
- Smells

#### **The people present**

- Names
- Descriptions
- Role or function
- Designated "safe person" such as a counselor, activity leader, etc.

**The activity taking place**

- Rules
- Why he is participating
- Working as a team
- Being an individual

**Boundaries and rules**

- For the activity
- Social “hidden curriculum” rules the child may not know

***Provide Opportunities***

If your child wants to participate in leisure activities, provide the opportunity for her to do so. You may need to ease her into a group function, so practice first at home playing one-on-one with your child. Eventually, invite three or four children over to play. Provide a structured activity for a predetermined, short length of time. As your child develops, transition her into a larger group, a bigger arena, or a lengthier interaction using increasingly more skills.

- If your son wants to play Little League, teach the basic skills one-on-one or invite boys to play baseball. Practice throwing, catching, and batting. After your son learns the subtle rules of team play and develops basic skills, invite the boys over again for a short game. Eventually, your child will be ready to transition into a full Little League team.

If your child wants to participate in non-sport leisure activities, practicing at home can also be beneficial. Create a scenario and role-play with your child prior to an actual encounter.

- Pull out shelves of books and a plastic card to pretend you are at the library. Review rules of being quiet and how to look for a book.
- For lunch, create a menu of choices. Present it to your child and ask her to make a selection. Review table manners, what to do while she waits, and choice making.



## **Encourage Your Child's Strengths and Interests**

Ask your child in which activities he wants to participate. Getting consent from your child will increase his desire to participate. Find avenues to pursue the interests and activities that he loves and in which he excels, and then adapt them for his level of participation and skill. Create leisure activities and social opportunities out of your child's interest. For example, if your child enjoys reading, start a small reading group, having the children read a story and complete activities that pertain to the theme. If your child enjoys playing a particular game, for example, chess, invite others over and create a chess tournament. If your child likes to play baseball, start a small, informal team in your neighborhood.

## **Talk with the Leaders**

Prior to the event or start of a sport season, visit with the director, coach, or a parent of a peer to exchange information and create a plan of success for your child. Take time to explain your child's strengths and needs, providing information about sensory needs, need for visual supports, stress triggers, and how to anticipate and support a potential meltdown. Ask for information about the routine of the event, gathering as many details as possible. Also discuss adaptations that would be beneficial and determine how they will be incorporated.

Often when a child is starting or encountering a new leisure activity, parents participate in a leadership role, such as being a coach or facilitating a troop. This allows you to add needed support and make accommodations for your child.

## **Bullying**

Bullying is a pressing issue for many schools. While this damaging behavior affects both typical children and children with special needs, children with special needs are at more risk for being targets of a bully. Being bullied can cause kids to experience fear and anxiety and interfere with school work and self-esteem.

### **Types of Bullying**

- Physical – hitting, kicking, pushing, etc.
- Verbal – name calling, teasing
- Emotional – excluding and ignoring others
- Sexual – touching, teasing, coercing
- Cyberbullying – sending threatening emails, text messages, harassing cell vphone calls, etc.

Because children with ASD have trouble with language and social cues, they can become easy targets for bullies. Further, one of the main ways children protect themselves from being bullied is to predict the behavior of others and respond accordingly. Children with ASD have a very difficult time predicting what others may be thinking. For example, a group of students may talk a child with ASD into doing something he knows is wrong, but he may think they are trying to be friends and not realize what they are doing and comply after all. Students with ASD may also mimic what others do, including bullying others, without understanding the consequences. They may also try to retaliate.

The best bullying prevention programs involve the whole community and all staff at your school. Children not only need to learn ways to handle a bully, they also need to be able to address students who may watch, called bystanders. If your child is reporting increased headaches, stomachaches, or other physical problems or complaining about going to school more than usual, consider explaining what bullying is and ask if it is happening to her.

If your child is being teased, excluded, or harmed repeatedly by schoolmates, take action.

- Ask about school policies, training, and programs for bullying.
- Ask if there is supervision in hot spots like hallways, lunchrooms, bathrooms, and locker rooms. Bullying typically occurs under the radar of adults.
- Ask if there are classroom discussions about bullying.
- Look for teachers who are flexible and can help your child feel more alike than different.
- Consider using a social story and/or power cards to help your child know how to respond to bullies.
- If needed, you can address it on the IEP.

### Resources

#### Books

Heinrichs, R. (2003). *Perfect targets – Asperger Syndrome and bullying: Practical solutions for surviving the social world*. Shawnee Mission, KS: Autism Asperger Publishing Company.

#### Websites

Stopbullying.gov: <http://www.stopbullying.gov/index.html>

Stop Bullying Now: [www.stopbullyingnow.com](http://www.stopbullyingnow.com)

Pacer Bullying Prevention Center: <http://www.pacer.org/bullying/>

# GROCERY LIST

## *Items to Find*

*Velcro Strips for Picture*

*Velcro Strips for Picture*

*Velcro Strips for Picture*



## *Items to Buy*

*Velcro Strips for Picture*

*Velcro Strips for Picture*

*Velcro Strips for Picture*



## CHAPTER 4

# Interventions

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Someone you love has been diagnosed with autism – what treatments are available for autism? What can you do to help them to reach their full potential? Cope in the world?

Autism has no common cause and no known cure. Be wary if someone claims to be able to “cure” autism, especially if the only information available is from the person promoting the “cure”. This chapter will describe a variety of treatment options for autism, guidelines for choosing treatments, things to consider when choosing treatments, and how to determine if a treatment really helped.

Because there is no common cause, because autism is a spectrum disorder – that is, symptoms range from mild to severe – and because each individual with autism is “uniquely autistic”, there is no “one-size-fits-all” treatment. This puts the burden of determining what treatments will work best for a particular individual directly on the family and the professionals working with the family. Treatments and therapies can vary widely in cost and focus.

### **Research on Autism Interventions**

Individuals with autism spectrum disorders require individually designed interventions that meet their needs. In fact, no one intervention has been universally identified as being effective for all children with ASD. It is important, however, that parents and school professionals working together as a team select empirically valid techniques (National Research Council, 2001; Olley, 1999).

Carefully research and review the information available on the intervention you are considering. Many books and research journals can aid you in your search. As you read about various autism therapies, keep in mind the research that has been conducted on whatever therapy you intend to implement.

To say that a methodology is grounded in scientifically based research means there is reliable, independent evidence that a given program or practice works. To obtain reliable evidence about a reading strategy or instructional practice, for example, an experimental study may be done that involves using an experimental group that uses the intervention and a control group that does not to see if the method is effective in teaching children to read. Ultimately, family members and professionals together must determine whether a particular strategy or method is effective, or if a scientifically based method is suitable for an individual student.

Research is derived from theory and practice. While not all methodologies are currently founded in empirically based research (studies that follow specific scientific rules), many are backed by anecdotal reports (observations of individual cases by parents, caregivers, and professionals) of effectiveness. Care must be taken to evaluate each methodology on its merits and appropriateness for the particular needs of the individual with ASD.

## Choosing Interventions

Choosing appropriate intervention(s) for your child can be confusing; the amount of information available in print and on the Internet is overwhelming. The following are some important questions to help parents and caregivers make decisions regarding the best interventions for their child.

### Questions for Parents/Caregivers to Ask Regarding Specific Treatments and/or Programs

- What characteristic behaviors of ASD am I trying to target?
- Does the program/therapy and anticipated outcomes address these targeted concerns?
- Does the method meet the unique strengths/challenges/goals for my child?
- Are there any harmful side effects associated with this treatment? What are the potential risks? Is there any risk of discontinuing the intervention?
- Are there any activities, foods, and so on, that will be restricted during treatment?
- What positive effects of treatment would I hope to see?
- What are the short-term and long-term effects?
- Can the treatment be integrated into my child's current program?
- How will the goals/outcomes be evaluated? How will I know if the child is making progress toward desired outcomes? What method will be used to evaluate the child's progress?
- What is the cost of treatment? Will my insurance company pay for the treatment?
- How much time does the treatment take? Can I realistically devote the time required to the treatment?

- Has this treatment been validated scientifically? Have I collected information about this from a variety of sources?
- Was I able to interview other parents and professionals about the treatment? If so, list pros, cons, and other areas of interest.
- Do proponents of the treatment claim that this procedure can help nearly everyone? If so, this should be seen as a “red flag” to slow down and be more careful in consideration of this technique, considering the wide range of abilities represented on the autism spectrum.
- What do my pediatrician and other professionals involved with my child think about the treatment’s appropriateness?
- Are there alternatives that are: less restrictive? better researched?

## Determining Effectiveness

Stephen M. Edelson, Ph.D., Center for the Study of Autism, Salem, OR (2007), offers these important tips for parents and caregivers to help determine if a particular treatment is effective:

- **Implement one treatment at a time.** Change one thing at a time, allowing plenty of time to see the effects of a treatment. (Edelson suggests at least two months)
- **Keep your own data.** Keep a daily record prior to the intervention as well as during the intervention. Your personal record can help you determine if any changes are taking place.
- **Seek objective information.** Consider, if possible, not telling other adults your child may come in contact with about the new treatment to prevent biased feedback.
- **Collect data from those involved in treatment implementation.** Ask teachers or clinicians to keep written data. After a period of time, compare others' data with your own.
- **Note unexpected or unanticipated changes.** Make note of surprising or unexpected changes your child may exhibit.
- **Educate yourself about the treatment.** Be sure you learn as much about the treatment as possible before beginning. Look for both positive and negative information. Be aware of possible side effects.

As mentioned, no one treatment will have the same impact on all individuals with ASD. For this reason, it is important to make informed choices and use written data to monitor effectiveness.

## Interventions

The following are common therapies, program models, biomedical interventions, and strategies used with individuals with ASD. The section begins with the core deficit areas of autism and corresponding interventions, some of which are available to children in the school setting. It does not include research studies for effectiveness of treatment; rather, the selections are for informative purposes only.



## Communication

Communication difficulties, both verbal and nonverbal, are inherent in the diagnosis of ASD. The typical sequence of communication development is disrupted. As a result, communication skills can range from nonverbal, gestural, the use of single words, to verbal conversation, and may include:

- Perseveration (repetitive verbal and physical behaviors)
- Echolalia (immediate and/or delayed “echoing” of words, music, phrases or sentences)
- Hyperlexia (precocious knowledge of letters/words or a highly developed ability to recognize words but without full comprehension)
- Dactolalia (repetition of signs), pronoun reversals, inappropriate responses to yes/no questions, and difficulty responding to “wh” questions

When designing intervention strategies, it is important to understand both the individual's receptive (comprehension) and expressive communication skills. Stressful situations that increase anxiety often interfere with the ability to communicate. Difficulty understanding humor, idioms (“keep your eye on the paper”), sarcasm, and other complex forms of verbal and written expression is common. Even the highly verbal individual may understand and use literal (concrete) language, but have difficulty with abstract concepts needed for higher order thinking skills.

A person's communication ability usually changes over time. Therefore, it is important to maintain an ongoing communication assessment from diagnosis through adulthood as this provides current information, which is necessary to support appropriate communication strategies.

Supporting all forms of communication – verbal, signing, pictorial, augmentative devices (and often a combination of more than one) – promotes learning.

## Therapies

### Speech-Language Therapy

During therapy, the child's functional communication skills, or the child's *intent*, such as requesting and protesting, are assessed, and programs are developed to address communication deficits and improve communication skills. Therapy may occur in individual settings or in small groups. Families will always be involved in the therapy process in order to facilitate functional communication across various situations. Parent and caregiver training is a large component of speech-language therapy to maximize its benefits.

Be sure to choose a speech-language pathologist (SLP) who holds a Certificate of Clinical Competence from the American Speech-Language-Hearing Association (ASHA). The SLP is a skilled professional who can address the following areas of concern:

**Receptive language** – the understanding of spoken or written messages as well as other forms of language. This includes identifying objects, actions, adjectives, prepositions, people, and so on.

**Expressive language** – the production of language. This includes sentence structure, verb tenses, regular/irregular plurals, length of utterance, and so on.

**Articulation/phonology** – includes developing speech sound production, the use of tongue, lips, teeth, and so on, to produce speech sounds.

**Oral-motor skills** – includes improving the range, rate, complexity, strength, and coordination of oral motor movements. May also include massage of cheeks, lips, and gums, brushing teeth, and decreasing teeth grinding.

**Feeding and swallowing** – includes ability to close lips, manipulate food with tongue, age-appropriate chewing pattern, and safe swallowing. Other areas that can be addressed include oral desensitization to different tastes, textures, smells, temperatures, and consistencies of foods.

**Social skills/play skills** – includes appropriate social language, ability to read facial expressions, ability to understand social cues/body language, and age-appropriate play skills such as sharing, turn taking, and playing independently or with others.

**Pragmatics** – the use of language in social context.

**Cognition** – the mental process of knowing, including aspects such as awareness, perception, reasoning, and judgment. (Source: [dictionary.com](http://dictionary.com))

**Alternative or augmentative communication (AAC)** – the use of any device, technique, symbol system, or combination thereof to supplement, enhance, or increase a person's communication abilities.

## **Common Communication Options**

**Sign language** – use of signs alone or paired with speech.

**Picture Exchange Communication System (PECS)** – involves using picture symbols to communicate wants/needs, label, and so on. The child goes through a learning process that teaches initiation of communication and then expands to the use of sentences. Many children who use PECS develop some verbal skills and may graduate to speech as the primary form of communication.

**Communication boards** – can be made with pictures or objects that the child points to or removes from the board to communicate wants/needs.

**Other communication devices** – a wide range of devices designed to enable the user to create longer messages. These devices can also act as a universal remote, allowing the user to operate electronic devices in the environment such as the TV, lights, and so on. The speech-language therapist can assess the child’s abilities to use high-tech devices and make recommendations about the type of device that is best suited for the child’s individual needs.

**Facilitation** – involves holding the child’s hand or having the child hold the facilitator’s hand to help her write or keyboard messages.

**Total communication** – communication system that pairs simultaneous production of speech with manual signs or another augmentative devices or symbol systems. The child is encouraged to use the words/phrases that he is capable of producing and supplementing communication with signs, symbols, and so on, for what he cannot communicate verbally.

### **Resources**

American Speech-Language-Hearing Association: [www.asha.org](http://www.asha.org)

Ohio Speech Language Hearing Association: [www.ohioslha.org](http://www.ohioslha.org)

## **Physical Therapy**

Physical therapists (PT) are specialists in sensorimotor development, muscle and joint function, posture, balance and coordination, and gait and functional mobility. They are knowledgeable about orthotic and prosthetic devices, and assistive technology. Physical therapists identify movement problems and determine what is interfering with a child’s ability to develop age-appropriate gross-motor skills.

Physical therapists help young children with autism learn to walk, run, jump, ride a tricycle, and catch a ball. They assist preschoolers and school-aged children in becoming safe in their environments, walking up and down stairs, and climbing, and help children acquire the gross-motor skills necessary to play on the playground or participate in physical education classes with their peers.

Physical therapy may work closely with occupational therapy, sensory integration and/or speech therapy to help maximize the effects of each therapy.

### Resources

American Physical Therapy Association: [www.apta.org](http://www.apta.org)

Ohio Physical Therapy Association: [www.ohiopt.org](http://www.ohiopt.org)

## Occupational Therapy

Occupational therapy (OT) is concerned with an individual's ability to participate in desired daily life tasks, or "occupations," that give life meaning. If a person's ability to perform life tasks is impacted by an illness, disease, and/or disability, occupational therapy can be important.

Performance areas include:

- activities of daily living (grooming, oral hygiene, toilet hygiene, dressing – as related to school performance), feeding and eating, socialization, functional communication, and functional mobility;
- work and productive activities (educational and vocational activities) and home management such as meal preparation, shopping, or clothing care; and
- play or leisure activities (play or leisure exploration and play or leisure performance).

Following an evaluation of the child's functioning, OT intervention is targeted towards those areas that are interfering with the child's ability to function. Tasks that may be targeted include writing, improving hand-eye coordination, buttoning a shirt, tying one's shoes, getting dressed, and feeding oneself. OT intervention with persons with autism often includes a sensory-integrative approach, which focuses on providing controlled sensory input during specific activities (see next section on Sensory Integration).

School-based occupational therapy is focused on educationally relevant goals and tied to curriculum standards. In order for school-based therapy to be effective, a consultative approach is necessary. Therapy may encompass the more traditional "pull-out"/ direct service approach, working with the student within the classroom, consulting with the parent, student and educational team to ensure that interventions and accommodations (in the home as well as in the classroom) are effective.

Areas addressed by occupational therapy may include the following:

**Fine-motor control/written output** – The OT may implement a fine-motor strengthening and coordination program, and/or recommend adaptations (i.e., use of pencil grips, specially lined paper, use of keyboard, extended time, shortened work load, use of note-taker or adapted software programs).

**Visual-motor and visual-perceptual skills** — Occupational therapists may also address the student’s ability to control eye movements to smoothly shift visual focus, track objects across midline, and perform the visual motor control needed to read text as well as write. Accommodations may include slant boards, copy of all work on chalkboard available at desk, paper window guided, and colored transparencies.

**Postural stability and control** — Occupational therapists may address difficulties students may have in maintaining efficient seating postures. Recommendations may include dynamic seating using a partially inflated beach ball or camping pillow, or a Move n’ Sit Cushion.

## ***Sensory Processing***

A. Jean Ayres, Ph.D., an occupational therapist, first researched and described the theories and frame of reference that we now call sensory integration. Briefly, sensory integration is a process used by the brain to locate, sort, and make sense out of incoming sensory information. This process is important to successfully accomplish life tasks.

Ayres described sensory integrative dysfunction as a sort of “traffic jam” in the brain. Some bits of sensory information get “tied up in traffic” and certain parts of the brain do not get the sensory information they need to do their jobs. Children who have ASD may experience this.

For example, a child may scream when wearing certain clothing because her sensory system is hypersensitive to the sense of touch. This same child may crave bear hugs (deep touch) because her proprioceptive system is hyposensitive. (See Proprioception below.) These hypersensitive and hyposensitive sensations impact the child's independent functioning in many facets of life, including peer interaction, attention at school, and activities of daily living at home.



**Proprioception** (sensation from joints, muscles and tissues that lead to body awareness), obtained by lifting, pushing and pulling heavy objects as well as engaging in activities that compress (push together) or distract (pull apart) the joints. It is the sense that allows a person to guide his arm or leg movements without having to observe the movement to make sure it is happening.



**Vestibular** (the sense of movement, centered in the inner ear), obtained by spinning and swinging and, to a lesser extent, any type of body movement or change in head position. It coordinates the movement of one's eyes, head, and body and tells the body where it is in space. The vestibular sense is central in maintaining muscle tone, coordinating two sides of the body, and holding the head upright against gravity.



**Tactile** (sense of touch) obtained by providing a variety of input from textures, temperature, and pressure.



**Auditory** (what we hear and closely connected with the vestibular sense), obtained by listening to various types of music or natural sounds. Some auditory input can have an organizing and calming effect. Music containing 60 beats per minute can be particularly organizing, whereas irregular beats and contrasts in volume may be energizing.



**Visual** (what we see), can be used to calm or alert the system. Care must be taken that the child's environment is not too visually stimulating or distracting.



**Olfactory** (smell) input can stimulate, calm, or send a child into sensory overload.



**Taste**, obtained by the use of sweet, salty, crunchy, or chewy foods, can help calm, alert, or organize the system.

\*Sensory Gang used with permission from the Autism Asperger Publishing Company; <http://www.aapcpublishing.net>

## **Sensory Diet**

Once the child's sensory processing abilities and needs have been evaluated, the therapist may work with the educational team as well as the family to develop a *sensory diet*, a term coined by Patricia Wilbarger, OT. The sensory diet is a carefully designed personalized activity schedule that provides the sensory input a person's nervous system needs to stay focused and organized throughout the day. Because sensory needs vary from individual to individual and from day to day, careful monitoring and collaboration is crucial.

Components of a sensory diet might include brushing, swinging, heavy work (lifting, carrying), swimming, wearing weighted vests, wrist or ankle weights, wearing earphones, tactile play, trampoline jumping, chewing hard or crunchy objects, among many others.

Occupational therapists may also elect to use a system of tactile and proprioceptive input called the Wilbarger Protocol. This is a system using a soft bristle brush to provide carefully controlled sensory input, always followed by a deep pressure/joint compression system. While this protocol has been anecdotally reported to be effective in regulating sensory processing for some individuals, if done incorrectly, it can have harmful or dangerous results. Therefore, this procedure should only be used by trained personnel, and under the supervision of a trained occupational therapist.

### **Resources**

#### **Books**

Cohn, E. S. (2001). Parent perspectives of occupational therapy using a sensory integration approach. *American Journal of Occupational Therapy*, 55, 285-294.

Kranowitz, C. S. (1998). *The out-of-sync child*. New York: Perigee Book.

Linderman, T. M., & Stewart, K. B. (1999). Sensory integrative-based occupational therapy and functional outcomes in young children with pervasive developmental disorders: A single subject study. *American Journal of Occupational Therapy*, 53, 207-213.

Myles, B. S., Cook, K. T., Miller, N. E., Rinner, L., Robbins, L. A. (2000). *Asperger Syndrome and sensory issues: Practical solutions for making sense of the world*. Shawnee Mission, KS: Autism Asperger Publishing Company.

VandenBerg, N. L. (2001). The use of a weighted vest to increase on-task behavior in children with attention difficulties. *American Journal of Occupational Therapy*, 55, 621-628.

### Websites

A more extensive version of this explanation of OT services is available at these websites:

Action Based Learning: <http://abllab.com>

The American Occupational Therapy Association: <http://www.aota.org>

Brain Gym: [www.braingym.com](http://www.braingym.com)

The Kid Foundation: <http://www.spdfoundation.net>

Jenny's Kids Inc.: <http://spdconnection.com>

Occupational Therapy and Autistic Children: <http://autism.ca/occther.htm>

Occupational Therapy Innovations: [http://www.ot-innovations.com/component/option,com\\_weblinks/catid,16/Itemid,34/](http://www.ot-innovations.com/component/option,com_weblinks/catid,16/Itemid,34/)

The Ohio Occupational Therapy Association: [www.oota.org](http://www.oota.org)

OT Exchange: [www.OTExchange.com/](http://www.OTExchange.com/)

SI Focus magazine: [www.SIFocus.com](http://www.SIFocus.com)

## Vision Therapy

Some children with ASD experience difficulties related to visual-perceptual problems, or the means by which a person becomes aware of his body's relationship to external space, or the relationship in space between one object and another (Kranowitz, 1998). Vision therapy is a process of retraining the visual-perceptual system so it functions with optimal efficiency. The process follows a sequence of steps aimed at improving the visual system. Therefore, it is a procedure with therapy activities prescribed by the vision therapist which are carried out in the office, and frequently reinforced with home activities.



## Resources

Kranowitz, C. S. (1998). *The out-of-sync child: Recognizing and coping with sensory integration dysfunction*. New York: Perigree.

Optometrists Network: [www.visiontherapy.org](http://www.visiontherapy.org)

## **Recreational Therapies**

Recreational therapy is a general term used to describe the practice of using leisure activities as therapeutic interventions. Such therapies provide opportunities for supporting and enhancing communication and social and motor activities, and may include, but are not limited to, the following.

### **Aquatic Therapy**

Aquatic therapy is the use of water and specifically designed activities to help restore, maintain, and increase function. Aquatic/swimming therapy focuses on therapeutic play activities that improve range of motion and increase balance, endurance, and body awareness. Swimming provides movement that can help enhance motor planning. Water pressure can be soothing and calming for individuals with ASD.

## Resources

Aquatic Resources Network: [www.aquaticnet.com](http://www.aquaticnet.com)

Aquatic Therapy and Rehabilitation Institute: [www.atri.org](http://www.atri.org)

### **Art Therapy**

Art therapy is an established profession that uses the creative process of art to improve and enhance the physical, mental, and emotional well-being of individuals of all ages. It can increase fine-motor, visual motor, visual perception skills, organization, planning, and artistic expression.

## Resources

American Art Therapy Association, Inc.: [www.americanarttherapyassociation.org](http://www.americanarttherapyassociation.org)

Art Therapy Credentials Board: [www.atcb.org](http://www.atcb.org)

## **Music Therapy**

Music therapy is the prescribed use of music and musical interventions to work towards specific therapeutic goals and objectives. Goal areas include communication, academic, motor, emotional, and social skills. Music therapy can also have a positive effect on self-esteem and reduce anxiety while developing appropriate expression of emotions.

Music is a nonverbal form of communication. It is a natural reinforcer – it is immediate in time and provides motivation for practicing nonmusical skills. Parallel music activities are designed to support the objectives of the child as observed by the therapist or as indicated by a parent, teacher, or other professional. A music therapist might observe the child's need to socially interact with others. Musical games like passing a ball back and forth to music or playing sticks and cymbals with another person might be used to foster such interaction. Eye contact might be encouraged with imitating clapping games near the eyes. Preferred music may be used contingently for a wide variety of cooperative social behaviors like staying in a chair or remaining with a group of children in a circle.

### **Resources**

American Music Therapy Association, Inc.: <http://www.musictherapy.org>

Autism Research Institute (ARI): <http://www.autism.com/families/therapy/music.htm>

## **Therapeutic Horseback Riding**

Hippotherapy, or therapeutic horseback riding, uses horses as a source of treatment to improve balance, posture, and mobility. It can also improve the cognitive, behavioral, and communication functions of individuals of all ages. Riding enables an individual to participate in an enjoyable activity while increasing attention span, independence, and self-esteem. While learning from the horse, riders often bond with the horse as well as the other riders, thus providing a good foundation on which to build relationships with others.

### **Resources**

American Hippotherapy Association: <http://www.americanhippotherapyassociation.com/>

PATH International: <http://www.pathintl.org/path-intl-centers/find-center>

Other possibilities for recreational therapies include tumbling/dance, camping, 4H, animal therapy, peer play groups, community sports activities, swimming/aquatics, yoga, martial arts, and tae kwon do.

*When deciding on recreational therapies, the child's needs and interests must be considered.*

## Program Models

### Applied Behavior Analysis

Applied behavior analysis (ABA) is the scientific study of the principles of human behavior. The Florida Department of Children and Families defines ABA as:

*The design, implementation, and evaluation of systematic environmental modifications for the purpose of producing socially significant improvements in and understanding of human behavior based on the principles of behavior identified through the experimental analysis of behavior. ([www.abatherapy.net](http://www.abatherapy.net))*

ABA includes finding out the connection between an individual's behavior and his/her environment. In other words, what is causing the behavior? ABA uses direct observation and measurement of behavior and environment. Measurement looks at how often, what time, how long, to whom, or how intense a behavior occurs. ABA also looks at what happens in or to the environment right before a behavior occurs, otherwise known as the *antecedent behavior*. Antecedent behavior includes verbal, gestural or physical prompts, cues, materials, language, and environmental factors (sensory input: noise, light, smell, taste, touch), either naturally occurring or intentionally manipulated to affect a behavior. The consequence of the behavior is what occurs after the behavior. *Consequences* include reinforcement, both positive and negative, and punishment. *Reinforcement* increases the likelihood of the behavior occurring again. Punishment procedures increase the likelihood of the behavior diminishing or disappearing (known as *extinction*).

The sequence of ABA is sometimes referred to as ABC: antecedent, behavior, consequence.

A substantial amount of research has shown that ABA can be effective for children with ASD.

#### Resources

Association for Behavior Analysis International: [www.abainternational.org](http://www.abainternational.org)

Clinical Behavior Analysts: [www.abatherapy.net](http://www.abatherapy.net)

Cooper, J., Heron, T. E., & Heward, W. L. (2006). Applied behavior analysis (2<sup>nd</sup> ed.). New York: Macmillan.

## Discrete Trial Training

ABA is not synonymous with discrete trial training (DTT), although many erroneously use the terms interchangeably. DTT is an ABA strategy. DTT is a distinct and complete behavioral event that includes a discriminative stimulus or the antecedent (what happens before the behavior), the response or behavior (what the child is required to do), and the consequence for the behavior (reinforcement). The term “Lovaas Therapy” comes from Dr. O. Ivar Lovaas, whose landmark research led to the application of DTT techniques to teach children with autism.

### Resources

Association for Behavior Analysis International: [www.abainternational.org](http://www.abainternational.org)

Harris, S. L., & Weiss, M. J. (1998). *Right from the start: Behavioral intervention for young children with autism: A guide for parents and professionals*. Bethesda, MD: Woodbine House.

The Lovaas Institute for Early Intervention: [www.lovaas.com](http://www.lovaas.com)

Wisconsin Early Autism Project: [www.wiautism.com](http://www.wiautism.com)

## Verbal Behavior (VB) Intervention

Also called *applied verbal behavior*, this is a type of ABA that is based on B. F. Skinner’s 1957 analysis of verbal behavior. Like the Lovaas model, VB emphasizes the importance of using very structured and organized learning environments, including readily accessible reinforcers delivered after a correct response. The model teaches both speaker and listener behavior. The VB format uses discrete trial instruction as well as natural environment training (NET), a practice that differentiates itself from the Lovaas model. The NET supports the generalization of responses in different settings and different stimulus conditions.

The VB model focuses on teaching the functions of language. This includes teaching children the many uses of language such as requesting, labeling, speech imitation, describing, categorizing, reading and commenting (Skinner used the words *mand*, *tact*, *echoic*, and *intraverbal* to describe these functions). VB begins with teaching “mands”, which are commands, demands, requests; then “what do you want?” to elicit language; moving on to echoic, receptive, “tacting” (labeling objects); then receptive language by function (“what does it do?”), feature (“what does it look like or what are characteristics?”), and class (category); and finally “intraverbals”, both simple and complicated, which are word “associations.”

Partington and Sundberg (2005) developed the Assessment of Basic Language and Learning Skills – Revised (ABLLS-R). The ABLLS-R is an assessment, curriculum guide, and skills tracking system for children with autism or other developmental disorders based on Sundberg’s and Partington’s (1998) book, *Teaching Language to Children with Autism and Other Developmental Delays*. The ABLLS assesses a child’s skills and deficits to establish a baseline for programming. The curriculum guide uses task analysis to teach the skills needed for speaking and listening. It also includes scoring instructions and a skills tracking system.

## Resources

B. F. Skinner Foundation: [www.bfskinner.org](http://www.bfskinner.org)

Dr. Vincent J. Carbone: [www.dr-carbone.net](http://www.dr-carbone.net)

Partington, J. W., & Sundberg, M. L. (1998). *Teaching Language to Children with Autism and Other Developmental Delays*. Pleasant Hill, CA: Behavior Analysts, Inc.

Partington, J. W., & Sundberg, M. L. (2005). *The Assessment of Basic Language and Learning Skills – Revised (ABLLS-R)*. Pleasant Hill, CA: Behavior Analysts, Inc.

## Pivotal Response Training (PRT)

PRT is a comprehensive service delivery model that uses both a developmental approach and applied behavior analysis (ABA) procedures. PRT aims to provide opportunities for learning within the context of the child's natural environments (Koegel & Koegel, 2005).

PRT was designed based on a series of studies identifying important treatment components. It includes clear and appropriate prompts, child choice, turn taking, maintenance tasks, reinforcing attempts, responding to multiple cues, and a direct response-reinforcer relationship. PRT does not define the specific types of prompts to use: however, implementation of the procedure usually involves the same prompting strategies as those used in milieu teaching and interrupted behavior chains. In contrast to the other procedures that have focused almost exclusively on increasing verbal and nonverbal communications, PRT has been adapted to teach a variety of skills including symbolic and sociodramatic play and joint attention. (Schreibman & Ingersoll, 2005, p. 884)

## Resources

Koegel, R., & Koegel, L. (2005). *Pivotal Response Treatments for Autism: Communication, Social, and Academic Development*. Baltimore: Paul H. Brookes.

Schreibman, L., & Ingersoll, B. (2005). Behavioral interventions to promote learning in individuals with autism. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders: Volume II: Assessment, interventions, and policy* (pp. 882-896). New York: John Wiley.

## **TEACCH**

Developed in the early 1970s by Eric Schopler, the TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) approach focuses on the person with autism and designing a program around her skills, interests, and needs. Thus, the individual, rather than the instructional method, is the priority.

The program uses structured teaching in a variety of settings. Organizing the physical environment, developing schedules and work systems, making expectations clear and explicit, and using visual materials have been found to be effective ways of developing skills and allowing people with ASD to use these skills independently of direct adult prompting and cueing.

Cultivating strengths and interests, rather than drilling solely on deficits, is another important priority. The relative strengths of those with autism in visual skills, recognizing details, and memory, among other areas, can become the basis of successful adult functioning (Mesibov & Shea, 2006).

### **Resources**

Division TEACCH: [www.teacch.com](http://www.teacch.com)

## ***The Hanen Approach***

The Hanen Centre based in Montreal, Canada, supports the belief that parents can be their child's language facilitators. Since parents have the strongest bond with their children and also have multiple opportunities to interact with their children on a daily basis, parents are the obvious choice for language facilitators. Parents involved in the program are trained by Hanen-certified speech-language pathologists.

Through training, parents learn how to adapt the Hanen approach to meet the needs of their own child. There are three programs for parents:

- *It Takes Two to Talk* – The Hanen program for parents.
- *More Than Words* – The Hanen Program for Parents of Children with ASD
- *Target Word* – The Hanen Program for Parents of Children who are Late Talkers.

In order to support special educators, the Hanen Centre has developed special materials for teachers, including *Learning Language and Loving It – A Guide to Promoting Children’s Social, Language, and Literacy Development* (2nd ed.) (Weitzman & Greenber, 2002).

The Hanen approach puts parents and others who work with young children in the forefront as language facilitators. The child is recognized as having the most important role in the learning process and experiences provided by adults are the learning opportunities.

## Resources

Hanen: [www.hanen.org](http://www.hanen.org)

Weitzman, E., & Greenber J. (2002). *Learning language and loving it: A guide to promoting children’s social, language, and literacy development* (2<sup>nd</sup> ed.). Toronto, Canada: Hanen Centre.

## Integrated Play Groups

The concept of Integrated Play Groups was developed by Pamela J. Wolfberg, Ph.D. Based on the nature of play among peers without disabilities, Dr. Wolfberg established a format that promotes socialization and imagination in children with autism and other developmental delays. Integrated Play Groups follow rules for creating an appropriate play environment, including play areas and selected materials; preparing the typical peers for play; use of assessments and measurements of progress; as well as play guidance. Integrated Play Groups focus on social communication, especially in the autistic deficit areas of imitation, joint attention, and imaginative and creative play.

## Resources

Wolfberg, P. J. (2003). *Peer play and the autism spectrum: The art of guiding children’s socialization and imagination*. Shawnee Mission, KS: Autism Asperger Publishing Company.

## **SCERTS Model™**

SCERTS stands for Social Communication, Emotional Regulation, and Transactional Support. The SCERTS Model™ is a comprehensive model that is based on a developmental perspective and was designed to support individuals with ASD. The SCERTS Model™ is interdisciplinary in its approach, in that it addresses social communication and emotional regulation throughout the child's daily activities and routines, and guides and supports parents and caregivers through a multidisciplinary team effort. The model uses the knowledge base and experience of general and special educators, speech language pathologists, occupational therapists, child psychologists, psychiatrists, and social workers.

The SCERTS Model™ is not prescriptive, nor is it a curriculum. Instead, it is based on fundamental beliefs and values that address the core deficits of ASD. The model is systematic, semi-structured, but flexible, so that the individual goals of the family and child with ASD can be addressed at specific developmental levels. The model is based on the belief that children learn best when they are emotionally regulated and can communicate within a social context. The SCERTS Model™ was systematically developed to be implemented based on those beliefs. It does not exclude other educational models, but accepts them within its framework of intervention as appropriate.

### **Resources**

Prizant, B., Wetherby, A., Rubin, E., Laurent, A., & Rydell, P. (2006). *The SCERTS model™: A comprehensive educational approach for children with autism spectrum disorders*. Baltimore: Brookes.

## **Relationship Development Intervention (RDI)**

Relationship Development Intervention, created by Steven Gutstein, Ph.D., is modeled on how typical children become competent in the world of emotional relationships. It is an intervention approach quite different from the typical social skills programs currently available.

RDI uses assessment information to develop clear, specific, developmentally appropriate treatment objectives and customized activities. The RDI curriculum is composed of six levels, each representing a dramatic developmental shift in the central focus of relationships. The six levels are: Novice, Apprentice, Challenger, Voyager, Explorer, and Partner. RDI provides a path for people on the autism spectrum to learn friendship, empathy, and a love of sharing their world with others. Language comes alive when integrated with real emotion. People with ASD learn not only to tolerate but to enjoy change, transition, and going with the flow. The path begins at the edge of each person's current capability and carefully, systematically teaches the skills needed for competence and fulfillment in a complex world.



## Resources

Connections Center: [www.rdiconnect.com](http://www.rdiconnect.com)

### **D.I.R./Floortime**

Dr. Stanley Greenspan and his colleague Serena Weider created the Developmental-Individual Differences-Relationship (D.I.R.)-based model as an intervention for children with autism and other developmental delays.

Greenspan and Weider (1998) specify six functional milestones of development in this order: self-regulation and interest in the world, intimacy, two-way communication, complex communication, emotional ideas, and emotional thinking. According to the authors, these milestones lay a foundation for more advanced learning since they are based upon emotional interactions usually developed early in life.

The D.I.R. model uses a comprehensive evaluation, including developmental history, biomedical assessment, current functioning, child-caregiver interactions, auditory processing, sensory processing, sensory modulation, motor and perceptual motor functioning, and family patterns, to develop a comprehensive intervention plan for the child and family. The primary goal of the D.I.R.-based intervention is to enable children to form a sense of themselves as intentional, interactive individuals and to develop cognitive language and social capabilities from this basic sense of intentionality.

Part of the D.I.R. method uses “floortime”, which is an intensive, one-to-one experience during a 20- to 30-minute period when a caregiver physically gets down on the floor and interacts with the child. The focus is on relationships, based on Greenspan and Weider’s belief that the more intellectual functions of the brain do not develop without a constant source of relating. During floortime, the adult follows the child’s interest or intent, even if the interest is a self-regulatory behavior, in order to encourage interaction. For example, if the child spins the wheels on a car, the adult may help him or spin a different wheel. The adult may limit the number of toys available so that the child has to interact to get more toys. The goal is not just to follow the lead of the child but to help the child expand his interactions. According to the authors, the four goals of floortime are two-way communication, logical thought, attention and intimacy, and the expression and use of feelings and ideas.

### Resources

Floortime/DIR Model: <https://www.autismspeaks.org/what-autism/treatment/floortime>

Greenspan, S., & Weider, S. (1998). *The child with special needs*. Reading, MA: Addison-Wesley.

## Individual Strategies

The following table identifies individual strategies that have been found effective in supporting individuals with ASD. These strategies can be effective in a variety of settings, such as home, community, and educational settings. The name of each strategy is listed in the first column, followed by an explanation and description of the strategy in the second column. The last column lists where to find more information on the strategy.

## Strategies Found Effective in Supporting Individuals with ASD

Strategy	Description	Resources
<p><b>Social Stories™</b></p>	<p>Created by Carol Gray, a Social Story™ is a short story written from the child's perspective to encourage appropriate behavior in a particular situation. The story includes a description of the situation, a positive statement of what the child will do (that is, the appropriate behavior the story is written to encourage), and how others react to the situation. The final sentence in the story is added with the child after reading the story. It offers a connection to something the child knows, or another strategy to help her remember the appropriate behavior. Depending on the individual, Social Stories™ may include pictures.</p>	<p>Carol Gray offers information on how to write Social Stories™ as well as other related information on her website: <a href="http://www.thegraycenter.org">www.thegraycenter.org</a>.</p> <p>In addition, the book <i>The New Social Story Book</i> by Carol Gray is available in the OCALI Lending Library.</p>
<p><b>Video modeling</b></p>	<p>Video modeling is the use of videos of someone behaving appropriately in a given situation to model appropriate behavior for a child. While the video can be of the child behaving appropriately in his own environment, the technique is also effective if someone else, a complete stranger, exhibits the behavior in a different environment.</p>	<p>This websites offers information on video modeling: <a href="http://www.iidc.indiana.edu/index.php?pageid=3766">http://www.iidc.indiana.edu/index.php?pageid=3766</a></p>
<p><b>Priming</b></p>	<p>Priming is a way of letting a child know what to expect or what is coming. You can prime for a short or a long period of time. For example, you may prime a child for a Saturday shopping trip by going over where you will go, when you will go, how long you will be there, and the things you need to accomplish at each place. You may also identify what behavior is expected for each stop. Typically, you would put the same information in a visual format to cue the child throughout the trip. For example, you may have a visual schedule for the day that you look at with the child as you discuss the day.</p>	<p>A practical manual on priming may be accessed from <a href="http://www.iidc.indiana.edu/index.php?pageid=409">http://www.iidc.indiana.edu/index.php?pageid=409</a> and <a href="http://www.txautism.net/uploads/target/Priming.pdf">http://www.txautism.net/uploads/target/Priming.pdf</a></p> <p>The following books offer explanations and ideas for using priming:</p> <ul style="list-style-type: none"> <li>• <i>Children and Youth with Asperger Syndrome: Strategies for Success in Inclusive Settings</i> by Brenda Smith Myles</li> </ul> <p><i>Finding Our Way</i> by Kristi Sakai</p> <p>Both books are available in the OCALI Lending Library.</p>

<p><b>5-Point Scale</b></p>	<p>The 5-point scale is a technique used to help a child break down an abstract concept into a visual system that is easier to understand. For example, a concept such as using appropriate voice volume can be broken down into a 5-point scale, with 1=no voice, 2=whisper, 3=normal voice/dinnertime, 4=loud voice/playing outside, and 5=screaming. A visual representation of the scale is used as the scale is introduced and explained to the child. It is reviewed repeatedly so it becomes very familiar. A picture of the scale is later used as a visual support to remind the child to use an appropriate voice level. The teacher points first to the level the student is using, and then slides her finger down to the appropriate level for a given situation. For example, if the child was screaming while the family was in the store, the parent would point to number 5, then move her finger down to 3 – an acceptable level.</p>	<p>More information about this technique, which was developed by Kari Dunn Buron and Mitzi Curtis, may be found at <a href="http://www.5pointscale.com">www.5pointscale.com</a>.</p> <p>The books <i>The Incredible 5-Point Scale</i> by Kari Dunn Buron and <i>Mitzi Curtis and When My Worries Get Too Big!</i> by Kari Dunn Buron are both available in the OCALI Lending Library.</p>
<p><b>Power Cards</b></p>	<p>The Power Card, developed by Elisa Gagnon, is a strategy to teach a child appropriate behavior for a particular situation. The Power Card strategy relies on the power of a child's special interest. It includes a story in which the person or object of special interest behaves appropriately in a situation in which the child is having difficulty. The child is given a small card, which includes approximately three points to guide appropriate behavior, along with a picture or some visual reference to the person or special interest to cue the child.</p>	<p><a href="http://www.education.com/reference/article/social-scripts-stories-asperger-ASD/">http://www.education.com/reference/article/social-scripts-stories-asperger-ASD/</a> and <a href="http://www.ocali.org/project-resource_gallery_of_interventions/page/power_cards">http://www.ocali.org/project-resource_gallery_of_interventions/page/power_cards</a></p> <p>Elisa Gagnon's book <i>Power Cards: Using Special Interests to Motivate Children and Youth with Asperger Syndrome and Autism</i> is available in the OCALI Lending Library.</p>
<p><b>Visual strategies (First ... Then Board, Visual Schedule)</b></p>	<p>For individuals with ASD visual learning is generally a strength. Therefore, it is often helpful to present information in some visual form in place of, or in addition to, verbal information or directions. There are a number of visual strategies, including first-then cards, visual schedules, visual lists, prompt/cue cards. In addition, many other strategies include visual strategies, such as Power Cards and the 5-point scale.</p>	<p>The following websites provide information on visual supports: <a href="http://autismdigest.com/visual-strategies-valuable-support-at-any-age/">http://autismdigest.com/visual-strategies-valuable-support-at-any-age/</a> and <a href="http://education.jhu.edu/PD/newhorizons/Journals/specializedjournal/Harris">http://education.jhu.edu/PD/newhorizons/Journals/specializedjournal/Harris</a></p> <p>The following helpful books, <i>Visual Strategies for Improving Communication</i> by Linda Hodgdon and <i>Do-Watch-Listen-Say</i> by Kathleen Quill, and books and videos on the specific visual support listed, are available from the OCALI Lending Library.</p>

<p><b>Social Interpretation Strategies</b></p>	<p>Social interpretation strategies are an important element of social skills instruction. Strategies involve systematically breaking down hypothetical or past social experiences of the child in a visual manner. An adult facilitates this breakdown, and then discusses other choices the child could make in a similar situation, as well as the consequences of different choices. Examples of social interpretation strategies include: social autopsies, Situation Options Consequences Choices Strategies Simulation (SOCCSS), cartooning, and flowcharts (i.e., The Way To A).</p>	<p>The website <a href="http://www.txautism.net/uploads/target/SOCCS.pdf">http://www.txautism.net/uploads/target/SOCCS.pdf</a> and <a href="http://www.erinoakkids.com/media/EOK_Documents/Autism_Resources/5-Social-Autopsy-for-interacting-with-someone-you-like.pdf">http://www.erinoakkids.com/media/EOK_Documents/Autism_Resources/5-Social-Autopsy-for-interacting-with-someone-you-like.pdf</a> offers information on these strategies.</p> <p>More information on social interpretations strategies may also be found in Do-Watch-Listen-Say by Kathleen Quill, and Children and Youth with Asperger Syndrome: Strategies for Success in Inclusive Settings by Brenda Smith Myles, which are available from the OCALI Lending Library. In addition, there are other sources detailing the specific strategies listed, including The Way to A by Hunter Manesco.</p>
<p><b>Home Base</b></p>	<p>For many individuals with ASD, the world, in particular the school environment, can cause a great deal of anxiety. In such cases, a Home Base may be assigned. The Home Base is a place where the child feels comfortable and can relax. The child is always allowed to leave her current setting and go to Home Base when she feels her anxiety level rising. A self-calming technique, this strategy recognizes that a child may have to remove herself from an environment in order to calm down.</p>	<p><a href="http://www.ocali.org/project/resource_gallery_of_interventions/page/home_base">http://www.ocali.org/project/resource_gallery_of_interventions/page/home_base</a> describes the home base strategy and how it can be used for children and youth with ASD.</p> <p>The book Children and Youth with Asperger Syndrome: Strategies for Success in Inclusive Settings by Brenda Smith Myles explains Home Base and is available from the OCALI Lending Library.</p>
<p><b>Graphic Organizers</b></p>	<p>Graphic organizers are visual ways to organize information or materials. These can range from idea webs and Venn diagrams to color-coding folders and books for each school subject. Graphic organizers can be effective tools for helping a child organize the environment, as well as organize information to enable learning.</p>	<p>Graphic organizers can be found at the following website: <a href="http://do2learn.blogspot.com/2012/01/graphic-organizers-lets-make-it-visual.html">http://do2learn.blogspot.com/2012/01/graphic-organizers-lets-make-it-visual.html</a></p> <p>There is also information in the book Children and Youth with Asperger Syndrome: Strategies for Success in Inclusive Settings by Brenda Smith Myles, which is available from the OCALI Lending Library.</p>

# Biomedical Interventions

## Medications

A variety of medications have been prescribed for individuals with ASD, and several have been researched. However, no one medication works for every person with ASD. Hyperactivity, sleep problems, obsessive tendencies, anxiety, aggression, and self-injury are some of the symptoms that may be targeted with specific medications.

When medication is being discussed or prescribed, it is important to ask:

- What is the safety of its use in children with autism?
- What is the appropriate dosage?
- How is it administered (pills, liquid)?
- What are the long-term consequences?
- Are there possible side effects?
- How will my child be monitored and by whom?
- What laboratory tests are required before starting the drug and during treatment?
- Are there possible interactions with other drugs, vitamins, or foods?

Given the complexity of medications, drug interactions, and the unpredictability of how each patient may react to a particular drug, parents should seek out and work with a medical doctor with expertise in the area of medication management.

Medications should be given on a trial basis with close monitoring of positive and negative effects. Since there are few objective measures of a person's response to a medication, reliance on subjective information (parent, teacher, and caregiver reports) is common. This is particularly important for children with ASD, who have difficulty understanding and expressing feedback from their bodies and their emotions. The observations of parents and caregivers should be systematically collected by logs, charts, scales, or other accepted behavioral documentation. Occasionally, a trial of medication tapering and discontinuation is a way to determine its efficacy and/or whether it is still needed. Like any medical treatments, medications should be reviewed at every follow-up visit.

### Resources

Autism Society of America: [www.autism-society.org](http://www.autism-society.org)

## **Nutritional and Dietary Interventions**

Individuals with autism may exhibit low tolerance or allergies to certain foods or chemicals. While not specific causes of autism, food intolerances or allergies may contribute to behavioral issues. Nutritional therapies may be used for a variety of reasons. Some parents and professionals have reported changes when specific substances are eliminated from the child's diet.

*Parents wishing to pursue dietary interventions should consult a gastroenterologist or nutritionist who can help ensure proper nutrition. Be sure to consult with a doctor, nutritionist, or dietician before beginning any dietary or nutritional supplement interventions.*

### **The Gluten-Free/Casein-Free Diet (GFCF)**

According to theory, some individuals are unable to completely digest the protein in cereals (gluten) or in dairy products (casein). The molecular structure of the partially undigested proteins, known as peptides, resembles opiates. Such peptides are thought to have an effect much like opiates on the brain and nervous system. From this premise it follows that long-term exposure to these peptides can have damaging effects on the developing brain and can also affect behavior, just as any narcotic would.

Beginning a GFCF diet can be difficult but not impossible. Gluten is most commonly found in wheat, rye, and barley, and sometimes contaminates oats grown nearby or processed on the same equipment as gluten-containing cereals. Casein is found in dairy products. Wheat and dairy make up a large proportion of the Western diet. One of the biggest obstacles parents face is that children needing GFCF diets often crave these foods. In fact, parents often report withdrawal symptoms when gluten and casein are eliminated from their child's diet.

Although there are reports of immediate improvement, it may take as long as six months for gluten and one month for casein to clear out of the system. Advocates of the diet recommend trying it for at least a year as it can take that long for some children to show improvement. The diet affects changes in the body at a cellular level and promotes healing of the stomach and intestinal lining, both of which can take time.

Calcium is very important in bone development and maintenance. Most people get their calcium from dairy sources. If your child is on a dairy- or casein-free diet, a calcium supplement may be necessary.

**Resources**

Autism Network for Dietary Intervention: <http://autismlink.com/dir/autism-network-for-dietary-intervention-andi/>

GFCF Diet Support Group: [www.gfcfdiet.com](http://www.gfcfdiet.com)

**Feingold Diet**

The Feingold diet is a food elimination program developed by Ben F. Feingold, MD, to treat hyperactivity. The diet is free of artificial colors, artificial flavors, aspartame, three petroleum-based preservatives, and (on Stage One) certain salicylates. All (except for the salicylates/phenols) are made of petroleum, and breaking them down into digestible compounds uses up the PST enzyme, which is the main enzyme for detoxification in the body. If you remove artificial foods from the diet, people with a marginal amount of natural PST enzyme (proponents suspect individuals with ASD fall into this group) will have it available to detoxify the body, including the brain. Salicylates and phenols also depress the levels of PST enzyme.

**Resources**

Feingold Association: [www.feingold.org](http://www.feingold.org)

Wikipedia: [en.wikipedia.org/wiki/Feingold\\_diet](http://en.wikipedia.org/wiki/Feingold_diet)

**Specific Carbohydrate Diet**

The specific carbohydrate diet (SCD) is a strict grain-free, lactose-free, and sucrose-free dietary regimen. Initially developed for individuals with celiac disease and other intestinal disorders, the diet may help individuals with ASD who experience gastrointestinal problems.

The theory behind this diet is that carbohydrates, being forms of sugar, promote and fuel the growth of bacteria and yeast in the intestines, causing an imbalance of and eventual overgrowth of bacteria and yeast. Bacterial overgrowth can prevent the digestion and absorption of carbohydrates. This causes the carbohydrates to remain undigested in the intestines, providing even more fuel for bacteria and yeast. Toxins and acids can be formed by the bacteria and yeast and injure the small intestine lining. Excessive mucus may be produced as a defense mechanism against the irritation caused by toxins, acids, and undigested carbohydrates.

**Resources**

Horvath, K. (1999). Gastrointestinal abnormalities in children with autistic disorder. *Journal of Pediatrics*, 135, 533-535.



## **Anti-Yeast Diet**

This diet was developed to address the overproduction of or allergies to *Candida albicans*, a single-celled yeast that is impossible to keep out of the body. Normally, it does no harm, because it is kept in check by beneficial bacteria, but if there is an imbalance in the beneficial bacteria, candida can grow uncontrolled, releasing extremely acidic toxins into the bloodstream. These chemicals slow the brain down so that it no longer works correctly. The chemicals should be cleared by the liver so that they never reach the brain. However, in some, they are apparently not cleared, causing problems. The anti-yeast diet consists of removing fermented foods from the diet. The worst offenders are alcoholic beverages and non-alcoholic beer, vinegar, barley malt, chocolate, pickles, soy sauce, and aged cheese. Some believe that individuals with ASD are likely to have an allergy to or overproduce *Candida albicans*.

### **Resources**

Nutrition Institute: [www.nutritioninstitute.com](http://www.nutritioninstitute.com)

## **Supplements**

Over the past 10 years or more, claims have been made that vitamin and mineral supplements may improve the symptoms of autism in a natural way.

If you are considering adding vitamins or minerals to your child's diet, a laboratory and clinical assessment of her nutritional status is highly recommended. The most accurate method for measuring vitamin and mineral levels is a blood test. It is also important to work with someone knowledgeable about nutritional therapy. While large doses of some vitamins and minerals may not be harmful, others can be toxic. Once supplements are chosen, they should be phased in slowly (over several weeks), and the effects should be observed for one to two months. The reported benefits of supplements range from behavioral changes, to improved language.

Supplements can include the following.

### **B6 and Magnesium**

B6, often combined with magnesium, is reported to help improve language, eye contact, brain electrical activity, behaviors, and immune system function. Magnesium is needed with high doses of B6 because, when taken alone, B6 may cause a deficiency in magnesium and other B vitamins. Also, magnesium may decrease some possible side effects, such as irritability, bed-wetting, and sensitivity to sound.

### **Vitamin B12**

Vitamin B12 deficiency is characterized by the inability to absorb food. Vitamin B12 is essential for metabolism of fats and carbohydrates and the synthesis of proteins. Vitamin B12 is involved in the manufacture of the myelin sheath, a fatty layer that insulates nerves in the brain.

### **DMG/TMG**

Dimethylglycine (commonly known as DMG) is classified as a food substance rather than a vitamin. It is found in very small amounts in brown rice and liver. Parents have reported positive results with a similar product, tri-methyl-glycine (TMG). TMG breaks down into DMG and SAME in the body. SAME is a nutritional supplement and is sometimes used to treat mood disorders such as depression. There are, as yet, no published reports on the efficacy of DMG or TMG for individuals with ASD.

### **Melatonin**

Melatonin is a hormone made by a part of the brain called the pineal gland. Melatonin may help our bodies know when it is time to go to sleep and when it is time to wake up. Melatonin supplements come in two pill forms, natural and synthetic (man-made). Natural melatonin is made from the pineal gland of animals.

Children with ASD often have sleep disturbances, which suggests that there may be some problem associated with the body's production and use of melatonin. Children receiving melatonin regularly exhibit benefits that cannot be explained in simple terms, like better sleep. It may be a combination of better sleep and better control of biological rhythms.

*Especially in children, melatonin should be given only under the supervision of the child's regular physician.*

### **Vitamin A**

For years, high doses of this vitamin have been used successfully to treat the measles virus. Using cod liver oil, Megson (2004) began vitamin A therapy with some of her patients and observed some positive results. Some patients spoke more frequently and clearly; others made gains in eye contact. Megson has reported that vitamin A in the natural form, such as cod liver oil, helps to rebuild areas in the brain, called receptors, that are dramatically affected by ASD. The natural form of vitamin A is claimed to also improve cell growth, repair of epithelial cells found in the gut wall, immune system function, and gene expression and transcription.

*Consult your doctor if you are considering a Vitamin A supplement as too much vitamin A or D, which is also found in cod liver oil, can be toxic.*

### **Vitamin C**

The benefits of vitamin C are widely known in the general public, and it may be of help for children with autism as well. Vitamin C is an antioxidant that helps the brain utilize oxygen. Without this vitamin, confusion and depression can develop. Vitamin C can also help support the immune system, aid in detoxification, and fight viruses and bacteria. Vitamin C is nontoxic, even in high doses.

### **Folic Acid**

Folic acid is a nontoxic B vitamin, and a nutrient essential to the brain's health. It has been reported as helpful in treating autism. It is widely recommended that pregnant women take extra folic acid during their pregnancy to help prevent some birth defects. It is most effective when taken with vitamins B12 and C.

Other supplements can include essential fatty acids, zinc, probiotics, and cod liver oil, but should be carefully researched and taken only under the supervision of a physician.

### Resources

Autism Research Institute: [www.autism.com](http://www.autism.com)

Kirkman Labs: [www.kirkmanlabs.com](http://www.kirkmanlabs.com)

Megson, M. (2004). Autism and vaccination. Retrieved January 7, 2007, from <http://www.sciencedirect.com/science/article/pii/S0306987799909994>

## ***Defeat Autism Now! Protocol (DAN)***

The Defeat Autism Now!, or DAN, protocol is a guide for clinical assessment of individuals with autism developed by participants in the DAN conferences organized originally by the Autism Research Institute. (ARI is the Autism Research Institute, a non-profit organization, founded in 1967 by Dr. Bernard Rimland. ARI is focused on conducting research and providing information on ASD to both parents and professionals.)

Some practitioners who know the DAN! protocol regularly use the medical tests to assess a child's health. There are also practitioners who will be willing to read the DAN! protocol and implement it. The basic premise of the DAN! protocol is that heavy metal toxicity in the form of thimerosal in vaccines, amalgams, or some other source, is the cause of the symptoms of autism. Most also recommend the use of the GFCF diet.

### Resources

Autism One: [www.autismone.org](http://www.autismone.org)

Autism Research Institute: [www.autism.com](http://www.autism.com)

Defeat Autism Now!: [www.defeatautismnow.net](http://www.defeatautismnow.net)

Generation Rescue: [www.generationrescue.org](http://www.generationrescue.org)

## ***Chelation***

Chelation therapy is a process involving the use of chelating agents to remove heavy metals from the body. For the most common forms of heavy metal intoxication, those involving lead, arsenic or mercury, the standard of care in the United States dictates the use of DMSA Dimercaptosuccinic acid. This, in addition to other chelating agents such as DMPS, EDTA, and alpha lipoic acid (ALA), is used. Chelation originally had to be administered intravenously. Now prescription chelating creams are available that can be applied to the skin.

*Chelation must be done under the supervision of a doctor familiar with the DAN! protocol – it is only part of what should be an interconnected medical-based treatment.*

## **Resources**

See DAN! resources above



## CHAPTER 5

# Accessing Educational Services

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*My son was struggling in school. He was frustrated with math and never seemed to play with the other children in his class. I asked the school if we could have him evaluated. They told me to wait and see how the year progressed. My son's behavior went from bad to worse. We needed answers and I was not willing to wait any longer to get them. No one told me to put my evaluation request in writing. I didn't know that was necessary. I don't want any other parents to go through this. When children need help, they need it now.*

”

This chapter describes how a child receives an educational identification of autism to qualify for special education services under the Individuals with Disabilities Education Act (IDEA). In addition, it provides an explanation of the Individualized Education Program (IEP) and offers tips for participating successfully in the IEP meeting, including suggestions for communicating effectively with school personnel.

## Educational Identification

Under the Individuals with Disabilities Education Act (IDEA), all children with disabilities have a right to a free and appropriate education. The local school district is responsible for locating, identifying, and evaluating all children who may be eligible for special education services from 0 to 22 years of age. This process is called Child Find. (See Appendix E.)

If you are concerned about your child's development and the child is 3 years old or younger, you can contact the *Help Me Grow* program in your county, as discussed in Chapter 2. If you are concerned about a child who is 3 and older, you can request support from your local school district. If your child is in preschool or kindergarten, request a meeting with your child's teacher to discuss your concerns. Ask the teacher to observe your child's performance in social as well as academic situations and compare those observations with your own.

If your child does not attend school, discuss your concerns with your pediatrician or contact your local school district. Your school district is responsible for identifying all children with disabilities. Ask to speak to someone in the special education department. When you explain your concerns, your child will be referred for screening to determine if further evaluation is necessary.

If your child is in school and needs help to be successful in the classroom, school personnel will initiate one of the following to identify the type of support your child needs.

- *Intervention assistance team (IAT)*. This is a group of school personnel who meet to support classroom teachers in addressing issues with an individual student, whether they are behavioral or educational. The team identifies supports the student may require to be successful in the classroom. Parents are included in the IAT process for their child.
- *Response to intervention (RTI)*. This is the process of identifying and assessing the effectiveness of interventions identified to support a student who is experiencing learning difficulties. The interventions will be identified and carried out by school personnel.



In both instances, the accommodations and supports are carried out for a specific length of time while data are being collected on the student's progress. The IAT/RTI team will meet to review the data and then determine whether to continue the intervention process by adding and/or adapting supports. If the team feels that the student is not responding to the intervention or showing expected progress, the team must request a multi-factored evaluation.

## ***Multi-Factored Evaluation (MFE)***

The IAT/RTI process discussed above should not replace the Multi-Factored Evaluation (MFE) process required under IDEA; however, it usually takes place before an MFE.

The Multi-Factored Evaluation is the process required by IDEA to determine if a child is eligible for special education services. The process may be initiated by either school personnel or a parent. Education professionals along with a child's parents are members of the MFE team, who work together to determine if a child qualifies for special education services. Team members should include a school psychologist, the child's parent(s) or guardian(s), a special education and/or general education teacher, appropriate related service personnel, such as a speech-language pathologist or an occupational therapist, and others based on the child's needs.

The purpose of the MFE is twofold:

1. To determine whether or not the child has a disability, and
2. To identify the child's specialized educational needs.

Having a diagnosed disability is not a guarantee that your child will receive special education services. The disability must also have a "significant impact" on your child's educational, emotional, and/or functional skills. This means that your child's ability to learn and function in school is impaired by the disability to the extent that specially designed instruction is necessary for the child to be successful.

## Steps to Obtaining an MFE

If school personnel do not share your concerns about your child's functioning in school, you, as parents, still have the right to request an MFE from the district. You must request an MFE in writing and must give written consent for the evaluation to your local school district.

There are three ways to request an MFE:

- Send a letter of request and consent to your child's school principal or the special education coordinator/director.
- Go to the Ohio Department of Education website and print out the Request for Evaluation Form, complete it, and send it to the school with the letter for requesting a multi-factored evaluation (see Appendix D).
- Set up a meeting with the principal or special education coordinator to complete the necessary paperwork at school.

Be sure to keep dated copies of all paperwork completed.

Within 30 days of your request, the school district is required to send you a letter, called "prior written notice," telling you whether or not the district will perform the MFE. Usually schools comply with a parent's request for an evaluation, but if they do refuse, there are other options to explore. (See Appendix C.)

- If the school agrees, an MFE team will be identified. At a minimum, the team must include the parents, a district representative, and a school psychologist. The school and the parents will have a planning meeting to determine and document what assessments will be done for the child. According to IDEA, this evaluation process must be completed within 60 days from the day of the parent's written consent.

The MFE process includes various assessments (see Chapter 2 for some of the ASD assessment tools that may be used) as well as observations of your child completed by school personnel and you, the parents.

After the evaluation process is complete, an evaluation team report (ETR) will be prepared and a meeting will be held to review the report. At the meeting all assessment information is reviewed and explained to the parents. Parents can submit additional information to school personnel and ask the MFE team to consider it and address it in the ETR. Information from other sources may include therapy reports, medical reports, and reports from other evaluations that have been performed. At the ETR meeting, the team determines whether the child qualifies for services under IDEA in the autism category.

If you believe that the ETR represents a true picture of your child, including developmental, academic, and functional skills, as well as areas of need, present levels of functioning, and how the disability affects your child's progress in the general curriculum, you, along with all other

team members, will sign the final page of the ETR. By signing the report, parents are agreeing to the results of the report. If the report recommends special education services for the child, these services are determined by the IEP team and written into an IEP document. Once the team determines that the child qualifies for services under IDEA, and the ETR is signed by all MFE team members, a copy is given to the parents.

At this point, a team is formed to develop an IEP. The IEP team has 30 days to develop an IEP that addresses the child's areas of need as defined in the evaluation report.

If parents disagree with the ETR, they may request further evaluation by the school in specific areas, or they may request an *independent evaluation*. This refers to an evaluation completed by another qualified professional or group of professionals. This request for an independent evaluation must be made in writing. If the team determines that the child does not qualify under IDEA in the autism category and you disagree, you may seek an independent evaluation. (See Appendix C for how to obtain and independent evaluation.)

## What Is an IEP?

When your child is determined to be eligible for special education services, an IEP is written. The IEP is a plan developed to identify the services and supports necessary for a child to be successful in the general education curriculum. It is a written agreement between the parents and the school district of what constitutes a free, appropriate public education (FAPE) for the child which is required by IDEA.

## **IEP Team Members**

The IEP is developed by a team that consists of the following:

### **Parents**

You, the parent(s), are a very important and equal member(s) of the IEP team. There is no other person who knows your child better than you.

### **General education teacher**

Under IDEA, a general education teacher who has had or will have your child in class should attend the IEP meeting to share his or her knowledge of the general education curriculum.

### **Special education teacher**

This should be the special education teacher who has served your child or will be serving your child. The information he or she shares with the team is vital in understanding how your child learns. The special education teacher will help the general education teacher assess what accommodations and/or modifications your child will need to be successful in the general education classroom.

### **District representative**

The district representative knows what resources are available in the district and can make decisions regarding the use of resources. This person is responsible for knowing how the services listed on the IEP will be provided and is able to commit to the expense of the service.

*If the district representative says he/she does not have the authority to commit resources during the IEP meeting, you may need to reconvene another meeting when someone with authority to commit to the expense can attend.*

### **Psychologist**

For any testing or evaluations that have been done by the school district, IDEA requires that someone attend the IEP meeting who can explain the results as well as the instructional implications. This may include a school psychologist or guidance counselor. The results must be explained so everyone involved understands their implications.

*If you do not understand the evaluation, you cannot give informed consent. Parents must know what the evaluation results mean to make good decisions about their child's identification and the IEP.*

### **Student**

The student is a very important member of the IEP team. Students should be involved when they are capable of participating in the decision-making, and should always be involved when issues regarding transition to the community are discussed. If the student cannot be present or does not want to attend the meeting, efforts must be made to establish the interests and concerns of the student before the meeting so they can be considered.

### **Therapists and other related service personnel**

If the ETR identifies a need for a related service such as speech-language or occupational therapy, it is important that the relevant related service provider(s) attend(s) the IEP meeting. His or her expertise is vital to planning an appropriate IEP.

### **Community members, service providers**

When transition to community is addressed as the child gets older, community members may be invited to the IEP to discuss community programs and transition services that may be needed.

While each of these people may not all be in attendance at your child's IEP meeting, the IEP team needs their expertise. If your child's needs indicate that a specific area of knowledge is needed, the team can request their input in writing prior to the meeting.

## **Who Else Can Attend the IEP Meeting?**

IDEA allows parents or the school district to bring anyone to an IEP meeting who has a working knowledge about the child or the child's disability.

## Components of the IEP

The IEP form is broken into several sections, and discussion of each section provides an agenda of topics to be addressed at the meeting. After members of the IEP team have discussed each topic, the information is added to the form. The components of the IEP and the information they include are as follows.

- **Future planning** – a statement by the parents that describes their hopes, dreams, and future plans for their child.
- **Present levels of performance** – information retrieved from the MFE and other documentation that addresses the child’s strengths, areas of need, current level of functioning, and how the child’s disability will affect his progress in the general education curriculum. This includes the child’s emotional and social levels of functioning.

While not specifically required, the child’s involvement in extracurricular and nonacademic activities, as well as nutritional and safety needs, should also be considered and addressed in present levels of performance.

- **Needs** – the most significant needs to be addressed in the current school year.
- **Measurable annual goals** – goals developed to address each of the significant needs identified above. Goals should be written according to the child’s current level of functioning as the measurable starting point and identify where the child will be functioning after 180 days of school (one school year).
- **Measurable objectives** (for students who take alternate assessments) – sequential steps to achieving identified goals above.
- **Student progress** – a statement of how often parents will be informed (at least as often as parents of students without disabilities) and how they will be informed of their child’s progress; for example, through charting, daily notebooks, parent-teacher meetings, and so on.
- **Services** – identification of all services needed for the child to attain the annual goals and progress in the general education curriculum. Services may include specially designed instruction, related services (such as occupational therapy or speech therapy), supplementary aids, support services provided to school personnel on behalf of the child (for example, specialized training or consultation), and a statement of program modifications, and/or accommodations. Dates services will begin, including frequency, location, and duration, should also be included on the IEP.

## Accommodations vs. Modifications

Accommodations refer to “whatever it takes” to make sure that a child with a disability can participate as fully as possible in the general education curriculum and achieve the academic content standards. Accommodations are changes in the way that material is presented (for example, a child may listen to a reading passage on tape instead of reading it) or in the way a student responds to the material (students may dictate their responses to questions instead of writing them), as well as changes in setting, timing, and scheduling.

Accommodations involve many kinds of techniques, strategies, and support systems. They help students work around limitations related to their disability. An accommodation refers to “how” the general education curriculum will be presented to the student with disabilities so that he can understand the general education curriculum. Accommodations may include:

- Visual schedules
- Notetaker/assistive technology
- Sensory regulation items
- Visual organizers

Modifications are changes that can be made to “what” students are expected to learn. For most students with disabilities, modifications should be considered only after all types of accommodations have been exhausted. Modifications involve partial completion of program or course requirements. When determining a modification, the IEP team should ask the following question: *What part of the curriculum does this child need to know that will help them in their adult life?* Because the purpose of special education services is to prepare children with disabilities for further education, employment and independent living, that is, for life as adults.

- **Related services** – all related services included on the IEP should be accompanied by a designation of the amount of time per week the child will be receiving the services, who will be providing the services, in what manner the services will be given, and where the services will take place (e.g., speech at least two times a week for 20 minutes with speech-language therapist in a small group setting).

The following services may be included on the IEP (this is not a complete list):

- Support of an intervention specialist
- Speech-language therapy
- Occupational therapy
- One-on-one aide
- Physical therapy
- Social skills training
- Sensory processing training
- Assistive technology services

*Any type of services, accommodations, and modifications that the child is to receive must be documented on the IEP.*

- **Amount of time child will not participate with nondisabled children in regular classes** – This statement identifies the least restrictive environment (LRE) for the child to receive her educational program.
- **Least Restrictive Environment (LRE)** – Where services will be provided is the last decision made by the team in developing the IEP and it is based on the goals, accommodations, and modifications included in the IEP. IDEA requires that each IEP contain an explanation of the extent, if any, to which the child will *not* participate with *nondisabled* children in general education classes or nonacademic activities. IDEA assumes that all children will be educated in the general education setting and that the supports and services needed by the child will be delivered in that setting. It was never the intent of special education to set up a segregated system of education for children with disabilities and to separate them from their peers and communities. The legislation does acknowledge, however, that some educational services will need to be delivered in a separate setting – like individual or small-group speech language services or academic tutoring in a resource room – and that some students needs will require that they are educated in a special classroom, and at times in a special school.

The requirement of the law is that the decision about least restrictive environment is not an all-or-nothing decision based on the fact that a child has a disability. IDEA requires that the decision about where a child receives particular services is based on the child's needs, the services being provided, and the goal being addressed. Children are only separated from their peers for specific educational reasons.

The LRE for the child is not determined by the disability of the child, nor the finances of the school district. The IEP team should always look at the general education classroom first, with services and supports coming to the student before removing the student to a more restrictive environment.



- **Transition plan** – The plan for transition to community addresses three areas: employability, independent living, and community involvement. When the student is 16, a transition plan must be written into the IEP. Transition may be addressed earlier than at 16 years of age if the IEP team feels the student’s needs warrant it. The purpose of the transition plan is to assist students with disabilities in becoming independent adults, making a smooth transition from school to competitive employment/postsecondary education, independent living, and community involvement. (See Chapter 8, Future Planning.)
- **Special factors** – This is a list of factors that fundamentally affect a child’s educational performance. The IEP team should consider and discuss how these factors will be addressed if they are pertinent to the child’s needs. Special factors include:
  - Behavior
  - Limited English proficiency
  - Visual impairment
  - Communication
  - Assistive technology
  - Physical education
  - Extended school year services
- **Statewide testing** – This section includes a list of allowable accommodations for the student’s participation in statewide testing. Students with disabilities are to be included in all state- and district-wide assessments. How the student can participate in the testing is documented on the IEP in one of three ways.

The student will:

1. Take the test without accommodations;
2. Take the test with allowable accommodations that are provided daily in the general education classroom;
3. Or take an alternate assessment as determined by the IEP team.

The signatures of individuals participating in the IEP meeting conclude the IEP document. This document is a legal contract outlining the goals, services, and supports that will be provided over the school year to implement an appropriate education program. An annual review of the IEP is required by IDEA, although the IEP can be changed prior to that if the child’s needs change. Either the parents or school personnel can call an IEP meeting to review the child’s progress and consider changes to the IEP.

The format of the IEP document is designed specifically to guide a step-by-step process of development with each section building on the one before. It is important to remember that the information listed in the Present Levels of Performance must be accurate in order for the team to write appropriate measurable goals. When written properly, the IEP documents the provision of a free, appropriate public education (FAPE).

## ***Summary of Student's Performance Upon Leaving School***

IDEA requires that school personnel develop a Summary of Performance (SOP) document upon a student's departure from high school to identify the student's level of achievement in academic and nonacademic areas. This is a separate document and is not considered part of the IEP.

## ***Helpful Hints for Preparing for the IEP Meeting***

How can I plan for an IEP meeting?

- Ask for and review evaluation data before the IEP conference.
- Take an agenda to the IEP meeting to guide the discussion of points you want to cover.
- Tell the school who you will bring to the meeting and ask who will attend from the school.
- Gather information you want to share, including medical or other assessments.
- Bring a friend to the meeting to help in taking notes and clarifying information discussed.
- Before the meeting, write down your priorities and questions.
- Talk to a parent mentor or an advocate before the meeting. They can give you suggestions on how to work effectively with the team at the meeting and explain your rights under IDEA.
- Take a picture of your child to place on the table so the focus of the discussion remains on the child.
- Consider bringing food to share.
- Let the school know if the meeting time or location does not work for you. Offer alternative suggestions in writing to the school.
- Ask the question "How is this going to help my child?" This will help focus the discussion of services and supports being considered.

## ***IEP Questions to Consider***

- Are my child's goals measurable? That is, does the IEP state his level of functioning now so that it can be compared to his functioning in the future to determine how much, if any, progress has been made?
- Does the IEP identify the modifications, accommodations, and other supports my child needs to succeed?
- Is the school expecting the kind of progress I think my child should make?
- How often will my child's IEP goals be reviewed and how often will I be informed of his progress?

## ***Frequently Asked Questions***

- **When should the IEP be implemented?**

Once the IEP has been agreed upon and signed, it should be implemented immediately or no later than the start date on the document.

Parents should receive a final copy of the IEP within 30 days after the IEP meeting. Parents can request a draft copy of the IEP the day of the meeting.

- **What is a parent mentor and what can he or she do to assist me?**

Parent mentors are parents of children with disabilities who are hired by a local school district or an educational service center. The role of the parent mentor is to provide information and support to parents of children with disabilities and to attend IEP meetings with parents upon request. Parent mentors are trained in the requirements of IDEA and special education issues and can answer your questions about the IEP process and school procedures. They work with parents in their district regarding their concerns and can represent parents' questions and concerns to educators. They also conduct trainings and provide support groups for parents within their districts to help parents become knowledgeable and informed about special education issues. Not all school districts have a parent mentor program. Call your local district to find out if there is a parent mentor available in your district.

- **What is an advocate and what can he or she do to assist me?**

An advocate is an individual who is knowledgeable about special education issues and the requirements of IDEA. Advocates work for organizations other than the local school district and parents can invite them to IEP meetings to help represent their concerns when they and the school district disagree. Advocates can be volunteers for a local autism parent group, a local parent support group, or from statewide organizations like the Ohio Coalition for the Education of Children with Disabilities or Ohio Legal Rights. Their role is to represent your interests at school meetings about your child's education.

- **What if I refuse to sign my child's IEP?**

The IEP process is designed to be a tool for discussion between parents and professionals regarding what is required for a child to make progress in her educational program. Decisions about the IEP are supposed to be the result of the team coming to an agreement by consensus. When the team cannot come to agreement, parents may refuse to sign the IEP. This may be because the parents disagree with the type of services included, the omission of a service they think should be included and is not, or they disagree with the amount of time a service is to be provided. In this case parents believe that their child's right to an appropriate education is being violated because the IEP is not adequate.

There are specific steps parents can take to negotiate with school personnel about an appropriate educational program. For more information about what to do when you disagree with your child's school, see Appendix C.

### Resources

Ohio Department of Education, (2002). Operating standards for Ohio's schools serving children with disabilities. Columbus: Ohio Department of Education.

Ohio Center for Autism and Low Incidence, (2008). *Transition to Adulthood Guidelines for Individuals with Autism Spectrum Disorders (ASD)*. Columbus: Ohio Center for Autism and Low Incidence.

# Building a Working Relationship Through Communication

Nothing is closer to parents' hearts than their children. Meetings that concern your child's educational program can be emotional and frustrating. One of the best things you can do to support your child is to establish a working relationship with your child's educational team. Knowing the basics of effective communication will help. Effective communication means knowing how to say what you want, and making sure others understand what you said.

## Hints to Help You Communicate Effectively

- 1. Be prepared.** Plan ahead and write down the points you want to make before a meeting. This will keep the conversation focused on the issues that are important to you.
- 2. Be respectful of others.** Effective communication takes place in a relaxed and safe environment. There is no problem that does not have a solution if we work together to address it. Communication is a team activity. Participation on the team is influenced by the energy each participant brings to the discussion:
  - how much they want to invest in resolving the issue at hand,
  - the priority they place on the communication, and
  - the respect they have for those involved in the discussion.
- 3. Repeat what is said to you to confirm your understanding.** This ensures accurate understanding on your part and also shows respect.
- 4. Understand that disagreements are not inherently bad.** Disagreements show a need for further discussion and information gathering, they may broaden the search for alternative solutions, and they may ultimately produce better solutions. Working through disagreements can also build stronger and more productive teams. Some compromise and creativity should be a part of any type of communication.
- 5. Remember that body language and tone affect what is understood.** Knowing the difference between *nudging* versus *shoving* and *aggression* versus *assertion* can mean the difference between being able to work through issues or fostering further conflicts that delay identification of solutions.
- 6. Use comments that begin with *what, when, how, where* to help to clarify the issue under discussion.** Avoid blaming, gather information, and move to problem solving.

The focus of successful communication is not necessarily getting exactly what you asked for. It is finding the best solution to a problem being discussed AND leaving the door open for future communication.



# Social Service Programs

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## Ohio Social Service Agencies

Several publicly funded social service agencies and many different programs provide services and supports to eligible individuals with ASD and their families. It can be difficult to determine what services are available and how to access them. This is a basic guide to the services in Ohio and how to directly contact the service provider. The information provided here is taken directly from the organizations' materials and websites.

***An asterisk (\*) identifies programs that provide financial assistance to families.***

### ***Help Me Grow***

*Help Me Grow* is Ohio's statewide system for funding and coordinating early intervention services for children 0-3 years of age. *Help Me Grow* works collaboratively with each county's Family and Children First Council (see below) to ensure that families have access to community-based, family-centered services. The *Help Me Grow* program was designed to serve expectant mothers, newborns, infants and toddlers up to 3 years of age, and their families to promote the health and well being of Ohio children. To find out about services in your county, contact *Help Me Grow* at (800) 755-4769.

## ***Family and Children First Council***

The Family and Children First Council (FCFC) is a partnership of government agencies and community organizations working together in every county to provide services necessary to improve the well being of children, youth, and families. FCFC is the county agency that includes the *Help Me Grow* program and is responsible for coordinating all early intervention services for infants and children 0-3 years of age. A service coordinator is hired by each county FCFC to help families identify and access the services they need. Services include screening and diagnosis, health services, and individual and family supports. Services offered can differ from county to county.

Contact the governor's office of Ohio Family and Children First at (614) 752-4044 to get the FCFC phone number in your county.

## ***Ohio Department of Health – Early Intervention Services***

The Ohio Department of Health (ODH) receives federal funds from the Individuals with Disabilities Education Act (IDEA) to organize and provide early intervention services for infants and toddlers, with disabilities (0-3 years of age), and their families. ODH uses these funds to support local agencies (Family and Children First Councils [FCFC] and the *Help Me Grow* program) to provide family-centered services.

Services can include assessments and evaluations by child development specialists, physical, occupational or speech therapy, and/or family services from social workers or case managers. Services are accessed through the county Family and Children First Council and are determined by an Individual Family Service Plan (IFSP).

The IFSP is a plan developed jointly by parents and service providers. It describes the family's strengths and needs related to supporting the development of an infant or toddler, lists desired outcomes for family services, and identifies the resources and services necessary to achieve the outcomes.

To get the number of your local *Help Me Grow* program, call (800) 755-4769 or check the website at <http://www.helpmegrow.ohio.gov>

Address: Ohio Help Me Grow, 246 North High Street, P.O. Box 118, Columbus, OH 43216-0118.



## **Bureau of Services for Children with Medical Handicaps (BCMh)**

The Bureau of Services for Children with Medical Handicaps (BCMh) is charged with ensuring that children with special health care needs and their families receive comprehensive, family-centered care. The program promotes early identification of children with special health care needs and treatment of those children by appropriate health care providers.

BCMh provides funding for services, diagnosis, and treatment of children with conditions that are *medically eligible*. At this time, autism spectrum disorders are not considered medically eligible for year-to-year treatment.

Children with ASD often have medically eligible conditions like seizures, hearing loss, and gastrointestinal problems. BCMh can cover the treatment of these chronic medical conditions, even though it does not cover the treatment of ASD. However, parents can obtain a three-month diagnostic enrollment for their child that will pay for testing and assessment services from a BCMh-approved provider.

This three-month period can be extended up to nine months to ensure that comprehensive evaluation services are completed. This diagnostic enrollment can allow parents to access the evaluation services of knowledgeable ASD diagnostic professionals. The diagnostic enrollment requires a referral from an appropriate medical professional.

Parents can identify BCMh providers by visiting the Ohio Department of Health website: <http://www.odh.ohio.gov/odhPrograms/cmh/cwmh/bcmh1.aspx> Click on: Locate BCMh Providers by County, located down middle of page. An Ohio map will appear, and you can click on your county to see a list of BCMh providers in your county. You can also check the county where your doctor's office is located. (You are not required to use a provider in your county.) For general information about the program, contact the BCMh office at (614) 466-1700 or toll free at (800) 755-4769.

## **\*Women, Infant and Children Program (WIC)**

WIC is the special supplemental nutrition program for Women, Infants and Children that helps income-eligible pregnant and breastfeeding women, women who recently had a baby, and infants and children up to 5 years of age who are at health risk due to inadequate nutrition. The program improves outcomes of pregnancy by providing or referring women to support services necessary for full-term pregnancies; reduces infant mortality by reducing the incidence of low birth weight (infants under 5-1/2 pounds are at greater risk of breathing problems, brain injuries, and physical abnormalities); and provides infants and children with a healthy start in life by improving poor or inadequate diets.

WIC provides nutrition education, breastfeeding education, and support; supplemental, highly nutritious foods; referral to prenatal and pediatric health care and other maternal and child health and human service programs (examples: Head Start, Medicaid and Food Stamps).

For more information, contact the WIC Program at (614) 644-8006 or email [OHWIC@odh.ohio.gov](mailto:OHWIC@odh.ohio.gov)

## **Ohio Department of Developmental Disabilities**

The County Boards of Developmental Disabilities (CBDDs) are responsible for educational and vocational services for people with intellectual disability and developmental disabilities (DD).

Eligibility for services is determined through evaluation by a service coordinator at the request of a parent.

An assessment will be conducted, called the Children's Ohio Eligibility Determination Instrument (COEDI), to determine eligibility for DD services. If your child has not already received an official diagnosis, you will be asked to offer documentation of your child's suspected delays when requesting a determination.

Contact your county DD office and ask to speak to an intake worker to find out what services are offered. Families will get information about the waiver system from their assigned county Services and Supports Administrator (SSA) after they have enrolled with the county DD agency.

At the age of 16, an individual must be re-qualified for DD services as an adult. If the person with an ASD has not been placed on a waiver waiting list by that time, make sure to do this.

County boards can provide education, employment, and support services to children and adults of all ages. The DD system in Ohio operates with local, state, and federal funds. Services offered can differ according to each county.

Services provided by the DODD can include:

- **Intake and assessment services** – provided to determine if individuals meet the eligibility requirements for DD services.
- **Service coordination** – provided to link individuals to needed supports and to coordinate services. Service coordinators assess individual needs, arrange for services, and monitor the provision of those services on an annual basis or more frequently if necessary. Service coordinators also assist families with questions, planning, or referrals on subjects such as Social Security, guardianship and family support services.
- **Early childhood services** – provided for children under the age of 6 who have developmental delays, disabilities, or intellectual disability.
- **School-age services** – provided for students who have multiple handicaps, ranging in age from 5 through 21, in conjunction with local school districts.

- **Vocational services** – provided through sheltered workshops or programs that support community placement.
- **Residential services** – provided through group homes, supported living apartments, and various community living arrangements.
- **Respite services** – (or short-term residential care) provided for families in their homes or at an approved respite facility. Generally, respite care is provided anywhere from four hours to two weeks at a time.
- **Family resources** – funds provided to support families with a member who has a developmental disability for family-identified uses. Funds can covers the expenses related to such things as attending a conference or training event. Funds are limited, and families must have prior approval.

## Waivers

Medicaid home- and community-based waivers allow states to provide Medicaid funding to pay for services for children with disabilities *without* considering family income for eligibility. Waivers were developed to direct funds that previously would have been spent to support an individual with a disability in an institution to supporting that individual in the community.

The county board of DD administers Ohio’s Medicaid waiver programs for individuals with disabilities. Funding for waiver programs is provided with state and federal Medicaid dollars, and the local board of DD must provide a local match to use those funds. Services across counties may differ based on the amount of county match dollars available.

Access to waiver funds is also restricted by the number of “slots” made available annually to each county by the state. Therefore, funding available both at the state and the county level will affect the number of individuals who can access the waiver. As a result, not all individuals who are eligible receive waiver funding. County boards of DD must maintain waiting lists to distribute the waiver slots available in their county on a first-come, first-serve basis. Obtaining a waiver for in-home support does not necessarily mean that there will be 24-hour supervision. The goal of the waiver program is to teach individuals skills that will allow them to live more independently. (There are exceptions for emergency situations, such as the illness or death of a caregiver.)

There are two basic waiver programs for which your child may qualify. This information is basic. For more details, request brochures from the Ohio Board of DD at (877) 464-6733 about the waiver program. Also, talk to other families who have received waivers to learn more.

- **Individual Options Waiver (IO Waiver)**

The IO waiver can cover a broad range of in-home and community support services for individuals with intensive needs. The individual must meet the level-of-care-requirements for an intermediate care facility for intellectual disability.

For more information about the IO waivers, call the number above or go to: <https://doddportal.dodd.ohio.gov/INF/finditfast/publications/Documents/IO%20Waiver%20Handbook,%20New%20Rev.%207-15-11.pdf#search=Individual%20Options%20Waiver%20Handbook>

- **Level 1 Waiver**

The Level 1 Waiver provides for a more limited range of services and has a \$5,000 per year limit for services such as respite care and homemaker/personal care. There is a \$6,000 limit to cover environmental modifications, specialized equipment and supplies, and a personal emergency response system. There is an \$8,000 limit over three years for emergency assistance, if required.

*Because the waiting lists are very long, it may be years before your child is approved for waiver funds (large counties have waiting lists of over 1,000 individuals). Parents are encouraged to get their child on the waiting list as early as possible. Exact services to be covered by the waiver can be determined at the time the child is eligible. Contact your County Board of DD now to enroll your child and place his/her name on the waiting list in your county. It is an opportunity, not a commitment to a particular program or service.*

Your service coordinator at the county board of DD can guide you through the application process for waiver eligibility.

For more information on the Ohio Department of Developmental Disabilities and the County Boards of Developmental Disabilities, call toll free (877) 464-6733, or check at [dodd.ohio.gov](http://dodd.ohio.gov)

### **Background on Waivers**

Parents are frequently asked by well-intentioned people, “Does your child have a waiver?” The first thing the parents might say back is, “What do you mean, a waiver?” In the state of Ohio, a waiver refers to one of several federally funded programs that use Medicaid funds. All waivers are governed by state departments to provide funds to particular individuals such as retired elderly individuals, medically involved children, disabled adult citizens, and disabled children under the age of 18. There are income eligibility requirements to determine whether an individual is eligible for Medicaid funding.

In the case of waivers, the income of the family with whom the individual lives is not taken into consideration to determine eligibility; that is, the state *waives* the family’s assets as a factor in determining need.

Only the individual’s income, savings, and other assets are considered. The individual’s needs are the basis for which funds and services are granted.

In Ohio two state agencies, the Ohio Department of Developmental Disabilities (DODD) and the Ohio Department of Jobs and Family Services (ODJFS), govern waivers for adults and children with disabilities. DODD governs the Individual Options Waiver and Level 1 Waiver. (See section on DODD.) In both cases, the county boards of DD oversee their use and administration.

ODJFS governs the Transition Waiver. It uses the Carestar agency to administer the waiver and provide service coordination to families.

Originally, the Transition Waiver was called the Ohio Home Care Waiver, and it was designed to support families with very ill and/or medically fragile children who would otherwise need to be hospitalized or live in a nursing home. It was determined that for these children, medical needs, not a developmental disability, should determine the funding source for the waiver funds. This waiver strand is governed by ODJFS.

Some children with ASD were awarded these waivers, even though they did not have serious medical needs. This was because these children had very urgent needs (safety issues, serious sleep disorders, and behavioral problems that required specific therapy) but not *medical* needs (feeding tubes, catheters, and breathing machines). Because of the waiting list for IO waivers, these children were not going to receive support for years.

During a routine federal review of Medicaid expenditures, the state of Ohio was told that the Ohio Home Care Waiver was not being administered according to federal guidelines. As a result, ODJFS could no longer accept children who did not meet the original medical guidelines for the waiver.

Children who were already receiving services under the ODJFS waiver, but who met the guidelines for the IO waiver under the DODD, were transferred to a new type of waiver under the ODJFS called the Transition Waiver. The families receive all the benefits that they had been receiving when they were accepted under the Ohio Home Care Waiver. Eventually, these children should be transferred to the IO waiver.

### ***How Do I Get a Waiver for My Child?***

You cannot begin the process of obtaining a waiver without a service coordinator through your county board of DD. (However, you can be placed on the waiting list at intake without a service coordinator.) The process is rather complicated, and it is not the intent to cover this in detail here. Your service coordinator's will take you through all the steps for obtaining a waiver, beginning with determining eligibility. Not everyone who applies for a waiver will receive one. Be sure to appeal the decision if you are denied a waiver.

### ***What Does My Child Receive with a Waiver?***

Depending on the type of waiver your child is eligible for, you may receive approval to hire care providers for respite services or a provider to act as an aide for daily living. You may hire care providers through an agency or use someone who is an independent provider. You may also be approved to receive psychological services, therapies, and some kinds of safety equipment. If your child is approved for a waiver, she will receive a Medicaid card that can be used to supplement your existing medical insurance or cover expenses for a child who has no insurance.

## **Ohio Department of Mental Health**

The Ohio behavioral health care system is organized into three levels or tiers:

1. state level
2. county level
3. board level

At the state level, there is the Ohio Department of Mental Health. This state agency certifies, monitors, and funds not-for-profit and for-profit agencies that provide services directly to the consumer. Planning, funding, and contracting with the provider agencies is managed at the county level by county mental health boards.

In some counties, the mental health and alcohol and drug addiction boards are combined into one organization. The boards do not provide any direct service to the consumer. Instead, they contract with agencies to provide these services

### **Statewide Coordinating Center for Excellence in Dual Diagnosis**

The Ohio Coordinating Center for Excellence in Dual Diagnosis is a statewide project funded by a three-year grant to improve services to individuals with a mental health diagnosis along with intellectual disability. The project has established a partnership of university programs and children's hospital programs. In addition, the statewide effort has resulted in some county boards of mental health and county boards of DD joining efforts to provide training, increase knowledge, and improve services to this population.

The partnership of the DODD and the Mental Health Department is working to develop: (a) four regional training programs where identified systemic and clinical best practices will be presented; (b) a series of consultative mini-grants to foster collaboration at local levels across the state to increase service capacity; (c) consultative services in Ohio for clinicians treating individuals with dual diagnosis; and (d) research efforts and identification of other funding sources to expand systemic and clinical best practices for individuals with dual diagnosis living in Ohio.

Check the following website to find out if your county boards are participating in this program:  
<http://dodd.ohio.gov/Initiatives-and-Partnerships/Pages/CCOE.aspx>

## **Coordination of Services**

The National Alliance for the Mentally Ill of Ohio (NAMI Ohio) has created a booklet to guide families in accessing services from multiple Ohio agencies. The booklet may be downloaded from <http://www.namiohio.org/images/publications/Publications/ServiceCoordination200601111.pdf>

If you do not have access to the Internet, call NAMI Ohio toll free at (800) 866-2646 to request a copy of the service coordination guide.

## **Ohio Jobs and Family Services**

The Ohio Department of Job and Family Services (ODJFS) develops and oversees programs and services designed to help Ohioans become independent through education, employment, job skills, and training. ODJFS programs help to ensure a safe and healthy environment for individuals and families who need help caring for their basic needs due to temporary or on-going situations.

The state ODJFS works with county departments of job and family services, county child support enforcement agencies, county public children's services agencies, and other community organizations to provide social service programs for families. The goals of the programs are to strengthen families, protect children, and provide children with opportunities for a better life.

Support programs offered through the ODJFS are listed below.

For a guide to all these programs, contact the ODJFS at (877) 852-0010 or (614) 466-2100 or visit their website: <http://jfs.ohio.gov>

To find the number for the office in your county, view your county contact information at [http://jfs.ohio.gov/County/County\\_Directory.pdf](http://jfs.ohio.gov/County/County_Directory.pdf)

If you do not have access to the Internet, contact the ODJFS at (877) 852-0010 or (614) 466-2100 to request the phone number of your local office.



## Support Services

\*The **Disability Financial Assistance** (DFA) program offers cash to individuals who meet eligibility requirements, including one of the covered categories. An individual may receive assistance if he or she is: disabled as determined by ODJFS or at least 60 years of age and in receipt of DFA as of June 2003. The most cash one person can usually receive on DFA is \$115 a month. An individual must apply at his or her county job and family services office to receive DFA.

The **Emergency Food Assistance Program** and the **Commodity Supplemental Food Program** are two of the U.S. Department of Agriculture's food distribution programs. They provide surplus and price-supported agricultural goods to state agencies. ODJFS uses food banks to distribute food. Eligibility is based on federal income guidelines. To access this program, contact your county office of jobs and family services.

\*The **Food Stamp Program** helps people with low incomes obtain nutritious food. Food stamp benefits are issued by the U.S. Department of Agriculture through county Jobs and Family Services Departments and are used to purchase specific staples and grocery items at participating grocery stores. Food stamp benefits are dispersed through an electronic benefits transfer system. Thus, at the grocery store checkout counter, the amount purchased is deducted electronically via a plastic card from the individual's or family's total monthly allotment of food stamp benefits. Eligibility, determined by the county Departments of Jobs and Family Services, is based on federal guidelines, including income, resources, and household size. Contact your local office to access the food stamp program.

**Ohio's Best Rx** is a statewide prescription drug discount program designed to lower the cost of prescriptions for Ohio residents who have no prescription drug coverage. Applicants under the age of 60 cannot earn more than 250 percent of the federal poverty guideline while those age 60 and over are not subject to any income restrictions. The goal of Best Rx is to improve access to needed medications at a reduced cost through a statewide network of participating pharmacies. Spanish, Somali, and large-print applications are available. A mail-order delivery option is also available. For more information, visit [www.ohiobestrx.org](http://www.ohiobestrx.org) or call toll free at (866) 923-7879.

**Ohio Works First** (OWF), part of Ohio's **Temporary Assistance to Needy Families** (TANF) program, initially provides time-limited cash assistance to eligible needy families for up to 36 months. During that time, county Departments of Jobs and Family Services provide support to adult participants to become job-ready, obtain necessary job skills, and find employment.

After 36 months, families are ineligible for further cash payments, unless the county Jobs and Family Services office approves an extension of benefits. Three kinds of extensions are offered: state hardship, good cause, and federal hardship. There is a federal 60-month limit on TANF benefits; however, a county office of job and family services can approve a “federal hardship” extension. Applications and eligibility determinations for Ohio Works First are completed at county job and family services offices.

The **Prevention, Retention, and Contingency** (PRC) program is designed to assist low-income families with the necessary resources to:

- Prevent families from having to apply for OWF cash assistance when crises arise.
- Help family members retain employment by enhancing job skills, overcoming barriers, and providing short-term assistance or wage-supplementing wages, if necessary.
- Provide for contingent needs by helping families with one-time urgent problems that, if left unattended, could result in families needing long-term public assistance. Examples of family-related PRC services include family preservation/support services (including counseling); family reunification services (when children have been removed from the home); family planning/clinical services; and shelter and personal/family support services in instances of domestic violence.

## Health Care

**Medicaid** is a state and federally funded health care plan administered by the ODJFS. Medicaid provides health care coverage to low-income and medically vulnerable people of all ages. More than \$11.1 billion of the annual ODJFS budget goes to the Medicaid program to provide health care to lower-income, elderly, and disabled Ohioans. The Medicaid Consumer Hotline can answer general questions and is open evenings and weekends at (800) 324-8680 (TTY 1-800-292-3572). More information about eligibility, services, and programs may be found at <http://medicaid.ohio.gov>.

The **Hospital Care Assurance Program** supports hospitals that provide health care to low-income patients who cannot pay their hospital costs. Ohioans whose income is at or below 100 percent of the federal poverty guideline are guaranteed hospital services free of charge. Each hospital is responsible for administering this program. Ask your local hospital for more information.

The **Disability Medical Assistance Program** (DMA) is state and county funded and provides basic outpatient medical coverage, most notably prescription drugs, for people with very low incomes who are medication-dependent. DMA is available to certain persons ineligible for federally supported public assistance programs. Consumers must apply at the local county office of Jobs and Family Services.

For a program guide of all the programs listed here, contact the ODJFS at (800) 852-0010 or (614) 466-2100 or visit [jfs.ohio.gov/](http://jfs.ohio.gov/)

If you do not have access to the Internet, contact the ODJFS at (800) 852-0010 or (614) 466-2100 for the phone number of your county jobs and family services office.

## **Ohio Rehabilitation Services Commission, Opportunities for Ohioans with Disabilities (OOD), and Bureau of Services for the Visually Impaired (BSVI)**

The Ohio Rehabilitation Services Commission is Ohio's state agency that provides vocational rehabilitation services through the Opportunities for Ohioans with Disabilities (OOD) and the Bureau of Services for Visually Impaired (BSVI). The focus of these services is to help people with disabilities become employed and live independently.

Eligibility is based on three factors:

- A physical, mental, or emotional impairment creates or results in a substantial barrier to employment
- Vocational rehabilitation services will benefit employment outcome
- Services must help an individual get and keep a job

Through local offices, OOD and BSVI provide services leading to employment for people with physical, mental, and emotional disabilities. Parents can work with school personnel and their DODD service coordinator to refer their son or daughter for services from OOD/BSVI at the age of 16. Sometimes a rehabilitation counselor will attend IEP meetings to coordinate transition services prior to graduation to prepare the student for work.

Once a referral is made, an initial interview is set up between the individual and a professional rehabilitation counselor. A friend or family member can be present at the interview to help answer questions about the individual's skills and interests. The counselor will talk with the individual about career plans and the services needed for employment.

BVR services can include:

- continuing education or specialized job training, including supplies and books
- work adjustment training
- tools and equipment, including assistive technology or adaptive devices/low-vision aids that enable a person to work
- on-the-job training
- job placement and follow-up

An individual plan for employment will be developed by the counselor and the individual to identify the services to be provided through OOD/BSVI. The OOD/BSVI counselor will be involved throughout the implementation of the plan and will monitor the individual's progress. The implementation of the plan may take from several months to several years.

OOD/BSVI can also provide assistance to help maintain a job. For example, the counselor can work with the individual and the employer to determine the services necessary for the job placement to be successful. In addition, a rehabilitation counselor can identify employment support programs that will allow an individual to protect access to Medicaid services. Individuals can also use their earnings to fund needed supports for employment, such as job coaches, in order to maintain employment.

For more information, contact OOD toll free at (800) 282-4536 or visit <http://ood.ohio.gov>

## **Ohio Department of Education and Local School Districts: Educational Services**

Your local school district is responsible for providing a free, appropriate public education (FAPE) to all children with disabilities ages 3-21 in accordance with IDEA. This includes preschool programming for students 3-5 years of age who are eligible, and special education school services for eligible students ages 5-21. Eligibility for services under the IDEA is determined through a Multi-Factored Evaluation (MFE) conducted by the school at no cost to the parent. (See Chapter 5.)

Your local school district is also responsible for evaluation and identification of children with disabilities even prior to the age of 3 years (a process called Child Find). The purpose of this requirement is to ensure the earliest possible identification of children who may benefit from early intervention or early education services. (See also, the Ohio Department of Health and *Help Me Grow* sections in this chapter.)

## ***Preschool Special Education Programs***

Your local school district is responsible for providing preschool special education programs for eligible children with disabilities from 3-5 years of age. Eligible children include those identified as having a deficit in one or more of the following areas: communication, vision, hearing, motor skills, social emotional/behavioral functioning, self-help skills, and/or cognitive skills.

Deficits can be identified through the Multi-Factored Evaluation (MFE) process conducted by local school districts to identify eligible children for special education (see Chapter 5).

The Ohio Department of Education (ODE) is responsible for ensuring and overseeing local school districts' compliance with the IDEA regarding special education programs for preschool children with disabilities.

Procedures have been identified to guide the transition of children with disabilities from early intervention services to preschool special education services. The Individual Family Service Planning (IFSP) teams and the local school district are required to begin planning for the transition to preschool special education services six months before the child's third birthday. Parents participate in planning for this transition to preschool special education services. (See Chapter 5 for more information about how to access special education services for your child.)

## ***Autism Scholarship Program***

The Autism Scholarship Program is operated by the Ohio Department of Education (ODE) to provide funds of up to \$20,000 to parents of a qualified child with ASD. The autism scholarship program gives parents the choice of declining the local school district's proposed special education program by placing their child in an out-of-district or private school program.

Parents can choose a special education program provided by an ODE-approved autism scholarship provider to receive the services outlined in the child's IEP. A list of approved providers is located on the ODE website.

Ohio follows the federal definition of autism, a definition that was meant to be inclusive of pervasive developmental disorder-not otherwise specified, autism, and Asperger Syndrome. Children are eligible for the scholarship if they are identified by the local school district under the category of autism.

To find more information on the Autism Scholarship Program, see the Children with Disabilities portion of the ODE website. Scroll down to the middle of the page to see the autism scholarship heading. [www.ode.state.oh.us](http://www.ode.state.oh.us)

If you do not have access to the Internet, call The Ohio Center for Autism and Low Incidence (OCALI) toll free at (866) 886-2254 to request a copy of the autism scholarship information.

## ***Ohio Center for Autism and Low Incidence (OCALI)***

The Ohio Center for Autism and Low Incidence (OCALI) serves families, educators, and professionals working with students with autism and low-incidence disabilities. It is a statewide project under the direction of the Ohio Department of Education, Office for Exceptional Children (ODE-OEC).

OCALI serves as a statewide clearinghouse for information about ASD. OCALI maintains a collection of resources, including books, CDs and DVDs, for loan at no cost to parents and professionals; It provides professional development opportunities on ASD and assistive technology for educators, parents, and other professionals; maintains a services and supports database that is searchable online; loans assistive technology devices for purposes of assessment; and disseminates current information and research through its website and publications. OCALI is responsible for pursuing activities to address the recommendations made by the Ohio Autism Taskforce (OAT).

For more information, contact OCALI at their toll free number (866) 886-2254 or check the website: [www.ocali.org](http://www.ocali.org)

## **Federal Assistance Programs**

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

Based on parents' income, some children with disabilities are eligible to receive a cash benefit through Supplemental Security Income (SSI). Eligibility requirements are related to family income, including income from salary or wages, as well as savings and property. In other words, the amount of money or property a family has determines how much SSI a child can receive each month. Children may become eligible to receive benefits themselves when they reach the age of 18 if they cannot work.

To be eligible under the disability rules, a child must have a "marked and severe" functional limitation from a physical or mental condition. Children who are eligible for SSI benefits are also eligible for medical care under Medicaid.

Apply for SSI for your child by contacting your local Social Security Administration office or by calling the following toll free number (800) 772-1213. Have your social security number available when you call.

### ***\*Social Security Disability Insurance (SSDI)***

Social Security Disability Insurance (SSDI) is a program that provides for a worker who becomes disabled and who has paid into social security. Sometimes SSDI also pays for the worker's dependents. When a worker retires, becomes disabled, or dies, any dependent children will get monthly cash benefit. How much the child receives depends on the size of the benefit the worker received. There is a cap or a maximum amount one family can receive, when both the worker and dependent children get benefits.

Apply by contacting your local Social Security Administration office or by calling the following toll free number (800) 772-1213 TTY (800) 325-0778.

### ***\*Internal Revenue Service: Tax Deductions and Tax Credits for Families***

According to IRS rules, a federal tax credit is available for eligible low- and moderate-income individuals and families who work. The Earned Income Tax Credit (EITC) reduces the amount of tax you owe. Workers with one or more eligible children could apply if their income was less than the federal guidelines. For example, in 2008, workers with one eligible child could apply if their income was less than \$33,995. To determine if you are eligible for the credit, you can complete an assessment online at: <http://www.irs.gov/Credits-&-Deductions>

## **\*Tax Deductions for Medical Expenses**

Eligible medical expenses may be used as a tax deduction under IRS rules. The deduction can be taken only for unreimbursed medical expenses that amount to more than 7.5 percent of the adjusted gross income. To be eligible, parents must itemize deductions and not take the standard deductions.

Eligible expenses include health insurance payments, dental payments, transportation and hotel costs associated with getting medical care, and costs for assistive technology and durable medical equipment. You can combine the costs of medical care for yourself, your child with a disability, and any other family member to reach the 7.5 percent limit required.

For more information, contact the IRS at (800) 829-3676 or visit the IRS website at [www.irs.gov/taxtopics/tc502.html](http://www.irs.gov/taxtopics/tc502.html)

## **Ohio Support and Advocacy Services**

### **Disability Rights Ohio**

The mission of the Disability Rights Ohio (DRO) is to protect and guarantee the human, civil, and legal rights of Ohioans with disabilities. DRO provides information about the rights of children and adults with disabilities through the agency's publications and advocacy resources. DRO also offers advocacy services that are free and confidential. Services range from information and referral, to mediation, negotiation, and legal advocacy.

To contact DRO, call 1-800-282-9181 or visit their website at <http://www.disabilityrightsohio.org>

## **Non-Profit Organizations**

### **AT Ohio**

AT Ohio, a federally funded non-profit organization housed at the Ohio State University in Columbus, is designed to help Ohioans with disabilities acquire assistive technology. Several programs are available through AT Ohio, including:

- An adaptive toy library
- An assistive technology trading post
- A computer refurbish and redistribution program
- Low-interest loans to purchase assistive technology
- Links to assistive technology websites, vendors, and information sources

To find out more, contact AT Ohio at (800) 784-3425 or check out their website at <http://www.atohio.org>



## ***Lions Club International***

Since 1917, Lions Clubs have offered people the opportunity to give something back to their communities. Lions tackle problems like blindness, drug abuse prevention, and diabetes awareness. The organization has a rich history of helping low-income individuals with disabilities, mostly with vision and hearing disorders, by providing grants for medical equipment, surgeries, glasses, hearing aids, and so on.

To find the club closest to you, visit <http://www.lionsclubs.org/EN/index.php>

You may also contact the Lions Club headquarters at (630) 571-5466.

## ***Sertoma Club***

Sertoma is an international organization dedicated to “SERvice TO MAnkind.” Every year Sertoma clubs raise more than \$20 million for local community service projects. Through these projects, as well as grants and scholarships, Sertoma clubs return those funds to their respective communities. Since 1963, Sertoma clubs have assisted more than 24 million Americans who have speech and hearing disorders through its varied programs, scholarships, grants, endowment campaigns and local events.

To find the chapter close to you visit the Sertoma website at <http://www.sertoma.org/sertoma-new-pages/find-a-club-selection>

You may also contact the Sertoma headquarters at (816) 333-8300.

## ***Rotary International***

Rotary is a worldwide organization of business and professional leaders that provides humanitarian service, encourages high ethical standards in all vocations, and helps build goodwill and peace in the world. Rotarians worldwide provide individuals with disabilities with education, employment, accessibility, and equal participation opportunities. Each club develops its individual service program from nine areas – one of which is helping people with disabilities. Several clubs have donated medical equipment and helped fund surgeries to low-income individuals with disabilities. Rotarians also work with children with disabilities in community programs like sporting events.

To find the club nearest you, contact the headquarters at (847) 866-3000 or visit <https://www.rotary.org/en/search/club-finder>

## ***Kiwanis Club***

Founded in 1915, Kiwanis International is an organization of service- and community-minded individuals who support children and young adults around the world. Service projects also address other needs within the community, such as working to stop substance abuse, helping the elderly, promoting literacy, supporting youth sports and recreation, responding to disasters, and supporting specific persons in need.

Aktion Clubs are community service groups made up of adults with mental and physical disabilities who perform service to help others. It is a sponsored organization of the Kiwanis Club. The purpose of the clubs is to provide a way for adults with disabilities to develop leadership skills, to serve their communities, to be integrated into society and to demonstrate the value and dignity of citizens living with disabilities.

Contact the Kiwanis headquarters for more information (800) 549-2647 or visit their website to find a Kiwanis Club or Aktion chapter near you: <http://www.kiwanis.org/kiwanis>.

## ***Parent and Family Support Programs***

### ***Ohio Autism Coalition (OAC)***

The OAC is comprised of representatives of the autism advocacy organizations throughout the state, providing a forum for the various autism groups to meet with each other, combine resources, and work together to further the improvement of services and supports to families dealing with ASD.

The following groups belong to this organization:

- Autism Society of Ohio
- Asperger/PDD Syndrome Parent Information Education Support (ASPIES)
- Autism Society of Greater Cleveland
- Autism Society of Greater Cincinnati
- Autism Society of Northwest Ohio
- Autistic Spectrum Kids (A.S.K.)
- Central Ohio Chapter, Autism Society of America
- Central Ohio Families for Effective Autism Treatment
- Cincinnati Families for Effective Autism Treatment
- Dayton Families for Effective Autism Treatment
- Fight Autism Now
- Autism Project of Southern Ohio
- Marietta Area Autism Group
- North Central Ohio Chapter
- Tri-County Chapter

You can find out more about the Ohio Autism Coalition at [http://www.autismohio.org/index.php?option=com\\_content&view=category&id=165](http://www.autismohio.org/index.php?option=com_content&view=category&id=165)

## ***Autism Society of Ohio***

The Autism Society of Ohio is dedicated to improving the lives of all affected by autism in Ohio through family and individual support, autism awareness activities, information and referral services, an information packed website ([www.autismohio.org](http://www.autismohio.org)), a weekly e-newsletter, and an information phone line. The Autism Society of Ohio advocates for individuals with autism, their families and those who work with them in Ohio by working with all of the different state agencies (ie. Ohio Departments of Health, Mental Health, Developmental Disabilities, Education, etc.) to improve and increase services. The Autism Society of Ohio advocates with the Ohio General Assembly on legislation affecting individuals with autism, organizes grassroots advocacy to do the same through the Ohio Autism Advocacy Network and collaborates with other state disability organizations.

Learn more about the Autism Society of Ohio at: [www.autismohio.org](http://www.autismohio.org)

You may also call their information line (614) 487-4726.

## ***Regional and Local Autism Groups***

Several regional and local autism organizations and parent support groups exist around the state. Check the Autism Society of Ohio website to find a listing of groups:  
[www.autismohio.org](http://www.autismohio.org)

You may also call the ASO at (614) 487-4726 to find the nearest autism group near you.

## ***Ohio Coalition for the Education of Children with Disabilities***

The Ohio Coalition for the Education of Children with Disabilities (OCECD) is a statewide organization dedicated to advancing the educational interests of all children with disabilities. Its mission is to help educate parents to become strong, informed advocates for their children. Through state and federal funding OCECD provides information, training, and assistance to parents of children with all disabilities regarding educational issues.

OCECD employs parents of children with disabilities as central and regional office staff to provide training and one-to-one assistance to other parents. OCECD publishes a bimonthly newsletter, maintains an informational website targeted to the interests of parents of children with disabilities, provides assistance by phone, conducts parent trainings across the state, and convenes an annual statewide conference.

OCECD also provides training and technical assistance to the network of parent mentors throughout the state. Parent Mentors (see Chapter 5 for more information about parent mentors) provide support to parents on special education issues and help parents address issues of concern with school personnel.

OCECD has produced a number of training booklets and special topic publications that are available to parents at no cost. Learn more about OCECD and its services by calling toll free (800) 374-2806, or visiting their website at [www.ocecd.org/](http://www.ocecd.org/).

# Advocacy and Disability Awareness

“*‘This is never going to get better,’ I kept hearing myself say under my breath as I talked to professionals about my children’s well-being – educationally, medically, and mentally. Often I got caught up in ‘this isn’t fair’ and ‘what can I do?’ (As if I didn’t already have enough on my plate, I was running kids to nine therapies a week in addition to scheduling the numerous appointments to see my kids’ specialists.)*”

*One day I was watching a TV program and heard someone talk about how one person could make a difference, make a change that could affect many, but that it would take dedication and determination. The next morning I started to make phone calls to local county agencies to find out what committees I could join or how I could give input to people making decisions about services. I wanted to make a difference!*

*I was amazed at how many agencies valued my participation. I felt good knowing that I was going to help make a difference in services, not just in my local community, but at a state level as well. In addition to that, these changes would benefit my own children with ASD.*

Advocacy by parents and family members is essential to ensure that children with ASD have an opportunity to achieve their fullest potential. As important as professionals are in furthering our knowledge of individuals with ASD and how to meet their needs, parents and family members have been critical in their role of educating professionals and policy makers.

As parents, we evolve from the time we first encounter the diagnosis of our child - from needing information and support to becoming educated and providing support and information to others. Because we all talk about what is important to us, we naturally become advocates as we talk with other parents about our experiences.

The opening of this chapter illustrates a parent coming to the realization that what she knew about her children and what she had learned about the service system as she supported her children was knowledge that could make a difference for others.

## Levels of Advocacy

### 1. Advocating for your child

The first step in becoming an advocate is learning to advocate for one's own child. Parents must learn about the diagnosis and what it means for their child's development, about the services and supports available to address their child's needs, and about how to work with professionals to ensure that their child's needs are met. These skills are learned by:

- reading pertinent articles, books, and websites
- participating in IEP meetings and other service planning meetings
- talking with other parents who are willing to share what they know
- attending training and discussions offered by parent support groups and parent organizations

### 2. Sharing information with other parents

The next level of advocacy is sharing information with another parent who needs it. This can be done informally in the hallway at school, in a parent support group, or over the phone. It can also be done more formally by leading a parent support group discussion on a topic or by providing a training session to a group of parents on a particular topic.

### 3. Supporting a parent in a service planning meeting

This level of advocacy is when a parent chooses to attend an IEP meeting with another parent to help that parent participate fully when she is unfamiliar with the process, or when he feels his concerns are not being addressed.

### 4. Participating in activities to influence how services are delivered

At this level parents advocate to change or influence the laws, regulations, and policies that affect the provision of services their child and other children with ASD or other disabilities need. At that point, child advocacy becomes systems advocacy.

## **5. Encouraging your child to advocate for himself**

It is important that parents of a child with autism work with their child to be his/her own advocate. Individuals with autism need to be encouraged to share their strengths and unique talents with others. This will allow members of the community to better understand what individuals with ASD can contribute to their communities.

We need advocates at all levels. Parent-to-parent support is critical for parents when all they have is a diagnosis and a load of questions. No one is more effective at answering those questions than another parent who has been in the same place. The Individuals with Disabilities Education Act (IDEA) acknowledges the importance of parents providing information to other parents by providing funding to support at least one parent training and information center run by parents in each state. Many parents have served in an advocacy role by helping to create this document to provide information to other parents.

When parents are educated about their child and about the service system, they are able to take an active role in supporting other parents and in providing input to public agencies and policy makers about effective ways of supporting individuals with ASD. By making their voices heard, parents can help create the schools and communities where the people they love can live, work, and play.

## Where to Advocate

There are many areas related to aspects of service delivery where parents' voices need to be heard. At the local school district or at the state level, here are some issues that parents have identified as important.

### ***Education***

- Increasing the number of educators who understand the complexities of ASD
- Placing students with ASD appropriately to best support their needs
- Providing accommodations and/or modifications tailored to the student's needs (not according to the student's label)
- Using research-based methods for instruction
- Providing social skills training and development
- Encouraging the full participation of children with ASD during the school day and in after-school activities
- Providing effective transition services to ensure jobs and community living outcomes
- Increasing partnerships with families

### ***Medical***

- Increasing early screening and diagnosis opportunities
- Educating medical personnel who may come in contact with children with ASD
- Increasing the availability of specialists knowledgeable about ASD
- Encouraging medical personnel to work in partnerships with families

### ***Social Services***

- Increasing the number of providers who specialize in the unique needs of children and adults with ASD
- Making providers more easily accessible
- Encouraging providers to work in partnership with families



# The Importance of Parent-to-Parent Support in Advocacy

Parent-to-parent support offers not only emotional support, it also serves as a step in learning to advocate effectively. Many organizations working to improve supports for those with disabilities were originally created by concerned family members. In any way you can, online or through parent support groups, stand with other parents and family members. When you do that, you become involved in systems advocacy.

We make countless decisions in the process of living with ASD. Since such decisions are individualized, you may find yourself choosing different treatment options than other parents. Or you may become involved with an organization that is different from what other parents or family members prefer. Your child may be significantly affected by autism and you may know families who have children that are only mildly affected and, therefore, feel you do not have that much in common.

It is unrealistic to expect everybody to agree on every choice. It is important to respect each family's choice and also stand with them to support policy changes or legislative changes that will make a difference in our communities, our state, and our nation.

A large strong united voice cannot be ignored. Here are some pointers for systemic advocacy.

- Get involved in efforts that impact the entire ASD community.
- Be publicly supportive of programs and services that may help any person affected by ASD, even if it does not affect your family directly.
- Respect each individual's level of commitment to advocacy however small or large it may be.
- Give first priority to being the best advocate you can for your child and family. Consider all the demands you may face at the current stage of your journey.

Individuals with ASD are entitled to rights and services. This statement sounds simple and straightforward, but as many parents and family members know, it can get complicated and be frustrating when you are working with a system that does not understand your family member's needs. People with their own agenda are often urging law makers to make decisions that are not appropriate for our ASD community, such as mandating one specific type of intervention be used with all children with ASD. At these times, your voice needs to be heard. You have the personal experience that others may not. Let your locally elected officials know how you feel on certain issues and suggest how they should vote on proposed policies, budgets, and legislation.

## There Are Many Ways You Can Advocate: Home, School, and Community

- Join an advocacy organization
- Advocate for your child
- Advocate for other children
- Call/write/email your legislators
- Vote
- Call a radio station to explain your position on a particular topic
- Write a letter to the editor of your local paper
- Hold a town meeting to discuss issues of concern
- Attend a school board meeting to discuss your concerns
- Attend local/state social services board meetings to discuss your concerns
- Join local or state committees that address what you are trying to accomplish
- Visit your senator
- Attend a rally at the State House to raise awareness of ASD

### Tips for Talking with Leaders

- Always be respectful, courteous and professional.
- Thank them for the job they are doing.
- Educate yourself on the issues.
- Be brief and to the point.
- Ask for reasonable objectives.
- Don't be negative.
- Get to know contacts on their staff.
- Write letters thanking them for their time and efforts.
- Offer to serve as their "autism expert."

## Grassroots Advocacy

“Grassroots” advocacy refers to people working together to write letters, place calls, send emails, and visit officials to communicate ideas and opinions to government officials. Most of the time, efforts are concentrated to senators, representatives, and agency personnel. As a constituent, you have the right to express your opinion and advise your elected officials about the issues that you are knowledgeable about.

Start small. Begin with your own child. This means working with your child’s teacher, school district and/or even school board on issues that arise regarding your child’s educational progress.

## Awareness Campaigns

An awareness campaign is slightly different from advocacy work because it is geared toward educating a particular group of people or the general public. A good example of an awareness campaign is the annual Autism Awareness Month promoted by the Autism Society of America (ASA) and celebrated every April. Each ASA chapter is encouraged to hold events, obtain proclamations, and distribute literature to the local community to inform them of the issues related to autism.

Local organizations often plan public events like runs and walks, community festivals, or open houses to help community members learn about autism and raise money for research or other projects. If you are interested in planning an event in your town, talk with other parents and family members to get their support. Also contact a state organization like the Autism Society of Ohio. They can link you with national organizations that may provide materials and guides for planning and staging events. Some national organizations are ASA (<http://www.autism-society.org>), and Autism Speaks ([www.autismspeaks.org](http://www.autismspeaks.org)).

## Ways to Spread Autism Awareness

Sponsoring a community-wide campaign is a major undertaking. But there are many other, less time-consuming ways to spread awareness, including the following:

- Arrange to give a presentation to students at your local public school.
- Volunteer to educate local first responders (police, firefighters and paramedics) on how to handle individuals with ASD.
- Take time to educate your own family so they can become advocates for your child with ASD, as well.
- Write a letter to the editor of your local paper during Autism Awareness Month to outline the severity of the problem and what needs to be done.
- Wear the autism awareness ribbon, autism awareness bracelets or pendants every day.
- Stick an autism awareness ribbon magnet or bumper sticker on all your vehicles.
- Buy an Ohio license plate featuring the autism awareness ribbon.
- Distribute informational literature from national groups like ASA and Autism Speaks to local doctors, human service agencies, professionals, and therapists, etc.

In 2003, the Ohio state legislature created an Ohio Autism Taskforce to develop a report for the legislature on services for persons with ASD in the state. The report contains 43 recommendations for improvements in services. Many of these recommendations, such as implementing new supports and service programs, will require legislation.

It is important for you to become aware of what legislation is pending, both at the state and federal level. You can learn about federal issues on the ASA website at [www.autism-society.org](http://www.autism-society.org). You can learn about state legislation on the Autism Society of Ohio website at [www.autismohio.org](http://www.autismohio.org). Both websites have email "alert" systems that allow you to sign up to receive legislation notices and recommendations for how to take action.

It is important for you to make your voice heard by your state and federal legislators. You can identify your current state legislators by visiting [house.state.oh.us](http://house.state.oh.us). Click on "Your Representatives" and enter your zipcode. Visit [senate.state.oh.us](http://senate.state.oh.us) and click on "Your Senators" and enter your zipcode. It is also easy to find your federal legislators. Visit [www.house.gov](http://www.house.gov), click on "Write Your Representative" and enter your zipcode. Visit [www.senate.gov](http://www.senate.gov), click on "Senators" and enter your zip code.

Contact your legislators and make them aware that you have a family member with ASD. Describe the challenges faced by individuals with ASD and their families in Ohio and the barriers they encounter in getting needed services. Remember to always be constructive and considerate.

Our legislators represent us – and they want to hear from us. The best way to do so is via post card, letter, or fax. They are bombarded with email so it is not always effective.

You can also hold a “candidates’ forum” and invite several candidates to meet with families dealing with autism in their district to hear their stories and learn about their needs. Don’t invite legislators in for a complaint session, but for positive dialogue on the issues. Remember, we want them thinking about how to be a part of the solution.

Finally, when you find candidates who support your positions, support them financially. Private citizens can contribute \$50 per person or \$100 per couple to the candidate of their choice and receive a dollar-for-dollar tax credit! Nothing speaks to our legislators like money and votes.



# Future Planning

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*My son was two years from finishing high school when the IEP team finally took up his transition plan. “Shouldn’t we send him for manual assembly activity assessment?” the work-study coordinator suggested for the third time. My son had a 35 on the ACT in math. He was on his high school’s “In the Know” team. He has the fine-motor coordination of a 6-year-old. Somehow, an assembly job doesn’t seem to be the best fit, I thought. Then I reminded myself that parents are an integral part of the IEP team and spoke up!*

”

Although this chapter covers topics related to your child's life beyond high school, it urges parents to work on them even while their child is still in school. This chapter includes many suggestions for planning for the transition of your child from a school program to adult services, employment, and living in the community. It also introduces important legal and financial planning issues that every family should think about.

## Life After High School

We hope you won't wait until your child is a teenager to formulate plans for the future.

One of the most challenging times for individuals with ASD and their families is when an adolescent is about to transition from a school program to the uncertainty of adult services. Questions about postsecondary education, vocational training, employment, community living, and sources of financial support for the individual with ASD must be addressed.

The Individuals with Disabilities Education Act (IDEA) requires that transition planning for this shift to adulthood and adult service systems begin by age 16, although it may begin earlier than age 16 if the IEP team agrees.

The student, parents, and members of the IEP team should work together to help the student make choices about his path for the future. This will involve discussions about where he wants to live, what kind of work he wants to do and what recreation and leisure time activities he would like to be involved in when not working. Transition planning through the IEP process identifies the student's goals and a plan for reaching them in each of these areas.

## Mandated Services Versus Eligibility-Driven Services

One of the biggest changes that parents face at the time of their child's transition from education to community services is the shift from the mandated services of education to the eligibility-driven services of the adult service system. All children are entitled to educational services. But in the adult service system there are no entitlements. Individuals must "qualify" or be determined eligible for services. Transition services within education should support parents and their child in applying for the services for which they are eligible.

In addition to the transition planning within the IEP process, IDEA also requires that the school develop a document called the Summary of Performance (see Chapter 5) to help with this planning. When a student is no longer eligible for educational services, the school district must provide the student with a summary of their academic achievement and functional performance. This summary of performance must include recommendations on how to assist the child in meeting the student's postsecondary goals (IDEIA §300.305(e)(3).

As mentioned in Chapter 6 under the section on the Ohio Department of Developmental Disabilities (DDD), at age 16 a child who has been determined eligible for DDD services will have to be re-evaluated using adult standards. Your child's Service and Support Administrator should discuss this re-evaluation with you. If not, or if your child has not received DDD services, call the DDD intake worker to schedule an appointment for evaluation for eligibility. (See Chapter 6.)



Remember, you have the right to be present during this assessment. If your child is deemed eligible, she will be assigned a Service and Support Administrator who will serve as a case manager to assist you in identifying the range of services needed and in helping you establish her eligibility.

*Ask your service and support administrator to explain all of the services your child may be eligible for. Make sure you ask to have your child placed on waiting lists as early as possible for any services your child may wish to access in the future. You can always decline these services when they are offered if he doesn't need them.*

## Transition Planning

All students receiving special education services in public schools have regular meetings with family and school staff to discuss the student's IEP. Once a student is in high school, these meetings should begin to plan for the transition from high school to adult life.

IDEA defines transition services as a coordinated set of activities for a student that promotes movement from school to post-school activities, including:

- Education after high school
- Job training
- Range of employment opportunities
- Help with coordinating support services (“case management”)
- Preparation for living independently in the community
- Recreation and volunteer opportunities

According to IDEA, these activities must be based on the individual student's needs, preferences and interests and include activities in the areas of:

- Instruction
- Community experiences
- The development of employment and other post-school adult living objectives
- Acquisition of daily living skills and functional vocational evaluation

*It is important that families and schools start planning early to ease the transition for the person with an ASD and to increase success and independence in adult life. According to IDEA, this should begin by age 16. Beginning earlier, however, can only benefit the child.*

## Individualized Transition Planning

Because transition planning is the foundation for a student's adult life, IDEA has provided much guidance to school districts on the content and process for developing an individualized transition plan to support students with disabilities.

In transition planning the following four points should be considered:

- The plan, including goals and services, must be based on the individual needs, preferences, and skills of the person with an ASD.
- Planning should be oriented to life after high school, not limited to what will be accomplished before leaving school.
- There should be a master plan that includes long-range goals and a coordinated set of activities for each goal.

- The services provided should promote positive movement towards a life after school. (Autism Society of America, n.d.)

## ***Interagency Planning***

Interagency collaboration is an important part of a student's transition planning. Other agencies and organizations may provide training or direct services to individuals with disabilities that will help schools support a student's transition to community life. Ask your school district to involve other agencies in developing your child's plan for transition. This can include the local office of the Opportunities for Ohioans with Disabilities (OOD) and the county board of DD. (See Chapter 6 for more information on these agencies.)

Schools may also seek support from other local agencies and organizations, such as independent and supported living centers, if they are located in your area. Parents should strongly encourage interagency collaboration as part of transition planning.

Transition planning can involve finding opportunities for job experience for your child. These can be arranged for the school year and during summer breaks. When a student is given the opportunity to experience different settings and develop work-appropriate skills, he will be able to choose the best path. A good transition plan will allow the student's parents, school officials, and agency personnel to work together to make these opportunities available.

## ***Ohio's Employment First Initiative***

In 2012, Ohio's Governor took action to establish the Employment First initiative. Follow-up legislation required Ohio agencies to collaborate and align their services to make employment in the community the preferred option for youth and adults with developmental disabilities regardless of severity of the disability. It is based on the belief that every person has abilities, skills and talents to enrich the community and those around them when provided the proper support. Every agency, school, organization and individual within Ohio's developmental disabilities system plays a role by focusing on what everyone can do and in providing the best supports and services to enable people to choose and succeed in community employment. The effort has engaged parents, professionals and people with disabilities in planning and implementing new rules and policies for employment services at the state, regional and local levels. To find out more about the Employment First work check out this website: [www.ohioemploymentfirst.org](http://www.ohioemploymentfirst.org)

## ***Questions to Guide the Transition Process***

Parents can begin thinking about transition planning as early as when the child enters middle school. It can be helpful to start the process with a list of questions to act as a springboard for discussion. These questions can be similar questions parents develop when preparing for an IEP meeting. (See Chapter 5.) Some families hold family meetings with siblings and the adolescent with ASD so that they can all share in the planning.

Below is a list of questions developed by a mother whose son has autism (Autism Society of America, n.d.):

- What can your child do?
- What does your child like to do?
- What does your child need to explore?
- What does your child need to learn to reach his or her goals?
- What about college (four-year university, two-year community college), vocational education, or adult education?
- How about getting a job (competitive or supportive employment)?
- Where can your child go to find employment and training services?
- What transportation will your child use?
- Where will your child live?
- How will your child make ends meet?
- Where will your child get health insurance?

Many people think of adulthood in terms of getting a job and living independently, but having friends and a sense of belonging in a community are also important. Transition planning through the IEP process is designed to help students and parents plan for this aspect of community life as well. To address these areas, we have added the following questions to guide discussion and decision-making in this area.

- Are supports needed to encourage friendship?
- Do people in the community know your son or daughter?
- Are supports needed to structure time for recreation? Exercise?
- Does your child have any special interests that others may share as a hobby?
- Can you explore avenues for socializing such as religious affiliation or volunteer work?

*Make sure the IEP team is reminded that the pattern of strengths and weaknesses in ASD is unique. Don't design a plan that relies heavily on the individual's weaknesses.*

## Taking Action

It is also important that the transition process involve taking action. After identifying areas of interests and setting goals, school personnel, parents and the student should take active steps to meet those goals.

For example, the BVR representative arranges a job experience for a student with ASD who has particularly sharp computer skills. The student is dismissed from school early a few days a week and accompanied by an aide to work at a data processing office. In preparation for this job, the student's school program is designed to teach the student appropriate office skills, office procedures, such as using a time clock, and social skills.

Another student, who prefers to be outdoors, would be more suited to work with a community clean-up project than in an office. Her school program is designed to teach landscaping and horticultural skills, as well as social and job skills. The team would identify a job experience site that would allow the student to work in a local nursery. The transition plan must be tailored to each individual's skills and preferences.

Experience with three or four different work activities during transition planning is helpful in assessing a student's interests and capabilities while she is still in high school. For some students transition activities will be designed to prepare them for further education. The transition plan should address the student's goals for life after high school whatever they may be.

The National Information Center for Children and Youth with Disabilities (NIHCY) has published a Transition Summary series to help families and students with disabilities focus on taking definite steps toward a successful transition. Although NICHCY no longer exists the NICHCY Transition Summary, No. 7, September 1991, is available in its entirety from the Center for Parent Information and Resources (CPIR) <http://www.parentcenterhub.org/?s=nichcy+transition+summary>. Below we have adapted a portion of the NIHCY Transition Summary.

## ***Middle School: Start Transition Planning***

- Involve your child in career exploration activities.
- Visit with a school counselor to talk about interests and capabilities.
- Have your child participate in vocational assessment activities.
- Along with your child, use information about interests and capabilities to make preliminary decisions about possible careers (academic versus vocational or a combination).
- Along with your child, make use of books, career fairs, and people in the community to find out more about careers of interest.
- Keep in mind that while self-determination needs to be considered, students with ASD may mature more slowly than others. Therefore, their timetables for independence may be longer. Beware of eliminating options too early based on academic and behavioral expectations they may not have achieved at the same age as their peers.

## ***High School: Define Career/Vocational Goals***

- Make sure the IEP includes a transition plan and work with school staff, and community agencies to define and refine the transition plan.
- Help identify and make sure your child takes high school courses that are required for entry into college, trade schools, or careers of interest.
- Help identify and make sure your child takes vocational programs offered in high school, if a vocational career is of interest.
- Encourage your child to become involved in early work experiences, such as job try-outs, summer jobs, volunteering, or part-time work.
- Reassess interests and capabilities, based on real-world or school experiences. (Is the career field still of interest? If not, redefine goals.)
- Make sure your child participates in ongoing vocational assessment and identify gaps of knowledge or skills that need to be addressed and address these gaps.

## ***After High School: Achieve Your Goals***

- If eligible for OOD services, make sure your child works with a BVR counselor to identify and pursue additional training or to secure employment (including supported employment) in her field of interest.
- If your child is not already receiving Supplemental Security Income, contact the local Social Security Administration office shortly before she turns 18. Family income is no longer considered in determining eligibility for benefits after the person's 18<sup>th</sup> birthday. If eligible for social security benefits such as Supplemental Security Income, find out how work incentives apply.
- Contact your county board of DD to determine your child's eligibility for services, including Medicaid and waiver services. (See Chapter 6 for contact information.) Even if your son or daughter can be maintained on your medical insurance plan, Medicaid can be useful as supplemental insurance. In addition, Medicaid eligibility is required for many adult DD services.
- Contact agencies that can help, like disability-specific organizations such as the state or local chapter of the Autism Society of America. Ask about all services the student may be eligible for.
- Continue to work through the plan by following through on decisions to attend postsecondary institutions or obtain employment.

## **Education and Training Prior to Employment**

- Have the IEP team and other disability support organization can help identify postsecondary institutions (colleges, vocational programs in the community, trade schools, etc.) that offer training in a career of interest for your child.
- Identify the accommodations that would be helpful to support your child. Make sure that documentation is current on your child's IEP. This will support your child's request for accommodations at an educational institution. Find out if the educational institution makes, or can make, these accommodations.
- Write or call for catalogues, financial aid information, and request an application.
- Help identify and make sure your child takes any special tests (e.g., PSAT, SAT, ACT) necessary for entry. Deadlines to apply for this testing are generally earlier when accommodations are requested.
- Visit the institution, contact the office of disability services at the institution, and confirm that the accommodations needed for college coursework are available.

### **Resources**

Ohio Department of Education, (2002). Operating standards for Ohio's schools serving children with disabilities. Columbus: Ohio Department of Education.

Ohio Center for Autism and Low Incidence, (2008). Transition to adulthood guidelines for individuals with autism spectrum disorders (ASD). Columbus: Ohio Center for Autism and Low Incidence.

For more information on transition planning and other transition resources, as well as webcasts of transition to adulthood topics, visit the OCALI transition webpage at <http://www.ocali.org/topic/transitions/>

Ohio Employment First: <http://www.ohioemploymentfirst.org/>

## Other Future Planning Issues

There are other aspects of planning for your child's future that are not covered in the transition planning process through the IEP. These address issues like quality-of-life support for your child if you are not available and legal issues such as guardianship, and financial planning to protect government benefits.

Despite the growing number of persons with developmental disabilities in this country, fewer than 20 percent of families have done any futures planning to address these issues. Like all of us, your child with a disability will be an adult longer than she will be a child, so futures planning is critical.

CareGuide@Home (2003) reported that at least one individual in 20 percent of U.S. households is a caregiver, either part-time or full-time. Planning for the futures of people with disabilities is something parents and caregivers must address – and the sooner the better. Whether the person with special needs is 4 or 40 years old, it is imperative that families create a plan.

The following planning topics need to be addressed:

- Quality-of-life issues
- Legal
- Financial
- Government benefits

To guide decision-making when you are not available, discuss information regarding the needs and desires of the child with ASD and compose a directive document. This document should address lifestyle, financial, legal, and government-benefit issues. Whether people with ASD function entirely on their own or need assistance, such a directive can provide instruction for their daily care, as well as provide guidance for unexpected contingencies. Some of the questions this directive should cover include:

- How would your child like to be bathed and dressed?
- Does your child have special dietary needs and requirements?
- Does your child have any chronic medical conditions? Who monitors your child's medication?
- What leisure activities (music, computer, hobbies) does your child enjoy?
- What things can help your child live with dignity, quality, self-esteem and security?

While most people realize they need to plan, for a variety of reasons many fail to do so. Some believe the task is overwhelming and don't know where to find qualified professionals who understand their needs and how to resolve their concerns. The cost of professional services can also be an issue, as can privacy concerns.



## **Establishing an Advisory Team**

As families begin to develop their plan, they should begin by identifying a group of people who will act as an advisory team. This should include, when possible; family members, the person with an ASD, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, and anyone involved in providing services to the individual. Having input from each of them can help ensure that all parts of the plan are coordinated and complete (Stevens, n.d.).

## **Letter of Intent**

Lifestyle planning is a process in which a family records what they want for the future of their loved one in a document called the “letter of intent.” Although not a legal document, it is as important as a will and a special needs trust. This letter of intent will include information on a variety of important issues.

## ***Quality of Life***

Quality-of-life issues are those everyday things that need to be in place for each of us to be comfortable in our daily lives. Addressing quality-of-life issues for our loved one with ASD requires decisions and information regarding:

- Where the person will live
- Religious affiliation
- Continuing education programs desired
- Employment preferences
- Social activities preferred
- Medical care required
- Behavior management practices
- Advocacy and/or guardianship needs
- Trustees identified for financial planning purposes
- Final arrangements desired
- Detailed instructions for assisting the person with the typical activities of daily living such as bathing, dressing, feeding, and toileting
- Description of any special ways of communicating that only the immediate family knows and understands are included

*TIP: Use videotaping to record the individual performing activities of daily living, including communicating. Consider taping the individual having a meltdown and demonstrate the best ways of responding if that tends to be a relatively common occurrence.*

Should parental support no longer be available, imagine how much easier and less traumatic it will be for the person with ASD and his or her care providers if they have detailed instructions immediately available, rather than having to figure things out on their own. What could take weeks or months to adjust to, could be shortened to a few days.

The ultimate goal of the letter of intent is to make the transition from parental care to independent or supported living or moving in with other family members as easy as possible, bearing in mind the comfort and security of the individual.

## Guardianship

As each child approaches age 18, parents need to research guardianship issues and decide which options are appropriate for their young adult. Guardianship is a legal determination that involves your child's ability to make decisions regarding her own affairs, including financial, medical, and educational decisions. If you do nothing when your child turns 18, you legally lose the right to make decisions and sign legal documents for your child. Determining guardianship can sometimes be a difficult decision. Parents should discuss the issue with professionals and with other parents to learn about all the implications.

For current information on guardianship in Ohio, refer to the Disabilities Rights Ohio documents on future planning and guardianship at: <http://www.disabilityrightsohio.org/faq-guardianship>

These documents also may be requested by calling toll free (800) 282-9181.

# Estate Planning

“Who will care when you are no longer there?” is an overwhelming question that parents of children with disabilities must address, but solutions and help are available.

Estate planning allows the family to state its wishes regarding the distribution of the family's assets and to appoint executors to settle the estate. In conjunction with estate planning, a trust can be established to provide supplemental funds for the individual with ASD, but in a way that maintains the individual's eligibility for government benefits. An estate planning team should include:

- Attorney
- Accountant
- Life underwriter/financial services provider
- Trust officer

A comprehensive estate plan should:

- Provide lifetime supervision and care if necessary
- Maintain government benefits
- Provide supplementary funds to help ensure a comfortable lifestyle
- Provide for management of funds
- Provide dignified final arrangements
- Avoid family conflict

Once you have decided to prepare a plan, find someone to help you or hire a professional planner. Referral sources are available through governmental agencies, organizations, or local support groups. Use a life-plan binder. Place all documents in a single binder and notify caregivers/family where they can find it. At least once a year, review and update the plan and modify legal documents as necessary.

## Establishing a Trust

Government entitlements play a key role in the lives of many persons with autism spectrum disorders by providing money and health care benefits under SSI (Supplemental Security Income), SSDI (Social Security Disability Insurance), Medicaid, and/or Medicare. A basic understanding of federal and state entitlement programs is essential in order to be sure that an individual gets all that he or she is qualified to receive. That said, laws change, so it is crucial to hire professionals with up-to-date legal expertise.

In establishing a trust, financial planning is used to determine the supplemental needs of the person over and above the government benefits they may receive. First, a monthly budget is established based on today's needs while projecting for the future. Then, by using a reasonable rate of return on the principal, the family identifies how much money is needed to fund the trust. The life expectancy of the person must be considered and then the need projected into the future using an inflation factor.

Once this is done, the family must identify the resources to be used to fund the trust. They may include stocks, mutual funds, IRAs, 401(k)s, real estate, and home or life insurance. Professional management for investing the assets may be done by the trustee, or the trustee may hire advisors.

This information was updated and adapted for Ohio from information posted on the Autism Society of America's website, [www.autism-society.org](http://www.autism-society.org).

Legal language has changed over time as state policies and legal decisions have evolved. When carefully drawn according to strict legal guidelines, trusts have been able to provide spending money to enhance the individual's daily life. Trusts can be a valuable tool for families, regardless of the size of their estate.

Information about trusts and special needs trusts is available from the Disability Rights Ohio at the following web address: <http://www.disabilityrightsohio.org>

You may also call Disability Rights Ohio toll free in Ohio at (800) 282-9181.

*Make sure that the attorney and other planning professionals you hire have specific expertise in planning for people with disabilities.*

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- Ohio Department of Jobs and Family Service website: [jfs.ohio.gov](http://jfs.ohio.gov)
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## Sexuality

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## Curricula

*Circles I, II, and III. Intimacy and Relationships* (teaches appropriate social distance skills), *Stop Abuse* (an abuse prevention curriculum), and *Safer Ways* (HIV/AIDS prevention education). Leslie Walker-Hirsch, M.Ed. and Marklyn Champagne, R.N., M.S.W.

*Life Horizons I and II, Sexuality Education for Persons with Severe Developmental Disabilities, Life Facts – Sexuality and Sex Abuse Prevention.*

These curricula are available from:

James Stanfield Co. Inc.

Drawer 189

PO Box 41058

Santa Barbara, CA 93140

Phone: (800) 421-6534; Fax: (805) 897-1187

*YAI's Relationship Series: Friendship Series, Boyfriend/Girlfriend Series, and Sexuality Series*

YAI/National Institute for People with Disabilities

Tapes and Publications

460 West 34<sup>th</sup> Street

New York, NY 10001-2382

Phone: (212) 273-6517 fax: (212) 629-4113

## Assistive Technology

Gierach, J. (2009). *Assessing students' needs for assistive technology (ASNAT)*  
<http://www.wati.org/content/supports/free/pdf/ASNAT5thEditionJun09.pdf>

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OCALI AT Center website: <http://www.ocali.org/center/at>

*Project Team: Technology to Educate Students with Autism*, Johns Hopkins University - Center for Technology in Education, 6740 Alexander Bell Drive, Suite 302, Columbia, MD 21046.

Phone: (410) 312-3800; fax (410) 312-3868

## Community Transition

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## Transition

*Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities* (booklet). Available from the U.S. Dept. of Education, Office for Civil Rights.

To order copies, write:

ED Pubs

Education Publications Center

U.S. Dept. of Education

P.O. Box 1398

Jessup, MD 20794-1398

or fax: 301-470-1244

or email: [edpubs@inet.ed.gov](mailto:edpubs@inet.ed.gov)

or call: 1-877-433-7827; TDD or TTY 1-800-437-0833

or go online [www.ed.gov/pubs/edpubs.html](http://www.ed.gov/pubs/edpubs.html)

or go to the website: [www.ed.gov/ocr](http://www.ed.gov/ocr)

You can also get it in alternative formats from 202-260-9895.

Help for College Students with Disabilities from [Wrightslaw.com](http://Wrightslaw.com)

Lots of links: [www.wrightslaw.com/flyers/college.504.pdf](http://www.wrightslaw.com/flyers/college.504.pdf)

Coulter Video [www.coultervideo.com](http://www.coultervideo.com) (phone: 336-794-0298)

Several articles, including:

- First Year at College: Lessons Learned <http://www.coultervideo.com/#!/First-Year-of-College-Lessons-Learned/cw9s/95254E91-6D75-413F-B1E9-8CDA9EFD40FA>
- ASDs and Choosing College Courses <http://www.coultervideo.com/#!/Autism-Spectrum-Disorders-and-Choosing-College-Courses/cw9s/D2B2ADCB-648D-4A6A-9991-876D46F9CF0D>
- Helping Students with AS Prepare for the Workplace <http://www.coultervideo.com/#!/Helping-Students-with-Asperger-Syndrome-Prepare-for-the-Workplace/cw9s/BFD35FDB-121F-4A31-A8C0-0C77CCEEF130>

Also available from Coulter Video at [www.coultervideo.com](http://www.coultervideo.com):

Asperger Syndrome: Transition to College and Work

This program lists essential preparation for students with ASD to find and hold a job. For high school age and above.

Ohio Department of Education, (2002). Operating standards for Ohio's schools serving children with disabilities. Columbus: Ohio Department of Education.

Ohio Center for Autism and Low Incidence, (2008). Transition to adulthood guidelines for individuals with autism spectrum disorders (ASD). Columbus: Ohio Center for Autism and Low Incidence

This program includes two sections: How to get ready for college and how to prepare to go from high school or college to the workplace. (Note: this video includes all the information in the "Transition to Work" video and also includes college prep information.) For high school age and above.

### College Prep Portfolio

The right tool to help high school students identify, collect and organize the documents required in the college application process – and those that highlight their accomplishments to give them an edge in applying to the college of their choice. For high school students.

Article: This is for Universities – "Good Practice Guidelines for Universities":  
[www.users.dircon.co.uk/~cns/guidelines.html](http://www.users.dircon.co.uk/~cns/guidelines.html)

Resource: The Workforce Recruitment Program for College Students with Disabilities:  
[www.dol.gov/odep/pubs/brochures/wrp1.html](http://www.dol.gov/odep/pubs/brochures/wrp1.html)

Chamberlain, C. E., & Strode, R. M. (1999). *The source for Down syndrome*, East Moline, IL: LinguSystems.

Self-Employment and Social Security Work Incentives for Persons with Disabilities  
(Consulting and Training on Employment and Transition to Work):  
[www.griffinhammis.com](http://www.griffinhammis.com)

## Internet

*NOTE: Please be advised that this is not a comprehensive list of Internet resources. It is provided as a general guideline as to the types of Internet resources available.*

## **Autism Organizations**

Autism Society of Ohio: [www.autismohio.org](http://www.autismohio.org)

Autism National Committee: [www.autcom.org](http://www.autcom.org)

Autism Network International [www.auttreat.com/](http://www.auttreat.com/)

Autism Society of America: [www.autism-society.org](http://www.autism-society.org)

Autism Speaks: <https://www.autismspeaks.org>

Bethesda Lutheran Homes and Services, Inc.: <http://bethesdalutherancommunities.org>

Collaborative on Health and the Environment:

[http://healthandenvironment.org/resources/practice\\_prevention](http://healthandenvironment.org/resources/practice_prevention)



Environmental Factors – Cure Autism Now: [www.autismspeaks.org/](http://www.autismspeaks.org/)  
FEAT (Families for Early Autism Treatment): [www.feat.org](http://www.feat.org)  
Friendship Ministries: [www.friendship.org](http://www.friendship.org)  
Jewish Council for Disabilities: [www.njcd.org](http://www.njcd.org)  
Human Genome Project Information: [www.ornl.gov](http://www.ornl.gov), and [www.genome.gov](http://www.genome.gov)  
More Advanced Individuals with Autism, Asperger: <http://www.aspergersyndrome.org/Home.aspx>  
National Apostolate for Inclusion Ministry: <http://www.ncpd.org>  
National Council of Churches Committee on Disabilities: <http://nationalcouncilofchurches.us>  
Neuro Immune Dysfunction Syndromes [www.nids.net](http://www.nids.net)  
OASIS - Online Asperger Syndrome Information and Support: <http://www.aspergersyndrome.org>

## **Autism Research**

Autism Research Institute: [www.autism.com/](http://www.autism.com/)  
Autism Society of America: <http://www.autism-society.org>  
CAN (Cure Autism Now): <https://www.autismspeaks.org/site-wide/cure-autism-now>  
Autism Speaks: <https://www.autismspeaks.org>

## **Bookstores /Videos**

Autism Asperger Publishing Company: <http://www.aapcpublishing.net>  
Autism-Related Books: [www.autism-resources.com/books.html](http://www.autism-resources.com/books.html)  
Autism Web Bookstore: <http://www.autismweb.com/bookstore.htm>  
Future Horizons: <http://fhautism.com>  
Jessica Kingsley Publishers: [www.jkp.com](http://www.jkp.com)  
North Carolina ASA: <http://www.autismbookstore.com/mm5/merchant.mvc>  
Phat Art 4 Autism: [www.autism-resources.com/childrengenres/aspergers.html](http://www.autism-resources.com/childrengenres/aspergers.html)  
Stanfield Publishing, Specialists in Special Education: [www.stanfield.com](http://www.stanfield.com)

## **Federal Agencies**

Centers for Disease Control and Prevention: Autism Information Center:  
<http://www.cdc.gov/ncbddd/autism/facts.html>  
Congressional Information: [www.congress.org](http://www.congress.org)  
National Institute of Health: [www.nih.gov](http://www.nih.gov)  
Office of Special Education Programs (OSEP): <http://www2.ed.gov/about/offices/list/osers/osep/index.html>  
U.S. Department of Education: [www.ed.gov](http://www.ed.gov)  
U.S. House of Representatives: [www.house.gov](http://www.house.gov)  
U.S. Senate: [www.senate.gov](http://www.senate.gov)

## Other Disabilities Organizations

American Association of People with Disabilities: [www.aapd.com](http://www.aapd.com)  
 ARC of Ohio: [www.thearcofohio.org](http://www.thearcofohio.org)  
 ARC of the United States: [www.thearc.org](http://www.thearc.org)  
 Attention Deficit Disorder: [www.chadd.org](http://www.chadd.org)  
 Autism Spectrum Disorders (Pervasive Developmental Disorders) by National Institute of Mental Health and National Institute of Health: [www.nimh.nih.gov](http://www.nimh.nih.gov)  
 Council for Exceptional Children – Ohio: [www.cec-ohio.org](http://www.cec-ohio.org)  
 Easter Seals Northeast Ohio: <http://www.easterseals.com/noh/who-we-are/locations/>  
 Learning Disabilities Association: [www.LDOnLine.org](http://www.LDOnLine.org)  
 Mental Health NAMI Ohio: [www.namiohio.org](http://www.namiohio.org)  
 National Info Center for Children and Youth with Disabilities (NICHCY): [www.nichcy.org](http://www.nichcy.org)  
 National Institute for People with Disabilities: [www.yai.org](http://www.yai.org)  
 National Organization on Disabilities: [www.nod.org](http://www.nod.org)  
 National Parent Network on Disabilities: <http://bryanking.net/national-parent-network-on-disabilities-npnd/>  
 Ohio Coalition for the Education of Disabilities: [www.ocecd.org](http://www.ocecd.org)  
 Ohio Developmental Disabilities Council: [www.ddc.ohio.gov](http://www.ddc.ohio.gov)  
 Ohio Family and Children First: [www.fcf.ohio.gov/](http://www.fcf.ohio.gov/)  
 Ohio Speech and Hearing: [www.ohioslha.org](http://www.ohioslha.org)  
 Riverbend Down Syndrome Parent Support Group: [www.riverbendds.org/index.htm](http://www.riverbendds.org/index.htm)  
 Technical Assistance Alliance for Parent Centers – The Alliance: [www.taalliance.org](http://www.taalliance.org)  
 The Association for Persons with Severe Handicaps (TASH): [www.tash.org](http://www.tash.org)  
 Tourette Syndrome: [www.tsaohio.org](http://www.tsaohio.org)

## Special Education

Ohio Center for Autism and Low Incidence: [www.ocali.org](http://www.ocali.org)  
 The Educational Regional Services System (ERSS): State Support Teams (SSTs)  
 SST 1 - Northwest Ohio: [www.sstr1.org](http://www.sstr1.org)  
 SST 2 - Northern Ohio: [www.sstr2.org](http://www.sstr2.org)  
 SST 3 - Cuyahoga: <http://www.esc-cc.org/StateSupportTeam.aspx>  
 SST 4 - East Shore: [www.sst4.org](http://www.sst4.org)  
 SST 5 - Northeast Ohio: [www.sstr5.org](http://www.sstr5.org)  
 SST 6 - West Central Ohio: [www.sst6.org](http://www.sst6.org)  
 SST 7 - North Central Ohio: [www.sst7.org](http://www.sst7.org)  
 SST 8 - Mid-Eastern Ohio: [www.sst8.org](http://www.sst8.org)  
 SST 9 - Lincoln Way: [www.sst9.org](http://www.sst9.org)  
 SST 10 - Miami Valley: [www.sst10.org](http://www.sst10.org)  
 SST 11 - Central Ohio: [www.sst11.org](http://www.sst11.org)  
 SST 12 - East Central Ohio: [www.sstregion12.org](http://www.sstregion12.org)  
 SST 13 - Southwestern Ohio: [www.sst13.org](http://www.sst13.org)  
 SST 14 - Hopewell: [www.ohioregion14.org](http://www.ohioregion14.org)  
 SST 15 - Pilasco-Ross: [http://www.rpesd.org/statesupportteam15\\_home.aspx](http://www.rpesd.org/statesupportteam15_home.aspx)  
 SST 16 - Southeastern Ohio: [www.sst16.org](http://www.sst16.org)  
 Tin Snips: A special education resource for Autism: <http://www.tinsnips.org/snippet/site/autism.html>

## **Special Education Law**

COPAA (Council of Parent Advocates and Attorneys): [www.copaa.org](http://www.copaa.org)

Disability Rights Advocates: [www.dralegal.org](http://www.dralegal.org)

IDEA Practices and IDEA News: [www.ideapractices.org](http://www.ideapractices.org)

National Center for Learning Disabilities: [www.nclld.org](http://www.nclld.org)

Disability Rights Ohio: <http://www.ideapartnership.org>

Wrightslaw: [www.wrightslaw.com](http://www.wrightslaw.com)

## **State Agencies**

Developmental Disabilities: [dodd.ohio.gov](http://dodd.ohio.gov)

Legislative Service Commission: <http://www.lsc.ohio.gov>

Mental Health: [mha.ohio.gov](http://mha.ohio.gov)

Office of the Governor: [governor.ohio.gov/](http://governor.ohio.gov/)

Ohio Department of Education Office for Exceptional Children: <http://education.ohio.gov/Topics/Special-Education/Office-of-Exceptional-Children-Contact-Information>

The Educational Regional Services System (ERSS): State Support Teams (SSTs)

SST 1 - Northwest Ohio: [www.sstr1.org](http://www.sstr1.org)

SST 2 - Northern Ohio: [www.sstr2.org](http://www.sstr2.org)

SST 3 - Cuyahoga: <http://www.esc-cc.org/StateSupportTeam.aspx>

SST 4 - East Shore: [www.sst4.org](http://www.sst4.org)

SST 5 - Northeast Ohio: [www.sstr5.org](http://www.sstr5.org)

SST 6 - West Central Ohio: [www.sst6.org](http://www.sst6.org)

SST 7 - North Central Ohio: [www.sst7.org](http://www.sst7.org)

SST 8 - Mid-Eastern Ohio: [www.sst8.org](http://www.sst8.org)

SST 9 - Lincoln Way: [www.sst9.org](http://www.sst9.org)

SST 10 - Miami Valley: [www.sst10.org](http://www.sst10.org)

SST 11 - Central Ohio: [www.sst11.org](http://www.sst11.org)

SST 12 - East Central Ohio: [www.sstregion12.org](http://www.sstregion12.org)

SST 13 - Southwestern Ohio: [www.sst13.org](http://www.sst13.org)

SST 14 - Hopewell: [www.ohioregion14.org](http://www.ohioregion14.org)

SST 15 - Pilasco-Ross: [http://www.rpesd.org/statesupportteam15\\_home.aspx](http://www.rpesd.org/statesupportteam15_home.aspx)

SST 16 - Southeastern Ohio: [www.sst16.org](http://www.sst16.org)

Ohio Department of Health: [www.ode.state.oh.us](http://www.ode.state.oh.us)

Ohio Department of Health – Help Me Grow: [www.ohiohelpmegrow.org](http://www.ohiohelpmegrow.org)

Ohio Department of DD: <http://dodd.ohio.gov/Pages/default.aspx>

Ohio Developmental Disabilities Council: [www.state.oh.us/ddc](http://www.state.oh.us/ddc)

Ohio General Assembly: [www.legislature.state.oh.us](http://www.legislature.state.oh.us)

Disability Rights Ohio: <http://www.disabilityrightsOhio.org/>

State of Ohio: [www.ohio.gov](http://www.ohio.gov)

Opportunities for Ohioans with Disabilities: <http://ood.ohio.gov>

## **Transition**

[www.socialsecurity.gov/work/](http://www.socialsecurity.gov/work/)

[www.socialsecurity.gov/disabilityresearch/wi/generalinfo.htm](http://www.socialsecurity.gov/disabilityresearch/wi/generalinfo.htm)

<http://www.ocali.org/center/transitions>

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

APPENDIX A

# DSM-5 Diagnostic Criteria

## DSM-5 Diagnostic Criteria

OCALI is pleased to provide this information from Autism Speaks which offers the full-text of the diagnostic criteria for autism spectrum disorder (ASD) and the related diagnosis of social communication disorder (SCD), as they appear in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. As of May 2013, psychologists and psychiatrists will be using these criteria when evaluating individuals for these developmental disorders. For further context, please see our full DSM-5 coverage [here](#).

### **Social (Pragmatic) Communication Disorder** **315.39 (F80.89)**

Diagnostic Criteria:

- A. Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:
  1. Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.
  2. Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on the playground, talking differently to a child than to an adult, and avoiding use of overly formal language.
  3. Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.
  4. Difficulties understanding what is not explicitly stated (e.g., making inferences) and nonliteral or ambiguous meanings of language (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).
- B. The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.
- C. The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).
- D. The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains of word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.

# **Autism Spectrum Disorder 299.00 (F84.0)**

Diagnostic Criteria:

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify current severity:*

**Severity is based on social communication impairments and restricted repetitive patterns of behavior** (see Table 2).

- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
  3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
  4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify current severity:*

**Severity is based on social communication impairments and restricted, repetitive patterns of behavior** (see Table 2).

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

**Note:** Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

*Specify if:*

**With or without accompanying intellectual impairment**

**With or without accompanying language impairment**

**Associated with a known medical or genetic condition or environmental factor**

**(Coding note:** Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

**(Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

**With catatonia** (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition)

**(Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)



Table 2 Severity levels for autism spectrum disorder

<b>Severity level</b>	<b>Social communication</b>	<b>Restricted, repetitive behaviors</b>
<p><b>Level 3</b> "Requiring very substantial support"</p>	<p>Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches</p>	<p>Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.</p>
<p><b>Level 2</b> "Requiring substantial support"</p>	<p>Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.</p>	<p>Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.</p>
<p><b>Level 1</b> "Requiring support"</p>	<p>Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.</p>	<p>Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.</p>



## APPENDIX B

# Useful Forms

---

The following forms may be helpful and can be printed out for your personal use:

### ***Developmental Milestones Form***

This is a form to record your child's development. It can help you keep track of developmental delays; therefore, it can serve as a reference when visiting the doctor or going through the evaluation process.

### ***Family Health History***

This form allows you to track your family's health history and can serve as a reference when completing paperwork in the future.

### ***Emergency Contact Information Form***

This form is intended to provide basic medical information in case of emergency.

### ***Parent Record-Keeping Worksheet***

This form may be filled out and provided to the local police or fire and rescue departments, either in preparation for possible emergencies or to be ready at their arrival at an emergency.

### ***Child/Student Profile***

The following is one possible way of organizing this information and has been created for your use. The first page is a sample, completed form, the following page is blank for your use.

This form can be used to give some basic information about your child to a service provider, relative, babysitter, respite worker, or educational professional. It may be used as your child transitions from one provider or teacher to another. While its format can vary according to your needs and preferences, it is helpful to include:

- child's name
- child's disability
- family dynamics
- how the child learns best
- special interests
- strengths
- challenges
- things that upset
- signs the child is upset
- calming or soothing techniques
- motivators and preferences
- modifications, including curriculum, environmental, organization, and social support.

*Adapted from Judy Marks, personal communication. Used with permission.*

## **Home School Communication Form**

The following is one example of a form, that can serve as a way to pass information from home to school and back to home. Also included is an issue of Disability Solutions, which offers several other excellent examples of such forms, as well as information on how to create your own.

You may want to keep all of your child's records and official documents in one place. You may want to include:

- Birth Certificate
- Social Security
- Medical/Insurance Card
- Immunization Record
- Copies of Evaluations and Assessments
- Multi-Factored Evaluation (MFE)
- Copies of IFSPs/IEPs (current and previous)
- Other School Records

## Developmental Milestones

Date of Birth: \_\_\_\_\_ Date Completed: \_\_\_\_\_

Weight at Birth: \_\_\_\_\_ Length: \_\_\_\_\_

Complications/Notes: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Age when child was able to: (Represents typical age range)

1. \_\_\_\_\_ Hold head up (6 weeks)
2. \_\_\_\_\_ Smiles (2 months)
3. \_\_\_\_\_ Babbles (3-4 months)
4. \_\_\_\_\_ Roll over (4 months)
5. \_\_\_\_\_ Reaches for object (4-7 months)
6. \_\_\_\_\_ Sits without support (6-7 months)
7. \_\_\_\_\_ Crawls (6-7 months)
8. \_\_\_\_\_ Drink from cup (6-9 months)
9. \_\_\_\_\_ Stands alone (11-12 months)
10. \_\_\_\_\_ First word mama, dada (12 months)
11. \_\_\_\_\_ Walks alone (12-18 months)
12. \_\_\_\_\_ Uses two-word phrases (18 months-2 years)
13. \_\_\_\_\_ First tooth (6 months-1 year)
14. \_\_\_\_\_ Toilet trained (2-3-½ years)



## Family Health History

Condition	Yes	No	Family member/relative	Age began
<b>Autism Spectrum Disorders</b>				
<b>Attention Deficit Hyperactivity Disorder (ADHD)</b>				
<b>Obsessive Compulsive Disorder (OCD)</b>				
<b>Anxiety Disorder</b>				
<b>Bipolar Disorder</b>				
<b>Schizophrenia</b>				
<b>Depression</b>				
<b>Other Psychiatric Disorders:</b>				
<b>Other:</b>				
<b>Other:</b>				
<b>Other:</b>				





# Emergency Medical Form

Name				Date of Birth / /	
Blood Type	Age	Eye Color	Height	Weight	Gender
Allergies					
Address			City	State	Zip
Home Phone ( )			Cell Phone ( )		
<b>Current Medications</b>					
Medication	Dosage	Schedule	Reason	Prescribing Physician or Over The Counter (OTC)	
<b>Emergency Contact Information</b>					
Emergency Contact Person			Relation		
Home Address			City	State	Zip
Daytime Phone ( )			Cell Phone ( )		
Evening Phone After 5 p.m. ( )			Alternative Phone ( )		
Work Address			City	State	Zip
<b>Primary Physician Information</b>					
<b>Name of Primary Physician</b>					
Address			City	State	Zip
Phone ( )			Emergency Phone ( )		
<b>Other Physicians/Specialists</b>					
<b>1. Physician/Specialist</b>				Reason	
Address			City	State	Zip
Phone ( )			Emergency Phone ( )		
<b>2. Physician/Specialist</b>				Reason	
Address			City	State	Zip
Phone ( )			Emergency Phone ( )		
<b>Other Information</b>					
Disabilities or Other Conditions					
Primary Language					
Primary Method of Communication					
Adaptive Equipment					
Special Notes or Considerations					
<b>Insurance Information</b>					
Insurance Company			Policy Number		
Primary Subscriber Name			Group Number		



## Emergency Response Information for Individuals with a Disability

Name of Person with Disability \_\_\_\_\_

Home Address \_\_\_\_\_

Date of Birth \_\_\_\_\_ Home Phone \_\_\_\_\_

Cell Phone \_\_\_\_\_ Work Phone \_\_\_\_\_

Emergency Contact Name \_\_\_\_\_

Relationship to Person with Disability \_\_\_\_\_

Home Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_

Work Phone \_\_\_\_\_

Name and telephone of person's specialist (doctor or teacher) if emergency contact cannot be reached \_\_\_\_\_

Is the individual able to communicate with speech? \_\_\_\_\_

Does the individual understand receptive language (what is being said to him/her)? Yes / No

If not, describe his/her method of communication \_\_\_\_\_

\_\_\_\_\_

Would the individual be able to communicate his name, address, and telephone number in a high stress situation? \_\_\_\_\_

\_\_\_\_\_

Does the individual engage in any unusual behaviors that might seem disrespectful or threatening (e.g., yelling, giggling, standing too close to people)? If so, please describe \_\_\_\_\_

\_\_\_\_\_

In a high-anxiety situation, how would the individual most likely communicate? \_\_\_\_\_

\_\_\_\_\_

Is the individual prone to respond in an unusual manner to sensory input (sounds, lights, smells, etc)? Yes / No



Circle what may result: seizure   panic   flight   fight   withdrawal  
other (please describe)

\_\_\_\_\_

What might trigger what is circled above (e.g., dog bark, siren, touch)?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Does the individual have any specific fascinations (e.g., tree climbing, water)?  
If so, please describe \_\_\_\_\_

\_\_\_\_\_

Is the individual threatened by any physical traits (e.g., whiskers, hats, uniforms)?  
If so, please describe \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Does the individual have an accurate sense of danger? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Does the individual have any other medical conditions or is he/she taking medication? If so,  
please describe \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Please describe anything else that would be helpful to emergency personnel (police, fire, EMT)  
who may have to respond to your household and interact with the individual \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*Adapted from Jackson County Sheriff Department, Jackson, MI.*



## Parent Record-Keeping Worksheet for Important Phone Calls and Meetings

Date: \_\_\_\_\_ Subject: \_\_\_\_\_

Phone Call: Received/Placed \_\_\_\_\_ Phone # Dialed: \_\_\_\_\_

Left Message: Yes / No Other Message Dates: \_\_\_\_\_

Name of Contact Person: \_\_\_\_\_

Company/Agency Name: \_\_\_\_\_

Meeting Location: \_\_\_\_\_

Other Attendees: \_\_\_\_\_

Referred to: \_\_\_\_\_ Reason for Referral: \_\_\_\_\_

Telephone #: \_\_\_\_\_ Email: \_\_\_\_\_

Notes/Key Points of Conversation: \_\_\_\_\_

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

Results of Conversation/Next Steps: \_\_\_\_\_

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

Other Thoughts/Notes: \_\_\_\_\_

*Adapted from the Autism Society of Northwest Ohio. Used with permission.*





Name: JohnnieDate of Birth: Feb 20, 2002

<b>This Is Me:</b> I have autism. This means I have trouble understanding you, and letting you know what I want and how I feel. Sometimes it seems like I don't want to play with you or other kids, but I really do, I just don't always know how! I am very active and love to move all the time. I find it hard to try new things or when my routine changes.		
<b>My Family:</b> I live with my mommy. She has to work all day so I go to school. I have lots of friends that love me and help take care of me at our church. They are kind of like my family since my grandma and papa live far away. I also go to a social group 2 days every week; there my friends and I learn to play better.		
<b>My Strengths:</b> <ul style="list-style-type: none"> <li>remembering the rules</li> <li>colors, numbers and letters</li> <li>saying Hi to everyone I meet</li> </ul>	<b>My Challenges:</b> <ul style="list-style-type: none"> <li>understanding what adults ask me or tell me to do</li> <li>telling you how I feel and what I want</li> <li>trying something new (food or activity)</li> <li>looking at you when I talk to you</li> <li>playing with other kids</li> </ul>	
<b>I Learn Best When ...</b> <ul style="list-style-type: none"> <li>I know what you want from me</li> <li>I know what's coming next</li> <li>Visuals are used</li> </ul>	<b>My Special Interests:</b> <ul style="list-style-type: none"> <li>Blues Clues</li> </ul>	
<b>My Motivators and Preferences:</b> Singing, playing in water, Hide and Go Seek (anything that lets me move and run around), bubbles, tight hugs, French fries and ketchup, anything else I can dip in ketchup.		
<b>Things That Upset Me:</b> <ul style="list-style-type: none"> <li>changes in routine</li> <li>stopping Blues Clues</li> <li>sitting still</li> <li>waiting</li> </ul>	<b>Signs I'm Upset:</b> <ul style="list-style-type: none"> <li>picking at my fingers</li> <li>laying my head down</li> <li>closing my eyes</li> </ul>	<b>How I Calm Down:</b> <ul style="list-style-type: none"> <li>a picture of when I get a break or can go back to Blues Clues</li> <li>go for a walk</li> <li>get a tight hug</li> </ul>
<b>Modifications for Me:</b> Visual schedule, visual prompts, timers, lots of praise and reinforcement, breaks to run around during long sitting or waiting activities.		



Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

<b>This Is Me:</b>		
<b>My Family:</b>		
<b>My Strengths:</b>	<b>My Challenges:</b>	
<b>I Learn Best:</b>	<b>My Special Interests:</b>	
<b>My Motivators and Preferences:</b>		
<b>Things That Upset Me:</b>	<b>Signs I'm Upset:</b>	<b>How I Calm Down:</b>
<b>Modifications for Me:</b>		



# Home-School Communication

Name: \_\_\_\_\_

Date: \_\_\_\_\_ **Monday Tuesday Wednesday Thursday Friday**

## At home I ...

Slept all night       Did not sleep well       Had a good morning  
 Ate all of my breakfast       Ate some of my breakfast  
 Did not eat breakfast       Was not feeling well

Other Comments: \_\_\_\_\_

\_\_\_\_\_

## Today at school I did ...

Discrete Trial DTT       Story Time       Table Tasks  
 Independent Work       Art Activity       Reading  
 Sensory Play       Playground       Other

Comments: \_\_\_\_\_

\_\_\_\_\_

I mastered \_\_\_\_\_ today at school.

## Today at school I ate ...

Snack       Most of my lunch      I had some \_\_\_\_\_  
 All my lunch       Very little lunch       I used my book

Comments: \_\_\_\_\_

Bathroom routine:  I had no accidents today      I had  accidents today.

Needed supplies: \_\_\_\_\_

*Adapted from: Home-School Communication Form from the Autism M.O.D.E.L. Community School, Great Lakes Center for Autism, 1615 Holland Rd, IRN-134122, Maumee, OH 43537, (419) 897-4400. Used with permission.*



# Disability Solutions

A Journal for Families and Professionals in Early Childhood and School Settings

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Introducing...

## The Idea Exchange

### Home- to- School Communication

Communication between home and school can make or break your day. How many times have you assumed the school understood something that is a basic need for your child with Down syndrome only to learn later they did not? How did you find out there was a miscommunication? Chances are it went something like one of these two scenarios:

Jon comes home from school, tosses his pack in the closet, and runs to play Nintendo. When you come in the room, you ask him if he has any homework. He smiles happily and says, "Nope!" continuing his game. It seems as though he's had little homework for quite some time. At the end of the week, Jon's classroom teacher calls to discuss his project that is not completed. His teacher is surprised that you do not know about the project that Jon has been told to work on for the last month. She explains the modifications made in vocabulary, construction, and length of the assignment. Jon said he understood what was expected when she asked him about it. When you ask Jon about it, he seems confused and sad because he is now in trouble at home and at school.

You arrive to pick up Rachel from her full-day Kindergarten class to go to her weekly play group. When you arrive, everything and everyone seem fine. But when you get in the car, five-year-old Rachel dissolves into a puddle of hysterical tears, cannot explain what she's feeling, and is inconsolable. All you can think is, "What happened today?" Instead of going to play group, you head for home. It is hours before Rachel seems calm again. By then, you are exhausted from the emotional turmoil and still unclear about what happened. Will you ever find out?

*Continued on page 3*

Home-to-School Communication	1	"How Was Your Day?"	9
Letter from the Editor	2	Designing Home-to-School Communication for Your Child	
Ideas for Home-to-School Communication	5	Resources	15
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in this issue

## The Idea Exchange

...What Is It?

One of my favorite things to do is get together with a group of people who are full of ideas. There is a charge to the room as people share what they're doing and others toss out suggestions to refine it or problem solve. Even if the ideas are not something I will use for my son, it might be helpful to someone else I know. The process is exhilarating. I often leave with more ideas than I can get onto paper before I forget them.

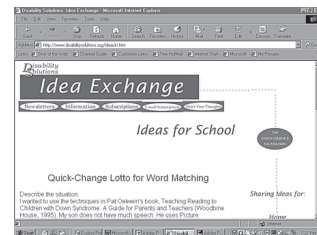
We wanted to capture that feeling—the energy of brainstorming by people who are invested in the outcome—to share with readers through *Disability Solutions*. Therefore, we created *The Idea Exchange*: a place for parents and professionals to share ideas that work.

This first installment of *The Idea Exchange* gathers ideas for home-to-school communication systems parents have designed with their IEP teams across the country. Each one designed due to lessons learned—some through tough situations. Those lessons are reflected in the lead story, “Home-to-School Communication.”

In her article, “How Was Your Day?’ Designing Home-to-School Communication for Your Child,” Kim Voss shares methods to design home-to-school communication systems for your child to complete on her own. Kim is one of those people whose ideas and energy are infectious, seemingly endless, and effective. As she wrote the article, she kept thinking of “just one more way” something could be done, but we had to confine her to these few. While you read Kim’s article, be open to other ways to use these techniques to enhance your child’s participation throughout the school day.

These ideas and others will be posted on our website in *The Idea Exchange* section. In addition, the journal will periodically feature ideas sent from our readers. If you have access to the Internet, stop by *The Idea Exchange* and take a peek. If you or someone you know has a great idea, send it in. This is an easy way to share with others across the country and around the world. Remember, if it was something you had to work through with your child, there are at least ten other families facing a similar situation. It’s much easier to adapt an idea to fit your situation than it is to start from scratch.

Joan E. Guthrie Medlen, R.D.



[www.disabilitysolutions.org/idea.htm](http://www.disabilitysolutions.org/idea.htm)



## Home- to- School Communication

*Continued from page 1*

All parents understand the importance of knowing what is happening at school. Whether or not your child has a disability, parents need to know what is expected for school the next day. For younger students, this is often done through a weekly newsletter sent home from the classroom teacher. As students get older, they are asked to assume some of that responsibility by keeping assignment sheets that track projects and the date they are due for different subjects that are initialed by parents. By the time students are in high school, parents are left out of the loop requiring students to be responsible for their own work.

It is no different for parents of children with Down syndrome. However, you may need more frequent and detailed information than parents of students without disabilities. This includes notes from consultants or therapists, directions for adapting homework assignments, or information about school activities given verbally to the classroom. Teachers also benefit when parents have a way to share special occasions, medical information that may affect behavior at school, or ask questions about homework or other school activities.

Just as every child needs different levels of support to be successful, every classroom teacher, parent, and student need to know different information to be supportive. Some teachers enjoy writing a daily narrative to parents. Others find it cumbersome and time-consuming. Some parents want to know what each therapist is doing with their child while others want information about their child's behavior during the day. How do you find the right balance?

Home-to-School communication systems are only effective if they meet the needs of everyone on the team. They are used more

often when they are quick, understandable, and easy to use. To accomplish this, it is a good idea to discuss what to include and the frequency of use at a team meeting. Some questions to ask include:

- ◆ Should we use a checklist or narrative system?
- ◆ Should the student participate in the activity?
- ◆ Who do we want to contribute information (Teacher, Speech Therapist, Occupational Therapist, and so on)? Remember the bulk of daily communication should come from the classroom teacher rather than the Educational Assistant (see "Paraprofessionals in the Classroom: What Role Do They Play?" by Patti McVay. *Disability Solutions*, 3:1).
- ◆ How often should each person write in the notebook?
- ◆ What do we want to know (Information on behavior, activities with friends, food, homework assignments, and so on)?

Once your team has discussed these topics, you can design how you want your home-to-school system to look. Each one will look a little different. The examples in this issue of *Disability Solutions* are provided for you to adapt and create systems that will work best for your team and your child.

There are times when the relationship between families and school personnel is strained. During these times, everyone is reluctant to share narratives regarding the days' events, successes, or challenges. Whenever possible, stress the importance of laying aside the problems between the adults involved in your child's education and supporting your child. Unless a home-to-school communication system is clearly listed in

*Continued on page 4*

## Home- to- School Communication

*Continued from page 3*

your child's IEP (under accommodations or modifications), there is no way to insist on anyone's participation. Try to find a balance that everyone can agree to that reduces the number of questions you have about your child's mood, homework, or information needed for her success in the classroom.

In addition to facilitating communication between home and school, these systems can be an effective teaching tool. Sharing what happened at school each day, providing the day, date, and month and keeping track of homework assignments are all skills that children with or without disabilities must master. Involving students in the process of sending information between home and school encourages responsibility and can be designed for each child's ability (Samples 4, 5, and 7). The samples that follow this article illustrate different types of communication systems. Each one is designed for a specific student and therefore has a slightly different focus. Some are designed for student participation while others are for parents and team members only.

Whether it is a spiral bound notebook or an individually designed form, communication systems between home and school are necessary and common. Even so, there is little information or examples available in professional literature for parents and team members to consider. With so many families and professionals using them, there are abundant examples available from those who use them. A few months ago, we asked parents and professionals to share the home-to-school communication systems they are using. Home-to-school communication systems were also sent to us for "The Idea Exchange," a new feature in forthcoming issues of *Disability Solutions*. The following samples

and suggestions in this article are what we learned from our readers.

Most of the systems we received are best used if they are copied and then bound together as a book. If you don't have a home-to-school system that is working well, consider taking these examples to your next team meeting and discussing how you can create a tool that is helpful to everyone. We hope you will find these ideas and examples helpful as you create a communication system that meets your child's needs.

---

*Thank you to our readers who sent samples and stories to create this article: Janice Daley, Grafton, WI; Patti MacPhee, N. Attleboro, MA; Kay Cook, Batavia, NY; Cheryl Ward, Virginia Beach, VA; Lauren Weinstock, Raleigh, NC; Peggy Doyle, LaConner, WA; Mindy James, St Louis, MO; and Patti McVay and Heidi Wilson from the Outreach Center for Inclusive Education, Portland, OR.*

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- ◆ Samples 1, 2, 3, 5, 6, and 8 copyright © 1999 Patti McVay. Permission to use for education purposes. Outreach Center for Inclusive Education, MESD, 11611 N.E. Ainsworth Circle, Portland, OR 97220

# Ideas for Home-to-School Communication Systems

The following are examples of home-to-school communication systems used by IEP teams, including parents, for specific students. Each one has a slightly different focus and method of communication reflecting what the student's family and educational team felt was most important to share on a regular basis. They will be posted along with other topics in *The Idea Exchange* on the *Disability Solutions* website.






**Sample 1:**

A checklist to track three specific areas in activities throughout the day that may or may not be on the IEP. The activities are filled in for greater flexibility.

1

Date: \_\_\_\_\_

**Today I:**

 I'll answer you when you say it nicely.	 Hands and feet to yourself.	 Talk respectfully.
<b>Activity</b> 	<b>Activity</b> 	

Messages from Mrs. Copeland: \_\_\_\_\_

Messages from home: \_\_\_\_\_


**Sample 2:**

This communication sheet combines fill-in-the-blank opportunities with a checklist. The topics covered are both IEP related (problem-solving skills) and general information about the day.


**Sample 3:**


A combination of fill-in-the-blank and simple yes/no questions to track IEP objectives in a variety of areas: educational activities, social activities, and specific therapy activities


2


Chuck's Day:  Date: \_\_\_\_\_

Today in class Chuck enjoyed: \_\_\_\_\_





During class we worked on:  \_\_\_\_\_


Today Chuck's buddy was:  \_\_\_\_\_

At recess Chuck had fun:  \_\_\_\_\_


For lunch Chuck had:  \_\_\_\_\_


Today Chuck used his problem solving skills by:

 taking time to think <input type="checkbox"/>	 talking with a peer <input type="checkbox"/>
 compromising <input type="checkbox"/>	 asking for adult help <input type="checkbox"/>


Today Chuck was feeling:  \_\_\_\_\_

News from Mrs. Aschenbrenner: \_\_\_\_\_


Comments from the team:  \_\_\_\_\_


News from home:  \_\_\_\_\_

3






Julie's Day:  Date: \_\_\_\_\_

Today Julie said hello to: \_\_\_\_\_


Today Julie's buddy was:  \_\_\_\_\_

The center activity I chose today was:  \_\_\_\_\_

In class, we worked on these puzzles, letters, numbers, shapes and signs:

 Julie used markers.....	yes	no
 Julie matched letters in her name.....	yes	no
 Julie worked on buttons.....	yes	no
 Julie used the computer.....	yes	no
 Julie worked on readiness skills.....	yes	no

Today for motor time I: \_\_\_\_\_

News from home:  \_\_\_\_\_

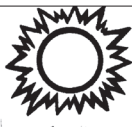
ideas ideas ideas Continued on page 6


Continued from page 5


ideas ideas ideas


Ask me about my day.....

Date: **17**

The weather  Sunny

During 2nd hour I:  Walked around the ramp

Today I also:  unloaded dryer

In the community:  Owens STORE

4a

4b

Samples 4a & 4b: This communication system combines adult input and student participation. The student sheet focuses on tracking activities and learning calendar skills. The sheet for staff members serves as a medication and therapy log.

JENNIE DALEY'S SCHOOL DAY

DATE: \_\_\_\_\_

1st hr. (7:29 - 8:24) \_\_\_\_\_

2nd hr. (8:28-9:20) \_\_\_\_\_

3rd hr. (9:24-10:16) **GAVE JENNIE 3 TSP. PROPULSID & 1/2 TSP. PEPCID @ 9:30**

4th hr. (10:20-11:12) \_\_\_\_\_

LUNCH (11:15-12:08) ATE ALL ATE 1/2 ATE HARDLY ANY

5th hr. (12:30-1:30) \_\_\_\_\_

6th hr. (1:38-2:27) \_\_\_\_\_

SPEECH (Group: Wednesday 12:30-1:30, Individual: Friday 8:30-9:00)

PHYSICAL THERAPY (Wednesday 12:45-1:00, Friday 1:45-2:00)

ADAPTIVE PHY. ED (Group: MWF 8:30-9:30, Individual: Tuesday 8:00-8:30)

SWIMMING (Group: Friday 12:00-12:30, Individual: Monday 12:30-1:30)

B.M. TODAY?            GAGGING?            THROW UP?           

Sample 5:

The focus of this communication sheet is Erika working with other students. Together, Erika and her peer mentor fill out the paragraph describing their activities. Her peer mentor signs the section of the sheet they participated in. The reverse side of this sheet is for notes from home.

**Erika's Day**

Today, I worked with: \_\_\_\_\_

We: \_\_\_\_\_

Peer Signature: \_\_\_\_\_

Today, I had lunch with: \_\_\_\_\_

Peer Signature: \_\_\_\_\_

In Leadership, we: \_\_\_\_\_

Peer Signature: \_\_\_\_\_


Other cool stuff we did today: \_\_\_\_\_

5


6

Sample 6:


This communication sheet combines fill-in-the-blank with a yes/no form to track activities and goals that highlight increasing independence. The phrasing used in the sentences encourages positive feedback focused on increasing independence.


Anna's Day: 

Date: \_\_\_\_\_


Today in class, Anna enjoyed:  \_\_\_\_\_

In class we worked on these concepts, Braille skills, and concepts: \_\_\_\_\_


Today, Anna's buddy was:  \_\_\_\_\_

On recess, Anna had fun:  \_\_\_\_\_

Bathroom Successes: \_\_\_\_\_

For lunch Anna had:  \_\_\_\_\_

She used her fingers: spoon: fork: \_\_\_\_\_


She was successful: with/without assistance. 


Other activities:


Speech.....yes no

O.T.....yes no

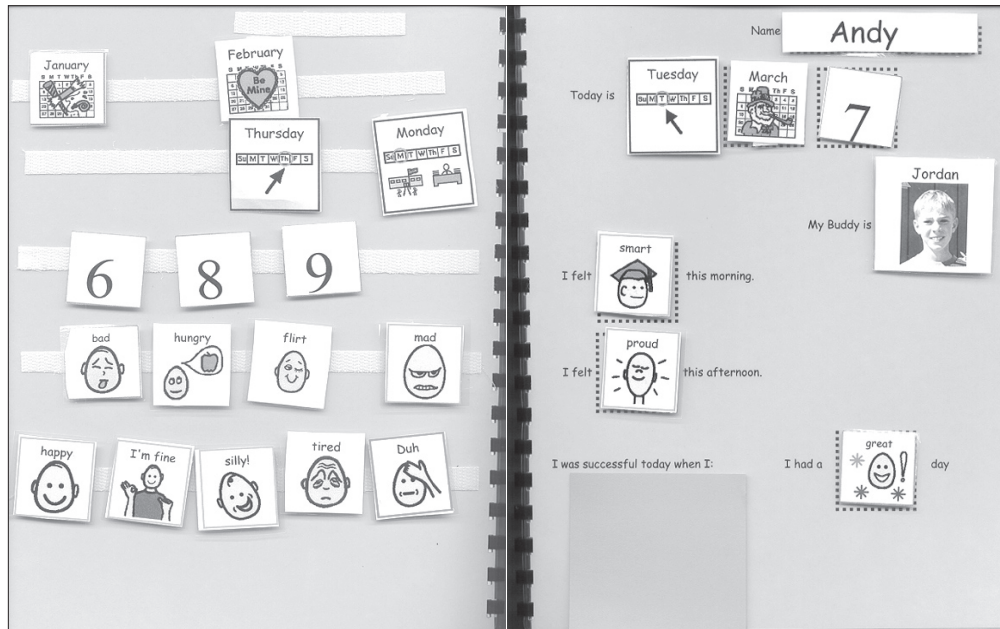
O. & M.....yes no

Comments from team:  \_\_\_\_\_

News from Mrs. Fryback:  \_\_\_\_\_

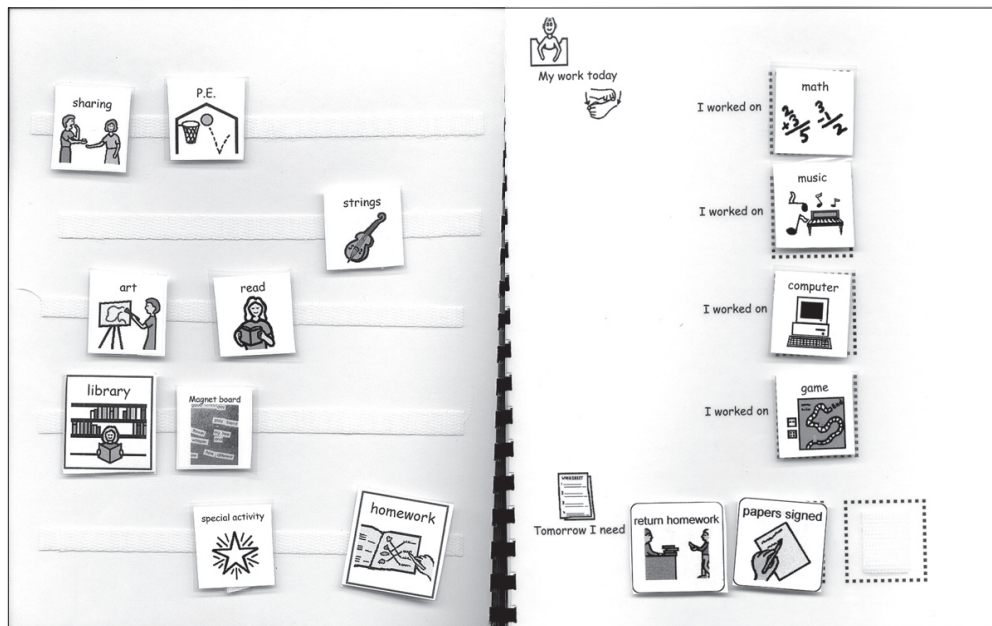
News from home:  \_\_\_\_\_

ideas ideas ideas



Samples 7a & 7b:

The purpose of this communication notebook is to involve the student in reporting about the day by completing sentences. Choices are provided on the left page to complete the sentence on the right. In addition to these sheets, there are pages for narratives from team members and messages from home.



ideas ideas ideas


ideas ideas ideas


Continued from page 7


A-Day



News from School  
on: \_\_\_\_\_

Notes by: \_\_\_\_\_

● Period 1-Computer 

Period 3-Rec. Sports 

● Period 5-Global Studies 

Period 7-English  

8a

8b

News from my house  
on \_\_\_\_\_

● Yesterday, last night, on the weekend:

Written by: \_\_\_\_\_

Samples 8a & 8 b:


This system could be used by only parents and teachers or by the student. Designed for middle and high school students, there is room for listing homework assignments or providing other information if needed. A page for information from home is also available for either parents or the student to complete.

Sample 9:

This communication sheet is a checklist that tracks behaviors and goals. Some specific information about the day is added that is used for conversations at home (song choice).


9

**Erika's Day**


 Today, I worked with: \_\_\_\_\_

We: \_\_\_\_\_


Peer Signature: \_\_\_\_\_

 Today, I had lunch with: \_\_\_\_\_

Peer Signature: \_\_\_\_\_

 In Leadership, we: \_\_\_\_\_

Peer Signature: \_\_\_\_\_

 Other cool stuff we did today: \_\_\_\_\_

ideas ideas ideas

# “How Was Your Day?”

## Designing Home-to-School Communication for Your Child

---

by Kimberly S. Voss

It seems like a late afternoon ritual, somewhere between the after school snack and the newest episode of *Arthur*. It always starts off with the same question posed to the kids: “How was your day?” The kids have the routine down and know that they have my attention as they begin to rattle off various memorable moments: which classmate had to move their clip for misbehaving, what guest speaker was at school, or who sat with them at lunch. Now that we have hit the teenage years, this afternoon ritual feels a bit more like an interrogation. After asking three times, “How was your day?” I might hear a pleasant, “Fine!” Even that gives me some sense of satisfaction that I have heard something about her day as we move on to competing with the incoming phone calls from friends while my child escapes to a back room to talk.

But the afternoon ritual is much different for the parent of a child with disabilities. At the earliest opportunity, you grab her backpack and begin to dig, and dig, and dig. Is there anything that could give you a clue about her day? Some scrap of paper, a note from the classroom teacher, a completed project, or a piece of artwork? Anything? The questions begin to arise in your mind: did she have someone other than the paraprofessional to sit with at lunch? Did she feel a part of the classroom that day? Did she learn anything new?

As a parent of child with expressive aphasia and apraxia, learning about Ashley’s day is often puzzling because verbal communication is limited and very difficult for her. Communication from school is essential. It is not always forthcoming, but it is essential. For years, if school did not tell me, I typically did not know. Now that Ashley is older, her friends in the regular education environment are a wonderful source of information. They remind me of upcoming projects or field trips, let me know what she loves or hates in her lunch bag, and share stories about Ashley’s school experiences.

As much as I appreciate hearing about Ashley’s school experience from everyone else, I crave to hear it from Ashley. Rather than someone else interpreting segments of her day, it would be wonderful to devise a method for Ashley to share information herself.

Using a computer, I can create a number of different solutions for doing just that. They range from simple methods to more complex ones. Technology allows me to design methods for Ashley, to share information about her day while sidestepping tasks that are difficult for her, such as the need to talk, write, or keyboard. Maybe one of these methods will give you a new idea for a way to provide your child the opportunity to succeed at sharing something they have not been able to share before.

*Continued on page 10*

# “How Was Your Day?” Designing Home- to- School Communication for Your Child

Continued from page 9

## Simple Communication Sheet

### Equipment and Supplies:

- ❖ Icons (such as Boardmaker from Mayer-Johnson),
- ❖ Word processing program with a paint/draw feature,
- ❖ Dashed text fonts (*School Fonts for Beginning Writing* from Mayer-Johnson),
- ❖ A bingo dabber or marker,
- ❖ Computer, and
- ❖ Printer.

### Design Instructions:

- ❖ Design a communication sheet using icons to convey simple messages. (Figure 1)
- ❖ Choose icons to select that communicate meaningful messages about school activities.
- ❖ Use dashed text at the top of the page for your child’s name. This gives her an opportunity to trace her name in a functional activity.

### Instructions for Teaching:

- ❖ When you begin to use this communication sheet, limit the number of choices for answers to reduce confusion. For instance, cover the symbols for “Tuesday,” “Wednesday,” and “Thursday” to offer only two choices for the day of the week: “Monday” or “Friday.” As her confidence grows, increase the number of choices shown on the page.
- ❖ Read the sentence to complete aloud with your child and the choices available. For instance, “Today is, Monday (point to Monday), Tuesday (point to Tuesday),” and so forth.
- ❖ Your child can choose her answer by marking it with an “X,” circling the symbol, touching with the bingo dabber, or pointing.

### Variations

- ❖ If using a pencil or felt pen is a problem, use the sheet like a bingo board. Have your child make her icon selection by placing a marker (a chip, coin, or game piece) on top of her choice. This takes little effort and requires no handwriting expertise.

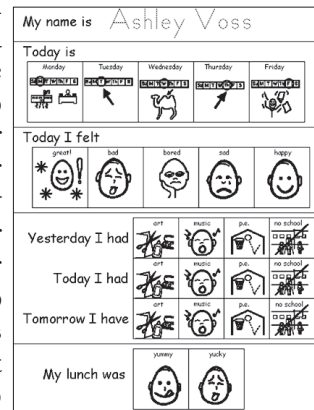


Figure 1

- ❖ If she is unable to trace letters, use a name stamp or sticker to place her first and last name in the proper order at the top of the page.
- ❖ Always use symbols that make sense to your child. If using a sign language symbol is more familiar than a picture symbol, use them.
- ❖ As your child begins to recognize words (sight reading), reduce the size of the icon while increasing the size of the text (number of points). This helps her focus on the word rather than the icon.

### Fill-in-the-Blank Using Magnets

#### Description:

Filling-in-the-blank is a great method for responding to simple questions. Answering questions about a school day is a motivating topic to begin to learn this skill. Using magnets is a fun and easy way to fill-in-the-blank and is a great alternative to conventional pencil and paper tasks.

Learning to fill-in-the-blank is easy to teach and reinforce using a communica-



## “How Was Your Day?”

### Designing Home- to- School Communication for Your Child

tion sheet designed with this in mind. This method is a wonderful alternative to many tabletop designs since the materials are front and center on a magnetic board. This is especially important for kids with visual impairments or limited attention who are more successful with materials presented in an upright fashion.

#### Equipment and Supplies:

- ❖ Icons,
- ❖ Word processing program with a paint/draw feature,
- ❖ Photocopying machine,
- ❖ Magnetic board with stand or the front of the refrigerator at home,
- ❖ Magnetic sheet with adhesive,
- ❖ Computer, and
- ❖ Printer.

#### Design Instructions:

- ❖ Design the communication sheet to share information about your child’s day. Draw a box in the area of the sentence your child will fill in. Make the box slightly larger than the card that will be placed in it. Print the sheet. Laminate it for durability. (See Figure 2)
- ❖ Make magnetic choice cards to fill-in-the-blank boxes. Lay out a page of the various

My name is	<input type="text"/>	<input type="text"/>
Date	<input type="text"/>	<input type="text"/>
Today is	<input type="text"/>	
This morning I had	<input type="text"/>	
This afternoon I had	<input type="text"/>	
My lunch was	<input type="text"/>	
I sat with	<input type="text"/>	<input type="text"/>
My day was	<input type="text"/>	

Figure 2

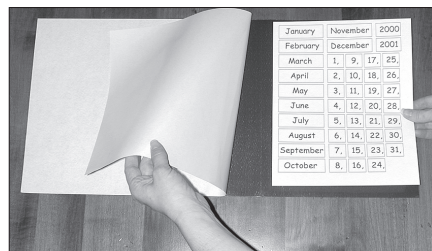


Figure 3

responses using a software application with a draw feature (one which allows you to make boxes which can be filled with text). Ideas for choices include: months of the year, dates (1-31), the year, and so on.

- ❖ Print the page of choice cards and attach it to the adhesive side of the magnet sheet. Cut out the individual magnetized cards. (Figure 3)
- ❖ Place the fill-in-the-blank communication sheet on an upright magnetic board. Use a clip, tape, or magnets on the corners to hold it in place.
- ❖ In the beginning, provide only the appropriate choice (such as the correct month, day, and year) for each blank box to teach the sentence and process of filling in the sheet. Gradually increase the number of choices, allowing your child to make her own selections from the set provided. (Figure 4)

#### Instructions for Teaching:

- ❖ Your child chooses the words to complete the sentence from the choices on one side of the board. She then places them in the boxes on the communication sheet.
- ❖ When she is done, have her photocopy the completed communication sheet while on

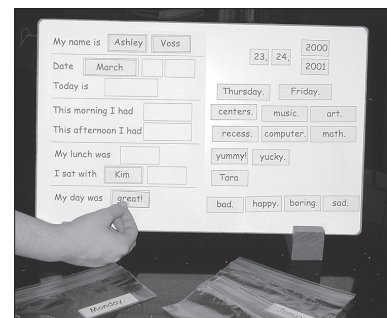


Figure 4

Continued on page 12

# “How Was Your Day?” Designing Home- to- School Communication for Your Child

Continued from page 11

the magnet board. She now has a completed copy to take home.

### Variations

- ❖ If your child is learning the concepts of calendar, color-code the background color of the response boxes and choice cards. This gives her an extra clue of what to use to fill-in-the-blank. For example, color the blank box for the month on the communication sheet with a light yellow background. Print all corresponding magnetic choice cards (“January” through “December”) with the same light yellow background. Use a different color for each box.
- ❖ Allow your child to do the photocopying. She learns how to use a copy machine as well as number concepts such as “just one for Mom” or “two copies: one for me and one for you.”
- ❖ Print the magnetic choice cards with dashed text. Once the completed communication sheet has been photocopied, she can trace over the text of all her choices.

### IntelliTools: Powerful Technology

#### Description:

The computer is a wonderful tool for teaching Ashley various instructional objectives since it can be multi-sensory, providing both graphics and sound. This example takes advantage of these features.

*IntelliKeys* is an alternate input device, like a keyboard, for a computer. Selections are made when your child touches the surface of the *IntelliKeys*. Custom overlays are designed for the *IntelliKeys* using *Overlay Maker*. When used along with *IntelliTalk* (a text-to-speech program), the computer becomes a powerful high-tech communication device, speaking her selections while typing

them onto the computer screen. This strategy requires no talking, no writing, or keyboarding, and requires only the touch of a finger.

#### Equipment and Supplies:

- ❖ Icons,
- ❖ *IntelliTalk* and *Overlay Maker* software from *IntelliTools*,
- ❖ Dashed text font,
- ❖ *IntelliKeys* by *IntelliTools*,
- ❖ Computer, and
- ❖ Printer.

#### Design Instructions:

- ❖ Design an overlay to relay information about her school day. (Figure 5)
- ❖ Your child makes selections and hears them spoken by the computer. This allows her to build sentences, pair thoughts, and construct more complex messages and paragraphs.

#### Instructions for Teaching:

- ❖ Encourage your child to explore all the various choices provided on the Custom

Today is	Monday.	Tuesday.	Wednesday.	Thursday.	Friday.
This morning I had					
This afternoon I had					
I have homework in					
I ate lunch with					
My day was					

Figure 5

Overlay by encouraging her to touch them, then seeing them spoken and typed by the computer.

- ❖ Your child then constructs sentences by touching them on the *IntelliKeys* overlay and sees them typed on the computer screen.

## “How Was Your Day?” Designing Home- to- School Communication for Your Child

- ❖ Once sentences are constructed and spoken by the computer, these sentences and paragraphs can then be printed like any other word processing program. (Figure 6)

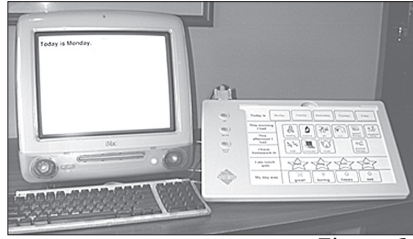


Figure 6

### Variations

- ❖ Use dashed text by selecting it as the font for *IntelliTalk*. When the selection appears on the computer screen in the *IntelliTalk* word processor, the text will be dashed.
- ❖ Once your child has completed and listened to her selections, print out her completed sheet. Have her trace over the text for a functional handwriting activity.
- ❖ As writing skills improve, include punctuation selections on the overlay so that your child can properly punctuate her own sentences.

### Configuring Pop-Up Menus in a Software Application

#### Description:

The power to make choices becomes that much easier with pop-up menus. Providing a larger list of choices, Ashley can use pop-up menus to share a great deal of information while creating a wonderful document that requires no keyboarding.

Relational database software, such as *FileMaker Pro*, can create pop-up menus filled with a list of text options. When a pop-up

menu is placed within a sentence, it becomes a method to answer fill-in-the-blank questions or complete fill-in-the-blank sentences. Although this method requires more reading than earlier examples (because text is not paired with icons or photographs), sentences and corresponding responses can be individualized for your child’s reading ability. If it is not necessary for the text size to be exceptionally large, this is a wonderful method for your child to independently share a great deal of information about her day.

#### Equipment and Supplies:

- ❖ *FileMaker Pro* relational database software,
- ❖ Computer, and
- ❖ Printer.

#### Design Instructions:

- ❖ Create a fill-in-the-blank communication sheet.
- ❖ Use pop-up menus to fill in blank sections of sentences. For instance, use a pop-up menu to provide the months (from January through December) for your child to choose from to complete the date. Insert a pop-up menu for the days of the month (1-31) and so on.

#### Instructions for Teaching:

- ❖ First, teach the skill of using pop-up menus by providing only one choice in each pop-up menu. Provide hand over hand instruction with the computer mouse as your child learns their ability to fill-in-the-blank by making a selection from the pop-up menu.
- ❖ Read the sentence aloud with your child.
- ❖ When she reaches the choice box, have her click on the box to see the pop-up menu.

*Continued on page 14*

## “How Was Your Day?” Designing Home- to- School Communication for Your Child

Continued from page 13

Have her scroll down the menu while you read the various choices. (Figure 7)

- ❖ Once she has made her selections to fill in the sentences, print the completed sheet to take home.
- ❖ Use a dashed font for writing practice after printing the completed document. Your child has created a meaningful, functional worksheet for practicing handwriting skills.

### Variations

- ❖ Increase the number of choices in the menu as your child becomes comfortable with the process.
- ❖ Add background color to the pop-up menu fields. This allows the pop-up menu to stand out from the white background of the rest of the document.
- ❖ Using pop-up menus is also a good method for creating and administering tests or quizzes. Your child can read the question and select the appropriate answer from a pop-up menu.
- ❖ The ability to use pop-up menus is a valuable skill for school and vocational settings. Many computer software menus also require this skill.

These are just a few ways of individualizing the method of sending a note home about school activities. The best part of all is that these are all methods that allow your child to do this independently. Isn't that what educa-

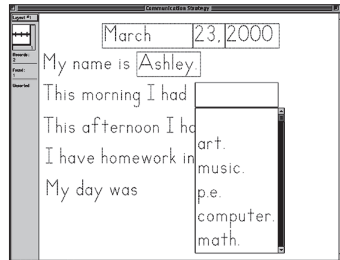


Figure 7

tion is all about: independence? In addition, your child is being taught new skills she can use throughout her education. While on the surface it appears the only issue addressed is delivering a series of messages about her school experience, many other educational objectives are addressed at the same time.

The examples above meet many different instructional objectives such as:

### Name Recognition and Word Order

Common objectives for these goals include recognizing her name, placing her first and last name in order, and placing it in the correct position at the top of the page. A communication sheet can be designed to teach and reinforce these skills. Some children can write their name on their paper independently. But for many children, this task is not so simple.

### Concepts of Time and Order

The concept of time is an abstract and challenging skill to teach. Use concrete and motivating experiences that occur throughout the school day to teach concepts of “yesterday,” “today,” and “tomorrow,” “this morning” and “this afternoon.” Completing communication sheets as an ongoing activity throughout the day is one way to teach these concepts.

### Handwriting

One of the most obvious ways to fill in any worksheet is sometimes the most challenging: handwriting. Using a dashed text font in a computer or rubber stamps that print a dashed text for your child to trace over provides an opportunity to practice handwriting in a meaningful context.

## “How Was Your Day?” Designing Home- to- School Communication for Your Child

### Calendar

What elementary classroom doesn't have calendar time? The concepts of the calendar are also abstract and challenging to teach any child. They may be even more challenging for a child with special needs. It is helpful to tie calendar concepts to concrete activities such as the communication sheet. Using the calendar to identify a particular day of the month to fill in on the communication sheet, rather than passively looking at it on a wall, may improve your child's interest and ability to learn and understand its use.

### Reading

Motivating sight words, such as classmate's names and classroom activities, may inspire your child to use the words they are learning to read. Design communication sheets with a mixture of icons and photographs to represent various words. The text of the words can be used with or without the icons or photographs they represent. This encourages

your child to rely more on the configuration of the letters within the word than the icon or photograph it represents.

There are countless ways to use these ideas to design communication sheets that are meaningful to your child, parents, and staff, and meet educational goals at the same time. These are just a few ideas Ashley has used to tell me about her school day. I hope they will inspire you and your team at school to create similar strategies that are motivating, meaningful, and challenging to your child. They are certainly more effective than digging through backpacks searching for scraps of information.

*Kimberly S. Voss is the mother of three daughters, one of whom has Down syndrome and additional disabilities. She designs software and instructional materials and is the owner of Ashley's Mom, Inc. Kim resides with her husband and daughters in Tulsa, Oklahoma.*

## RESOURCES

Teaching Resource Center  
P.O. Box 82777  
San Diego, CA 92138-2777  
800-833-3389  
800-972-7722 (Fax)  
www.trcabc.com

- ♦ Magnetic Board

IntelliTools, Inc.  
55 Leveroni Court  
Suite 9  
Novato, CA 94949  
800/899-6687  
www.intellitools.com

- ♦ IntelliKeys
- ♦ IntelliTalk
- ♦ Overlay Maker

Ashley's Mom, Inc.  
P.O. Box 702313  
Tulsa, OK 74170-2313  
www.ashleymom.com

- ♦ Adhesive Magnet Sheets:  
1'x2' magnet sheets, 3 mil thick,  
with adhesive front.

Avery Office Products  
Consumer Service Center  
P.O. Box 129  
Brea, CA 92829-0129  
www.avery.com

- ♦ White Printable Magnet Sheets  
for InkJet Printers:  
8 1/2" x 11" paper thin magnet  
sheet for inkjet printers.

Mayer-Johnson  
P.O. Box 1579  
Solana Beach, CA 92075-1579  
800/588-4548  
www.mayer-johnson.com

- ♦ Boardmaker
- ♦ School Fonts for Beginning Writing
- ♦ Boardmaker Sign Language Libraries Vol. I and II
- ♦ Picture Communication Symbols

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Creating Solutions  
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# Disability Solutions

A Resource for Families and Others Interested in Down Syndrome and Developmental Disabilities

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# Current IEP





# Previous IEPs



# Current Multi-Factored Evaluation



# Previous Multi-Factored Evaluations



# Diagnostic Assessments





APPENDIX C

# Navigating the Rough Waters

---

What to Do When You Disagree with the  
School District's Decisions

## Education: Navigating the Rough Waters

*The IEP being written was not addressing my son's needs. The principal stated that the team only had until 3:00 to finish the IEP, which was one hour from the start of the meeting. Frustration was building, and voices started to rise. I started crying while trying to explain why the services presently being given to my son were not working. People took it personally, and disagreements began. The principal closed the meeting with the IEP left unwritten. All I could think on my way home was that I had had it with the school and that my son would never receive an IEP that would teach him the skills he needed.*

### ***When You Disagree with the School District's Decisions***

The Individuals with Disabilities Education Act (IDEA) values the input of parents regarding their child's education program. It provides for actions parents can take when they disagree with school district personnel about their child's educational program. These are options parents have:

1. **Request a case conference** – this is a meeting with school personnel to discuss concerns and explore how to resolve the issues.
2. **Request an administrative review** – this is a meeting that will include the district superintendent or designee to review the issues of disagreement. This person is able to reverse the decision of school personnel.
3. **Request mediation** – this occurs when parents and schools cannot agree after both the case conference and administrative review. You and the school must both agree to mediation. A trained, qualified and impartial representative hired by the Ohio Department of Education will be assigned to conduct the mediation between you and the school district representatives. The school district will take responsibility for scheduling a mediation time that you, the mediator, and the school district representatives agree upon.
4. **File for an impartial due process hearing** – this is a formal, administrative procedure that is held to resolve disagreements between the parents and the school district. The district will contact the Ohio Department of Education and a list of potential impartial hearing officers will be sent to the district. In Ohio, all hearing officers must be attorneys and all hearing officers must have completed training on the process through the Ohio Department of Education. Parents and the school have to agree upon a hearing officer to hear the case.

## **Complaint Process**

Parents may also file an official complaint with the Ohio Department of Education. This is an official notice that a school district may have violated one or more of the federal or state special education laws. Complaints must be about students, or groups of students who are eligible or thought-to-be eligible for special education services.

This does not require a hearing officer. The complaint is reviewed by staff of the Ohio Department of Education who investigates the complaint by talking with both the parent and the school districts to establish the facts of the case. An official decision is made regarding the complaint and the parent and the school district are informed in writing of the decision of the Ohio Department of Education. If the district is found in violation of federal or state law, the district is required to correct the violation.

Complaints must be made in writing and sent to the Ohio Department of Education, Office for Exceptional Children, 25 S. Front Street, Columbus, OH 43215.

## **Types of Disagreements**

### ***School district denies the request to perform a Multi-Factored Evaluation (MFE)***

In order for a child to be eligible parents' special education services, the child must meet two conditions. The child must:

1. Have a disability under one of the 13 IDEA categories, and
2. The disability must have a documented adverse affect on the child's educational program

If the school does not observe an adverse affect on the child's educational performance based upon educational data, the school may refuse to perform an MFE when parents request one.

If the school district refuses to perform an MFE, it must provide the parents with a *prior written notice* letter. The letter must contain information regarding why the evaluation will not be provided and what documentation was used to determine that an evaluation is not needed.

In response the parents may do one of the following:

- Request a mediation with an Ohio Department of Education-appointed mediator to review the issues of disagreement and make a decision, or
- File a complaint with the Department of Education, Office for Exceptional Children

### ***School district determines that the child is not eligible for special education services after the MFE is performed***

If this happens, parents can refuse to agree with the results of the MFE and request an *independent educational evaluation* at public expense. A request for an independent evaluation should be made in writing.

The district can agree to provide for an independent educational evaluation and provide parents with a list of approved evaluators that parents can use at the school's expense. Parents may choose an evaluator from the list or choose someone else.

For a publicly funded evaluation, the school must agree to the evaluator that the parent chooses. IDEA requires that the school agree to the location of the evaluation and the qualifications of the examiner (they must be the same as the criteria for evaluators that the district uses (such as a licensed psychologist).

The school district can initiate a due process hearing to show that its first evaluation is appropriate and, therefore, deny the independent educational evaluation. In this case, a hearing is scheduled before a hearing officer while the school presents evidence to support its position and the parents do the same. The hearing officer then decides if the school must provide for an independent educational evaluation.

Any time a district refuses the independent evaluation at the school's expense, parents have the option of obtaining an independent evaluation at their own expense. When the parents receive the results of any independent educational evaluation, they must request a case conference in writing with school district personnel to consider (and discuss) the results of the evaluation. At this meeting, parents are requesting school district personnel to review any decisions related to the child's eligibility or educational programming based on the new information provided.

### ***If parents and the school district disagree after a review of the independent evaluation results***

If you and the district cannot come to an agreement about how to address your child's needs, parents can file for an impartial due process hearing, as described above.

### ***The IEP is not appropriate or is not being implemented appropriately***

If this is the case, request in writing a review of your child's Individual Educational Program with the team and identify your concerns. At this meeting the team can address your concerns and make revisions to the IEP, if appropriate, or identify additional areas of assessment and programming needed to address your concerns.

If you can't come to agreement about your concerns, refer to the parent's options sections above. For more information, you can also refer to the booklet provided to you by the school district about parents' rights called *Whose IDEA Is This?* IDEA requires that all schools provide parents of children with disabilities with information about their rights. *Whose IDEA Is This?* describes

parents' rights in detail and lists the procedural safeguards afforded to you as a parent under IDEA.

In addition, IDEA funds parent training and information centers in every state and territory specifically to answer parents' questions about special education issues and provide training to give parents the information they need to advocate for their child's educational interests. In Ohio, parents can call the Ohio Coalition for the Education of Children with Disabilities at (800) 374-2806.

## **Section 504**

If you do not want to pursue a due process hearing to challenge the school district's decision about your child's eligibility for special education services, another mechanism is available to obtain accommodations for your child. When a child has an identified disability that does not meet the criteria under one of the 13 IDEA categories, or that does not adversely affect the child's educational performance, parents can request that the district provide the child with a 504 Plan. This may be the case for children with Asperger Syndrome.

Section 504 of the Rehabilitation Act is a broad civil rights statute that prohibits discrimination on the basis of disability. It states that no person with a disability can be, by reason of his or her disability, denied access to or excluded from participation in or denied the benefits of a public program or service.

Upon request, a 504 Plan is developed to provide the accommodations necessary for the individual with a disability to access an identified service or program. Each local district is required to identify procedures to implement the requirements of Section 504. A district is also required to identify individual(s) responsible for the coordination of Section 504 services. Ask for information regarding your district's procedures for compliance with Section 504.

## **Importance of Knowing Your Educational Rights**

It is important to approach the educational planning for your child with the school team from a positive perspective. Be open to ideas and solutions as long as they meet your child's needs. Still, understand that you have the right under IDEA to question the school district's decisions and that there are procedural safeguards written into the law to help you protect your child's right to a free and appropriate public education.

Several resources are available to help parents understand their rights regarding the education of their child. The Ohio Coalition for the Education of Children with Disabilities (see contact information below), the Autism Society of Ohio (see contact information below), and other local autism groups provide parent trainings on educational rights on a regular basis. These groups also offer assistance to families by phone and through their websites. There are many websites available that also provide information for parents on advocating for their child's educational rights.

(Information adapted from materials developed by the Ohio Coalition for the Education of Children with Disabilities, Marion, OH. Used with permission).

### Resources

Autism Society of Ohio, (614) 487-4726: [www.autismohio.org](http://www.autismohio.org)

National Center for Learning Disabilities: [www.nclld.org/](http://www.nclld.org/)

Center for Parent Information and Resources (CPIR): <http://www.parentcenterhub.org>

Ohio Coalition for the Education of Children with Disabilities, (800) 374.2806; [www.ocecd.org](http://www.ocecd.org)

Wright, P., & Wright, P. (n.d.). From emotions to advocacy – The special education survival guide. Hatfield, VA: Harbor House Law Press, Inc. (Available from [www.wrightslaw.com](http://www.wrightslaw.com))

Wrights Law Special Education Law and Advocacy: [www.wrightslaw.com](http://www.wrightslaw.com)

APPENDIX D

# Letter to Request a Multi-Factored Evaluation

Date you write your letter **(Include month, day and year)**

Your Name

Your Full Address

Full Name of Person to whom you are writing **(the Principal or the Special Education Director)**

Person's Title **(Principal, Special Education Director)**

Name of School

Full Address of School

Dear **(Use their title [Dr.; Mr.; Mrs.; Ms.] and last name):**

I am the parent of **(Your child's name)**, who is in the \_\_\_\_ grade at **(Name of school)**. My child is not performing successfully in the general education classroom. **(Briefly state your concerns; examples: failing grades; problems with friends at school; it takes a very long time for your child to complete homework; child comes home very upset; etc.)**

Under Ohio Administrative Code 3301-35-06, the general education teacher is required to do interventions to assist in my child's success. Since my child is still not performing successfully, I suspect he/she a disability. Under Child Find §300.125 in IDEA '97, I am requesting a complete Multi-Factored Evaluation.

Please consider my signature on this letter as my permission to test my child. It is my understanding that when a Multi-Factored Evaluation is requested, the school district is required to provide parents with their procedural safeguards. Please forward them to me at the above address.

Thank you for your attention to my request. I may be reached at **(Your daytime phone number)**. I will expect to hear from you within 5 school days of receipt of this letter.

Sincerely yours,

**Your Full Name**

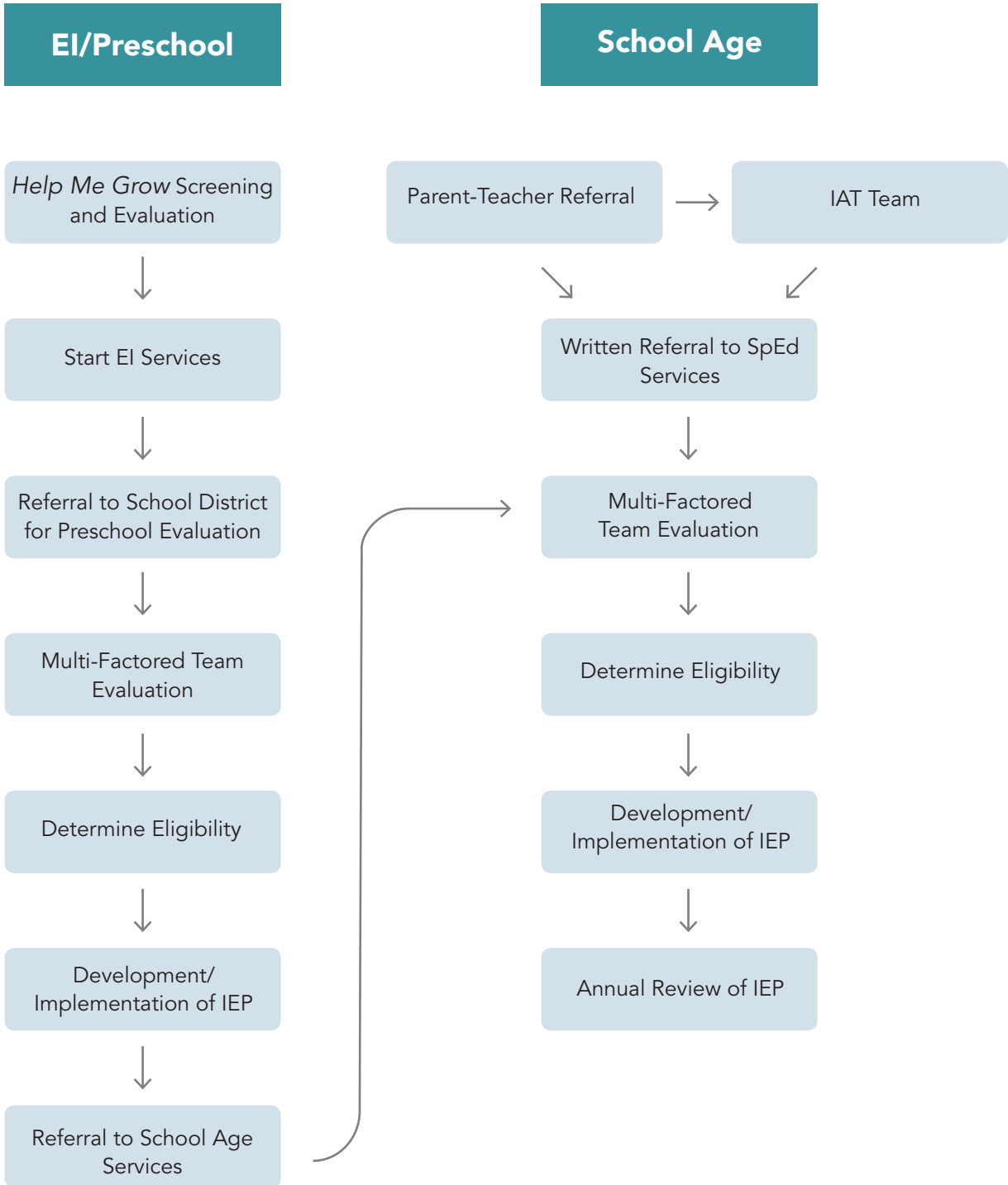


APPENDIX E

# Process for Determining Eligibility for Special Education Services



Process for Determining Eligibility for Special Education Services





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<https://www.oplates.com>

[ocali.org/family](https://ocali.org/family)



Family Center