

**Speak Softly and Carry a Big Binder**  
***Tips for Managing the Mountain of Paperwork***

It is amazing how quickly the paperwork begins to pile up once someone you love is diagnosed with an Autism Spectrum Disorder (and possibly before as it sometimes takes a long time to get a definitive diagnosis). As you start on this journey, be advised that organizing this paperwork from the beginning will save you time and effort and stress in the future. Here are a few tips that can be helpful in getting it organized.

**1. Educational Binder**

- A. Current EDC/MDC – copy (establishes need for services-done every 3 years)
- B. Current year IEP – copy (goals and objectives determined from EDC-done every year)
- C. Significant reports and evaluations, official diagnosis if possible-copies
- D. General handouts about autism to give to staff
- E. Handout with the top 10 things others should know about your child
- F. List of medications your child is on, dosage and times (if any)

**2. Communication Binder –Home and School**

- A. Daily communication sheets (for home and teacher comments about the day)
- B. List of medications your child is on (useful in an emergency situation)
- C. Emergency telephone numbers

**3. Medication Binder – Home and Doctor's Office (if applicable)**

- A. Current medication information
- B. List of medication trials – with dates, names and reactions
- C. Good place to accumulate information you want to share with your doctor at the next visit.

**4. Filing cabinets in home**

- A. Educational – originals of IEP's, EDC's & assessments & report cards
- B. Medical reports
- C. Conference notes & information
- D. Miscellaneous

## A Few Words About **PEOPLE FIRST LANGUAGE** by Kathie Snow

Visit [www.disabilityisnatural.com](http://www.disabilityisnatural.com) to see the original, full-length article.

People with disabilities constitute our nation's largest minority group. It's also the most inclusive and most diverse: both genders, any sexual orientation, and all ages, religions, socioeconomic levels, and ethnicities are represented. Yet the only thing people with disabilities have in common is being on the receiving end of societal misunderstanding, prejudice, and discrimination.

*The difference between the right word and the almost right word is the difference between lightning and the lightning bug.*

Mark Twain

And this largest minority group is the only one which *anyone can join, at any time:* at birth, in the split second of an

accident, through illness, or during the aging process. If and when it happens to *you*, how will you want to be described?

**Words matter!** Old and inaccurate descriptors perpetuate negative stereotypes and reinforce an incredibly powerful attitudinal barrier, which is the *greatest obstacle facing individuals with disabilities*. A disability is, first and foremost, *a medical diagnosis*, and when we define people by their diagnoses, we devalue and disrespect them as individuals. Do *you* want to be known primarily by your psoriasis, gynecological history, or the warts on your behind? Using medical diagnoses incorrectly—as a measure of a person's abilities or potential—*can ruin people's lives*.

**Embrace a new paradigm:** "Disability is a natural part of the human experience..." (*U.S. Developmental Disabilities/Bill of Rights Act*). Yes, *disability is natural*, and it can be *redefined* as a "body part that works differently." A person with spina bifida has legs that work differently, a person with Down syndrome learns differently, and so forth. People can no more be *defined* by their medical

diagnoses than others can be defined by gender, ethnicity, religion, or other traits!

A diagnosis may also become a *sociopolitical passport* for services, entitlements, or legal protections. Thus, medical, educational, legal, or similar settings are the *only places* where the use of a diagnosis is relevant.

**People First Language** puts the person *before* the disability, and describes what a person *has*, not who a person *is*. Are you "cancerous" or do you have cancer? Is a person "handicapped/disabled" or does she "have a disability"? Using a diagnosis as a defining characteristic reflects prejudice, and also robs the person of the opportunity to define himself.

Let's reframe "problems" and into "needs." Instead of, "He has behavior problems," we can say, "He needs behavior supports." Instead of, "She has reading problems," we can say, "She needs large print." And let's eliminate the "special needs" descriptor—it generates pity and low expectations!

A person's self-image is tied to the words used about him. People First Language reflects good manners, not "political correctness," and it was started by individuals who said, "*We are not our disabilities!*" We can create a new paradigm of disability and change the world in the process. Using People First Language is right—*just do it, now!*

### A FEW EXAMPLES OF PEOPLE FIRST LANGUAGE

Say:	Instead of:
Children/adults with disabilities.	Handicapped, disabled, special needs.
He has a cognitive disability.	He's mentally retarded.
She has autism.	She's autistic.
He has Down syndrome.	He's Down's/mongoloid.
She has a learning disability.	She's learning disabled.
He has a physical disability.	He's a quadriplegic/crippled.
She uses a wheelchair.	She's confined to/wheelchair bound.
He receives special ed services.	He's in special ed; a special ed kid.
People without disabilities.	Normal or healthy people.
Communicates with her eyes/device/etc.	Is non-verbal.
Congenital disability/Brain injury	Birth defect/Brain damaged
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.

# Top 10 Things to Remember

## When Working With Children With Autism Spectrum Disorders

**1. Use calendars, schedules, and checklists.**

We all use checklists, calendars, and visual cues. Individuals with autism may find it difficult to organize their activities, so these techniques are even more important for them.

**2. Organize the environment.**

This can be very helpful and will give the individual with autism cues about what, when, and how. Reserve one area of the room for reading, one for puzzles, and another for schoolwork. Keep supplies handy and accessible to the child if possible.

**3. Avoid phrases that are confusing; do not use sarcasm.**

Individuals with autism have difficulty with abstract thought. They interpret verbal information very literally.

**4. Avoid repeating instructions.**

Individuals with autism find it difficult to interpret auditory information. Give the person time to process the information. Augment verbal communication with visual cues, gestures, or physical prompts.

**5. Be observant of the environment and make changes in lighting and noise when necessary.**

Individuals with autism can experience unusual responses to sensory stimuli.

**6. Prepare the individual for changes or transitions.**

Changes in routine are particularly difficult for individuals with autism. Using visual schedules and written reminders will help make transitions easier and smoother.

**7. Emphasize social learning.**

Individuals with autism must learn social skills that many of us take for granted. Social groups that are organized around favorite activities can provide a safe forum for early social learning. Socially interactive games (pat-a-cake, peek-a-boo) that require coordination between people can be very helpful in developing social skills and helping the child to "tune in" to those around him. Older children can be asked to help with daily chores that require coordination (handing mother the clothes pins, setting up an assembly line to put the groceries in the pantry, etc.). Use games that require turn taking.

**8. Encourage the individual with autism to communicate their needs and wants.**

For example, do not automatically provide dessert for your child with autism. Get dessert for yourself, and wait for your child to indicate their desire for dessert.

**9. Seek out support from other parents of children with disabilities.**

**10. Have fun.**

Make sure that you have some activities that are not related to autism.



# Tips

## For Working With Children With Autism Spectrum Disorders

The Autism Program gets tips from parents, professionals and others working in the field. If you have a tip or special trick that you use or have used in the past that you think would be of interest to others please e-mail it to: [theautismprogram@thehopeschool.org](mailto:theautismprogram@thehopeschool.org).

### Communication Tips

#### Helping your child communicate more effectively:

- Teach communication skills that are functional and meaningful
- Teach communication in the context of everyday activities
- Provide multiple opportunities for communication practice throughout the day
- Arrange the environment as necessary to create the need to communicate
- Reduce stressful speaking situations by avoiding:
  - o Competition for speaking opportunity
  - o Frequent interruptions
  - o Demand for display speech
  - o Loss of listener attention
  - o Frequent questions
  - o Excitement when speaking

#### Communicating more effectively with your child:

- Slow down when speaking with your child
- Replace long, complex sentences with short simple sentences
- Stress key words
- Use other modalities to enhance meaning
- When using spoken commands, make them simple
- Use visual supports
- Use object supports
- Be consistent

### General Tips

#### Consistency, consistency, consistency

Do things the same way with your child each time, and do things the same way with other people. Without consistency your child may become confused or discover opportunities for manipulation.

#### Catch 'em being good

Whenever the opportunity presents itself, use a lot of positive reinforcement. Some children thrive on positive attention. Let them know when they are acting appropriately. If we praise good behavior we can hopefully decrease the need for inappropriate behavior.

#### Remain neutral and calm

Be sure not to raise your voice or show emotional reaction when your child uses inappropriate behaviors.



## **Use few words when addressing an inappropriate behavior**

Using too many words provides unneeded attention. Keep requests simple. Tell your child what TO do rather than what not to do. Avoid using "stop" or "don't" statements and always use a firm, calm respectful tone of voice.

# **FAQ's**

## **1. What symptoms or observations signal an immediate need for an evaluation?**

- 9 months: No babbling
- 12 months: No pointing or other gestures
- 16 months: No single words
- 24 months: No functional 2-word phrases
- Any age: Any loss of any language or social skills

## **2. Are Autism Spectrum Disorders rare?**

No. Current statistics from the Center for Disease Control indicate that 1 in 166 children have an Autism Spectrum Disorder.

## **3. Do all children with autism have intellectual impairments?**

No. The intellectual abilities of children with autism vary from the gifted range to severe and profound mental retardation. Studies indicate that 50 to 70 percent of individuals with classic autism have some level of mental retardation. It is important to note that intellectual functioning is difficult to assess in individuals with autism, and assessment of intellectual functioning in very young children may not be accurate.

## **4. Do all children with autism have some special gift, such as the ability to calculate dates or compose music?**

No. There are a limited number of people with autism who are identified as savants. Savants are individuals with isolated giftedness in one or more areas. It is true that individuals with autism have what is called, splinter skills or scattered abilities. These terms refer to the fact that many people with autism have an uneven pattern of intellectual strengths and weaknesses.

## **5. Can individuals with autism respond to treatment?**

Yes. We know that individuals with autism spectrum disorders learn through visual presentation, repetition and predictability. An environment that provides visual supports, structure, and repetition is most helpful. For more information on treatment options you should research University of North Carolina-Division TEACCH; Applied Behavior Analysis and Picture Exchange Communication.

## **6. What are some common elements seen in effective programs for young children?**

- Comprehensive assessment leading to diagnosis and to an individualized treatment plan
- Individualized programming that is reevaluated to keep pace with the child's progress
- Predictable routines
- Functional analysis of problem behaviors
- Active family involvement
- Careful transitions across intervention settings (EI to School Programs; Grade Levels)
- Highly trained staff and use of empirically demonstrated strategies
- Focus on Early Intervention
- Intensive intervention (intensity measured by frequency of interactions and level of engagement)
- Attempts to generalize learning across environments (carrying things learned at school to home, etc.). A good program will assure that the child can demonstrate gains with multiple people and in multiple settings.



**THE AUTISM  
PROGRAM**

*Your Illinois Resource*

# Autism At A Glance

## What is Autism?

Autism Spectrum Disorders (ASDs) are a group of neurologically-based developmental disabilities. Scientists do not know exactly what causes the problem. ASDs can impact a person's functioning across a wide range, from very mild to severe. Individuals with ASD are not different in appearance, but they may communicate, interact, behave and learn in ways that are different from typical peers.

## Is Autism a common disorder?

Recent statistics from the U.S. Centers for Disease Control and Prevention (CDC) suggest that 1 in 166 people in the United States could be diagnosed with ASD. That means 22,000 children in Illinois have an ASD.

## Autism Spectrum Disorders (ASDs) include:

- Autistic Disorder
- Asperger's Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder

## What are some of the signs of ASDs?

People with ASDs may have problems with social, emotional, and communication skills. They might repeat certain behaviors and might not want change in their daily activities. Many people with ASDs also have different ways of learning, attending, or responding to their environment. ASDs begin during early childhood and last throughout a person's life.

## A child or an adult with ASD might:

- Not play "pretend games" (like feeding a doll)
- Not look at objects when another person points at them
- Have trouble relating to others or not have an interest in other people at all
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Prefer not to be held or cuddled or may cuddle only when they want to
- Appear to be unaware when other people talk to them but respond to other sounds
- Be very interested in people, but not know how to talk, play or relate to them
- Repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language
- Have trouble expressing their needs using typical word or motions
- Repeat actions over and over again
- Have trouble adapting when a routine changes
- Have unusual reactions to the way things smell, taste, look, feel or sound
- Lose skills they once had (for instance, stop saying words they were once using)

## What should you do if you think a child or an adult has an ASD?

If you or your doctor think there could be a problem, ask for a referral to see a developmental pediatrician or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). Right now, the main research-based treatment for ASDs is intensive structured teaching of skills, often called behavioral intervention. It is very important to begin this intervention as early as possible in order to help your child reach his or her full potential. Acting early can make a real difference!



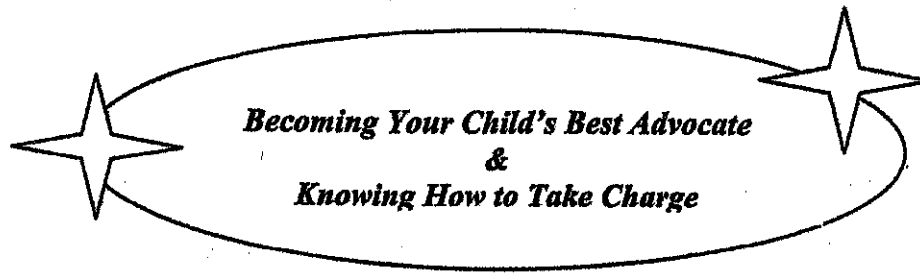
## **My Child Has Autism**

### ***What to do after the Diagnosis***

When a child receives a diagnosis of Autism, families are usually overwhelmed and confused. Here are a few helpful tips the parents of the C-U Autism Network have put together for new families.

- Have evaluations done for every area of concern. Not every child will need every evaluation. Possible evaluations – speech & language, occupational therapy for fine motor and sensory needs, behavioral therapy, social skills. (see Local Information handout)
  - ~ If your child is age birth to 3 years, contact your local early intervention provider for evaluations.
  - ~ If your child is over 3 years of age, contact your local public school for evaluations.
- At any age, you can contact therapists in private practices.
- Investigate services available from The Autism Program, Developmental Services Center (DSC), Easter Seals, Family Matters, and others. (refer to Local & Regional Support handout)
- Get connected with local, state and national autism support and awareness groups.
  - ~ ASI Champaign-Urbana Autism Network ([www.cuautismnetwork.org](http://www.cuautismnetwork.org))
  - ~ Autism Society of Illinois ([www.autismillinois.org](http://www.autismillinois.org))
  - ~ Autism Society of America ([www.autism-society.org](http://www.autism-society.org))
- Start a binder or filing system to keep track of records and evaluations. (see Speak Softly & Carry a Big Binder handout)
- Investigate options that are available to help your child learn. Learn the benefits and differences in ABA, TEACCH, Miller Method, Higashi Method, Floortime, PECS and Social Stories. Learn about special education law and your child's rights. (refer to the Selected Internet Resources handout for more information)
- Research biomedical interventions for children with autism.
- Give serious thought to dietary interventions and possible food allergies.
- Become your child's advocate by educating yourself through conferences and workshops. Conference stipends are available through STARnet and The Arc of Illinois, many are now free. (see the Local & Regional Support, Education & Training Groups handout)
- Read books on Autism Spectrum Disorder. (refer to Illinois Autism/PDD Training & Technical Assistance Project Regional Team Lending Library Resource Materials handout for titles)
- Find time to spend alone and with other family members. If finding adequate childcare for an occasional evening out is a problem, contact your local PAS agency to see if you can qualify for respite services. In Champaign County, Developmental Services Center is the respite provider. The respite coordinator can be contacted at 217-356-9176.

While there are many more ways you can educate yourself and help your child, we hope this list gives you a place to start and to begin to feel connected to others who have walked this path.



***Becoming Your Child's Best Advocate  
&  
Knowing How to Take Charge***

- ❖ **Build a Strong Base of Information...**you know your child. Get to know your child's school environment. Visit your child's classroom(s). Be sure to use appropriate visiting procedures. During the IEP meeting ask questions if you do not understand. You are the expert on your child, but you are not expected to understand all school terminology. Never go alone, take someone with you, a grandparent, aunt/uncle or friend.
- ❖ **Be First...**make sure you speak first, particularly if you requested the IEP meeting. By speaking first you will be taking control of the meeting and running it accordingly. Bring notes, share notes and make necessary introductions. Put your priorities on the table for discussion first. Using a written agenda is an excellent format for providing each member of the IEP team a list of your concerns. Consider sharing your agenda with the IEP team prior to the scheduled meeting.
- ❖ **Understand Your Rights...**Public Law has provided all children with disabilities rights and schools legal responsibilities. How can you advocate for important issues if you are not sure of your child's legal rights? Remember, "Knowledge is Power", obtain it! Contact the Illinois State Board of Education to obtain a *free* copy of the "Parents Guide".
- ❖ **Know How to Say No...**be gracefully firm. Take a firm stand on important issues and only those that are important. Be willing to compromise and be a team player. Have a clear explanation ready, and always speak carefully by using phrases such as "that is unacceptable". If there are areas of disagreement, have it written on the IEP or attach to the IEP a written letter documenting the areas of disagreement.
- ❖ **Learn How to Communicate...**by being assertive rather than passively or aggressively. An assertive person clearly and positively states his/her point of view and takes into account what others say. Show that you want to listen. Look and act interested. Be aware of your body language, which can often times make other uncomfortable.
- ❖ **Make Friends...**at school. Volunteer to be a room mother or to help whenever you can. If you are respected as a supporter of the school, you are more likely to be respected at the IEP meeting. Let people know you appreciate them. A few kind words can open doors for you and your child. Teachers need to know they are appreciated.



- ❖ **Keep Your Cool...**try to remain in control of your feelings. Members of the IEP team automatically write off angry parents. Although anger is sometimes needed to get your point across, remember, parents who lose their temper are quickly labeled as unreasonable as well as uncooperative. Once you lose control of your temper, school personnel can use that as proof to others within the school that you are unreasonable.
- ❖ **Keep a Records File...**of all documents relating to your child. Place all medical, IEP's, evaluations, consent forms and any other correspondence pertaining to your child's education in a file or folder. Maintaining a file is extremely important if you at some point need proof of or documentation of specific information related to your child or his/her education. Think of your child's IEP as a legal document one that must be protected.
- ❖ **End Your Child's IEP...**by reviewing the document/IEP that was just developed or amended. Read it very carefully before leaving the meeting. Just because there was discussion on a particular issue doesn't mean it was documented or that corrective action was written into the IEP. Remember, *if it's not written down, it wasn't said!*

The ultimate responsibility for your child's growth and education is in your hands. Reach out to professionals who can help you, but *don't give your responsibility* over to them. Remember, you are the constant in your child's life and you will need to manage and coordinate the services your child needs, as professionals will come and go!

***Family Matters***  
***Parent Training & Information Center***  
2502 South Veterans Drive  
Effingham, Illinois 62401  
Toll Free: 866-436-7842  
[www.fmptic.org](http://www.fmptic.org)  
&  
***East/Central PTIC Regional Training Coordinator***  
Vickie Henley  
Office: 217-237-2818

## **Therapeutic Options and Interventions For the Treatment of Autism**

**Applied Behavior Analysis (ABA)** – ABA is an intensive, structured teaching program. Practitioners of applied behavior analysis aim to improve socially important behavior by using interventions that are based upon principles of learning theory and that have been evaluated in experiments using reliable and objective measurement. ABA methods are intended to support persons with autism in many ways: To increase desirable behaviors and to teach new skills; to maintain desirable behaviors; to generalize or to transfer behavior from one situation or response to another situation; to restrict or narrow conditions under which interfering behaviors occur and to reduce interfering behaviors. Different methods are used to help the child learn, such as prompting, shaping and rewarding for correct response. Task analysis, discrete trial teaching, the Lovaas method, verbal behavior therapy and errorless learning are all parts of applied behavior analysis. ABA interventions should be supervised by a qualified behavior analyst.

**Assistive Technology** – Assistive Technology includes any item or piece of equipment that is used to maintain, increase or improve the functional capabilities of individuals with disabilities.

**Early Intervention Services (EI)** – Early Intervention services are those that are provided to children less than thirty-six months of age who meet state eligibility criteria. Appropriate Early Intervention services must be tailored to meet the unique needs of the eligible infant or toddler and his or her family. These services must be designed in collaboration with the family to enhance both the development of the child and the family's capacity to meet the needs of the child.

**Interdisciplinary Council on Developmental and Learning Disorders (ICDL)** – This council works with developmental and/or learning problems to improve the identification, prevention and treatment of developmental and learning disorders.

**Gluten Free and Casein Free Diet** – Some researchers find that autistic symptoms are sometimes caused by food allergies, particularly gluten (wheat) and casein (dairy products). More information can be found on this topic at Autism Network Dietary Intervention (ANDI) which provides the latest news, cooking tips and recipes, safety advice, articles by doctors and nutritionists and more.

**Greenspan Method** – Dr. Stanley Greenspan's D.I.R. (Developmental, Individual-Difference, Relationship-Based model) has the goal of helping children form a sense of themselves as "intentional, interactive individuals and develop cognitive language and social capabilities from this basic sense of intentionality." This is done during a process called "floor-time".

**Music Therapy** – Explore the American Music Therapy Association (AMTA) and learn how music can make a difference in individuals with autism.

**Occupational Therapy (OT)** – OT is a therapy or treatment provided by an occupational therapist that helps with individual development of physical skills that will aid in daily living. It focuses on sensory integration, balance and coordination of movement, and fine motor and self-help skills such as dressing, eating with a fork and spoon, etc. Visit

the American Occupational Therapy Association's web site to learn about OT and autism.

**Physical Therapy (PT)** – PT is a treatment of physical disabilities given by a trained physical therapist (under doctor's orders) that includes the use of massage, exercise, etc., to remediate mobility and gait and to modify strength, balance, tone and posture, and to help the person improve the use of bones, muscles, joints and nerves.

**Picture Exchange Communication System (PECS)** – PECS is an alternative communication system that uses picture symbols. It is taught in six phases starting with a simple exchange of a picture symbol for a desired item. Individuals learn to use picture symbols to construct complete sentences, initiate communication and answer direct questions.

**Relationship Development Intervention (RDI)** – A therapy approach that teaches children with autism to become more aware of their surroundings by learning to use nonverbal cues from the environment.

**Respite Care** – Respite is temporary, short-term care provided to individuals with disabilities. Respite care allows caregivers to take a break in order to relieve and prevent stress and fatigue. In Champaign- Urbana, contact DSC. In other areas, check with your county agency.

**Sensory Integration Therapy (SI)** – SI is a therapy designed for individuals with sensory integration deficits; this can include one or more of the senses. The goal is to improve an individual's ability to use incoming sensory information appropriately and encourage tolerance of a variety of sensory inputs.

**Speech/Language Therapy** – Speech/language therapy is provided by a speech therapist or a speech and language pathologist with the goal of improving an individual's ability to communicate. This includes verbal and nonverbal communication. The treatment is specific to the individual's needs.

**Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)** – An intervention program developed in North Carolina which employs a structural approach to treating autism.