

# Leading the Way

## Autism-Friendly Youth Organization Guide



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It's time to listen.

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# Introduction



# About the Autism-Friendly Youth Organization Guide

The purpose of this guide is to better prepare youth-serving organizations to serve youth and families with autism. In this document, autism refers to Autism Spectrum Disorder (ASD), which includes individuals diagnosed with Autistic Disorder, Pervasive Developmental Disorders, Not Otherwise Specified, and Asperger's Disorder.

Autism Speaks believes that recreation and leisure activities are particularly important for people with autism. We know that participating in such activities often produces opportunities to practice social skills, physical aptitude and increase motivation while also increasing self-confidence and fuller integration into the community.

The information that follows will be useful for helping integrate youth with autism into your existing programs, communicating with parents, and training your staff. With help from respected experts in the field of autism and special education, experienced parents and caregivers, we have included an introduction to autism and specific strategies that will allow you to lead the way for youth with autism to have the same formative experiences through community organizations that are available to their typical peers.

We have included a wealth of information, from a wide variety of sources. New tools and resources will be added as they become available. We encourage you to become familiar with the kit and share it with your youth organization colleagues.

The **blue text** are links you can click on for further information.

## About Autism Speaks

Autism Speaks is the world's leading autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Suzanne and Bob Wright, the grandparents of a child with autism, founded Autism Speaks in February 2005. Mr. Wright is the former vice chairman of General Electric and chief executive officer of NBC and NBC Universal. Since its inception, Autism Speaks has committed over \$180 million to research and developing innovative resources for families. Each year *Walk Now for Autism Speaks* events are held in more than 95 cities across North America. On the global front, Autism Speaks has established partnerships and related activities in over 40 countries on five continents to foster international research, services and awareness. To learn more about Autism Speaks, please visit [AutismSpeaks.org](http://AutismSpeaks.org).





*“One in every 88 youth in America is on the autism spectrum. That is at least one athlete in every six youth basketball teams, one youth in every two Scout troops and countless kids among summer camps and after-school programs.*

*My professional and personal worlds collided when a college student, earning his Wood Badge beads, approached me – a professor, a Scouter, the Executive Director of the Nonprofit Leadership Alliance and the parent of a child with autism. We worked together to develop a local Boy Scout leader training on autism-friendly scouting, which expanded my interest on working with youth organizations so that they can more effectively serve youth with autism.*

*Nearly every major national youth-serving organization in the United States focuses on specific areas of youth development. Boy Scouts of America focuses on character and moral development, personal fitness, and citizenship. Boys and Girls Clubs of America focus on developing youth into productive, caring, responsible citizens. Camp Fire builds caring, confident youth and future leaders.*

*Ultimately, serving youth with autism as part of these programs coincides with the missions of nearly all youth-serving organizations. I like to call including people struggling with autism in youth organizations a Mission Match. This makes the responsibility of youth-serving organizations to serve young people and families struggling with ASD not only a good idea, but also a mission-focused ethical responsibility.”*

**Dr. Nathan A. Schaumleffel, CPRP, CNP, CFRM, IYD**

**Parent of a Child with Autism**

**Associate Professor of Recreation and Nonprofit Leadership & Campus/Executive Director,  
Nonprofit Leadership Alliance Certification Program Indiana State University**





## Autism Speaks Autism-Friendly Youth Organization Survey Findings

In 2012 Autism Speaks conducted a national survey on community youth organizations. Through this effort, we've learned more about the barriers youth with autism face in fully participating in these programs and have a better understanding of what would help organizations successfully include young people with autism.

This survey assessed the needs and wants of parents /caregivers of youth with autism in the area of youth organizations. Of the 1,018 respondents, 83% parents of males, and 17% parents of females – youth with autism.

- When asked about the organized youth activities they would like made available to their youth, team sports and camping/outdoor adventure topped the list.
- The key unmet needs families experience in relation to youth organizations are:
  - Staff educated on autism and trained on effective interventions to help people with autism
  - Programs and/or summer camps offering adaptive services for people with autism
  - Affordable programs
  - Opportunities for socialization with neurotypical youth
- Of those respondents whose youth participate in youth organization programs:
  - 56% felt that their child was moderately or extremely safe, while 18% felt their child was not safe at all.
  - 57% were moderately or extremely satisfied with the program their child participated in while 19% were not at all satisfied with their current program.
- The top barriers that families experience to having their child participate in a youth organization are:
  - No programs specifically designed for youth with autism (55%)
  - Lack of behavior management services (50%)
  - Untrained staff (50%)
  - Expense of the program, lack of scholarships (48%)

Survey respondents felt the key training needs for youth organization staff that Autism Speaks should address were behavior management, tips for working with people with autism, communication strategies, and activity safety risks like wandering, hypothermia, drowning, etc.

This survey served as some of the impetus for the development of this guide and a web portal that will serve to better prepare staff and volunteer youth program leaders on appropriate ways to interact with, mentor, and manage youth on the autism spectrum. These resources will be updated regularly, as new information becomes available, so I encourage you to check back regularly at [www.autismspeaks.org/family-services](http://www.autismspeaks.org/family-services).

Marianne Sullivan, RN, MN  
Assistant Director of National Outreach and Resources  
Autism Speaks  
Mother of an adult son with autism





## Credits and Acknowledgements

Autism Speaks would like to recognize the Autism-Friendly Youth Organization Guide Advisory Board for their support and guidance.

### **Dr. Nathan A. Schaumleffel, CPRP, CNP, CFRM, IYD**

Parent of a Child with Autism

Associate Professor of Recreation and Nonprofit Leadership &

Campus/Executive Director, Nonprofit Leadership Alliance Certification Program

Indiana State University

### **Andrew Bowman**

Undergraduate Project Assistant & Wood Badge Trained Boy Scout Leader

Recreation and Nonprofit Leadership Program

Indiana State University

### **Kelli Ember**

Executive Director

Autism Speaks – Charlotte, North Carolina

### **D.D. Gass**

Director, Program Planning & Effectiveness Camp Fire

### **Liz Godwin**

Associate Director of Youth Programs

The Y of Charlotte, North Carolina

### **Lynn Koegel, Ph.D.**

Clinical Director of Autism Services

Koegel Autism Center

University of California, Santa Barbara

### **Jay Lytton**

Self-Advocate

Job Coach and Project Development

New Horizons

Los Angeles, California

### **Diana Yeisley**

Parent Advocate

Fundraising Chair, Greater Hartford Community Leadership Council

Autism Speaks



About Autism:  
What You Need  
to Know



# About Autism: What You Need to Know



*Goal: To acquire a basic understanding of what autism is and understand the challenges and strengths possessed by people with autism.*

## What is Autism

Autism is a general term used to describe a group of complex neuro-developmental disorders also known as Pervasive Developmental Disorders (PDD) or Autism Spectrum Disorders (ASD). These disorders are characterized, in varying degrees, by challenges related to:

- Communication
- Social Interaction
- Restrictive or repetitive behaviors and interests

People with autism may also experience other difficulties including medical issues, differences in coordination and muscle tone, sleep disturbances, altered eating habits, anxiety or disordered sensory perceptions.

## Keep in Mind

- Autism is a neurological/biological disorder, not a psychological or emotional condition.
- The features, abilities and severity of symptoms vary considerably among people with autism.
- Always assume intelligence, teach competence, promote independence and be respectful.





## What Causes Autism?

Not long ago, the answer to this question would have been “we have no idea.” Research is now delivering the answers. We now know that there is no one cause of autism just as there is no one type of autism. Over the last five years, scientists have identified a number of rare gene changes, or mutations, associated with autism. A small number of these are sufficient to cause autism by themselves. Most cases of autism, however, appear to be caused by a combination of autism risk genes and environmental factors influencing early brain development.

Although autism appears to have its roots in very early brain development, the most obvious signs and symptoms tend to emerge between two and three years of age. Often parents are the first to notice that their child is showing unusual behaviors such as failing to make eye contact, not responding to his or her name or playing with toys in unusual, repetitive ways. Sometimes an autism spectrum disorder is diagnosed later in life, often in relation to learning, social or emotional difficulties.

## What's Different About People with Autism?

Things that may make a person with autism different can also be seen as exceptional abilities. It is important to think of him or her as intelligent, even if language or behavioral difficulties do not reveal this in the way you expect. Characteristics of someone with autism can be seen as both challenges and strengths. For example, a child who seems inflexible or rigid may also be the one who is the best at following the rules of your program.

People with autism may display some or all of these characteristics:

- Difficulty understanding language, gestures and/or social cues
- Limited or no speech
- When there is speech, it can be repetitive or relate primarily to one particular topic
- Limited or no eye contact
- Difficulty participating in back-and-forth conversations or interactions
- Social awkwardness
- Intense interest in unusual topics or objects
- Repetitive behaviors, such as pacing or lining things up, spinning, hand flapping or rocking

### Autism Spectrum Disorders per DSM IV

- Autism
- Asperger Syndrome
- PDD-NOS (Pervasive Development Disorder – Not Otherwise Specified)
- Rett Syndrome
- Childhood Disintegrative Disorder

Note: There are planned revisions to the definition of autism spectrum disorder (ASD) in the upcoming 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), scheduled for publication in spring 2013. Please visit [Autism Speaks \[www.autismspeaks.org\]\(http://www.autismspeaks.org\)](http://www.autismspeaks.org) for regular updates.





- Sensitivity to light, sound, smell, taste or touch
- Abnormal fears and/or lack of appropriate fear for real dangers
- Difficulty managing transitions, changes in routine, stress and frustration
- Strong visual skills
- Good rote learning and long-term memory skills (math facts, sports statistics, etc.)
- Adherence to the rules
- Honesty
- Intense concentration or focus, especially on a favorite activity
- Ability to understand and retain concrete concepts and patterns
- Strong interest and/or ability in mathematics, technology, music and art



## *Tips for Communication with People With Autism*

- Speak calmly.
- Use direct, concrete phrases.
- Instructions should contain no more than two steps.
- Allow extra time for the person to respond.
- Avoid using phrases that have more than one meaning, like “cut it out.”
- Avoid touching. If necessary, gesture or gently guide the person.
- Be alert to the possibility of outbursts or unexplained behavior. If the person is not harming themselves or others, just wait for these behaviors to subside.

## Other issues that often accompany autism:

- Seizure disorder
- Tic disorders
- Poor nutrition
- High rates of accidents and injuries
- Gastrointestinal disorders
- Mental health disorders (anxiety, depression, mood disorders)
- Sleep Problems





## *Tips to Support Children with Autism in Youth Programs:*

### **Be Welcoming and Supportive**

- Meet the child where he is and learn from him.
- Respect him as an individual.
- Do not talk about him in his presence as if he isn't there.
- Set clear expectations and boundaries.
- Be consistent.
- Develop and implement structure.
- Practice and provide repetition to help with understanding and to build skills.
- Expect growth. Keep your standards high.

### **Develop Strategies to Compensate for Challenges**

- Offer preferred seating or placement and allow for additional response time.
- Provide organizational supports like written schedules, lists, visual cues, and specific verbal directions.
- Be aware of a child's sensory needs. Avoid or prepare for triggers like fire alarms.
- Give breaks for self-regulation.
- With small steps and supports, allow the participant to exhibit success.
- Reward what you want to see with positive reinforcement. Use the child's interests to engage and motivate him.

### **Educate and Communicate**

- Educate other youth participants about autism.
- Promote acceptance and understanding among peers and staff.
- Support social development with role-playing, modeling, and rewards. Make sure to include typical peers.
- Communicate with family members and caregivers.
- Ask questions and share what works. Problems solve what isn't working.
- Always keep learning and be creative.

### **Finally**

- Relax and have fun.
- Celebrate success.
- Treasure the individual.





## Reflect:

In what ways do you think the unique strengths of people with autism could benefit your youth organization?

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People with autism are all unique. One child can have very different strengths, needs and challenges from another. The first goal of someone working with children with autism is to seek to understand.

How do you think you can work best with family, caregivers and the child to understand them?

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## Resources:

**Autism Speaks Video Glossary** [www.autismspeaks.org/what-autism/video-glossary](http://www.autismspeaks.org/what-autism/video-glossary)

This glossary contains video clips that can help you see what autism “looks like.” It shows the subtle differences between typical and delayed development in young children.

**Autism Speaks Resource Library** [www.autismspeaks.org/family-services/resource-library](http://www.autismspeaks.org/family-services/resource-library)

For those who want to learn more about autism, browse the latest books, magazine articles, educational manuals, software, and much more.

**Autism Speaks Resource Guide** [www.autismspeaks.org/family-services/resource-guide](http://www.autismspeaks.org/family-services/resource-guide)

A comprehensive list of autism services and providers by geographic location. You can use this information as a referral tool for families who have children with autism, and as a way to find potential partners in your local area.

*The Official Autism 101 Manual* by Karen L. Simmons with contributions by Temple Grandin, Anthony Attwood, Darold A. Treffert, Bernard Rimland, Jed E. Baker, and more

*Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger’s Syndrome, Pervasive Developmental Disorder, and Other ASDs* by Chantal Sicile-Kira

*Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child’s Life* by Lynn Koegel, Claire LaZebnik





# Examples of People First Language

By Kathie Snow

visit [www.disabilityisnatural.com](http://www.disabilityisnatural.com) to see the complete article.

Remember: a disability descriptor is simply a medical diagnosis; People First Language respectfully puts the person before the disability; and a person with a disability is more *like* people without disabilities than different!

## Say:

## Instead of:

People with disabilities.	The handicapped or disabled.
He has a cognitive disability/diagnosis.	He's mentally retarded.
She has autism (or a diagnosis of...).	She's autistic.
He has Down syndrome (or a diagnosis of...).	He's Down's; a mongoloid.
She has a learning disability (diagnosis).	She's learning disabled.
He has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
She's of short stature/she's a little person.	She's a dwarf/midget.
He has a mental health condition/diagnosis.	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.
He receives special ed services.	He's in special ed.
She has a developmental delay.	She's developmentally delayed.
Children without disabilities.	Normal or healthy kids.
Communicates with her eyes/device/etc.	Is non-verbal.
Customer	Client, consumer, recipient, etc.
Congenital disability	Birth defect
Brain injury	Brain damaged
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs... or she uses...	She has problems with...has special needs.

**Keep thinking—there are many other descriptors we need to change!**

Excerpted from Kathie's People First Language article, available at [www.disabilityisnatural.com](http://www.disabilityisnatural.com).

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# Ten Things Every Child with Autism Wishes You Knew

by Ellen Notbohm

from the book *Ten Things Every Child with Autism Wishes You Knew* (2005, Future Horizons, Inc.)

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute — the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look “normal” but his behavior can be perplexing and downright difficult.

Autism was once thought an “incurable” disorder, but that notion is crumbling in the face knowledge and understanding that is increasing even as you read this. Every day, individuals with autism are showing us that they can overcome, compensate for and otherwise manage many of autism’s most challenging characteristics. Equipping those around our children with simple understanding of autism’s most basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is an extremely complex disorder but for purposes of this one article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and

whole child/self-esteem issues. And though these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at

a different point on the spectrum. And, just as importantly — every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

**1. I am first and foremost a child. I have autism. I am not primarily “autistic.”** My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about.

As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don’t think I “can do it,” my natural response will be: Why try?

**2. My sensory perceptions are disordered.** *Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. It his means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a “simple” trip to the grocery store may be hell for me:*





My hearing may be hyper-acute. Dozens of people are talking at once. The loudspeaker booms today's special. Musak whines from the sound system. Cash registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can't filter all the input and I'm in overload!

My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle 3 with ammonia... I can't sort it all out. I am dangerously nauseated.

Because I am visually oriented (see more on this below), this may be my first sense to become overstimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing — the space seems to be constantly changing. There's glare from windows, too many items for me to be able to focus (I may compensate with "tunnel vision"), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular and proprioceptive senses, and now I can't even tell where my body is in space.

**3. Please remember to distinguish between won't (I choose not to) and can't (I am not able to).** Receptive and expressive language and vocabulary can be major challenges for me. It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, this is what I hear: "\*&^%\$#@, Billy. #&^%\$&\*....." Instead, come speak directly to me in plain words: "Please put your book in your desk, Billy. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it is much easier for me to comply.

**4. I am a concrete thinker. This means I interpret language very literally.** It's very confusing for me when you say, "Hold your horses, cowboy!" when what you really mean is "Please stop running." Don't tell me something is a "piece of cake" when there is no dessert

in sight and what you really mean is "this will be easy for you to do." When you say "Jamie really burned up the track," I see a kid playing with matches. Please just tell me "Jamie ran very fast."

Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.

**5. Please be patient with my limited vocabulary.** It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong.

Or, there's a flip side to this: I may sound like a "little professor" or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Because language is so difficult for me, **I am very visually oriented.** Please show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of consistent repetition helps me learn.

A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, helps me manage my time and meet your expectations.

I won't lose the need for a visual schedule as I get older, but my "level of representation" may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.





**7. Please focus and build on what I can do rather than what I can't do.** Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need "fixing." Trying anything new when I am almost sure to be met with criticism, however "constructive," becomes something to be avoided. Look for my strengths and you will find them. There is more than one "right" way to do most things.

**8. Please help me with social interactions.** It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, it may be that I'm delighted to be included.

I do best in structured play activities that have a clear beginning and end. I don't know how to "read" facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know the proper response. Teach me to say "Are you OK?"

**9. Try to identify what triggers my meltdowns.** Meltdowns, blow-ups, tantrums or whatever you want to call them are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, activities. A pattern may emerge.

Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment.

*Parents, keep in mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders and gastrointestinal problems can all have profound effects on behavior.*

**10. Love me unconditionally.** Banish thoughts like, "If he would just..." and "Why can't she..." You did not fulfill

every last expectation your parents had for you and you wouldn't like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you – I am worth it.

And finally, three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I'm not good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, tattle on my classmates or pass judgment on other people? Also true that I probably won't be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh.

They may have had autism too.

The answer to Alzheimer's, the enigma of extraterrestrial life — what future achievements from today's children with autism, children like me, lie ahead?

All that I might become won't happen without you as my foundation. Be my advocate, be my friend, and we'll see just how far I can go.

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Ellen Notbohm is author of **Ten Things Every Child with Autism Wishes You Knew, Ten Things Your Student with Autism Wishes You Knew, and The Autism Trail Guide: Postcards from the Road Less Traveled**, all ForeWord Book of the Year finalists. She is also co-author of the award-winning **1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders**, a columnist for *Autism Asperger's Digest* and *Children's Voice*, and a contributor to numerous publications and websites around the world. To contact Ellen or explore her work, please visit [www.ellennotbohm.com](http://www.ellennotbohm.com).



Inclusion:  
Leading the  
Way in Access  
for Everyone



# Inclusion: Leading the Way in Access for Everyone



*Goal: To realize the importance and benefit of including people with autism in youth-serving organizations and programs.*

## What is Inclusion?

*“For me, inclusion is about a community where everyone is recognized for their differences and everyone is recognized as belonging – not only in our schools, but in our communities.” - Dr. Joseph Petner, Educator*

Inclusion is about offering the same activities to everyone, while providing support and services to accommodate people’s differences. Inclusive organizations actively reach out to people with disabilities and seek to understand and appreciate their differences, while fostering a sense of belonging.

## *Inclusion in Community Programs Means...*

- Making all programs in which typically developing youth and their families participate accessible and available to youth with disabilities and their families.
- Developing community programs for individuals with and without disabilities.
- Placing individuals with disabilities in the same community programs that their parents would choose for them if they did not have disabilities.
- Providing opportunities for special services to be provided and individual needs to be met, within typical community settings.
- Providing opportunities for social relationships between individuals with and without disabilities.
- Teaching all youth to understand, accept, and value human differences.

## Why is Inclusion Important?

*“If every child matters, every child has the right to a good start in life. If every child matters, every child has the right to be included. And that is so important for children with special needs.” - Cherie Blair*

Ultimately, the most important thing about inclusion is that it recognizes and honors the fundamental value of each person.





## Inclusion is a Right and a Responsibility

- Inclusion in employment, educational, recreational and community settings is a basic element of human rights.
- Integrating people with disabilities is the right thing to do. We do not want to live in a world that is divided into the typical world and the disabled world.
- It is the responsibility of our youth organizations, community groups, and faith communities to take an active role in promoting the idea of inclusion. Most youth organizations focus on specific areas of character development and growth for young people, which makes including people with disabilities a good idea, but also a mission-based responsibility.

## Inclusion Works to the Benefit of All

*“Through the program, Sara has gained a sense of responsibility with learning to help others. Her leadership qualities have increased along with her confidence. She wants to continue staying in the program since she has developed friendships.”*

*- Sara’s mom*

### The youth with autism:

- get to participate in programs in their community with their siblings, friends and neighbors.
- learn from their peers who serve as role models to help them with social skills and communication.
- receive preparation for adult life in the community.

### Peers:

- learn empathy and are exposed to diversity. Our youth begin to see people first and the disability second.
- become comfortable interacting with people with disabilities.
- see that people with disabilities are like them in many ways, and that they have unique strengths along with their challenges.

## Did You Know:

Safeguards such as the Americans with Disabilities Act and Section 504 of the Rehabilitation Act guarantee youth with disabilities the right to participate in youth programs. Enacted in 1990, the Americans with Disabilities Act is a powerful civil rights law that applies to most programs serving youth.

## Types of Inclusion

### Full Inclusion

Youth with disabilities are always included in activities with non-disabled participants, while being provided with appropriate supports and services.

### Partial Inclusion

Wherever possible, youth with disabilities are included in general activities and treated like a full member of the group. However, they can be pulled out for specialized activities that might be disruptive to the full group.





## What is the ADA:

The Americans with Disabilities Act is a civil rights law that gives children and adults with disabilities the right to play, work and live in the community with the same opportunities as people without disabilities. The essence of the ADA is to have a more inclusive society and to remove stereotypes that may get in the way of people who have disabilities as they participate in the daily life of our communities.

## What Does ADA Cover?

To ensure non-discrimination, your program or organization needs to have the following standards in place:

- **Equal Opportunity:** Youth with disabilities must not be denied equal opportunity to participate and benefit from programs and activities.
- **Eligibility:** Eligibility criteria that would screen out youth with disabilities may not be used unless necessary for the provision of services and activities.
- **Integration:** Integration is central to the purpose of ADA. Youth with disabilities must be integrated into your programs to the maximum extent appropriate. Separate programs are permitted when necessary to ensure equal opportunity, but this doesn't mean that youth with disabilities can be excluded from regular programs if they chose to participate in them.
- **Reasonable Modifications:** When necessary to ensure equal opportunity, reasonable modifications must be made to policies, practices and procedures. If the program can demonstrate that a modification would fundamentally alter the nature of the services it provides, it is not required to make the modification.
- **Surcharges and Costs:** Extra charges cannot be imposed on youth with disabilities or their families.
- **Additional Requirements:** Additional requirements may not be imposed on people with disabilities that are not imposed on others.



## *Tips: A Successful Inclusion Program*

- Commitment for a successful inclusion program must come from the top down. Your board and staff leadership must recognize and support the program.
- Teamwork among program staff, family members, caregivers, and the child's team is crucial.
- Parents should be actively involved in planning for inclusion.
- Disability training and awareness programs should be made available to staff and volunteers.
- Incorporate program modifications that allow the child with autism to share activities and experiences with other participants.
- Focus on the participant's strengths.
- Encourage interaction between youth with autism and their typically developing peers.
- Be flexible. If something doesn't work well, be prepared to try again with something new.





## Reflect:

Is inclusion currently a part of your youth organization? If so, what is working for you? If not, what do you think are the first steps toward getting started?

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How do you think inclusion benefits:

Youth with autism and their families?

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Other non-disabled participants in your organization?

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Staff and volunteers?

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## Resources:

### The Institute on Community Integration

<http://ici.umn.edu>

This is the website for the University of Minnesota Institute on Community Integration, a Center for Excellence in Developmental Disabilities. The site offers research, training and information sharing on policies and practices to ensure that all children, youth, and adults with disabilities are valued by, and contribute to, their communities of choice.

### Kids Together Inc.

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

Kids Together, Inc. was an organization founded by parents of young children with disabilities. Their goal is to promote children with disabilities being a part of what every other child was and to promote the understanding that having a disability was one small part of their children's lives. Great resources on how to be an "includer."

### Disability is Natural

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

The mission of Disability is Natural is to encourage new ways of thinking about developmental disabilities, in the belief that our attitudes drive our actions, and changes in our attitudes and actions can help create a society where all children and adults with developmental disabilities have opportunities to live the lives of their dreams, included in all areas of life.

### Americans with Disabilities Act (ADA) Information

[www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)

The U.S. Department of Justice ADA site provides FAQs, technical support and guidelines related to implementing the Americans with Disabilities Act.

*Inclusion: 450 Strategies for Success: A Practical Guide for All Educators Who Teach Students With Disabilities*  
[Paperback] Peggy A. Hammeken (Author)





# Autism/Disability Inclusion Self-Assessment

*Adapted from the Disability Inclusion Self-Assessment developed by Partners for Youth with Disabilities*

<b>Accessibility:</b>	<b>Always</b>	<b>Usually</b>	<b>½ the Time</b>	<b>Seldom</b>	<b>Never</b>
Do your materials (print and web) include an inclusion or non-discrimination policy?					
Does your registration process include a question related to any accommodations that might be required?					
Does staff know how to respond to requests for reasonable accommodations?					
Is program staff trained to use, arrange for or produce materials in alternative formats for the purpose of orientation and program activities?					
Do you promote and market your accessibility to people with autism?					
<b>Creativity and Flexibility:</b>	<b>Always</b>	<b>Usually</b>	<b>½ the Time</b>	<b>Seldom</b>	<b>Never</b>
Do relevant staff and/or volunteers have the skills and commitment to adapt program activities, games, and sports OR offer a variety of activities to engage all participants?					
When designing program activities, are multiple learning styles taken into consideration?					
Do program participants have flexible and alternative opportunities for demonstrating skills or lessons learned?					
Are staff and/or volunteers sensitive to sensory issues participants may have and willing to work to minimize triggers that can be discomforting (can include light, noise, bright colors, and textures)?					
Are participants allowed adequate time to learn a new skill or perform tasks?					
Do staff and/or volunteers give warning and provide extra support for participants in case of changes in schedule and/or as they transition from one activity to the other?					





### Communication:

	Always	Usually	½ the Time	Seldom	Never
Are staff and/or volunteers trained in person-first and inclusive language?					
Are rules and directions (and, where applicable, rewards and consequences) stated in a clear, concise and step-by-step manner?					
Are pictures, gestures and role modeling used to ensure that all participants understand rules and directions?					
Are participants encouraged to demonstrate their understanding of rules and directions to ensure they understand?					

### Promoting Social Skills:

	Always	Usually	½ the Time	Seldom	Never
Are all participants held to the same expectations with regard to participation and achievement?					
Do staff and/or volunteers recognize the unique skills, talents and contributions of those with varying abilities?					
Do staff and/or volunteers work to engage participants socially and guide them in developing relationships with others?					
Do staff and/or volunteers model respect for diversity and take advantage of changes to normalize differences?					
Are staff and/or volunteers careful not to single out or stigmatize people with disabilities?					
Are relevant staff and/or volunteers trained on how to coach participants on when, how and with whom to disclose his or her disability and, when necessary, reasonable accommodation needs?					
Are relevant staff and/or volunteers trained to respond appropriately to instances of bullying?					
Are relevant staff trained in positive behavior modification/ reinforcement techniques?					





**Organizational Policies and Procedures:**

	Always	Usually	½ the Time	Seldom	Never
Does your organization collaborate with entities that specifically serve people with disabilities to promote visibility within the disability community?					
Are staff and/or volunteers offered disability etiquette training at the start of their involvement with the program?					
Are parents of youth with disabilities encouraged to strategize adequate support for their children?					
Are staff and/or volunteers encouraged and provided tools to gather more information about a specific disability when appropriate?					
Are mechanisms in place to monitor the program’s success with regard to inclusion?					
Does your organization have a financial plan to reasonably accommodate people with disabilities in programs and activities?					

**Human Resources:**

	Always	Usually	½ the Time	Seldom	Never
Are efforts made to incorporate inclusion as a point on staff agendas?					
Are efforts made to hire staff with expertise related to disability inclusion?					
Are efforts made to recruit qualified people with disabilities for open positions?					
Are efforts made to bring people with disabilities onto the board of directors?					



Getting Started:  
Leading the  
Way to an  
Autism-Friendly  
Inclusive  
Environment



# Getting Started: Leading the Way to an Autism-Friendly Inclusive Environment



**Goal: To learn what steps your organization needs to take to incorporate youth with autism into your program.**

## A Commitment to Inclusion and Diversity

Youth with autism constantly experience barriers to experiencing the enjoyment of so many activities that the rest of us take for granted. Their abilities are overlooked and their capacity underestimated. The barriers they face are often more a result of the environment in which they live rather than a factor of their ability to participate.

Downloading this guide is an important step in your commitment to inclusion and to valuing the lives of all youth. You are creating an opportunity for children with autism to experience the community activities that are so important to the development of our youth.

Successful inclusion will only happen with an organization-wide commitment to serving all of your community's youth. All levels of staff and volunteers must adopt an inclusive philosophy, and this new way of thinking can transform the organization. Your organization will be a true reflection of the community you serve.

## Overcoming the Fear of the Unknown

*“Initially I had some apprehension about incorporating children with autism into our regular activities. By the end of the session though, I saw how much their inclusion had changed all of us for the better – my team and the other campers. Seeing them strive to overcome obstacles and persevere helped all of us grow and become a closer group. Our campers with autism are my inspiration.”*

*Working with children with autism has provided me with an opportunity to see the world in a different way. I see them strive to overcome obstacles and persevere, and learn to persevere myself. They are my inspiration.”*  
- Steven, YMCA Summer Camp

Inclusion is going to take time, preparation and patience. One of the first barriers that you may have to overcome is the negative attitudes and fear of the unknown. Your staff and volunteers may fear that their time will be taken up almost exclusively by youth with special needs, leaving little time for other program participants. Typically developing youth may be afraid of being with others who aren't like them. Fear is a natural reaction to something we don't understand and/or have experience with. However, we need to make sure that fear faced instead of avoided. When fears are avoided, we see people with disabilities either excluded all together or integrated physically, but not socially.





## Conquering Fear

- Don't pretend fears and negative attitudes about people with disabilities don't exist among your staff and volunteers. Address them and design a plan to help your team overcome them.
- Question all the stereotypes or beliefs you may have about autism, and do your homework. Refer to the About Autism section of this guide and the resources provided to learn more. Remember, you are relating to a young person, not a disorder.
- The most effective way of eliminating fear and changing attitudes is through exposure. As your team and program participants are exposed to more people with autism, their attitudes will change.
- Focus on similarities instead of differences; strengths instead of limitations.

## Five Steps to Becoming an Inclusive Youth Organization

1. **Examine your organization's mission statement.** Does it encompass your philosophy on inclusion and your desire to serve people of all abilities? An example of a strong inclusive mission comes from the Boys and Girls Clubs of America:

*“To enable all young people, especially those who need us most, to reach their full potential as productive caring, responsible citizens.”*

Make sure that your mission statement is not exclusionary and invites participation from all. If you aren't sure what message your mission is sending, share it with a few others and ask for feedback.

Share your inclusive mission statement wherever you can. Display it in your facilities. Include it on your website and on printed materials. This is a statement that all staff and volunteers should be familiar with.

2. **Review your admissions policy.**

Take a moment to review your admission policies. Are they very rigid? Are they mostly based on achievement of certain skills? Youth organizations must have policies related to admission and enrollment, but it is important to make sure they do not exclude groups of people by demanding a particular skill.

### **Example of a Rigid Policy**

An organization's policy states that youth will not be allowed in the swimming pool with flotation devices. Many children with disabilities would benefit from the opportunity to be in a pool with their typically developing peers, but would not be able to participate without a flotation device. Therefore, an inclusion support you could provide would be to allow a youth to participate with a flotation device.

### **Example of a Skills Based Requirement**

A music camp may have a requirement that to participate a child must perform a solo song, dance or instrumental arrangement. This may not be possible for all children. An example of an inclusion support would be to find another way for the child to participate – perhaps as a technical assistant.





### 3. Create or modify your existing intake and enrollment process to be mindful of inclusion.

A youth organization's intake and enrollment process helps acclimate the family to your services and gives them the opportunity to provide you with the information you need to serve their child.

This process usually begins with a telephone or e-mail inquiry from a parent. It is important that the people who respond to these general inquiries are aware of the organization's commitment to inclusion and have participated in basic training. It is very easy for a parent who is used to running into roadblocks to get discouraged.

Usually, if there is an interest from the family, the parent and child will visit the program so they can see the facility and get more information. This is a good time for you to learn more about the child, what the family's goals are and the need for accommodations or support might be. At the end of this section is a list of sample intake questions to use when speaking with families. This is also a good time to assure parents that the information about their child will be kept confidential.

Other things to consider with the family when they are enrolling their child:

- Establish a plan for ongoing communication, whether it is a written log, phone calls, e-mails, or check in at drop off or pick up.
- Be thorough in your description of activities. Ask questions and be a good listener.
- If the participant uses assistive technology, consider asking the family to train a staff member on the equipment.
- Invite the parent to share information about the child with program staff at a staff meeting or other appropriate time.

## Registration Do's and Don'ts

- If your program is full, you are not required to create a space for a child with a disability, but you also cannot deny a space if there is an opening because of the disability.
- Your registration and/or enrollment form should include a question that asks whether the participant requires any type of accommodation for a medical condition or disability.
- You may not ask for a diagnosis, but you should ask open-ended questions that will help you understand what kind of supports will be needed.





#### 4. Evaluate your program from an inclusion perspective.

Use the checklist provided at the end of the Inclusion section to evaluate your program as you plan for inclusion. Remember, for inclusion to be effective, the process must involve everyone from board members to program staff to the receptionist and the custodial team. Everyone working in the organization needs to understand the commitment to inclusion and be allowed to share their thoughts and have an impact on decision-making.

#### 5. Make a commitment to training for all staff and volunteers.

Committing to ongoing training for staff and volunteers around inclusion is crucial to the success of your program. The organization's philosophy of inclusion should be regularly communicated – and the most successful training not only raises awareness about people with disabilities, but also increases the knowledge and skills of your teams.

##### Lots of Ways to Learn

- All new employees and volunteers should receive orientation that includes information on inclusion.
- Provide orientation that includes information on inclusion for all new employees and volunteers.
- Give presentations at staff or other regularly scheduled meetings.
- Incorporate job coaching from supervisors or senior staff members
- Attendance at inclusion-related conferences
- Begin online training
- Share stories about successful inclusion experiences in organizational materials
- Assign seasoned staff to present training that they have researched at meetings with other staff.
- Have families of children with autism speak at meetings.

## Inclusion involves all team members

- The board and executives who help craft the inclusion policy and establish the commitment to an inclusive youth organization
- The financial team who develop budgets
- The program or administrative staff
- The marketing team who design printed and web materials
- The people who answer the phones and are the first point of contact for families
- The facilities and custodial staff who ensure the environment is conducive to inclusion





## Sample Non-Discrimination Statements

**The Department of Parks and Recreation** actively seeks and supports participation by all people with a variety of interests and abilities in our programs and services.

**The Mathematics Foundation of America** does not discriminate based on gender, race, creed, color, national or ethnic origin, disability, marital status, or sexual orientation in the administration of its educational programs, admissions policies, employment practices, financial aid, or any other programs. At Canada/USA Mathcamp, we strive to create a diverse community that welcomes students and faculty from all backgrounds; we feel that this diversity is one of our greatest strengths.



### *Tips: Reaching out to the Community for Participants*

*“Since taking a more inclusive approach to marketing, we have seen an increase in membership of kids with disabilities in the Boys & Girls Club. Making a few small changes has made the Club more welcoming. Kids with and without disabilities have formed new and lasting friendships. Creating an inclusive environment is teaching our children to embrace the diverse community in which we all live.”*

- Develop relationships with organizations and professionals in your area that serve people with autism. The [Autism Speaks Resource Guide](#) is a great place to start to find out what groups are serving people with autism in your community.
- Include information about your inclusion philosophy in all of your marketing materials – your website, brochures, flyers, posters, e-mail, social media.
- Make sure that non-discrimination statements are on all of your promotional material, and that material is welcoming and inviting.
- Spread the word via current parents and participants, teachers, community leaders that your organization is an inclusive program.





## Working with Parents

*“I spent months trying to find a summer camp that would accept my five-year-old son, Corey, who has autism. Because he is non-verbal, all of the camp directors were hesitant to include him because they had never worked with someone with autism before. When I finally found a camp that accepted him without hesitation, I almost didn’t believe what I’d heard. He attended camp with typical peers along with his aide. It was an incredible experience for him that really impacted his social development for over the next year.” - Corey’s mom*

The people who know the child you will be working with best are the parents or caregivers. Your relationship with them is important to building an environment of success for youth with autism.

## Building Successful Relationships with Families

- Be considerate of the family’s needs and expectations.
- Be a good listener. Listen with compassion and respect. Always respect the family’s confidentiality.
- Invest in the relationship. Take time to get to know the family members and build a rapport. This will go a long way toward developing trust.
- When presenting concerns about their child, make sure to frame them in a positive way and be ready to develop solutions hand-in-hand with the family.
- Communicate, communicate, communicate.

## Inclusion is Happening Now

A number of youth organizations are developing programs and practices to attract and accommodate youth with disabilities. Following is a partial list:

- Academy for Educational Development
  - Big Brothers Big Sisters
  - Boy Scouts of America
  - Boys & Girls Clubs of America
    - Camp Fire USA
  - Chabot Space and Science Center
    - City Year
    - Girl Scouts of the USA
    - Imagination Stage
    - Mass Mentoring
  - Minnesota Conservation Corps
- National 4-H Council
- National After School Association
- National Recreation and Park Association
  - National Wildlife Federation
    - Operation Fresh Start
  - The After-School Corporation
    - The Corps Network
    - The Washington Center
  - Utah Conservation Corps
    - Wilderness Inquiry
  - YMCA





## Reflect:

What are your current attitudes about people with autism or other disabilities?

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How can you support your team members in becoming more comfortable working with people with autism and other disabilities?

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## Resources:

### Kids Included Together

<http://kitonline.org/>

Kids Included Together (KIT) specializes in providing best practices training for community-based organizations committed to including children with and without disabilities into their recreational, child development and youth development programs.

### Autism Education

[www.autismeducation.net](http://www.autismeducation.net)

Their primary purpose is to provide information and training to families and professionals regarding best practices in autism treatment.

### Autism Internet Modules

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

The Autism Internet Modules were developed with one aim in mind: to make comprehensive, up-to-date, and usable information on autism accessible and applicable to educators, other professionals, and families who support individuals with autism spectrum disorders (ASD). Written by experts from across the U.S., all online modules are free, and are designed to promote understanding of, respect for, and equality of persons with ASD.





# “About Me” Profile Form

Student’s Name: \_\_\_\_\_

What are some of the things that you are most interested in? \_\_\_\_\_

What upsets you? \_\_\_\_\_

What are you afraid of? \_\_\_\_\_

What makes you laugh? \_\_\_\_\_

What is ONE thing you would like to get better at this year? \_\_\_\_\_

What calms you down when you are overwhelmed or upset? \_\_\_\_\_

What rewards work well for you? \_\_\_\_\_

What do you do after school or on weekends? \_\_\_\_\_

Person completing form: \_\_\_\_\_

Relationship to student: \_\_\_\_\_

Email address of family or caregiver contact: \_\_\_\_\_

Phone number of family or caregiver contact: \_\_\_\_\_

What is the best way to contact you? \_\_\_\_\_

What days or times are convenient for you to meet with the school team? \_\_\_\_\_

Are there any issues that you would like to discuss or hear more information about? \_\_\_\_\_





# Parent Questionnaire: Creating a Successful Experience for Your Child with Autism

## About Our Program

What do you see here that you think your child will really enjoy? What are his favorite activities?

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What are some of his fears?

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Do any particular sounds, smells or tactile sensations bother him?

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How can we adjust the environment to meet him/he needs?

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What kind of accommodations can we make to help him be successful in our program?

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## Special Interests and Talents

What does him/he like to do at home in his free time?

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What are his favorite books, games, and television shows?

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What is he really good at?

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## Development

Does him/he require any adaptive equipment?

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What does he do when upset? What helps to calm him down?

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How does he communicate? Does he use words, pictures, or gestures? Does he use assistive technology for communication?

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Does him/he need assistance when using the toilet?

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Are there specific things that he needs help with (opening his lunch or blowing his nose)?

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## Safety

Does your him/he have allergies?

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Does your child require a special diet? What are him/he preferred snacks and eating schedule?

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Is the child a flight risk (i.e., does him/he run away)?

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## TRAINING RESOURCE

# Baseline Autism Quiz

By Sonia Dickson-Bracks

Name \_\_\_\_\_ Date \_\_\_\_\_

**1. When a child receives a diagnosis of autism, he needs to meet diagnostic criteria in three areas. What are the three areas?**

1. sensory, behavior and language
2. communication/ language, social and behavior
3. language, social and special diets
4. language development, behaviors and sensory

**2. What are the current statistics for the prevalence of autism spectrum disorders in the USA?**

1. 1:150
2. 1:88
3. 1:166

**3. When supporting a student with autism, what key areas will you need to address first in order to support learning, social skills and independence?**

- communication, organization and sensory
- behavior, learning and friendships
- social, play, academics

**4. What is a Positive Behavior Support Plan?**

- A plan that is put in place after a functional assessment is completed to address behaviors and teach replacement strategies for those behaviors
- An intervention plan that is used to provide consequences for behaviors when they occur
- A system that all staff needs to follow and take data on

**5. Why do some individuals with autism exhibit behaviors?**

- because they are willful and stubborn
- because they often have challenges expressing their needs verbally so they use behavior to communicate
- because they are angry
- because they hate school and want to avoid all work

**6. Sensory dysfunction is:**

- a process by which you motor plan a movement
- challenges processing incoming sensory information that affects the your response to the environment
- hyposensitivity to smell





**7. ABA stands for:**

- Autism Behavior Analysis
- Applied Behavioral Analysis
- Autism and Behavior and Advice

**8. When supporting a student in the classroom, what is the staff's primary role?**

- helping the student to access the academics, socialize with peers and develop skills that will help him manage the group/ classroom setting
- doing everything for the student and making sure he has everything he needs
- speaking for the student, staying next to him and never leaving his side

**9. A schedule provides a student with autism with:**

- a list of what he has to do in the exact order it's written
- a visual representation of the day's events that he must follow at all times
- a system by which he can organize himself, understand daily occurrences, be warned of unexpected changes, and know the who, what, where of the day

**10. What does ASD stand for?**

- Autism, Symptoms and Disorder
- Autism Spectrum Disorder
- Autism, Solutions and Decisions

**11. Why is autism described as a spectrum disorder?**

- it covers a range of symptoms from mild to severe, and the symptoms present in each individual differently
- the spectrum is an overview of what autism may be
- it affects students of all races and ethnic backgrounds

**12. If you had to define what you think autism is to someone who does not know, how would you describe it?**

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**13. In the classroom it is your role to help support the student and also to help the student be part of the group. How best do you think you can help the student you support?**

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## TRAINING RESOURCE

# Sensory Processing Quiz

By Sonia Dickson-Bracks

Name \_\_\_\_\_ Date \_\_\_\_\_

### 1. List the five senses:

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### 2. List the two “hidden senses”:

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### 3. What is hypersensitivity?

- a. under responsive to a sensation
- b. senses running all around
- c. over responsive to a sensation

### 4. What is hyposensitivity?

- a. over responsive to sensory input
- b. sensitive to everything
- c. under responsive to sensory input

### 5. Tactile defensiveness is a condition in which:

- a. an individual is extremely sensitive to touch, which may lead to misinformation or behavioral responses regarding touch
- b. an individual needs light touch and craves brushing
- c. an individual likes to be brushed with a feather or withdraws from strong smells

### 6. The Vestibular System refers to:

- a. structures within the inner ear
- b. structures within the muscles and joints
- c. structures within the chest cavity

### 7. Dysfunction within the vestibular system may manifest itself in two different ways. Some individuals may be hypersensitive to vestibular stimulation and have fearful reactions to ordinary movement activities (e.g., swings, slides, ramps, inclines) OR some may actively seek very intense sensory experiences such as excessive body whirling, jumping, and/or spinning.

True      False

### 8. Proprioceptive System refers to:

- a. the system that provides the body with information about head position and ear ache
- b. components of muscles, joints, and tendons that provide a person with a subconscious awareness of body position

### 9. What is sensory dysfunction?

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## TRAINING RESOURCE

# Autism/Asperger Simulation Activity

By Lori Ernsperger, PhD

The following simulation activity is intended to be implemented with school teams to increase awareness and understanding of students with autism. The activity takes 5-10 minutes and can be used with staff at any grade level, or with peers from upper elementary and older. The steps for implementation include:

### Prep Work:

1. Copy the following sheets on Pink, Blue, or White paper. If the paper says “Talk to the person with the Blue sheet” that page should be on Pink paper and vice versa. The sensory sheet is copied on to white paper.
2. Cut the papers in half.
3. Collate the pages into sets of Pink/Blue/White. The number of sets is determined by the number of participants. Each participant will receive one half-sheet of paper.

### Activity:

1. Tell the group that they are going to do a fun interactive activity. Don't share too much in the beginning. Let them come to their own conclusions.
2. Have participants get into groups of 3, this activity does not work with groups of 2 or 4 people.
3. Hand-out the sets of Pink/Blue/White papers to each group. Each participant should take a half sheet of paper and quickly review the instructions on their sheet only. Let participants know that they are not to read each other's paper.
4. After a few seconds, tell the groups to begin. The participants with the Pink/Blue sheets should quickly begin talking about food.
5. The participants with the White sheets may need some encouragement to interrupt their colleagues to discuss the sensory system. Walk around and encourage all participants to follow the directions exactly as they have on their papers.
6. After two minutes, stop the group. Most groups will have uncovered the hidden meaning of this activity.
7. Discuss the hidden intent of this activity. Ask the following questions:
  - What did it feel like to play your role in the group? Have the participants explain in one word how it felt, i.e. awkward, lonely, annoying, uncomfortable, sad.
  - Ask the participants with the White sheets if they observed the non-verbal cue their peers were using when they were speaking. Did they observe the non-verbal cue?
  - How was it different for the people with the Pink/Blue sheets vs. the person with the White sheet?
  - Relate their experience to students with autism and their peers. How does this two-minute simulation impact the educational experience of students with autism?
  - Discuss the importance of teaching social skills to help to avoid these situations.
  - Discuss the impact on bullying and depression for older students.





## Participant #1: Please follow directions below.

1. Have a normal conversation with the person with the Blue sheet only.
2. Talk only about the following topic: Food, which includes-
  - Favorite restaurants
  - Best meals
  - Recipes
  - What did you have for dinner last night
3. The person who is speaking should clasp their hands in front of them when they are talking. This non-verbal signal will indicate who is talking.
4. Carry-on a conversation for 3-5 minutes. Have fun!

## Participant #1: Please follow directions below.

1. Have a normal conversation with the person with the Blue sheet only.
2. Talk only about the following topic: Food, which includes-
  - Favorite restaurants
  - Best meals
  - Recipes
  - What did you have for dinner last night
3. The person who is speaking should clasp their hands in front of them when they are talking. This non-verbal signal will indicate who is talking.
4. Carry-on a conversation for 3-5 minutes. Have fun!





## Participant #2: Please follow directions below.

1. Have a normal conversation with the person with the Pink sheet only.
2. Talk only about the following topic: Food, which includes-
  - Favorite restaurants
  - Best meals
  - Recipes
  - What did you have for dinner last night
3. The person who is speaking should clasp their hands in front of them when they are talking. This non-verbal signal will indicate who is talking.
4. Carry-on a conversation for 3-5 minutes. Have fun!

## Participant #2: Please follow directions below.

1. Have a normal conversation with the person with the Pink sheet only.
2. Talk only about the following topic: Food, which includes-
  - Favorite restaurants
  - Best meals
  - Recipes
  - What did you have for dinner last night
3. The person who is speaking should clasp their hands in front of them when they are talking. This non-verbal signal will indicate who is talking.
4. Carry-on a conversation for 3-5 minutes. Have fun!





### Participant #3: Please follow directions below.

1. Speak Directly to your group.
2. It is your responsibility to share with your group the following facts:

#### The Sensory System

<b>Tactile System:</b> located on the skin. This area has a density of cells distributed all over the body, which includes the mouth, hands, and feet.	The function of the tactile system is to provide information about the environment and object qualities i.e. soft, sharp, dull, cold, hot.
<b>Visual System:</b> Located in the retina of the eye-stimulated by light	Provides information about objects and persons. Helps us define boundaries as we move through time and space.
<b>Auditory System:</b> Located in the inner ear and stimulated by air/sound waves.	Provides information about sounds in the environment i.e. loud, soft, low, near, far.
<b>Gustatory System:</b> The taste system is located on the tongue and closely related to smell	Provides information about different types of taste i.e. sour, bitter, salty, spicy, sweet.
<b>Olfactory System:</b> Located in the nasal structure.	Provides information about different types of smells i.e. musty, acrid, putrid, flowery, sweet.

3. It is extremely important that your group thoroughly understand the facts of the Sensory System.  
So, please be bold in your attempts to share the information.

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People and  
Places:  
Creating an  
Environment  
for Success



# People and Places: Creating an Environment for Success



*Goal: To show you how to make your program the best it can be for incorporating youth with autism.*

Understanding autism as well as the strengths and challenges of each participant with autism is important for all staff and volunteers. Here are some things to consider when working with youth with autism in general and in specific areas that might be part of your youth organization.



## *Tips for Staff and Volunteers Working with Youth with Autism*

### Things for All Team Members to Keep in Mind

*“Our son loved being at Camp Fire USA, I think we see the best in him in your programs, staffed with people who are trained on his strengths and challenges and allow him to interact with other neurotypical kids. All I can say is we loved it so much we want more!” - Joseph’s mom*

Your team will need to be prepared to support participants with autism in a way that is beneficial both to them and to the other participants. Planning, coordination, cooperation and supports are necessary to create a positive experience for everyone. Expect to be successful, but also understand that you may need to adjust your definition of success along the way. Remember to celebrate the small victories.

### Strategies for Success

- Be calm and positive.
- Model appropriate behavior for the youth with autism, as well as the other program participants, by greeting him and engaging in a respectful way.
- Situate the youth with autism for optimal attention to the group and learning activities.
- Be aware of sensory issues that may affect him.
- Provide written rules or pictures of expectations of behavior. People with autism often follow rules better when they know why a rule exists.
- Use descriptive praise to build desired behavior. For example, “I like the way you put your trash in the trash can.”





- Give positive directions, minimizing the use of don't and stop. By saying "Please sit in your seat" instead of "Don't stand up" you are clearly describing your expectations.
- It may be necessary to wait for a response to a question, use an alternative communication device or a communication strategy such as picture exchange.
- Collaborate with the participant's parents or aide to modify your curriculum or materials.
- Make sure that activities such as field trips, presentations, talent shows, plays or anything out of the usual is discussed ahead of time. Think about ways to include them and discuss and plan with their family and support team.
- Be aware of the vulnerability of youth with autism and the propensity for them to be victims of bullying behaviors, especially in areas with little supervision.

## Sports and Physical Activity Strategies for Success

Many youth with autism are able to participate in sports and are a great asset to their team. The amount of support required to make this happen will vary greatly from person to person. Some people with autism have great skills in learning rules and keeping track of statistics and may make great scorekeepers or coach's assistants. Some may be good at individual sports as they are not required to keep track of a ball and other team members while processing auditory and visual information from several sources at the same time.



- Be aware of motor, timing, language and attention issues that might affect his performance and interest and make appropriate accommodations.
- Know that Echoing locker rooms, whistles and the sound of others running and shouting might be overwhelming for someone with autism.
- Know that even though he may not be able to keep up with the pace of learning and the activity of the whole group, he might still be able to learn components of a sport or activity that provides a valuable social outlet and physical exercise.
- Break tasks into small components and celebrate successes.
- Promote as much independence as possible. For example, let him get the sport's equipment. Teach him the steps to warm up and cool down before playing.
- Practice and help troubleshoot skills outside of group practice time. Let him start getting ready five minutes before the others arrive. Ask his support team to help teach techniques for learning to kick a ball, throw, catch, etc.
- Solicit the assistance of his and support team to provide training in appropriate locker room behavior and social conventions regarding privacy.
- Help his peers support him, in a respectful way, in adhering to social conventions by modeling and/or directly instructing.





## Transportation Strategies for Success

Often part of the youth organization experience includes field trips or other activities where traveling on a bus might be necessary. It may be necessary for a person with autism to be routed on a smaller bus and/or have an aide assigned to ride the bus with them.

- Youth with autism may have impaired judgment, sensory issues or significant fears that might cause unexpected behaviors – for example, a lack of respect for traffic may cause them to dart into the street or a dog on the sidewalk might make them refuse to get off the bus. Know what to do to avoid or manage particular needs.
- Transitions are difficult for people with autism. This may result in some issues getting on to or off of the bus. Be prepared for this.
- Visual schedules can be helpful for managing behavior. This is particularly important if he or she only rides the bus periodically for field trips. Following is a generic example that could be created easily by using a digital camera to take a picture of each step or action:
  1. Wait for the bus doors to open.
  2. Get on the bus.
  3. Sit down.
  4. Buckle my seat belt.
  5. Ride quietly to school.
  6. Get off the bus.
- Allow someone who may be overwhelmed by noise on the bus to use earplugs or music and headphones.
- Consider assigning peer buddies to support and shield a vulnerable youth from bullying.

## Suggestions for When Behavior Problems or Incidents Occur

When a youth with autism exhibits maladaptive behavior that is seen as aggressive, dangerous or disruptive, it is essential to remember that behavior is a means of communication, and not necessarily an overt desire to influence or harm others. Here are some tips for staff on how to handle this if it occurs:

- Remain calm.
- Do not embarrass or reprimand the youth immediately and in the view of others.
- When addressing him, use limited verbal directions. Less can be more.
- Excessive talking and agitated adults can escalate a situation and overwhelm the participant. It can impede his ability to understand and comply with directions or communicate to his best ability. A few minutes of quiet followed by short, simple sentences will help everyone.
- Use established guidelines for communication, and be prepared to wait for a response.





- Give choices to help engage him and de-escalate his sense of being pushed around. For example, “Would you like to talk about this outside or in my office?”
- Sending the message that you are working to understand his perspective and trying to figure out why he exhibited the maladaptive behavior (and then following up by instituting appropriate supports and preventive measures) may be more helpful to changing the behavior than instituting a consequence. Remember, the goal is to halt the behavior and prevent it from occurring in the future.
- Obtain the facts from a variety of sources. Remember to gather information on behavior as well as what led up to the behavior. It is especially important to take into consideration sensory issues that may not usually be considered. Find out the consequences typically given for similar behaviors if they have occurred previously. Responses or inadvertent rewards for maladaptive behaviors can increase, rather than reduce, them.
- Take care in interacting with his family, who generally dread reports of behavior issues. Be mindful of their perspective and insights in working as a team to understand the underlying cause of the behavior and developing a plan for promoting a positive replacement behavior.

## Helping Peers Support Youth with Autism

*“Abby loves the program and has even said that she wants to teach autism when she grows up.” – Abby’s Mom*

Many youth have had little or no experience interacting with people on the autism spectrum. The best thing you can do to support their understanding is to create an atmosphere of open communication about the issues that may concern them. This type of atmosphere allows them to ask questions, get their curiosity satisfied, and can go a long way towards alleviating fears and embarrassment.

It is important to communicate with the parents of the youth with autism before sensitivity training is done to make sure what they are comfortable with in terms of disclosure. Some families may be comfortable with general training and acknowledgement of their child’s strengths and challenges to the class, but not with sharing the autism diagnosis. Other families are more open about their child’s diagnosis and are willing to be active participants in the education and sensitivity training. These are personal decisions that each family must make.

It is also important to keep in mind that some families may not have told their children about their diagnosis yet. Some children may know they have autism but may not want to share that information with their classmates. Again, these are individual decisions. The other consideration to discuss in advance is if the participant with autism will be present during the training.

### Why Autism Awareness?

- Break down stereotypes
- Answer questions and satisfy curiosity
- Reinforce the positive images and the strengths of people with autism





Often a parent, caregiver or staff member who knows the youth with autism well can introduce him or her to other program participants. Out of respect, a more specific introduction can also be done when he or she is not in the room. It is important to present the participant as a person with unique abilities and similarities (a family, siblings, pets, love of music, favorite foods, video games, movies, etc.) while also sharing some of the challenges and differences that typical peers may notice or need to be aware of.

## Bullying and Harassment of Children with Autism

Children with autism are especially vulnerable to bullying. The Interactive Autism Network (IAN) conducted a national survey on the bullying experiences of children with autism in 2011. The preliminary findings showed that 63% of the 1,167 children surveyed between the ages of 6 to 15 were bullied at some point in their life.

Your organization should have a zero tolerance for bullying. Creating a safe environment is necessary for participants to learn, grow and thrive. Celebrate when your participants show acts of kindness or social good. This isn't just about discipline and punishment – good anti-bullying practices include reward and recognition for doing the right thing.

## Important Facts to Know About Bullying

- Youth with disabilities are much more likely to be bullied than their non-disabled peers.
- Bullying affects a child's ability to learn.
- Bullying based on a youth's disability may be considered harassment.
- Disability harassment is a civil rights issue.
- Students with disabilities have legal rights when they are the target of bullying.
- The adult response is important. It is never the responsibility of the child to fix the bullying situation.
- More than 50% of bullying situations stop when a peer intervenes.

## Modeling Positive Interactions

Creating an environment of acceptance, modeling appropriate behavior, and creating situations where youth with autism can readily interact will actively support inclusion.

- Allow youth without disabilities to look for solutions to problems and for ways to enhance the participation of the youth with autism.
- Prompt positive interactions if they are not occurring. (Example: "Joey, I bet Albert would like to play that game with you.")
- When positive interactions occur, make sure to reinforce them.
- If either person gets off task or isn't behaving appropriately, redirect their behavior.
- Step in if the situation is deteriorating. Sometimes a child will need to be removed for a time to cool off.





## Strategies for Dealing with Targets of Bullying

- Listen, be compassionate and use a calm voice.
- Provide as much privacy as possible.
- Take reports seriously and reassure participants that they were right to come to you and that you will advocate for them.
- Decrease self-blame by identifying the bullying behaviors as wrong and unjustified.
- Be proactive in manipulating the classroom environment for success (for example, incorporating helpful peers).
- Look for cues that participants may need help developing social competence.
- Discuss whether other bullying has occurred.
- Continue to monitor behaviors and have a follow up conversation with the participant.

## Strategies for Dealing with Kids who Bully

- Stay calm but use a firm, straightforward style.
- Provide as much privacy as possible.
- Give a brief, clear summary of the unacceptable behavior(s) and consequences, if appropriate.
- Note the behavior so a pattern can be established if behaviors continue.
- Do not get drawn into arguments or lengthy discussions.
- Correct the bully's thinking errors (e.g., blaming the target).
- Identify the target's emotions to help promote empathy.
- Consider other ways to help build empathy for the target (e.g., role-play incident with the bully taking the target's role).
- Re-channel the bully's need for power into more positive, socially appropriate endeavors.
- Model respect and look for opportunities to pay attention to positive behaviors.
- Provide formative/pro-social consequences whenever possible (e.g., making amends).
- Take into consideration any exceptionalities and how they may impact bullying situations; individualize strategies and responses accordingly.

Extracted from: *Perfect Targets; Asperger Syndrome and Bullying; Practical Solutions for Surviving the Social World*,  
By Rebekah Heinrichs





## Safety

Safety is a critical part of all of our lives, whether we are at home or out in the community, alone or with loved ones. Being aware of our surroundings and taking precautions to stay safe is even more important for individuals with autism.

Some key issues to keep in mind for youth organizations:

- **Wandering**

Children with autism are known to wander or elope at a rate nearly four times higher than children without autism. Make sure to discuss with parents their child's wandering history and learn any particular triggers or obsessions. If a child wanders from your program, you should call 911 IMMEDIATELY and notify parents of any wandering incidents. Ensure that fences are gated and exterior doors are shut.

- **Drowning**

91% of wandering related deaths in the last three years were a result of accidental drowning. Youth with autism in your care should know how to swim if there is an ungated pool or body of water in the area of your activities. Make sure that youth with autism are properly supervised around water.

- **Sexual Abuse**

A study done in Nebraska of 55,000 children showed a child with any type of intellectual disability was four times more likely to be sexually abused than a child without disabilities. While no specific numbers exist for individuals with autism, research suggests that this population is extremely vulnerable. If a child with autism discloses abuse, it is critical to stay calm, listen carefully, and NEVER blame the child. Thank the child for telling you and reassure him or her of your support. If you know or suspect a child is being sexually abused, please call the Childhelp National Child Abuse Hotline at 1.800.4.A.CHILD.

## The Physical Environment

When creating a physical environment that is safe and comfortable for people with autism, it is important to keep in mind that heightened sensory issues are one of the most common that will relate to their environment. Youth organizations have a wide variety of places where learning and activities take place – from a classroom, to a playground, to out in nature – it isn't one size fits all. We've provided some general tips for environments that support youth with autism.

- **Reduce Distractions**

Many people with autism find it difficult to filter out background noise and visual information. A space without too many distractions will decrease sensory overload and help the person with autism focus his attention on the task at hand instead of other stimuli.

- Eliminate non-essential visual materials such as posters and signage.
- Block out distractions with window shades and screens.
- Declutter the room as much as possible.
- Avoid flickering and humming from fluorescent lighting.





- Reduce the intensity of lighting by using fewer bulbs, natural light or lamps from home.
- Block out mechanical noises from heaters or fans as much as possible.
- Do not use room deodorizers or fragrances.

● **Personal vs. Public Space**

Because youth with autism have specific social challenges, providing some personal space is more of a priority than for their typical peers.

- Space should allow for social interaction, but also provide a space where they can be separated from the group to get their bearings.
- Create a soothing area where the person with autism can escape when they become overwhelmed – or where they can watch the activities at a distance until they are comfortable enough to participate.



## *Reflect:*

What are some of the things specific to your organization and programs that you think staff and volunteers should be aware of when working with children with autism?

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How can you support the non-disabled youth in your organization to accept and include youth with autism?

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What are key safety issues to keep in mind for youth with autism as part of your program?

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## Resources:

### Autism Internet Modules (AIM)

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

Free interactive empirically based training modules on autism topics.

Presented in small increments with pre/post testing.

### Dennis Debbaudt's Autism Risk & Safety Management

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

Information & Resources for Law Enforcement, First Responders, Parents, Educators and Care Providers

*Out and About, Preparing Children with Autism Spectrum Disorders to Participate in Their Communities*

By Jill Hudson, Amy Bixler Coffin (Autism Asperger Publishing Company, 2007)

Easy to read, practical explanations and examples of simple and effective strategies

*Social Relationships and Peer Support, Second Edition*

By Rachel Janney, Ph.D. and Martha E. Snell (Brookes Publishing, 2006)

*With Open Arms; Creating School Communities of Support for Kids with Social Challenges Using Circle of Friends, Extracurricular Activities, and Learning Teams*

By Mary Schleider, M.S. (Autism Aspergers Publishing Company, 2007)

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

*Gray's Guide to Bullying (Spring 2004 Jenison Autism Journal)*

By Carol Gray

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





## How to Be a Friend to Someone with Autism

- **Take the Initiative to Include Him or Her** - Your friend may desperately want to be included and may not know how to ask. Be specific about what you want him to do.
- **Find Common Interests** - It will be much easier to talk about or share something you both like to do (movies, sports, music, books, TV shows, etc.).
- **Be Persistent and Patient** - Remember that your friend with autism may take more time to respond than other people. It doesn't necessarily mean he/him isn't interested.
- **Communicate Clearly** - Speak at a reasonable speed and volume. It might be helpful to use short sentences. Use gestures, pictures, and facial expressions to help communicate. Speak literally – do not use confusing figures of speech (He may truthfully tell you, “the sky” if you ask “What’s up?”)
- **Stand Up For Him or Her** - If you see someone teasing or bullying a friend with autism, take a stand and tell the person that it's not cool.
- **Remember Sensory Sensitivity** - Your friend may be very uncomfortable in certain situations or places (crowds, noisy areas, etc.). Ask if he/him is OK. Sometimes your friend may need a break.
- **Give Feedback** - If your friend with autism is doing something inappropriate, it's OK to tell him nicely. Just be sure to also tell him what the right thing to do is because he may not know.
- **Don't Be Afraid** - Your friend is just a kid like you who needs a little help. Accept he/him differences and respect strengths just as you would for any friend.



*Adapted, Peter Faustino, Ph.D.*





## Books for Students with Autism, Siblings, Peers

### *A is for Autism, F is for Friend: A Kid's Book for Making Friends with a Child Who Has Autism*

By Joanna Keating-Velasco (Autism Asperger Publishing Company, 2007)

### *Different Like Me: My Book of Autism Heroes*

By Jennifer Elder (Jessica Kingsley Publishers, 2006)

### *Do You Understand Me? My Life, My Thoughts, My Autism Spectrum Disorder*

By Sofie Koborg Brosen (Jessica Kingsley Publishers, 2006)

### *Everybody is Different: A Book for Young People who have Brothers or Sisters with Autism*

By Fiona Bleach (Autism Asperger Publishing Company, 2002)

### *Join In and Play (Learning to Get Along); Listen and Learn; etc.*

By Cheri J. Meiners (Free Spirit Publishing, various)

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

### *My Friend with Autism: A Coloring Book for Peers and Siblings*

By Beverly Bishop (Future Horizons, 2003)

### *Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism (Illustrated)*

By Mary Wrobel (Future Horizons, 2003)

### *The Autism Acceptance Book; Being a Friend to Someone with Autism By Ellen Sabin*

(Watering Can Press, 2006)

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

### *The Mind That's Mine*

By Melvin D. Levine, Carl Swartz, Melissa Wakely (All Kinds of Minds, 1997)

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

### *The Sixth Sense II*

By Carol Gray (Future Horizons, 2002)

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

### *The Social Skills Picture Book; Teaching Play, Emotion and Communication to Children with Autism*

By Jed Baker, Ph.D. (Future Horizons, 2001)

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

### *The Social Skills Picture Book for High School and Beyond*

By Dr. Jed Baker (Future Horizons, 2006)

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

### *Trevor, Trevor*

By Diane-Twachtman-Cullen

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

### *What did you say? What did you mean? An illustrated guide to understanding metaphors*

By Jude Welton (Jessica Kingsley Publishers, 2003)

### *Wings of Epoh*

By Gerda Weissman Klein (FableVision/SARRC, 2008)

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





# Emergency Information at a Glance

Autism Safety Project [www.Autismsafetyproject.org](http://www.Autismsafetyproject.org)

In case of emergency: Call 911 • Poison Control Center: 800-222-1222

## Personal Information:

Family Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_

Zip \_\_\_\_\_

Home Phone \_\_\_\_\_

Work Phone \_\_\_\_\_

Mobile Phone \_\_\_\_\_

Pager Number \_\_\_\_\_

Individual's Name \_\_\_\_\_

Diagnosis \_\_\_\_\_

Medical Diagnosis \_\_\_\_\_

## Local Emergency Contact Information:

Name \_\_\_\_\_ Phone \_\_\_\_\_

Name \_\_\_\_\_ Phone \_\_\_\_\_

Name \_\_\_\_\_ Phone \_\_\_\_\_

## Primary Care Physican:

Name \_\_\_\_\_ Phone \_\_\_\_\_

## Insurance:

Policy \_\_\_\_\_ Group # \_\_\_\_\_

## Activity Schedule Special Instructions:

\_\_\_\_\_  
\_\_\_\_\_

## Other Important Information:

\_\_\_\_\_  
\_\_\_\_\_

\*Display this form in a handy place for caregivers and others who may need emergency information.



Strategies  
for Success:  
Supporting  
Learning and  
Growth in  
Youth with Autism



# Strategies for Success: Supporting Learning and Growth in Youth with Autism



*Goal: To people with autism, by definition of their diagnosis, have difficulties with communication and socialization. This section provides basic suggestions for dealing with these challenges in a youth organization environment.*

## Communication

Communication encompasses a broad range of challenges for people with autism, from intake and processing of information, verbal or representational output, to reading and writing skills. Picking up on non-verbal cues, body language and subtle intent, intonation and interpretation is also difficult for people with autism.



## Tips for Supporting Receptive Language Skills

### Receptive Language:

To understand what is said or written.

- Make sure you have the youth's attention before you deliver an instruction or ask a question.
- Consider the participant's processing challenges and timing. For example, begin an instruction with the participant's name – this increases the likelihood that he will be focused on what you are saying by the time you deliver the direction.
- Avoid complex verbal directions, information or discussions. Keep instructions short and give information in chunks.
- Minimize the use of don't and stop. For example, "Please stay on the sidewalk," is much more effective than "Keep off the grass," because you are being clear about the behavior you desire.
- Be prepared to wait for a response – whether it is an action or an answer. Avoid immediately repeating the instruction or inquiry. Think of it like a computer – when it is processing, hitting the command again does not make it go any faster, but rather causes it to freeze or sends it back to the beginning to start the process all over again.
- Supplement verbal information with pictures, visual schedules, gestures, or written directions.
- Do not reprimand a participant for not listening or responding. That only serves to highlight his or her challenges.





## Tips for Supporting Expressive Language

- Take responsibility for finding a way to access the participant's need for communication. Many people with autism have word retrieval issues – even if they know an answer, they may not be able to come up with the words. Offer visual supports, cue cards, or multiple-choice answers.
- Support the youth in saying “I don't know” to reduce the anxiety associated with not being able to answer a question.
- Add visual supports to the environment as necessary.
- If the youth has an augmentative or alternative communication device, learn how to use it. Ask parents or the support team for help.
- Sing! Musical processing occurs separately from language processing, and singing can be used to promote both receptive and expressive skills.
- Be aware of echolalia, where someone with autism repeats phrases he has heard before. Sometimes this is a seemingly self-stimulatory behavior, but many people with autism also use functional echolalia to comment, inform or request.
- Many people with autism have a favorite topic or special area of interest that may interfere with social interaction. To shape their expectations and minimize the impact of the obsession:
  - Provide scheduled opportunities to discuss the topic.
  - Establish boundaries on when and where it is appropriate to discuss the topic.
  - Set a timer to establish duration.
  - Reinforce the participant for talking about other subjects or the absence of the topic.

## Expressive Language:

Spoken language and communicative output such as written language and picture exchange.



## Social Interaction

People with autism often have the desire to interact with others, but they do not have the skills to engage appropriately or may be overwhelmed by the process. Some youth are painfully aware of their social deficits and will avoid interactions even though they may want to connect with others. Or they could go in the opposite direction and engage in attention seeking behavior to connect with others until they build the skills they need to interact. Social challenges in autism go both ways. They may manifest as deficits (a lack of social initiation) or excesses (a one-sided conversation in a highly verbal youth with Asperger's Syndrome).





## Tips for Supporting Social Interaction

- Extend a feeling of welcome and model for other participants that the youth with autism is a valued part of the group.
- Get to know the youth with autism and meet him where he currently is in terms of social skills and interests.
- Be aware that free play or other unstructured times are the most difficult for people with autism. Think about how to impose some structure on these activities.
- People with autism often have a difficult time maintaining eye contact. Insisting on eye contact can cause additional stress.
- Youth with autism, especially those who are more verbal, can be the target of teasing and bullying. They often do not pick up on non-verbal cues such as tone of voice or the hidden intention of a request or comment. They often go along with the teasing or bullying because they do not identify that it has a negative intent. The desire to make friends and their difficulty doing so, means they often encounter peers with negative intentions. Be on the lookout for this and respond quickly if teasing/bullying becomes an issue.
- Many people with autism are very logical and will always play according to the rules. If the rule is that basketballs are not allowed outside at a particular time, a participant may become agitated if they come out for a special activity. Similarly, he may not understand special circumstances in game play such as penalty shots, and his insistence on following the rules he has learned could become problematic.
- Identify peers who model strong social skills and pair the youth with autism with them. Provide peers with strategies for eliciting communication, but be careful not to turn the peer into a teacher. Strive to keep peer interactions as natural as possible.
- During group activities, define his role and responsibilities within the group. Assign a role or help him mediate with peers as to what he should do. Rotate roles to build flexibility and broaden skills.
- If you leave it up to the group to pick partners, youth with autism are sometime chosen last, causing unnecessary humiliation.





## Challenging Behaviors

Sometimes the difficulties of autism can lead to behaviors that are quite challenging to understand and address. Here are some tips that can be helpful in preventing negative behaviors:

- Recognize behavior as communication. Try to understand the communicative intent of the behavior.
- Catch him being good and reward the behavior!
- Provide organization and support transitions.
- Communicate expectations, use short-term schedules, warn of changes to routine or personnel, and prepare them for unexpected events.
- Offer choices and provide some sense of control.
- Consider sensory needs and interventions.
- Respect her personal space.
- Provide a home base or safe place where he can feel safe and regroup, calm down, or escape overwhelming situations and sensory overload.
- Be flexible.
- Be aware of and work to avoid known triggers that may result in frustration, overload or anxiety. Make a list and share it with the team.
- While they are occurring, ignore attention-seeking behaviors as much as possible. Redirect instead.

## Sensory Stimulation

Sensory challenges can affect people with autism's ability to take in information, respond to requests, participate in social situations and maintain calm. Either through internal imbalances or in response to the environment, the sensory and emotional regulation of a person with autism can become overwhelmed and result in anxiety and stress. Working to maintain a modulated state can help the youth remain calm and focused.

Ways to support sensory needs:

- Be aware of sensory issues and alter the environment where possible, such as minimizing exposure to loud noise.
- Some people with autism find standing too close to others difficult. This needs to be addressed when deciding where to place a participant in line or other area among a group of people.
- People with autism may have difficulty looking and listening at the same time.
- Highly decorated areas can be over stimulating and distracting for some people with autism.
- Some people with autism may need to transition earlier than other participants or may need a few minutes to unwind after being in a noisy environment.





## Reflect:

There are many things to think about when working with youth with autism. What do you think are the things that will be the easiest and most difficult to incorporate when it comes to your specific organization or program?

With communication:

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With sensory issues:

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With behavior challenges:

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## Resources

### Association for Positive Behavior Support

Research information, application strategies, information on school-wide PBS programs, fact sheet summaries of PBS practices and a section on autism.

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

### Do2Learn

Easy to use and downloadable resources including social games, organizational tools, picture cards, etc.

[www.do2learn.com](http://www.do2learn.com)

### Kansas Autism Spectrum Disorders

Free examples and banks of visual strategies, social narratives and power cards, and podcasts of speakers such as Linda Hodgdon and Paula Kluth.

<http://kansasasd.com>

### *Solving Behavior Problems in Autism*

By Linda Hodgdon (Quirk Roberts Publishing, 1999)

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





# Presuming Intellect: Ten Ways to Enrich Our Relationships Through a Belief in Competence

By William Stillman

**1. Don't define people by their diagnosis.** Remember playing tag? Nobody wanted to be *IT*. And if you were *IT*, you wanted to get rid of *IT* because being *IT* was stigmatizing, a detriment, and something undesirable — that was the game; being *IT* was to be avoided and feared. Remaining *IT* longer than we'd like becomes challenging to catch up to the others, to belong, and to feel accepted. When we define someone by their diagnosis, our perception of them may become something to be dreaded: someone defective, someone who has the *IT* with which we don't wish to risk an association of any sort. For that person, this attitude is the lubricant that greases the wheel for the vicious cycle of a selffulfilling prophecy. That is, when people define you as having *IT* and that's all you know of yourself, you will reflect back precisely what others project upon you. This is a natural and defensive reaction; and if you don't speak or can't articulate your feelings, your outpourings of "behaviors" will only further validate the diagnosis (hence the vicious cycle).

**2. Shatter myths and stereotypes.** Clinical diagnosis is but a framework for explaining "behaviors" or atypical attributes. This may include judgments about severe intellectual and physical limitations, and further speculation about other incapacities. It can also set a negative precedent of using "us and them" language in labeling someone as different, retarded, autistic or mentally unstable. However, it wasn't so long ago that persons who were epileptic, homosexual, or even those lefthanded, were labeled as mentally deviant. This led to unfair, inaccurate and unjust myths and stereotypes. All of psychology and psychiatry is educated guesswork; no single clinician can state with absolute authority what someone experiences in the way that medical science usually can. In considering three factors, insight, foresight and hindsight, we need to encourage others and ourselves to look beyond our history of deficitbased labeling in favor of perceiving a person's humanity—regardless of their diagnosis or way of being. The label which may perpetuate clinical myths and stereotypes is an incomplete truth; it should be but one point of reference in fully supporting the whole person.

**3. Don't talk about people in front of them.** Have you ever been in conversation with two or more people and someone talks out of turn, interrupting, belittling or disputing your contributions? Or have you temporarily lost the use of your voice as others tried to interpret your wants and needs? How did either instance make you feel? If we don't value what people have to offer, especially if they are unable to speak at all, we send a message of superiority versus inferiority. When we define people by their diagnosis and perpetuate myths and stereotypes, we presume the authority to talk about them in front of them as an entitlement. After all, it shouldn't matter if we share information about someone's "behaviors" with their parents, doctors, and others in front of them because they are retarded, autistic, and unaware — right? Wrong! Presuming intellect requires us to believe an individual's intellectual competence is intact. This means we do not speak about them in front of them in ways that are hurtful, embarrassing or humiliating. We must also gently but firmly advocate by disallowing others from doing it as well. We need to include people in conversation by directing questions to them not about and around them. It also means we employ person-first language (boy with autism, not autistic boy) because it compels us to be conscious of the words we use when discussing someone. So, before you speak, ask yourself if you would welcome someone talking about you in precisely the same way without a voice to defend yourself. We cannot have a mutually respectful and trusting relationship if we talk about someone in front of them.





**4. Interpret “behavior” as communication.** Have you ever been so angered that words escaped you in the moment, and the only way you could express yourself was by screaming or throwing something? You probably felt justified in your actions because it was the only way you could vent your expression of extreme upset. But what would life be like if you could *never* retrieve the words you wanted when you needed them *and* you always seemed to be grappling with overwhelming or frustrating circumstances that caused you to react in extreme ways as the only option? In the same way you could rationalize your own behavior, let’s remember that we *all* have good reasons for doing what we’re doing, and we’re doing the best we know how to do in the moment. You wouldn’t want to be defined or stereotyped by the times you just had to yell and shout would you? We need to extend the same courtesy to others by not jumping to conclusions about their “behaviors” as willful misconduct, noncompliance, or “attention seeking.” You may respectfully deconstruct “behavior” in terms of *communication* by appreciating the following three reasons why people may engage in what others call “acting out” or “aggressive behaviors.” 1) The inability to communicate in ways that are effective, reliable and universally understandable. 2) The inability to communicate one’s own physical pain and discomfort in ways that are effective, reliable and universally understandable. 3) And the inability to communicate one’s own mental health experience in ways that are effective reliable and universally understandable.

**5. Offer communication enhancements and options.** We have become a culture that values instantaneous, rapid-fire response to our need for information. This includes the immediacy with which we communicate to one another through e-mail, instant messaging, text messaging, and round-the-clock accessibility via cellular telephones. When others do not communicate with us on par with the manner with which we’ve become accustomed, we may lose patience, become bored or distracted, or dismiss their communication attempts altogether. This may be especially true of those challenged in articulating language such as small children, the elderly, and those with a neurological difference resulting from stroke, Tourette’s, Alzheimer’s, Cerebral Palsy or autism. We may wrongly interpret the inability of others to speak as quickly as we’d like as an incapacity when, in fact, most often just sensitively allowing for process time beyond what is standard is all that is required for those individuals to cognitively retrieve spoken language. In providing support to others, we must acknowledge that not everyone is neurologically “wired” for verbal communication; this is not the same as not having something to say. It is unacceptable to accept that because someone doesn’t speak, there’s nothing we can or should do. There are myriad communication options and opportunities to offer as speech alternatives. These may include pointing to “yes” and “no”; some basic sign language; photographs and symbols; computers and other keyboards; and technology of all kinds. The person will guide us to the device, or combination thereof, that makes sense for her. Engaging in conversation by discussing someone’s most passionate of interests in the context of a mutually-pleasing relationship is a great incentive to entice someone into trying a communication alternative that is new and different. Honoring another’s communication requires us to acknowledge that we might not like what we hear.

**6. Offer age-appropriate life opportunities.** When we are unpresuming of an individual’s intellect, there is a belief that the individual likely possesses a juvenile aptitude, childish thought processes, and skills on par with someone who is chronologically much younger. This stereotype of the “perpetual child” leads some to interact with the stigmatized individual in ways that are pretentious, patronizing, and insulting. It also means that we limit the life opportunities that we offer someone in favor of preserving the “perpetual child” mindset. Instead, we provide adolescents, adults, and





even persons who are elderly, with dolls and toys, and reading and viewing material suited and intended for very young children. You can only know what you know; and if someone is only ever afforded such opportunities, a childlike affect persists and permeates our interactions. But, if we presume intellect and acknowledge that an individual's "behaviors" might really be cries of boredom or offense with educational curriculum, vocational options, or recreational activities that are dehumanizing, we will know better how to partner with an individual in planning *age-appropriate* learning, work and freetime opportunities. The greatest obstacle to implementing this is our own attitude in how we perceive supporting someone with a different way of being.

**7. Make compassionate accommodations.** Have you ever been trying to read or listen attentively to something, and someone near you is constantly coughing? You can react one of two ways: either with annoyance, or with consideration. Reacting with annoyance will only foster bad feelings between both parties; you may feel as if the person should know to be more socially considerate, and the person, who may be struggling to care for themselves, may feel hurt or attacked. Reacting with consideration may include gently approaching the individual to offer them a cup of water, a mint or lozenge, or to simply commiserate about a human experience we've *all* endured at one time or another. Responding with the latter approach requires discounting initial impressions and making a compassionate accommodation, not only in our thoughts but in our deeds. In considering compassionate accommodations for the individual with a different way of being, think in terms of *prevention* instead of *intervention*. Prevention means knowing fully what an individual requires *in advance* of a situation, environment, or activity in order to feel safe and comfortable and able to participate. This relates to the ability to think, communicate, motor-plan movement, and assimilate with the senses. It means foregoing the antiquated model of multiple, overwhelming community integrations (which often sets the overloaded individual up for an *intervention*) in favor of simple, subtle, and interest-based activities in a qualitative relationship context.

**8. Respect personal space and touch.** If we perceive someone in our care to be less than equal, be it a child, adult or someone elderly, we seem to take ownership of touching their physical being with a sense of entitlement in order to gratify our own needs. For example, instead of allowing someone the time required to bathe, eat or dress for themselves, we may grow impatient and begin handling them ourselves to "get the job done." Or, in desiring to be affirmed, we initiate physical touch by embracing, back-rubbing or hair-tousling—all of which may be intrusive, unwelcomed and without permission. (In recent years, some colleges have even implemented "touch protocols" for dating co-eds to avoid misinterpretation of any sexual intent.) Conversely, many of us are extremely uncomfortable brushing against others in the cramped quarters of an airplane, bus, subway, or train. Personal space and touch are a matter of individualized perception for each of us based upon our culture, upbringing, and relationship experiences. A friendly slap on the back, which you've been conditioned to convey as communicating "hello," may send shock waves through the nervous system of the recipient. Instead, respectfully await the invitation *in*. Await the acknowledgment that coming closer, touching, even eye gazing, is welcomed once it's communicated by the person with whom you are developing a relationship. The invitation *in* may be as subtle as someone who rarely makes eye contact locking eyes with you and tracking your movement, or the individual who carefully, gently, extends a finger to initiate touching you. Be very mindful of the mixed messages we send to children whom we routinely embrace and then confuse once we define such as "inappropriate" come adolescence. It is also fair to state your own acceptable preferences for touch limitations.





**9. Seek viable employment for others.** The system that serves people with different ways of being endeavors to be altruistic and well-intentioned but it is an industry nonetheless; one that, in seeking viable employment opportunities for its clients, attempts to conjoin with mainstream industries that may be unassuming of intellect. More often than not, this translates to menial tasks that are believed to require no thought: adult training facilities, repetitive factory work, janitorial cleanup, emptying trash receptacles, or replenishing the fast-food salad bar to name a few. For most others, such jobs are temporary steppingstones; but for persons who are perceived as largely incapable, these employments have become a norm that perpetuates stereotypes. In seeking to pursue viable employment, we need to think in terms of cultivating gifts, strengths, and talent areas as early on in one's life as possible. Begin by identifying an individual's most passionate of interests—those subjects or topics for which she wants most to talk about, watch, draw or write, reenact, engage with, and read about. When we value passions instead of labeling them as obsessions (unless they seriously impair one's quality of life), we are better poised to creatively envision a blueprint of possibilities for one's future. This may include higher education, virtual employment via the Internet, or self-employment opportunities.

**10. Acknowledge that we are all more alike than different.**

Remember the last time you drove somewhere and, upon arriving, had no recollection of the drive? How about when you hear a song you haven't heard since high school, and memories you associate exclusively with that era come flooding back? Or what about the times you've halted, blocked, stuttered or stammered over calling up someone's name? These are examples of common neurological blips, misfires and disconnects that make us all kindred in our humanity. While others may have traits that appear more exaggerated, like physically rocking or handflapping, you may catch yourself engaging in a similar action if you've been shaking your leg, tapping a pen, or twirling your hair



or a piece of jewelry. When we embrace the philosophy of presuming intellect we are in a position to become agents of transformation. Doing so requires forgiveness of our own ignorance—which need not hold negative connotations—as well as seeking the forgiveness of others whom we have not held in the same regard as our typical peers. We have become a culture that elevates perfectionism to exalted heights, which is an unrealistic and potentially damaging aspiration. When we acknowledge the kinship we share with one another, we are most apt to value diversity in our lives within the context of mutual respect, co-collaboration for greater good, and the presumption of intellect.

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