



Autism Speaks®

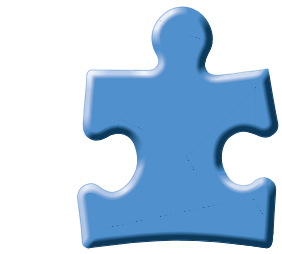
FAMILY SERVICES

Challenging Behaviors Tool Kit









AUTISM SPEAKS®

It's time to listen.

Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information provided in this toolkit is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. Autism Speaks has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism.



© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Aggressive and Challenging Behaviors Tool Kit

Johnny runs away and requires constant supervision. Susie screams and covers her ears whenever an airplane is overhead—and she always hears them before anyone else. She screams other times too and it is hard to get her to stop. Tommy refuses to wear shoes and throws them at anyone who tries to get him to put them on. Maria doesn't like riding the bus, and bites her mom each day as it rolls up to the bus stop. Jose will only eat three foods, and they can never touch each other on his plate or everybody is sorry. Sally hits herself in the head whenever someone tells her 'no.'

Sometimes the difficulties of autism can lead to behaviors that are quite challenging for us to understand and address. Most individuals with autism will display *challenging behaviors* of some sort at some point in their lives. These behaviors can often be the result of the underlying conditions associated with autism.

Purpose and Scope of this Tool Kit

Challenging behaviors represent some of the most concerning and stressful features of autism. These behaviors can often cause harm or damage, family and staff stress, isolation, and caregiver burnout. Parents may feel guilty or responsible, but it is important to know that you should not blame yourself for behaviors that you find difficult. Sometimes, the extraordinary steps parents go through for their children with complex needs might not be enough, and additional supports and resources might be necessary. It is important not to think of your child, or these behaviors, as 'bad,' but to learn how to better understand and respond to challenging situations to make them more manageable for everyone. Hopefully this kit will help provide you with strategies and resources, and lead you to professionals within your community.

For the purposes of this tool kit, we classify challenging behaviors as behaviors that:

- are harmful (to the individual or others)
- are destructive
- prevent access to learning and full participation in all aspects of community life
- cause others to label or isolate the individual for being odd or different

Challenging behaviors can occur throughout the lifespan of an individual with autism. The core and associated symptoms of autism can adjust over time and as a result, many individuals with autism experience changes at various stages of life that might result in new behaviors. An individual's behavior can often vary considerably even minute by minute in response to internal (such as stomach pain) or external (people, places, noises, activity levels, etc.) issues. In addition, many individuals with autism experience other associated concerns and co-occurring (*co-morbid*) conditions that can layer on additional concerns, such as those described here and here.

As time passes, families and caregivers adapt to meet the needs and demands of their loved ones. At times their responses and expectations can drift into a place that becomes difficult for everyone. These feelings often increase stress levels and may even limit access to their own friends and community.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Sometimes as children age and become stronger, challenging behaviors can reach crisis levels. Many families who have previously managed the trials presented by autism might experience crisis situations when their child hits older childhood or the teenage years. This may be because the challenges have grown as the child becomes bigger and stronger, or because of new factors that accompany growing up or *puberty*. To address more significant concerns that might create risk to the child or others, later in the kit there is section to help with Managing a Crisis.

"When James reached age 18, he was 6'2" and 210 pounds, and strong. He was learning that aggression was an effective way to avoid tasks that he didn't like because it worked – I was afraid of him. Every morning when I asked James to make his bed, he would usually begin doing it correctly but would often make mistakes. When I told him that he had made a mistake, he would start biting himself and hitting me, so I would back away and leave the room. But this allowed James to escape the task of making his bed and taught him (and me) that his aggression worked! With a little help from a behavioral consultant, I decided that whenever James began to get upset while making his bed, I would prompt him to say, "Help me please." It was explained to me that this behavior served the same purpose as his aggression and self-injury. When James asked for help, I'd give him some assistance, which made us both a lot less frustrated."

– AG, mother

The guiding principle used in developing this kit is that each individual with autism and his family should feel safe and supported, and live a healthy life filled with purpose, dignity, choices, and happiness. With this in mind, positive approaches and suggestions are highlighted throughout the kit. The general framework and *intervention* principles included are relevant at any stage of life, and we have included basic background information, with links to further information and resources on a variety of topics.

In this tool kit, the term autism will be used to include all *Autism Spectrum Disorders* that result in the social, communication and behavioral differences characteristic of this population. While we recognize that the autism spectrum encompasses both males and females, for the sake of simplicity, we have used 'he' throughout to represent an individual of either gender.

The kit is broken into different sections. You may want to read the kit in its entirety or work through a section at a time. Please visit the Autism Speaks Resource Guide to find services, contacts or resources in your area, as well as information specific to your state. If you have resources to share, you can add them to the Resource Guide here.

Document Key

- The definitions of the words highlited in the *clay colored italic text* can be found in the Glossary.
- The *blueberry italic text* are quotes from *Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting* by Helen Yoo, Ph.D, New York State Institute for Basic Research *Autism Speaks Family Services Community Grant recipient*
- The blue text are links you can click on for further information.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Table of Contents

- Why is Autism Associated with Aggressive and Challenging Behaviors? ..... Page 1
  - 1. What is helpful to know about behavior? ..... Page 3
  - 2. Function of Behavior ..... Page 4
- Why is it Important to Do Something about Challenging Behaviors? ..... Page 7
  - 1. What are some Challenging Behaviors Commonly Displayed by Individuals with Autism? ..... Page 9
  - 2. Less Common Challenging Behaviors ..... Page 11
- Who Can Help? What is this Idea of a Team? ..... Page 12
  - 1. Team Members to Consider ..... Page 12
  - 2. Things to Look for in Your Child's Team ..... Page 16
  - 3. How and Where to Find a Team ..... Page 19
  - 4. Funding Sources ..... Page 20
- What are the Things to Consider? ..... Page 22
  - 1. Physical Concerns ..... Page 24
  - 2. Mental Health Considerations ..... Page 26
  - 3. Medication ..... Page 28
  - 4. Behavioral Considerations ..... Page 30
  - 5. Other Concerns to Consider ..... Page 33
- What are the Positive Strategies for Supporting Behavior Improvement? ..... Page 39
  - 1. Adapt the Environment ..... Page 41
  - 2. Use Positive Behavior Supports ..... Page 42
  - 3. Teach Skills and Replacement Behaviors ..... Page 44
  - 4. C.O.P.E.S.™ ..... Page 51
- What might I need to know about Managing a Crisis Situation? ..... Page 52
  - 1. Have a Plan ..... Page 52
  - 2. Managing a Crisis at Home ..... Page 54
  - 3. Managing a Crisis at School ..... Page 54
  - 4. Managing a Crisis in the Community ..... Page 54
  - 5. How do I know it's time to get more help? ..... Page 56
- *Long Term Solutions: What if we just can't do this anymore?* ..... Page 62
  - 1. Where can we learn more? ..... Page 63
  - 2. Family and Caregiver Training ..... Page 63
- Challenging Behaviors Glossary ..... Pages 66 – 71

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

As a companion to the information in this kit, we have two video series of frequently asked questions regarding challenging behaviors. One is from a legal perspective and the other from a clinical perspective. You can find them on the homepage of the Challenging Behaviors Tool Kit. The questions addressed in these videos are listed below.

Legal FAQ's

General Crisis Information:

- Can you tell me what a crisis is?
- What's my first objective in a crisis situation?

Crises & Schools:

- What is a school's immediate responsibility if a crisis happens in school?
- What about after the crisis?
- Can my child get kicked out of school for this kind of behavior?
- What should I do if my child does get kicked out of school?
- What is a manifestation hearing?
- What is a school's responsibility if the crisis happens at home?
- If my school isn't helping or can't help with the situation, what should I do?

Adults & Guardianship:

- Is there anybody responsible for helping adults who are having crisis behavior?
- What happens in a crisis situation if the family has no guardianship and the individual is over 18?
- Is there emergency or temporary guardianship for a situation like this?
- If I want to obtain emergency or temporary guardianship, how would I do that?
- What's the advantage of seeking guardianship before a child turns 18?

Hospitals & Residential Placement:

- What are the responsibilities of a hospital and your rights regarding medical interventions?
- Is the hospital required to provide behavioral supports?
- If my child is in the hospital, what happens to their schooling?
- What happens if my child is being repeatedly kicked out of school and sent to hospital settings? Are there any other options?
- If an adult is in residential placement, what is the responsibility of the facility or home in a crisis situation?

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Calling 911:

- If I call 911 for an emergency, what should I tell the dispatcher?
- Are there specific terms or phrases that should be used to get help in a crisis situation?
- When the first responders arrive, what information should I give them?

Other Advice:

- What other legal advice do you have for families in crisis?

Clinical FAQ's:

Understanding Challenging Behaviors:

- What are challenging behaviors?
- What's the most important thing to know about challenging behaviors?
- What's important to know about aggressive or self-injurious behaviors?

Addressing Challenging Behaviors:

- Why is it important to address challenging behaviors?
- What should I know before addressing challenging behaviors?
- How important is consistency in addressing challenging behaviors?
- What if I'm having trouble carrying out a behavior plan?

Dealing With A Crisis At Home:

- What should families do in a crisis situation?
- Where can families turn if they feel unsafe in a crisis situation?

Other Advice:

- Can you use Applied Behavior Analysis (ABA) on adolescents and adults with autism?
- What role can medication play in addressing challenging behaviors?
- When should I consider residential placement?
- Where do siblings fit in with all of this?
- Do you have any general advice for families dealing with challenging behaviors?

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

With gratitude, we thank the members of our Advisory Committees for generously donating their time, experience and resources to this project.

Parent Committee

- *Kameena Ballard*
- *Sallie Bernard*
- *Brandy Krupa*
- *Mia W. McNary*
- *Beverly Moore*
- *Marianne Sullivan*

Self-Advocates

- *Ruth Elaine Hane*
- *Charles Joiner*

Professional Committee

- *Ryan Cramer, LSW*, Center for Autism and Developmental Disorders, Western Psychiatric Institute and Clinic of UPMC
- *Dennis Debbaudt*, Autism Risk & Safety Management
- *Peter Doehring Ph.D*, Director of Autism Services, Foundation of Behavioral Health
- *Richard B. Graff, Ph.D., BCBA-D*, Clinical Director, New England Center for Children
- *Terry Hamlin Ed.D.*, Associate Executive Director, The Center for Discovery
- *Johanna Lantz, Ph.D.*, Assistant Chief of Psychology, Center for Discovery
- *Lucille Esralew, Ph.D.*, NADD-CC, Clinical Administrator SCCAT & S-COPE, Trinitas Regional Medical Center
- *Gary S. Mayerson*, Founding Attorney, Mayerson & Associates
- *Valerie Paradiz, Ph.D*, Director, Valerie Paradiz LLC, Director, Autistic Global Initiative
- *Ricki Robinson M.D., M.P.H*, Co-Director of Descanso Medical Center for Development and Learning Author, Autism Solutions
- *Matthew Siegel, M.D.*, Director, Developmental Disorders Program, Spring Harbor Hospital, Assistant Professor, Tufts University School of Medicine
- *Nicole Weidenbaum, M.S. Ed., SAS*, Executive Director, Nassau Suffolk Services for Autism
- *Joanne Wilken*, Special Education Teacher and Autism Speaks Chicagoland Chapter Board Member
- *J. Helen Yoo, Ph.D., BCBA-D*, Applied Behavior Analysis Laboratory, Department of Psychology, New York State Institute for Basic Research

The Challenging Behaviors Tool Kit was edited by Liz Bell and designed by Joe Shea.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Why is Autism Associated With Aggressive and Challenging Behaviors?

Autism itself does not cause challenging behaviors. It is likely, however, that some of the underlying biological processes that result in autism might also result in behaviors that are outside of a person's control—similar to how the tremors associated with Parkinson's Disease are brought on by impulses that the person cannot direct. In addition, some behavioral responses are simply reflexes—no more of a choice for your child than when your leg jerks upward when the doctor uses his hammer on your kneecap.

"Some of those behaviors that most professionals and many families would not consider challenging, such as making odd noises, repeating phrases over and over, closing and opening doors in a repetitive fashion, might not be dangerous or destructive. But they sure can be annoying, and raise everyone's stress levels. And when the individual is told to stop again and again but still doesn't, those little things can lead to big things. They can create a tension that makes everyone behave in ways that become problematic. Learning how to think about and deal with these low-level, irritating behaviors certainly changed how we functioned as a family and improved our quality of life."

– NM, mother

In addition, the core features of autism are areas in which difficulties can lead to feelings of frustration, confusion, anxiety or lack of control, resulting in behavioral responses. Since behavior is often a form of communication, many individuals with autism (as well as those without autism) voice their wants, needs or concerns through behaviors, rather than words. This does not mean that they are always knowingly communicating. For example, running away from a barking dog might be the child's biological fight or flight response to scary situations, or even to something that you might not view as frightening. Similarly, shutting down and retreating to a quiet place might be a child's way of saying 'this situation is far too noisy and crowded for me to handle.' This may be an automatic response in the moment, not a choice he is making.

Challenging behaviors are more likely to appear when a person is feeling unhappy or unhealthy. Medical concerns, mental health issues, or sensory responses that we cannot see might bring pain or discomfort to a person with autism that we might not understand, especially when he is unable to say so.

"All of a sudden when Mark was about 8 years old, he needed order. The change came overnight. If we opened a cabinet, he closed it. Loading and unloading the dishwasher was impossible—he could not tolerate the door being open. It was maddening to us, and so clearly compulsive for him. He became anxious and acted out if the order was not maintained. Thankfully, our doctor ran some tests and determined that he had high antibodies to strep, and the compulsiveness was likely due to a sort of obsessive compulsive disorder called PANDAS. The biological factors were not easy to treat and took a long time to resolve, but how we responded to his behavior changed completely when we realized that he wasn't doing this to drive us crazy, and that he was no more in control of what he was doing than we were. We worked a lot on building his tolerance for flexibility, in tiny bits and using positive rewards. Eventually, he returned to his flexible self, but we had to adapt our behavior to help him through this in a way that worked for all of us."

– SP, father

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Many behaviors are also responses to previous experiences. A baby who gets a smile when he coos usually learns to coo more often. The same is true for challenging behaviors. If a child has learned that screaming gets him out of a difficult task, he might scream in the future to escape.

How we respond to his actions can have a significant effect on what he does the next time he is in a similar situation.

Because of the learning differences that autism can bring, people with autism might need specialized approaches to learning appropriate behavior. For example, the scolding look that stops your typical two-year-old in his tracks may mean nothing to a 30-year-old with autism who has not learned to recognize emotions and facial expressions.

Without some of the abilities and skills that most of us have developed as children and adults, people with autism are often just using the tools they know how to use. Therefore, it is likely that behavior can be improved by helping them to increase the tools they have available—to communicate, to recognize their own biological and behavioral responses, and to build an increased ability to self calm and self regulate.

Research on Aggression in Autism

A recent study of aggression in autism showed some interesting trends in terms of *risk factors*, which may give some insight into challenging behaviors overall.

- There is a much higher rate of aggression towards caregivers in autism than in the general population and in others with intellectual disabilities.
- Unlike the risk factors in a typical population, aggression was equally common in girls as boys with autism. Several other usual risk factors (lower IQ, lower parental education, less language ability) were not associated with greater risk in autism.
- The research also showed that just like in the typical population, age was a risk factor, with higher levels of aggression occurring at younger ages, which may suggest that learning and growth may help behaviors improve.
- Those children with autism at highest risk of aggression exhibited the following characteristics:
  1. More repetitive behaviors, especially self-injurious or ritualistic behaviors, or extreme resistance to change
  2. More severe autistic social impairment



These results show that core symptoms of autism are associated with the risk of aggression. Perhaps underlying conditions such as a lack of social understanding or the discomfort associated with breaking a routine might promote aggressive behavior.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

What is helpful to know about behavior?

Before considering challenging behavior in isolation, it is helpful to think about human behavior in general. Some behavior is biologically driven (we eat when we are hungry) or reflexive (we cover our ears when a noise is too loud). But for the most part, ***behavior occurs because it serves a function and/or produces an outcome.*** Eating serves the function of satisfying hunger, and covering our ears softens the impact of the loud noise. Behavior also serves as a form of communication. Seeing someone cover his ears, even when we did not find a noise to be offensive, can communicate that he is particularly sensitive to sound.

It is critical to remember that any individual is doing the best he can do in each situation, given his skills, education, physical and emotional state, and past experiences. We classify certain behaviors as challenging because we as individuals or a society find them to be difficult to accept. It will be important for you to become a careful observer, working to understand the purpose of behaviors. Taking a step back and considering why a person might behave in a certain way is the first important step toward understanding and learning how to help. It is also essential to reducing your own frustration. In fact, it is often helpful to think of an individual's actions as a response, rather than a pre-determined or willful behavior.

However, there is a difference between understanding behaviors that we or society might not find appropriate and accepting those behaviors. For example, determining why a child needs to kick, and then developing his skills for communication should be the objective (e.g. ' I need a break.'), instead of allowing kicking as a form of speech. Similarly, working to understand and treat biological conditions that might cause challenging behaviors is essential.

"Sam's teacher moved to another city, so he entered his second year of high school with a familiar but less skilled instructor. Soon he was headed to the nurse's office each morning and spending first period on her bed. Clearly the new teacher had anxiety, and the school staff believed that this was being reflected in Sam's behavior and increasing his anxiety as well. Or perhaps it was task avoidance, as there were a lot of language demands in that first period social skills class. Then one morning, he actually gagged and vomited, but once he got home it was clear that Sam was not sick. Soon after, other staff noticed that he would turn his head to the side and his eyes would roll during the period immediately after lunch. We also noticed a tendency to retreat to the couch at home after dinner. That's when we consulted the gastroenterologist, and sure enough, he was diagnosed with reflux. All of these odd behaviors and the trips to the nurse's office subsided once he was treated."

– ED, mother

When thinking about your loved one with challenging behaviors, it is also important to consider his positive features and strengths. Show respect for his thoughts, feelings and the likelihood that he understands far more — or alternately, perhaps far less—than you might consider. Take care not to speak about him in his presence, for it is likely that he understands more than he is able to show. Talk to him and provide him with information, even if you are not sure that he understands what you are saying. It is important to build your child's trust in your support, and shape his motivation and purpose into more acceptable behaviors.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Function of Behavior

Whenever behavior occurs, it is important to consider its purpose, or what is most often called its function. Although some behavior is biologically driven, much behavior is learned over time and through experiences, and shaped by what happens before and after the behavior takes place. Other behaviors may have begun as biologically driven (such as scratching an itch) but may turn into something that serves a different function (perhaps scratching to gain a teacher's attention).

"Special educators [and parents] need to look at what a child can do instead of what he/she cannot do. There needs to be more emphasis on building up and expanding the skills a child is good at. Too often people get locked into a label such as dyslexia, ADHD, or autism, and they cannot see beyond the label. Kids that get a label often have uneven skills. They may be talented in one area and have a real deficiency in another. It is important to work on areas where a child is weak, but an emphasis on deficits should not get to the point where building the area of strength gets neglected."

– Temple Grandin, Ph.D.

An example of a productive behavior might be asking for something to eat, then receiving a cookie. The function of making the request is to get the cookie. For a child with limited language skills, the strategies involved in getting a cookie might look very different. But if the end result is the same, whatever the individual needed to do to be fed is the method by which he has learned to 'get a cookie.' Over time, an individual with significant communication challenges is likely to develop some creative and interesting methods for communicating—some of which might be considered challenging.

The Function of Challenging Behaviors

Challenging behaviors, such as aggression, disruption, or self-injury are often a chief concern of caregivers of individuals with autism and other developmental disabilities. Many of these challenging behaviors are learned and maintained by what happens immediately before and after the problem behavior. Because they are learned behaviors, problem behaviors can be modified by manipulating or changing situations in the environment, especially the events before and after the problem. In most cases, challenging behavior is seen as a way to request or communicate a preferred outcome (e.g., access to toys, food, social interaction, or cessation of unpleasant activity). Therefore, the goal is to replace the inappropriate "request" with more adaptive (appropriate and effective) communication.

-p.13 Targeting the Big Three

Questions you might ask about why a person is behaving in a certain way include:

- Did this behavior start suddenly? If so, might my child be sick or is there another change that might have caused this?
- Is there some underlying medical concern or condition that is making him reactive? Tired? Stressed?
- What is my child attempting to gain from this behavior? Is he trying to escape something?
- What is he trying to tell me? What can I learn from this?
- Does it happen in certain places, with specific people or in situations where he is hungry or tired? Is there something we might adjust in his surroundings that might improve the situation?

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- What happens before the behavior? Is there something that makes it more likely to occur?
- What happens after the behavior occurs? What is helping this behavior persist? What maintains it or makes it work as a tool for this individual?
- What do I typically do to get my child to stop engaging in the behavior? Am I (or is someone else) giving him more attention then, or doing something that might be making the behavior work to get him what he wants?

If you can develop an idea of when or why a behavior is happening, you may realize there are simple solutions that help to improve a situation and make an undesired behavior less likely to occur.

It is also essential to remember that behavior changes, and people adapt. The same behavior that serves a specific function in one situation may serve a different purpose in another setting. In other words, one bite might be out of frustration when a child wants something he is unable to ask for. Another might occur when he is afraid and needs to get away, and yet another might be an automatic response to intense stress. And although biting is the same behavior, the reasons it happens (the function) can be very different.

Behavior generally serves one of several functions:

- Obtaining a desired object or outcome
- Escaping a task or situation
- Getting attention, either positive (praise) or negative (yelling)
- Trying to self-calm, self-regulate or feel good (*sensory input*)
- Blockingor staying away from something painful or bothersome (*sensory avoidance*)
- Responding to pain or discomfortAttempting to gain control over an environment or situation (*self-advocacy*)

Improvements can often be made by changing the situations and environment, or the things that come before and after problem behaviors occur. And since behavior is often a form of communication, teaching more adaptive and appropriate ways of communicating can often reshape problem behaviors into more appropriate requests, protests and responses.

"Before I was able to express myself with my speech, the only way I knew how to escape from situations and people I didn't like was to hit and bite and run. I didn't want to hurt anyone, but I just couldn't stand being there anymore and I couldn't explain my thoughts or feelings in any other way. So many things bothered me, it was like being in intense pain. Now that I've had years of practice – first with signing and then my communication device – I can use my speech and other forms of communication to ask for a break or to move to a quiet space, instead of using aggression. Things are much better for me now."

– DR, a young woman with autism

Before formal interventions are developed, it is important to consider the wide array of possible contributing factors, including the biological ones. Appropriately determining function is then essential to creating a plan that might effectively address the behavior.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

For example, if a child is hitting his mom in order to get out of making his bed, putting the child in 'time out' would actually give the child what he wanted (avoiding the task), and therefore support (*reinforce*) the behavior. In this case, he would be inclined to hit again to escape. Instead, if it is determined that the child hits because the task is too difficult, making the task easier to build success might allow him to stay engaged, and eliminate the need to hit. You may want to start by helping him make the bed, but be sure that he has to finish the job correctly by putting on that last pillow.

In considering behavior, it is important to look at the individual as a whole, and to consider productive as well as challenging or *maladaptive* behaviors. It is also important to recognize that what we might consider negative behavior might have positive elements—the individual might be standing up for his wants or desires. Building appropriate self-advocacy and self-determination skills is essential. Visit the *Positive Strategies for Supporting Behavior Improvement* for more information.

People with autism often report that they find the world confusing and anxiety-producing. Many of the successful supports for increasing appropriate behavior involve creating more predictability and safety, while also building self-regulation, communication and self-determination skills. Meet your child where he is now, celebrate the things he does well, and take small, positive steps to build the skills and the trust that will make him more adapted to your family and the world around him.

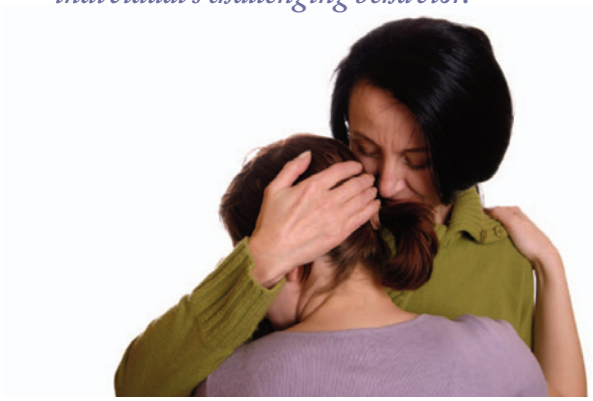


Two Vital Things to Remember

By applying the principles of behavior, you will teach the individual a more appropriate way to obtain what she wants (i.e., attention, access to leisure materials, or avoiding doing a task, etc.).

- *Consistency is Vital - While function-based behavior intervention can be very effective, for it to be most successful, it must be implemented consistently at all times by the majority of people who interact with the individual.*
- *Continuation is Vital - More importantly, the behavior intervention should continue even if the challenging behavior begins to decrease, much like the way medication or diet works. Hoping for a lasting effect without continuing the changing agent (i.e., behavior treatment, medication, and diet) will only lead to frustration and failure. With consistency and adherence to the behavioral guidelines, you will see gradual change in the individual's challenging behavior.*

–Page 72 – Targeting the Big Three



© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Why is it Important to Do Something about Challenging Behaviors?

Easily seeing what the problem is and adjusting the situation may be simple enough to change challenging behaviors. But sometimes this is unsuccessful, in which case continued challenging behaviors may be a sign that an individual needs help. This may be a medical evaluation or a particular treatment if something is affecting his health. Or it may require some changes in the supports, skills or tools that will allow him to feel comfortable, safe, heard and validated.

Challenging behavior might reflect an individual's only way to cope with a certain difficulty at any given time. Without proper intervention, these behaviors tend to continue and may get worse, creating an increasingly challenging cycle for you and your loved one. Promoting and teaching adaptive behavior as early as possible is essential for long term growth.

"Before Lindsay had speech, we could only guess at what was causing her so much pain. It was truly awful to feel so powerless to help your own child. And when she was aggressive or hurting herself, there was no way I was going to sit back and take my time to figure out what was causing it. I had to intervene right away either by moving away from her or restraining her arms. Once we learned to see her behaviors as her form of communication, we could begin to understand the purpose behind them. Then we could really focus on strengthening the few communication skills she had. Eventually, her problem behaviors became less and less frequent as they were replaced by language."

– BK, a father

Your ability to learn the tools to address and reshape challenging behaviors as early as possible is important for the day to day quality of life for your loved one, as well as your family. Many parents make subtle adjustments to adapt to their child's behavior, but over time, they can drift into patterns that become a "new normal." This may mean they no longer take their child shopping because of his aggression in the community. They may no longer bring him to visits with family or friends because he is disruptive, and so they lose their supports and relationships. They may accept that a child is an early riser, but then 6 AM becomes 5 AM, then 4 AM, and everyone is exhausted and no one is functioning well. Over time, these subtle adjustments (sometimes called *behavioral drift*) can become difficult to change, and can accumulate to limit the child's and his family's access to many important things in life.



© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Challenging behaviors can have a significant impact on the individual in many ways. They can:

- Interrupt academic learning and as a result limit long term growth and development
- Limit experiences and keep a person out of many opportunities for growth over his lifespan, including play dates, mainstream classrooms, recreational options, and eventually his work options, living conditions and ability to be integrated into the community
- Cause physical decline, pain, injury, especially when aggression and self-injury are involved
- Compromise an individual's psychological state, resulting in depression, stress, anxiety, and reduced self-confidence and self-respect
- Impair social relationships, as well as long term interactions with siblings, parents and other family members
- Affect finances as a result of employability, medical and supervision expenses
- Reduce independence and choice

Challenging behaviors can have a significant impact on the family and caregivers in many ways. Effects include:

- Added stress and worry
- Social isolation as a result of the embarrassment or stigma that accompanies the maladaptive behavior
- Anxiety and/or depression for parents and siblings
- Less time and attention for other children, responsibilities or interests
- Physical danger
- Fear of harm to themselves, other family members, others or the individual himself
- Less support from other caregivers, extended family or friends due to added complexities
- Financial concerns that result from the costs of constant care and supports, damage to property, medical bills, or the necessity of a parent to stop working
- Faster staff burnout and increased turnover
- Problem behaviors that might overwhelm the family's ability to cope or intervene

It is important to address challenging behaviors for many reasons, and the sooner the better. A 25 pound toddler with reactive behavior and a fist is a challenge, but that same behavior in a teenager who weighs 175 pounds is a threat. If your child has challenging behaviors that you are not able to change, it is important to seek out professional help.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

What are some Challenging Behaviors Commonly Displayed by Individuals with Autism?

Sometimes knowing more about a behavior itself, or learning the language to describe the behaviors you see to a professional, can help others to recognize the seriousness of the problem or find the right team members or approaches to understanding your concerns. The intensity, frequency and severity of behaviors will vary considerably across individuals and settings, and may change over time. For many families, the list below may seem overwhelming and well beyond the concerns you have about your child. Some of these behaviors occur only rarely and many will not describe what you see in your child. However, any of these may require you to learn new skills or perspective and can be addressed with assistance from professionals when they do occur.

Disruption occurs when an individual exhibits inappropriate behaviors that interfere with the function and flow of his surroundings. Examples include interrupting a classroom lesson, the operation of a work environment, or a parent's ability to make a meal. Behaviors might include banging, kicking or throwing objects, knocking things over, tearing things, yelling, crying, or swearing.

Elopement refers to running away and not returning to the place where a person started. In autism, elopement is often used to describe behaviors in which a person leaves a safe place, a caretaker, or supervised situation, either by 'bolting,' wandering or sneaking away.

"There was a young man who was always eloping, He would run and we could not figure out why. Unfortunately this running was both scary and dangerous. We worked to try and figure out why he was running and when we couldn't we decided to try and teach him how to ask to run. Once we opened this door up he would ask before he would run and the parent was able to tell him where he could run and sometimes she would run with him. It wasn't the perfect solution but it worked to keep him safe and that was the best we could do at the time and it worked".

– Behavioral Consultant

Incontinence is the (usually) involuntary passing of feces or urine, generally not into a toilet or diaper. Sometimes there is an underlying physical concern that might need treatment or incomplete toilet training that may need additional teaching. For some individuals, it may be a sign that there is difficulty recognizing body signals before it is too late. Sometimes an individual learns to use 'peeing his pants' or urinating on the floor as a means of gaining attention or escaping an undesirable task or situation.

Non-compliance is used to describe when an individual does not or refuses to follow the directions, rules or wishes of someone else. Non-compliance can be passive, such as not following a direction, or active, such as whining/crying, becoming aggressive or self-injurious. It is helpful to remember that non-compliance can be purposeful, but at times can also result from lack of understanding, lack of motivation, fatigue, or poor organizational or motor planning issues.

Obsessions, compulsions, and rituals are often strong, irresistible urges that can result in difficulty with a person's ability to cooperate, to manage change or to be flexible and adjust. The compulsion involved in obsessions and rituals can often lead to additional challenging behaviors if they are interrupted or forbidden.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- An *obsession* is when a person's thoughts or feelings are dominated by a particular idea, image or desire, such as a person who only wants to talk about elevators.
- A *compulsion* is the drive to do something in particular or in a particular way, such as the need to straighten all the forks at the dinner table.
- A *ritual* is used to describe a repetitive behavior that a person appears to use in a systematic way in order to promote calm or prevent anxiety, such as arranging all the pillows in a certain way before being able to settle in to sleep.

Physical aggression is an act of force that may cause harm to another person, and might include hitting, biting, grabbing, hair pulling, slapping, kicking, pinching, scratching, pulling, pushing, head butting, or throwing things.

Property destruction includes behavior in which belongings or property are harmed, ruined or destroyed and might include breaking, throwing, scratching, tearing, defacing, etc. belongings (his or those belonging to others).

Self-injury is the attempt or act of causing harm to a person's own body severe enough to cause damage. Self injury can present in a wide range of behaviors including head banging, hand-to-head banging, body slamming, hitting or punching oneself, eyeball pressing, biting oneself, wound picking, and hair pulling. Self mutilation such as cutting one's skin, burning, or bone breaking, is less common in autism unless other psychiatric conditions co-occur.

Sexual inappropriateness can take many forms in autism, and might be described as a lack of sexual inhibition or 'acting out' behavior. Lack of impulse control and poor social understanding might result in acting on sexual impulses that others know to keep private, such as sexual advances (propositions), sexual touching, promiscuity, exposing one's genitals, masturbating in public, sexual talk, obscene phones calls or voyeurism (watching others in private situations). Depending on the severity and the circumstances, sexual inappropriateness may lead to, or be considered, sexual aggression.

Threatening behavior includes physical actions that do not involve injury or actual contact with another person (such as holding up a knife), or stated or written threats to people or property.



Tantrum or meltdown describes an emotional outburst that might involve crying, screaming, yelling and stubborn or defiant behavior. The person might lose control of his physical state, and may have difficulty calming down even if the desired outcome has been achieved.

Verbal aggression generally involves the use of threats, bullying tactics, negative language, ultimatums and other destructive forms of communication.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Less Common Challenging Behaviors

Fecal digging occurs when an individual puts his fingers into his rectum (backside). Fecal smearing and handling of feces (poop) occurs when feces are spread on property or the individual himself. Each of these might be rooted in medical causes such as skin or digestive tract concerns, or may be learned behaviors that serve a purpose such as access to attention or escape from unpleasant situations.

Food refusal occurs when a person refuses to eat anything at all.

Pica is an eating disorder that involves eating things that are not food. Some individuals with autism and other developmental disabilities eat items such as dirt, clay, chalk or paint chips. Pica can also occur when a body craves certain nutrients or minerals that are lacking in the diet/body, as sometimes occurs in women during pregnancy.

Rumination describes the practice of (voluntarily or involuntarily) spitting up partially digested food and re-chewing it, then swallowing again or spitting it out. Rumination often seems to be triggered by reflux or other gastrointestinal concerns.

Purposeful or self-induced vomiting is throwing up on purpose. Contributing factors such as reflux, hyper gag reflexes and eating disorders (*bulimia*) should be considered.

It is important to repeat that while these behaviors might all be challenging, they should not be assumed to be purely behavioral, or purposeful. As discussed earlier, they are often learned responses. Sometimes there is a biological root or trigger that might require investigation or treatment in order to help the individual get to a more comfortable place where he might be able to learn adaptive skills. Even if treatment is not immediately effective, sometimes just knowing of a medical or neurological cause of a behavior can change how you think about it and how you respond.

Resources:

- *Asperger's Syndrome: Meltdowns;* IAN Community,
  http://www.iancommunity.org/cs/about_asds/aspergers_syndrome_meltdowns
- *Autism Solutions, How To Create a Healthy And Meaningful Life For Your Child*,
  Ricki Robinson, MD, MPH
  http://www.drrickirobinson.com/
- *Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting*
  by Helen Yoo, Ph.D, New York State Institute for Basic Research
  Autism Speaks Family Services Community Grant recipient
  http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf
- *The Autism Revolution*, Martha Herbert
  http://www.marthaherbert.org/

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Who Can Help? What is this Idea of a Team?

Individuals with autism are often quite complex, so it is helpful to take a broad approach when evaluating concerns, and deciding how to provide appropriate support. In order to meet their various needs, many individuals with autism, especially those with challenging behaviors, need a team to develop specialized and individualized care.

Team Members to Consider

Depending on the placement, circumstances, services, supports and concerns surrounding your loved one with challenging behaviors, the team might include the individuals and professionals from the disciplines outlined below. The actual mix of professionals and titles will vary across situations, but for most people it will be important to have someone in each of the roles described, either as an ongoing advisor, or as a consultant at some point.

- *Individual with Autism:* To maintain a person-centered approach and treat your loved one with dignity and respect, it is essential to include his voice at the table. Keep his wellbeing in the forefront of your mind as you plan and program as a team. Seek his perspective on the behaviors that are concerning, and why they take place. With some kids, it might help to ask, *'Why do you need to do this? How can we help?'* Wherever possible, involve him in the decision-making. Some individuals will have strong preferences that can greatly affect outcomes.

  Even if it seems that your child is not able to understand what you are saying, let alone make decisions about his care, talking to him directly might deliver more information and generate more understanding than you might expect. In addition, a person who does not respond verbally can deliver a great deal of information about his comfort, preferences and dislikes through his behavior. Involving him in the treatment process can help to build his social skills, self-advocacy skills, and independence. Remember to be sensitive to talking about him in his presence, as it is possible that he understands more than he can show.

Below is an excerpt from A Full Life with Autism, from the perspective of Jeremy, a young man with autism who learned to type to communicate:

"I have often times been the victim of ignorance. I think you have to be brave to get over the horrible times people hurt you by talking like you don't understand the comments they are making about you within earshot. I don't think people realize the kind of effect they have on nonverbal people. You know that intentional abuse is unforgiveable, but in some cases ignorance is just as painful. I remember when I was in junior high the occupational therapist told the teacher I would never learn and she did not understand why I was in mainstream classes ….. I was so upset because even though I could not talk or type, I could listen and learn. I wanted to die."

From A Full Life with Autism by Chantal Sicile-Kira and Jeremy Sicile-Kira. Copyright © 2012 by the authors and reprinted by permission of Palgrave Macmillan, a division of Macmillan Publishers Ltd.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Parent(s):* You are the key informant and advocate and an absolutely essential member of the treatment team. Outcomes are better with family involvement. No one knows your loved one, his history or the dynamics of your beliefs and your household the way you do. You might need to tell a story or give an example to fully describe the situations you find difficult or the needs you might see in your child.

  Be prepared to ask questions, raise your concerns and preferences, and ask for help. Effective communication across the team is essential, and in many cases you may be the one facilitating the sharing of information. Take notes, but also request information, suggestions and treatment plans in writing, since afterwards it may be hard to recall what was said. Ask for referrals to additional resources and share concerns about time and financial abilities. Ask for training and where else you might find help.

  If you are asked to do something you cannot do because it is too expensive, too difficult, or you don't understand the objective, speak up and ask for other ideas.

  You are likely to fall into a role as the team leader or coordinator, but if this is too much for you to take on, there might be help. Look into finding a case manager (see below), *special needs parent advocate*, family member or friend. Ask for suggestions from a primary care provider. Ask someone to accompany you to medical or specialist appointments to take notes and help you understand the choices and information being presented. You do not need to do this alone, but you may need to seek out and advocate for the level of supports that your family needs.

"When my daughter was moving from 1st grade to a new school, I created a 3-ring binder notebook with plastic inserts and dividers. In each plastic insert, I placed sheets of her school work both good and bad to show her growth. I included artwork, certificates and added a picture to the front. Almost just as important, I included information from her Medical Home and all of the other care providers on her team. This gave each team member and everyone who saw it, the full scope of who my daughter was. That notebook gave me the tools I needed to be the best Team Leader for my daughter. Not to mention, it helped me effectively communicate with our entire team. I still update and use this notebook method for everything from IEPs to Summer Camps...it works!!" - KD, parent

- *Case Manager:* Depending on the age or placement of your loved one, this might be a school case manager, or a representative from a service agency, such as a regional center (in California) or your state's Division of Developmental Disabilities or Department of Child and Family Services. Ideally, this person should be your direct contact, and should be helping to gather resources, team members and ideas. The effectiveness, skill set and time availability of a case manager will vary considerably due to many factors, and in some circumstances, you may not have one. You may have to advocate strongly in order for the case manager to understand the level of your concerns. If you do not have a case manager, sometimes a friend or family member can help you to research, track and organize the body of information that comes with the challenges of your loved one.

- *Medical Professional:* If you do not yet have one, try to build a 'medical home'—a relationship with a doctor who knows your child, and who you know and trust. Involve your primary doctor in evaluations, as he should be able to help when considering medical triggers for behavioral concerns. If your provider does not have a lot of experience in autism, it might help to share the list of Things to Consider in the next section and work through the possibilities together. Your doctor might refer you to specialists in areas of concern, and may be helpful in finding some of the other team members or therapists in the roles described below.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- Among others, referrals to specialists might include:
- hearing assessments (*audiologist*)
- vision evaluation (*ophthalmologist or optometrist*)
- stomach or digestive tract concerns (*gastroenterologist*)
- diet or nutrition issues (*nutritionist*)
- allergies (*allergist*)
- immune concerns (*immunologist*)

Just because an individual has autism, it does not mean that he is exempt from any of the other health concerns that affect any of us.

Sometimes doctors try to consider symptoms and signs, relate them back to what they know about autism and write off anything difficult to interpret as behavior. This is especially difficult if your loved one has limited language and cannot describe pain or perception issues. You might have to advocate in order to keep the focus on the individual and your concerns. Just because a broken leg is not associated with autism in the research literature, doesn't mean your child who just fell out of a tree does not have one!

In some states, you might have access to an **Autism Treatment Network** site, where the medical concerns associated with autism are being researched and treated according to collaboratively developed protocols with teams who specialize in autism treatment.

Is your loved one an adult or approaching adulthood?

It is important to note that while pediatricians are becoming increasingly aware of some of the issues related to autism, individuals on the spectrum are still relatively rare and novel in the world of adult medicine. Sometimes individuals with developmental disabilities stay in pediatric care far beyond childhood. If a switch to an adult provider is necessary, try to facilitate a transition of medical records as well as conversations with the pediatric caregiver. You may want to pass along this introduction for internists: **'Gently does it,'** caring for adults with autism, from the American College of Physicians.



If you find your loved one in the care of an adult doctor new to autism, you may need to share the information and resources provided in this tool kit, or additional general background information such as **Your Next Patient Has Autism….**

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Behavioral Health Provider* or *Behavior Analyst:* A team member who is trained in behaviorally based evaluations and interventions is often instrumental in understanding your child's challenging behaviors and developing supports and strategies. This might be a school *psychologist*, general psychologist, *Board Certified Behavior Analyst* (BCBA) or other behaviorally trained provider. These providers will use the elements of *Applied Behavior Analysis* (ABA) in supporting your loved one.

  ABA techniques involve controlling factors in the environment and monitoring interactions prior to a behavior (antecedents) and responses after a behavior (consequences). These techniques, including using positive reinforcement, are powerful in shaping behavior in individuals with autism. For more information, see the ATN Applied Behavior Analysis: A Parent's Guide and tips on Partnering with your Child's ABA Instructor.

"I honestly do not know where my son, Tyson, would be today without ABA. I am a true believer, although it was definitely not easy in the beginning. I hadn't realized how much work it was going to be for me and my wife, not to mention for our BCBA, but it was well worth it in the end. We basically started breaking down every task in Tyson's life into very small, manageable steps, and we rewarded him for even his 'smallest' successes. Then the BCBA would have us systematically raise the bar as he did more and more independently. I can say that Tyson is in an inclusive middle school today (with lots of accommodations) because ABA therapy helped him learn how to do almost everything from looking, listening, and sitting in his chair."

– HK, a father

- *Educator/Job Coach/Habilitator:* If your child is under the age of 21, it is likely that he is in a school based program with a teacher. Once he reaches adulthood, instruction is more likely to come through a habilitator or staff member at a day program, or a job coach. In both instances, finding a lead educator with autism experience and background in behavioral interventions will likely be helpful. Schools will require credentials on a state-by-state basis, but there is very little licensing or required training for adult service providers in most states.

- *Mental Health Provider:* Consideration of emotional and mental health concerns, as well as training and supports for the individual and the family, can come from a psychologist, school psychologist, psychiatrist, social worker, or community mental health worker.

- *Speech Pathologist or Speech Language Pathologist (SLP):* A trained speech specialist can evaluate an individual's ability to understand language as well as produce speech. These specialists are trained to see subtle concerns that might reflect communication deficits that an individual might find frustrating., A speech professional can also be invaluable in developing *functional communication* skills.

  Sometimes schools or agencies will resist providing speech services for a person who is non-verbal. But it is the development of communication systems (e.g. use of gestures and visuals, *picture exchange systems (PECS)*, sign language, *voice output technology*), not the pronunciation of sounds, that is the target for many speech therapy interventions in autism. Be persistent!

- *Occupational Therapist (OT):* An occupational therapist can help to evaluate concerns with fine motor issues, as well as the sensory and stimulation differences. Many OTs have also been trained in interventions and coping strategies to help make individuals feel more comfortable in their surroundings.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Physical therapists (PT), who generally work on large motor tasks and functions, may also be trained in related techniques. Both OTs and PTs can be instrumental in developing effective exercise programming.

Each of these team members might bring a different view of the same person to the table, providing perspective and expertise in understanding and creating systems of support. It is up to the parent, hopefully with the support of another key team member such as the case manager or doctor, to weigh and prioritize the input from these team members. A combined approach from the team should help to address physical, mental and learning concerns, and create a positive support plan for addressing challenging behaviors and helping you help your loved one with autism to grow and adapt.

Things to Look For in Your Child's Team (and Questions You Might Ask)

It might be helpful if you first go through the list of questions included below so that you have a sense of your own expectations and perspectives and can find a good match. Also keep it mind that certain personalities and styles will fit you or your child better than others.

- *Person-centered approach:* Professionals who think of your child as a person first—not the disability or the behaviors—will be the most helpful in discovering his strengths and his challenges. A person-centered approach will allow your team to find the tools and strategies that will be most helpful to him as an individual and to you as a family. A family-centered approach is also important, so it is essential to consider the values, priorities and specific needs of your family.
  - *What do you see about my child that you think is meaningful? Helpful? Different?*
  - *What are his strengths? What can you see of his preferences and fears?*
  - *This concern is as much about the questions the provider asks you, as it is about how he answers your questions. Does he try to understand your loved one, family dynamics, priorities, strengths, confounding factors, etc?*
- *Collaborative:* The challenging behaviors that might develop from a variety of factors will require many points of view. There may be a need for multiple providers or even multiple agencies, and the team will need to work together on the person's behalf. Collaboration also requires good communication between the members of the team. Some parents carry a notebook, an informational sheet and even makeshift brochures regarding their child to share with other team members.
  - *How do we communicate as a team?*
  - *What information can you give me to share with other team members?*
  - *How have you worked collaboratively in the past?*

"I have to say, we were lucky enough from the beginning to have assembled a group of fine people who had the very best intentions of helping my son Eli. But a few months into his preschool year, after Eli's progress seemed to have stalled, the school psychologist realized that we were not communicating well enough with each other. We were a patchwork team in which one hand hardly knew what the other one was doing. Once we started holding monthly

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

team meetings at the school where we could coordinate what each person found helpful, Eli really started to make a lot of progress. Keeping a daily communication book in his backpack (and now an email chain) was terrific because it kept us all in the loop and it was a way to document everyone's ideas." – SW, a mother

- *Broad thinking approach:* Given the complexities and variability associated with autism, it is critical that team members think about all of the possible driving and complicating factors that might influence an individual's behavior. (See Things to Consider) Especially when a challenging behavior is new or has dramatically increased, medical issues should be considered early in the evaluation process.
  - *What do you know about other interventions?*
  - *Do you have any suggestions for other team members with ____ expertise who might be helpful?*
  - *Do you think _____ might reflect something physical or emotional? Is there something else we should be considering?*
- *Experience with Autism:* Especially when it comes to challenging behaviors, it is important to try to connect with providers who are experienced with autism. For example, a doctor who understands that a minimally verbal child cannot report pain may have developed other ways of gathering information about possible concerns. A psychologist who understands that sensory issues may cause a child to be more anxious in certain situations may utilize a different approach to evaluation. You can learn about the provider's experience by asking at his office, or by connecting with school or agency staff, other parents, or local support groups for suggestions and recommendations.
  - *What is your experience in working with individuals with autism? This age group? This type of challenging behavior? This intervention plan?*
- *Commitment to evidence-based interventions:* Team members should focus on medications, interventions and programming that research has shown to be effective. However, it is important to remember that each individual should be treated as such. An intervention that has been validated in a diagnosed co-occurring condition, such as depression, should not be tossed aside just because it has not been established as a treatment in autism.

  The team should treat the person and the presenting symptoms, not the 'autism.'

  In addition, the field of autism is evolving, and for many interventions the research has not been done. A lack of research may not mean a lack of effect or relevance to your child's situation. Consult other team members to help you assess suggestions, but also know that you might not all agree. You should work within your team to weigh risks and benefits. For more on autism best practices, see the National Autism Center's **A Parent's Guide to Evidence-Based Practice and Autism** and the **National Professional Development Center on Autism Spectrum Disorders**.
  - *What does the research say about the use of this intervention for ____? What other information is available?*

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Professional judgment:* While research studies show the general effects of an intervention across a population, an evaluation of effectiveness should take place for interventions used with any specific person. Assessing effects requires set targets, goals and protocols, as well as a plan for collecting and analyzing data. Data analysis is important so that you know what is working, and when and if alternate treatment choices should be considered.
  - *What is the target behavior of this intervention?*
  - *How will we know if it is working? What are we tracking?*
  - *What are the side effects?*
  - *What is our role in the intervention?*
- *Responsiveness:* Providers should give you as much information as you need to understand the intervention and your role in it. They should listen to your concerns and priorities—cultural, familial, financial, etc.—and be able to adjust interventions to make them work for your family, the team, and the individual's needs. Voice your concerns and challenges so the providers can best support you and your loved one.
  - *What is my role in this plan or intervention?*
  - *How can we adjust _____ to take into consideration our family's needs? My travel schedule? Our insurance plan?*
  - *This is too hard. Data reflects that it is not working. This medication is making him worse. What do we do now?*
- *Licensing, board certification or other credentials:* It might be helpful to request references and talk to others who have used a provider you are considering. A list of certification and credentials required for the team members above is listed below:
  - *Occupation Therapist/Physical/Speech Therapists:*
    OT/PT/SLT State Certification Required (available online)
    National Board for Certifying Occupational Therapy (voluntary certification)
    American Speech-Language-Hearing Association (voluntary certification)
  - *Mental Health Provider:*
    Psychologist License: State Licensing Board (available online)
    Psychologist Certification: American Board of Professional Psychology or
    National Association of School Psychologists
    Clinical Social Worker: State license or certification (available online)
  - *Behavioral Health Provider:*
    Certification, required for BCBA designation, but not required to use ABA:
    Behavior Analyst Certification Board
  - *Medical Professional:*
    License: United States Medical Licensing Examination
    Certification required: American Board of Medical Specialties or American Osteopathic Association

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

How and Where to Find a Team

For school age children, many of these providers will be available through your school (ask your child's teacher or *Individualized Education Plan (IEP)* team case manager), or by referral from your school team or your doctor. Schools are required under the *Individuals with Disabilities Employment Act (IDEA)* to use *Functional Behavior Assessment (FBA)*, and then to support the learning of a child in school using a *Behavior Improvement Plan (BIP)* when necessary. Further information is available here and here.

Additional case management and referral ideas might come through your state disability agency, county offices, or social services agencies. Often there are printed resource directories or you might search online for your state's agency for developmental disabilities. Check phone books and county websites for government offices that might lead to the right agency. You may need to call several numbers to find out how to get to the right place for what you need. This may be quite frustrating, but be persistent! Public health departments, offices of children and family services, disability services or developmental disabilities may be helpful; sometimes their work is subcontracted to other organizations such as Easter Seals or United Cerebral Palsy, or groups that only exist in your state or city. The Autism Speaks Resource Guide also contains state information by age.

"Each time we saw a new doctor or therapist, or my daughter joined a new group or activity, I became increasingly overwhelmed. I oftentimes found myself just staring at papers and numbers and not knowing where to start. A friend of mine, whose child is also on the spectrum, suggested I reach out to a case manager to help me sort through everything. I wanted to think I could do this all on my own but decided to call. After an hour-long meeting with a case manager at a local organization I felt much better. There's still so much to do but I feel like I have a clear path to get there now."

– MM, a parent

Some states have *wraparound* programs, designed to build teams of providers, family members and natural supports to help keep complex youth in their homes and communities. In autism, wraparound services can sometimes fund behavioral programming. You can find a Board Certified Behavior Analyst (BCBA) here.

For adults, referrals might come through an existing service provider, medical home or *Medicaid* case manager. Contacting the county or state agencies will be similar to what is described above, but different agencies may be involved in care for adults.

It is important to note that your primary or initial contacts may not have the necessary time or specific skills necessary to fulfill the needs of your child, his evaluation, or ongoing supports and interventions. You may need to ask for additional referrals and supports. Keep asking.

Contacting other parents, often through your child's school, program or local autism support groups, might reveal additional suggestions and resources, especially for providers who are already working in the field of autism. Attend conferences, lectures, or fundraising events such as Walk Now for Autism Speaks. Even if you don't have time for the lectures or the event itself, take a pass through the vendor tables that are often set up just outside to meet area providers who might be able to help.

To access supports or resources specific to your state, please consult the Autism Speaks Resource Guide. If you have found providers that have been helpful, please submit them to the database here.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Funding Sources

Even if you have an experienced professional team assembled, paying for the additional services and supports can be yet another hurdle. Services provided by the school under the stipulations of IDEA are required to be free and appropriate. That means you do not need to pay, and if the school does not have the necessary skills or staff to meet your child's needs, it is their responsibility to pay for the services required to do so. It may require significant advocacy to get them to do what the law requires. More information on your rights under IDEA can be found here.

Ask your Human Resources officer about benefits, or check with your insurance company. Contact the public health department to learn about community plans such as those for mental health or those targeted to children. Funding for medical needs is often covered through health insurance and/or Medicaid. Speech and occupational therapists, as well as medical specialists, are often covered under medical plans. Historically, some of these benefits were specifically denied for autism and developmental disabilities, but as autism has become more common and research and advocacy efforts have increased, coverage for these items is improving.

Some states have mental health parity laws, which indicate that mental health care has to be covered to the same degree as physical health issues. Some insurance plans also have stipulations for behavioral health supports and interventions, and Medicaid programs provide *wrap around* services for behavioral interventions. It may take some significant investigation through your Human Resources department, your insurance company or the Medicaid office to find out the details of the mental or behavioral health coverage available. You may find assistance through your primary care provider or a case manager.

Military families are covered by *TRICARE*, the military healthcare program, which provides for limited ABA coverage for certain beneficiaries under the TRICARE Extended Care Health Option (commonly referred to as the ECHO program). Learn more about TRICARE eligibility criteria here.

Autism insurance legislation is in the process of being enacted state by state, with various terms regarding implementation and coverage. More than 30 states have passed autism insurance laws; they are listed on the National Conference of State Legislatures website. It is advisable to investigate and understand your coverage so that you know what to expect before beginning services. To find out the status of specific laws for insurance coverage for autism services in your state, visit the Autism Speaks Autism Votes website and select your state.

Certain state agencies can also provide funding for *respite*, which is helpful in giving you a chance to catch your breath. These agencies, such as Departments or Divisions of Developmental Disabilities or Children and Family Services may have programs, supports or suggestions of resources.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Sources/Resources:

Behavior Analyst Certification Board, Inc. (BACB)
http://www.bacb.com/

'Gently does it,' caring for adults with autism
http://www.acpinternist.org/archives/2008/11/autism.htm#sb3

National Autism Center's *A Parent's Guide to Evidence-Based Practice and Autism*
http://www.nationalautismcenter.org/learning/parent_manual.php

National Conference of State Legislatures (autism insurance information)
http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx

National Professional Development Center on Autism Spectrum Disorders
http://autismpdc.fpg.unc.edu/

Special Needs Parent Advocate
www.specialneedsadvocate.com

Wrightslaw (special education and disabilities legal information)
www.Wrightslaw.com

US Bureau of Labor Statistics *Occupational Outlook Handbook*
(Information on practitioner training and qualifications)
www.bls.gov/OCO/

Your Next Patient Has Autism…
http://www.northshorelij.com/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobkey=id&blobtable=MungoBlobs&blobwhere=1247088820137&ssbinary=true

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

What are the Things to Consider?

When trying to understand what might be contributing to challenging behaviors in any person at a certain point in time, the team needs to utilize a broad approach. Thoughtful consideration must be given to the various issues that might be resulting in the individual's actions. You may want to have your providers explore possible medical and mental health factors (also referred to as applying the principles of *differential diagnosis*). In this way, they can better evaluate what might set up, trigger, or maintain the behavior.

Some of these concerns might be quite obvious. For example, you would expect pain if a child has a visibly broken arm. However, other issues might require the skills of an expert who knows what subtle signs to look for, such as staring spells that might suggest seizure activity, certain behaviors that might suggest belly discomfort, or patterns that suggest an additional mental health concern.

"Until age 9, generally I lived in my own world relating to things, shiny coins, marbles and sparkly objects that I collected and hid in a secret place. I focused intently on these objects, lining them up over and over in patterns only I understood. If anyone disturbed them I had a tantrum, a meltdown, banging my head against the floor or wall for fifteen minutes. Nothing seemed to assuage my rage, it seemed to run a predictable course. I pulled my hair, picked at my skin and bit my arms. When it was over I was very thirsty and tired. Often, I returned to my activity to repair the interruption. My world was a house of cards, any breeze could collapse it.

I was an escape artist. I ran wildly, arms flailing until I became too winded to continue. Then I fell down, rolled onto my back and stared at the sky. I usually fell asleep. I believe that I had seizures.

I played with others if I could lead, and control the activities. If not, I left without a word. I seldom fought with other kids, except my bossy older sister who felt responsible for me. I didn't have a connection to people until I was in grade school.

High School and College I succeeded academically and socially pursuing artistic interests. I had many casual friends, none were close."

– Ruth Elaine Hane,*
a married woman with High Functioning Autism

**To read more about Mrs. Hane, please refer to Appendix 1 at the end of this section.*

It might be helpful to know that in general, people with developmental disabilities (including autism) are more likely to receive inadequate or inappropriate medical treatment. They receive fewer routine physical examinations, less preventative dental care and less mental health care than other Americans. People with communication issues are at greater risk of poor nutrition, overmedication, injury, neglect and abuse. There are likely multiple factors involved in these statistics, but certainly it is harder to care for someone who does not reliably say 'This hurts,' or 'Hey mom, why can't I see the blackboard at school?' Often, it is the parent's ability to be a watchful observer and careful reporter, combined with the skilled listening and evaluation of an experienced provider, that brings the necessary factors of a person with autism's health and other factors into consideration.

The following chart lists areas of potential consideration for the professionals on your team, and the types of questions you might ask in each area. This list is not complete, but hopefully it will support you and your team in considering topics that might be relevant with respect to your loved one and his concerns. If this list suggests an area that a provider is not investigating, be sure to bring it up. Know that you may have to be persistent or consult with other team members for each of your concerns to get the attention your loved one deserves.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Things to Consider

Possible Cause	Potential Areas of Focus	Questions to ask
Medical	Pain e.g. ear infection? Toothache?	Could this person be in pain?
	Seizure	Could this be seizure related?
	Sedation / Poly pharmacy (multiple medications)	Is this individual sedated? Is he on too many medications? Is he on the wrong medications or dose?
	Insomnia/Inadequate sleep	Does the person get enough sleep?
	Allergies	Are there seasonal, food or environmental allergies involved?
	GI Issues/Nutrition	Is behavior related to meal times or food? Has there been a change or concern about bowel habits?
	Dental concerns	When was the last dental exam? Is there tooth pain?
	Vision/Hearing	Is there a change in or problem with perception?
Genetic	Fragile X, Down Syndrome, etc.	Could this behavior be related to an undiagnosed genetic syndrome?
Mental health	Co-occurring mental illness	Could he be experiencing anxiety, depression, ADHD? OCD?
Cognitive	Intellectual ability/ Processing abilities	Are the demands on the individual too high or low for his cognitive level?
Communication	Adequacy of communication system	Does this person have a functional communication system? Does he use it spontaneously (without prompt)?
Sensory Dys-regulation	Unmet or overwhelming sensory factors	Is the behavior supplying sensory input/ attempting to meet sensory needs?
	Sensory defensiveness	Is the behavior in response to sensory overload? Are there big responses to things in the environment? (Loud noises, etc.)
Environmental factors	Location, time of day, setting, activity	Is he too exhausted at the end of the day to handle this demand? Why is he okay at other doctors' offices, but not here? Is this task beyond his motor ability?
Environmental reinforcement of behavior	Family/ Staff / Educator / Caregiver responses to behavior	Is the behavior responded to with attention? Removal of a request? Other?
Family / Staff dynamics	Changes in family environment	Have we had losses/changes in our family?
	Changes in staffing	Has a favored staff member left? Are new staff members adequately trained? Is there a shift in schedules/patterns?

Adapted from: *"Psychopharmacology of Autism Spectrum Disorders: Evidence and Practice,"* in press, Child and Adolescent Psychiatry Clinics of North America, 2012, Matthew Siegel, M.D.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Physical Concerns

As the previous chart outlines, there are many potential physical causes of and medical contributors to behavior. Gathering information about pain and symptoms can be especially difficult in individuals with autism due to communication difficulties, variable responses to sensory input and pain and even in those with good verbal ability, a lack of self-awareness.

It is also important for the team to know about **medical concerns** that often accompany autism, or more specifically, challenging behaviors. Addressing these less obvious concerns can often change behaviors. The most recognized of these include the following:

- *Seizure disorder* or epilepsy occurs in as many as a quarter of individuals with autism. Spotting seizures is sometimes tricky, since some seizures might occur at night but leave daytime effects, and others can appear in milder forms such as *staring spells* or times of 'spacing out.' Sometimes the after effects of a seizure can leave the person lethargic or reactive. You can find resources related to epilepsy **here**.
- *Gastrointestinal complaints or digestive disorders* such as reflux, stomachache, constipation, bowel pain, and diarrhea are often reported in autism. Investigation can be difficult in light of language challenges, but treatment has been shown to improve comfort and increase access to learning environments. See **Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.**
- *Sleep disorders or disturbances* such as difficulty falling asleep, insomnia, *sleep apnea* (disrupted breathing), and night waking are often reported in autism. Sleep is always an important consideration, both for the individual and the caregiver. Sleep is essential for physical as well as psychological restoration. It is hard to remain calm and keep perspective when you are exhausted, so evaluating and treating sleep concerns is essential. See the **ATN Sleep Strategies Guide**.
- *Sensory issues* are important to consider, since many individuals with autism respond to sensory input in an altered way. Sounds are louder, lights are brighter, words and visuals cannot be taken in at the same time, and the world is hurtful or confusing. It is also important to remember to assess sensory input. Have your child's eye sight and hearing checked? Make sure the doctor uses the right tests, since these concerns can be a challenge to evaluate in people with autism. In addition, these issues can change over time. Any of these factors might change a person's reactivity and promote a behavioral response.
- *Allergies, immune dysfunction, or autoimmune conditions* may show behavioral features that vary with exposure. Seasonal or *food allergies* or *intolerances* only occur at certain times of year, or when a particular food is eaten. Some food intolerances cause discomfort but not obvious rashes or breathing concerns, and may be **difficult to identify**. Immune activation such as eczema, joint pain or other conditions can cause a chronic discomfort that goes unnoticed.
- *Headaches or migraines* can result in a person with autism walking around with pain that you or I might readily fix with an over the counter pain killer. The inability to report pain—or even in more verbal individuals to identify pain in a certain place—can lead to discomfort that results in challenging behavior.
- *Genetic disorders* are associated with autism, and some can be accompanied by additional challenges that are worthy of medical consideration. Sometimes knowing about genetic differences can help you be more aware of other associated conditions, such as seizures.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Reflections on my childhood:

"I had terrible belly pain, and I did not know what to do about it. So I would run. I ran for miles just to try to get away from the pain. Of course, it was a small town and everyone knew me, so eventually I would end up back at home."
– RT, adult with autism

Other medical conditions have been noted in individuals with autism that may cause significant changes in behavior. These concerns may not immediately come to mind for your medical provider. But there is growing awareness of and investigation into the role they may play in autism, and sometimes in the appearance of challenging behaviors.

- *Whole body condition* is important to consider as autism is being increasingly recognized as a condition of the body, not just the brain. Many of the associations discussed above highlight the idea that there is likely more going on physically than was once thought. Insights into **nutrition** and **various body processes** might be worth considering.
- *Missed infections*, such as **Lyme's Disease**, **PANDAS**, an ear infection, an ongoing upper respiratory infection that harbors strep, or other low grade infections might cause immune activation but perhaps not obvious signs like a fever. Sometimes, there are effects on the nervous system as well as physical results of these infections. A doctor might check blood samples to look for titers (evidence of infection in the immune system) if behavior changes, such as extreme lethargy, tics, or a sudden onset of obsessions take place.
- *Catatonia* might be worth investigation if there is behavioral regression and significant changes in *motor* function (the ability to move, or to control one's movements). With catatonia, an individual may appear to hesitate, develop strange body postures, limit eating, and develop odd movements and tremors. Behaviors can appear such as self injury and aggression as a result of the individual's lack of motor control. Though it is not well recognized in the U.S., catatonia has been shown to develop in a significant number of teenagers and young adults with autism in studies in the UK as discussed in *Catatonia in autism* and may be worthy of consideration if these symptoms sound familiar.
- *Changing hormones* and the onset of *puberty* can make a typical child seem like a stranger, and these same effects can occur in people with autism. However, in autism, additional considerations come into play because of the language and social deficits. It is important to consider whether some of the behavioral features you are seeing are a natural, developmentally appropriate strive towards greater independence. If so, you should consider allowing additional choices and other proactive strategies (described in the next section) that will address this need. In addition, statistics show that individuals with developmental disabilities are at greater risk of abuse, including sexual abuse. The team should give consideration to this as a potential factor in sudden challenging behaviors. You can learn more by visiting the **Autism Speaks Safety Project** website.

Although it is not specific to autism, the chart of *"Common" behavior problems and speculations about their causes* might trigger some thoughts of additional considerations in your child (please see Appendices 2 & 3).

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

For some children, evaluations may have been skipped or avoided because of difficulty or fear of the procedures themselves. If anxiety about procedures affects the ability of your medical or dental team to evaluate your child, these tool kits, which were created by the *Autism Treatment Network (ATN)* might be helpful to you or your providers:

- Blood Draw Tool Kit
- Dental Tool Kit for Families
- Dental Tool Kit for Professionals

Mental Health Considerations

Studies of individuals on the autism spectrum show frequent overlap with symptoms that meet diagnostic criteria for other mental health conditions. This is a difficult area and interpretation often varies by provider, since many of the features of autism also occur in other named disorders and there is no distinct line. For instance, various providers might use different criteria in distinguishing between the repetitive behaviors of autism and a diagnosis of obsessive-compulsive disorder.

Sometimes the features of *depression*, *anxiety*, *ADHD*, *obsessive compulsive disorder*, *Tourette's Syndrome*, *bipolar disorder* or *schizophrenia* are significant enough that they stand on their own as worthy of specific diagnosis and treatment. When a person has two or more diagnosed conditions, this is called a *co-morbid condition* or *dual diagnosis*. Challenging behaviors are common in individuals with dual diagnoses, and it may be that another mental health concern has not yet been diagnosed or considered.

Statistics for dual diagnosis in individuals on the 'higher functioning' end of the spectrum or with Asperger's Syndrome are high. This might be because they are better able to report concerns. It may be that the combination of the social aspects of autism and the effects of the co-morbid condition combine to cause challenges that drive them to evaluation, services and hopefully, treatment. More information is available through the National Association of Dual Diagnosis (NADD).

The role of the mental health provider might include differential diagnosis, medications, therapy and/or *cognitive behavior* interventions, as well as partnership with other team members. It might be important for a mental health provider to educate the team about the features of a dual diagnosis, so that, for example, the uncontrollable tics of *Tourette's* might be considered and treated as something different from *behavioral stereotypy*. A mental health provider might ask questions about the behavior, as well as changes in behavior that might reveal new circumstances or areas of concern such as depression, anxiety, *post-traumatic stress*, or *psychosis*.

It is important to note that mental health disorders and symptoms should not be considered purely psychological. There are biological factors that can drive anxiety, anger, tics and other behaviors. Just as it may be impossible to know when a seizure is coming, the biological triggers for some of these symptoms in some individuals, and the resulting behaviors, can be unpredictable. If this is the case, your mental health provider should help you understand this situation better and may be able to help. Together with your behavioral/educational team, you may be able to determine subtle signs that your child is headed towards a surge and then develop approaches that will minimize its effects.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Recent **research** has shown preliminary evidence of ***biomarkers*** of depression in teenagers. A biomarker is a sign of an objective, measurable biological state. For many, the presence of a biomarker makes something 'real', like high cholesterol or an infection with a specific virus. In contrast, autism and most mental health concerns are diagnosed based on observed behaviors, and therefore more subjective and likely to be thought of as psychological in nature. Identification of biomarkers in autism is an objective of the research field, but even if only potential co-morbid conditions can be assessed this way, it could be helpful in defining concerns, and tailoring treatments for many individuals.



Another potential factor is the role of adolescence in changing behaviors. Puberty is often a time when conditions such as depression and anxiety appear. The physiological changes, as well as the developmentally programmed need for greater independence and breaking away from parental control, are just as real in an individual with autism as they are in a typical teen. For those who have academic and functional skills closer to their peers, such as young people with Asperger's Syndrome, teenage years can be a sensitive time when a growing awareness of their differences or difficulties making friends and fitting in becomes increasingly frustrating. A mental health provider might be able to help your child, and also aid in your understanding of these changes and how you might adapt to grow with your child as he strives for more autonomy and self-advocacy.

Post-traumatic stress (PTSD is another condition worthy of consideration, especially for someone who cannot describe what he has experienced. Some individuals may have been in situations that have caused significant stress, such as medical concerns/pain/procedures, changes in surroundings/staff/family, neglect, or abuse. ***It is important to be aware that research also shows a higher likelihood of sexual abuse in the developmentally disabled population.*** The possibility of abuse or trauma should be considered when challenging behaviors develop suddenly.

Other individuals may feel additional stress in response to interventions that have targeted challenging behaviors using approaches such as ***seclusion*** (putting a person in a place alone), ***restraints*** (tying, wrapping or otherwise restricting a person's ability to move), ***over correction***, ***'aversives'*** (interventions that are painful or disliked), or other punishments. In these instances, caregiver/staff responses to challenging behavior may be instrumental in creating a disturbing cycle that raises stress and increases the likelihood of more difficult behaviors. In other words, how the people around your child are responding to his behavior might be making his situation even more stressful and challenging. More discussion of the effects of intervention is included in the behavioral section that comes later in this tool kit.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Medication

If your loved one takes medicine, it might also be worthwhile to talk to your doctor about the possible effects on behavior. Many of the medications we use affect more than just the intended outcome. These side effects can sometimes be quite significant and can change an individual's sensitivity or ability to regulate. For example, some medications can be *ototoxic*—which means they might be damaging to the ears, causing sound sensitivities, dizziness or balance issues. Other medications might cause stomach pain in a person who never had digestive issues before. It is not just traditional *psychotropic* (acting on the brain) medications that need to be considered. It is possible that a prescription for acne medication might be having an effect that might trigger new behavior. Carefully review side effect lists and discuss the side effect profiles of each medicine with your doctor, especially in someone who might not be able to report on his symptoms.

In considering medication, note that proper dosage can be very sensitive, particularly in individuals with autism. Sometimes too much medication can be *over-stimulating* or *sedating* (tiring), perhaps even causing the person to find other ways (through new or difficult behaviors) to try to get back to a sense of stability or normality. Some medications can have unexpected or rebound effects. Layering on multiple medications at one time, called *poly pharmacy*, can also have unintended effects. Some doctors have reported success in slowly taking a person off all medications to re-establish 'baseline' in an effort to sort out 'what is the autism?' from 'what is the medication?'

"I recall that when Jack was little our doctor suggested that we try a stimulant. This was meant to calm and focus him. As time went on, Jack didn't sleep for 48 hours sometimes, and we were all a mess as he was bouncing off the walls. We couldn't imagine what he would be like without the benefit of those calming meds. Eventually we tried a weekend drug holiday as they often suggest for stimulants, and he was lethargic the whole weekend. Aha! We realized it was the drugs, not the autism, that was causing the behavior. In hindsight it seems obvious, but in the moment, it was hard to see the relationship."

– SG, parent

As an individual grows and changes, medication may need to do so as well. For example, a larger teen might need more medication to achieve the same effect on attention or anxiety. Medical expertise specific to autism is often quite helpful in carefully determining the right pharmacological interventions for an individual at any point in time.

Families often struggle with decisions about the role of medication in addressing challenging behaviors, and when and what kinds of medication might be useful. This **Medication Guide** is designed to help in defining your values and goals surrounding medication use. It also provides perspective and talking points to assist in speaking with your doctor and making decisions. It can be used for new medication decisions, or in re-evaluating current medications.

If medication is started, it is important to track side effects and look for other concerns to ensure that the medication is helping where it is supposed to help, and not causing other problems. Sometimes a provider might use a measurement tool that involves asking the family or staff questions prior to starting a medication or other intervention. One often-used tool is the **Aberrant Behavior Checklist**. The provider might repeat this test after a few weeks or months as a way of measuring the effects of the medication. It is wise to have multiple responders, as well as to compare baseline and follow-up responses from the same person.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

The use of simple *tracking scales* for both target behaviors and side effects is another way to assess the effects of a medication. This might be undertaken in cooperation with a behavioral provider or team using their data collection systems, or you could create or modify something like this tracking scale:

Date: _____

Medication Name: _____

Medication Dose: _____

Behavior/Symptom Occurred	Morning	Midday	Evening
Burping			
Sleepiness			
Uses iPad to make request			
Hitting			
Kicking			
Other			

"We did not like the weight gain associated with the meds that Sammy was on, and we weren't even sure it was helping. So, every few months, I would decrease his dose just as the doctor instructed, and I would start on a Friday so that we would be able to see changes that we wouldn't see while he was off at school. I would not tell my husband, so that at least one of us was getting a 'blinded' view of any changes. By Sunday afternoon, in the midst of some frustrating situation, he would say, 'are you doing that meds withdrawal experiment with Sammy again?' And we knew the meds were still working."

– BW, parent

Sometimes it is helpful to keep some team members or family members *'blinded'* to a new intervention. Often, if we know something is supposed to help in a certain way, we are more likely to see it, even if it is not really there. For example, if you tell the lead teacher about a new medication but not the classroom aides, you might get better information from the team about the true effects of a medication on your child's behavior.

Consideration of changes in the effects of medications should be ongoing. Sometimes adjusting dosage, form (some medications come in time-release forms for more even delivery), time of delivery (before vs. after meals, at bedtime instead of morning, etc.), or other factors can help to increase the benefits and reduce the side effects of a medication.

Being a careful observer and a good reporter to your doctor, and discussing both the benefits and downsides of a medication in advance and as the intervention progresses, can often help to manage a medication so that it is most helpful. Using a chart such as the one above can help you to see if the medication is effective. If medical concerns are a feature of your loved one's profile, it is important to maintain good records and share information among team members.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Behavioral Considerations

When a person behaves in a way we find difficult or offensive, we often reflect on the impact of that person's actions on us—how we feel threatened or embarrassed or hurt. This is absolutely normal, but not always helpful. Instead, it is important to think about the behavior from the individual's perspective.

What is so scary about entering this place that my child is so panicked that he has to bite me? What pain is occurring in his body that he might be trying to over ride it by hitting himself in the head? Is this something biological over which he does not have control? If so, can we help him to learn how to adapt?

Shifting our thinking from how a particular behavior affects us (and the siblings, the classmates, the furniture, etc.) to what might be happening from the individual's perspective is an important step in finding ways to understand behavior. Understanding the behavior will allow you to support the replacement of disturbing or *maladaptive* behaviors with functional skills.

Going back to the basics of behavior, it is important to consider the possible purpose or function. *How does this behavior serve the person? Does he get something out of it? Does he get to escape something boring or difficult? Does he get attention? Does it allow him to assert a little bit of control over his life or surroundings? Does it help to block out pain? What is good about the behavior? Is he trying to tell me something?*

Taking the time to understand the function can often give a window into the motivation behind the behavior. Proper evaluation of function is usually essential to crafting an appropriate response.

For example, suppose a child kicks when it is time to go to gym class and the response to his kicking is to put him in a 'time out.' This is likely to be an ineffective intervention if the whole reason for kicking was to avoid going to gym. He just got what he wanted, and he learned that kicking is an effective way of making his argument. Next time he doesn't want to go to gym class, what is he likely to do? But if kicking keeps him out of the loud, echoing chaos of gym that he finds hurtful or disturbing, he is likely to use the communication he has learned *unless and until* he is taught a better way of coping with gym class (e.g. asking for a different activity) or advocating for avoiding the unpleasant situation.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

In the field of Applied Behavior Analysis, the three components that are documented and considered in looking at a specific behavioral episode are called *A-B-C (antecedent-behavior-consequence) analysis*, and include the following components:

- a clear description of the behavior (behavior)
- the situation, events and conditions that occurred before the behavior began (antecedent)
- the situation and events that immediately followed the behavior (consequence)

These behaviors may be tracked using a sheet such as this:

ABC SHEET

Student: _____ **Observer:** _____

Target Behavior: _____

Antecedent: The event that occurs immediately before the behavior

Behavior: The occurence of the target problem behavior (reecord frequency)

Consequence: The event that immediately follows the occurence of the behavior

Date	Time	Antecedent	Behavior	Consequence	Comments

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

A professional with expertise in behavioral assessment and intervention (e.g. a BCBA) will use a variety of tools to help understand the function of a behavior at any given point in time. It is important to remember that the scales are tools, not answers. A good *functional behavior assessment (FBA)* will use several measures—questionnaires as listed below, observational assessments, active listening, and the professional's experience and background.

An FBA should be broad based and should take into account the observations of behaviors and how and when they occur. They should also seek to be empathetic and to understand why the person might feel the need to behave in a certain way. Make sure your provider is using a broad approach, since this is essential to getting a good handle on the concerns, potential causes of the behavior, and possible interventions and solutions for replacing this behavior with skills.

The following resources will help you learn more about how behavior is often evaluated and considered by professionals:

- **Parents' Guide to Functional Assessment**
- **Functional Behavioral Assessment and Positive Interventions: What Parents Need to Know**
- **Targeting the Big Three parent training manual**

For a school-aged child, the school district is responsible (under the laws of *IDEA*) to perform a FBA and create positive interventions for a child whose behavior inhibits his learning, or the learning of those around him. If they do not have this expertise on staff, they need to secure these services through other agencies or consultants. Some schools will provide additional training and instruction in the home, or through other community providers such as *wraparound* supports. Behavioral interventions through your health insurance provider may also be able to provide this support.

If you do not have access to a behavioral support provider or team, you can begin to become a more advanced observer of the elements of behavior yourself. Tools such as Barbara Doyle's **data collection** and **communication dictionary** might be helpful.

After defining and evaluating the behaviors, the behavioral team, teaching staff or other providers should explain the results to you and develop instructional strategies using *Positive Behavior Supports (PBS)* and *Reinforcement Strategies*. Using Positive Behavior Supports is a way to promote functional skill development and motivation and can be used at home, school, work, and in the community. These supports often need to be individualized to the needs of the child, and the functions of his behaviors, to be effective. Classroom based supports are often not sufficient for challenging behaviors, so you may have to advocate for these to be individualized. More on positive behavior supports, training and resources for families, schools and staff, and strategies for building positive behavior are included in the next chapter.

If the function of the behavior is to gain attention, challenging behavior can be reduced if attention and interaction are no longer given when the individual engages in the problem behavior. This means not giving direct eye contact or calling the individual's name, no reprimands, no reasoning and lecturing, or showing that you're upset. Attempts to redirect the behavior by giving attention may inadvertently increase the problem behavior.

Note: Ignoring challenging behavior may initially increase the challenging behavior because that is how he communicated what he wanted and how he got his way until now. Keep the faith. Ignoring will ultimately decrease the likelihood that the individual will engage in challenging behavior to gain attention.

-Page 73 Targeting the Big Three

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Other Concerns to Consider

Communication Issues

Teachers, behavioral providers and/or speech pathologists should also evaluate the ***functional communication*** skills available to an individual, as this can be a critical factor. After all, behavior is often a form of communication—sometimes the only form available to an individual who has not learned other skills.

It will be helpful to consider: *Did he understand what I said? Can he independently use speech or other forms of communication to raise concerns? Report pain? Make requests? Ask to get away? If not verbally, does he have cards or a device that he uses independently for this? Even if he can speak well, does he have the language or the confidence to make his needs and concerns known verbally?* If not, it is likely he is finding other ways to express wants, frustration, fear or other information.

Many individuals with autism have difficulty processing information—hearing all the parts of what someone said, matching what they see to what they hear, or being able to decide what information is important and relevant in light of all the possible sights, sounds, smells, etc. Many people with autism are visual learners, or otherwise benefit from information presented in pictures, words or video. Verbal information (speech) disappears as soon as it is said, but visuals have staying power—they can be available and accessed as long or as often as the individual needs.

It is essential that the functional communication system is something that your child can initiate and use independently. Often a speech pathologist can perform an evaluation and design appropriate interventions. Many skilled autism intervention teams have also developed expertise in communication supports and development. If supports and training in functional communication are needed, there are a variety of systems that the team should explore, such as PECS and voice output devices, to find a fit for the individual and his specific needs and preferences.

"I remember how he would throw himself to the floor when he was thirsty. The speech pathologist taught me how to take his little hand and shape his fingers into a point, then lead his hand to touch the cup. We did this hundreds of times, moving from the cup to toys and movies he wanted to watch. When he pointed, he got what he wanted. He started pointing. He was learning to ask!"

- TO, parent

Sometimes even highly functional individuals with autism can have difficulty communicating certain concerns. For example, many individuals with Asperger's Syndrome lack self-awareness. So as a result, isolating pain, describing emotions or identifying what is causing a negative feeling can be very difficult. Expectations that a 'straight A student' should be able to navigate social situations or other challenging experiences can often leave an individual unsupported, and as a result, increasingly anxious and reactive. Specific instruction in social and self-awareness can be hugely beneficial for someone who might have an incredible vocabulary but difficulty communicating about socially relevant concerns.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Sensory Concerns

Individuals with autism often report on their different ways of experiencing the world, and it is helpful to keep these issues in mind when considering a person's specific behaviors. A child may scream or run out of the singing of the Happy Birthday song not to be difficult, but because the singing and/or the cheering that follows is truly painful for him. Often these responses are more like reflexes than behavioral choices. When a person stays away from certain experiences—sounds, touch, smells, food tastes/textures, certain types of movement, etc., it is often called *sensory avoidance* or *sensory defensiveness*. Even in these same individuals, there is often a contrasting need for additional stimulation of certain senses as a way of maintaining attention or achieving a calmer state. This is called *sensory-seeking behavior*.

It is important to consider whether the individual has some sensory need that is otherwise not being met. Is he jumping up and down because it feels good? Alternatively, is there sensory defensiveness? Is there something about this tag in his shirt, this lighting, this sound, this crowd, these odors that he finds painful or overwhelming?

"He had a fascination with birthday parties and blowing out candles, and at one point we would have to re-light, re-sing, and re-blow – 20 times or more each birthday. We developed a program to teach Joey how to end Birthday Parties. Of course all of this was after at age 5, because until then he couldn't tolerate listening to the song 'Happy Birthday' at all."

– BH, Parent

To investigate whether sensory factors might be a consideration with your loved one, an Occupational Therapist or other provider might use an age-appropriate form of the Sensory Profile or the Sensory Processing Measure (SPM). A sensory checklist and additional information are available at the Sensory Processing Disorder Foundation website. More information can be found here.

Support Systems and Environment—Family, Staff, Supports Dynamics

Change is difficult for any of us, but it may be more so for those who do not understand what changes are taking place and why. Consider potential contributing factors that might be leaving your loved one with autism feeling confused or anxious.

If challenging behaviors come on suddenly or intensify, it is important to ask what changes have occurred in his life. *Have there been changes in schedules? School, work or residential placement? Changes in the family environment? A sibling heading off to college? Loss of a family member? Have there been changes in staff? Loss of a preferred staff member? If there is a behavior plan, is it being followed consistently? Perhaps new staff who need additional training or who employ methods that are stressful? Is there any concerning behavior in caregivers? What is their stress level?*

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Resources:

General:

Ask and Tell, Self-Advocacy and Disclosure for People on the Autism Spectrum

Autism Solutions; How to Create a Healthy and Meaningful Life for Your Child,
Ricki G. Robinson, MD, MPH

National Autism Center's A Parent's Guide to Evidence-Based Practice and Autism
http://www.nationalautismcenter.org/learning/parent_manual.php

Behavior Function and Evaluation:
Functional Behavioral Assessment and Positive Interventions: What Parents Need to Know
http://www.wrightslaw.com/info/discipl.fba.jordan.pdf

How to Think Like a Behavior Analyst, Jon Bailey and Mary Burch
Parents' Guide to Functional Assessment
http://pages.uoregon.edu/ttobin/Tobin-par-3.pdf.

To Walk in Troubling Shoes: Another Way to Think About the Challenging Behavior of Children and Adolescents,
Bernie Fabry PhD, 2000
http://www.parecovery.org/documents/Troubling_Shoes_2000.pdf

Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting
IBR Autism Speaks Family Services Grant Challenging Behaviors Curriculum
http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf

Skill Evaluation/Development:
The ABLLS-R; The Assessment of Basic Language and Learning Skills,
James Partington and the AFLS too!

Severe Behavior Problems: A Functional Communication Training Approach (Treatment Manuals for Practitioners),
V. Mark Durand

Sensory Profile
http://www.pearsonassessments.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=076-1638-008

Sensory Processing Measure (SPM)
http://portal.wpspublish.com/portal/page?_pageid=53,122938&_dad=portal&_schema=PORTAL

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Medical/Medication:

Buie T, Campbell DB, Fuchs GJ, et al.,
Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.
[Consensus Development Conference, Journal Article, Research Support, Non-U.S. Gov't]
Pediatrics 2010 Jan.:S1-18.
http://pediatrics.aappublications.org/content/125/Supplement_1/S1.long

Buie, et al.
Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.
http://pediatrics.aappublications.org/content/125/Supplement_1/S19.long

Herbert, Martha,
The Autism Revolution
www.marthaherbert.org

Loschen, EL and Doyle, B,
Considerations in the Use of Medication to Change the Behavior of People with Autism Spectrum Disorders
http://www.asdatoz.com/Documents/WebsiteCONSIDERATIONS%20IN%20THE%20USE%20OF%20MEDs%20ltrd.pdf

Siegel M & Beaulier A, Journal of Autism and Developmental Disorders, November, 2011
Psychotropic Medications in Children with Autism Spectrum Disorders: A Systematic Review and Synthesis for Evidence-Based Practice.
http://www.ncbi.nlm.nih.gov/pubmed/22068820

Siegel, M,
Psychopharmacology of Autism Spectrum Disorder: Evidence and Practice,
Child and Adolescent Psychiatry Clinics of North America, 2012, in press,
http://www.ncbi.nlm.nih.gov/pubmed/22068820

Appendix 1

Ruth Elaine Hane, who was diagnosed with High Functioning Autism in 1995, lives in Minneapolis, with her husband and their two cats. Contributing author to *Ask and Tell, Self-Advocacy and Disclosure for People on the Autism Spectrum* and *Sharing Our Stories* and numerous other publications, Ruth Elaine mesmerizes audiences with her vivid memories of growing up in a large family without knowing the characteristics of autism. Born as a Rubella measles baby; unable to swallow or tolerate touch, Ruth Elaine did not talk until nearly five years old, when she began using full sentences with reciprocal language. Her strength lies in her unique view of how things are, and an insatiable desire to improve her life by learning to read faces and understanding complex nonverbal messages. Ruth Elaine mentors and coaches others, effectively teaching the skills she has learned, and serves on boards and task forces for many autism organizations. Presently she is focusing on developing her Face Window idea to work to overcome face blindness , by assisting in Child Psychology research at the Fraser Family Services and the University of Minnesota. Ruth Elaine is a gifted healer, utilizing Reiki Energy to balance the whole body system, believing that an underlying deficit in autism is an unbalanced whole- body system.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Appendix 2

Common "problem" behaviors and speculations about their causes

Ruth Myers, MD, James Salbenblatt, MD, Melodie Blackridge, MD

"High pain tolerance"
- A lot of experience with pain.
- Fear of expressing opinion.
- Delerium
- Neuropathy (disease of the nerves)/many causes

Fist jammed in mouth/down throat
- Gastroesophageal reflux
- Eruption of teeth
- Asthma
- Rumination
- Nausea

Biting side of hand/whole mouth
- Sinus problems
- Eustachian tube/ear problems
- Eruption of wisdom teeth
- Dental problems
- Paresthesias/painful sensation (e.g., pins and needles) in the hand

Biting thumb/objects with front teeth
- Sinus problems
- Ears/Eustachian tubes

Biting with back teeth
- Dental
- Otitis (ear)

Uneven seat
- Hip pain
- Genital discomfort
- Rectal discomfort

Odd unpleasurable masturbation
- Prostatitis
- Urinary tract infection
- Candidal vagina
- Pinworms
- Repetition phenomena, PTSD

Waving head side to side
- Declining peripheral vision or reliance on peripheral vision

Walking on toes
- Arthritis in ankles, feet, hips or knees
- Tight heel cords

Intense rocking/preoccupied look
- Visceral pain
- Headache
- Depression

Won't sit
- Akathisia (inner feeling of restlessness)
- Back pain
- Rectal problem
- Anxiety disorder

Whipping head forward
- Atlantoaxial dislocation (dislocation between vertebrae in the neck)
- Dental problems

Left handed or fingertip handshake
- Frightening previous setting
- Pain in hands/arthritis

Sudden sitting down
- Altlantoaxial dislocation (dislocation between vertebrae in the neck)
- Cardiac problems
- Seizures
- Syncope/orthostasis (fainting or light-headedness caused by medication or other physical conditions)
- Vertigo
- Otitis (thrown off balance by problems in the ear)

Waving fingers in front of eyes
- Migraine
- Cataract
- Seizure
- Rubbing caused by blepharitis (inflamation of the eyelid) or corneal abrasion.

Pica
- General: OCD, hypothalamic problems, history of under-stimulating environments
- Cigarette butts: nicotine addiction, generalized anxiety disorder
- Glass: suicidality
- Paint chips: lead intoxication
- Sticks, rocks, other jagged objects: endogenous opiate addiction.
- Dirt: iron or other deficiency state
- Feces: PTSD, psychosis

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Common "problem" behaviors and speculations about their causes continued

Ruth Myers, MD, James Salbenblatt, MD, Melodie Blackridge, MD

General scratching

- Eczema
- Drug effects
- Liver/renal disorders
- Scabies

Self-restraint/binding

- Pain
- Tic or other movement disorder
- Seizures
- Severe sensory integration deficits
- PTSD
- Parasthesias

Scratching stomach

- Gastritis
- Ulcer
- Pancreatitis (also pulling at back)
- Porphyria (bile pigment that causes, among other things, skin disorders)
- Gall bladder disease

Scratching/hugging chest

- Asthma
- Pneumonia
- Gastroesophageal reflux
- Costochondritis/"slipped rib syndrome"
- Angina

Head banging

- Pain
- Depression
- Migraine
- Dental
- Seizure
- Otitis (ear ache)
- Mastoiditis (inflammation of bone behind the ear)
- Sinus problems
- Tinea capitis (fungal infection in the head).

Stretched forward

- Gastroesphageal reflux
- Hip pain
- Back pain

Reprinted with permission from:
Ruth Myers, MD

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

What are the Positive Strategies for Supporting Behavior Improvement?

As highlighted in the previous section, there are many possible contributors to the development of challenging behaviors. It is important to investigate and evaluate these, but also to take action sooner rather than later, since many behaviors can become increasingly intense and harder to change as time goes on.

Often a necessary approach to managing behavior involves a combination of addressing underlying physical or mental health concerns, and using the behavioral and educational supports to teach replacement skills and self-regulation. There is no magic pill, but there are a number of strategies that can often be helpful.

The use of *Positive Behavior Supports* is more than just a politically correct approach to behavior management. Research shows that it is effective. The alternative is usually *punishment*, which decreases the likelihood of a behavior by taking something away (such as removing a favorite toy) or doing something unpleasant (yelling, spanking.) While punishment might work immediately, it has been shown to be ineffective in the long run and can increase aggressive behavior, provide a model for additional undesirable behaviors, and strain the relationship with the caregiver (you). It is worth noting that to continue to be effective and maintain improvements, positive supports and feedback need to be ongoing as well.

"Withholding reinforcement for problem behavior (i.e., extinction) is technically an example of punishment. Proponents of Positive Behavior Support (PBS) acknowledge that controlling access to reinforcement is necessary when trying to change behavior. What PBS does not condone is the use of aversive (e.g., demeaning, painful) procedures to suppress behavior. Such approaches have been demonstrated to be ineffective in producing durable changes in people's behavior and do not improve to quality of their lives." –Association for Positive Behavior Support

If you have made changes to improve your child's health or happiness, and these have not helped to improve his behavior in a reasonable time frame (a couple of weeks), or you are concerned about safety, help may be needed. Positive strategies and an intervention plan can be developed by a behavioral or educational team, usually in response to what is learned in a *functional behavior assessment* (FBA) as described in the previous section.

When several challenging behaviors exist, it is important to establish priorities. You may want to first target behaviors that are particularly dangerous, or skills that would help to improve situations across several behavioral scenarios. Remember to set goals that are realistic and meaningful. Start with small steps that can build over time. A non-verbal child is not likely to speak in full sentences overnight, but if learning to hold up a 'take a break' card when he needs to leave the table allows him to exit, and keeps him from throwing his plate, that is a huge success.

A plan for you and your team should meet four essential elements:

- *Clarity:* Information about the plan, expectations and procedures are clear to the individual, family, staff and any other team members.
- *Consistency:* Team and family members are on the same page with interventions and approaches, and strive to apply the same expectations and rewards.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Simplicity:* Supports are simple, practical and accessible so that everyone on the team, including the family, can be successful in making it happen. If you don't understand or cannot manage a complicated proposed behavior intervention plan, speak up!
- *Continuation:* Even as behavior improves, it is important to keep the teaching and the positive supports in place to continue to help your loved one develop good habits and more adaptive skills.

Please recognize that many skills take time to develop, and that changes in behavior require ongoing supports to be successful. In some cases, especially when you are ignoring a behavior that used to 'work' for your child, behavior may get more intense or more frequent before it gets better. Your team should keep good records and track progress and responses to intervention to know if the plan is effective.

There are increasing numbers of tools and apps for behavioral intervention tracking that are portable and simple to use.
Links can be found here.

Being realistic at the outset is crucial. It can help parents and caregivers appreciate that they are making small yet meaningful changes in their lives and the lives of the individual they care for. Making goals realistic means they are achievable. Being realistic keeps the picture positive. It focuses attention on progress towards a goal, rather than perfection.



Setting Realistic Behavioral Goals:

Setting goals allows us to objectively measure progress toward an identified desired outcome. It also allows caregivers and parents to ask themselves, "What behavioral changes would really make the greatest improvements in our lives together?" It allows them to identify what really matters. For instance, it may be more important to address a behavior such as throwing things during a classroom activity than to address that person's tendency to stand up during meals.

p.23 – Targeting the Big Three

For example, it is possible that you or your team may have misinterpreted the function of a behavior, or that the function has changed over time. A-B-C data often indicates that screaming has the function of attention, because attention from others is a common (and usually natural) consequence. But it may be that screaming is triggered by painful reflux and attention is not the true function. Tracking and interpreting the data is important since it may help to show that more investigation is needed, and the plan may need to be adjusted to be effective.

Information on supports for teaching behavior management can be found in the Autism Treatment Network's An Introduction to *Behavioral Health Treatments* and *Applied Behavior Analysis;* A Parent's Guide.

In the end, you are trying to teach your child that life is better, and that he can get what he needs, without having to resort to challenging behaviors. The suggestions below are strategies to help make individuals with autism feel more comfortable and more empowered.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Adapt the Environment

As you learn to think like a detective about your child's behavior, your observations (or the FBA) are likely to show that behavior occurs at specific times, with certain people or in particular environments. You and your team will need to tune in, learning to recognize the signs of increasing tension, anxiety or frustration that eventually lead to challenging behaviors. Often there is a ramping up, or escalation period, and learning to recognize that early and using many of the approaches here can help to calm a situation and prevent behavioral outbursts. Sometimes these signs may be very subtle—red ears, a tapping foot, heavier breathing, higher pitched speech—but it is essential that everyone on the team responds to the importance of tuning in and working towards *de-escalation*.

Changing the environment can often reduce behavioral episodes. Expand situations, relationships, places and opportunities that are successful. If possible, try to adjust or avoid situations that are triggers for challenging behavior. Incorporate ways to reduce frustration and anxiety and increase understanding. Below are some things to consider when working to create a more successful environment:

- *Organize and provide structure:* Provide clear and consistent visual schedules, calendars, consistent routines, etc. so that the person knows what is coming next.
- *Inform transitions and changes:* Recognize that changes can be extremely unsettling, especially when they are unexpected. Refer to a schedule, use countdown timers, give warnings about upcoming changes, etc.
- *Use Visual Supports:* Pictures, text, video modeling and other visuals are best for visual learners, but they are also critical because they provide information that stays. The ATN Visual Supports Tool Kit provides a step-by-step, easy-to-understand introduction to visual supports.
- *Provide a safe place and teach when to use it:* A calming room or corner, and/or objects or activities that help to calm (e.g. bean bag) provide opportunities to regroup and can be helpful in teaching self-control.
- *Remove or dampen distracting or disturbing stimuli:* Replace flickering fluorescent lights, use headphones to help block noise, avoid high traffic times, etc.
- *Pair companions or staff appropriately for challenging activities or times:* Some people are more calming than others in certain situations. If going to the store with dad works better than with mom, focus on that and celebrate successes.
- *Consider structural changes to your home or yard:* These changes might address some of the specifics of your situation to increase independence or reduce the risks when outbursts occur. Making Homes that Work includes a range of potential changes that can be made to reduce property damage, improve safety, and increase choice and independence.

"One of the barriers that we often find for children with autism in toilet training has to do with the condition of the bathroom itself. Often times we find that people with ASD can be very tactfully defensive so the space itself needs to be as neutral as possible. There needs to be enough room around the toilet so people don't feel too confined. It is really helpful if the space is warm and you address other types of sensations around the toileting experience. For example, is it cold, is there a fan running, is the light too bright, or not bright enough? You can sometimes help encourage people to use the toilet if the bathroom is a friendly place for them to be

– George Braddock, President,
Creative Housing Solutions LLC

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

What else can I do to promote a Safe Environment?

Even the best-laid plans don't always work in every situation or at the necessary speed. Despite proactive strategies, particularly challenging times and stressful situations can get beyond our control. Aggression or self-injury can get to a point where the situation is dangerous. It is good to be prepared if you think this might happen.

Communicate to Others

Many families have found it helpful to communicate to those around them about their child's special needs and some of the behavioral situations that might arise. Sometimes it is helpful to let others know what is going on so that they can also be observers and help provide helpful input about your child. Some families have found it helpful to talk to their neighbors, or to communicate with others in the community using stickers, cards, or other visuals.

I carry a note card stating:

"Thank you for your concern. My child has autism. He finds many situations difficult, including this one. Right now, we are doing a treatment plan recommended by our therapist, Dr. BCBA. This includes not giving attention to my child when he is acting out in order to discourage it. If you have any questions, you can contact Dr. BCBA at 123-456-7890."

I post these cards in the windows of my car, on the front door of my house and at any other environment, like family members houses. My child has Autism printable card
http://card.ufl.edu/handouts/Autism-Card-w-border.pdf

Preparing for an Autism Emergency

Because autism often presents with special considerations, tools have been developed to help families prepare ahead of time for some situations that might arise. The following resources have suggestions for families, as well as information that can be shared with local law enforcement and first responders:.

- Autism Speaks Autism Safety Project
- First Responders Tool Kit
- Community and Professional Training Videos for First Responders
- National Autism Association's Big Red Safety Boxes
- Autism Wandering Awareness Alerts Response and Education Collaboration (AWAARE)
- Making Homes that Work

Use Positive Behavior Supports

Your team should develop strategies for you to use to increase the behaviors you want to see in your child. These will need to be individualized to his particular needs and challenges. They can often be helpful in building a sense of pride in accomplishments and personal responsibility, and a sense of what is expected. This will reduce the anxiety and reactivity that results in aggression or other behaviors. Some helpful strategies:

- *Celebrate and build strengths and successes:* Tell him what he does well and what you like. A sense of competence often fosters interest and motivation. Strive to give positive feedback much more frequently than any correction or negative feedback. 'Great job putting your dishes in the sink!'
- *Respect and listen to him:* You may have to look for the things he is telling you, verbally or through his choices or actions. 'You keep sitting on that side of the table. Is the sun in your eyes over here?'
- *Validate his concerns and emotions:* Do not brush aside his fears or tell him not to worry. His emotions are very real. Help to give language to what he is feeling. 'I know you do not like spiders. I can see that you are very afraid right now.' 'I can see that you are angry that our plans have changed.'

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Provide clear expectations of behavior:* Show or tell your child what you expect of him using visual aids, photographs or video models. A great way to teach new skills is Tell-Show-Do.
- *Set him up for success:* Provide accommodations. Accept a one word answer instead of demanding a whole sentence. Use a larger plate and offer a spoon to allow him to be neater at the dinner table. Use Velcro shoes or self-tying laces if tying is too frustrating.
- *Ignore the challenging behavior:* Do your best to keep the challenging behavior from serving as his way of communicating or winning. This is hard to do, but in the long run it is effective. Do not allow his screams to get him out of brushing his teeth, or his biting to get him the lollipop that he wants. Behaviors may get worse before you start to see them get better. Stay the course! And make sure all family and team members are consistent in this approach and that you pair this with other positive strategies.
- *Alternate tasks:* Do something that is fun, motivating or that your child is good at. Then try something hard. He will be less inclined to give up or get agitated if he is already in a positive framework.
- *Teach and interact at your child's or loved one's learning level:* Take care to set him up for growth and accomplishment, rather than the anxiety produced by constant failure or boredom.
- *Give choices, but within parameters:* Everyone needs to be in control of something, even if it is as simple as which activity comes first. You can still maintain some control in the choices that you offer. 'Do you want to eat first, or paint first?'
- *Provide access to breaks:* Teach the individual to request a break when he needs to regroup (e.g. use a *PECS* card that represents "break"). Be sure to provide the break when he asks so he learns to trust this option and does not have to resort to challenging behaviors.
- *Promote the use of a safe, calm-down place:* Teach him to recognize when he needs to go there. This is a positive strategy, not a punishment.
- *Set up reinforcement systems:* Use simple, predictable processes that reward your child for desired behavior. Catch him being good and reward that, verbally and with favored activities, objects or 'payment.' *'I love that you stayed with me during our shopping trip. You earned a ride on the airplane toy!'*
- *Allow times and places for him to do what he wants:* Even if it is a 'stim', it is important to provide these options when it is not an intrusion or annoyance to others.
- *Reward flexibility and self control: 'I know you wanted to go to the pool today and we were surprised when it was closed. For staying cool and being so flexible about that change in plans, let's go get some ice cream instead!'*
- *Pick your battles:* Strive for balance. Focus on the behaviors and skills that are most essential. Be sure to include positive feedback and intersperse opportunities for success and enjoyment for you, your family, and your loved one with autism. Be resilient. Celebrate the fun and the good things!
- *Use positive/proactive language:* Use language that describes what you want the individual to do (e.g. *'I love how you used a tissue!'*), and try to avoid saying 'NO', or 'don't' (e.g. *'stop picking your nose.'*).

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Teach Skills and Replacement Behaviors

Since behavior often represents communication, it is essential to replace behavior by building more adaptive skills. It is important that you and your team not assume that a child has the skills needed to do something 'the right way' and that you are prepared to use systematic instruction and motivation to build new abilities.

Focus on communication and functional skills to promote greater independence, social skills to promote greater understanding and reduce apprehension, and self-regulation skills. The team should specifically work on skills that will address the behavior's function, and thereby help to replace, the target behavior. Skill building can take some time, so be persistent and celebrate the small steps along the way.

"Communication-based intervention refers to an approach that reduces or eliminates problem behavior by teaching an individual specific forms of communication. Because the communication forms that are taught are more effective ways of influencing others than the problem behavior, they eventually replace the problem behavior itself… By communication training, we mean that individuals are taught specific language forms including, for example, speech, signing, and gestures that can be used to influence other people in order to achieve important goals."

– Ted Carr, Ph.D.,
State University of New York at Stony Brook

When you adjust to give different feedback or to help your child develop a new skill, celebrate yourself as much as you celebrate your child's growth! Reward a sibling for being extra patient or modeling a skill you are teaching. Use the pride in your successes to help you stay focused and dedicated, and to help you reflect on the good things in your child and your family.

It is essential to teach skills in the context of a positive learning situation, which is NOT while a behavior is occurring. These skills need to be part of a comprehensive educational plan. Just like math facts, they may need to be practiced many times during the day when the child or adult is calm and attentive. Label 'calm' and 'ready to learn' states and teach your child what they feel like.

- *Develop and expand functional communication:* Find a way to build effective communication that is appropriate for the person across his daily activities. Use language instruction, *PECS*, sign language, communication devices or other tools. For example, teach an over-stimulated child to ask for quiet time (using his words, PECS, pointing to a picture, or an iPad app), instead of running away. Functional communication should be rewarded with immediate access to the requested item to build the connection. This allows you to use request = item rather than behavior = item. A trained autism specialist or speech therapist will be very helpful in choosing and supporting effective interventions for functional language development. More information and possible resources:
  - The National Professional Development Center's Functional Communication Training
  - Functional Communication Training
    http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf
  - Severe Behavior Problems: A Functional Communication Training Approach (Treatment Manuals for Practitioners), by V. Mark Durand

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- Picture Exchange Communication System (PECS) and Associated Apps
- Other Autism Apps, such as Proloquo

Developing a voice can be life changing, and finding the right supports can help to increase functional communication in a variety of ways. For one dramatic example, watch Carly's story.

- *Teach Social Skills*: Use social stories to explain expectations and build skills and awareness. Recognize that some skills might require a team approach. For example, messy eating or toileting can be the result of a combination of sensory concerns, motor planning and social awareness, so working with an occupational therapist and using social stories as well as behavioral interventions might be needed
- *Create Activity Schedules:* Teach the use of schedules using pictures, written words or videos to help organize a chunk of time (e.g. a day, a class period, etc.) and break tasks into small, manageable steps. These schedules often reduce anxiety, provide skill development, and promote independence. Examples and resources:
  - Picture Activity Schedules, from Do2Learn
  - Activity Schedules for Children With Autism, Second Edition: Teaching Independent Behavior, by Lynn E. McClannahan and Patricia Krantz
  - Other Autism Apps, such as ReDo
- *Teach Self-Regulation and De-escalation Strategies:* Learning to self regulate is essential to a person's ability to remain calm in the face of the assaults that the world will undoubtedly bring his way. Your child is most likely to show problem behaviors when he is in an emotional state of anxiety or agitation. Strategies and programs for building self-regulation relate to both arousal and emotions. Many of us have had to learn these ourselves—counting to ten, taking a deep breath—and the same principles apply to the learning needs of an individual with autism.

"My behavior began to improve when I started to learn about emotions-- how to recognize them not only in others, but in me. This was an essential step to learning self-regulation, and it was then that I started to take more control of my actions."

– RH, adult with autism

- Use The Incredible 5-Point Scale to teach social awareness and emotions
- Teach recognition of arousal levels: The Alert Program: How does your engine run?
- Employ Behavioral Relaxation Training (BRT) which uses motor exercises (posture, breathing, etc) to find a relaxed state, and has been shown to be helpful in individuals who are less able to talk through issues or concerns.
- Teach self control and behavioral targets using Social Stories or Cognitive Picture Rehearsal.
- Teach the individual to recognize the triggers for his behavior, and ways to avoid or cope with these when they occur.
- Find ways to arouse and ways to calm your child, which can vary from person to person, and teach him to do these when he needs to.
- Review additional tips and hundreds of sample behavior charts and targets, including feeling charts.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Find providers who use Cognitive Behavior Therapy* or teach cause and effect, self-reflection, and social understanding through tools such as the Social Autopsy. While these techniques lend themselves to more verbal individuals, they can be used with individuals of all verbal abilities with appropriate accommodations such as use of visuals and role-play.
- *Teach Self-Management Skills:* Self-management focuses on becoming aware of one's actions and learning responsibility for behavior and tasks without the support of caregivers. This is especially important in the adolescent years, as young adults with autism often feel the need for greater autonomy and independence just like their peers. Teaching self-management provides your child with a sense of personal responsibility, pride and accomplishment. Some books include:

  1. How to teach self-management to people with severe disabilities: A training manual, by Lynn Koegel
  2. Self-Management for Children With High-Functioning Autism Spectrum Disorders, by Lee A. Wilkinson

- *Promote Exercise:* Exercise can be a powerful factor in overall quality of life, for reasons beyond just physical fitness and weight issues. Research shows that aerobic exercise can influence behavior, decreasing self-stimulatory behaviors such as rocking and spinning, as well as discouraging aggressive and self-injurious behavior. Sometimes the challenges of autism (e.g. sensory input, motor planning, social aspects of team sports, etc.) can require a little extra creativity in terms of designing an approach to physical activity that is beneficial and motivating for a specific person. However, if implemented appropriately, the addition of physical activity to an autism intervention program can address some of these specific challenges, increase self-confidence and social interactions, and improve overall quality of life. The same interventions that are used to teach other skills (ABA, structured teaching, etc.) can be used to build exercise skills and routines.

  - The Benefits of Sports and Exercise in Autism
  - Top 8 Exercises for Autism Fitness *from AutismFitness.com*
  - Autism Fitness Exercise Videos *from AutismFitness.com*

- *Address Hormones and Sexuality Considerations:* The hormone and brain changes of puberty can make a typical child seem like a stranger, and these same effects occur in people with autism. However, in autism, additional considerations come into play because of the language and social deficits. Tell your child, even if you think he may have difficulty understanding, about what is happening to his body. Specific teaching to the skills of appropriate social considerations (personal space, privacy, feelings vs. actions, etc.) can help to keep an individual with autism out of situations that others might find disturbing or inappropriate. Responding to Inappropriate Sexual Behaviors Displayed by Adolescents With Autism Spectrum Disorders by Jenny Tuzikow, Psy.D., BCBA-D has helpful insights.

Editor's Note: This story reflects the need for the team to take into consideration the culture and comfort of those being asked to take part in an intervention. Your family's perspective and concerns need to be considered as you program, as a team, for your child.

"Just like any other teenage boy, my 13 year old son with autism starting having occasional, unexpected erections that seemed outside of his control. He found them funny, but obviously others did not. We explained to him what was taking place, but that it was something that he should keep private. Even if he understood what we were saying, we recognized this would be difficult to do when you don't have the language to let others know you just 'need a few minutes at the desk.' His behavioral team thought the way to address this was to give it an outlet, suggesting some

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Victoria's Secret catalogs and some modeling from Dad. I was so relieved that I could not be asked for this duty! But we were also concerned about what else we were teaching him. What if Victoria's Secret became his 'trigger' and we went to the mall??? We reasoned with the team, and instead taught our son to ask for Private Time-- in his room, at home, with a Private Time sign on his door. Eventually he outgrew this phase and it has not been an issue. We can even go to the mall and pass Victoria's Secret without concern!"

– ES, a mother

An Intervention Example: C.O.P.E.S. ™

One school intervention team has had success using strategies for 12 teenage students with long histories of failed interventions and high incidence of aggressive and self-injurious behaviors. C.O.P.E.S. ™ involves consistent implementation of a collection of individualized approaches. This program incorporated several interventions to greatly reduce behaviors and build positive skills and happier students. For a description and accompanying visual examples, please see the Appendix at the end of this section.

Punishment vs. Rewards: What does science tell us?

Punishment is often used in shaping behavior. It works because it reduces the chances that the behavior will happen again. Punishment often takes two forms— *doing something* such as spanking or giving extra chores, or *taking something away* such as TV time or the car keys. We often use punishment in its more subtle forms without even realizing it—raising our voices, removing a favorite toy or withdrawing attention.

The short term consequences of punishment bring focus to a problem and may stop the behavior in the moment. But studies show that punishment is largely ineffective in the long run, especially when it is not used together with positive and preventive approaches. It can promote emotional responses such as crying and fearfulness, and aggressive behavior by providing a model (e.g. hitting). It can also promote a desire for escape and avoidance of the person or the situation that caused the punishment. It often needs to be repeated and often becomes more intense, because punishment may teach what *not to do*, but does not build skills for what *to do*. The negative feelings associated with punishment are often paired with the person delivering the punishment, causing the relationship with the parent or caregiver to be affected as time goes on.

Of course, every child exhibits behavior that needs to be corrected, or shaped, so what else can I do?

Rewards, or using *reinforcement*, are one of the most consistent ways to change behavior and build desired responses. For people with jobs, the reward is a paycheck at the end of the month. Children, especially those with autism, often need their rewards much more immediately, and in connection with the desired behavior. So, as soon as he buckles his seatbelt, he gets a 'high five'.

Sometimes reinforcement is viewed as simple, such as giving an M&M after a correct response, but reinforcement can be much more than that. When a tangible reward (M&M) is paired with a social reward (*'Great job saying Good Morning to your brother!'*), the positive feeling of success gets paired with both the verbal praise, and the person giving the reward. This helps to build the desired behavior, and also often improves the relationship with the parent or teacher using the reward.

Reinforcers can vary considerably from person to person. It is important to observe your child to learn what he finds rewarding so that you can give him what he wants after he has responded in the way that you desire. Watch what he does in his free time, or when he has choices—some children love to be tickled, others do not. Consider edibles (such as a cookie or other favorite food) but also other *tangibles* (a toy, bubbles, etc.) or experiences (listening to music, taking a walk, curling up on the bean bag). Be creative and mix it up. Know that the more opportunities a person has to encounter a reinforcer, the less rewarding it might become—so the 'power' of a reward is often increased if it is saved for certain times when you want to celebrate your child's behavior.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Research shows that positive, reinforcement-based strategies are most effective in creating long-term behavioral change. However, it is also important to have an immediate response to a behavior in order to maintain safety or minimize disruptions. Planning in advance for the type of situation is important, so that caregivers across settings (home, school, etc.) are consistent in their responses and delivery of consequences. Most reactive strategies fall into three areas as listed below.

- *Ignoring the behavior* (*extinction*) is often used when the behavior is used for attention, and is mild or not threatening.
- *Redirection*, often supported with visuals, may involve redirection to an appropriate behavior or response and is often paired with positive strategies.
- *Removal from a situation or reinforcement* through a time out is often used for calming down opportunities.

Ignoring challenging behavior means not giving in to the behavior that you are trying to eliminate, to the best of your ability. If he kicks to get a cookie, ignore the kicking and do not give him a cookie. But, use other strategies here to teach him to request a cookie, and be sure to give the cookie when he asks, so as to build his trust in you. Note that when you first start to ignore a behavior (called *extinction*) it may increase the behavior. This is called an *extinction burst* and is very normal. Stay the course.

- Certain behaviors (those that are dangerous or injurious) are more difficult to ignore and sometimes need to be redirected or blocked (e.g. putting a pillow by his head so that his self-hitting does not do damage), even as you strive to not allow the behavior to 'win.' link to Yoo section on ignoring?

"When Joey was little, every time he spilled his glass of water, he banged his head on the edge of the table. I learned to wipe-up his spilled water quickly, in order to avoid this self-injurious behavior. If I was really fast, he'd attack me on my way to cleaning it up – grabbing my hair and pulling. I also noticed that his aggression didn't stop once I had cleaned up the obvious puddles, but continued as I wiped what I thought was a dry surface.

This behavior continued because, try as we might, we could not completely avoid spilling water. By the time Joey was age 9, the entire family was very alert to the importance of not spilling water and the need to respond quickly trying to reduce the duration of Joey's aggression. Only after we started a home ABA program was it pointed out that my rushing to clean up spilled water followed Joey's becoming self-injurious and aggressive. By wiping up the water, we were reinforcing Joey's inappropriate behaviors. I realized that Joey did not know how to clean up the water himself. He also did not have another way to ask us to clean up the spilled water or to tell us that it bothered him, other than banging his head or pulling our hair.

With the help of our behavior consultant, we learned to clean-up the spilled water only before Joey becomes aggressive or self-injurious. We also learned to prompt appropriate language "clean up" as we cleaned up. If Joey aggressed, we ignored the spilled water and followed our behavior protocol. After practice, Joey learned to say "clean up" instead of banging his head and pulling hair. Eventually, we taught Joey how to ask for a towel or to get a towel and clean up the water himself."
– BH, parent

Redirection can be a very powerful tool, giving you the opportunity to steer your child into a situation that is more positive, or more manageable. It also helps to avoid or calm an escalating situation. The use of a time out can vary considerably, and to be most effective, it is important that it is done correctly. A time out is not just a change in location—it means your child loses access to something he finds rewarding or cool. For more complete discussion on how best to use time out, see the ATN ABA guide or this parent training information.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Other strategies your behavioral team might employ include teaching accountability (if he spilled the milk, he is the one to clean it up), or using positive practice, sometimes known as do-overs. For example, if he let the door slam in someone's face, he might practice in the doorway how to enter the house and hold the door five or ten times. *'Oops, let's practice doing that that the right way.'* In doing this, try to limit the sense of punishment, keeping positive strategies employed (reinforcement, praise) to build the desired behaviors over time. *'I love that you noticed I am right behind you and you held the door open!'*

- When behavior does occur, be careful not to:
- Feed into the behavior, give in or provide what your child wanted to get from the behavior
- Show disappointment or anger
- Lecture or threaten
- Physically intervene (unless necessary for safety, such as keeping a child from running into the street)

A new look at time-out

Contrary to popular belief, time-out is not sitting in a chair for a few minutes. Time out is losing access to cool, fun things as a result of exhibiting problem behavior, usually by removing the individual from the setting that has those cool, fun things. Time-outs can only occur when the individual is in time-in. That is, if nothing enjoyable was happening before time-out, you are simply removing the individual from one non-stimulating, non-engaging room to another.

For example, if the individual is watching her favorite TV show, but hits and screams at her sibling for getting in the way, taking her to a chair located in the same room will not serve as a time-out since she can still see and listen to the TV. Removing her from accessing the TV completely, however, is an example of a time-out. In this case, time-in (watching a favorite show) was in place, allowing for time-out to be effective upon the occurrence of the problem behavior. Once the individual is in time-out, let her know that she must be calm for at least 10 seconds (or a duration of your choosing, usually shortly after he is calm) before she can return to time-in. Do not talk to the individual or explain to her what she did wrong while she is in time-out. You may use a timer to indicate to the individual when the time-out will be over. When the timer goes off, he should be allowed to return to what he was doing, i.e. time-in.

How to use time-out correctly

- *A fun, enjoyable activity should be in place before using time-out (e.g. playing video game, visiting friends).*
- *Time-out should not lead to the individual avoiding or delaying an unpleasant task or work activity*
- *Time-out should take place in a boring and neutral setting.*
- *No attention should be given during time-out. Simply tell the individual, "You hit your brother, no TV. Go to time-out until you are calm".*
- *Time-out should be discontinued shortly after the individual is calm and quiet (approximately 10 seconds of calm behavior).*

– page 74, Targeting the Big Three

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Resources:

Behavioral Relaxation Training and Assessment
by Roger Poppen

Behavioral Relaxation Training (BRT): Facilitating acquisition in individuals with developmental disabilities
by Theodosia R. Paclawskyj, Ph.D., BCBA, and J. Helen Yoo, Ph.D.,

The Cycle of Tantrums, Rage, and Meltdowns in Children and Youth with Asperger Syndrome, High-Functioning Autism, and Related Disabilities
by Brenda Smith Myles and Anastasia Hubbard

How to teach self-management to people with severe disabilities: A training manual
by Lynn Koegel

Self-Management for Children With High-Functioning Autism Spectrum Disorders
by Lee A. Wilkinson

Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism
by Mary Wrobel

Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting
by Helen Yoo, Ph.D, New York State Institute for Basic Research
Autism Speaks Family Services Community Grant recipient

Autism Fitness.com : Leading Authority in Autism Fitness
Eric Chessen

Depression and Anxiety: Exercise Eases Symptoms
Mayo Clinic

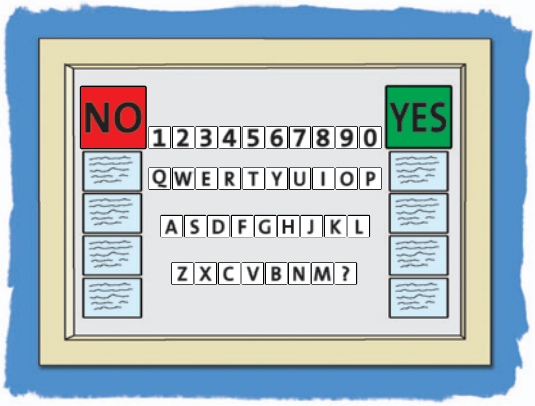
Exercise for Mental Health
Primary Companion to the Journal of Clinical Psychiatry

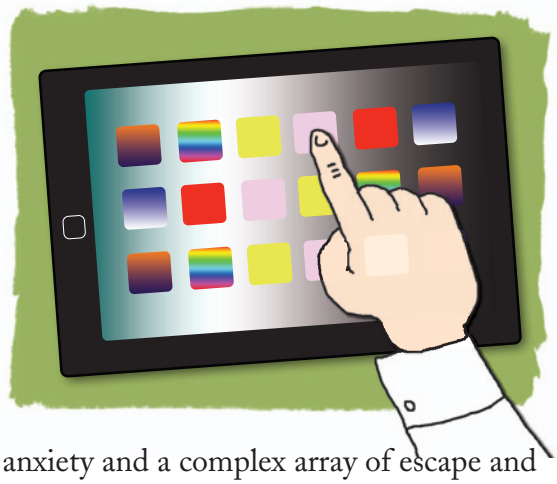
© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

C.O.P.E.S.™

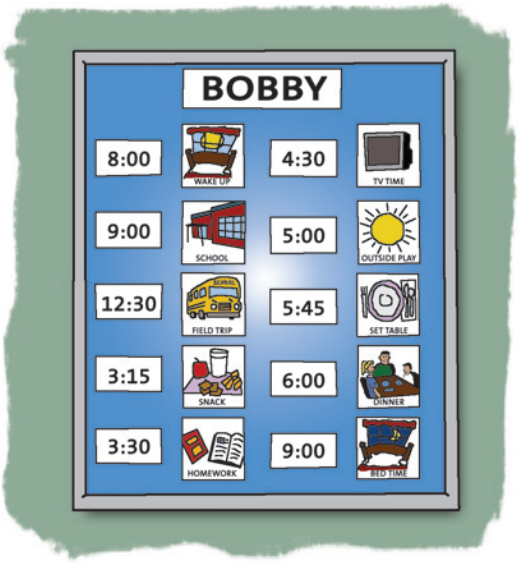
The COPES program uses individualized programs for each of their students that incorporates the following elements:

- *Communication:* students were given immediate access to communication for emotional issues. Multi access approaches were tailored to the student's needs using YES - NO boards, icons, and iPads with augmentative apps. Teach communication at his level and start with what is most essential.





- *Organization:* many of the students showed considerable anxiety and a complex array of escape and avoidance behaviors since they had no systems to help them organize and anticipate events, daily schedules, changes in schedules and or future events. Simple schedules and training on basic contingency management and use of visual supports showed rapid changes in behavior and reduced anxiety.

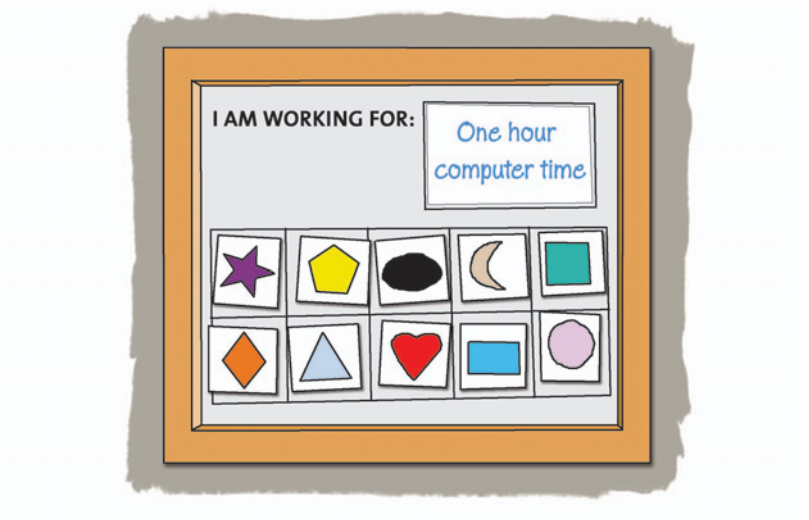


Tommy's Schedule Monday	All Done
Put Backback in Cubby	
Independent Work	
Morning Meeting	
Reading Time	
Music Class	
Lunch	
Recess	
Special Reading Group	
Pack Up Backback	
Go Home	

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Postive behavior supports:* Even though all of the students had prior FBAs and complex contingency management systems, the interventions often failed since they were too little, too late. By being reactive instead of addressing why the behavior occurred in the first place, the previous interventions were sending the message that the student's behavior was frustrating, but missing the opportunity to prevent its occurance in the future. Prevention had to be addressed as a primary objective and replacement skills needed to be built using positive behavior supports. Simple token charts were introduced and each student was reinforced for success, as simple as walking into a room nicely to sitting for a minute in a chair. The students responded immediately to being honored and acknowledged for the things they did right, though they were in shock at first since they were accustomed to primarily negative feedback. You could almost see the questions in their faces—What do you mean I'm being given constant feedback? And it's positive!

  Example of reinforcement steps to earning computer time:



- *Emotional regulation:* Starting on day one of the behavior support plan, each student was systematically taught to understand and identify his own regulatory state and escalation cycle. Proactive programming was essential. Empowerment and self-determination was a significant part of the program and the students responded immediately to their involvement in their plans. The plans were based on knowing that the student who understands that stress, anxiety and specific activities or situations often result in tension, frustration, and behaviors, is a student who has a chance of self-regulating.

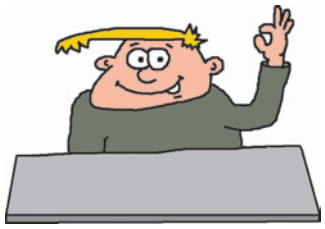
  The program has been taught successfully to numerous students with limited to no verbal skills. Individuals with limited verbal skills are often assumed to be without a full range of emotions, with limited ability to comprehend what others are saying. As a result they live frustrating lives. These students are often misunderstood and their emotions, feelings and responses are not fully considered. People talk about them as if they are not there and they make judgments and statements that do not take into account for the full depth of their feelings, thoughts and opinions.

  - Teaching the student his escalation cycle does two main things:
  - it allows him to have some say or opinion in his program
  - it teaches him to be aware of the things that cause him anxiety or frustration that often leads to disruptive behaviors, and teaches him corresponding strategies for self-regulation

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

An example of the visuals used to teach a student to identify his regulatory state and what to do to 'get to green':

My Self -Management Plan

	The behaviors I exhibit when I feel this way	What I need to do-
 I AM HIGH	■ I grab others ■ I hit and bite ■ I yell loud ■ I cry loudly	■ Sit and breath- deep breaths ■ I need to be in a safe place ■ go to the beanbag and stay there! ■ Get to yellow
 I AM LOW	■ I look tense, my shoulders and body are tense ■ I bite my tongue ■ I click my neck and fingers ■ I look red and sad ■ I need everything to be in its place	■ Take a sensory break ■ Ask for help ■ I need someone to write and explain what's going on! ■ I need to take DEEP breaths
 I AM CALM	■ I can sit and focus ■ I can follow my schedule ■ I can answer with my voice ■ I do respond to others and I look relaxed!	■ I can earn my points and get preferred breaks

■ *Sensory and social:* Each student has a systematic exposure to community and or social outings that includes the golden rule--no community and/ or social access when the student is in any other state but green. This decreases the chances for the student to be in dangerous situations where staff have to try to manage behavior and risk inadvertently reinforcing behaviors because the safety risk is too high.

Social skills are focused on as reciprocal interaction, not necessarily frustrating, overwhelming exposure to typical students. The social success is based on the student being motivated and able to access the social situation. Start small and be successful. Building confidence in the student has to come first and regulation is key to that confidence.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

What might I need to know about Managing a Crisis Situation?

Generally, when a child is engaged in the active, disruptive stage of a behavior, such as a tantrum or aggression, the essential focus has to be on the safety of the individual, those around them, and the protection of property. It is important to keep in mind that when he is in full meltdown mode, he is not capable of reasoning, being redirected, or learning replacement skills. However, this level of agitation does not usually come out of thin air. You can learn skills to help anticipate and turn around an *escalating* situation that seems to be headed in this direction.

In case of emergency, call 9-1-1. Always take suicide threats seriously!

"Both my husband and I have thought of calling 911 before but we were too scared of the unknown. Finally one afternoon we were in a difficult situation with our son and we knew it was time to make the call. It was one of the hardest decisions we have ever had to make, but it was the right one – for our son's safety and ours as well."
–CH, Mother

Have a Plan

Preparation and strategies for coping and staying safe in these situations is essential and it is important for the team, including the family, to develop a *crisis plan* together. A well-designed plan will include:

- Defined setting events, triggers or signs that a crisis situation might develop
- Tools and strategies for keeping the individual and those around him safe in any setting (school, home, community)
- Intervention steps and procedures promoting de-escalation that are paired at each level with increasing levels of agitation
- Lists of things to do and NOT to do specific to the history, fears and needs of the individual
- Hands on training and practice for caregivers and staff
- Data collection and monitoring for continued re-evaluation of the effectiveness of the plan
- Knowledge of the best prepared facility if hospitalization or an Emergency Room visit might be necessary
- Secured guardianship if your child is above age 18 and you need to continue to make decisions for him (See the Autism Speaks Transition Tool Kit for more information)

Providers and families who have experienced crisis highlight the need to maintain safety first and foremost. This is not the time to teach, make demands, or to shape behavior.



Know Ways to Calm an Escalating Situation

- Be on alert for triggers and warning signs.
- Try to reduce stressors by removing distracting elements, going to a less stressful place or providing a calming activity or object.
- Remain calm, as his behavior is likely to trigger emotions in you.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- Be gentle and patient.
- Give him space.
- Provide clear directions and use simple language.
- Focus on returning to a calm, ready state by allowing time in a quiet, relaxation-promoting activity.
- Praise attempts to self-regulate and the use of strategies such as deep breathing.
- Discuss the situation or teach alternate and more appropriate responses once calm has been achieved.
- Debrief with the individual, as well as the team, to prepare for increased awareness of triggers and strategies for self-regulation in future experiences.

In the midst of a Crisis Situation

- Remain as calm as possible
- Assess the severity of the situation
- Follow the Crisis Plan and focus on safety
- Determine whom to contact:
  - Dial 211 for free, confidential crisis counseling
  - Dial 911 for an emergency: fire, life-threatening situation, crime in process, serious medical problem that requires mental health and basic life support ambulance services
  - Call local police for non-emergencies

Disclosure to a Police Officer:

"The decision to disclose your (or your child's) diagnosis to a police officer will always be yours to make. If you have learned through experience that disclosure would be helpful in the particular situation, you may decide to disclose to a police officer. Law enforcement officers report that they make their best decisions when they have their best information. A good, strong autism or Asperger Syndrome diagnosis disclosure that includes the use of an information card, contact information for an objective professional, and proof of diagnosis should be considered."

– Dennis Debbaudt, a parent and leading voice on autism training for law enforcement and emergency responders

When severe and dangerous behaviors pose a risk of physical harm to the individual or to others in the vicinity, physical restraints or seclusion as a brief intervention are sometimes necessary to maintain safety.

Physical restraints are physical restrictions immobilizing or reducing the ability of an individual to move their arms, legs, body, or head freely.

Seclusion (putting the individual briefly in a room by himself to 'calm down') is often employed in schools and other group environments. Seclusion can provide a quick halt to an immediate threat, but in the long run, seclusion is not a solution to the behavior itself, especially if the function of the behavior is to escape or avoid something. School programs should be focused on developing functionally based, positive behavior intervention plans to eliminate the need for seclusion practices all together.

It is important to note that while restraints and seclusion can serve to maintain safety, it is an intervention of last resort and should only be used when less restrictive and alternative interventions are not effective, feasible,

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

or safe. Improper use of these techniques can have serious consequences physically and emotionally. Parents and caregivers should seek out and receive professional guidance and training on positive behavior interventions and supports, crisis prevention, and the safe implementation of restraints and seclusion techniques when necessary.

Managing a Crisis at Home

Having a Crisis Plan is an important step, and it might be helpful to create this with your team or behavioral provider. Some families have emergency information cards with vital information and signs posted to alert first responders. Strategies for keeping the individual with autism and other family members safe during episodes of aggression or self-injury are most important. Being prepared for an individual who is inclined to outbursts and times of aggression or property damage can help everyone feel safer. The strategies outline in Making Homes that Work might be helpful.

Managing a Crisis at School

For school age children, there are protections under the *Individuals with Disabilities Education Improvement Act (IDEIA)* that pertain to behavioral considerations, functional behavior assessments, and positive supports. The school will need to have a behavior intervention plan (BIP), and your child's educational team should provide you with materials to explain your rights and your child's rights under educational law. You need to approve the plan, and the defined behavioral targets, expectations and interventions should be clear to you, your loved one and his entire team. If you need information or training, ask! Be persistent.

In the case of a significant aggressive or other concerning behavior at school, the staff or the family can call an emergency IEP meeting to discuss placement, BIP and other considerations. Special Needs, Special Gifts offers some insights into challenging behaviors in the school environment and the responsibilities and warning signs.

Your school team may suggest the use of seclusion and/or restraints, but these controversial interventions should not be undertaken lightly. It may also be helpful to know the regulations as they pertain to challenging behaviors and the use of suspensions and expulsions. There are certain protections afforded students with special needs under a provision in IDEA. The Wrightslaw page Behavior Problems & Discipline: What Parents and Teachers Need to Know contains great information on this topic.

Managing a Crisis in the Community

"My daughter has had quite a few tantrums in our community that have escalated. This encouraged my family and I to take steps to let my local neighborhood know about my daughter's behavior— by posting autism cards, in my car window, on our front door, etc.

The other thing that really helps my family is that we travel in pairs. This means that someone is always around to help whomever my daughter is with. As a parent, I always worry about my child's safety, so I try to find a "safe place" while I'm out to take her to when there's a problem, Places like family bathrooms or even dressing rooms in clothing stores work when she needs to calm down or re-focus. I also spoke to our state's DMV about getting a handicap placard for my car that I only use when my daughter is with us--so I can make that bee-line to the car even faster!

The other thing that helps a lot is placing a Family Emergency Kit in the trunk of each car we travel in. Much like the ones used during pregnancy and in Disaster Emergency Preparedness Kits, I add a comfortable change of shoes/clothes, personal items, an extra insurance card, her medic alert necklace info, even my CPI card-to show that I'm trained. I complete each kit with a few extra sensory items she might like and extra water and snacks, in case she might be cranky because she's hungry and cannot say so. Also, in each kit, I started packing a few care items for myself, just in case we had to go to the hospital so that I would be more at ease, during our wait. The last thing I do very

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

frequently, is make sure I bring any medication for my child and for myself so that neither one of us get off our meds. One time my daughter's meds had changed recently, and my daughter had to go to the ER. As it turned out ,I was the only one with the meds she needed, right there in my kit!"

– KV, a parent

Emergency Personnel Response and Interacting with Law Enforcement

Training in autism awareness is increasing, but has certainly not been universal across the United States. It is important that you understand that EMS personnel might not know that 'he has autism' means that he might have difficulty understanding directions, or respond poorly to flashing lights, a blood pressure cuff or other actions. It can be helpful to have information (on a card) ready to pass along or to find ways for your local responders to get to know your child. You might advocate for training in your local emergency departments. Visit the **Autism Safety Project** page for tools and more information for emergency personnel.

Police and Law Enforcement Response, Judicial System

It is important to remember that police and law enforcement officers, such as security guards and TSA agents, often have little training in autism awareness and response. Sometimes a person with autism will appear to be dangerous or on drugs to a law enforcement officer. The unpredictable behaviors and communication challenges of autism, coupled with variable social understanding of authority have been known to have dire consequences. It is important to keep these factors in mind when **interacting with law enforcement**.

You may encounter law enforcement when you are out in the community. If your loved one has especially troubling behaviors, you may have occasion to call them into your own home. It is important to get to know your local police department and have them get to know your child. Advocate for training and sensitivity concerns. Find resources and training information to pass along to law enforcement officers and other professionals on the **Autism Safety Project** page.

If police are involved and your loved one is charged with a crime, there are special considerations within the **legal system. Information for Advocates, Attorneys, and Judges** supplies additional background information and statistics on autism for legal representatives.

"Persons with autism who are able to navigate the community without assistance should strongly consider developing personal handouts, along with the skills and resiliency to risk necessary to appropriately disclose their need for accommodations. Remember that the initial uninformed contact with police presents the highest potential for a negative outcome. What's the best tool to use when you decide to disclose your autism or Asperger Syndrome to a police officer? A handout card:

- *Develop a handout card that can be easily copied and laminated.*
- *Remember that the handout card is replaceable. You can give it away to the officer on the scene.*
- *Carry several at all times.*
- *The handout card can be generic or specific to you.*
- *Work with an autism support organization to develop a generic handout.*
- *Work with persons whose opinions you trust and value to develop a person-specific handout."*

– Dennis Debbaudt, a parent and leading voice on autism training for law enforcement and emergency responders

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

How do I know it is time to get more help?

Many families work diligently at home to help their children with autism negotiate the many challenges the world presents for them. However, it is important and necessary to seek professional help when:

- Aggression or self-injury become recurrent risks to the individual, family or staff
- Unsafe behaviors, such as elopement and wandering, cannot be contained
- A threat of suicide is made
- An individual presents with persistent change in mood or behavior, such as frequent irritability or anxiety
- A child shows regression in skills
- The family can no longer care for the individual at home

Sometimes this journey starts with a trip to the Emergency Room, when a person is in crisis and the caregiver or family needs immediate help. Sometimes it occurs in a more planned way, at the advice or urging of a doctor, mental health provider or other member of a team.

What can I expect at the Emergency Room?

Whether it is for behavioral concerns or just necessary medical care, the emergency room can be a difficult place for people with autism. **Treating autism patients in emergencies presents challenges** describes some of the challenges and makes suggestions for medical staff regarding how they might be more accommodating. It might be helpful to pack this in your emergency prep kit and pass it along to ER staff upon your arrival. Be prepared to advocate yourself.

If you are requesting a ***psychiatric evaluation***, it is important to bring documentation of the behaviors that are causing concern, information about psychiatric history, any previous psychiatric evaluations, recent FBA and/or BIP, a list of current and past medications and other relevant information. Names and contact information for doctors, your behavioral provider or other important team members will be helpful. Having all of this information in writing, in one place, will help you be prepared in the event of a crisis.

Alternately, a call to the police might trigger their concern for the person or those around him, and the officer might issue orders to have the individual transferred to the ER, even if that is not your wish. In either case, the police officer or the hospital staff can place the person on a ***Mental Health Hold***. When a person is placed on a mental health hold, they can usually be held for up to 72 hours for a psychiatric evaluation. This does not necessarily mean that the person will be held for the entire 72 hours. The evaluation often takes place within 24 hours.

Before a psychiatric evaluation can occur, the ER staff must evaluate and medically clear the individual. In many cases, they are likely to do a drug screen and toxicology report. The process to get medical clearance may take several hours, and maybe longer based on the staffing and volume at the ER and the complexity of the medical situation. Then a psychiatric evaluation will be performed, and will include interviews, a record review and an examination. For more information, see **Psychiatric Evaluations in the Emergency Room**.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Many trips to the emergency room will involve calming the individual, often with medication, and then releasing him and sending him home. Arriving at an ER does not necessarily translate into an admission to the hospital. Sometimes, the ER visit will turn into a longer stay of 1-2 weeks, with the length of stay sometimes a reflection of insurance issues.

If the hospital staff decides that the individual is at particular risk of harm to himself or others, they may recommend commitment to a mental hospital or psychiatric ward. It is important to know that if you or the adult patient does not approve, the law provides for a process known as *Involuntary Commitment* or *Civil Commitment*. This allows for court-ordered commitment of a person to a hospital or outpatient program against his will or protests.

Psychiatric Inpatient Hospitalization: How do you choose a facility?

Often individuals are brought to the nearest hospital or the closest one that has an open bed. While this may be the fastest response in a crisis, it is best to be at a facility that can best respond to the needs of your child. If possible, discuss with your providers ahead of time if there is a preferred treatment setting for individuals with autism in the event of crisis. Some hospitals have a psychiatric emergency room.

In a few states, there are specialized hospital programs specifically designed for individuals with autism and other developmental disorders. These **Crisis Intervention Centers** can often provide more targeted treatment options and assessment expertise. Pre-planned stays in *bio-behavioral units* may be hard to arrange since so few of these facilities exist, but the length of stay is generally a 3 to 6 month period.

What happens when you check into a hospital?

Just as you might do when planning a trip, it is important to remember to bring your loved one's necessary supports, including communication devices, visual supports, preferred toys and sensory items, as well as a familiar blanket or pillow. Entering a hospital can be quite stressful, so anything you can do to reduce anxiety and increase predictability should be considered.

If your child or loved one is placed in a psychiatric facility or ward, it will be important for you to help the staff understand his particular skills and challenges. You should be prepared for the fact that unlike many medical situations you may have experienced, a psychiatric ward is likely to have locked doors and may have stricter limits on visitation. You may not be able to be present during your child's entire stay or there to be his 'interpreter' of behaviors, food aversions, fears and anxieties as you might otherwise do. These facilities are not obliged to provide behaviorally-based treatments and interventions, though some do.

You may need to advocate for a role in helping the hospital to understand your child. In particular, it might be important to advocate against the use of restraints for your loved one, as this may increase anxiety and the intensity of negative behavioral responses. There are established policies on the use of restraints and seclusion in healthcare that you can read **here**. You can also request that a medical provider who knows your child be involved with the hospital staff.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

"When Kevin ended up in the psych unit at our state hospital, it was incredibly valuable to have out autism doctor involved in his care. The hospital staff did not get it when it came to autism and Kevin, and our doctor was very helpful at running interference."

– SB, parent

Most hospitals are family-friendly and have extended visiting hours for children. Separating from your child can be difficult and leave you with feelings of guilt, but it is essential to remember that this is in the child's best interest. He needs specific help, and you need an opportunity to recover from a challenging situation.

Patient Rights

Patients receiving services in a hospital have the same human, civil and legal rights accorded all minor citizens (those under the age of 18) or adults. Patients have the right to a humane psychological and physical environment. They are entitled to respect for their individuality and to recognition that their personalities, abilities, needs and aspirations are not determined on the basis of a psychiatric label. Patients are entitled to receive individualized treatment and to have access to activities necessary to achieve their individualized treatment goals.

Commitment–Involuntary vs. Voluntary: As mentioned above, a psychiatric evaluation will be performed to determine if the individual is a danger to himself or others. If he is considered a danger, he can be committed against his (or your) will with a court order.

Parent Rights

Parents (or guardians) retain their legal rights for decision-making regarding the health and welfare of their child under the age of 18. Parents have the right to informed consent to treatment, including notification of the possible risks and benefits of any treatment that is proposed. Parents have the right to be involved in the treatment that is provided to their child, which includes visiting their child during the course of their treatment, ongoing communication from the providers about the child's progress, and copies of medical, behavioral and educational records.

If you feel your child would be better served in a different setting, you should engage the attending physician and other members of the hospital clinical team in a discussion of the risks and benefits of changing treatment programs. While you know your child best, it is important to evaluate the implications for safety and treatment in any setting being considered.

Age of Majority and Guardianship: For many years, you have been making decisions on behalf of your loved one with autism. But at the age of 18, the law says he gets to decide for himself and can give the required *'informed consent.'* He can refuse treatment or be declared unfit to decide. Either way, unless you apply for and are granted *guardianship*, the decisions are now out of your hands. If you think your loved one will need your assistance in making medical, safety and/or financial decisions, it will be important for you to learn about and consider your state's laws and procedures for obtaining guardianship status. This may take some time and the process involves a series of procedures, so it is important to consider this in advance of his 18th birthday, if possible. Sometimes there are allowances for temporary guardianship status while guardianship proceedings are in process. Guardianship is different from conservatorship, which allows for financial responsibility of another person. You can learn more in the Transition Tool Kit section on Legal Matters to Consider.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

What happens when the Hospital Stay is over? What is a Discharge Plan?

When the hospital stay is complete, your child or loved one should leave with a Discharge Plan created by the hospital, ideally with the input of other team members. It is not necessary for you to agree to the terms or components of the plan, but the hospital is required to counsel you, your loved one and other relevant team members about the components of the plan. The hospital is also supposed to begin implementation of the plan and assist in the coordination and connection to local social services organizations, making referrals or transfers and forwarding information and records. Such a plan is not likely to occur after a brief ER stay, but should be developed for your child over the course of an extended inpatient hospitalization. A discharge plan should include:



- A statement of your child's need, if any, for:
  - Supervision
  - Medication (what, when, how much)
  - Aftercare services and supports
  - Assistance in finding employment
- Recommendation of the type of residence in which your child is to live and a listing of the services available to your child in such residence
- Lists of the organizations, facilities, and individuals who are available to provide services in accordance with each of your child's identified needs
- Notice to the appropriate school district, if relevant, regarding the proposed discharge or release of your child
- An evaluation of your child's need and potential eligibility for public benefits following discharge, including public assistance, Medicaid, and *Supplemental Security Income*
- Follow-up evaluation plans

For anyone who has been hospitalized for any reason, recovery is best when there is a solid support network. This network can be family, friends or team members, often working together. Involving others in the discharge process will help your loved one and support you in moving forward. To learn more, visit Discharge Planning in Mental Health.

Contributions to this section were made by Matthew Siegel, M.D.

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Long Term Solutions: What if we just can't do this anymore?

Sometimes, a team gels beautifully and medical supports and positive interventions are effective in bringing an individual with autism the sense of security and the skills he needs to thrive in his home or community environment. However, sometimes factors such as limited resources, dual diagnoses, biological triggers or learning history can mean that a family needs more support than can be provided at home, and alternate solutions need to be considered.

This is not an easy decision to make, and often comes with considerable stress for everyone involved. It is important to remember that this decision is NOT giving up on your child. In many ways, it is recognizing that your child needs more than you can provide, and taking the steps necessary to allow him to grow and thrive in a place that is able to provide what he needs. This might mean a place with a 24-hour staff who can provide something that is not possible for a single individual, or a residential facility that supports his physical concerns as much as his behavioral needs. It is hard to be consistent and upbeat and follow a behavior plan when you are exhausted and deflated. It is difficult to be a family and support each person's needs, wants and growth, when everyone is afraid. Many families who have experienced a family member with significant challenging behaviors have reported on a much-improved relationship with their child once he was placed in a residential program that met his needs.

"If I could give any advice to parents going through this, I would tell them that it's not always an easy road, and a lot of times it can be scary. But you aren't alone, it can get better. I would tell them to reach out for help, because you can't walk this road alone. Each day is a new adventure, new challenges and new successes."

– DM, a mother

Residential placement is a personal decision that should be made when a family is no longer able to care for the needs of their child at home. For individuals with challenging behaviors such as aggression or self-injury, this may occur earlier in life than the usual transitions that occur in adulthood. It is also important to note that a residential placement is not necessarily permanent. If your team is able to build supports and skills and address underlying concerns, it may be possible for your child to return home.

A case manager or service coordinator from your school or social services agency can help to search for an appropriate setting for your child. Often, parents want to find something close to home so that they can maintain a relationship and contact with the child and his providers.

For help, visit these resources:

- Autism Speaks Housing & Residential Supports Tool Kit
- Autism Speaks Catalog of Residential Services
- National Disability Rights Network
- Disability.gov Housing Resources
- Global & Regional Asperger Syndrome Partnership (GRASP) – list and map of GRASP support groups

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Where can we learn more?

Family and Caregiver Training

This tool kit is a lot of information in writing, and that is not always the best way to learn. Families who need additional information and supports will benefit from specific training and supports.

- *Hands on Training:* Ideally, this is from a behavior analyst or other behavioral provider who is part of your child's team at school or home who can individualize training to your child's needs. It is individually designed to the needs of your child, your family, and responsive to the findings of the functional behavior assessment. It would occur in your home or in the settings where you need the assistance and training. Insurance laws are increasingly providing coverage for autism services, including ABA and behavior supports. Ask your doctor or case manager for suggestions.
- *State or local ABA or autism conferences:* Many conferences, presentations and workshops will focus on autism and case studies related to the treatment of challenging behaviors, or skills that might help to replace those behaviors. Visit ABA International to learn more.
- *Training Classes in Behavioral Approaches:* Parenting classes are often held at autism support groups, local hospitals, YMCAs, social services agencies, and the National Alliance on Mental Illness. Only some will be autism specific. These classes may provide you with tips and skills, as well as access to people and resources you might not already know about who can provide or suggest more specific services. Mental Health First Aid USA may also be a helpful resource.
- *Watch SuperNanny episodes on TV or YouTube:* She employs good behavioral strategies with respect to setting boundaries and expectations, staying calm, rewarding desired behavior and incorporating fun. These principles apply in autism just as they do with typical children.
- *Take care of yourself:* Parenting is hard enough, let alone when the demands of a child with special needs and challenging behaviors are added into the mix. Find strategies to improve your sleep, your *resilience* and your ability to remain calm and nourished. Classes in yoga, mindfulness and other stress reducers might be helpful. Talk to your friends and family, and find some time for fun. Seek out local supports for *respite* from community agencies, your place of worship or friends and family. Spend time with your other children and your spouse. Ask for help. Breathe. Visit the Autism Speaks Resource Guide to find respite care and support groups in your area.

"My friends were always reaching out to me to get lunch or a cup of coffee. Most of the time I felt too busy to step away from taking care of my son. Any time away from his needs felt like I wasn't being a good parent. One day my friend happened to call just as I was running out to the grocery store – she convinced me to meet her for a cup of coffee beforehand. Once I met her and sat down to chat and relax for a few minutes, I realized how much I needed it. I now make time every week to see my friends, or have a little 'me' time. Ultimately I think I'm a better parent and person because of it."

– AC, a mother

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Resources:

211 Database Service
Available in much of the US, this service connects people with important community services, sponsored by United Way Worldwide (UWW) and the Alliance for Information and Referral Systems (AIRS).

ABA Training & Treatment - Behavior Frontiers

Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage and Meltdowns
by Brenda Smith Myles and Jack Southwick

Managing Threatening Confrontations DVD
from the Attainment Company

No More Meltdowns: Positive Strategies for Managing and Preventing Out-Of-Control Behavior
by Jed Baker Ph.D.

The Way to A: Empowering Children with Autism Spectrum and Other Neurological Disorders to Monitor and Replace Aggression and Tantrum Behavior
by Hunter Manasco

Provider Training

Many schools and service providers will have trained staff accustomed to handling challenging behaviors. Others will not. Service providers who need additional information on positive supports and crisis prevention and management can utilize the following resources for information and training:

- Positive Behavior Supports
- Kansas Institute for Positive Behavior Support
- The New England Center for Children "CALM" Curriculum
- Safe and Civil Schools
- Crisis Prevention Institute
- Quality Behavioral Solutions to Complex Behavior Problems
- Mental Health First Aid USA

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Conclusion

Autism can bring a family many challenges, especially when a loved one with autism exhibits behaviors that are challenging, disruptive, or dangerous. These are often experiences that our siblings, parents and best friends do not quite understand, since they have not necessarily faced the same concerns. As a result, many families with loved ones with autism experience significantly high levels of stress, which can be disruptive and unsettling. However, many families have also shown resilience and an ability to bounce back from the challenges that autism presents with humor, grace and increasing strength.

It is important to get help. Cry when you need to. Lean on your friends, extended family, and other social supports. Connect with other parents who are experiencing similar challenges and swap stories and vent together—find them at support groups or places like www.meetup.com. Investigate counseling supports through your insurance plan, place of worship or community services agency.

Use the information in this tool kit to seek out information and team members who will support you, and help your loved one to grow to become all he can be. Take small steps, and celebrate the growth and accomplishments along the way. Be the detective that helps you better understand—and hopefully better accept—your child and the difficulties he faces as he goes through life. Use the strategies and resources in this kit and from your team to help you build a place in which everyone feels safer and more successful. Advocate for help when you need it. Find resources or create a plan for respite care so that you get a break too, and use it!

Recognize the resilience your loved one with autism shows each and every day. Celebrate the things he says or does that make you laugh: his dimples, his artwork, his smile. Sure, you may cry or swear sometimes. But also rest. Breathe. And celebrate the successes one at a time, whenever and wherever they come.

"A multidimensional, comprehensive approach to ASD that emphasizes the development of positive, constructive behavior, builds family cohesiveness and mutual support, focuses on successful home and community living, and addresses systemic barriers to progress will not "cure" autism, but it will make it possible to live happily with autism. These goals are realistic and can be achieved now."

– Ted Carr, Ph.D.,
State University of New York at Stony Brook



© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

Challenging Behaviors Glossary

- *A-B-C Analysis:* an approach to understanding behavior by examining the Antecedent (the cause), the Behavior, and the Consequence (the result)
- *ADHD (Attention Deficit Hyperactivity Disorder):* a problem with inattentiveness, over-activity, impulsivity, or a combination, that is out of the normal range for a child's age and development
- *Age of majority:* the age established under state law when an individual is no longer a minor and has the right to make certain legal decisions without consent
- *Allergies:* adverse immune responses or reactions to substances that are usually not harmful (i.e. pollen, peanuts, gluten)
- *Anxiety disorder:* a pattern of constant worry or tension under many different circumstances
- *Applied Behavior Analysis (ABA):* the systematic approach to the assessment and evaluation of behavior, and the application of interventions that change behavior
- *Audiologist:* a professional who diagnoses and treats a patient's hearing and balance problems using advanced technology and procedures
- *Autism Spectrum Disorders:* a group of complex disorders of brain development characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors
- *Aversive:* an unwanted stimulus designed to change an individual's behavior through punishment
- *Behavior Improvement Plan (BIP):* a plan to improve a student's behavior in school created based on the results of a Functional Behavior Assessment
- *Behavioral disorder:* a condition in which behavior significantly deviates from acceptable norms
- *Behavioral drift:* changes in behavioral patterns resulting from gradual and subtle adjustments over time
- *Behavioral stereotypy:* repetitive or ritualistic movements such as body rocking or crossing and uncrossing of legs
- *Biobehavioral unit:* a psychological and psychiatric clinic within a hospital or research center that treats behavioral, anxiety and mood disorders
- *Biomarker:* an indicator of a certain biological state
- *Bipolar disorder:* a brain disorder that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day tasks; also known as manic-depressive illness
- *Blinded:* unaware of a new or different intervention, which prevents bias during evaluation
- *Board Certified Behavior Analyst (BCBA):* a professional certified to provide ABA therapy by the Behavior Analyst Certification Board (BACB)
- *Bulimia:* an illness in which a person binges on food or has regular episodes of overeating and feels a loss of control, then uses different methods – such as vomiting or abusing laxatives – to prevent weight gain



© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Case manager:* a professional from a school or service agency such as the Department of Developmental Disabilities who serves as a direct contact for families and helps gather resources, team members and ideas
- *Catatonia:* a state in which a person does not move and does not respond to others
- *Challenging behaviors:* behaviors that are destructive and harmful to the individual or others, that prevent learning and cause others to label or isolate the individual for being odd or different
- *Civil Commitment:* a legal process in which an individual experiencing a mental health crisis is ordered into treatment against his or her will, including to a hospital
- *Comorbid:* pertaining to a disease or disorder that occurs simultaneously with another
- *Cognitive behavioral therapy:* a type of therapy designed to help improve an individual's inappropriate or challenging behaviors by replacing the negative thoughts that cause these behaviors with positive thoughts
- *Compulsion:* the drive to do something in particular or in a particular way, such as the need to straighten all the forks at the dinner table
- *Conservatorship:* the legal right given to a person to be responsible for the assets and finances of a person deemed fully or partially incapable of providing these necessities for himself or herself
- *Crisis plan:* a document that outlines in specific detail the necessary strategies and steps that must be taken when a crisis occurs
- *Data analysis:* the process of thoroughly inspecting information related to challenging behaviors in order to draw out useful information and conclusions that may result in strategies to improve behavior
- *De-escalation:* the process of stopping a challenging behavior or crisis from intensifying, and calming the situation
- *Depression:* a mood disorder in which feelings of sadness, anger, or frustration interfere with everyday life for an extended period of time
- *Differential diagnosis:* distinguishing between two or more diseases with similar symptoms to identify which is causing distress or challenging behavior
- *Disruption:* an event that causes an unplanned deviation from a situation
- *Dual diagnosis:* the identification of an additional mental health disorder individuals with developmental disabilities
- *Elopement:* a situation in which an individual leaves a safe place, a caretaker, or supervised situation, either by 'bolting,' wandering or sneaking away
- *Epilepsy:* a brain disorder in which a person has repeated seizures (episodes of disturbed brain activity or convulsions) over time
- *Escalating:* increasing or worsening rapidly
- *Extinction:* a response used to eliminate a behavior that involves ignoring a mild behavior when it is used for attention

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Extinction burst:* the short term response to extinction in which there is a sudden and temporary increase in the response's frequency, followed by an eventual decline
- *Face blindness:* an impairment in the recognition of faces
- *Fecal digging:* the process in which an individual puts his fingers into his rectum
- *Fecal smearing:* the process in which feces are spread on property or the individual himself
- *Food allergies:* an adverse immune response to a food protein (i.e. dairy products) that may cause rashes, gastrointestinal or respiratory distress
- *Function:* the purpose or desired result
- *Function of behavior:* the purpose or reason behind a specific behavior for an individual
- *Functional Behavior Assessment (FBA):* the process by which a school thoroughly examines a student's problem behavior using strategies such as close observation, questionnaires, active listening, previous experiences, etc.
- *Functional communication:* effective and appropriate communication that an individual uses across his daily activities to meet his or her needs
- *Gastroenterologist:* a professional specializing in disorders of the digestive system
- *Guardianship:* the legal right given to a person to be responsible for the food, health care, housing, and other necessities of a person deemed fully or partially incapable of providing these necessities for himself or herself
- *Hormones:* chemical messengers that travel in an individual's bloodstream to tissues or organs slowly, over time, and affect many different processes, including brain activity and behavior
- *Immunologist:* a physician specially trained to diagnose, treat and manage allergies, asthma, and other immunologic disorders
- *Incontinence:* the (usually) involuntary passing of feces or urine, generally not into a toilet or diaper
- *Individualized Education Program (IEP):* a written statement for each child with a disability that is developed, reviewed, and revised in meetings within the school so an individual's education best meets his or her needs
- *Individuals with Disabilities Education Improvement Act (IDEIA):* the 2004 reauthorization of the Individuals with Disabilities Act that states that in exchange for federal funding, states must provide a free appropriate public education (FAPE) to individuals with disabilities in the least restrictive environment (LRE)
- *Individuals with Disabilities Education Act (IDEA):* a law ensuring services to children with disabilities throughout the nation that governs how states and public agencies provide early intervention, special education and related services to more infants, toddlers and children with disabilities
- *Informed consent:* a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention
- *Intervention:* a strategy or process put in place in order to improve or modify an individual's behavior (i.e. medication, Applied Behavior Analysis)

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Intolerance:* the inability, unwillingness or refusal to endure something (i.e. specific foods)
- *Involuntary Commitment:* a legal process in which an individual experiencing a mental health crisis is ordered into treatment against his or her will, including to a hospital
- *Lyme Disease:* a bacterial infection spread through the bite of the blacklegged tick
- *Maladaptive behavior:* a type of behavior that is often used to reduce anxiety, but the result does not provide adequate or appropriate adjustment to the environment or situation
- *Medicaid:* a government program that provides healthcare coverage for low-income families and individuals with disabilities in the United States
- *Medical home:* a team based healthcare delivery model led by a physician that provides comprehensive and continuous medical care to patients
- *Mental Health Hold:* involuntary hospitalization due to a mental health crisis
- *Motor function:* the ability to move that results from messages sent from the brain to the muscular system
- *Nutritionist:* a professional specializing in diet and nutrition issues
- *Obsession:* a repetitive thought or feeling dominated by a particular idea, image or desire, such as a person who only wants to talk about elevators
- *Obsessive Compulsive Disorder (OCD):* an anxiety disorder in which people have unwanted and repeated thoughts, feelings, ideas, or sensations (obsessions) that make them feel driven to do something (compulsions)
- *Ophthalmologist/optometrist:* a professional specializing in vision issues and eye care
- *Ototoxic:* damaging to the ears, causing sound sensitivities, dizziness or balance issues
- *Over correction:* a punishment mechanism for a challenging behavior that involves requiring an individual to engage in repetitive behavior to an excessive extent in an attempt to prevent the behavior from reoccurring
- *Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS):* a subset of children and adolescents who have Obsessive Compulsive Disorder (OCD) and/or tic disorders, and in whom symptoms worsen following infections such as "Strep throat" and Scarlet Fever
- *Pica:* an eating disorder that involves eating things that are not food (i.e. dirt, plastic)
- *Picture Exchange Communication System (PECS):* a unique augmentative/alternative communication intervention package that involves teaching an individual to give a picture of a desired item to a “communicative partner,” and goes on to teach discrimination of pictures and how to put them together in sentences
- *Polypharmacy:* the use of multiple medications by a patient
- *Positive Behavior Supports (PBS):* an approach to helping people improve their difficult behavior by understanding what is causing it, and then developing strategies to increase positive behaviors
- *Post-Traumatic Stress Disorder (PTSD):* an anxiety disorder that can occur after witnessing or experiencing a traumatic event

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It’s Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Psychiatric evaluation:* a mental health examination by a psychiatrist or other mental health professional
- *Psychologist:* a professional with the training and clinical skills to help people learn to cope more effectively with life issues and mental health problems
- *Psychosis:* a loss of contact with reality that usually includes delusions and hallucination)
- *Psychotropic:* a medication or intervention that affects brain activity, behavior or perception
- *Puberty:* the process of physical changes that occur when a child's body matures into an adult
- *Regional center:* agencies throughout the state of California that serve individuals with developmental disabilities and their families
- *Reinforce:* to strengthen with additional material or support
- *Reinforcement strategies:* methods used to promote or increase positive behavior by providing motivating reinforcers (i.e. praise, a favorite toy, a cookie)
- *Resilience:* an ability to recover from or adjust easily to change or a difficult situation
- *Respite care:* a service that provides short-term breaks that can relieve stress, restore energy, and promote balance for caregivers
- *Restraints:* physical restrictions immobilizing or reducing the ability of an individual to move their arms, legs, body, or head freely
- *Reward:* a prize, token, or preferred activity given to an individual for good behavior, designed to promote the same behavior in the future
- *Risk factors:* conditions that increase the likelihood of aggression
- *Ritual:* a repetitive behavior that a person appears to use in a systematic way in order to promote calm or prevent anxiety, such as arranging all the pillows in a certain way before being able to settle in to sleep
- *Rumination:* the practice of (voluntarily or involuntarily) spitting up partially digested food and re-chewing it, then swallowing again or spitting it out.Rumination often seems to be triggered by reflux or other gastrointestinal concerns
- *Schizophrenia:* a chronic, severe, and disabling brain disorder that makes it hard for individuals to think clearly and tell the difference between what is real and not real
- *Seclusion:* a situation in which an individual is put briefly in a room alone to 'calm down'
- *Sedating:* calming, sleep-inducing, numbing an individual experiencing challenging behaviors or struggling during difficult situations
- *Self-advocacy:* the ability of an individual to communicate his or her wants and concerns, and make his or her own decisions
- *Sensory avoidance:* blocking or staying away from something that is painful or bothersome

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

- *Sensory defensiveness:* a tendency to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating
- *Sensory input:* any source that creates sensation and activates one or more of the senses -vision, smell, sound, taste, and touch
- *Sensory-seeking behavior:* behaviors caused by a need for additional stimulation of certain senses as a way of maintaining attention or achieving a calmer state
- *Sleep apnea:* a usually chronic, common disorder in which an individual has one or more pauses in breathing or shallow breaths up to 30 or more times per hour during sleep, and results in daytime sleepiness
- *Special needs parent advocate:* an advocate for parents of children with special needs who helps ensures that the child's rights and needs are met in school and in the community
- *Staring spells:* occasions when an individual is in a trance staring into space, which can often signal seizure activity
- *Stimulation:* excitement or activity triggered by a stimulus either internally or externally
- *Supplemental Security Income (SSI):* a Federal income supplement program designed to help aged, blind, and disabled people who have little or no income, and provides cash to meet basic needs for food, clothing, and shelter
- *Tangibles:* items or rewards that can be touched, such as a toy or piece of candy
- *Tourette's Syndrome:* a neurological disorder characterized by tics, or repetitive, stereotyped, involuntary movements and vocalizations
- *Tracking scales:* a document or other tool used to track information such as changes in an individual's behaviors, side effects of medications, school performance, etc.
- *TRICARE:* the health care program for Uniformed Service members, retirees and their families worldwide
- *Voice output technology:* a technological device that helps people who are unable to use speech to express their needs and exchange information with other people
- *Wraparound:* an integrated, multi-agency, community-based planning process designed to build teams of providers, family members and natural supports to help keep complex youth in their homes and communities

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.

AUTISM SPEAKS®
It's time to listen.

Have more questions or need assistance?
Please contact the Autism Response Team for
Information, Resources and Tools.

TOLL FREE: 888-AUTISM2 (288-4762)

EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG

WWW.AUTISMSPEAKS.ORG

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks owned by Autism Speaks Inc. All rights reserved.



Our Mission

At Autism Speaks, our goal is to change the future for all who struggle with autism spectrum disorders.

We are dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. We are committed to raising the funds necessary to support these goals.

Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.

AUTISM SPEAKS®

It's time to listen.

www.AutismSpeaks.org

© 2012 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are registered trademarks owned by Autism Speaks Inc. All rights reserved.