



UPC E-JOURNAL: AUTISM

Issue No.1 February 2008

AUTISM: HELPS FOR PARENTS

WELCOME to the first in a series of topical e-journals to be published by the Utah Parent Center. It is our hope that this journal will be a resource that is accessible to both parents and professionals. We have gathered together a selection of original and previously published articles. Not wanting to “reinvent the wheel”, we have included information on accessing other publications, such as the *Utah Special Educator* (see page 32).

This e-journal will be archived on the Utah Parent Center website at www.utahparentcenter.org. We hope that it will be a long lasting resource for families.

Thank you to the individuals who have authored articles or given permission to include previously published work. Thank you to the Autism Council of Utah and the Autism Conference Committee for providing input for this issue. Your donations of time and expertise are true gifts to the families who will read this.

To the parents who read this, we welcome your feedback and suggestions and your ideas for future issues. All that we do is for you --- to help you help your children live included productive lives as members of the community.

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EIGHT THINGS THE UTAH PARENT CENTER OFFERS TO ASSIST PARENTS OF CHILDREN WITH AUTISM

The Utah Parent Center (UPC) serves parents of children with all disabilities across the state of Utah and our staff includes parents who have children with autism. We collaborate with other organizations and agencies who serve families and/or work to improve services for children and youth with autism. We have a number of things in place that are provided for the purpose of addressing the needs of parents and families.

1. Free workshops and presentations. The Utah Parent Center provides training on a variety of topics.

Parents as Partners in the IEP Process will help you to understand how the special education process works and how you can successfully advocate for your child.

Communication and Conferencing Skills will help you communicate clearly and develop a better relationship with the professionals that serve your children.

Transition, From "No Where" to "Know Where" will make you aware of the many ways you can help your child to move successfully into the world after school.

Section 504, "The Other Service Option" gives information about a federal antidiscrimination law that protects students and adults with disabilities. It also requires accommodations in order to level the playing field in any program that receives federal funding.

These and other workshops can be requested by contacting our office. Check our electronic newsletter or website for information on upcoming events.

2. Individual Consultations/Information and Referral. Parents may call for individual free consultations concerning questions or concerns about special education or for information and referral to other agencies and resources.

3. Family Links Conferences. These highly anticipated conferences are held annually in three locations across the state. A number of disability organizations and agencies from across the state

collaboratively plan a program of informative and uplifting speakers on many different topics, including autism. Many of the session topics apply to the common issues across disabilities. These conferences are a great place to find resources and support, connect with other parents, and realize that you are not alone.

4. Autism Resource Lists and Fact Sheets. Parents are encouraged to check the UPC website or call for copies of our resource lists. Lists on many different topics and resources are maintained and posted online. Parents are also invited to let us know about things that could be included on the lists.

5. e-Connections Electronic Newsletter. The UPC regularly sends out an electronic newsletter that contains a calendar of upcoming events of interest to families of individuals with disabilities. Also included are short articles on resources and timely topics and links to other resources. Please contact the UPC staff to receive e-Connections or to add your events to the calendar.

6. Autism Newsletter/Basic Information on Autism. In 2005 the UPC published a newsletter edition for parents which contained basic information on autism. We have not repeated most of that information in this journal. Since this information continues to be helpful and popular, we have kept it available to be downloaded from the UPC website. Print copies may be requested by calling our office. The topics that are covered in the other newsletter include: Is it Autism? What Causes Autism? Aspergers Syndrome; Common Characteristics; Treatment Overview and Options; Behavior/Communication; Stress Management; Managing as a Family; Sibling Information; and much more!

7. Lending Library. A number of books and other materials on autism are available through our lending library. Call or visit the office to check out materials. A fully refundable deposit is required when checking out materials.

8. Website. The UPC website has recently been upgraded, and we are adding new materials all the time. Visit us at www.utahparentcenter.org.

THE AUTISM COUNCIL OF UTAH FOSTERS COLLABORATION

The Autism Council of Utah (ACU) is an important organization for parents to be aware of. The Autism Council consists of representatives of agencies and parents who are interested in working together to improve the lives of people with autism. Please visit the ACU website at www.autismcouncilofutah.org to find information regarding autism as well as to find information on joining the Council or participating with one of the many committees of the Council. Check the website also to find information on upcoming seminars, conferences, and parent training events.

The Utah Parent Center is pleased to be represented on the ACU, and we often include ACU events and news in our electronic newsletter.

Following is some information taken from the ACU website:

Autism Council of Utah Mission Statement: The Autism Council of Utah is an independent council working to foster collaboration, communication, and learning among families and agencies. Our aim is to promote access to resources and responsible information for individuals of all ages who have, or are affected by autism, or related conditions. The Council will accomplish this by supporting statewide partnerships to collaborate on special projects, research, and training.

WHAT IS AUTISM?

Primary Authors: Janet Lainhart, MD and Deborah Bilder, MD (2004)

Taken from the Autism Council of Utah Website, reprinted with permission

BRIEF DESCRIPTION

Autism Spectrum Disorders (ASD's): Autism spectrum disorders are neurodevelopmental disorders currently defined by significant qualitative impairments in 3 developmental domains:

- Reciprocal social and emotional interaction
- Communication
- Stereotyped behaviors and restricted interests and activities (this sounds more like a description of their behaviors than a developmental domain)

For reasons that are not yet understood, abnormalities in these 3 developmental domains tend to cluster together in affected individuals. All individuals with autism-spectrum disorders have behavioral evidence of qualitative abnormalities of social development in combination with qualitative abnormalities of communication and/or stereotyped repetitive interests and behaviors. ([click here for DSM-IV criteria for autism](#)) (Source: [American: 2000.](#)) What comes naturally to most children about socially relating to others, does not come naturally to children with autism-spectrum disorders.

Many individuals with autism and PDD-NOS also have developmental delays. Because developmental delays are not found in all individuals with these disorders, developmental delay is not required for a diagnosis of autism-spectrum disorders.

Affected individuals may have a variety of other cognitive, emotional, and behavioral problems. Because these associated problems are not present in all affected individuals, they are not part of the criteria for autism-spectrum disorders, though they occur frequently and are very important to recognize and treat. There are many behaviors and deficits that relate to each of the three domains above. As children with ASD's mature, these characteristics can change but the diagnosis remains.

Autistic Disorder: An ASD in which there is significant impairment in all three domains with onset before 3 years of age. Alternative names are autism, infantile autism, primary autism. A subtype is "high-functioning autism". IQ in children with autism can range from profound mental retardation to superior intelligence and verbal ability can range from absent to articulate speech.

Asperger's Disorder: An ASD in which there is significant impairment in social interaction and range of interests and activities, similar to a child with autism but what distinguishes the child with Asperger's from one with autism?. Persons with Asperger's Disorder do not have delayed onset of language, but their communication is often impaired by an inability to read social cues, making socially inappropriate comments, or having a narrow focus of interest. Verbal IQ is generally greater than 70. An alternative name is Asperger's Syndrome.

Pervasive Developmental Disorder NOS (not otherwise specified): This diagnosis is currently ill-defined. It could apply to a child with the same qualitative deficits in social and communication development as a child who has autism, but who does not meet criteria for Autism or Asperger's Disorder due to age of onset or extent of impairment. They may meet criteria for autism in the social or communication domain and may show some impairment in the other of these two domains. It could also refer to a child with global developmental delay who demonstrates impairment in some but not all of the three developmental domains listed above. This must be viewed in the context of the child's developmental age. This disorder is also referred to as PDD NOS.

PREVALENCE (2004):

Autism Spectrum Disorders (Autism, Asperger's, and PDD NOS): 27.5/10,000
Autism: 10/10,000
Asperger's Disorder: 2.5/10,000

Previously, the rate of autism was felt to be much lower (4/10,000). There is no clear explanation for the increase. This may reflect changes in the diagnostic criteria and an increased awareness of

For updated information on prevalence, see *Autism: An Urgent Public Health and Education Concern* by Zimmerman and McMahon on page 8 of the *Utah Special Educator*, February 2008 edition, which can be found online at www.updc.org.

autism rather than a true increase in incidence. The increase in diagnosis of autism has occurred across the spectrum of intellectual ability. Asperger's Disorder is the most uncommon of the autism spectrum disorder with a prevalence of only one quarter that of autism. Many children thought to have Asperger's Disorder upon further evaluation are found to have high functioning autism.

PAGE BIBLIOGRAPHY: American Psychiatric Association - *Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR* (Text Revision). 4th edition (June 2000) ed. American Psychiatric Association; 2000. ISBN 0890420254. *Information in this article is courtesy of The Utah Medical Home Project Team. Visit their website at www.medhomeportal.org.*

TRANSFORMATIONS; ONE PARENT'S STORY

By Cathi Garfield

Current participant in the Utah Parent Center's Leadership Academy for Mentor Parents

Ten months after my husband and I were married, we were blessed with our first child, a happy little boy we named Zachary Thomas after my husband's grandfather. Fifteen months later Alexa joined our family. She was a quiet little girl who was content to just lie there and watch the world go by. Our third child was born 18 months later. Jaylyn completed our family and is the peacemaker between her brother and sister.

"Ptchew, ptchew, kapow. . ." I hear from the other room as Zach becomes one with his latest fascination, Transformers...more than meets the eye! We have had nothing but "Transformers this" and "Transformers that" for some time in our house, which actually isn't all that bad, because Star Wars had been going on for so long that it is nice to have something new be surrounded in...at least it was for the first couple of months.

"Ch ch ch ch ch ptchew." There it goes again--back to Transformers. What a great concept! More than meets the eye. How true that is for everyone around us, including ourselves.

Physically Zach progressed faster than the charts. He met every milestone ahead of time--walking by 9 months and stringing words together before a year. We just knew he was brilliant! It was easy at first to dismiss the odd things he did--the hours he would spend creating elaborate zoos with his plastic animals that were the same day after day. Every animal had a place, and day after day its place never changed. Even so, it was easy to ignore the nagging feeling. After all, he was so smart and so ahead of all the other kids we knew his age, and he did include us in his play. His idea of including us, though, was to have us watch him play. He never wanted us to touch or move any of his toys--just watch. For him, the thought of being alone was painful. He was the kind of little kid that every time you turned around you literally stepped on him, because he gave you no room to maneuver. By the time Zach was about two and a half, we started searching for someone to help us determine what was going on with him. We found lots of people who were less than helpful. Finally, when he was 4 he was diagnosed with Asperger's by the Children with Special Health Care Needs Child Development Clinic at the Utah State Department of Health. It had been a long journey from the perfect little dream that every mother has as she watches her

newborn those first few weeks of life to watching him knowing he needed help and not being sure where to find it for him. Then, finally, we found the sliver of the edge of the iceberg that was ours to climb.

When Zach was first given the diagnosis of Aspergers Syndrome, I, as I imagine any parent would, felt like I had just been punched in the gut. I could hardly bring myself to say the word "Autism". How could my perfectly bright child have Autism? Initially in my shock I was sure that I would never recover from hearing those words. But, of course, I did. It didn't take long for me to realize that he was still the same happy, smart, funny little boy he always had been. He hadn't changed. As time progressed, I gradually came to accept his autism and instead of avoiding it, I embraced it. I began to learn all I could about his disorder.

As time progressed, the signs became more and more obvious to my husband and me that our boy was different. The next challenge came as he started school--to tell or not to tell? We were so afraid that if people knew Zach would be treated differently--that people would look at the autism and fail to see the boy. We decided at first not tell. Zach was doing well in school at the time, and so we waited. With each year, however, new challenges have surfaced and we have done our best to deal with them. At the end of first grade, it became necessary to inform the school that Zach had been diagnosed with Aspergers. It didn't take long to realize that working with the school would present challenges.

When Zachary was about 8 years old, he started asking why he was different from the other kids and what Aspergers was. We have always believed that when a question is asked by our children, we should give the best answer for that time and their age. So, the process of discovering himself began. With these questions came the start of the biggest transformation for our family. I came to the realization that it wasn't fair for me to keep his autism from him. He needed more than for us to love and accept him. We needed to help him understand how special and unique he is--to help him understand and appreciate himself for his abilities and realize that all people have things they are good at and things they struggle with.

About the same time Zach began asking all these questions he really began to struggle in school, not with the academics, but at recess. I got in touch with the principal. The school resisted providing services at first, citing the fact that even though he has several diagnoses he wasn't failing and, therefore, did not need any help. This is the current transformation we are undertaking--trying to advocate—to communicate with the school and convince them to provide the services needed by our son, and all kids, because of their disabilities. This transformation is far from over. There is still a need for education about which students need assistance and which don't.

This life is full of transformations. The challenge we all face is what we do once our transformation has begun and, when that transformation is complete, how we will progress in our new form. We all transform. Some transformations are obvious and others are not. That is why we can't judge people, including children with autism, by appearances. More often than not, there is more to a person than meets the eye.

TEN THINGS YOUR STUDENT WITH AUTISM WISHES YOU KNEW

These ideas make sense for other kids, too!

By Ellen Notbohm, ©2005; Reprinted by the Utah Parent Center with permission.

Author's note: When my article Ten Things Every Child with Autism Wishes You Knew was first published in November 2004, I could scarcely have imagined the response. Reader after reader wrote to tell me that the piece should be required reading for all social service workers, teachers and relatives of children with autism. "Just what my daughter would say if she could," said one mother. "How I wish I had read this five years ago. It took my husband and I such a long time to 'learn' these things," said another. As the responses mounted, I decided that the resonance was coming from the fact that the piece spoke with a child's voice, a voice not heard often enough. There is great need – and I hope, great willingness – to understand the world as special needs children experience it. Ten Things Every Child with Autism Wishes You Knew became a book in 2005, and now the voice of our child returns now to tell us what children with autism wish their teachers knew.

1. **Behavior is communication.** All behavior occurs for a reason. It tells you, even when my words can't, how I perceive what is happening around me. Negative behavior interferes with my learning process. But merely interrupting these behaviors is not enough; teach me to exchange these behaviors with proper alternatives so that real learning can flow.

Start by believing this: I truly do want to learn to interact appropriately. No child wants the negative feedback we get from "bad" behavior. Negative behavior usually means I am overwhelmed by disordered sensory systems, cannot communicate my wants or needs or don't understand what is expected of me. Look beyond the behavior to find the source of my resistance. Keep notes as to what happened immediately before the behavior: people involved, time of day, activities, settings. Over time, a pattern may emerge.

2. **Never assume anything.** Without factual backup, an assumption is only a guess. I may not know or understand the rules. I may have heard the instructions but not understood them. Maybe I knew it yesterday but can't retrieve it today.

Ask yourself:

- Are you sure I really know how to do what is being asked of me? If I suddenly need to run to the bathroom every time I'm asked to do a math sheet, maybe I don't know how or fear my effort will not be good enough. Stick with me through enough repetitions of the task to where I feel competent. I may need more practice to master tasks than other kids.
 - Are you sure I actually know the rules? Do I understand the reason for the rule? Am I breaking the rule because there is an underlying cause? Maybe I pinched a snack out of my lunch bag early because I was worried about finishing my science project, didn't eat breakfast and am now famished.
3. **Look for sensory issues first.** A lot of my resistant behaviors come from sensory discomfort. One example is fluorescent lighting, which has been shown over and over again to be a major problem for children like me. The hum it produces is very disturbing to my hypersensitive hearing, and the pulsing nature of the light

can distort my visual perception, making objects in the room appear to be in constant movement. An incandescent lamp on my desk will reduce the flickering, as will the new, natural light tubes. Or maybe I need to sit closer to you; I don't understand what you are saying because there are too many noises "in between" – that lawnmower outside the window, Jasmine whispering to Tanya, chairs scraping, pencil sharpener grinding. Ask the school occupational therapist for sensory-friendly ideas for the classroom. It's actually good for all kids, not just me.

4. **Provide me a break to allow for self-regulation *before* I need it.** A quiet, carpeted corner of the room with some pillows, books and headphones allows me a place to go to re-group when I feel overwhelmed, but isn't so far physically removed that I won't be able to rejoin the activity flow of the classroom smoothly.
5. **Tell me what you want me to do in the positive rather than the imperative.** "You left a mess by the sink!" is merely a statement of fact to me. I'm not able to infer that what you really mean is "Please rinse out your paint cup and put the paper towels in the trash." Don't make me guess or have to figure out what I should do.
6. **Keep your expectations reasonable.** That all-school assembly with hundreds of kids packed into bleachers and some guy droning on about the candy sale is uncomfortable and meaningless to me. Maybe I'd be better off helping the school secretary put together the newsletter.
7. **Help me transition between activities.** It takes me a little longer to motor plan moving from one activity to the next. Give me a five-minute warning and a two-minute warning before an activity changes – and build a few extra minutes in on your end to compensate. A simple clock face or timer on my desk gives me a visual cue as to the time of the next transition and helps me handle it more independently.
8. **Don't make a bad situation worse.** I know that even though you are a mature adult, you can sometimes make bad decisions in the heat of the moment. I truly don't mean to melt down, show anger or otherwise disrupt your classroom. You can help me get over it more quickly by not responding with inflammatory behavior of your own. Beware of these responses that prolong rather than resolve a crisis:
 - Raising pitch or volume of your voice. I hear the yelling and shrieking, but not the words.
 - Mocking or mimicking me. Sarcasm, insults or name-calling will not embarrass me out of the behavior.
 - Making unsubstantiated accusations
 - Invoking a double standard
 - Comparing me to a sibling or other student
 - Bringing up previous or unrelated events
 - Lumping me into a general category ("kids like you are all the same")

9. **Criticize gently.** Be honest – how good are you at accepting “constructive” criticism? The maturity and self-confidence to be able to do that may be light years beyond my abilities right now. Should you never correct me? Of course not. But do it kindly, so that I actually hear you.
- Please! Never, *ever* try to impose discipline or correction when I am angry, distraught, overstimulated, shut down, anxious or otherwise emotionally unable to interact with you.
 - Again, remember that I will react as much, if not more, to the qualities of your voice than to the actual words. I will hear the shouting and the annoyance, but I will not understand the words and therefore will not be able to figure out what I did wrong. Speak in low tones and lower your body as well, so that you are communicating on my level rather than towering over me.
 - Help me understand the inappropriate behavior in a supportive, problem-solving way rather than punishing or scolding me. Help me pin down the feelings that triggered the behavior. I may say I was angry but maybe I was afraid, frustrated, sad or jealous. Probe beyond my first response.
 - Practice or role-play – *show* me—a better way to handle the situation next time. A storyboard, photo essay or social story helps. Expect to role-play lots over time. There are no one-time fixes. And when I do get it right “next time,” tell me right away.
 - It helps me if you yourself are modeling proper behavior for responding to criticism.
10. **Offer real choices – and only real choices.** Don’t offer me a choice or ask a “Do you want...?” question unless are willing to accept no for an answer. “No” may be my honest answer to “Do you want to read out loud now?” or “Would you like to share paints with William?” It’s hard for me to trust you when choices are not really choices at all.

You take for granted the amazing number of choices you have on a daily basis. You constantly choose one option over others knowing that both *having* choices and being *able* to choose provides you control over your life and future. For me, choices are much more limited, which is why it can be harder to feel confident about myself. Providing me with frequent choices helps me become more actively engaged in everyday life.

- Whenever possible, offer a choice within a ‘have-to’. Rather than saying: “Write your name and the date on the top of the page,” say: “Would you like to write your name first, or would you like to write the date first?” or “Which would you like to write first, letters or numbers?” Follow by showing me: “See how Jason is writing his name on his paper?”
- Giving me choices helps me learn appropriate behavior, but I also need to understand that there will be times when you can’t. When this happens, I won’t get as frustrated if I understand why:
 - “I can’t give you a choice in this situation because it is dangerous. You might get hurt.”
 - “I can’t give you that choice because it would be bad for Danny” (have negative effect on another child).
 - “I give you lots of choices but this time it needs to be an adult choice.”

The last word: *believe*. That car guy Henry Ford said, "Whether you think you can or whether you think you can't, you are usually right." Believe that you can make a difference for me. It requires accommodation and adaptation, but autism is an open-ended disability. There are no inherent upper limits on achievement. I can sense far more than I can communicate, and the number one thing I can sense is whether or not you think I "can do it." Expect more and you will get more. Encourage me to be everything I can be, so that I can stay the course long after I've left your classroom.

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*Ellen Notbohm is author of **Ten Things Every Child with Autism Wishes You Knew** and **Ten Things Your Student with Autism Wishes You Knew**, both ForeWord Book of the Year finalists and iParenting Media Award recipients. She is also co-author of the award-winning **1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders**, a columnist for *Autism Asperger's Digest* and *Children's Voice*, and a contributor to numerous publications and websites around the world. Her new book, **The Autism Trail Guide: Postcards from the Road Less Traveled**, is a September 2007 release. To contact Ellen or explore her work, please visit www.ellennotbohm.com.*

EARLY INTERVENTION

By Jody Jones, Parent Consultant, Utah Parent Center

Why Early Intervention? There are three primary reasons for intervening early with a child showing developmental delays: to enhance the child's development, to provide support and assistance to the family, and to maximize the child's and family's benefit to society.

Early Intervention is a family centered teaching program where staff and families of eligible children, birth to three years old, work together to help children grow and develop. Teaching a child and helping him or her to learn at this age will create later success with life, school readiness and self sufficiency. If a parent is taught how to help the child and how to work with the child, then the parent will be more involved with the child's learning and growth.

The purpose of Early Intervention programs is to provide help early on for babies and toddlers who exhibit significant developmental delays. Babies and Toddlers ages 0-3 are at a critical age of development. The rate of human learning and development is most rapid in the preschool years.

Early Intervention provides parent education, therapies, motor and speech specialists, and developmental specialists as well as other services. These specialists along with services from nurses and social workers provide intervention programs that may be center-based, home-based, hospital-based, or a combination.

Early intervention services have a significant impact on parents and siblings of a developmentally delayed infant or young child. The family of the young child often feels disappointment, social isolation, added stress, frustration, and helplessness. Families of children with special needs are found to experience increased instances of divorce. Early Intervention provides a way for families to set goals that are accomplished and to network with other families. Having the opportunity to be successful with goals and to see and work with other families will help parents not feel alone and allow them to talk with other families experiencing similar challenges. Early

intervention goals and networking can result in parents having improved attitudes about themselves and their children, improved information and skills for teaching their children, more time for leisure and employment, decreased stress and better family relationships.

"After nearly 50 years of research, there is evidence--both quantitative (data-based) and qualitative (reports of parents and teachers)--that early intervention increases the developmental and educational gains for the child, improves the functioning of the family, and reaps long-term benefits for society. Early intervention has been shown to result in the child: (a) needing fewer special education and other rehabilitative services later in life; (b) being retained in a grade less often; and (c) in some cases being indistinguishable from non-handicapped classmate's years after intervention". (www.kidssource.com)

As parents, we need to realize that the interventions we are doing now are likely to make a big difference in our child's future. Take a minute to picture your child. Think of the greatest dream you have for the child. Visualize it. Now DOUBLE it and you will be getting close to the child's potential. Know about your child's disability but focus on the abilities!

References: Kids on the Move Early Intervention DVD, Davis School District website Early Intervention page; and www.kidssource.com.

SOCIAL STORIES

As developed by Carol Gray, The Gray Center for Social Learning and Understanding, and Presented by Jocelyn Taylor, MA, Autism Specialist, Utah State Office of Education Review and information written by Jody Jones, Parent Consultant, Utah Parent Center

What are Social Stories?

Social Stories are a tool for teaching social skills to children with autism and related disabilities. They provide accurate information about situations that children may find difficult or confusing. The story is told in a first person, present-tense layout and is used to provide a student with as much information about a social situation as possible. The situation is described in detail. Focus is given to a few key points and prepares the student to face that situation and act appropriately

What are the main features of a Social Story?

A social story has a story line that includes the child in the starring role, important social cues, accurate information about the child's environment, actions that might be expected of him and why, and Positive Behavioral Supports. It teaches social understanding.

What does a Social Story do?

A social story creates a shared understanding, alleviates fear, stress and confusion and often results in improved behavior. The goal of the story is to increase the individual's understanding, make him more comfortable, and suggest appropriate responses for the situation in question.

Four-Step Method for Writing a Social Story

Step-one: Picture the goal. How would you like the child to act?

Step-two: Gather information and identify what the child needs to learn. A Functional Behavior Assessment can help to determine needs. Look at how a child socializes overall and determine what impairments need to be addressed. Social impairments may fall in three broad categories;

1. Social avoidance (having tantrums, shying away from, or attempting to escape social situations)
2. Social indifference (common to the majority of children with autism who don't actively seek social interaction nor do they aggressively avoid such interaction). And
3. Social awkwardness (seen typically in higher functioning kids who may try hard to gain and keep friends, but are hindered by a lack of reciprocity in conversation and interest).

Step-three: Narrow the needs down and choose one skill or behavior to teach. Write the story.

- Tailor the text, writing with the child in mind.
- Use an appropriate vocabulary and an appropriate type size.
- Include positive language, literal accuracy, and non-anxiety producing vocabulary,
- Reflect the student's age, characteristics, and interests.
- Use visual supports.

- Answer “wh” questions (where, who, what, why, when).
- Make it fun!

The story’s layout should have an introduction, body and conclusion. Four types of sentences are used to present information in a Social Story. Include 2-5 sentences of each type except the Directive. Only include 0-1 Directive sentences.

- Descriptive sentences address the “wh” questions: *where* the situation takes place, *who* is involved, *what* they are doing, and *why* they may be doing it. This is the story frame work with observable truths, such as:
 - “My name is...”
 - “Many children play on the playground...”
- Perspective sentences give a peek into the minds of those involved in the story; they provide details about the emotions and thoughts of others, such as:
 - “Some children like to play the piano”, or
 - “My mom is happy when...”.
- Directive sentences suggest a desired response or action tailored to the individual. These are also known as “control” sentences. It is to help the student deal with the situation, such as:
 - “I will try to stay in my chair.”
 - “I can think of an idea”.
- Affirmative sentences enhance surrounding statements. These are also known as “cooperative” sentences, such as:
 - “This is a good idea.”
 - “Mom and dad will remain calm when I talk to them.”

Step-four: Teach with the title. Label the story to illustrate the desired end result. Here are 2 examples geared for different children:

Hugging: Why Do People Hug?

People hug to show that they love each other.

When I hug someone I put my arm around them and squeeze gently.

Sitting on the Carpet

Sometimes our class sits on the carpet. (Descriptive)

We sit on the carpet to listen to stories and for group lessons.

(Descriptive)

My friends are trying hard to listen so they can enjoy the story or learn from the lessons. (Perspective)

It can be hard for them to listen if someone is noisy or not sitting still.

(Descriptive)

I will try to sit still and stay quiet during our time on the carpet. (Directive)

This is a good idea because my teacher and friends will be happy when I am sitting still and quiet. (Affirmative)

Writing with the Child in Mind - Is Your Social Story Complete?

Check for the following ingredients in your Social Story as appropriate.

1. Introduction, body and conclusion
2. Answer "wh" questions
3. First person, the child as the starring role
4. Positive language
5. Literal accuracy
6. Non-anxiety vocabulary
7. Appropriate vocabulary and text size
8. Concrete text
9. Visual supports
10. Reflects student's age and characteristics
11. Reflects interests of student
12. Check the ration of sentence types; descriptive, perspective, directive and affirmative.

Presentation, Variations and Authoring styles

There are a variety of presentation styles and options that can be used to meet the needs of a variety of children.

- **Text on paper** is likely the easiest presentation to prepare and use but it may not be the most appropriate for every child (non-readers, etc.).
- **Illustrations** – The child (or parent/teacher) can illustrate each page of the story, or photographs can be taken of the child and his peers in the social situation. These pictures can add interest and visual support for the presented ideas. Pictures (photographs, especially) should be as visually uncluttered and as simple as possible.
- **Symbols** – The text of the story can be augmented with pictures representing various words or ideas. The Mayer-Johnson Picture Exchange symbols are typically good choices for this use.
- **Social Stories on tape** – A story can be recorded on audio tape with a tone or verbal cue for the child to turn the page.
- **Video** – A film can be made of the student and peers acting out applicable scenes from the story eventually fading the video for the written text.
- **Story boxes** – The child and an adult can act out scenes from the stories with small figures, rooms made of shoeboxes, etc. This can add interest and increase understanding of the concepts.

Other variations of stories may include checklist stories, curriculum stories, generic stories, goal stories, judgment stories, stories addressing aggression, stories addressing fears, stories addressing obsessions and compulsions, question and answer stories, media stories, group stories, and comic strip conversations.

Implementation, Monitoring and Fading out

Prior to the implementation of a story, it should be shared with as many people who are involved in the child's program as possible. This will allow cooperation and support to be gathered while also checking for over-looked information or key points. Before the introduction of the story to the child, those who may be involved in the situation and people in the student's life should be presented with a copy of the story. It can also be helpful to actually have the child present the story to other students, staff or family members.

A consistent schedule for reviewing each story should be maintained. At first this is typically once a day, usually right before the targeted situation (e.g. right before the bell dismissing the class to recess, if the story is about the need to take turns on the monkey bars). For some kids it may be helpful to read the story early in the day and then simply review the highlights prior to the activity.

The effectiveness of the story should be monitored consistently. If after a week or two of working with a story and there is little noticeable change, the story should be reworked. The motivation behind the behavior may need to be re-evaluated. As the child becomes more and more successful with the situations presented in a story, that story can begin to be faded out or changed to meet the new needs of the child. The number of review sessions can be lessened from once a day, to every other day, to once a week, to twice a month, and so on until they are no longer needed or the directive sentences in the story can be reduced or eliminated. As the story is mastered, it should be kept visible in the child's environment for review. Because the stories are personalized, they can often be favorites, and the child might want to look through them on his own, even when not working on them specifically.

What a Social Story is NOT...

A social story is not a behavior program or a rote compliance program.

Summary

"A social story describes a social skill or situation in terms of relevant cues and information and common response. The goal of each social story is to describe what occurs, over directing the behavior or responses of the student. Understanding the goal, and translating social information into tangible, concrete and easily understood text and illustrations is critical to writing four different basic types of sentences which occur in a specified proportion. In addition, guidelines based on the learning characteristics of students with A.S.D. (Autism Spectrum Disorder) and the specific interests and abilities of an individual student are also essential to every social story. Social story titles are developed with careful consideration of the goal. This helps to focus the efforts of the author and results in a social story that covers a reasonable amount of information. Sometimes, a series of related social stories might be needed to cover a single, general topic." Gray, Carol 1999 *From both sides now: teaching social understanding with social stories and comic strip conversations*.

For more information or examples of social stories, parents may wish to consult the book, **Social Stories**, by Carol Gray or visit her website at www.thegraycenter.org. You may also contact Jocelyn Taylor at the Utah State Office of Education by emailing her at: jocelyn.taylor@schools.utah.gov.

HIGH FUNCTIONING KIDS WITH AUTISM: HOW TO WORK WITH THE SCHOOL WHEN YOUR CHILD DOESN'T QUALIFY FOR SPECIAL EDUCATION

By Holly J. Mahoney, Esq., Parent

As an attorney, I have worked for 15 years in Education Law. I believed I understood my clients well, and was empathetic to their child's needs, and their perspective. Then, two years ago my oldest son was diagnosed with Asperger Syndrome at the age of 8. My perspective changed drastically, and my empathy for my clients deepened, because frankly everything is different when it is your child you're trying to help. The purpose of this article is to share my experience in working with my son's school following his diagnosis, and to provide some strategies parents of children with high functioning autism, PDD, or Asperger syndrome can use when seeking services at their child's school.

In preface, my son has always excelled academically, but has struggled somewhat in school with controlling his emotions, and he seemed immature compared to his classmates when it came to social skills. He had been relatively successful in school, and did not have significant behavioral issues. However, following his diagnosis, and after researching the effects of Aspergers, it was not clear to me how or if his autism affected his ability to understand everything he was reading. I knew he could recite a story or book that he had read back sequentially, but it did not seem like he understood what the point of the story or book was. Given this, I requested that he be tested, and that they determine what if any difficulties he had in this area. In addition, I worked with the principal, and school psychologist to determine the appropriate class for his fourth grade year, and some strategies the teacher could use to help him to develop coping skills and continue to develop socially. My experience in working with my son's school was very effective in meeting his needs, and helping him to have a positive and successful school experience.

"My experience in working with my son's school was very effective in meeting his needs, and helping him to have a positive and successful school experience."

In order to help my child I used four primary strategies which were effective in getting my son's needs met at school, and helping him to have a successful and positive experience. First, I gathered as much information as I could about my child's disability, and what things had been, or might be effective in helping him develop socially, emotionally and academically. Second, I requested a comprehensive evaluation to help the school and I understand what my son's specific needs were. Third, I developed, and continue to maintain an open and cooperative relationship with the school personnel, including my son's teacher, the principal, school psychologist, and speech and language specialist. Finally, as a cooperative team, we developed a plan regarding how my son's specific needs would be met. I believe that these strategies can be used by all parents of children with disabilities. But, in discussing each of these strategies I will be discussing how these strategies are particularly useful for parents whose children do not qualify for special education services.

“As the expert, it is important that you educate the school about your child, perhaps educate them regarding the strategies which may be effective for your child.”

The first step is to gather as much information as you can regarding your child’s needs, and what types of things have worked in the past or at home, or what things might work to meet his/her needs at school. Every child with autism is different. Their needs are different, and what is effective with one child is not necessarily effective for all children. As a parent you are the expert when it comes to your child. You understand best how your child’s autism affects him/her, and what kinds of strategies work and what kinds of strategies don’t work. In addition, if you have done some research, you may be aware of strategies which the school may not be aware of which may be effective with your child. As the expert, it is important that you educate the school about your child, and perhaps educate them regarding the strategies which may be effective for your child. Sometimes school personnel are limited in their knowledge of autism, or the strategies which have been developed which have been effective in helping children similar to your child succeed in school. The ultimate goal in working with the school is to help your child be successful and have a positive school experience. Thus, as you discuss the information you have with school personnel, it is important to provide it in a spirit of cooperation and teamwork.

Although you have a significant amount of information to provide regarding your child, it is still important to have a comprehensive evaluation performed for your child. This second step will give you and the school the best picture of his or her needs. In addition, it will determine if your child is eligible for special education services. Sometimes it may be difficult to identify or clearly understand how your child’s autism affects him/her. Traditional academic testing may not identify your child’s areas of need. With my son, he tested very well on all the academic tests. However, he still struggled with more abstract language comprehension. He is a very literal thinker, and has difficulty identifying the main idea or point of a story. Therefore, I had to request additional testing which would be more effective in identifying these deficits. You as a parent must make sure that if you don’t feel that the tests that are done are sufficient to identify all of your child’s needs that you ask for additional testing. In some cases, the school speech and language specialist may understand the types of testing which would be most effective in identifying your child’s language and processing issues. However, you may also have to describe what your primary concerns are, and perhaps provide the name of the types of evaluations you would like to have done. These may also include sensory integration evaluations performed by a qualified occupational therapist. This is important even if your child does not qualify for special education services.

This was the case with my son. I did not believe he would be eligible for special education, however, the testing performed by the school was very valuable in help both me and the school understand exactly what my son’s needs were academically, and allowed us to discuss what strategies could be used to best help him in the classroom. As with the first step, it is always

important that your communication with the school be done in a spirit of teamwork and cooperation, with the ultimate goal being helping your child succeed in school.

That brings us to step three, which is probably the most important step in working with your child's school. You must develop and consistently maintain an open and cooperative relationship with your child's school. This includes most importantly your child's teacher, but also includes the principal, school psychologist, speech and language specialist, and any other person who may work with your child, or have information to help in developing a plan to address your child's needs.

Having a great relationship with your child's teacher is critical as your child's needs will probably be very fluid. As his/her needs change your strategies in how to help him/her may change. Also, there may be external stressors outside of school which may need to be addressed at the time. Your job as the parent will be to help your child's teacher understand what is happening with your child which might effect school performance, and discuss with the teacher how best to deal with each situation. I have been very fortunate with my son's teachers. They have been very cooperative and we have worked together to help my son have a positive and successful school experience. I respect their efforts, and their expertise as educators, and they respect my understanding of my son's specific needs.

In addition to the teacher, other school personnel bring much to the table in helping your child succeed in school. The principal is an important member of the team. He/she as head of the school can keep things on track, and make sure all the needed players are involved in the process of helping your child. In addition, the principal is important in helping to insure that your child is placed with the teacher that will best meet his/her needs. The psychologist, speech pathologist, and/or occupational therapist also are a great resource for you as a parent. They each have valuable information and insight into strategies which could make your child's school experience a positive one. It has been my personal experience as both a parent and an attorney working with parents to get services for their child, that the school personnel care about your child, and want them to succeed in school. Keeping this in mind, open cooperative communication between you and your school will create the best environment for your child, thus allowing your child to succeed academically, socially and emotionally.

Finally, whether formal or informal, it is important to develop a plan for meeting your child's needs. This should include what the school will do to meet your child's specific needs. How they will implement the strategies developed to meet these needs. And, what role you will have in this process. In my son's case, his needs were very simple and could be met through an informal arrangement with his teacher. We review my son's progress frequently, and have made adjustments as needed. The result has been very positive. My son's organizational skills have improved significantly, his frustration level has decreased, and he is doing fairly well socially in his class.

If your child's needs are more involved this type of arrangement might not work for you. In that case, I would suggest a much more formal plan. As a child with autism, your child qualifies for services under Section 504 of the Rehabilitation Act. As part of this, the school can and should develop what is called a 504 Accommodation Plan. This is similar to an IEP (Individualized Education Plan) under special education. However, it does not include all of the procedural safeguards as the IDEIA (Individuals with Disabilities Education Improvement Act), and it does not allow for modifications to the curriculum. Section 504 does include classroom accommodations such as seating in a specific location, or perhaps the availability of a safe place for your child to go if he/she becomes overwhelmed with a situation. It can also include more time for tests, having tests or other information read to your child, or other things that would assist your child in the classroom or other areas of school. This is something that you can request. Your principal should understand the process for developing this plan. If not, you should contact your district administrator and ask to speak with the person responsible for 504 plans and compliance with this law.

"Remember that you are your child's best and most important advocate!"

My experience with working through these steps with my son has been very positive and successful. This may or may not be typical. I believe that it is. I have seen that the better a parent's relationship with the school is, the more effective they are at insuring that their child's needs are met. When your child has what he/she needs, they will be more successful both academically and socially. Remember that you are your child's best and most important advocate. You know his/her needs better than anyone and are critical to insuring that he/she succeeds in school. It is important for you to be assertive when necessary in order for your child to have a positive school experience. The key to this is an open and cooperative relationship with your child's school. You are all on the same team and together you can help your child achieve the most out of their school experience.

Contact the Utah Parent Center for more information on the IEP Process, Section 504 Plans, and suggestions for accommodations that can be considered by your child's school.

HOMWORK: MAKING IT WORK FOR YOUR CHILD

By Susan Blackham; Autism Specialist, Davis School District

Homework! Yuck! Few students enjoy it. Most teachers give it. For most, homework is just not fun. For other students, homework means the delay of after-school activities, sports, computer games, talking on the telephone, a favorite hobby or interest. For some, homework is confusing and frustrating. For our students on the Autism Spectrum homework can be many things including “why are we doing it” and “how are we to do it”.

For some of our students on the spectrum, doing homework is an extension of an already stressful day at school. Home is where they want to stim, relax or tend to their special interests. Some students wonder why they are expected to do school work at home. School should be for learning and home should be for fun or relaxation

There are actually three components in the homework cycle. One is getting the homework assignments home, another is getting the homework completed and the third is turning it in at school on time.

I. Getting the assignment home

Decide whether to provide time at school to complete the work or assign the task as homework. If the assignment is to be completed at home, you might consider the following:

- Create a “Homework Checklist” with all the necessary steps outlined for your student to refer to and check off before heading home.
- Provide a planner that has adequate space for the student to write all necessary information. The planner should have adequate cues to prompt your student to include all required information e.g. book necessary for completion, page number, due date.
- Decide if your student will write the assignment in the planner independently or will the teacher write or prompt the student to write. Having a check-in/check-out system with a teacher at school and the parent at home can ensure that all details are completed.
- Provide your student with a small tape recorder for the teacher to dictate directions. The student can add his own personal memo as a reminder of key information.
- Is there a “homework hot-line” when assignments need clarification? Parents and teachers may want to establish a communication system for parents to use when assignments need clarification.

II. The assignment is home...now what?

1. Provide a supportive learning environment.

- Establish a dedicated workspace for homework.
- Reduce the sensory problems that your student may have by considering appropriate seating, lighting and removal of distractions.
- Provide support for organizational skills by having a ready supply of pens, pencils, markers or your student’s favorite writing tool.

2. Chunk and time the work sessions.

- Prepare or help your student prepare a written schedule of assignments. This visual support will help your student predict what needs to be done and the order to complete each task.
- Your student may have difficulty allotting time to each homework component. Define the expected duration of each homework activity or assignment. Students are more willing to stick with homework when they can predict how long they will have to work on each assignment.
- A timer may help the student to visually understand how much time is remaining for each assignment.
- A task assigned in February may not be due until late March. For assignments that will require work over time such as term papers or country reports, “chunk” the larger assignment by breaking it into smaller segments. Create a timeline or calendar to “map” smaller segments of the report outlining when each segment needs to be completed. A visual timeline will help your student understand when to complete each smaller segment.

3. Establish a routine.

- Allow your student time to unwind and relax when he comes home. Set a specific time for him to begin his homework.
- Establish a daily homework routine. This might include his favorite snack when he arrives home, 15 minutes to enjoy his favorite pastime and/or 10 minutes to do a chore before he starts his homework. Write out the schedule and use a timer to provide a visual support for each activity.
- Define finish. Be sure that your student knows when homework is done at home and at school. Help your student understand that homework is not finished until it is returned, complete, to the teacher. A timeline will help your student to know how long a homework session will last at home.

4. Motivate

- Some students may benefit from a reward system. Establish the rules for work completion. Time might be added for your student to enjoy his favorite activity for each completed assignment. Sticker charts might be used to keep track of each completed assignment and tallied at the end of the week for a predetermined reward.
- If your student cannot easily work for an hour, allow for breaks after short periods of on-task behavior. Use a timer to help student visually see how long he needs to work as well as how long his break will last. Breaks should not include activities that can become distracting or absorbing so that your student will have difficulty stopping and returning to homework. Breaks might include a small snack, pencil sharpening or a quick trip to the bathroom.

III. Getting the homework assignment back to school

After the homework is completed, it needs to be organized to return to school.

- Place the completed work immediately into the appropriate folder in the student's backpack.
- Help your student to understand that homework is not finished until it is turned into the teacher.
- Provide a visual support as a reminder for your student to turn in his homework. Help establish a routine for turning in homework. Perhaps a business size card with a "Homework Check-in" list might be all the student needs to remember the steps of turning in homework.
- Make sure your student knows where to turn the homework in at school. Have the teacher provide a consistent box or location where the homework is always placed.

Know your student. Remember not all strategies work for all students and not all strategies are needed for all students. It is, however, important for parents and teachers to work together, starting in elementary school, to help students plan, organize and prepare to complete homework assignments.

LOOKING BEYOND BEHAVIOR SCHOOLWIDE DISCIPLINE AND INDIVIDUAL SUPPORTS FOR STUDENTS WITH ASD

By Kathy Gould and Cathy Pratt, Ph.D.

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Consider the following scenarios:

1 *A student with an Autism Spectrum Disorder (ASD) has a behavior meltdown, in the school hallway. He begins to scream and hit other students. An adult is able to redirect the student and thus eliminate the behavior. Afterward, the team meets to discuss behavioral approaches for the future and to try to find out what led to this behavioral incident. As the team discusses potential reasons for the behavior, they discover that the student has been the victim of intense bullying and teasing. In response, the team questions what they can do in the future to eliminate behavioral difficulties. The issue of dealing with the bullies is never discussed.*

2 *Another student has a history of behavioral challenges that were minimal during elementary school, but have intensified in middle school. The team realizes that middle school presents special challenges because of changing classes and working with multiple staff. Accommodations are discussed that may assist the student in making numerous transitions throughout the school day. Despite these efforts, behavior incidents continue to occur. The behaviors are most likely to*

occur in the cafeteria or hallways, which are incredibly noisy. It is suggested that in the future, in-school suspension be considered when there is a behavioral challenge. This is the approach used with other students, and the school has a strong zero-tolerance policy. The student is warned repeatedly. Despite these warnings, behaviors continue and actually escalate, resulting in removal from the educational setting.

Responding to Problematic Behavior

When a child with ASD engages in problematic behavior, a typical response includes trying to identify what is going on within the child that leads to this behavior crisis. Questions are asked, such as, "Why is he exhibiting this behavior?," "Why is she hitting others?," or "What will stop this behavior?" All too often, this last question keeps us focused on consequence procedures that are student specific. However, simply focusing on the student as the sole source of the behavior provides limited insight into potential solutions and problems. In these situations, there are multiple issues to consider.

First, the federal law guiding special education services, the 2004 Individuals with Disabilities Education Improvement Act (IDEIA), requires special procedures and safeguards to be used when considering discipline for students with disabilities. These IDEIA provisions regarding discipline were designed to ensure that children with disabilities maintain their ability to receive an appropriate education, even though the symptoms of their disability may include behaviors that require interventions. These provisions consider the amount of time a student may be removed from class or school due to behavior, and require the school team to analyze whether the behavior is related to the student's disability. This process is called manifestation determination. If the behavior is determined to be due to the disability, the law requires that a functional behavior assessment be conducted that results in an individually designed behavior support plan. This plan should use positive behavioral interventions, strategies, and supports to address the behavior and teach alternative ways of responding.

Utah's Behavior Initiatives (UBI) Behavioral Strategies for Educators & Parents

Utah's Behavioral Initiative is a set of personnel development activities sponsored by the Utah State Office of Education, the Utah Personnel Development Center and the Utah State Personnel Development Improvement Grant. The UBI promotes the implementation of effective behavioral support systems in Utah Schools. Adhering to behavioral research, UBI follows a school-wide model of prevention of problem behaviors and support of positive behaviors. Selected school districts in Utah are working with the UBI project to train and support staff. Implementing the model on a school-wide basis means that everyone in the school is trained and that everyone works together to provide consistent support to students.

To learn more about the UBI project and find links to other resources please visit www.updc.org/ubi/.

When conducting a functional behavior assessment, professionals and family members examine setting events or triggers that may increase the probability of these behaviors. These setting events may not be readily apparent. For example, a student with ASD is ill, has had a difficult morning ride on the bus or has not slept. These conditions will increase the likelihood that a behavior incident will occur. For most of us, stresses in life, changes in morning routines or skipping our morning coffee may set us up to be moody and agitated. These are setting events. Setting events that we often do not consider are related to the culture of the school. Schools that struggle with bullying, high rates of suspension or expulsion, or even high staff turnover may be settings that promote problematic behaviors. If this is the case, then schools should take a systematic approach in creating school culture that is responsive to students and staff.

Using Positive Behavior Supports

Through the work of positive behavior interventions and supports (PBIS), we have learned what schools that fully implement schoolwide positive behavior supports (SWPBS) have fewer discipline problems (e.g., office discipline referral and suspensions and expulsions) than those who do not (Horner et al., 2005). There is early research that indicates students with significant needs, including students with ASD, benefit from participating in SWPBS (e.g., Freeman et al., 2006; Turnbull et al., 2002).

Positive behavior supports at the schoolwide level involve three levels of support: universal (schoolwide), secondary (group) and tertiary (individual).

Universal Support

Universal supports include proactive skills taught to all students in the school that act to reduce or eliminate many of the problem behaviors from occurring for most students. Appropriate behavior is specifically taught to all students, staff is actively involved in regularly “catching” students performing appropriate behavior and reinforcements are provided. An example of a universal support is (1) posting three to five school rules that are operationally defined; (2) holding assemblies and providing class instruction about expected behavior based on these rules; and (3) having staff give tickets to students who are observed demonstrating one of the expected behaviors. These tickets are then entered into a daily drawing for a special acknowledgement or reward. Most students respond to this level of positive intervention and do not engage in problem behaviors.

Schools that take a school-wide discipline approach often use data to identify those times of the day, months, areas of the schools, teachers and activities in which problematic behavior is more likely to occur. For example, if it is found that bullying is more likely to occur in the lunch room, then more staff would be placed in the cafeteria to monitor the situation. Likewise, overall programming to minimize bullying would be used in these schools. Instead of focusing on “fixing” the student who is being bullied, the focus would be on trying to ameliorate the underlying problem.

Secondary (Group) Support

Secondary or group support is provided to a smaller number of students who, despite universal supports, continue to exhibit problem behaviors. Typically, these supports increase the intensity of teaching rules, and may provide smaller group instruction, more examples, and continual checking by staff, group or peers to ensure understanding.

Students with ASD can benefit from participation in these two less-intensive levels of support and, as a result, become part of the overall school community and culture. Some modification and tailoring of the presentation of the school rules may be needed to address the unique community and learning styles of the student with ASD while ensuring understanding of expectations and incentives. Using the PBIS framework, we can address many behavior concerns of students with ASD and, through universal and secondary levels of support, reduce or eliminate some of the problem behaviors as well as the amount of more intensive, individualized, tertiary support needs. This also results in an increased availability of staff and resources to address the more intense behaviors.

Tertiary (Individual) Support

Even as the student with ASD is involved in schoolwide and group support, there may be the continued need for additional and individualized support to address a smaller number of behaviors or a specific behavior across settings. In these cases, a functional behavior assessment is conducted, beginning with defining the behavior of concern, identifying its function, teaching alternative behaviors and skills, and developing a plan to support the new behaviors. All too often these behavior plans focus on punitive consequences. Students on the spectrum who are threatened with expulsion and suspension may become anxious anticipating these consequences. This heightened anxiety may actually result in increased behavioral incidents.

“Individualized supports needed for students with ASD to learn and integrate newly learned behaviors should include strategies in environmental organization, visual support, sensory support, communication/social support and curricular support.”

Individualized supports needed for students with ASD to learn and integrate newly learned behaviors should include strategies in environmental organization, visual support, sensory support, communication/social support and curricular support. It is critical that the needs of each student be individually assessed to determine how to address that person’s unique understanding and communication. Individual supports may include, but are not limited to:

1. individually designed classroom and workspace according to the student’s needs;
2. an accessible, individual daily schedule understood by the student;
3. changes in the student’s schedule that are planned for ahead of time;
4. activity schedules or task organizers used throughout the day to assist in understanding;
5. individually designed instruction modifications and supports;
6. sensory programming and individually designed breaks, as needed;
7. a positive and direct reinforcement system understood and used by the student, peers and staff;
8. a communication system that is readily available, understood and used by peers and staff at all times;
9. social coaching and skill building embedded throughout the day;

10. strategies to assist with transitions and movement throughout the day; and
11. family members who are involved in planning, evaluation, and support.

Benefits of Positive Behavior Supports

The use of a three-tiered PBS approach that includes students with ASD has multiple potential benefits. Including students with ASD at the universal (schoolwide) and secondary (group) levels of support may decrease many problem behaviors. Fewer students and problems would then need to be addressed at a higher and more intensive level of support. While the IDEIA offers additional requirements for the discipline of children with disabilities, research indicates that if teachers and other school personnel have the knowledge and expertise to provide appropriate positive behavioral supports and interventions at all levels in the school, behavior problems can be greatly diminished for all students, including those with ASD.

In Illinois, we are learning through the State Accountability for All Students (SAAS) data that students who are provided more individual accommodations spend a greater amount of their day in general education classes and have fewer behavior problems. Students who are in the classroom more and who have lower office discipline referral and suspension/expulsion rates will make greater academic progress (*SAAS Issue Brief: Discipline and Students with Disabilities*, May 2004). Additional benefits include more involvement in overall school activity, an increased number of staff and peers who understand the social and communication styles of the student with ASD, and increased positive interactions between students with ASD and others in their school community.

Schools that are more effective in teaching positive behaviors and addressing behavioral issues, such as bullying, in a more systematic manner are going to be more supportive settings for students on the spectrum. When a student on the spectrum acts out, we must look beyond the student and examine what is happening overall in the school. Schools that are more effective for all students are going to be more successful for students with ASD.

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References

- Freeman, R., Eber, L., Anderson, C., Irvin, L., Horner, R., Bounds, M., & Dunlap, G. (2006). Building inclusive school culture using school-wide positive behavior support: Designing effective individual support systems for students with significant disabilities. *Research and Practices for Persons with Severe Disabilities*, 31 (1), 4-17.

- Horner, R.H., Sugai, G., Todd, A.W., & Lewis-Palmer, T. (2005). Schoolwide positive behavior support. In L.M. Bambrara & I. Kern (Eds.), *Individualized supports for students with problem behaviors* (pp. 359-390). New York: Guilford Press.
- Turnbull, A., Edmundson, H., Griggs, P., Wickman, D., Sailor, W., Freeman, R., Guess, D., Lassen, S., McCart, A., Park, J., Riffel, L., Turnbull, R., & Warren, J. (2002). A blueprint for schoolwide positive behavior support: Implementation of three components. *Exceptional Children, 68, 377-402.*

AUTISM INTERVENTIONS

By Jocelyn Taylor, Specialist, Utah State Office of Education
(Adapted from Connecticut State Department of Education)

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In a review of 10 representative model programs, the National Research Council found that each program derived from either a behavioral or a developmental approach. While conceptual differences are real, the differences in practice appear to be narrowing. The developmental/relationship model is increasingly paying attention to environmental variables, including the provision of consistent structure, adult attention, and the use of reinforcement. Behavioral approaches look at antecedents, teaching in the natural environment, and direct instruction of social behaviors. These types of changes incorporate positive practices from each framework.

No single method guarantees success in the education of children with autism. The diverse needs of this population often dictate a more blended approach. "Blended" is not meant to sanction haphazard, watered-down methodology. Instead, it is intended to underscore the need to tailor programming to the individual needs of the child by selecting techniques from different approaches that have known effectiveness for children with autism.

Direct medical interventions are not the responsibility of the public schools, but need to be considered by families. However, some medically related issues may need to be brought to the attention of school staff if they affect educational programming.

Interventions have been classified and organized in alphabetical order as either an approach or a strategy. When considering a treatment, it is important to keep in mind that there are no quick fixes and that it is critical to investigate an approach before implementing with an individual child. This listing of interventions is neither exhaustive nor an endorsement. The descriptions are intended to provide teams with a starting point and direction to further explore resources if an intervention is being considered.

APPROACHES

In this context an approach is defined as a set of organizing principles underlying the rules and procedures used; it describes how the child's learning is approached.

Applied Behavior Analysis

Applied behavior analysis, ABA, is the science of applying principles of behavior to shape and change behavior in measurable ways. "Applied Behavior Analysis is the science in which procedures derived from the principles of behavior are systematically applied to improve socially significant behavior to a meaningful degree and to demonstrate experimentally that the procedures employed were responsible for the improvement in behavior" (Cooper, Heron, & Howard, 1989, p.15).

Functional behavioral assessment is a process for gathering information that can be used to build effective plans to reduce challenging behaviors. The outcome of a functional behavioral assessment helps predict behaviors and the function that maintains them. The analysis helps educators to plan effective interventions.

The principles of behavior are used as strategies to teach skills in a specialized sequence to increase socialization, communication, and adaptive functioning skills. The focus is often on training of small, discrete skills through multiple training and practice of trials referred to as discrete trial instruction (DTI). A skills series is taught using reinforcement until the student has mastered all the appropriate skills and can link them together and use them in the generalized natural environment. An important component of ABA is reinforcement procedures.

Developmental Intervention Model (Floor Time)

The Developmental Intervention Model (DIM) is an intervention model commonly referred to as Floor Time developed by Stanly Greenspan. The model is based upon the assumption that a child's symptoms reflect unique biologically based processing difficulties that may involve affect, sensory modulation and processing, motor planning, and symbol formation. Relationships and affective interactions may go awry secondarily, so intervention is aimed at helping a child to work around the processing difficulties to reestablish affective contact. Floor Time is an important component of DIM, whereby the caregivers (parents, teachers etc.) enter the child's activities and follow the child's lead. Through mutual, shared engagement, the caregiver uses techniques known as opening and closing circles of communication, to engage the child into more complex interactions. This developmental model seeks to address the deficit area of social communicative relationships found in children with autism.

LEAP (Learning Experiences Alternative Program)

LEAP was one of the first programs designed to educate children with autism with typical peers based on the premise that social isolation is the single most powerful predictor of adjustment problems. The curriculum uses peer-mediated social skill intervention taught in an integrated preschool environment. The LEAP curriculum targets goals in social, emotional, language, adaptive behavior, as well as cognitive and physical development. The overall goal of the program is to assist children to reach their optimum level of development and assist families in being effective as their children are integrated fully into their respective communities.

SCERTS™ (Social Communication, Emotional Regulation, Transactional Support)

This model is intended to provide a flexible, yet comprehensive framework for designing a multidisciplinary plan for children with ASD. The SCERTS™ model contains a core set of stated values and beliefs that become a filter for prioritizing educational decisions. Goals, specific objectives, progress ratings and evaluation procedures are recommended with an emphasis on developing goals that address the core deficit areas of children with ASD. **S**ocial **C**ommunication goals address the two major areas that present challenges to children with ASD, the capacity for joint attention and the capacity for symbol use (Prizant et al., 2003). Further, **E**motional **R**egulation is addressed as an essential component necessary for developing modifications and sensory techniques, building adaptive and coping strategies, making the child more available for learning the positive social exchange. Finally, natural settings with flexible grouping is desired, with individualized planning for the necessary supports and modifications. These **T**ransactional **S**upports include the visual and supports necessary to facilitate social interactions with partners.

TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children)

Treatment and **E**ducation of **A**utistic and related **C**ommunication **H**andicapped **C**hildren uses structured teaching as the principle of modifying the environment to accommodate the needs of individuals with ASD. Structured teaching involves organizing the environment through the use of clear visual information and programming that is geared towards the student's strengths, learning style, and interest. The four main components integrated of the approach are the physical organization of the environment, visual schedules, work systems, and organization of the tasks. Finally, structured teaching uses individualized assessments, establishment of proactive and adaptive routines and systematic use of visual supports. This increases the learning of new skills, independence and reduces behaviors that stem from confusion, anxiety and over stimulation.

Verbal Behavior

Verbal Behavior is an intervention that is focused on language as a skill that can be analyzed and targeted according to behavioral principles. The intervention is behaviorally based. It promotes language skills through intensive teaching and naturalistic environment training. It is anticipated that by teaching the missing skills identified by the language assessment the child will develop more appropriate functional language skills. The emphasis is on teaching the function of language through teaching procedures that focus on transferring the child's ability to respond across all environments.

STRATEGIES

In this context a strategy is defined as a careful plan or method; a tool that can be used to support the child's learning.

Assistive Technology (AT)

The federal definition of AT includes both assistive technology devices and assistive technology services. An assistive technology device is any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain, or improve the functional capabilities of children with disabilities. AT is not an end in itself. It is intended to support the child in achieving his or her goals. Therefore, it is critical to determine what the team wants the child to do before considering how and what AT can help facilitate the achievement of the outcomes.

Augmentative Alternative Communication (AAC)

Some children with ASD have difficulty making their needs known verbally. Augmentative alternative communication devices such as communication boards, vocal output communication systems, and assistive listening devices, including FM systems, may also be considered for a child. The Picture Exchange Communication System is one application of AAC. Research examining the impact of AAC on speech has found that the former does not impede the latter. To the contrary, AAC has been shown to facilitate speech in many cases.

Person-Centered Planning

Person-centered planning can be used to create a rich and meaningful life for an individual with ASD. The focus is on integrating the student's capacities, abilities, and interests through meaningful activities in the places where he or she spends time (e.g., school, home, neighborhood).

Picture Exchange Communication System (PECS)

PECS, originally developed for preschoolers with autism is a behaviorally based augmentative/alternative communication approach that uses pictures, photography, or other visual symbols. Requesting is taught as the first skill without requiring the student to demonstrate prerequisite skills such as eye contact, imitation, facial orientation, match to sample, or labeling. Thus, children do not need to

be able to know or understand a picture prior to learning to use it to request desired items or events. Instruction in PECS begins after potential reinforcers for the individual have been determined.

Pivotal Response Training (PRT)

Although the model is based on ABA, it supports a more naturalistic approach to behavior that (a) excludes negative interactions (b) incorporates the use of natural prompts in inclusive environments, and (c) is family-centered. Targeted at language skills, play skills, and social behaviors in children, pivotal behaviors within PRT include responding to multiple cues or stimuli, motivation, self-management, and self-initiation.

Positive Behavioral Intervention and Support

Positive behavioral intervention and support is an ongoing proactive, problem-solving approach that looks at the child's behavior in relationship to the context of his/her life. Based on an underlying belief that individuals are doing something for a reason, referred to as communicative intent (Dunlap & Fox, 1999) positive behavioral support changes the focus from trying to manage or eliminate negative behaviors to looking at how to proactively support the child so the negative behaviors are no longer necessary.

Relationship Development Intervention (RDI)

RDI is based on research that identified the inability to share experiences as the primary factor in limiting individuals with ASD in developing meaningful social relationships. RDI focuses on remediating relationship abilities rather than on teaching specific social skills. The intervention is based on the premise that the core deficits of ASD, rigid thinking, aversion to change, inability to understand other's perspective, failure to empathize, and absolute, "black-and-white" thinking, must be addressed (Gutstein & Sheely, 2004) to improve the quality of the individual's life.

Sensory Integration (SI)

Many individuals with ASD have difficulty processing sensory information. Sensory integration is based on the premise that addressing these difficulties through therapeutic intervention can lessen symptoms and increase adaptive behaviors so the child is able to be more comfortable and will function more effectively. Sensory integration therapy provides children with activities that challenge and support children's ability to process sensory input in a way that allows and develops organized and successful adaptive responses to sensory stimuli.

Social Strategies

Research and clinical and educational practice over the past 40 years has focused on the difficulties that children with ASD have with social relationships and human interactions in order to design effective treatment method for this deficit. Social skills are taught in a variety of ways using many modes of instruction. It is important that these skills not

only be taught through direct instruction but also in their natural environments to support generalization of the learned skills. Further, social skills training should focus on both initiation and reaction in social situations. The following list, although by no means exhaustive, includes several ways in which social skill training is currently being presented.

- **Comic Strip Conversations** are a conversation between two or more people using simple drawings. These drawings serve to illustrate the ongoing communication providing additional support to the individual who struggles to comprehend the quick exchange of information that typically occurs in conversations.
- **Social Stories™** consist of short stories that describe a situation in terms of relevant social cues and common responses, thereby providing a student with accurate and specific information regarding what occurs in a situation and why.
- **The Situation, Options, Consequences, Choices, Strategies, Simulation (SOCCSS)** strategy was developed to help student with social interaction problem put social and behavioral issues into sequential form. This strategy helps students understand problem situations and lets them see that they have to make choices about a given situation and that each choice has a consequence.
- **Home base** is way to help students with ASD cope with social situations by arranging for a place where they can go when they become overwhelmed and feel a need to regain control. When students feel the need to leave the classroom, they may take their assignment to "home base," a less stressful environment in order to maintain control and avoid a meltdown.
- **The Circle of Friends** is a method of developing friendships between people with and without disabilities. Circle of Friends provides a venue for students to practice social skills that they may have learned from adults in direct instruction situations.
- **Power Cards** are visual aids that assist children with ASD in understanding social situations, such as routines, the meaning of language, or what is referred to as the "hidden curriculum." "A brief scenario is used to explain how the hero or special interest has encountered and solved the problem. Then a Power Card (typically the size of a business card) is created that summarizes the strategy and contains a picture of the special interest." The student then uses the card as a reference or reminder about how to understand and work through difficult situations as they arise.
- **Peer tutoring** involves socially competent peers learning how to use effective teaching techniques and positive reinforcement to teach academic subjects to classmates with autism. In peer tutoring students with autism work in structured pairs or groups with trained tutors who are aware of the characteristics of autism.

THE UTAH SPECIAL EDUCATOR PUBLISHES SPECIAL ISSUE ON AUTISM

The Utah Special Educator serves as a medium for the dissemination of information related to promising practices and other dimensions in the provision of a Comprehensive System of Personnel Development. The *Utah Special Educator* is available in journal format (online subscription). All views and opinions expressed represent the authors' and do not necessarily reflect the views and opinions of the Utah Personnel Development Center, the Utah Special Education Consortium, or the Utah State Office of Education.

Parents will find much that is of interest in the just published Special Monograph Issue of the *Utah Special Educator* – the February 2008 issue. The issue is available on the website of the Utah Personnel Development Center (UPDC) at www.updc.org. Past issues of the Utah Special Educator Journal are archived on the website and may be downloaded by anyone.

A partial list of the more than 30 topics addressed in this special issue includes:

- Autism: An Urgent Public Health and Education Concern (Information on the latest research on prevalence)
- Are there Superior Interventions for Children with Autism?
- Autism and Applied Behavior Analysis (ABA): It's More Than You Think!
- Autism and Assistive Technology
- Handwriting is More Than a Paper and Pencil Process
- Early Diagnosis and Treatment of Infants and Toddlers with Autism Spectrum Disorders
- Autism and Social Communication
- Enhancing Literacy Instruction for Students with Autism
- Tips for Teaching High-Functioning People with Autism
- B is for Bullied
- Transition: Back to the Neighborhood School
- A Dual Diagnosis Perspective: An Approach to Treating Disruptive Behavior Associated with Autism
- Challenging Behavior on the Bus
- A List of Selected Autism Websites
- A Resource List (Books and Videos)

This special issue is sure to endure as a valuable reference in the months and even years to come. Kudos to the UPDC staff and all the contributors!

Download your copy today!

The UPDC conducts many different activities to provide training and information to special education professionals in Utah and are noted for their Mentor Teacher Academy and the conferences and trainings that they provide, often in collaboration with the Utah State Office of Education, the Utah Parent Center, and other organizations. Parents are encouraged to check the calendar on the website for information on upcoming events. Parents are welcome to register for many of the conferences and events.

GIFTEDNESS AND ASPERGER'S SYNDROME: A NEW AGENDA FOR EDUCATION

By Shelagh A. Gallagher and James J. Gallagher

From: *Understanding Our Gifted*, 14(2), Winter 2002. Open Space Communications

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"The principal looked around the table in bewilderment, the file of 9-year-old Jason open in front of her. The math teacher has proclaimed this child a genius: he understands ideas that others won't get for years. No wonder he has trouble talking to the other kids...he's just way beyond them. The English teacher thinks it's something different – Jason seems bright in math, but in English he's nowhere. She's not always really sure he knows the meaning of all those words he uses – she's not sure he should have been grade skipped. You know if you went in the hall and asked Jason's classmates, they'd have a diagnosis: geek, dweeb. Jason's parents simply look confused. They've come here for help, but it seems like a futile effort. Now the special education teacher pipes up: Jason isn't gifted, he's got Asperger's Syndrome. What's the problem with this scenario? The gifted education teacher wasn't invited to the meeting..."

Across the country, around the world, this scene is repeated. A relatively new category in the continuum of behavior disorders, Asperger's Syndrome (AS) is both compelling and alarming to educators in gifted education. What does it mean to be gifted with Asperger's? It's a question that gifted educators must learn to answer, to ensure proper programming for children who are gifted, children who are Asperger's, and children who are both.

What is Asperger's Syndrome?

Asperger's Syndrome is one of a number of pervasive developmental disorders, a group of disorders that includes autism. Early on Asperger's Syndrome was referred to as "high functioning autism." Now AS is recognized as a disorder separate from autism, although the primary difference between the two is level of mental functioning: while autistic children tend to also have lower than average measured intelligence, children with Asperger's Syndrome have average or above measured intelligence.

Characteristic Behaviors of Asperger's Syndrome

Asperger's Syndrome is primarily a disorder in social interactions. People with AS tend to be oblivious to social conventions (Attwood, 1998). They literally **don't know how** to share a conversation, to be "polite," or to seek friendship. The American Psychological Association (1994) divides the behaviors that indicate Asperger's Syndrome into four general categories:

- **impaired social functioning**, including inability to make friends, show empathy, read social cues or use social non-verbal communication (eye contact, posture, and gestures)
- **restricted and stereotyped behaviors or interests**, including a single intense area of interest, repetitive hand movement, sensory sensitivity, compulsive repetition

- **average or above average language development**--vocabulary and usage are normal, although some hyperlexia (basically, sophisticated usage without sophisticated comprehension) may be present, especially in an area of intense interest
- **average or above average cognitive development**--standardized IQ measures anywhere from average to highly gifted

The first two categories describe the problem, the second two clearly associate AS with people who are otherwise of "normal" or above average ability. A growing misconception is addressed in this description, for it is not true that all AS children are gifted; rather, gifted children are included in the range of abilities where AS can be diagnosed.

Appreciating the Different Drummer

"The math teacher bristles at the suggestion that Jason has a disorder: he's not sick, he's different, she insists. He sees the world in a different way. Socializing is hard because his thinking is so advanced. He's gifted--this doesn't require a cure!"

Advocates for Asperger's/gifted (AG) children are eager to have them appreciated as wonderful, special children. The presence of dual exceptionality always casts a shadow over this goal. So much of Asperger's Syndrome echoes the behaviors of healthy highly gifted children that some of the first discussions of AS in the gifted community are cautions not to mistake giftedness for Asperger's Syndrome.

Differentiating between AG and AS is simplified by remembering that Asperger's Syndrome is a spectrum disorder--representative characteristics lay on a continuum. An AS diagnosis is only warranted when the behaviors 1) occur together and 2) are extreme. This fact is pivotal for parents and professionals involved with gifted children because it allows for differentiation between behaviors typical of gifted children and the extremes of Asperger's Syndrome. Table 1 presents a thumbnail sketch of a few critical distinctions between the behaviors of gifted children and Asperger's children of average IQ. The differences are often those of degree more than kind. To take one example, seeing Jason sitting in the corner and knowing that he's depressed because he has no friends in class is not enough to determine the presence or absence of AS. All AS children have social problems, but not all children with social problems are AS.

Table 1: Distinctions in Behaviors of Highly Gifted and Asperger's Syndrome

Highly Gifted	Asperger's Syndrome
Socially Isolated	Socially Inept
Independent of Age Mates	Unskilled with Age Mates
Highly Focused Interest	Highly Focused Interest
Advanced, Sophisticated Vocabulary	Hyperlexia
Complex Cognition	Simple Cognition
Advanced Understanding	Advanced Memorization

Facing the Equal but Opposite Challenge

"Jason's English teacher sighs. She's only trying to help. Good vocabulary and good memorizing skills do not automatically mean giftedness. Jason is not functioning, and he won't without systematic intervention. Even if he is gifted, that doesn't make him immune to other problems. He needs special help."

Cautions against misdiagnosis are legitimate; however, there's an equal and opposite challenge--recognizing that although most gifted children do not have Asperger's Syndrome, some do. To that end, a group of parents have generously opened up their lives by responding to an extensive survey about their AG/AS children, their lives at school, and their lives at home. While this group is hardly a scientific sample, and provides no definitive answers, they do present valuable consistent insights that can be used as a springboard for dialogue, research, and ultimately services for AG/AS children. What follows are some of the most significant issues and ideas raised by the parents' descriptions of their AG/AS children and supported by separate research literature on AG and AS.

Gifted and Asperger's: First Signs and Identification Issues

For the most part, parents reported that giftedness was the first exceptionality identified, often in the form of advanced verbal skill, a trait shared by both AG and AS children, but more likely to be classified as gifted. Some parents indicated that identification of AS was delayed because attention was centered on giftedness. Failing to recognize the presence of AS, parents and teachers may focus only on the child's giftedness, thinking the child is simply "geeky." At other times, social interaction problems of AG/AS students may be attributed incorrectly to a diagnosis of a learning disability. Although the AS literature suggests that some girls are identified as AS, this group was typical because the children discussed were all boys. A couple of respondents made reference to a possible genetic link, even saying that the child's diagnosis led to a retrospective diagnosis for his father.

Despite any initial concerns about misdiagnosis, each parent who responded to the survey reported great relief when his child was identified AG/AS. Parents described their child's AS behaviors in detail and recounted extreme frustration with the contrast between extreme intelligence and social ineptitude. Most frequent in the list of AS qualities was poor social interaction, or a simple lack of attention to the social world:

"This last week, one of his previous teachers stopped to talk to him while he was with the counselor. This teacher was wearing a hat with a big bat on it in the spirit of Halloween. After they were done talking, the counselor asked B to turn around and describe the teacher. All he could come up with was that she had brown hair. When directly asked if she had a hat on, he said, 'Ummm, no?' He simply does not observe people at all."

The biggest challenges have been his wild outburst where he seems to lose the ability to control his actions and words.

Rigid need for order and predictability. BIG problems with transitions. BIG problems with departures from routine.

The Combining and Colliding Characteristics of AS and AG

Gifted children possess a set of characteristics that separates them from typical developing children. So do children with AS. Put the two together and the characteristics combine and collide in complex ways.

A small number of gifted children suffer from social isolation – isolation that may be exacerbated by the presence of AS. Consider combining the social inattention, motor clumsiness, and high verbal skill of Asperger's Syndrome with such traits as independent thinking, constant questioning, and heightened emotional sensitivity (Gallagher & Gallagher, 1994). It is the perfect formula for a social pariah. One parent pointed out that the child's isolation is made more poignant when his gifted insight perceived, but could not comprehend, his isolation:

“The more gifted and intelligent an AS child is, the more he is aware of his 'different-ness' and the social problems that accompany it. If he were merely gifted and didn't have the lack of social understanding, he could fit in with his peers while he excelled academically. This also presents challenges because the more aware he is of his differentness, the more depression he experiences”.

Giftedness and AS don't always work together. Sometimes the characteristics of one syndrome simply take over. Gifted AS students may unintentionally engage in behaviors that provoke ridicule or teasing from others in part because they lack the perspective to see their actions as inappropriate (Williams, 1995; Neihart, 2000). Table 2 contains a summary of some ways in which AG characteristics may look different when combined with AS.

Table 2: AG vs. AG/AS Characteristics

<u>Characteristics</u>	<u>AG</u>	<u>AG/AS</u>
Routines	Usually follow routines	Low tolerance for routine
Social Awareness	Know they are different can reason why	Know they are different, poor awareness of why
Humor	Receives/gives humor	Cannot reciprocate humor; does not understand timing
Motor Skills	Coordinated	Motor clumsiness
Insight	Keen insight	Social insight absent
Moral Sense	Empathy for others and for abstract whole	Empathy for abstract whole; difficulty with empathy for others
Social Interaction	Knows how to make friends	Unaware of how to establish friendships
Knowledge Base	Extensive knowledge base, both deep and complex	Extensive knowledge base, deep and sometimes complex

Occasionally, the characteristics of AG supersede the AS, especially in the cognitive domain. While parents mentioned pedantic speech and huge stored memory, they also discussed cognitive abilities and skills more advanced and flexible than the typical AS child. Conceptual reasoning, critical thinking, and strong abstract moral empathy were often cited as typically gifted characteristics.

School Services

Gifted AS students may require alternate interventions and strategies from normal gifted students or non-gifted AS students (Neihart, 2000). As Table 2 demonstrates, professionals speculate the AG/AS child is neither completely like an AS child, nor completely like an AG child. Contrasts in the perceptions of the disorder among parents, teachers, and AG/AS students themselves add to the dilemma. Parents and educators need to understand the nature of AG/AS in order to provide appropriate interventions.

Virtually all parents of public school children had an IEP or were in the planning process. The IEP provided parents and teachers with some direction and a common point of communication for Asperger's Syndrome. Giftedness was almost never included in the IEP, although some received gifted programming anyway. Ironically, the time that the students spent in gifted education settings was a powerful intervention for Asperger's; as such, it has a legitimate place on the IEP. "Keeping the child stimulated intellectually . . .," said one parent, "seems to improve the emotional state."

Classroom Interventions

The children represented in the surveys were equally likely to be enrolled in public or private schools, but none were homeschooled. Level of satisfaction with the school's response to either AG or AS varied and was dependent not on the structure of the school but the attitude of the school personnel.

The only commonality shared by the "success stories" was that the intervention was highly individualized. Most of the children had a full-time assistant working with them for a majority of the school day. Most children were being schooled in the regular classroom, although a few also attended gifted pull-out programs. One student had applied for a self-contained school for the gifted prior to his dual AG/AS diagnosis but was rejected because of concern for his "social maturity."

Praise was highest and satisfaction greatest when the school actively engaged in the intervention process. In some cases teachers and administrators alike took the opportunity to receive training in Asperger's Syndrome, worked to create a total school treatment plan, helped identify aides, collaborated with parents, and otherwise demonstrated an individualized, child-centered approach. Parents indicated a need for services directed towards both AS and AG, separately and occasionally in combination. One parent described a successful environment:

"They are firm with him about what they expect and require and don't let the AS excuse him from participating, but they are sensitive to his feelings and work with him to accommodate his unique personality. At the beginning of each school year we sit down with his new teacher and talk about strategies which, although not complicated, make a world of difference for him. This includes things such as making sure his

desk is near where the teacher spends most of the time talking so he can stay focused, allowing him to take time-out from PE class when his tactile defensiveness causes him to act wildly, and keeping involved and aware of his social interactions."

Other parents had enlisted the help of occupational therapists and counselors. An interesting note: While social skills training was deemed essential, therapy based on role play was unsuccessful. Role play requires social understanding; AG/AS children needed direct training in social skills because they had no initial knowledge of social rules.

Gifted resource or consultant teachers may also find unique challenges with the AG/AS child. The learning environment that is a part of basic training in gifted education – open, complex, free – will not support and nurture the AG/AS child. Rather, the AG/AS child requires structure, normalcy, focus, and freedom from distraction. Finding ways to adapt to the presence of an AG/AS child will require consulting with the special education teacher to find the optimal adaptation that suits both the intellectual and the social and structural needs of the child.

Helpful Guidelines

The parents' comments echo the recommendations of the professional community. The National Research Council recently impaneled a *Committee on Educational Interventions for Children with Autism*. This group study included a number of pervasive developmental disorders under their charge, including Asperger's Syndrome. After reviewing the available research, they recommended the following for all children with autism or related syndromes:

"Taking into account the needs and strengths of an individualized child and family, the child's schedule and educational environment, in and out of the classroom, should be adapted as needed in order to implement the IEP. Educational services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, developmentally appropriate educational activity aimed toward identified objectives. Where this activity takes place and the content of the activity should be determined on an individual basis, depending on characteristics of both the child and the family (National Research Council, 2000, p. 220)."

Other parents of AG/AS children may find these recommendations helpful in their efforts to establish services in their school districts.

A Call to Action for Gifted Educators

"Suddenly, the principal jumps out of her chair and leaves the room. She is halfway down the hall when she runs into the person she is seeking going the other way. 'You need to be in this meeting.'"

'I'd like to share my perspective on Jason,' they say simultaneously. Quickly they get back to the meeting room and proceed with the discussion. '

Gifted educators have valuable information to bring to the AG/AS discussion. There's new perspective on giftedness to learn about, too. Gifted professionals can contribute to the proper placement of all children by:

1. becoming familiar with the characteristics and behaviors associated with Asperger's Syndrome. Attend or request in-service on the topic in your district
2. sharing information on the characteristics of the highly gifted child with regular classroom teachers, school administrators, school psychologists, and other diagnosing clinics
3. requesting permission to be present at IEP meetings for Asperger's students who are also diagnosed as gifted
4. ensuring that AG services are included in the discussion as a treatment option for AS

Final Words

Jason is in the hands of caring, and increasingly knowledgeable, professionals. Does his ultimate diagnosis matter to us right now? No. What's important is that we all acknowledge the ambiguity that is ever present in cases like Jason's and to remember that, depending on the observed characteristics, any of the possible diagnoses--AS, AG, or AS/AG--may be correct. Also important is the reminder parents sent, loud and clear, that while the AG/AS child presents many difficult challenges, sleepless nights, and conflicts, he is also a child full of potential. Just ask them, "What do you see in your child that you would like others to see?"

"I see potential for a happy, successful life-just like every other parent sees in their child. That's all I want others to see in him."

"[I want to make] sure that the problems don't smother the beauty in such a child."

"His wonderful sense of humor about the world and life; his sweetness and good heart; his unique perception; his willingness to take responsibility for his actions, no matter the consequences."

Websites of Interest:

Asperger Syndrome Coalition of the U.S; www.asperger.org/index_asc.html

Asperger Internet Support Network; djensen.ourfamily.com/asin/network.html

Asperger Syndrome Education Network; www.aspennj.org

GT World; www.gtworld.org

National Research Council report on autism; www.nap.edu/catalog/10017.html

References

- American Psychological Association (1994). *Diagnostic and Statistical Manual of Mental Disorders*. Washington, DC.
- Attwood, T. (1998). *Asperger's Syndrome: A Guide for Parents and Professionals*. London: Jessica Kingsley Publishers
- Gallagher, J. J. & Gallagher, S. A. (1994). *Teaching the Gifted Child*. Boston: Allyn & Bacon.
- National Research Council (2001). *Educating Children with Autism*. Washington, DC.
- Neihart, M. (2000). Gifted Children with Asperger's Syndrome. *Gifted Child Quarterly*, 44(4), 222-230.
- Williams, K. (1995). Understanding the Student with Asperger Syndrome: Guidelines for Teachers. *Focus on Autistic Behavior*, 10(2), 9-17.

Table 3: Diagnostic Criteria for Asperger's Disorder

- A.** Qualitative impairments in social interaction, as manifested by at least two of the following:
1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 2. Failure to develop peer relationships appropriate to developmental level
 3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other
 4. People e.g., by a lack of showing, bringing, or pointing out objects of interest to other people
 5. Lack of social or emotional reciprocity
- B.** Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest,
 2. Abnormal either in intensity or focus
 3. Apparently inflexible adherence to specific, nonfunctional routines or rituals
 4. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements),
 5. Persistent preoccupation with parts of objects
- C.** The disturbance causes no clinically significant general delay in language (e.g., single words used by age 2, communicative phrases used by age 3).
- D.** There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- E.** Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia. (*American Psychological Association, 1994, p.77*)

Changes in Differentiation for Students with AG/AS

1. Establish orderly classroom routine for the child.
2. Build perception-taking skill through social training
3. Teach listening skills.
4. Focus on written irony in comics and humorous written works
5. Teach keyboarding
6. Teach social skills, and provide opportunities for safe practice of these skills

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DVD REVIEW: "THOUGHTFUL RESPONSE TO AGITATION, ESCALATION, AND MELTDOWNS IN INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS" BY REBECCA KLAW

Reviewed by Jody Jones, Utah Parent Center

The explosive child--do you know one or have one? Children, youth, and adults in the general population have meltdowns and explosions, and are easily agitated. They are usually capable of understanding why it happens and how to handle it. The individual on the Autism Spectrum however is neurologically affected and when frustration arises, may have limited ability to cope, process, resolve, manage, and control emotions that are associated with frustration.

Difficulty with managing emotions leads to lack of processing which in turn leads to the inability to calm down. This will further result in the problem not being solved often making the situation worse. In the midst of the meltdown, the child will not and does not remember the consequences and repercussions of the last meltdown. The child cannot process the new information being given such as; "Calm down right now or you will lose TV for the day. OK, now you are going to lose it for the week. Keep it up Buddy, and you will be looking at a whole month of no T.V." Professionals may describe the child as being **cognitively debilitated**, or having problems with recognition, information processing, communication, **inability to learn from experience**, attention, memory, and poor judgment.

Common characteristics for the explosive child include a low frustration threshold (being quicker to feel frustration) inability to process in the midst of crisis, and black and white thinking (seeing no middle ground). An explosion comes on like a tornado-- huge, intense and fast, and it can have an "out of the blue" quality. Some things that we see in children prior to the meltdown that are contributing factors could include feeling tired or hungry and sickness that is coming on, present or in the recovery stage. If you do not understand or notice the basic characteristics that cause distress in an individual with Autism, you might think that the child is just being "bad", "manipulative", or "controlling".

There is a group of children with neurological pathway problems who are extra prone to meltdowns. This group includes those with ADHD, Executive Function Deficits, Language Processing Difficulties, Mood problems and/or Difficult Temperament, Anxiety, Social Skills Deficits and Sensory Integration Dysfunction. When you understand that these characteristics are caused by neurological differences, you realize that it is never a battle where someone wins and someone loses. When a child becomes frustrated and loses control it is distressing for everyone and no one ever wins.

So how do we help the child who has Autism and create some win/win situations? It is important to know that there is a reason for the meltdown even when it appears to be for no reason. In order to help these children we must recognize the agitation triggers, some of which include; being told no, transitions, physical contact, noise, homework, tags in clothing, clothing, surprises, not understanding, puberty and physical pain such as earaches, stomach aches and headaches.

A meltdown can look like behaviors that are irrational, incoherent, destructive, abusive, or out of control or it can look like a debilitated state of being. When the meltdown behavior is present, we may see it as “being naughty”, but another way to look at the behavior may be to see it as “being Autistic”. We can relate to the present state of being if we picture a car that has gone into “vapor lock”. Vapor lock happens when excessive heat creates a bubble in the gas line and no gas can get in until it cools down and once again lets gas in. Vapor lock in our children prevents logic, reason, and information about consequences and punishments from getting in, until the child cools down enough to once again process and let in the information.

Remember that during the meltdown, what comes out of the child’s mouth is MENTAL DEBRIS. You must think about this mental debris as GARBAGE. Once the child moves past the meltdown, he is usually mortified, repentant, and self-condemning for the behavior. ALL triggers leading to a meltdown represent a demand to shift gears. All the reasons these situations trigger a meltdown can be summarized into four reasons;

1. Not getting what they want;
2. Not doing what they want;
3. Not being able to regulate environmental stimuli;
4. Not being able to regulate internal stimuli.

Understanding the meltdown and triggers associated with it does not mean that we accept the behavior. For a consequence to be effective, it has to counter the behavior for the next time. If the child cannot stop mid-anger and remember what happened last time, the consequences were not effective.

The first step in dealing with meltdowns is to prioritize our demands. Place demands in one of 3 levels.

Level A: NON-NEGOTIABLE

- Safety of self and others (street safety, weapons, fire, etc...)
- Health (bathing, eating, washing hands)
- Basic life expectations (going to bed, wearing shoes in winter)

Level B: IMPORTANT but NOT ESSENTIAL

- Growth and development (reading, writing, math)

These are most effective when a person is available to learn

Level C: NOT IMPORTANT

- Being conventional

These are things that don’t impact the big picture as much (mismatched socks, shirt untucked, drinking from a bowl).

LEVEL C ISSUES--LEAVE THEM ALONE. Do not even address them. They are not important (for now) and may cause a meltdown. Save your energy for the bigger issues. Level B issues can be compromised and negotiated. Do not push the issue right now, but deal with these when the individual is capable of handling new information and addressing them. Level A issues are the ones you want to use your energy and creativity on. These are the things you need to focus on.

Some additional ideas that have been found to be effective in dealing with meltdowns are:

- Give the child time and space. EXAMPLE: A child is drawing and is asked to stop. The child does not immediately respond, but in the next few seconds finishes the picture, puts down the pencil and stops.
- Empathize. This might give the child time to process and see you as a friend and not an enemy.
- Support in a calm, nonthreatening manner.
- DON'T escalate with the child. If the child goes up, you come down.
- Partner with the child. EXAMPLE: A child is on the floor rolling cars. Get on the floor and roll some cars too.
- Use humor. Put a sock on your hand and speak to the child with the sock.
- Use visual transition. Move to the next stage of learning, allowing the child to see what to expect next. EXAMPLE: Walk to the calendar and prepare for calendar time while in view of the child allowing time to make a mental shift.
- Sensory intervention. Give the child a drink of water or something to eat. Some children respond to a ball in their hand or pressure. Find what works for the individual, and have it on hand.

There are 3 MUST DO'S when working with a child who has meltdowns:

1. Only ONE Adult should handle the child at a time. You can switch off, but only have one on one with the child.
2. Be QUIET. Say nothing unless it is soft promptings of "you're ok" etc.
3. ISOLATE the child or remove the other children. Children are able to calm down faster when the outer stimulation is gone and there are no eyes staring at them. This also reduces the risk of hurt to others.

Recovery is the final stage of the meltdown. This is not a 5 minute process. It can take an hour, a day or even a week. Once you have moved into the recovery stage, use this time to prepare the child and yourself for the next meltdown. Make big rewards; focus on the positive behaviors and improvements. Use social stories in the 3rd person so the child can learn without seeing himself as wrong or bad.

Remember to ALWAYS respond to the child's basic needs of communication, safety, predictability, and the child's sensory differences. For more information on this topic, view the DVD "*Thoughtful response to agitation, escalation, and meltdowns in individuals with Autism Spectrum Disorders*", read Rebecca Klaw's books, or visit www.rebeccaklaw.com. One copy of the DVD is available in the Utah Parent Center lending library.

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The Utah Parent Center also created a newsletter dedicated completely to autism in 2004. It can be viewed online by visiting: http://www.utahparentcenter.org/docs/resources/UPC_Connectio ns_Autism_February_2008.pdf.