

PERSPECTIVES



Genesee Intermediate School District

Compiled By: Becky Downing,
Teacher Consultant for Autism



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Inside this issue:

Holiday Survival Guide	1 & 6
Letters to the Editor	2
ARRI	2
Advocate	2
Welcome to Holland	3
Conferences	7
Transition & Special Needs Care	7
Autism Support Group	8

Genetics and ASDs

Autistic spectrum disorders do run in families, but although the genetic connection is fairly strong, the pattern of inheritance is unknown. Many parents of children diagnosed with ASDs recognize a little of themselves when they look at their child's symptoms, or can recall close relatives who seem to have been somewhere on the autistic spectrum.

Often parents worry about whether their other children will also have an ASD. The current wisdom is that parents of a child with autism have a 3 to 4.5 percent chance of having a second child with autism, about 50 times the normal risk. Other studies have indicated that a great number of autistic children's siblings have some degree of autistic tendencies, rather than autism per se. In some cases there are no known relatives with even mild autistic tendencies.

Several teams of researchers around the world are searching for genes that contribute to autistic spectrum disorders. In 1997, one group of genetic researchers announced that the first of the three to five genes believed to cause most autistic spectrum disorders had been tentatively located on chromosomes 7 and 16. A genetic mutation associated with speech and communication disorders, and particularly with apraxia of speech, has also been located on the same general area of chromosome 7 previously linked to autism.

from Autistic Spectrum Disorders by Mitzi Waltz

Holiday Survival Guide for Children With ASD By Liane Holliday Willey, EdD

After reflecting on the rush and clamor of the holiday season, it occurred to me that there are three basic problem areas that cause the most difficulty for many of us with Asperger Syndrome and other autism spectrum disorders.

One: Mitigate Sensory Overload

Those seasonal sensory stressors! Among them are classrooms and public areas laden with loud music, busy crowds and long lines, twitching lights and decorations, heavy smells and a myriad of taste treats. Parents can make a conscious effort to reduce sensory com-motion by:

- * Asking restaurant personnel to seat their family in a remote corner.
- * Asking their child's teachers to plan for, and then provide, extra quiet-time opportunities.
- * Finding out when shopping malls are least busy, and shopping during those times.
- * Keeping a sensory overload emergency kit with them at all times (possible contents — sunglasses, ear plugs, squeeze ball, aromatherapy lotion and anything that might help avert sensory overload)

When children with ASD are overwhelmed, they should learn to use an agreed upon "I need help" code word with a responsible adult. The adult will then provide a means of helping the child de-stress by:

- * Going to a quiet room to relax with his/her "security blanket" or favorite stim.
- * Having a deep pressure massage.
- * Listening to a few minutes of his/her favorite music.
- * Watching his/her favorite video.

(Continued on page 6)

Letters to the Editor

Asperger's Disorder and Mathematicians of Genius

Journal of Autism and Developmental Disorders, (2002), Vol 32, pages 59-60

There is evidence that mathematicians of genius and originality over the past 2300 years for whom there are adequate data not uncommonly met criteria for Asperger's disorder. DSM-IV criteria are used here for Asperger's disorder. Data was summarized on Ludwig Wittengenstein, Eamon de Valera, Paul Erdos, G.H Hardy, Archimedes, Lagrange, Cauchy, Riemann, Galois, Lobatchensky, and William Hamilton the last mentioned being the only member of the group who did not meet criteria for Asperger's disorder.

Prof. Michael Fitzgerald

Henry Marsh Professor Child & Adolescent Psychiatry T.C.D



Read Elijah's Cup by Val Parady, who discovers that her son has Asperger Syndrome. Through learning about him, she began to notice similar patterns in well-known public figures such as Andy Warhol and Albert Einstein & believes they may have had Asperger Syndrome.

ARRI

New Social Aid Tested

A graduate student in Wales is experimenting with a system, dubbed PARLE (for Portable Affect Recognition Learning Environment), that could help people with Asperger's Syndrome or high-functioning autism feel more comfortable in social situations.

Jonathan Bishop recently tested the first generation version of his system, which uses an Internet-compatible mobile telephone. Using the phone, individuals with autism spectrum disorders—who often have difficulty interpreting common conversational phrases, because they tend to interpret them literally—can access a database of phrases and quickly obtain a "translation." (For instance, the phrase "cat got your tongue?" would be translated into a phrase such as, "you are quiet, why is that?") Eventually, Bishop says, the system could incorporate both facial and voice recognition, to provide users with clues about another person's emotions and nonverbal communication. In addition, he says, it could incorporate an earpiece to allow for real-time auditory feedback.

In a preliminary study, Bishop asked 10 individuals with autistic spectrum disorders to read social stories and enter phrases and sentences they found confusing. Participants said the system enhanced their understanding of the stories, and expressed a desire to use the device both at home and in public.

"An investigation into the potential of the Internet for educating individuals with social impairments," Jonathan Bishop and Mike Reddy, *Journal of Computer Assisted Learning*, in press. Address: Jonathan Bishop, 8 Heol-y-Parc, Efail Isaf, Pontypridd, Rhondda Cynon Taff, Wales, CF38 1AN, UK, jonathan@jonathanbishop.com.

Advocate

How can my family participate in an autism genetic research study?

The Center for Human Genetics at Duke University Medical Center has been conducting an autism genetic research study since 1995. Margaret A. Pericak-Vance, Ph.D., Director of the DUMC Center for Human Genetics, is the principal investigator of this genetic research study of autism and related disorders. If your family has one or more members with autism (age 21 or younger) you can help by participating in the study. For more information or to enroll your family in this research study, please contact the autism patient coordinators at 1-800-283-4316, ext. 1 or e-mail: center@chg.duhs.duke.edu.

To keep up-to-date about the latest genetic findings for autism please visit <http://www.exploringautism.org>.



Welcome to Holland

I am often asked to describe the experience of raising a child with a disability — to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

“When you're going to have a baby, it's like planning a fabulous vacation trip — to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo “David.” The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

“After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, ‘Welcome to Holland.’

‘HOLLAND?!?!’ you say. ‘What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.’

“But there's been a change in the flight plan. They've landed in Holland and there you must stay.

“The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

“So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

“It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has tulips. Holland even has Rembrandts.

“But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say: ‘Yes, that's where I was supposed to go. That's what I had planned.’

“And the pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

“But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.”

Emily Perl Kingley



Asperger's Syndrome and High Functioning Autism: Shared Deficits or Different Disorders?

Gillberg. C, M.D., Ph.D., *The Journal of Developmental and Learning Disorders*;5:79-94.

The terms are more likely synonyms than labels for different disorders.

I should perhaps add that it was not Asperger who first described the syndrome that now bears his name. A Russian neurologist, Eva Ssucharewa, published a paper in the mid 1920's in which she described "schizoid personality disorder" in children. Reading Sula Wolff's translation of that paper it becomes clear that Ssucharewa described the core deficits and major hallmarks of autism long before Asperger or Kanner (Ssucharewa 1926, Wolff 1995).

The ICD-10 (WHO 1992) and DSM-IV (APA 1994) criteria for the syndrome are virtually identical to each other. They are problematic in that they specifically exclude cases with signs of early language, developmental, or social delays. Virtually nobody with an autism spectrum disorder fits these criteria. Asperger's own cases do not meet criteria for DSM-IV Asperger's disorder.

In clinical practice, the DSM-IV criteria for Asperger's disorder are not helpful. I have yet met a patient with the clinical presentation that Asperger described who was completely normal in his development early on. Another problem is that the actual symptom threshold for qualifying for a diagnosis is very low; only two social and one behavioral symptom are required to reach diagnostic status. The ICD-10 has the additional problem that there is no specification that symptoms have to be handicapping in daily life. There are no universally agreed criteria for high-functioning autism.

There is always marked social impairment in Asperger's Syndrome, usually showing an extreme egocentricity. There is mostly a much decreased ability to interact with peers, often coupled with a lack of desire to interact with peers, a lack of appreciation of social cues, and socially and emotionally inappropriate behaviors.

Several years may pass before family, peers, relatives, and teachers understand that something is seriously amiss, and it may only be with hindsight that they realize that there was never a period of normal development. The narrow interest pattern was something that Asperger himself put a lot of emphasis on. He felt that this interest should lead to the exclusion of other activities, or be very repetitive, or be more relying on memory than underlying meaning. Even though the narrow interest pattern is highly characteristic of the most typical cases of males with Asperger's Syndrome, there are those, and particularly those females, who otherwise fit the criteria for the disorder, who do not demonstrate this feature. Some girls (and a very few boys) with the other core features of the condition have a strong tendency to avoid demands and to always say "no". It is as though their main interest in life is to say no, negative things, and to go around 'being bored.' They themselves cannot seem to find anything to interest them.

It is common for a child with Asperger's Syndrome to have "delayed" expressive language development; they do not speak at an early age, even though you had the feeling that they would have been able to if they wanted to/felt the need to. I certainly see a number of kids who say nothing for two-three years and then suddenly start speaking because they "have something to say." Some of them actually say: "Why should I speak before I have something important to say"? There are also children who, are able to read before they start speaking. They have superficially expressive perfect language and they are very often formal and pedantic in their style and they have, most of them, this very odd prosody.

Incidentally, it was only towards the end of his life that he believed that the syndrome could occur in any form in females. He thought it was an exclusively male disorder. Odd and awkward gait, strange posturing (sometimes approaching catatonia) and a mask-like facial expression are all common features.

(Continued on page 5)

(Continued from page 4)

The five prevalence studies — which have all come from the Nordic-countries — are in relatively good agreement, and it would seem reasonable to conclude that the rate of the disorder is about one in 200 of the general population of school age children.

Male: Female Ratios

The boy:girl ratio in most studies of Asperger's Syndrome have been reported to be 5-10:1. Both Asperger and Kanner described mostly prototypical boys, and that, therefore, our way of conceptualizing the syndrome is based on the phenotypical expression in males, not in females. Interestingly, we have found a high rate of Asperger's Syndrome/high functioning autism/PDD NOS in female teenagers/adults with anorexia nervosa and selective mutism.

Asperger's Syndrome is very often comorbid with at least one other condition. According to the population-study by our own group, tics (including full-blown Tourette Syndrome) and ADHD are the most common comorbidities, each occurring in more than half of all clear-cut or suspected cases. Developmental coordination disorder (DCD) is almost universal, but then, at least according to some of the diagnostic algorithms, clumsiness is part and parcel of Asperger's Syndrome, and it might therefore seem redundant to list DCD as a separate disorder.

Depression quite often develops in the pre-adolescent or adolescent period in children who have high-functioning autism or Asperger's Syndrome. This may either be a reflection of comorbidity with manic-depressive illness or be seen as a reactive condition following in the footsteps of feeling socially awkward and of being an "outsider." Many adults with Asperger's Syndrome or high-functioning autism apply for psychiatric help but are only occasionally correctly diagnosed as having an autism spectrum disorder. We have seen our previous patients diagnosed with borderline personality disorder, antisocial personality disorder, paranoid disorder, psychosis, and schizophrenia. It may be a matter of the adult psychiatrist not being familiar with the history and symptoms of an individual with Asperger's Syndrome/high functioning which makes him/her liable to make a diagnosis of a condition with some overlapping symptomatology for which there is a well-known framework. Alcoholism appears to be much over represented in Asperger's Syndrome as compared with the general population, but the studies published to date have either been on potentially biased groups or included very small samples making it impossible to draw any generalized conclusions at this stage.

Here are just some of the things that have been associated in a few studies with Asperger's Syndrome. The study was just completed on Megalencephalus, that is large head size in Asperger's and Autism suggest that it's only in the very high functioning group that you'll find a large excess of individuals with big heads. In fact 24% of classic Asperger's cases we have consistently Macrocephalus.

I have met many individuals with Asperger's Syndrome who have superficially excellent outcomes, who have had a university degree, an excellent job, and a family. Nevertheless, the spouses of the young Asperger's Syndrome men that we followed up still feel that their husbands have some terrible problems. The men themselves feel that they are fine and they're doing really well and there is not a major problem. Some of them have children. Unfortunately, at least in one case, that the child has turned out to have severe autism.

So, in conclusion, there is no good evidence, I think, that so-called high functioning autism and Asperger's are different disorders. When we use these concepts, we are probably referring to the same group of individuals, and depending on where we work, and what history we have, we tend to use one diagnosis more than the other.



(Continued from page 1)

Don't forget about home stressors too. Parents can do the following to avoid problems:

- * Shop with their child for holiday clothing, avoiding unnecessary ruffles and lace that scratch, tight waists that bind, or accessories that will drive both of them crazy.
- * Make a joint decision on holiday plans together so there aren't last-minute scheduling surprises.
- * Take your time decorating the house so that the change is gradual and things aren't rushed.
- * Given a choice, opt for simplicity whenever possible.
- * Create your own traditions and rituals that your family can look forward to from year to year.



Two: Maintain Routines and Order

Amid the clatter and chaos, children with ASD need their oasis — a sense of order to get them through the madness. The following will help parents AND children maintain their equilibrium:

- * Avoid travel away from home during the holidays, especially extended travel to family members who live far away.



Save those trips for less stressful occasions.

- * Maintain as much of your normal household routine and environment as possible.
- * Make a concerted effort to go to bed and get up at the same hour each day.
- * Do not let your child's bedroom (his/her refuge) become the guest bedroom for out-of-town visitors.
- * Avoid cancellation of regularly scheduled activities such as music or sports practices.

Three: Prepare for Seasonal Social Situations

The social demands of the holiday season are like no other! From our AS perspective, you need the social flexibility of a human pretzel to travel the maze of social challenges. Hopefully, the following plan will make our kids feel more comfortable at social gatherings.

- * Write social scripts for how your child will be expected to behave at various holiday related functions, and then role play the behaviors until they run smoothly.
- * Outline how to act while shopping, visiting friends, and receiving gifts, and incorporate "think it, but don't say it" strategies, and the "I need help" code word.
- * Agree on the tasks your child can be in charge of. For example, decide whether he/she wants to be the official disc jockey in charge of selecting and playing special holiday music or be the official holiday mail handler whose job will include posting and organizing the seasonal mail, or something else that she chooses to do. If the child becomes overwhelmed by the task, he/she can opt to relinquish it at any time.
- * Write social stories that include such things as the realities of holiday stress, how busy the shopping malls will be, the funny holiday characters they might see in public, and the most likely changes in the normal school routine.

This year, I have vowed that I will join our whole family in embracing the festivities with peace and joy and awe-inspiring wonder. I know that there are no absolutes, and that what works one day, may have little effect the next, but I've taken that first and most important step. This year, I have a plan!

Other Holiday Hints

- * Keep your child's needs in mind — they may need to be protected from the busiest part of the holidays.
- * For gift exchanges, provide a list of presents your child will be most likely to accept with gracious appreciation. To avoid disaster, you might elect to have a substitute toy with you, just in case!
- * Be prepared to answer countless questions. Use this time as an opportunity to guide your child to a deeper understanding of your faith.
- * Collect a list of all the possible symbols of the traditions you will celebrate and directly discuss each and every one.
- * Consider adopting a philosophy of ones - attend only one special event, purchase only one new outfit, entertain only one time in the home, and shop only once. If nothing else, you'll save a bundle of money.
- * Be creative! Use every means at your disposal, every scheme you have ever found successful, and every trick you can invent to help both your family and your child celebrate the season.

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Helpful Resources

www.tonyattwood.com
www.autism-society.org
www.udel/bkirby/asperger/index.html

www.autism-mi.org
www.asoakland.org
www.unc.edu/depts/teacch



Conferences

<u>Date</u>	<u>Title</u>	<u>Speakers</u>	<u>Fee</u>	<u>Contact Info</u>
Jan. 14, 2004	Social Thinking/Michelle Garcia Winner Video Workshop The Gray Center — Grand Rapids	Video	\$15.00	(616) 954-9747 www.TheGrayCenter.org
Jan. 19, 2004	Social Story Video Workshop The Grey Center — Grand Rapids	Carol Gray	\$25.00	(616) 954-9747 www.TheGrayCenter.org
Feb. 19, 2004	Communication & Best Practices Clinton ISD	Lynn Sweeney	Varies	www.autism-mi.org 1-800-223-6722
Feb. 21, 2004	Tony Attwood (Anger, Teacher, & Teens) 2nd Video Workshop	Video & discussion with Carol Gray	\$25.00	(616) 954-9747 www.TheGrayCenter.org
Feb. 26-27, 2004	Putting the Pieces Together Midland Conference Center	Laura Barker, MS, OTR Linda Hodgdon, M.Ed., CCC- SLP	1 Day \$100 2 Day \$165	Kpainter@mcesa.k12.mi.us
Feb. 27, 2004	Asperger Syndrome Jackson ISD	Dr. Richard Howlin	Varies	www.autism-mi.org 1-800-223-6722
Mar. 2, 2004	Social Thinking/Michelle Garcia Winner Video Workshop The Gray Center — Grand Rapids	Video	\$15.00	(616) 954-9747 www.TheGrayCenter.org
Apr. 24, 2004	Tony Attwood, Asperger Video Workshop The Gray Center — Grand Rapids	Video	\$15.00	(616) 954-9747 www.TheGrayCenter.org
Mar. 5, 2004	Asperger Syndrome: Clinical Features, Assessment, & Intervention Guidelines	Fred Volkmar, M.D.	\$139.00	Carolyn or Lisa 413-499-1489 www.neei.org

Transitions and Special Health Care Needs

Often the families of children with special health care needs struggle to keep up with day-to-day or week-to-week demands. Yet, it is important for these families to keep thinking about the future, when the child is an adult. The long-term goal is to allow the child maximal independence as an adult. Along the way to adulthood, all children go through a series of transitions, including transition toward preschool, school, adolescence, adulthood and post school options. Children with special health needs face the additional challenge of being knowledgeable about the special demands of their medical condition.

The ***Transition Timeline for Children and Adolescents with Special Health Care Needs*** from Adolescent Health Transition Project provides a simple visual overview of the process along with short descriptions of age appropriate parent/child interactions that encourage independence. The Adolescent Health Transition Project web site has two different versions of the timeline — one for children with developmental disabilities or delays and one for children with chronic illnesses and/or physical disabilities. The timelines also include contact information for suggested supports and services. The timelines are available for download in PowerPoint format at http://depts.washington.edu/healthtr/Timeline/timeline_instr.htm.

The site also offers an ***Adolescent Autonomy Checklist*** to help you keep track of your child's skills at home, in the community, leisure time, and for the future. The checklist is available in Word format at <http://depts.washington.edu/healthtr/Checklists/intro.htm>. Paper copies of the timelines and/or checklists are available from the project office: Adolescent Health Transition Project, Box 357262, University of Washington, Seattle, WA 98195, 206.685.1358 (voice), <http://depts.washington.edu/healthtr> (web), healthtr@u.washington.edu (e-mail). This information was originally published in the FAPE Newslines, April 28, 2003.

Genesee Intermediate School District

Special Education Services Center
2413 West Maple Avenue
Flint, Michigan 48507-3493

Phone: 810-591-4877
Fax: 810-591-4548



Coming Up: Autism Support Group



Date: Tuesday, February 10, 2004

Time: 6:00 p.m.

Place: Genesee Intermediate School District

Special Education Services Center-South, GenNET classroom
5089 Pilgrim Road, Flint 48507



(Pilgrim Road is south off Maple Avenue, between VanSlyke and Torrey Roads. Parking is located in the rear of the building. Enter through the far east doors.)

The Role of Sensory Integration in Autism

Jim Colley is an occupational therapist with GISD. He works in local districts in the Genesee County and provides services to many students with autism. Some sensory characteristics are: overly sensitive to loud voices, bumps into people in line, difficulty paying attention, difficulty with hair washing & brushing, picky eater, always "on the go," problems with handwriting, only likes certain types of clothing, or is clumsy. Come and find out more.

Parents, professionals, and others who are interested are invited to attend.

If you plan to attend or have questions, **PLEASE CALL** Becky Downing at 810-591-4868 and leave your name and phone number.
