

PERSPECTIVES



Genesee Intermediate School District

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Holland Schmolland
by Laura Kreuger Crawford

If you have a child with autism, which I do, and if you troll the Internet for information, which I have done, you will come across a certain inspirational analogy. It goes like this: Imagine that you are planning a trip to Italy. You read all the latest travel books, you consult with friends about what to pack, and you develop an elaborate itinerary for your glorious trip. The day arrives. You board the plane and settle in with your in-flight magazine, dreaming of trattorias, gondola rides, and gelato. However, when the plane lands you discover, much to your surprise, you are not in Italy -- you are in Holland. You are greatly dismayed at this abrupt and unexpected change in plans. You rant and rave to the travel agency, but it does no good. You are stuck. After a while, you tire of fighting and begin to look at what Holland has to offer. You notice the beautiful tulips, the kindly people in wooden shoes, the French fries and mayonnaise, and you think, "This isn't exactly what I planned, but it's not so bad. It's just different." Having a child with autism is supposed to be like this -- not any worse than having a typical child -- just different.

When I read that, my son was almost three, completely non-verbal and was hitting me over a hundred times a day. While I appreciated the intention of the story, I couldn't help but think, "Are they kidding? We are not in some peaceful countryside dotted with windmills. We are in a country under siege -- dodging bombs, trying to board overloaded helicopters, bribing officials -- all the while thinking, "What happened to our beautiful life?"

That was 5 years ago. My son is now 8 and though we have come to accept that he will always have autism, we no longer feel like citizens of a battle torn nation. With the help of countless dedicated therapists and teachers, biological interventions, and an enormously supportive family, my son has become a fun-loving, affectionate boy with many endearing qualities and skills. In the process we've created, well, our own country, with its own unique traditions and customs.

It's not a war zone, but it's still not Holland. Let's call it Schmolland. In Schmolland, it is perfectly customary to lick walls, rub cold pieces of metal across your mouth and line up all your toys end to end. You can show affection by giving a "pointy chin." A "pointy chin" is when you act like you are going to hug someone and just when you are really close, you jam your chin into the other

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person's shoulder. For the person giving the "pointy chin" this feels really good, for the receiver not so much - but you get used to it. For citizens of Schmolland, it is quite normal to repeat lines from videos to express emotion. If you are sad, you can look downcast and say "Oh Pongo." When mad or anxious, you might shout, "Snow can't stop me!" or "Duchess, kittens, come on!" Sometimes, "And now our feature presentation" says it all. In Schmolland, there's not a lot to do, so our citizens find amusement wherever they can. Bouncing on the couch for hours, methodically pulling feathers out of down pillows, and laughing hysterically in bed at 4:00 a.m., are all traditional Schmutch pastimes.

The hard part about living in our country is dealing with people from other countries. We try to assimilate ourselves and mimic their customs, but we aren't always successful. It's perfectly understandable that an 8-year-old boy from Schmolland would steal a train from a toddler at the Thomas the Tank Engine Train Table at Barnes and Noble. But this is clearly not understandable or acceptable in other countries, and so we must drag our 8-year-old out of the store kicking and screaming while all the customers look on with stark, pitying stares. But we ignore these looks and focus on the exit sign because we are a proud people. Where we live, it is not surprising when an 8-year-old boy reaches for the fleshy part of a woman's upper torso and says, "Do we touch boodoo?" We simply say, "No we don't touch boodoo" and go on about our business. It's a bit more startling in other countries, however, and can cause all sorts of cross-cultural misunderstandings. And, though most foreigners can get a drop of water on their pants and still carry on, this is intolerable to certain citizens in Schmolland who insist that the pants must come off no matter where they are, and regardless of whether another pair of pants are present.

Other families who are affected by autism are familiar and comforting to us, yet are still separate entities. Together we make up a federation of countries, kind of like Scandinavia. Like a person from Denmark talking with a person from Norway, (or in our case someone from Schmenmark talking with someone from Schmorway), we share enough similarities in our language and customs to understand each other, but conversations inevitably highlight the diversity of our traditions. "Oh your child is a runner? Mine won't go to the bathroom without asking permission." "My child eats paper. Yesterday he ate a whole video box." "My daughter only eats 4 foods, all of them white." "My son wants to blow on everyone." "My son can't stand to hear the word no. We can't use any negatives at all in our house." "We finally had to lock up the VCR because my son was obsessed with the rewind button."

There is one thing we all agree on: we are a growing population. 10 years ago, 1 in 10,000 children had autism. Today the rate is approximately 1 in 250. Something is dreadfully wrong. Though the causes of the increase are still being hotly debated, a number of parents and professionals believe genetic predisposition has collided with too many environment insults -- toxins, chemicals, antibiotics, vaccines -- to create immunological chaos in the nervous systems of developing children. One medical journalist speculated that these children are like the proverbial "canary in the coal mine" here to alert us to the growing dangers in our environment. While this is certainly not a view shared by all in the autism community, it feels true to me.

I hope that researchers discover the magic bullet we all so desperately crave. And I will never stop investigating new treatments and therapies that might help my son. But more and more my priorities are shifting from what "could be" to "what is." I look around at this country my family has created, with all its unique customs, and it feels like home. For us, any time spent "nation-building" is time well spent.

I would like to say that we are from Schmorway.

reprinted from

<http://www.eternallymine.com/archives/000074.html>



What About Me? Autism and Sibs

Children with autism undergo language and social difficulties that cause stress for the family. I should know. I was the oldest of five children growing up on a farm in Kansas. My sister, born in 1954, was diagnosed with autism at the age of four. The knowledge of autism at that time was scanty, so her difficulties were largely misunderstood and even unknown.

At that time persons with autism were estimated to be about one in ten thousand. Now estimates have risen to approximately one in five hundred. Today many more children are growing up with siblings who have autism. Parental attitudes make a big difference in the lives of all their children. These suggestions from my experience and from talking to others who have grown up with similar sibs may be helpful for parents who also have typically developing children.

Acknowledge feelings of the sib. Parents will feel shock, depression, guilt, anger, sadness and anxiety. So will the sibs. With fewer life experiences, including inexperience at recognizing feelings, children will be less prepared to cope with their emotions. Simple acknowledgement on an age-appropriate level can help. Especially if life seems too difficult, some families will want to consult a professional.

Hold family discussions. Discuss problems openly with other children in the family. Encourage questions and reactions. A disability needs to be talked about. Lack of communication made understanding and living with my sister more difficult. Avoiding dialogue will only encourage children to hide problems when they are adults with families of their own.

Keep sibs informed. As the parents learn about autism, children should be informed on an age-appropriate level. An excellent book for young people who have brothers or sister with autism is: *Everybody is Different* by Fiona Bleach, available from the Autism Resource Network, Inc., 904 Mainstreet #100, Hopkins MN 55343 USA. The book explains some general behavior, three characteristics of autism and then answers questions such as "Why does my brother or sister make strange noises?"

Encourage the sibs to go on after an embarrassing situation. Tiffany, now twenty-six, experienced many embarrassing situations while growing up with her sister Lindsey, who has severe autism. Once when the girls were much younger, they were singing in church in a minor key-'Lord, have mercy.' Lindsey suddenly burst out screaming-"Oh, no, we're all going to hell." Her mother hastily took her out of church. Tiffany said, "For the good of everyone, forgive, learn from the situation and move on.'

Have a sense of humor. This does not mean make fun of the person with a disability or laugh at him or her. However, laughter helps. Ceara chose her disabled brother to be at the guest book at her wedding. "I picked him because I love him," she said. She rehearsed for months with him what to say, 'Welcome to Ceara's wedding. Sign the book.' What he actually said was, 'You're late. Go home.' "You have to have a sense of humor," said Ceara. "He's kept his through all that's happened to him."

Give the brother or sister opportunities to find a friend whose sibling also has autism. This may be especially important in a family where there are not other typically developing children. Gordon, who's seventeen, has a twelve-year-old brother with autism. He made a friend, the drummer of a band he plays in. The drummer's brother is also in special education. "No one else [besides the drummer friend] knows what that's like [having a brother with disabilities], even my best friend." Places for brothers and sisters to find friends might be in a sibling support group or the children of those who attend a parent group.

Encourage the sib to develop a special interest. A strong interest can help through rough spots and even lead to a future career. Ceara loved playing the piano as a child and adolescent. Her college degree is in music therapy. My escape was always reading and creating stories. Though I taught for a number of years, today I spend much of my time writing. Other interests such as playing tennis or gardening can provide hours of enjoyment.

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Respect individual differences. As any parent knows, no two children are exactly alike. I am five feet two inches tall. One of my brothers is six feet four. A sister is almost six feet. Another brother and sister are five feet and ten inches. Our personalities are as different as our sizes. My daughters are also very different in size and personality. One started driving, reluctantly, at the age of eighteen. The other begged for car keys-and the car -- from the moment she turned sixteen. They chose to attend different high schools, both inconvenient and rewarding for me. In the long run, their choices benefited them both.

Promote an attitude of gratitude. At the age of three, my brother was thankful for "green beanz, pork'n beanz, and all other else beans." Though I like beans, this would probably not be my top priority in the thankfulness department. Nevertheless, kids have their own ideas. Though I do not do it daily, I keep a gratitude journal. In the journal I write down five things I'm thankful for and date it. When I look back, I am reminded of what was happening on that day, as well as many blessings. There's nothing magic about the number five. Two or ten will do just as well.

Support volunteering. As a college student, I volunteered in a chapel in a state school for the mentally retarded. With other college students, I helped escort residents back and forth from cottages for chapel. We organized choirs and bell choirs and Sunday school classes. We took some of the more able residents Christmas caroling to the cottages of the less able residents. One cold, wintry night I trooped through snow singing off-key, not that anybody cared. Afterward, we gathered in the chapel for hot chocolate. For me, that was a very rewarding experience. Opportunities to volunteer abound. Even children as young as ten can volunteer with a parent. A new study suggests that volunteering face to face, helping out strangers, is good for mental health for all of us.

Stay open to possibilities. Things are happening to benefit persons with autism and their family members all the time. Many children profit enormously from intensive speech and social skills therapy. Parents and professionals work diligently to learn more about what autism is, how it is caused and what can be done to assist those with the disorder. What is known today is different from what was known ten years ago.

Of course, living with a person with autism provides many rewards, but it is also fraught with many difficult moments, often overwhelming for parents and sibs. Maybe some of these strategies, helpful to me, can benefit others.

Annette Wood is a writer living in Wichita, Kansas. Over 250 of her articles have appeared in local, regional, and specialty publications. She is working on a book about living with her sister, *A Different Kind of Kin*. Email her at annette@woodwriter.com

reprinted from http://www.autismtoday.com/articles/What_About_Me.htm



Simple solution for picky eating

In some cases, getting a picky autistic eater to enjoy more foods might be as simple as adding ketchup, according to a recent study.

William Ahearn's subject was a 14-year-old autistic and profoundly retarded boy who avoided vegetables but ate other foods. Prior to intervention he refused to eat any of the three vegetables offered by Ahearn.

An assessment showed that the boy liked ketchup, barbecue sauce, and Italian dressing. During the intervention phase of the study, Ahearn offered vegetables with one of these three condiments. Immediately, the boy began accepting the vegetables every time they were presented. Afterward, the boy was taught to use a picture board to select condiments for each meal. His teachers reported that he ate his vegetables willingly, and he continued to do so at a one-year follow-up.

reprinted from *ARRI* Vol. 17, No. 4, 2003

Bullying and Teasing

This is an issue which needs to be addressed with all children. Children with Autism Spectrum Disorders have a higher risk of being the targets of bullying and teasing. Carol Gray's Guide to Bullying Part I and II (Winter 2000 & Spring 2001) give insight on bullying and a look at how we can help. The following are excerpts from her guides which are available at : www.TheGrayCenter.org.

How bullying is **defined** influences decisions regarding interventions. In terms of children with ASD the definition must account for their unique social characteristics. This article defines bullying as: 1) repeated negative actions (possibly coupled with negative intent) toward a targeted individual(s) over time; 2) an imbalance in the power (physically, verbally, socially, and/or emotionally) within the interaction; and 3) the possibility of contrasting differences in the immediate or delayed affect of the individual(s) involved.

Children play a variety of roles in a bullying interaction. Understanding children in the *social majority*, as *targets of bullying*, and *children who bully* is important to effective intervention:

- 1) *Children in the social majority demonstrate effective social skills and the ability to establish friendships*; they are 84% of a student population.
- 2) *Targets of bullying* are children frequently bullied by others. They often lack a positive self-esteem and the ability to readily form relationships. There are two identified types of targets: passive and proactive. Passive targets are often reserved and in the background, spending a lot of time in solitary activities. Proactive targets often irritate others, unaware of the negative impact they are having and not knowing "when to quit." They are often surprised and unprepared for the negative responses they receive.
- 3) *Children who bully others* frequently instigate aggressive interactions. They need to be in control or in charge, lack empathy for others, and often defy authority. To intimidate others, children who bully use direct confrontation (for example, verbal threats or physical aggression) or indirect gestures, rumors, or exclusion. They comprise 4% of the student population.

Bully Proofing Program

Jenison Public Schools did a Bully Proofing Program, developed by Dr. Marcia McEnvoy, Psychologist and Prevention Specialist, for all 4th graders. These were some of the issues discussed:

The Difference Between Reporting and Tattling An issue for fourth graders is the fear of being accused of "tattling" or "ratting." Dr. McEvoy makes a clear distinction between "ratting" and "reporting". It's ratting if the reason for telling an adult is to: get help for a problem you can solve yourself, get your own way, make yourself "look good", or get someone you don't like in trouble. Conversely, it's *reporting* if someone's body, feelings, friendships, or property is getting hurt.

Help for the Social Majority Children are the social "front lines" in any school. They are most likely to be among the first to observe or become aware of bullying relationships. Eighty-four of every one hundred students are empathetic to children who are bullied and not likely to be direct participants in a bullying interaction. Empowering this group by defining their role is critical. This is a friendly army that has previously never been given the opportunity to train or to demonstrate their potential. That is, not until today. Pinewood's fourth graders learn how to recruit adult assistance to help both the targets of bullying and the children who bully. They are encouraged to choose a course of action from the following:

- Privately report the incident to an adult.
- Encourage a child who is being bullied to report the bullying, accompanying that child if necessary.
- Encourage a good friend who is bullying to stop it before they get into trouble.

Learning these skills in a large group demonstrates that everyone is involved in the same effort, and that reports to adults will fall on informed ears. A new set of tools has just been handed to children who previously felt powerless.

The children are also trained regarding *how to report* bullying incidents to achieve the best results:

- Make the report privately, away from other children.
- When making the report tell *who* is involved, *where* the bullying occurs, and *what* form the bullying takes.
- Tell a second adult if the first adult does not take any action.

Having permission to report bullying concerns and the skills to do so, these fourth graders are a step closer to playing an active role in the social climate of their school.

Three rules are identified in the course of the assembly to ensure a safer school environment (Garrity et.al., 1994): 1) We will not bully other students; 2) We will help others who are being bullied; and 3) We will use extra effort to include all children, and report deliberate exclusion.

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Role-Plays. New rules require practice. Here that practice takes the form of role-plays. Children are asked to volunteer to participate. Consistently, they are placed in the role of the social majority or the child who is targeted; the role of the child who bullies is consistently assigned to adults. Students practice strategies for responding to a child who bullies. These include:

- **Poker Face.** The analogy is made to playing the game of Old Maid, where the ability to maintain an expressionless face increases the chances of fooling an opponent. Students are cautioned that — presented with the “Old Maid response” — a child who bullies may at first *try harder* to achieve the desired reaction until ultimately bored by the lack of response.
- **Act Like You Don't Care.** Students are coached to respond to the child who bullies with statements like, “Is this supposed to hurt my feelings?” or “...so?”
- **Stand Up to the Child Who Bullies.** Students practice using a straight posture, serious tone of voice, and direct eye contact while saying, “That’s not true,” “That’s not okay with me,” or “Stop or I’ll report you.” The tone of voice must be firm without being confrontational. The incident is reported if the bullying continues.
- **Use a Comeback.** Students are forewarned that comebacks are among the most difficult responses to use effectively in response to a child who bullies. There is a fine social line between defending and confronting that cannot be crossed; it is important not to hurt the feelings of the child who bullies. Comeback statements include: “Sorry you feel that way,” “Don’t go there,” “That’s getting really old,” “Talk to the hand” (hand up, walk away), “Have a great day” (big smile), “Thank you, what a kind thing to say.”
- **Compliment the Child who Bullies.** Students practice responses like, “I’m sorry you feel that way, but I think you’re really: pretty / good at math / great on a basketball court.”

Experts agree that most of the children who are bullied struggle with social skills and establishing relationships and so are often alone. Some students with Autism Spectrum Disorders make it through without being bullied because they have a friend who is well-liked and respected. Research also shows that increased adult supervision is the single most powerful factor to deter bullying. It is also important that the adults understand bullying and its unique profile and implications for children with Autism Spectrum Disorders.

Book Reviews

PERFECT TARGETS: Asperger Syndrome and Bullying (Practical Solutions for Surviving the Social World)

by Rebekah Heinrichs

“Perfect Targets provides helpful guidelines for administrators, teachers, and parents. The tools are specifically designed/adapted for the challenges faced by students with AS. One of my favorites is the Modified Inventory of Wrongful Activities—a guide to effectively interviewing students with AS to assess the specific bullying problems they are facing. This is a **MUST READ** for all parents & professionals serving individuals with Asperger Syndrome.” -Diane Adreon, Associate Director, University of Miami Center for Autism & Related Disabilities

The Asperger Parent: How to Raise a Child with Asperger Syndrome and Maintain Your Sense of Humor

by Jeffrey Cohen (March/April 03)

In this “carry-on support group,” Jeffrey Cohen, father of eleven-year-old Josh who was diagnosed with Asperger Syndrome at the age of five, examines what it’s like to be the parent of a child with AS—where the pitfalls are and how to do your best to avoid them. With a great sense of humor and welcome, at times unflinching honesty, Cohen looks at all the pride, fear, triumph—and offers a pat on the back, a shoulder to cry on, a kick in the pants or a warm hug, when needed. With an easy-to-read, anecdotal tone, *The Asperger Parent* provides essential information and emotional support without being clinical and dry.

What Parents and Professionals Are Saying

“Finally, a book that addresses the PARENTS of children with AS. In the *Asperger Parent*, Jeffrey Cohen addresses parental challenges—difficult ones that parents frequently encounter (such as family and friends believing the problem is the parents’ ‘parenting style’). I highly recommend this **WONDERFUL** ‘support’ book for all parents of children with Asperger Syndrome.” -Diane Adreon, Associate Director, Center for Autism and Related Disabilities and a parent of a child with AS

Upcoming Live Interactive Teleclasses

A teleclass is a virtual classroom created via a telephone conference call with many people from different areas of the country or world. Participants pay their own long distance phone fees. After you sign up and pay for the class, you will be given a phone number to call. The featured presenter will present 55-60 minutes of information on an specific topic.

www.autismtoday.com

Conferences

<u>Date</u>	<u>Title & Location</u>	<u>Speakers</u>	<u>Fee</u>	<u>Contact Info</u>
Apr. 2, 2004	Understanding "Behavior" in ASD Wayne RESA	Sally Burton-Hoyle, Kathy Johnson, Michelle Cypher	Vary	800-223-6722 ASM
Apr. 23, 2004	Special Education Law Macomb ISD	Tricia & Calvin Luker	Vary	800-223-6722 ASM
Apr. 30, 2004	The True Nature of Autism & Asperger Syndrome and Bullying Livonia	Richard Howlin, Ph.D. Rebekah Heinrichs, MSN, M.S. Ed.	Vary	800-223-6722 ASM
May 12, 2004	Autism/Asperger Syndrome and Medication Lansing	Dr. Luke Tsai	Vary	800-223-6722 ASM
Sept. 28-29, 2004	Adolescents & Young Adults with Asperger Syndrome: The Real World Grand Rapids	Liane Holiday-Willey Dr. Richard Howlin Dennis Debbaudt	?	www.unitingparadigms.com
Nov. 10-12, 2004	Geneva Center International Symposium on Autism	Multiple speakers		www.autism.net



Believe it or not, summer is coming! Camp-O-Rama is a list of Michigan camps for people with special needs. If you would like to receive this list contact:

Michigan Assistive Technology Resource
1023 South US 27
St. Johns, Michigan 48879
Phone: 517-224-0333 or 800-274-7426
www.matr.org

Free online newsletter at www.autismtoday.com

Resident experts, which includes people such as Temple Grandin, Jerry Newport, Dr. Simon Baron-Cohen, etc. can be asked questions online.



Perfect pitch and autism

One skill seen in many autistic individuals is perfect pitch—the ability to identify a musical note by name, or to sing a specific note perfectly in key. A recent study suggests that this talent may offer insights into genetic influences on autism.

Employing interviews and tests used to detect subclinical autism, W.A. Brown et al. evaluated 13 non-autistic musicians with perfect pitch, comparing them to musicians without this ability. The researchers report that nearly half of the musicians with

perfect pitch were socially eccentric, compared to only 15 percent of controls. The musicians with perfect pitch also scored higher on tests of block design than on other performance IQ subtests, a pattern common in autism spectrum disorders. The researchers suggest that the gene or genes involved in perfect pitch may be among those contributing to autism.



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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: Thursday, April 29, 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.)

A panel of parents will share some of their experiences raising their children with Autism Spectrum Disorders. A variety of ages, districts, and programs will be represented. Come share your experiences too and ask questions. 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.

Hope to see you there!

