



PERSPECTIVES

A publication for parents and professionals serving individuals with Autism Spectrum Disorders

GRASP, and the Word "Cure"

By Michael John Carley

When my son and I were diagnosed with Asperger Syndrome, or AS, one week apart in late 2000, I had no idea what kinds of debates were ongoing in the autism world. I thought initially that the autism world would all think the same: "How can they not, given that there's so much at stake?"

But they don't. There are hot debates about methods, ethics, and theories —many more so than those Alison Singer and I will touch on with this exchange. And these conflicts are probably a good thing, not a bad thing, even if it complicates matters. For in the grand scheme of things, we still know relatively very little about "all this autism stuff" and these discussions are really the correct, Darwinian road that we should all be on. The problem has only been where the debates have become *so* divisive; where one side's opinion has so invalidated the experiences of the other. *How* the disputes are played out can be vastly improved upon. And this exchange with Autism Speaks is a welcome opportunity to rectify some of the hurt that folks on both sides of this debate have experienced.

What I'm going to try to do is outline where we see the divisions existing, and then tell you why GRASP, and maybe other peer-run autism organizations (in other words, organizations run by adults on the spectrum) believe the way we do.

Where the disagreement lies

Yale's Fred Volkmar once used the words "lumpers" and "splitters" to define the two camps. I like these terms.

On one side are the splitters who think Autism and AS can be clinically separated. On the other, the lumpers, who feel the autism spectrum is all one and the same only with extreme ends, and a vast gradient in between.

Both lumpers and splitters would agree that if Albert Einstein (among many others) really did have AS, as people now say he did, then that's certainly not what people normally associate towards someone severely autistic who may be completely non-verbal. But while no one would want to have "cured" Albert Einstein of *anything*; if the lumpers are right, then that is exactly what we are saying — and this is where the two disagreements become one.

Splitters use the word "cure" believing that autism is a terrible thing to happen to a person, whereas AS, while presenting difficulties, is believed to be not so terrible, and maybe doesn't warrant use of the word. Lumpers (like us) do not believe in the opposite, i.e. that AS is somewhat terrible and/or that autism is not. Rather, they/we believe that the answers are far more complex.

The word "cure," like the word "disease," has historically reflected conditions, syndromes, and diagnoses that are *acquired*, meaning that you got it from somewhere after you were born. Now granted, genetic alteration — as proven by a Welsh lamb a few years ago — is not the impossibility we once thought it to be. And depending on what dictionary you're consulting, the descriptions of these words may not match the populist manner in which they are used. But in general, most people who

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believe that autism and AS are genetic do not use the words "cure" or "disease" because they feel primarily that what you were born with, i.e. your genes, you will die with. However, if you *do* believe that autism is acquired, then the word would seem to be medically appropriate.

Reprinted from www.autismspeaks.com

DOES AUTISM MAKE YOU A BETTER ARTIST?

AMONG those given MBEs in this year's New Year Honours was the artist Stephen Wiltshire. A big success, his immensely detailed cityscapes fly off gallery walls. He is also autistic. But are the two connected?

Ioan James, a professor of geometry at Oxford, is writing a book investigating whether Andy Warhol, among other influential figures in the arts, mathematics and history, suffered from Asperger's Syndrome, a mild form of autism. His use of grid patterns, paralysing shyness and tendency to repetitious behaviour may be clues that he did. Michael Fitzgerald's *The Genesis of Artistic Creativity: Asperger's Syndrome and the Arts* suggests it could also be added to Van Gogh's list of ailments. Likewise, LS Lowry. Seems that Scottish painter Peter Howson, who realised as an adult he was an Asperger's sufferer, is in good company.

James has said characteristics associated with creativity - "perseverance, perfectionism, disregard for social conventions and unconcern about the opinions of others" - are remarkably like those associated with Asperger's.



In Edinburgh, meanwhile, the work of three remarkable young artists is at the Atticsalt Gallery, 50 Thistle Street North East Lane, until next Saturday, to raise funds for the Autism Treatment Trust. Lloyd Allanson, 10, Danielle McLernon, 14 and Louis Laroche, 9, all suffer from autism to different degrees and all have produced artwork with an unusual degree of attentiveness and maturity.

Exhibition organiser Lorene Amet, Lloyd's mother, says: "A lot of people have autism. Are they more talented than others? I don't think you can be sure. I think their work stands out because it's different, they perceive the world differently."

Originated on news.scotsman.com

Reprinted from www.autismnews.co.uk

Autistic teen finds strength — and blue ribbon — in art

By Bob Wheaton

FENTON TWP. — Colored pencils and paint brushes have helped draw autistic teen Jacob Hoffman into a whole new world. Jacob, 14, who didn't talk until he was 3 ½, is now an award-winning artist who recently won the People's Choice prize in the youth art competition at the Michigan State Fair. That means more fair visitors picked his piece as their favorite than any of the more than 1,000 other youth exhibits.



Reprinted from The
Flint Journal, 9-16-06

ASA Signs on to Lifespan Respite Support Letter in the House

*Friday, September 29,
2006*

**ASA and Others
Cite Importance of
Respite Care
throughout the
Lifespan**

PERSPECTIVES

A publication of GISD's Special
Education Services Center

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On Wednesday, Sept. 20, a modified version of the Lifespan Respite Care Act was marked up in the House Energy and Commerce Committee. ASA signed onto a letter early last week in support of the act.

The Lifespan Respite Care Act would authorize federal grants that would jumpstart the creation and enhancement of respite programs across the country. Grants could be used for:

- Development of lifespan respite programs at the state and local levels
- Evaluation of such programs
- Planned or emergency respite care services
- Training and recruitment of respite care workers and volunteers
- Caregiver training to help make informed decisions about respite care services

Reprinted from www.autism-society.org

Boys With Autism Can Thrive in Scouting With Help

BY ELIZABETH M. JOHNSON

Parents need to assist unit leaders in working with a Scout whose behavior is affected by one of a variety of neurobiological conditions known as autism spectrum disorders.

When C.J. Hanson told his parents that he wanted to join Cub Scouts, his mother was terrified. "I didn't know how he could participate Crystal Hanson said. The Huntsville, Ala., youngster has Asperger syndrome, an autism spectrum disorder characterized by difficulties with social interactions and processing sensory information, an obsessive interest in one subject to the point that nothing else is of interest; a lack of physical coordination and a need for rigid routines.

"...he doesn't do well with loud noises, he's intimidated by new experiences, and he's not very coordinated," she explained. "He has trouble interpreting questions and following directions, and his play skills are



not well developed."

Children with Asperger syndrome have trouble understanding social cues and navigating the dynamics of friendship and group play. For instance C.J.'s mother noted that when other children play tag, her son may run around with them but he's playing his own game and not really joining the game of tag.

In preparation for C.J. joining Pack 234 Crystal Hanson sat down with the Cubmaster and Wolf den leader and explained her sons issues and his desire to be a Cub Scout. "They were very receptive and understanding from the get go," she recalled. "His leaders also strongly encourage C.J. to try new things, but if he doesn't feel comfortable, they never pressure him."

C.J.'s dad, Chris has also become actively involved with his sons participation. He attends meetings, interpreting information that C.J. has trouble processing and stepping in to help defuse any situation in which C.J. may get agitated or stressed out.



On a recent pack service project of cleaning a nature trail C.J. became paralyzed with fear at the prospect of crossing a boardwalk over wetlands. The Cubmaster was patient showing C.J. that the boardwalk was safe but reassuring him that he didn't have to cross if he didn't want to. He finally crossed and ended up having a great time removing leaves from the boardwalk.

Through Cub Scouting, C.J. made strides his mother never thought possible. "He made friends for the first time in his life," she said

"In school C.J. played alone. He didn't have the confidence or the skills to interact with other children. He didn't know how to start up a conversation, nor did he have the same interests as the others. In Cub Scouts he has found that all the boys are working toward the same goals and achievements. He now has a best friend who is also a Cub Scout, and they have begun discussing Scouting at school. Now that he has begun talking to this friend, he's branching out and talking and playing with other kids, too."



C.J. is also inspired by working on badge

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requirements in his Wolf handbook. "He doesn't stop working until he's accomplished each achievement," his mother said. "One weekend, he worked hard at balancing so he could walk on a small balance beam at the next meeting. Scouting has been very helpful for his self-confidence."

Reprinted from SCOUTING + SEPTEMBER 2006

ASA Advocacy Update—Keep the Emails Flowing

Ask Congress to Fund Autism Research Contact Your Congress Members to Sign Onto Appropriations Bills

It's September. School's back in session, and so is the U.S. Congress. The House and the Senate both returned last week and several key autism issues are on the agenda.

Each year, the Congress must pass a series of bills that fund the federal government. These bills, also known as appropriations, outline how much funding will be directed for all government programs, including autism research, education, and services. The House and Senate will be finalizing these bills in the coming weeks.

This year, the House included \$7.5 million for autism-related research in the funding bill for the Department of Defense. This funding would provide for early diagnosis and treatment for military families, and would also support research to identify the causes of autism and enhance therapies.

The Coalition for Autism Research and Education (CARE), led by Congressman Chris Smith (R-NJ), Mike Doyle (D-PA) and Carolyn McCarthy (D-NY) is circulating a letter to encourage appropriators to provide this \$7.5 million for an innovative research program at the Department of Defense. Senator DeWine (R-OH) and Senator Clinton (D-NY) are circulating a similar letter in the Senate.

Please contact your Representative and Senators

and urge them to sigil onto these important letters.

Reprinted from Reprinted from Autism Society of America.org

Invitation to Participate in Research Study

Research to Investigate Toxic Metals in Baby Teeth of Those with Autism and Typically-Developing Individuals

Jim Adams, Ph.D., and his team at Arizona State University are conducting a study to investigate the amount of toxic metals and essential minerals in the baby teeth of children with autism versus typically-developing children. The criteria for the study require that the participants:

- 1) Have a baby tooth unaltered by a filling, crown, cap or similar dental operation
- 2) Are born between June 1946 and June 2004
- 3) Have a diagnosis of autism spectrum disorder (autism, pervasive developmental disorder or Asperger syndrome) by a professional



If you have an old baby tooth and meet the above criteria, we are requesting your voluntary participation in our study. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. The results of the research study may be published, but your name will not be used, and we will maintain confidentiality of your test results.

Questions? Please e-mail Stephen.Villa@asu.edu or call 480-965-3316.

Reprinted from Autism Society of America.org

Study Denouncing Autism Epidemic Misses the Mark

April 2006
By: Kate Ranta

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ASA Calls for Studies Benefiting Families Now

Bethesda, MD — April 5, 2006 — The Autism Society of America (ASA), the oldest and largest grassroots organization serving the entire autism community, in response to a study by Dr. Paul Shattuck appearing in next week's edition of *Pediatrics* entitled "Diagnostic Substitution and Changing Autism Prevalence," says the study takes the focus away from the real issue: autism is affecting millions of people and families who need help today.

"We need to move away from a dialogue about prevalence," said ASA President & CEO Lee Grossman. "Whether it's 1 in 166 children or 1 in 1,166 being diagnosed with autism, each and every one of those affected today and in the future must be helped."

According to the study, the rise in number of autism diagnoses is not evidence of an epidemic, but shows that schools are diagnosing autism more often. Shattuck claims that autism rates have not increased over the last two decades, and children identified by U.S. school special education programs as mentally retarded or learning disabled have declined with the rise in autism cases between 1994 and 2003, suggesting a diagnostic substitution. Shattuck says there may be unknown environmental triggers behind autism, and his research suggests the past decade's rise in autism cases is a result of poor labeling.

ASA Board of Directors Chair Cathy Pratt, Ph.D. said that "in 30 years of working in the autism community, certain realities have become increasingly clear. More individuals are receiving a diagnosis on the spectrum. The needs of these individuals and their families continue to grow. And finally, the lack of options and resources place an incredible stress on all and threaten the future of these individuals. Any study that diverts our focus or that diminishes the perception of this need hurts us all. I know of no family who has enough resources for their child, nor any adult who has all the supports he or she needs."

Diane Twachtman-Cullen, Ph.D., co-chair of ASA's

Panel of Professional Advisors, noted that "the findings of Dr. Shattuck's study do not support the conclusion that there is or is not an autism epidemic. If we read more into this study than the findings support, we will be doing a disservice to the significant number of individuals with autism and their families who aren't mere statistics in a study, but rather, real people with real needs." Jim Ball, Ed.D., co-chair of ASA's Panel of Professional Advisors, added that regardless of Shattuck's study findings, more and more people are being diagnosed with autism and the focus must be on the services agenda.

"The fact remains that the numbers of those with autism have reached epidemic proportions, and we need to address this now," continued Grossman. "Let's put research into interventions, education and services for individuals with autism, not into a dispute about whether autism is being better labeled versus an epidemic."

Reprinted from www.autism-society.org

Perspective - A Poem for Jaren

by Barbara Spires

When you walked on your tippy toes
at the age of 11 months
We called you Skillful

When you playfully flapped your arms
at the age of one
We called you Adorable

When you methodically piled up the laundered
clothes
at the age of 15 months
We called you Eccentric

When you memorized every alphabet, number and
color
at the age of 18 months
We called you a Genius

When you climbed the tallest furniture piece
at the age of two
We called you Fearless

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When we told them all that you can do
at the age of two
They called you Autistic
And as you keep challenging yourself
to reach out to us
at the age of three
We choose to call you...Awesome

Reprinted from www.autismspeaks.org

Did you Know...

- ⌘ 1 in 166 children is diagnosed with autism
- ⌘ 1 in 104 boys is on the autism spectrum
- ⌘ 67 children are diagnosed per day new case is diagnosed almost
- ⌘ A new case is diagnosed almost every 20 minutes
- ⌘ More children will be diagnosed with autism this year than with AIDS, diabetes & cancer combined

Autism costs the nation over \$90 billion per year, a figure expected to double in the next decade

Autism is the fastest-growing serious developmental disability in the U.S.

Autism receives less than 5% of the research funding of many less prevalent childhood diseases

There is no medical detection or cure for autism

Boys are four times more likely than girls to have autism

Incidence vs. Private Funding

Leukemia:
Affects 1 in 25,000/Funding: \$310 million

Muscular Dystrophy:
Affects 1 in 20,000/Funding: \$175 million

Pediatric AIDS:
Affects 1 in 8,000/Funding: \$394 million

Juvenile Diabetes:
Affects 1 in 500/Funding: \$130 million

Autism:
Affects 1 in 166/Funding: \$15 million

National Institutes of Health Funds Allocation
Total 2005 NIH budget: \$29 billion

Of this, only \$100 million goes towards autism research. This represents only 0.3% of total NIH funding.

AUTISM SPEAKS
It's time to listen.

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Reprinted from www.AutismSpeaks.org

PAC Library

The Parent Advisory Committee (PAC) has a library of books, DVDs, & videos on various special education areas. Many of these resources are about autism spectrum disorders and can be checked out at GISD's SESC-N, 5075 Pilgrim Road, Flint, MI 48507. For further information contact Marcia Clark at 591-4881.

Perspectives

Perspectives is now on the GISD website at www.geneseeisd.org under Publications tab, then click on the newsletters link. Scroll down to find Perspectives. Publications from the past 3 years are also archived there.

Autism Spectrum Disorders DVD Workshops

The Autism Spectrum Disorders DVD Workshops are held the 2nd Tuesday of every month, except in April, which will be on April 3rd. View topics of upcoming workshops online at www.geneseeisd.org

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Conferences

Date	Title & Location	Speakers	Fee	Contact Info
Nov. 16, 2006	Challenging Behavior in Individuals with ASD Detroit, Michigan	Michael Powers, Psy.D.	\$149	www.neei.org Carolyn 413-499-1489, ext. 1
Nov. 16 & 17, 2006 AND Jan. 1, 2007 & Apr. 30, 2007	Picture Exchange Communication System Training Workshop Detroit, Michigan		\$425	www.pecs.com
Nov. 17, 2006	A.S. in School, Society, & the Workforce Grand Rapids, Michigan	Hawkins, Ziegler, Wiley, Howlin	\$99	www.aspergersyndrome.org 517-349-5959
Mar. 23, 2007	Practical Strategies for Working with Students with A.S. & High Functioning Autism Grand Rapids, Michigan	Kathy Morris	\$185	www.ber.org

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- ⌘ Move arrow over Training tab
- ⌘ Click on Professional Development
- ⌘ Search by alpha for Autism Spectrum DVD Workshop

Workshops can be viewed in the GenNet rooms at the following districts:

- ⌘ Davison High School (call 591-1157 to register)
- ⌘ Flushing High School (call 591-2320 to register)
- ⌘ GISD @ SESC-N, Register online to view at GISD
- ⌘ Goodrich Middle School
- ⌘ Lake Fenton High School (A129)
- ⌘ LakeVille High School Annex room 303
- ⌘ Swartz Creek High School

Call Patti Dombrowski at 591-4877 to register for Goodrich, Lake Fenton, LakeVille & Swartz Creek or if you don't have access to the Internet.

Up & Down...On & Off

Ever head of "yo yo" dieting? Sometimes you do. Sometimes you cheat. You lose weight only to gain it back. Lots of struggle with limited rewards.

Unfortunately, some people start out enthusiastically intending to use visual tools but they quickly forget. It is like going on and off a diet. This can frustrate students. They won't respond well to this

inconsistency. But...do you know how students can thrive?

Create a NO FAIL environment

What does that mean? I frequently have people ask me how to handle students who have lots of challenges. I answer by asking a question.

"What support does that student need to have a totally successful day?" Good question isn't it? It shows you where to begin. When you diet, you can't eat what's not there. Getting trouble foods out of your environment can help you be successful.

Visual strategies invite the opposite. Student's can't benefit from what's not there. Adding more visual helpers makes the difference. And what about the results?

Program yourself for success

There is no "one-size-fits-all" in diets or in using visual strategies. Develop a plan to follow, Make small deliberate changes in how you communicate. Watch for what works best and do it more. And be sure YOU have the support you need...

Develop a circle of support

Accountability works. Ask for help when you need it. Share your successes with someone. Help someone else get started. Good suggestions for lots of things in life. The bottom line...using visual strategies can help students participate more

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Support Groups

- ✦ Autism Support Group of Genesee County:
www.geneseeaautism.org
- ✦ Autism Support Group in Flushing: Christina Franklin (810) 732-1776
- ✦ Linden Community Schools Support Group for parents & guardians of children with an autism spectrum disorder: Moilanen (810) 591-9138 or 591-0708, Nyman (810) 591-9174
- ✦ ASA/Oakland County Chapter Events:
www.asaoakland.org
- ✦ Jack's Place for Autism: www.oakland.edu (click site map, then centers)



Websites on ASDs

Excellent websites for information on Autism Spectrum Disorders.

- ☞ Autism Society of America: www.autism-society.org
 - ☞ Autism Society of Michigan: www.autism-mi.org
 - ☞ ASA Oakland County Chapter:
www.asaoakland.org
 - ☞ Dr. Tony Attwood: www.tonyattwood.com
 - ☞ On-line Asperger's Information and Support-OASIS: www.aspergersyndrome.org
 - ☞ The Gray Center: www.TheGrayCenter.org
 - ☞ Liane Holliday-Willey: www.ASPIE.com
 - ☞ Free pictures of visual schedules, etc.:
www.usevisualstrategies.com
 - ☞ Picture Exchange Communication System:
www.pecs.com
 - ☞ TEACCH: www.teacch.com
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