

CHAPTER 8

Introducing Your Child to ASD: How and When to Talk to Your Child About the Diagnosis

I received my diagnosis of Asperger syndrome as an adult. This was a turning point in my life, as it explained the relationships between what I had previously seen as a large collection of strange behaviors, thoughts and preferences. Realizing that I was neurologically different helped me to finally see myself as a whole person. It also gave me a purpose and direction for my life. Advocating for respect and resources for adults on the autism spectrum has become my primary interest. I am a student in the College of Social Work at the University of Kentucky, and will graduate in May, 2008. I coordinate the statewide Social Club for Teenagers with Asperger Syndrome through Kentucky Partnership for Families and Children. I have presented information on autism to a variety of groups and maintain an advocacy related blog, Asperger Square 8.

Autism is not a detachable part of a person and it is not an outer shell behind which someone entirely different hides, waiting to be set free. Autism is intrinsic and cannot be removed. Even if it could, this would alter every aspect of the individual's being; he or she would no longer be recognizable as the person you know. This is the very meaning of the word "pervasive."

There can, then, be no "war on autism" without waging war on the person who is autistic. This does not mean that I don't believe parents should do everything possible to improve their autistic child's quality of life. But promises to "cure" autism should be viewed through a lens of skepticism. There are many schemes waiting to drain the bank accounts of parents. Worse yet, some of these unproven "treatments" may actually cause harm to children. The best source of information is peer reviewed literature found in established journals and written by scientists who have no financial interest in any particular therapy or treatment.

Without a doubt, being viewed by one's family as a tragedy is harmful. Many people believe that if a child does not respond verbally or show obvious signs of understanding speech, that this indicates he is "in his own world," oblivious to what is said about him.

This is not true. Many, many reports exist from autistic people who have acquired means of communication later in life, revealing the extent of harm done by this belief.

Lack of speech or of typical response does not indicate lack of understanding.

Autistic adults need to have a voice in all discussions concerning autism services. This has not been the policy of the large, well-known "charity" groups. A slogan borrowed from the general Disability Rights Movement expresses this most succinctly, "Nothing About Us Without Us." This is what I believe.

Bev Harp

A frequently discussed topic on autism message boards is “How and when do I tell my child about his or her diagnosis of an autism spectrum disorder?” How young is too young? Will my child understand? Will it add to his/her anxiety? Will it help him/her understand his/her differences? What about explaining to others, siblings and other family members, teachers, and peer groups? How does a parent go about helping others to understand autism without creating stigma or contributing to false beliefs about the condition?

These are a few of the questions parents will need to answer for themselves before approaching the subject with the child or teen that has been diagnosed. A growing collection of literature addresses this subject and is available to aid in the discussions. Included here are a few of the best resources for talking about the diagnosis.

For Children:

Elder, J and Thomas, M. (2005). *Different Like Me: My Book of Autism Heroes*. London: Jessica Kingsley Press.

This book introduces historical figures and other famous persons who fit the profile we now know as autism. Included are Einstein, Newton and Kant as well as Andy Kaufman, Andy Warhol and Temple Grandin. Suggested for ages 8 to 12, this book is also a joy to read as an adult, and would make an ideal introduction to the autism spectrum for a newly diagnosed child. Illustrated.

Elder, J and Thomas, M. (2007). *Autistic Planet*. London: Jessica Kingsley Press. A rhyming book for the younger set, this one is recommended for ages 4 to 8. *Autistic Planet* is a great book for building positive perspective from an early age, and would be appropriate for siblings of ASD kids, too. Here Elder envisions a world where children matter-of-factly prefer the weather report to cartoons, and where “We don't do something one time, when we can do it over and over again!” Illustrated.

Faherty, C. (2004). *Asperger's: What Does it Mean to Me?* Arlington, TX: Future Horizons.

This is an excellent workbook for older children, pre-teens and young teenagers. The sections are well formatted and designed to help the child explore issues of identity, self-esteem, learning styles and more. At just over 300 pages, the book is thorough, a great resource for teachers and parents as well. Foreword by Gary Mesibov.

Hoopman, K. (2006). *All Cats Have Asperger Syndrome*. London: Jessica Kingsley Press.

This is a small picture book which uses cats to illustrate some features of people with Asperger syndrome. It's cute and well-intentioned if not terribly informative. If you are going to buy just one kid's book about AS, this probably is not the one. However, it does a good job of what it sets out to do, and would be a nice addition to a small library or to leave on the coffee table for curious visitors to flip through.

Schnurr, R. (1999). *Asperger's, Huh?: A Child's Perspective*. Ontario: Anisor. Some children with Asperger syndrome will relate to this first-person narrative, while others will find its language too simplistic. While the publisher recommends this for ages 8 to 12, it is most appropriate for the younger end of that scale. It might be good for siblings of the AS child.

Strand, V.(2006). *I am Utterly Unique: Celebrating the Strengths of Children Asperger Syndrome and High Functioning Autism*. Shawnee Mission, KS: Autism Asperger Publishing.

This is an alphabet book for kids on the spectrum, ages 4 to 8. It presents a very positive perspective, celebrating the strengths and unique qualities of autism with humor and respect. 56 pages with color illustrations.

Welton, J., Newson, E., and Telford, J. (2004). *Can I Tell You About Asperger Syndrome?: A Guide for Friends and Family*. London: Jessica Kingsley Press.

Told from the perspective of a ten year old boy, this is a great little book for “bridging the gap” between AS kids and their peers or siblings. The author does an excellent job of explaining how people with AS struggle to learn those things which seem so automatic to others—body language, tone of voice, etc. Simple and direct without being condescending. For ages 8-13.

For Teens:

Ledgin, N. (2002). *Asperger's and Self Esteem: Insight and Hope through Famous Role Models*. Arlington, TX: Future Horizons.

Many teens on the autism spectrum could use a good self-esteem booster. Ledgin suggests that a number of scientists, artists and musicians have had much in common with young people now diagnosed with Asperger syndrome. Autistic traits of Marie Curie and Albert Einstein are discussed, as well as those of Glenn Gould and Mozart. For teens and adults. Foreword by Temple Grandin.

Jackson, L. (2002). *Freaks, Geeks and Asperger Syndrome*. London: Jessica Kingsley Press.

Luke Jackson wrote this book when he was just 13 years old, and offers one of the best and most thorough explanations to be found in the popular literature on AS. Jackson offers his experience and advice to other teens on such topics as class work, bullying, dating and hygiene. A great introduction for a young teen exploring the meaning of the Asperger diagnosis from a peer who writes with confidence and self-acceptance. Foreword by Tony Attwood.

For Teens and Adults:

Attwood, T. (2006). *The Complete Guide to Asperger's Syndrome*. London: Jessica Kingsley Press.

More than an expanded version of Attwood's 1996 *Asperger's Syndrome*, this book combines up to date research and clinical experience with personal insights from people on the spectrum. Chapters on marriage and career acknowledge the often ignored fact

of AS in adulthood. Written in accessible terms, this is a must have guide for family members, therapists and educators by one of the world's most respected authorities on the subject.

Attwood, T , Grandin, T., Bolick, T. and Faherty, C. (2006). *Asperger's and Girls*.
Arlington, TX: Future Horizons.

Asperger syndrome, like other conditions on the autism spectrum, is thought to occur four times more frequently in boys than girls. Therefore, the bulk of the research so far has focused on males. This book considers the questions specific to girls with AS as well as the possibility that AS is frequently overlooked or misdiagnosed in this population. Girls and young women with Asperger syndrome will appreciate this opportunity to read the personal perspectives included here.

Murray, D. (2005). *Coming Out Asperger: Diagnosis, Disclosure and Self-confidence*.
London: Jessica Kingsley Press.

This important book explores the impact of diagnosis and offers a number of strategies for disclosing autism. Learn the art of the "soft" disclosure and how to evaluate the level of risk for disclosing in various situations. This is an anthology offering viewpoints from professionals, family members and people on the autism spectrum.

Prince-Hughes, D. (2002). *Aquamarine Blue 5: Personal Stories of College Students with Autism*. New York: Swallow.

For the young adult considering college, here are some terrific first-hand reports of autism at the university level. Addressing social, communication and sensory issues from a variety of perspectives, each student describes his or her own experience with college life. Editor Prince-Hughes has a PhD in anthropology and is autistic as well.

Grandin, T.(1986). *Emergence: Labeled Autistic*. New York: Warner.

The first published book by the world's most famous autistic woman, Dr. Temple Grandin. Grandin talks about her childhood, sensory issues and her mother's work to have her included in mainstream schools.

Grandin, T.(1995). *Thinking in Pictures: My Life with Autism*. New York: Random House.

Further descriptions of life with autism from animal scientist Dr. Temple Grandin. This book includes more details of Grandin's thought processes and her work to bring more humane practices to the cattle industry.

Grandin, T. and Barron, S., (2005). *The Unwritten Rules of Social Relationships*.
Arlington, TX: Future Horizons.

What are autistic people thinking? What do neurotypicals (non-autistic people) expect? This is the book that explains it all. This is the key to understanding the "other" across the spectrum, separating the "musts" from the "shoulds" in social relationships, the secret codes everyone "just knows" but people with autism must be taught. Important. Invaluable. Every family with an autistic member should have this one.

Kearns-Miller, J. (2003). *Women from Another Planet?: Exploring Our Lives in the Universe of Autism*. First Books Library.

This anthology, written by women on the spectrum, offers a range of insight you rarely find in a single book. In addition to the individual chapters representing each author, there is a section in which several of the women discuss their perspectives on issues of importance to autistic women. In depth, varied and unique; highly recommended.

Newport, J. (2001). *Your Life is Not a Label: A Guide to Living Fully with Autism and Asperger's Syndrome*. Arlington, TX: Future Horizons.

Practical advice from an adult with Asperger syndrome. Much of this book focuses on basic life skills—riding a bus, opening a checking account, etc. Also included are chapters on dating and marriage. Not everyone will appreciate the author's emphasis on self-reliance and or his disdain for "labels." Newport also wrote the novel, *Mozart and the Whale*.

O'Neill, J.L. (1999). *Through the Eyes of Aliens: A Book about Autistic People*. London: Jessica Kingsley.

A book about acceptance by an autistic woman. The author views autism as a neurological difference to be respected, not marginalized or eradicated. Read this only if you love someone with autism and want to understand him or her better.

Williams, D. (1994). *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*. New York: Times Books.

This is a unique story of one autistic individual and her ways of coming to terms with a world which often seems harsh and confusing. Williams has written a number of books on autism and consults widely on related topics.

Zaks, Z. (2006). *Life and Love: Positive Strategies for Autistic Adults*. Shawnee Mission, KS: Autism Asperger Publishing.

Zosia Zaks shares her strategies on everything from grocery shopping with sensory issues to dressing for job interviews. Step by step details on subjects like cleaning an apartment will appeal to linear thinking Aspies who are struggle with executive functioning problems.