

# FASTimes

SUMMER 2010

## UM-NSU CARD Constituent Publishes Book!

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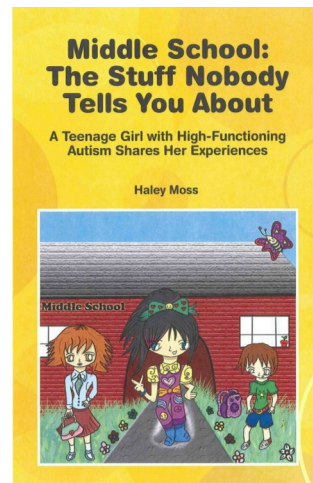
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This book was written by Haley Moss, a UM-NSU CARD Constituent! Congratulations to her and her family on this wonderful accomplishment!

Very few books are written from the perspective of a girl on the autism spectrum. For those of you who have a daughter, whether she is on the autism spectrum or not, this book may be very helpful.

*I highly doubt that you have ever heard someone say, "I wish I was back in middle school. Those were the days!"*

For most students, middle school is a tough time. For students with autism spectrum disorders (ASD), it can be particularly difficult. Social demands become more complex in adolescence. There is great pressure to "fit in" and children who are "different" are not always accepted.



Haley Moss devoted a lot of time and energy during her early teen years learning the hidden curriculum for middle school survival and social survival. Her book spells out, *in great detail*, the hidden curriculum that students with ASD need to know. She covers everything from school lockers, lunch, how to talk to teachers, homework, time management and friendship. She also addresses hidden curriculum items *specifically* for girls.

This book also tells Haley's personal story of life in middle school. You'll see that she was very successful.

Haley's story is just that.....Haley's story. In addition, the book includes experiences and advice from other girls on the spectrum as well as a teacher's perspective. These sections enhance the richness of this wonderful guide to middle school.

Adults may find some sections particularly helpful. For example, the section on *New Slang*, defines slang words and clarifies what kids are really saying. Haley also provides definitions of common internet communication lingo.



## Haley Moss (continued)

Haley decided that she wanted to do something that would help people with ASD. This book and the invaluable information that she has included will help many adolescents with ASD and their families.

I have had the pleasure of knowing Haley, and her parents, Sherry and Rick, since Haley was a toddler. Haley, with her parent's loving help and guidance, has progressed beautifully. She made a decision fairly recently to "come out" and tell people about her autism.

You can only imagine my delight at seeing how far she has come. Haley is a beautiful and lovely young lady. She is a high achiever in school and a talented writer. And, as you can see from her artwork throughout the book, she is a talented artist as well. Understandably, her parents are very proud of her accomplishments. Personally, I am proud of her and I believe that the autism community takes pride in learning about and from people with ASD like Haley.

By Diane Adreon, UM-NSU CARD

Haley's book, *Middle School: The Stuff Nobody Tells You About!* Is available from Autism Asperger Publishing. [www.asperger.net](http://www.asperger.net)

## Should I Tell My Child about His or Her Diagnosis of a High-Functioning Autism Spectrum Disorder? By Diane Adreon

Children with high-functioning autism spectrum disorders (ASD) are often seen by numerous professionals over a period of several years before someone diagnoses the child with an ASD. Finally, when given the diagnosis of an ASD, the pieces of the puzzle seem to make sense.

What is the purpose of a diagnosis? A diagnosis should help the family gain a holistic understanding of the child's

strengths and weaknesses, and help guide parents toward practitioners and interventions that are most likely to benefit their child. It takes time for families to learn about the ways in which having an ASD impacts their child.

Ultimately, to do well in life, we have to understand and accept ourselves. From my perspective, learning about one's diagnosis is part of that process. Often high-functioning children are aware that they are different from other children. Perhaps they are aware that they do not make friends easily. Learning that there is a reason they have difficulty making friends can be helpful. The child can learn that there are things he or she can learn to do that will help them develop better relationships with others. Children with high-functioning ASD frequently pride themselves on being "smart." These same children find it difficult to understand and accept the challenges they often face in school.



## Telling My Child about His or Her Diagnosis (continued)



It is my personal opinion that children with ASD should be introduced to their diagnosis at a young age. The child may not need a lot of information, just enough to acquaint them with the term and open the door for questions. Over the past several years we have learned a great deal from adults on the spectrum, many of whom have clearly articulated how important it has been for them to understand their difficulties (and strengths) in light of having an autism spectrum disorder.

Moreover, there are some potential “negatives” for NOT telling your child about his or her diagnosis. Perhaps a situation will arise and your child will come across some written material (like their diagnostic report or a letter that comes home from school that mentions autism) or will hear about their diagnosis from someone else.

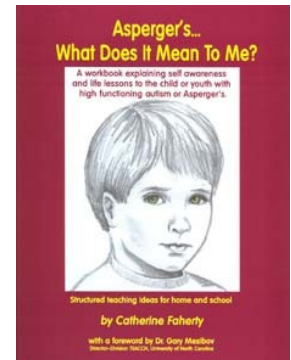
Keep in mind, that if your child has an IEP, he or she will be invited to participate in their IEP at the age of 16. In college and the workplace, adults with disabilities have to be able to self-advocate and seek out accommodations to which they may be entitled under the Americans with Disabilities Act.

The Indiana Resource Center for Autism has an excellent article, *Getting Started: Introducing Your Child to His or Her Diagnosis of Autism or Asperger Syndrome*. It can be found at <http://www.isdd.indiana>.

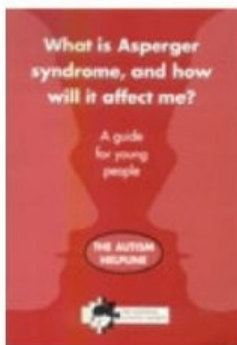


## RESOURCES FOR EDUCATING YOUR CHILD ABOUT AS/HFA

1. Faherty, C. (2001). **Asperger's... What Does it Mean to Me? Structured Teaching Ideas for Home and School.** Arlington, TX: Future Horizons. (800-489-0727) [www.FutureHorizons-autism.com](http://www.FutureHorizons-autism.com)



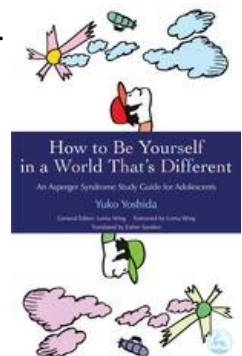
This is a book that will never become irrelevant or “outdated.” Every child who uses it also becomes its “coauthor.” Each chapter is divided in two parts: The first part-the “Workbook”-is for the child to complete, by writing “What is True for Me” in lists of simple statements. The second part-“For Parents and Teachers”-contains helpful tips/information for the adult who guides him through the exercises. This book is particularly good for elementary school students.



2. Ives, M. (2001). **What is Asperger Syndrome, and How will it Affect Me? A Guide for Young People.** The Autism Helpline. Shawnee Mission, KS: Autism Asperger Publishing. (877-277-8254) [www.asperger.net](http://www.asperger.net)

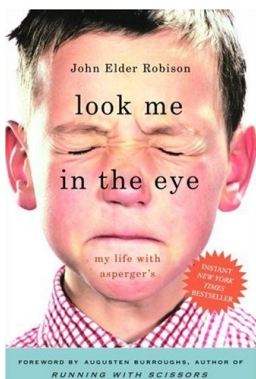
This is a simple booklet that answers basic questions about Asperger Syndrome in a neutral, realistic tone. Perfect for introducing young teens through young adults to Asperger Syndrome.

3. Yoshida, Y. (2005). **How to Be Yourself in a World That's Different An Asperger Syndrome Study Guide for Adolescents.** London and Philadelphia: Jessica Kingsley Publishing. [www.jkp.com](http://www.jkp.com)



This book is an ideal introduction to understanding and managing AS and ASDs for teenagers and young people with these conditions as well as the adults who support them.

4. Robinson, J.E. **Look Me in the Eye My Life with Asperger's.** Crown Publishing. [www.randomhouse.com](http://www.randomhouse.com)

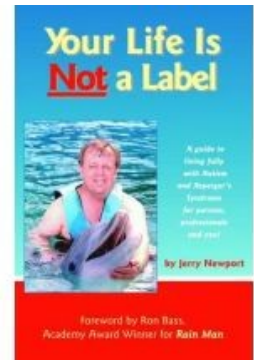


*Look Me in the Eye* is the moving, darkly funny story of growing up with Asperger's at a time when the diagnosis simply didn't exist. A born storyteller, Robinson takes you inside the head of a boy whom teachers and other adults regarded as “defective.” This is the story of Robinson's journey from his world into ours, and his new life as a husband, father, and successful small business owner.

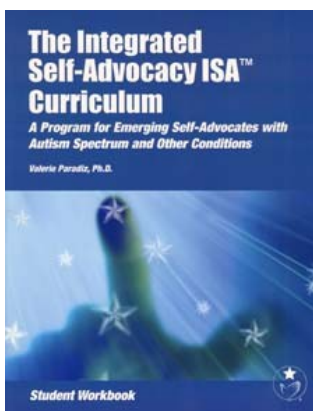
## RESOURCES FOR EDUCATING YOUR CHILD ABOUT AS/HFA

- Newport, J. **Your Life is Not a Label A guide to Living Fully with Autism and Asperger's Syndrome for Parents, Professionals, and You.** Future Horizons. 800-489-0727 [www.FutureHorizons-autism.com](http://www.FutureHorizons-autism.com)

Jerry Newport is an adult with Asperger Syndrome. His message: Everyone has the power-and the right-to improve the quality of their lives despite their disability. His candid, heartfelt advice stems from a deep sense of caring for “his people” on the spectrum.



## Resources on Self-Advocacy Issues



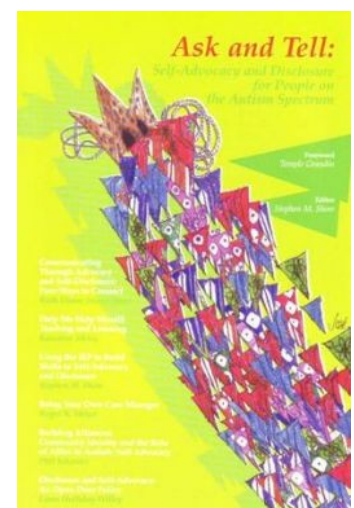
- Paradiz, V. (2009). **The Integrated Self-Advocacy Curriculum: A Program for Emerging Self-Advocates with Autism Spectrum and Other Conditions.** Autism Asperger Publishing. [http://asperger.net/bookstore\\_9028.htm](http://asperger.net/bookstore_9028.htm)

This curriculum helps professionals and family members provide safe forums for self-discovery, structured learning activities and a cumulative understanding of the many facets of self-advocacy. The ISATM Curriculum presents 11 units with detailed lesson plans, worksheets and activities, including scanning sensory and social environments, identifying how and when to self-disclose. Students' work throughout the lessons culminates in the creation of a personal self-

advocacy portfolio, a living document that can be adjusted over the life span.

- Shore, S., Hane, R.E., Sibley, K., Meyer, R.N., Schwarz, P., Holliday-Willey, L. (2004). **Ask and Tell: Self-Advocacy and Disclosure for People of the Autism Spectrum.** <http://nationalautismresources.com/ask-and-tell.html>

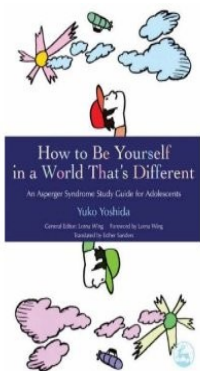
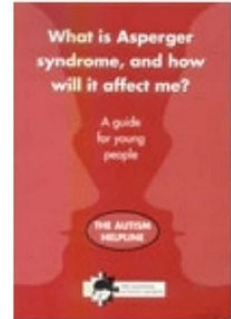
Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum aims to help people with autism effectively self-advocate in their pursuit of independent, productive, and fulfilling lives. Ask and Tell is unique by being the first book to speak to the twin issues of self-advocacy and disclosure for people with autism and by consisting exclusively - including the cover art and the preface by Temple Grandin - of contributions by those on the autism spectrum for persons on the spectrum.



## Resources on Self-Advocacy Issues

3. Martine; The National Autistic Society Helpline Ives (1998). **What is Asperger syndrome, and How will it Affect Me? A Guide for Young People.** Autism Asperger Publishing. [www.asperger.net](http://www.asperger.net)

Aimed at 8-13 year olds this booklet explains Asperger syndrome in simple jargon-free language for children with Asperger syndrome. This reader-friendly booklet is a valuable go-to resource for young people with Asperger Syndrome. Written by Martin Ives from the National Autistic Society helpline, it provides a brief introduction to the most common areas of difficulty for young people with AS, then gives an extensive list of practical tips to help deal with these common problems that young people will face. The guide ends with a list of answers to frequently asked questions by young people.



4. Yoshida, Y. (2007). **How to Be Yourself in a World That's Different An Asperger Syndrome Study Guide for Adolescents.** Jessica Kingsley Publishers [www.amazon.com](http://www.amazon.com)

"How to Be Yourself in a World That's Different" is an accessible guide to Asperger's Syndrome (AS) written for young readers who have been diagnosed with AS and other autism spectrum conditions. The book features a clear explanation of the condition, including symptoms that are common to people on the autism spectrum, such as a hypersensitivity to touch and difficulties with balance and coordination. The characteristics and symptoms of other syndromes that often coincide with AS are also discussed, for example ADHD and learning disabilities, as well as depression, anxiety, and obsessive and compulsive behaviors. This informative and encouraging text highlights the positive aspects of autism spectrum conditions, such as diligence, fairness, and a knack for unique ideas, but it also acknowledges the daily challenges faced by young people with AS and, crucially, offers strategies for dealing with these. Using case examples, Yoshida explores the difficulties of disclosing a diagnosis, takes readers through the stages of practicing key social skills, and offers advice on seeking support.

## Family Perspectives

By Dan Coulter

What's the most important skill a high school student with Asperger Syndrome or autism can learn before he or she graduates?

Run a list of candidate skills through your head. It's a good exercise.

Was self-advocacy on your short list? I think I can make a good case that it should be.

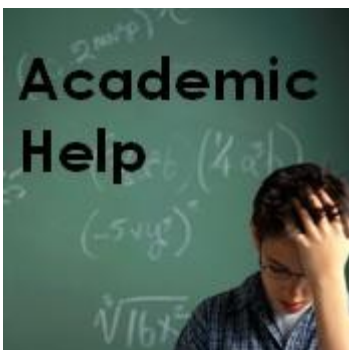
Whether your student is bound for a job or for college after graduation, he's almost certainly entering a much less protected environment. Many students on the autism spectrum are used to having a lot of things done for them. A student who hasn't learned to speak up for herself in high school isn't going to magically acquire the ability when handed a high school diploma.

If your son gets a job, will he ask the right questions if his boss gives him a task he doesn't understand?

If your daughter goes to college, how will she react if she doesn't catch the details of an assignment?



For many people on the spectrum, it's especially hard to speak up and ask for directions or for help. Sometimes that's because they don't want to call attention to themselves – or look different. And many kids on the spectrum would be at a loss to explain their challenges and what accommodations they need to perform well in a job or in a college class.



At a recent admissions seminar at High Point University near my home, a counselor explained a common reason that students with disabilities appeared before the academic review board after receiving poor grades. It was almost always the case that the students either hadn't asked for accommodations, or hadn't used the accommodations that they had been granted.

I've heard a number of accounts where someone on the autism spectrum lost a job because of problems that started with miscommunication with a supervisor.

Knowing this, you can help your kids avoid these pitfalls. Your son or daughter doesn't have to disclose his or her condition to everyone, but when they need and want to, can they – and will they? By the way, it's common for parents to assume that a child on the spectrum knows more about his condition than he actually does.

## Family Perspectives

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So, find out what your student knows. Sit down with your son or daughter and talk about the importance of self-advocacy. Ask them what they know about their condition and about any accommodations they're receiving at school. Use what you discover to fill in any gaps in their knowledge, then plan a program of activities that will continuously build their ability to explain their condition without embarrassment and describe what they need in a particular situation. Sometimes, what they need may turn out only to be detailed instructions on how an assignment or job needs to be done.

Show them the benefits of learning self-advocacy by tying their progress to privileges. The more situations they show you they can handle, the more independence you give them.

If your child has an Individualized Education Program at his school, make sure he knows what's in it. Discuss the plan with him before school IEP meetings and help him take an active part in the meetings. Consider making one of your child's IEP goals that he develops the ability to explain his condition and describe his needed accommodations to an employer or instructor. If you need help with your IEP, there's an excellent article titled, "Writing Individualized Education Programs (IEPs) for Success" by Barbara D. Bateman on the

["www.wrightslaw.com"](http://www.wrightslaw.com) website at:  
<http://www.wrightslaw.com/advoc/articles/iep.success.bateman.htm>



When your child has doctor appointments, get her used to talking to the doctor directly. You may want to explain to the doctor ahead of time, or at the beginning of the visit, that you're preparing your student to manage her own medical care, and that you'll be mainly an observer in the examining room.

It's also important to develop your child's ability to explain what he needs or wants when no mention of his condition is required. In stores, in restaurants, at events, etc., take every opportunity to have your student take the lead in interacting with people. Explain what he'll need to do in detail beforehand. You can stand by in case you're needed, but don't be too quick to step in and take over when there's a problem. You can think of yourself as a lifeguard. You don't want to let your charges drown, but everyone swallows a little water while learning to swim.

## Family Perspectives

By Dan Coulter

Recently, I interviewed Dorothy Wells, Assistant Director of Disability Support Services at the University of North Carolina at Pembroke. I asked her the most important things a high school student with Asperger Syndrome or autism should do to prepare for college. She said, "It's simple, start going to your IEP meetings and get comfortable talking to people about your special need."

You can think of self advocacy as a crucial "enabling skill" that allows your son or daughter to apply the other skills they've learned to succeed in class, in a career and in life. Self-advocacy may not be the most important skill on your list of things to teach your high school student. But it may be the most important skill that's not on your list – and should be.

ABOUT THE AUTHOR: Dan Coulter is the writer/producer of the videos, "Asperger Syndrome: Transition to College and Work" and "Asperger Syndrome: Transition to Work." You can read more of his articles at: [www.coultervideo.com](http://www.coultervideo.com).

It's simple, start going to your IEP meetings and get comfortable talking to people about your special needs.

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**University of Miami / Nova Southeastern University**

**Center for Autism & Related Disabilities**

This newsletter is an opportunity to share information, resources, and experiences.

We welcome your comments and contributions. We are also interested in highlighting artwork by children, adolescents, and adults with ASD. Please send items for consideration to Diane Adreon at: [dadreon@miami.edu](mailto:dadreon@miami.edu).

(Phone: 305-284-6556)

CARD is a state-funded resource and support program dedicated to improving the lives of individuals with autism and related disabilities including deaf-blindness and pervasive developmental disorders. CARD does not endorse specific programs or points of view presented in this newsletter.