




## Talking to Your Child About Their Diagnosis of ASD

Sylvia J. Acosta, PhD  
 Lauriann King, MFA




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## Overview

- Introduction and Quick Discussion
- The “W’s” of talking to your child about ASD
  - Who, what, when, where, why (and HOW too)
- Interviews and Group Activity
- Top 10 Tips
- Siblings
- Resources

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## Diagnosis of ASD

- The process...
- Parents/caregivers have been down the diagnostic and intervention roads
- They may or may not have come to terms with the diagnosis for themselves
- At some point, parents must decide when the best time to talk to their child about their diagnosis which is undoubtedly a challenge

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## To Tell or Not to Tell?

**Cons**

**Pros**

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## To Tell or Not to Tell?

**Cons**

- Don't want child to think he's different or create negative self-esteem
- Don't want to "label"
- Don't want to give an "excuse" for certain behaviors
- What will others think?
- Requires a lot of thought, time and continued effort
- Don't know what to say-it's not easy!

**Pros**

- Helps a child understand themselves (strengths and challenges)
- Empowerment and self-advocacy
- Provides an explanation for differences
- Increases self-acceptance
- Access to coping strategies
- Positive communication

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## Why Should We Talk?

- Children will otherwise create their own explanations (likely negative)
- Professionals (and parents) agree that talking to a child about their diagnosis of ASD (or any other diagnosis) is recommended in order to provide:
  - An understanding of themselves and the diagnosis
  - Self acceptance and positive view of themselves
  - Ways to cope and move on
- Children who know about their diagnosis may be less likely to develop low self-esteem, anxiety or depression

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## What to Consider

- Parent readiness
  - Coming to terms with the diagnosis
  - Be ready for questions and reactions
- Each person is different
- Age: chronological vs. mental age
- IQ
- Language level
- Timing of diagnosis

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## When is the best time to tell?

- There is no fixed age, but
  - Start the conversation as early as possible
- Use the terms "autism" or "ASD" as appropriate in conversation
- Consider developmental appropriateness and language level of the message




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## When is the best time to tell?

- Not only consider the child's age, but level of cognitive development



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## What do we say?

- One first step is to ASK the child what they think or what they have already heard
- Assure the child that they are loved/valued/special
- All children have differences
- He/she is not alone
- The child was born with ASD

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## What do we say to the young child?

- Early Childhood (under age 7 years)
  - Keep language simple
  - Use concrete examples from personal experience and observable behavior
  - Focus on hands-on tasks
- For example: create an "All About Me Book"




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## What do we say to the school age child?

- School Age (ages 7-12)
  - Develop increased self-awareness
  - Begin to observe differences in others and themselves
  - Can use books or activity sheets to help illustrate
  - Begin to discuss the characteristics of ASD
  - Provide them with coping strategies
- Example: Social Stories




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## What do we say to the teenager?

- Teenagers
  - May begin to think more abstractly
  - Can begin to understand the core deficits and what this means for them
  - May have more insight for their behavior
  - Can help develop their own positive coping strategies
- Example: The Attributes Activity



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## What do we say to adults?

- Adults
  - Provide more abstract information and facts on ASD
  - May be able to research on their own
  - Address emotional reactions
  - Provide resources of factual information and support groups
  - Read autobiographies




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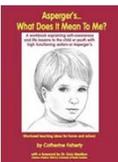
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## Examples

- *I Am Special: Introducing Children and Young People to their Autistic Spectrum Disorder* by Peter Vermeulen
- *What Does It Mean to Me? A workbook explaining self awareness and life lessons to the child or youth with High Functioning Autism or Aspergers* by Catherine Faherty

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## Where do we do this?

- Conversations might occur anywhere as long as you have:
  - Time
  - Focus/attention
- The idea is to create a **safe environment** and establish **healthy communication patterns**
- Family meetings

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## Healthy Communication

- Establish open communication with the child
  - Listening vs. Reflective listening
    - Respect feelings
    - Show empathy
    - Check for understanding- a very important step!
  - Talk about feelings
  - Be aware of own emotions, label emotions and model appropriate emotional expression
  - Let child know you are there to talk

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## How?

- Use a “matter of fact” and non-judgmental tone
- Be honest and open
- Keep sessions short
- Use visuals
- May need to set limits
- Manage your own emotions

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## Strength-based



- Always present the individual with examples of their strengths when talking about challenges
- Never provide an excuse for their behavior
  - "It's a reason not an excuse"
- Try to provide a coping mechanism each time

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## Who else needs to know?

- It is important to discuss who else needs to know and it may be different based on the age of the person
  - Family members
  - Teachers
  - Siblings
  - Friends/Classmates/Peers
  - Employers
  - Colleagues

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## Interview with an Adult with ASD

- Helping others was helpful in his acceptance of his differences
- Emphasized the importance of being involved in many different activities
- Importance that family, friends, and teachers understand autism
- Value of decision making
- Talk to your child as a person first

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## Interview of Father of a Middle School Child

- Never explicitly told him
- Waited until his son reached an age that it could be a discussion
- Be honest
- Less about how he is different and more about how he has unique qualities
- Ongoing conversation

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## Interview with a Mother of a Middle School Child

- Her son needed to know that he is a person first
- She felt he already knew his differences
- The sense that her son was relieved after the discussion about autism
- Parents need to be aware about their own feelings about the subject first
- Individualized and real for the family

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## Interview with the Mother of an Adult

- Keep the discussion "matter of fact"
- Don't agonize about the right time
- Talking about sensory experiences is a good place to start
- Had a lot more conversations about autism as she is older
- ASD is more public knowledge which helps the discussion

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## TOP 10 TIPS

- 1. TALKING ABOUT ASD IS A PROCESS (NOT A ONE TIME EVENT)**
- 2. BE PROACTIVE**
- 3. NEED TO KNOW BASIS**
- 4. CONCRETE → ABSTRACT**
- 5. DISCUSS THE CHILD'S STRENGTHS**

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## TOP 10 TIPS

- 6. KNOW YOU ARE NOT ALONE**
- 7. BE POSITIVE**
- 8. USE BOOKS AND ACTIVITIES**
- 9. DON'T BE AFRAID TO ASK FOR HELP**
- 10. YOU CAN'T GO WRONG!**

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## Challenging Questions

- Negative emotional reactions such as anger, sadness, or hopelessness
- Denial
- "Why Me?/It's not fair"
- Using the diagnosis as an "excuse"
- Dealing with other people's reactions

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## Supporting Siblings

- Talking to the individual's sibling about the diagnosis of ASD is just as important
- Normalize feelings
- Similarly, provide developmentally appropriate information
- Include the sibling in the process

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## Resources for Parents

- Informal support from family members and friends as well as other parents of children with ASD
- Parent support groups/information
  - New Mexico Autism Society: <http://www.nmautismsociety.org/>  
505-332-0306
  - CDD Information Network <http://cdd.unm.edu/InfoNet>  
Information Specialists 1-800-552-8195 Library Services 1-800-827-6380
- Formal support from professionals in the area who may be able to provide counseling
  - Family therapy/counseling

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## Resources for Parents

- Books:
  - *Making Sense of Autistic Spectrum Disorders* by James Coplan, MD
  - *Siblings of Children with Autism: A Guide for Families* by Sandra L. Harris, PhD and Beth A. Glasberg, PhD
  - *The Autism Sourcebook: Everything You Need to Know About Diagnosis, Treatment, Coping, and Healing* by Karen Siff Exkorn
- Web:
  - Autism Speaks- family support tool kits, resource guides and library: <http://www.autismspeaks.org/>
  - Asperger Syndrome and High Functioning Autism Association: [www.anany.org](http://www.anany.org)
  - Indiana Resource Center for Autism <http://www.iirc.indiana.edu/>
  - New Jersey Autism <http://www.autismnj.org/>

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## Books for Child/Adolescents with ASD

- *A Special Book About Me: A book for children diagnosed with Asperger's Syndrome* by Josie Santomauro
- *Freaks, Geeks & Asperger Syndrome: A User Guide to Adolescence* by Luke Jackson
- *Can I Tell You About Asperger Syndrome? A Guide for Friends and Family* by Jude Welton
- *Different Like Me: My Book of Autism Heroes* by Jennifer Elder
- *I Am Special: Introducing Children and Young People to their Autistic Spectrum Disorder* by Peter Vermeulen
- *What Does It Mean to Me? A workbook explaining self awareness and life lessons to the child or youth with High Functioning Autism or Aspergers* by Catherine Faherty




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## Books for Adults with ASD

- Temple Grandin books
- *Genius Genes* by Michael Fitzgerald and Bendan O'Brien
- *Look Me in the Eye: My Life with Asperger's* by John Elder Robison
- *Born on a Blue Day* by Daniel Tammet




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## Resources for Siblings

- Sibling Support Group or Activities
  - New Mexico Autism Society
  - Sibshops- <http://www.siblingsupport.org/>
- Sibling Pen Pal Program
  - <http://autismnj.org/WelcometoAutismNewJerseysKidsCorner.aspx>
- Reading List for Children/Adolescents
  - <http://autismnj.org/ReadingListforChildrenAdolescents.aspx>
- Kid's Booklet on Autism for Siblings and Peers
  - <http://autismnj.org/Doc/KidsBookFinalWeb.pdf>

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## Resources for Siblings

- Books:
  - *Everybody is Different: A book for young people who have brothers or sisters with autism* by Fiona Bleach
  - *My Brother is Autistic* by Jennifer Moor-Mallinos (available in Spanish)
  - *Autism Through a Sister's Eyes* by Eve B. Band Emily Hecht
  - *My Brother Sammy* by Becky Edwards and David Armitage
  - *Mari's Story: A Book About a Boy with Autism* by Zachary Gartenberg, Zachary
  - *Sometimes My Brother: Helping Kids Understand Autism Through a Siblings Eyes* by Angie Healy
  - *Joey and Sam* by Illana Katz and Edward Ritvo
  - *Ian's Walk: A Story About Autism* by Laurie Lears
  - *Living with a Brother or Sister With Special Needs and Views from Our Shoes: Growing up With a Brother or Sister with Special Needs* by Donald Meyer
  - *All About My Brother* by Sarah Peralta
- DVD for siblings of different ages and their parents:
  - *Understanding Brother and Sisters on the Autism Spectrum* by Coulter Video, 2007.

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## In Summary

- Talking to your child about his or her diagnosis of ASD will likely be necessary and is recommended as early as feasible
- Understanding a diagnosis can be a life-long process and it is important for parents to communicate openly with their child
- Present information in a positive, strength-focused and developmentally appropriate manner adding more information over time

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## References

Attwood, T. (2005). *Should you explain the diagnosis to the child?* Retrieved February 13, 2012 from <http://www.autism.org.uk>.

Coplan, J. (2010). *Making sense of autistic spectrum disorders*. Bantam Books: New York.

Foden, T. & Anderson, C. (2010). *ASD diagnosis: what do we tell the kids?* Kennedy Krieger Institute. Retrieved March 7, 2012 from [www.kennedykrieger.org/es/articles/telling\\_a\\_child\\_about\\_his\\_asd](http://www.kennedykrieger.org/es/articles/telling_a_child_about_his_asd)

Harris, S. & Glasberg, B. (2003). *Siblings of children with autism: A guide for families, Second Edition*. Woodbine House: Bethesda, Maryland.

Wheeler, M. (2003). *Getting started: Introducing your child to his or her diagnosis of Autism or Asperger Syndrome*. Indiana Resource Center for Autism. Retrieved March 7, 2012 from [www.iirc.indiana.edu/](http://www.iirc.indiana.edu/)

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## Contact

Sylvia Acosta

[syacosta@salud.unm.edu](mailto:syacosta@salud.unm.edu)

Lauriann King

[laking@salud.unm.edu](mailto:laking@salud.unm.edu)

The Autism Programs  
Center for Development and Disability  
2300 Menaul NE  
Albuquerque, NM 87107  
1-800-270-1861

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