Talking to Your Child About Their Diagnosis of ASD

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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

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
To Tell or Not to Tell?

<table>
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<th>Cons</th>
<th>Pros</th>
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<tr>
<td>• Don’t want child to think he’s different or create negative self-esteem</td>
<td>• Helps a child understand themselves (strengths and challenges)</td>
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<td>• Don’t want to “label”</td>
<td>• Empowerment and self-advocacy</td>
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<td>• Don’t want to give an “excuse” for certain behaviors</td>
<td>• Provides an explanation for differences</td>
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<td>• What will others think?</td>
<td>• Increases self-acceptance</td>
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<td>• Requires a lot of thought, time and continued effort</td>
<td>• Access to coping strategies</td>
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<td>• Don’t know what to say—it’s not easy!</td>
<td>• Positive communication</td>
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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
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

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

When is the best time to tell?

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

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”

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
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

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

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
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

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

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
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

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

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
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

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

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
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

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

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!
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

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/Institute 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

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: http://www.asperger.org
  - Indiana Resource Center for Autism http://www.indyautism.org
  - New Jersey Autism http://www.autismnj.org/
Books for Child/Adolescents with ASD

- *A Special Book About Me: A book for children diagnosed with Asperger’s Syndrome* by Josie Santomauro
- *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

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

Resources for Siblings

- Sibling Support Group or Activities
  - New Mexico Autism Society
  - Sibshops: [www.sibshopsupport.org/](http://www.sibshopsupport.org/)
- Sibling Pen Pal Program
  - [http://autismnj.org/WelcomeToAutismNewJersey/ReadingsListforChildrenAdolescentsForSiblings](http://autismnj.org/WelcomeToAutismNewJersey/ReadingsListforChildrenAdolescentsForSiblings)
- Kid’s Booklet on Autism for Siblings and Peers
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
  - Mom’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

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

References


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