Issues affecting siblings of children with autism spectrum disorders

02/27/2019

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Overview

• We’ll discuss:
  – Overview of impact on children who have siblings with special needs, and ASD in particular
  – What parents can do to help
  – Resources for siblings/parents/therapists
Autism Spectrum Disorder

• Now includes what used to be called Autism/Autistic Disorder, Asperger’s Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

• A neurodevelopmental disability that can cause significant social, communication, and behavioral challenges (www.cdc.gov)
  – Affects each person in different ways
    • “If you’ve met one person with autism...you’ve met ONE person with autism”

• Affects 1 in 88 people (www.cdc.org)
To give some context...

• Sibling relationships can be complicated. Period.
• Development is not static
• Every family is different
Overlap and differences between ASD and other conditions that affect siblings

• Similarities:
  – Siblings experience emotions such as jealousy, guilt, etc
  – Have to explain their unique family situation to others

• Differences:
  – People are often more understanding/empathetic to conditions they are familiar with or can “see”/easily identify
  – Their siblings’ symptoms are unique to autism and may more directly affect them
Emotional experiences of siblings

• Confusion

• Frustration

• Sense of loss/grieving

• Bitterness/resentment

• Jealousy
Emotional experiences of siblings

- Guilt
- Fear
- Acceptance
- Love
- Pride
Impact across the lifespan

Emotional responses are likely to change over time as both siblings continue to develop
Other impacting factors

• Number of siblings
• Birth order
• Age difference
• Family relationships
• Culture, religion, other factors of diversity
What parents can do to help

• Explain ASD
• Explain ASD...in the context of your child/their sibling
• Explain symptoms that may be confusing/frustrating
• Debunk myths
What parents can do to help

• Validate and normalize their emotional experiences
• Identify challenges AND strengths/gifts that their sibling displays
• Keep developmental stage in mind- for both the child with ASD and their sibling
• No “perfect” time to disclose
What parents can do to help

• As always, provide a model for celebrating victories and coping with challenges
• Keep it real
• Find small opportunities for one-on-one time
• Find opportunities to provide praise
What parents can do to help

• Remind them they can’t control how others respond to their siblings, but they can control their own attitude and response

• Role play how they would handle different scenarios

• Help foster the sibling relationship by identifying activities they can do together, and apart

• Allow for each sibling to have private space
Groups/camps for siblings

- Hearing others’ experiences
- Role playing how to handle situations
- Providing feedback
- Psychoeducation/parent training
Books, comics, videos, etc for siblings

- Social stories
- Books written for siblings
- Blogs, social media groups, online support groups
Questions?
References


• Sibling resource packet. The Autism Program at Boston Medical Center.
Resources- Books

• Everybody is Different: A Book for Young People Who Have Brothers or Sisters with Autism. By Fiona Bleach (Ages 9-12)
• Siblings: The Autism Spectrum Through Our Eyes. Edited by Jane Johnson and Anne Van Rensselaer
• Siblings of Children with Autism: A Guide for Families. By Sandra L. Harris, Ph.D. & Beth A. Glasberg, Ph.D.
• What About Me? A book by and for an autism sibling. By Brennan & Mandy Farmer. (Pre-K to 3rd grade)
Additional resources

- Autism Speaks: A parent’s guide to autism
  [https://www.autismspeaks.org/tool-kit/parents-guide-autism#siblings](https://www.autismspeaks.org/tool-kit/parents-guide-autism#siblings)
- Autism Speaks: A sibling’s guide to autism
- Siblings of Autism [https://siblingsofautism.org/](https://siblingsofautism.org/)
- Sibling Support Project [https://www.siblingsupport.org/](https://www.siblingsupport.org/)
- Sibshops [https://www.mwph.org/programs/pm-rehabilitation/services/sibshops](https://www.mwph.org/programs/pm-rehabilitation/services/sibshops)
- Today’s Man- a documentary made by a filmmaker who has an adult brother with ASD
- Very Special Camps [https://www.veryspecialcamps.com/summer/siblings-camps/](https://www.veryspecialcamps.com/summer/siblings-camps/)