

# Issues affecting siblings of children with autism spectrum disorders

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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



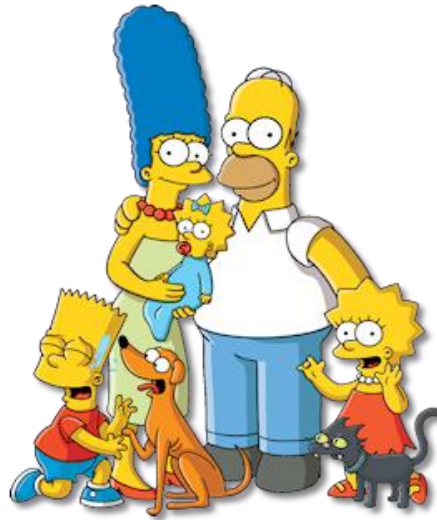
# Autism Spectrum Disorder

- 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](http://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](http://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

- Angell, M.E., Meadan, H., & Stoner, J.B. (2012). Experiences of siblings of individuals with autism spectrum disorders. *Autism Research & Treatment*.
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- Ferraioli, S.J. & Harris, S.L. (2009). The impact of autism on siblings. *Social Work in Mental Health*, 8, 1533-2933.
- Sibling resource packet. The Autism Program at Boston Medical Center.

[https://www.bmc.org/sites/default/files/Patient\\_Care/Specialty\\_Care/Pediatrics%20-%20Autism/Sibling-Resource-Packet.pdf](https://www.bmc.org/sites/default/files/Patient_Care/Specialty_Care/Pediatrics%20-%20Autism/Sibling-Resource-Packet.pdf)

# 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 3<sup>rd</sup> grade)

# Additional resources

- Autism Speaks: A parent's guide to autism  
<https://www.autismspeaks.org/tool-kit/parents-guide-autism#siblings>
- Autism Speaks: A sibling's guide to autism  
<https://www.autismspeaks.org/tool-kit/siblings-guide-autism>
- Siblings of Autism <https://siblingsofautism.org/>
- Sibling Support Project <https://www.siblingsupport.org/>
- 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/>