

# TO BE A SIB: AN EXPLORATION FROM THE PERSPECTIVES OF SIBLINGS OF CHILDREN WITH SPECIAL NEEDS

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# OBJECTIVES

- 1) Participants will be able to list some of the common feelings that siblings of children with special needs often hide from their caregivers.
- 2) Participants will be able to list some helpful resources specifically designed for sibs.
- 3) Participants will be able to increase their involvement with positively fostering meaningful sibling relationships between their children.

# SIBLINGS

- Our first peers
- A family member that will most likely be in our lives the longest
- Holders of our history- personal archives
- If biological siblings, the person on earth that has DNA that is closest to matching ours



# FAMILY SYSTEMS THEORY

- Individual members of the family are parts (subsystems) of the whole family
- All parts work together to function and comprise the family- Spousal subsystem, parental subsystem, sibling subsystem
- Within the family there are relationships, rituals, structure, boundaries, coalitions, and interdependence- parts comprise the whole
- The sibling subsystem is a unique coalition that can be heavily influenced by the parental subsystem. For example parents may create rules about friends...
- Family stress theory (Hill's ABC-X model)
- A (stressor) + B (resources) + C (meaning/perspective) all interact to produce = X (level of stress/crisis)

# SOME BRIEF HISTORY

- Historically, children with special needs were taken away from their families. Professionals operated out of fear and misconceptions especially when there was an obvious birth defect or inability to speak
- Think about the movie Rain Man and how the sibling with special needs was taken away thus leaving the neuro-typical child in the family confused and at a loss.
- There has been a radical shift in the field of autism as parents, advocates, educators, and SIBLINGS have sought to bring awareness and acceptance
- From blaming “refrigerator moms” for autism thus producing shame to worldwide autism awareness campaigns and massive fundraising research efforts
- Individuals with Disabilities Act (IDEA) was “recently” enacted by Congress in 1975  
<http://www.parentcenterhub.org/repository/idea/>

# IMPORTANT LANDMARKS

- *A Difference in the Family: Living with a Disabled Child* by Helen Featherstone was published in 1981. The author's acknowledgement of parental grief, stress, and honesty was instrumental in giving parents emotional support.
- The sibling subsystem is still important, however, it is the most often neglected relationship in the family. Often times the focus is on intervention for the child with special needs and parental education/support while sibs spectate.
- Don Meyer, founder of Sibshops and also a sib himself, has been a key figure in providing sibs a forum to talk about "the good and not so good parts of being a sib." There is an online forum for sibs (SibNet, SibTeen, SibKids) and other opportunities for communities at <http://www.siblingsupport.org/>

# COMMON FEELINGS OF SIBS

## Often Visible

- Happy
- Inquisitive
- Caring/Overbearing/Protective
- Outgoing
- Confident
- Mature/Adult-like
- A preoccupation with pleasing others

## Often Invisible or Disguised

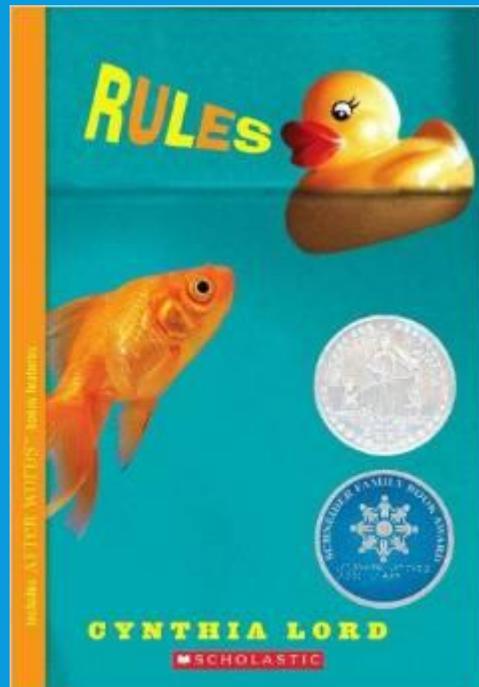
- Worried/Anxious
- Confused
- Scared
- Angry/Annoyed
- Jealous
- Sad/Depressed
- Deep feelings of guilt- age, birth order

# POSSIBLE RESOURCES

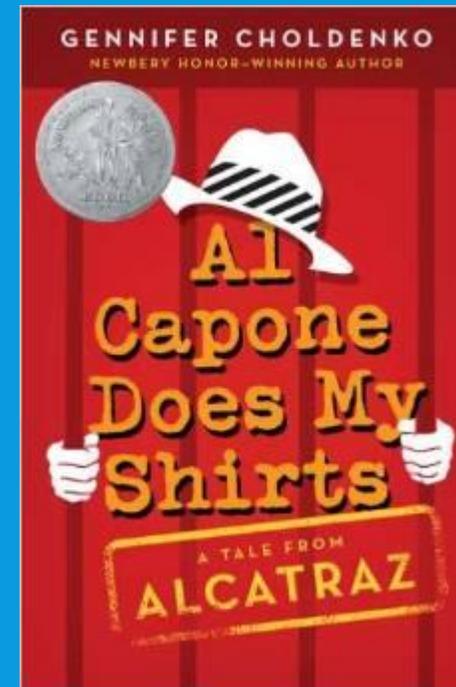
- Put your oxygen mask on first! ~*The Elephant in the Playroom: Ordinary Parents Write Intimately and Honestly About the Extraordinary Highs and Heartbreaking Lows of Raising Kids with Special Needs* (Denise Brodey, 2007).
- Realize that you are an expert on the parental subsystem, but your children are experts on the sibling subsystem
- Family therapy, support groups, and one-on-one dates with your children are important ways for your child to be heard, supported, informed, but mostly to be given attention
- Learn about your child's perspective- children's books are a great place to start
- Teen books are even better!

# RECENT FAVORITES

*Rules* (Lord, 2008)



*Al Capone Does My Shirts* (Choldenko, 2006)



# WAYS TO FOSTER POSITIVE SIBSHIPS 😊

- Establish some non-negotiable family rules.
- Collaboratively create some family rules
- Have one-on-one dates with your child and acknowledge their position in the family
- Talk about the good and not so good parts
- Involve your child in some decision-making, but not in a burdensome way



# TO BE A SIB

- Siblings are our first peers and often the family that will be a part of our lives the longest.
- These relationships teach us about working through conflict, supporting one another, and learning to be friends.
- To be a sib is a decision that is multi-faceted and happens throughout the lifetime
- Sibs are amazing people! Some local, fabulous sib projects: 1) Autism Awareness license plates were made by a sib!!! 2) Beading to Beat Autism founded by a sib. Parents were instrumental in both endeavors.

# QUESTIONS?

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