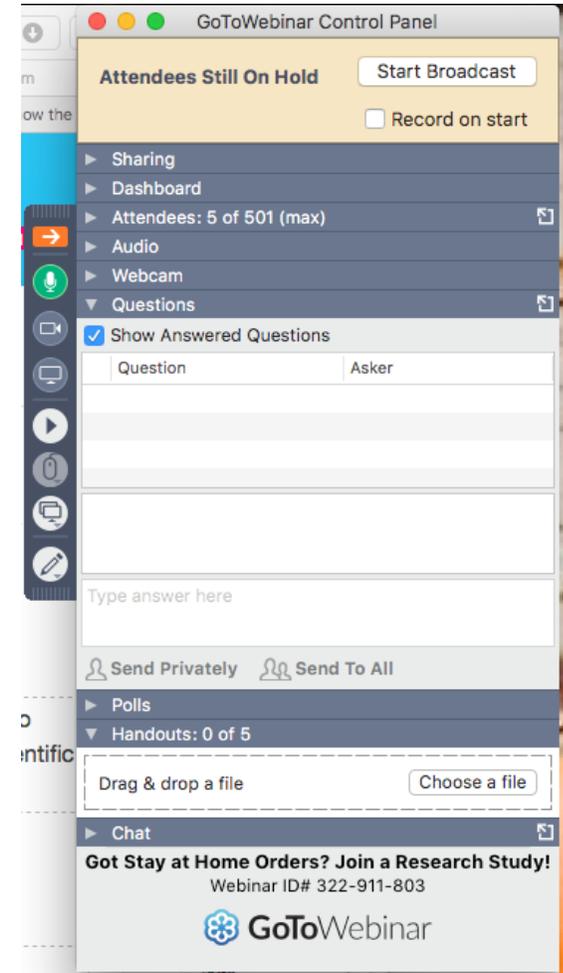


SIBS STICK TOGETHER



Guidelines for today:

- You are all on mute, no video.
Go wild!
- Use the question box for questions or comments
- You send questions to me, I will ask them anonymously
- We can also unmute people that need to speak

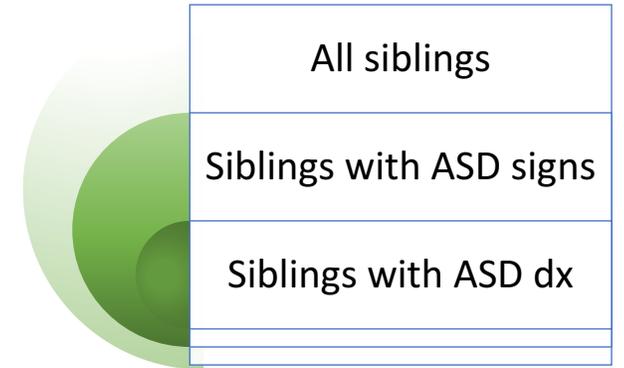


Things for you to consider

- What is the most challenging aspect of having a sibling on the spectrum?
- What is the most positive aspect?
- What questions would you like researchers to answer?
- What would you love to talk about with other siblings?

What do we know about siblings?

- Younger siblings have a 20% probability of an ASD diagnosis
- Of the other 80%, 30% show the “broader autism phenotype”
- Knowing this at birth allows for
 - earlier diagnosis, knowledge of red flags
 - more specific interventions, delivered in flexible settings
 - Faster delivered interventions
 - understanding of individual features of ASD or the BAP
 - awareness of planning for the growing family



[Home](#)[Family Information](#)[COVID-19 resources](#)[People](#)[Research Sites](#)[More](#)

HISTORY



The Baby Siblings Research Consortium (BSRC) is a multidisciplinary, collaborative community of researchers and clinicians committed to understanding the developmental origins and earliest signs of autism spectrum disorder (ASD) by studying infants at familial risk for ASD. Over the last decade, through rigorous studies conducted by investigators across multiple sites, the BSRC has identified both behavioral and biological markers of risk and disrupted development prior to the age of diagnosis, sparking studies of early intervention in infancy. The BSRC shares this knowledge with investigators, parents, and clinicians who provide care to communities and families, and shares research strategies with all those investigating high risk populations.

www.babysiblingsresearchconsortium.org



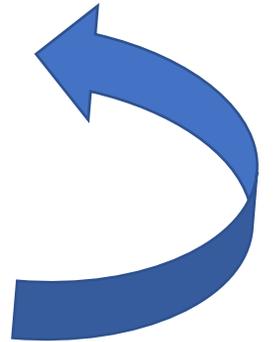
Challenges in siblings based on (presumably) genetics

Up to 6 years old:

- ADHD
- Learning disabilities
- Language problems
- Emotional issues

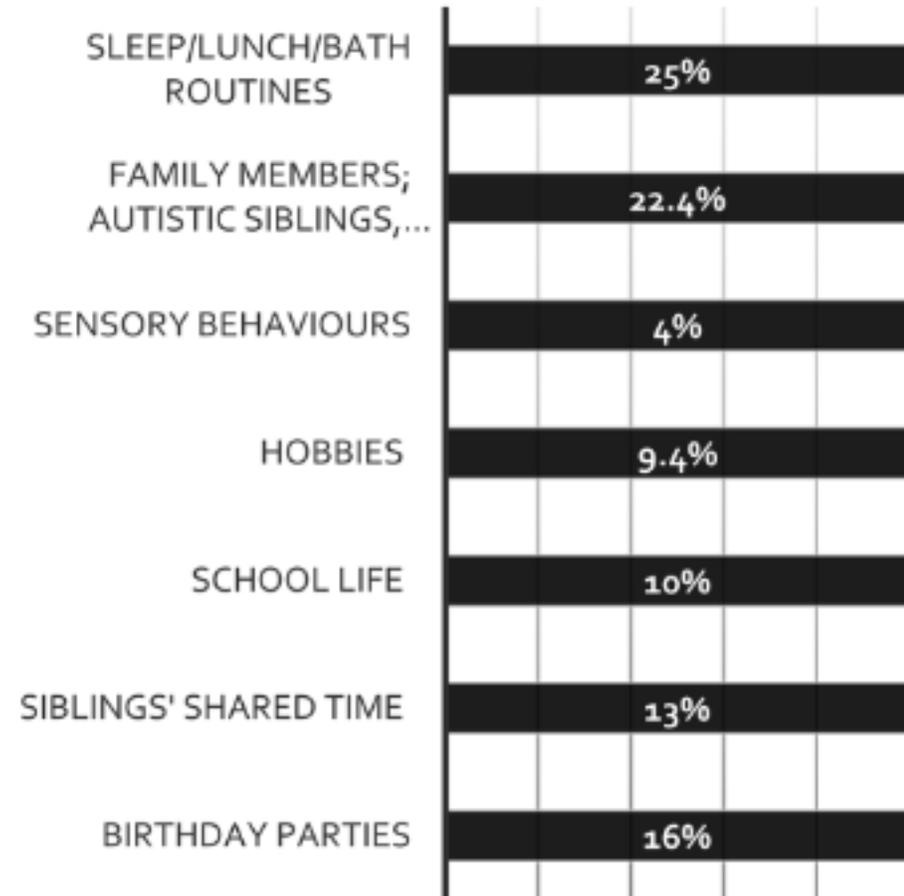
6-16 years old**

- Rates of attentional and emotional issues similar to other typically developing populations
- Still elevated
- Age discrepancies
- Number of neurotypical siblings
- **It's complicated**



Positive aspects

- Greater sense of acceptance, commitment, valuing difference
- Remember fun times
- Communicate in reciprocal ways to create flexible environments
- Participation with the community
- Better perspective taking
- Higher empathy
- Parents: “more mature”



Pavlopoulou and Dimitriou, 2020; Shivers, 2018

Beyond infancy – across the lifespan

- Fewer studies published
- Qualitative and quantitative



I worry about how I can best look after Seamus and make sure he lives his best life, while also having one of my own.

... I do someday want to have a child. But how would I do both? How would I do okay by her [Fiona] and by a child ... So yeah, that would be a worry for me. And the guilt. ... And it's the sense of duty, the sense of responsibility. The wanting to do it, it's not that you don't want to, but it's very hard then when that comes into conflict with the other relationship.

My cousin is one of the very few people of my age who can visit without us panicking. We are all comfortable with her as she knows us, she knows about autism and she is comfortable around my brother. That saves me and my parents from feeling worried or awkward having a visitor who does not understand my brother...You know, my brother can also run free and stim without having critical eyes on him. With my classmates I would feel worried to tidy up, to make sure my brother does not show up a lot in the living room...it's just harder.

- International perspectives (UK, Taiwan, US, South Africa)

What makes siblings special?

- Shared experiences of childhood create close emotional bonds with brothers and sisters with ID/ASD and a heightened sensitivity to their needs and feelings.
- These connections, reflective of ‘high interdependency, strong attachment, intimacy and responsibility over time’, all support the idea that in many cases, siblings feel a high moral obligation to care for their siblings.
- Care can be financial, or awareness of needs, staying close and supportive

Attitudes and adjustment

- SES may play a role in adjustment
- Siblings felt more positive emotions when younger, but also had less understanding about their relationship and poorer feelings about their interactions when they were younger.
- Adult siblings maintain positive feelings of sibling into adulthood
- Increased feelings of responsibility, challenges with aggression
- Strong emotional ties
- One neurotypical sibling usually ‘most involved’
- Poor quality of sibling relationship associated with anxiety
- Parent and sibling reports can be different. Effects are small, but parents **typically** report less positive and more negative behaviors within the sibling relationship.

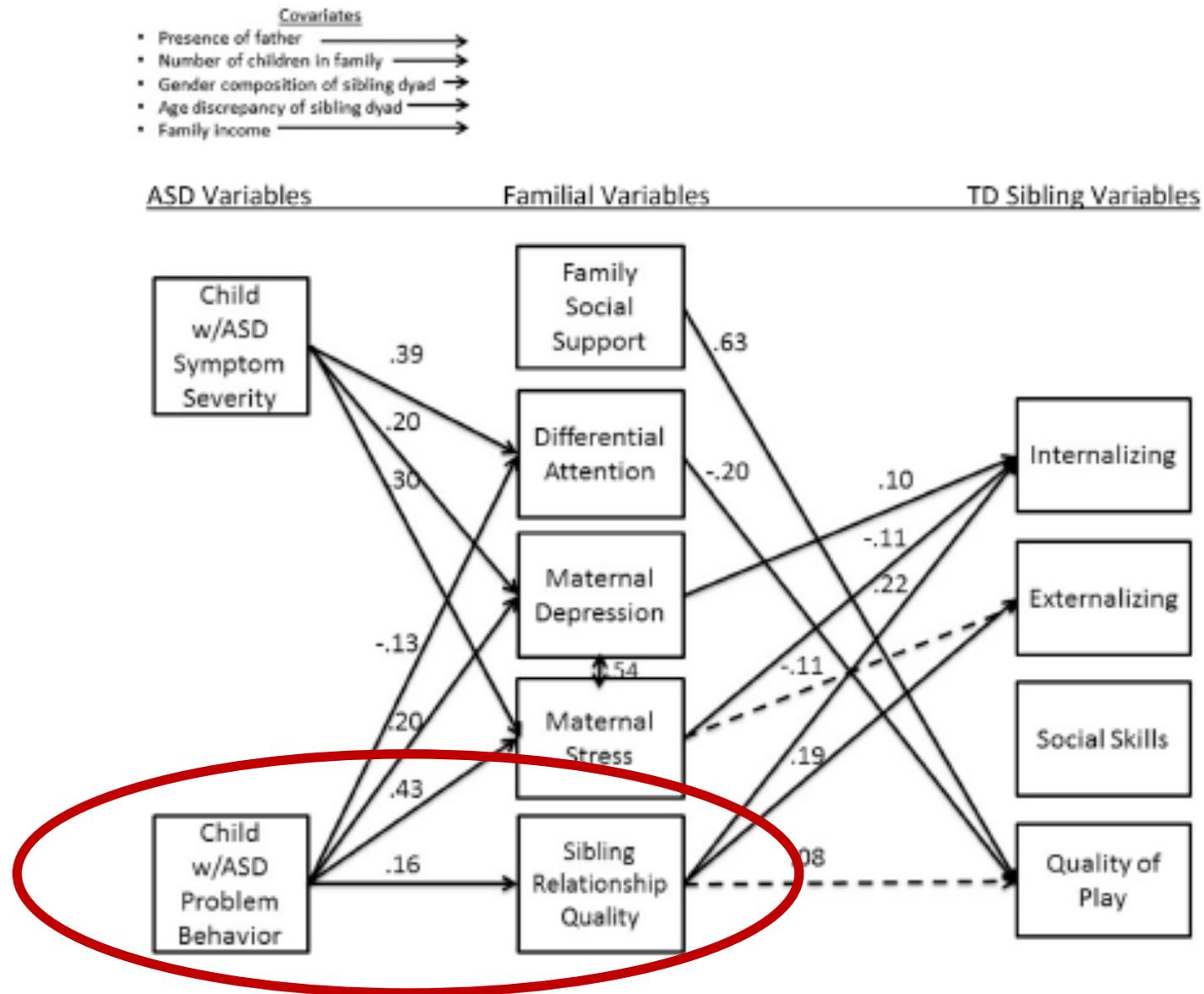
Van der Merwe et al., 2017; Braconnier et al., 2018; Leane et al., 2019;

Family functioning

- No "rule" about functioning in TD sibling based on whether or not siblings has ASD
- Quality of adult relationship predicted by adolescent relationship
- Sisters of sisters most involved and most engaged
- Difficult behaviors and level of aggression important
- Cultural differences (Taiwan vs. UK)
 - Stigma
 - Family dynamics
- ***Social support critical (larger families, spouse, parents, friends)***
 - Understanding autism, supportive environments, chance to relate to other siblings

Garrido et al., 2020; Malick et al, 2007; Tsai et al., 2018; Leedham et al., 2019

Model of functioning



Social support as an intervention tool

- Support group
- New parent training add-on
- Sibshop model
- Sibling Support Project
- Sibnet – only for adult siblings
“recreation tool”

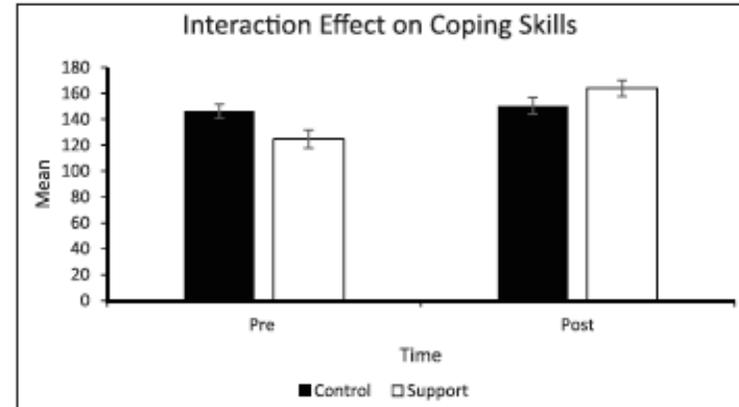


Figure 2. Significant group \times time effects on coping skills.



Jones et al., 2020

Sibshops intervention as a tool

Followed participants as adults many years later and found

- Over 90% of the respondents said Sibshops had a positive effect on the feelings they had for their siblings;
- Sibshops taught coping strategies to over two-thirds of respondents;
- Three-fourths reported that Sibshops affected their adult lives;
- 94% said they would recommend Sibshops to others.
- Overall, effects are positive and enduring



Johnson and Sandell, 2005

Kimberly – Els for Autism

- Prepared to start a family support group
- Family structure has changed in this pandemic. Siblings are going to be home with their special need siblings
- Started visual sib rooms (8-13 so far) – 4 to 6 people
 - Recreation piece, “get to know you”
 - Icebreaker
 - Counseling/therapy/coping skills
 - Created an environment to discuss positive and negative feelings, safe place to share.
 - Feeling lists
 - Not required to show their camera
 - End with something to bring back next week

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ahalladay@autismsciencefoundation.org

- Going to continue to serve that population
- There is a room called “families coping through conversation” that includes siblings and parents, Tuesday evenings at 8PM
- College population is essential.



Resources

- Siblings should be connected with age appropriate reading materials.
- Family activities outside the disability is important.
- Sibling Support Project
- Sibnet
- Sibshop
- Connecting your child with other siblings through a support forum is of value.
- Questions and fear of the future?
- In person support group for adults with autism, has been moved to virtual