Siblings: From Infancy to Adulthood

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On this webinar

How has studying infant siblings improved understanding of autism?

What do we know about siblings without a diagnosis through childhood and adolescence?

What scientific research out there is directed at siblings through their life?

What do siblings want to know about? What are their priorities?
A diagnosis affects the entire family. There are approx. 5.5 million siblings of autistic people in the US.

Few studies that focus specifically on siblings.

Siblings have specific challenges.

They also sometimes become the primary caregiver (~25%).

They go into "helping" fields within neurodevelopmental disorders.

Siblings are important, they make a real difference in the lives of people with ASD, they are also often forgotten.
From infancy: baby siblings

- Siblings have a 15x (1/5) chance of an autism diagnosis
- Can study early signs of ASD
- Biology
- Comparison of siblings with a diagnosis vs. those without
What do these studies look like?

- From weeks old to 3 years old
- Looking at emergence of autism features in younger sibling
- Factors that promote resilience and likelihood
- Biological features seen before a diagnosis
- Sibling features without a diagnosis
What can these studies tell families?

~20% are diagnosed with autism
What about the other 80%?
**Clinical Guidance**

- High-risk siblings who do not have an ASD diagnosis nevertheless exhibit slightly higher ASD-related severity scores on the ADOS and slightly lower verbal and nonverbal developmental functioning on the Mullen than low-risk control children at age 3.

- Among high-risk siblings who do not themselves have ASD outcomes, the majority (65%) occupy classes that appear typical with respect to mean ASD severity and developmental functioning.

- Another 14% occupy a class characterized by high ASD severity but high levels of developmental functioning.

- The final 21% of high risk siblings without an ASD outcome are overrepresented in two classes characterized by high levels of ASD severity in the presence of low-average developmental functioning, and by low levels of ASD severity in the presence of lower developmental functioning.

- High-risk siblings without ASD outcomes are nevertheless at high risk for the emergence of ASD-related behavioral characteristics and developmental difficulties, reinforcing the importance of developmental surveillance.
### Table 2. Mullen-Defined Outcomes (Developmental Delay and Language Delay) by Risk Group and Sex

<table>
<thead>
<tr>
<th></th>
<th>Low Risk non-ASD</th>
<th></th>
<th>High Risk non-ASD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (N = 473)</td>
<td>Females (N = 222)</td>
<td>Males (N = 251)</td>
<td>Total (N = 859)</td>
</tr>
<tr>
<td>No Delay</td>
<td>433 (91.54%)</td>
<td>206 (92.97%)</td>
<td>227 (90.44%)</td>
<td>709 (82.54%)</td>
</tr>
<tr>
<td>Developmental Delay (ELC &lt; 85)</td>
<td>16 (3.38%)</td>
<td>4 (1.80%)</td>
<td>12 (4.78%)</td>
<td>91 (10.59%)</td>
</tr>
<tr>
<td>Language Delay (T-score &lt; 40)</td>
<td>24 (5.07%)</td>
<td>12 (5.41%)</td>
<td>12 (4.78%)</td>
<td>59 (6.87%)</td>
</tr>
</tbody>
</table>

### Table 3. Elevated ADOS Scores (Total CSS 3-and-Above) by Risk Group and Sex

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<tr>
<td>ADOS CSS &lt; 3</td>
<td>393 (83.09%)</td>
<td>191 (86.04%)</td>
<td>202 (80.48%)</td>
<td>609 (70.90%)</td>
</tr>
<tr>
<td>ADOS CSS ≥ 3</td>
<td>80 (16.91%)</td>
<td>31 (13.96%)</td>
<td>49 (19.52%)</td>
<td>250 (29.10%)</td>
</tr>
</tbody>
</table>
• This is not to pathologize autism traits, we all have some to some extent

• Differences and diversity should be valued and appreciated

• Traits are not the same as a diagnosis

• However, more intense accumulating traits may signal specific needs of siblings that if don’t receive a full diagnosis, may go ignored
Likelihood of psychiatric conditions in siblings of children with autism

## Adolescence - Empathy

Table 3. Means and standard deviations of empathy by group.

<table>
<thead>
<tr>
<th></th>
<th>ASD-Sibs (n = 26)</th>
<th>TD-Sibs (n = 48)</th>
<th>t-Values</th>
<th>Cohen's d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fantasy</td>
<td>23.38 (5.97)</td>
<td>23.23 (5.69)</td>
<td>−0.11</td>
<td>.03</td>
</tr>
<tr>
<td>Perspective Taking</td>
<td>23.38 (5.87)</td>
<td>20.06 (6.19)</td>
<td>−2.25*</td>
<td>.55</td>
</tr>
<tr>
<td>Empathic Concern</td>
<td>26.92 (5.28)</td>
<td>26.10 (4.59)</td>
<td>−0.70</td>
<td>.17</td>
</tr>
<tr>
<td>Personal Distress</td>
<td>18.77 (5.26)</td>
<td>17.77 (5.02)</td>
<td>−0.80</td>
<td>.19</td>
</tr>
<tr>
<td>Total Empathy</td>
<td>92.46 (15.72)</td>
<td>87.17 (11.76)</td>
<td>−1.64</td>
<td>.38</td>
</tr>
</tbody>
</table>

Shivers, 2019
Adolescence - Empathy

Focus groups – 5 themes:
• Learning, empathy, compassion
• Relation between degree of functional impairment and nature of the relationship
• Reluctance to share information about ASD sibling with peers
• Worries and concerns about the future
• Hypervigilance associated with unpredictable behavior

Iannuzzi et al., 2021
Adults – reflection and feelings

Categories
• Positive emotions/experiences (13%)
• Acceptance (41%)
• Negative emotions/experiences (93%)

Positive aspects
• Tolerance/understanding/empathy
• Positive effects on family
• Positive effects of person with autism

Moss et al., 2019
How can we support siblings?

Zucker et al., 2010
What elements of support are important?

• Kirchhoffer, 2022
Take home

- Parent social support for siblings of children with an autism spectrum disorder in families with a
  - higher level of stress
  - parent health concerns
  - sibling depression symptoms
  - psychosocial adjustment problems

may be particularly important.
Helping autistic functioning

Rosen et al., 2021
Cultural factors

From Tsai et al., 2018
Cultural factors

Latino/a/x Siblings

- Positive (e.g., fun) and challenging (e.g., aggression) aspects
  - Emphasis on typicality

Non-Latino/a/x Siblings

- Positive (e.g., fun) and challenging (e.g., aggression) aspects
  - Emphasis on difference

Making Sense of Autism

- Perceiving Positive and Challenging Aspects of Autism and the Sibling Relationship
- Evaluating the Typicality of Autism

Playing Multiple Roles in the Sibling Relationship

- Being a Playmate
- Providing Care
- Protecting Child on the Spectrum

Shared activities

- Greater sibling interaction
- Parent-like caregiver role
- Protector role

Shared activities

- Less sibling interaction
- Helper to parent caregivers
- Protector role not apparent

From Long et al., 2021
Takeaways

• Siblings are special
• They provide enormous support to families
• They experience their own challenges
• They improve the lives of their autistic brothers and sisters
• We need more understanding of their needs and how they can be supported and helped
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