Exploring the Role of Siblings in Autism

Nicole Rosen, M.A.
Ph.D. Candidate
University of California, Los Angeles
Agenda

• Importance of siblings (particularly in autism)

• Review the literature on the impact of siblings on development across the lifespan in autism

• Present findings from a new study focusing on the perspectives of the nonaffected siblings of autistic individuals
Importance of the Sibling Relationship

• One of the most transformative and meaningful relationships that an individual may have.

• Unique lifetime duration.

• Siblings occupy many roles within the sibling relationship.
  • Roles often change over time.
Importance of the Sibling Relationship in ASD

• Inclusion of siblings in intervention can result in greater gains for individuals with ASD.

• Competencies can generalize to promote continued improvements in various areas of functioning.

• Siblings engage with individuals with ASD in a way that mirrors peer interaction.
Sibling Impact in ASD

- In ASD, having siblings has been shown to impact:
  - Adaptive functioning over time
  - Social functioning
  - Non-verbal communication skills
  - Theory of mind abilities
From one generation to the next, how does autism affect you and your family?
Autism Prevalence & Recurrence

• 1.5-2.7% of children are diagnosed with ASD.

• 6-20% of siblings of autistic individuals also have ASD themselves.

• 3-5% of individuals with an autistic aunt or uncle also have ASD themselves (“Next Generation”).
Aims

a) Recruit and engage typically developing adult siblings in focus groups to evaluate their experience having an autistic sibling

b) Gather siblings’ thoughts/feelings about how having a sibling with ASD impacted their own development and expectations for the future

c) Collect information on siblings’ perspectives on being a parent themselves

d) Gather ideas on willingness to participate in research
Methods Outline

Target Sample

N = 50-100 typically developing siblings

Sites

UCLA
(Target n = 25-50)
Longitudinal Study & Community

Emory University
(Target n = 25-50)
Emory Autism Center

Data Collection

4 focus groups
(n = 31)

5 individual interviews
(n = 7)

In Progress
### Demographics

<table>
<thead>
<tr>
<th></th>
<th>Non-Autistic Sibling</th>
<th>Autistic Sibling</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (M, SD)</strong></td>
<td>31.17 (3.02)</td>
<td>30.76 (1.95)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>69% female</td>
<td>77% male</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td>78% White</td>
<td>78% White</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>20% Hispanic or Latino</td>
<td>20% Hispanic or Latino</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 6.8% some college without a degree</td>
<td></td>
<td>• 5.6% no high school</td>
</tr>
<tr>
<td>• 65.4% 4-year college degree</td>
<td></td>
<td>• 11.1% some high school</td>
</tr>
<tr>
<td>• 27.8% graduate or professional degree</td>
<td></td>
<td>• 22.2% high school certificate</td>
</tr>
<tr>
<td><strong>Legal Guardianship</strong></td>
<td></td>
<td>27.8% own legal guardian</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td>83.3% married</td>
<td></td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td>61.1% have children</td>
<td></td>
</tr>
<tr>
<td><strong>Living Arrangement</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 5.9% alone</td>
<td></td>
<td>• 5.9% alone</td>
</tr>
<tr>
<td>• 17.6% romantic partner</td>
<td></td>
<td>• 17.6% romantic partner</td>
</tr>
<tr>
<td>• 47.1% parents</td>
<td></td>
<td>• 47.1% parents</td>
</tr>
<tr>
<td>• 29.4% support staff</td>
<td></td>
<td>• 29.4% support staff</td>
</tr>
</tbody>
</table>
Results: Categories of Key Takeaways

• Sibling relationship (past and current)
• Earliest memories of autism
• Family planning decisions
• Participation in future research
• Research topics of interest/How can we help
• Spousal/Partner perspectives
• Advice for younger self and new generation of siblings
Results: Categories of Key Takeaways

• Sibling relationship (past and current)
• Earliest memories of autism
• Family planning decisions
• Participation in future research
• Research topics of interest/How can we help
• Spousal/Partner perspectives
• Advice for younger self and new generation of siblings
Sibling contact **decreases over time** from childhood through adulthood as parents maintain the primary caregiving role for the autistic individual.
Common barriers to spending time with autistic siblings:

1. Physical distance
2. Social barriers (i.e., communication challenges)
3. Safety & behavioral concerns
Common barriers to spending time with autistic siblings:

1. Physical distance
2. Social barriers (i.e., communication challenges)
3. Safety & behavioral concerns
“He's currently living in a group home in a different state...because I am very busy with both of my kids, I don't have as much involvement in his day to day as I would like.”
“He's currently living in a group home in a different state...because I am very busy with both of my kids, I don't have as much involvement in his day to day as I would like.”

“Because we were not having the casual interactions on a daily or weekly basis, we didn’t end up having more meaningful interactions. Distance has hurt us.”
“He's currently living in a group home in a different state...because I am very busy with both of my kids, I don't have as much involvement in his day to day as I would like.”

“Because we were not having the casual interactions on a daily or weekly basis, we didn’t end up having more meaningful interactions. Distance has hurt us.”

“While I would love to see him more, it just is so hard now. We live in different parts of the state, and we both have our own things going on.”
Common barriers to spending time with autistic siblings:

1. Physical distance
2. Social barriers (i.e., communication challenges)
3. Safety & behavioral concerns
“...he definitely acknowledges the fact that I'm there, and he shows the interest in that...but it’s just a very kind of passive relationship. We're not able to carry on a conversation or anything like that. So, basically, obviously noticing each other and acknowledging each other is pretty much the extent of it.”
“...he definitely acknowledges the fact that I'm there, and he shows the interest in that...but it's just a very kind of passive relationship. We're not able to carry on a conversation or anything like that. So, basically, obviously noticing each other and acknowledging each other is pretty much the extent of it.”

“...he may not directly express that he likes having people around or having a family gathering, but when he misses something because he has work or another obligation, he is upset. He wants to be a part of it but doesn't necessarily express it.”
Common **barriers** to spending time with autistic siblings:

1. Physical distance
2. Social barriers (i.e., communication challenges)
3. Safety & behavioral concerns
Safety & Behavioral Concerns

“He can’t leave the group home because he elopes, and that is dangerous, so we are pretty limited. Hopefully that gets better with time.”
“He can’t leave the group home because he elopes, and that is dangerous, so we are pretty limited. Hopefully that gets better with time.”

“I never know when something is going to trigger him, so it is safer to just visit him at my parents’ home where everything is expected and he is comfortable.”
“He can’t leave the group home because he elopes, and that is dangerous, so we are pretty limited. Hopefully that gets better with time.”

“I never know when something is going to trigger him, so it is safer to just visit him at my parents’ home where everything is expected and he is comfortable.”

“...we're at that point where we've tried so many things. It makes me sad, and of course we still love him, and he's, you know, brilliant in his own way, but it's very hard for our family. He's just challenging behaviorally.”
Results: Categories of Key Takeaways

• Sibling relationship (past and current)
• Earliest memories of autism
• Family planning decisions
• Participation in future research
• Research topics of interest/How can we help
• Spousal/Partner perspectives
• Advice for younger self and new generation of siblings
Earliest Memories of Autism

- Professionals/providers in the home
- Repetitive behaviors
- Sensory needs
- Emotion dysregulation/self-injurious behaviors
- Communication difficulties
Earliest Memories of Autism

• Professionals/providers in the home
• Repetitive behaviors
• Sensory needs
• Emotion dysregulation/self-injurious behaviors
• Communication difficulties
“I was watching Cinderella and my brother had a staff member over playing with him. And I was just sitting there, watching TV, and I remember thinking, oh, some things are just different.”
“I was watching Cinderella and my brother had a staff member over playing with him. And I was just sitting there, watching TV, and I remember thinking, oh, some things are just different.”

“There was always some appointment that we were bringing him to or some person who was coming to our house. It was constant.”
“I was watching Cinderella and my brother had a staff member over playing with him. And I was just sitting there, watching TV, and I remember thinking, oh, some things are just different.”

“There was always some appointment that we were bringing him to or some person who was coming to our house. It was constant.”

“When I asked, my mom would tell me that [sibling] had a special friend coming over again. And I remember feeling somewhat jealous because I wanted that attention.”
Earliest Memories of Autism

- Professionals/providers in the home
- Repetitive behaviors
- Sensory needs
- Emotion dysregulation/self-injurious behaviors
- Communication difficulties
Repetitive Behaviors

• “...he just was pressing the button on the TV remote - mute and unmute. Over and over and over again.”

• “He spun in circles to the point where I remember getting dizzy looking at him. And it didn’t matter where we were. He was always just spinning.”

• “If I had any toys or objects missing, I remember going to [sibling] because he always had my things organized as part of his line. It became almost like a joke because he took random things from random places, making a mess in some ways, to then put them in a very organized line.”
Earliest Memories of Autism

- Professionals/providers in the home
- Repetitive behaviors
- Sensory needs
- Emotion dysregulation/self-injurious behaviors
- Communication difficulties
“...we had to have this huge swing installed in our home. I didn't think anything of it at the time. I just thought that was how it was for everyone.”
Sensory Needs

“...we had to have this huge swing installed in our home. I didn't think anything of it at the time. I just thought that was how it was for everyone.”

“I remember my parents asking me to always go outside with [her] before they did chores like vacuuming and cleaning up.”
“...we had to have this huge swing installed in our home. I didn't think anything of it at the time. I just thought that was how it was for everyone.”

“I remember my parents asking me to always go outside with [her] before they did chores like vacuuming and cleaning up.”

“[Sibling] would always lay down and stack random objects on top of herself. Or she would grab my hands and put them on her back. And I knew she wanted me to press down and hold it for a little. Then she would get up and walk around like nothing happened.”
“...we had to have this huge swing installed in our home. I didn't think anything of it at the time. I just thought that how it was for everyone.”

“I remember my parents asking me to always go outside with [her] before they did chores like vacuuming and cleaning up.”

“[Sibling] would always lay down and stack random objects on top of herself. Or she would grab my hands and put them on her back. And I knew she wanted me to press down and hold it for a little. Then she would get up and walk around like nothing happened.”

“He would always cover his ears any time there was a loud noise. So then we started avoiding doing things because it was too loud, and that was hard for me. I missed out on a lot.”
Earliest Memories of Autism

• Professionals/providers in the home
• Repetitive behaviors
• Sensory needs
• Emotion dysregulation/self-injurious behaviors
• Communication difficulties
“...he would just hit himself or bang his head against the wall. And I remember being so concerned. That was very different.”
Emotion Dysregulation/Self-Injurious Behaviors

“...he would just hit himself or bang his head against the wall. And I remember being so concerned. That was very different.”

“...he screamed a lot. I remember being at the mall with my mom getting a penny to throw in the fountain, the first time I ever saw a fountain, and she told me to make a wish. And I remember I wished that [sibling] would stop screaming.”
Emotion Dysregulation/Self-Injurious Behaviors

“...he would just hit himself or bang his head against the wall. And I remember being so concerned. That was very different.”

“...he screamed a lot. I remember being at the mall with my mom getting a penny to throw in the fountain, the first time I ever saw a fountain, and she told me to make a wish. And I remember I wished that [sibling] would stop screaming.”

“....every little thing made him upset. And once he was upset, we all knew that the activity was over. His mood decided all activities for us.”
Earliest Memories of Autism

- Professionals/providers in the home
- Repetitive behaviors
- Sensory needs
- Emotion dysregulation/self-injurious behaviors
- Communication difficulties
“It seemed so sudden, but I remember he went from saying a few words to nothing at all. I thought he was being silly, so I remember I would try to make it a game and talk for him. But those words just never came back.”
Communication difficulties

“It seemed so sudden, but I remember he went from saying a few words to nothing at all. I thought he was being silly, so I remember I would try to make it a game and talk for him. But those words just never came back.”

“I do remember playing with her, but I think that once I started preschool, and then it was like the stark contrast of coming home, and it was like the curtain was lifted. My sister is not like the other kids at school.”
“It seemed so sudden, but I remember he went from saying a few words to nothing at all. I thought he was being silly, so I remember I would try to make it a game and talk for him. But those words just never came back.”

“I do remember playing with her, but I think that once I started preschool, and then it was like the stark contrast of coming home, and it was like the curtain was lifted. My sister is not like the other kids at school.”

“...and then I don't know if I would just reach a breaking point, and it was like, ‘ok, I'm done trying to talk to you.’ I want to go in my room and hide like I can’t. It’s just too hard when it feels like you’re playing alone and talking to yourself.”
Results: Categories of Key Takeaways

- Sibling relationship (past and current)
- Earliest memories of autism
- Family planning decisions
- Participation in future research
- Research topics of interest/How can we help
- Spousal/Partner perspectives
- Advice for younger self and new generation of siblings
Many siblings were unaware that familial recurrence risk for ASD extends to the next generation (i.e., their own children).
Genetics and probability of ASD recurrence factored more heavily into siblings’ decisions to have a second child compared to a first child.
Results: Categories of Key Takeaways

• Sibling relationship (past and current)
• Earliest memories of autism
• Family planning decisions
• Participation in future research
• Research topics of interest/How can we help
• Spousal/Partner perspectives
• Advice for younger self and new generation of siblings
All siblings were interested in participating in future research.

Open to genetics, behavioral, cognitive, etc.
Results: Categories of Key Takeaways

- Sibling relationship (past and current)
- Earliest memories of autism
- Family planning decisions
- Participation in future research
- Research topics of interest/How can we help
- Spousal/Partner perspectives
- Advice for younger self and new generation of siblings
Trajectories of development and outcomes in adulthood in ASD.
Support around preparing the autistic individual for the transition to living with their sibling.
Caregiving Information for Siblings:

1. Transferring guardianship
2. Navigating social security
3. Accessing funds in trusts and wills
4. Housing options for different support needs
“...the official conversation hasn't necessarily happened. But there's this underlying, we all know, but we don't talk about it...there will be references to it. It’s very much like ‘and there is this trust. You are in charge of the trust. You know, we've talked about this before, right?’ And then I would confirm, ‘yes, I'm aware of that.’”
“...the official conversation hasn't necessarily happened. But there's this underlying, we all know, but we don't talk about it...there will be references to it. It’s very much like ‘and there is this trust. You are in charge of the trust. You know, we've talked about this before, right?’ And then I would confirm, ‘yes, I'm aware of that.’”

“We didn't do things as a four unit very much. It was about them keeping me away and free in a sense. It was always just like, you know, this isn't your battle to fight. He's not your kid. But I have no idea what will happen when my parents cannot take care of him. Yikes, haven’t planned for that.”
“...the official conversation hasn't necessarily happened. But there's this underlying, we all know, but we don't talk about it...there will be references to it. It’s very much like ‘and there is this trust. You are in charge of the trust. You know, we've talked about this before, right?’ And then I would confirm, ‘yes, I'm aware of that.’”

“We didn't do things as a four unit very much. It was about them keeping me away and free in a sense. It was always just like, you know, this isn't your battle to fight. He's not your kid. But I have no idea what will happen when my parents cannot take care of him. Yikes, haven’t planned for that.”

“I’m choosing to not have children of my own because I know I will be caring for my brother in the future. I told my parents that from an early age, and that has not changed. I initiated that conversation, but it would have been nice to know how to navigate that. It’s awkward.”
Results: Categories of Key Takeaways

• Sibling relationship (past and current)
• Earliest memories of autism
• Family planning decisions
• Participation in future research
• Research topics of interest/How can we help
• Spousal/Partner perspectives
• Advice for younger self and new generation of siblings
Spousal/Partner Perspectives

• Information about signs of atypical development (“red flags”)

• How to connect with the autistic person

• Support for parents

• Strategies for supporting spouse/partner
Spousal/Partner Perspectives

"...if there was a little pamphlet about autism or a handout of things we can look for. I didn’t grow up with autism, so how would I know?"

"...I come into this wonderful family and pretty easily connect with her other siblings. Then I find myself putting so much effort into connecting with [sibling], but it really is so hard. I would love to have that close relationship with [him]."

"What about support for us as parents navigating this? Life doesn’t prepare you for this if you didn’t grow up with it."

"I see [partner] struggling, but I don’t know how to help besides being there emotionally based off instincts. But this is different than the usual life stressors."
"...if there was a little pamphlet about autism or a handout of things we can look for. I didn’t grow up with autism, so how would I know?"

“...I come into this wonderful family and pretty easily connect with her other siblings. Then I find myself putting so much effort into connecting with [sibling], but it’s been really hard.”
Spousal/Partner Perspectives

"...if there was a little pamphlet about autism or a handout of things we can look for. I didn’t grow up with autism, so how would I know?"

“...I come into this wonderful family and pretty easily connect with her other siblings. Then I find myself putting so much effort into connecting with [sibling], but it’s been really hard.”

“What about support for us as parents navigating this? Life doesn’t prepare you for this if you didn’t grow up with it.”
Spousal/Partner Perspectives

"...if there was a little pamphlet about autism or a handout of things we can look for. I didn’t grow up with autism, so how would I know?"

“...I come into this wonderful family and pretty easily connect with her other siblings. Then I find myself putting so much effort into connecting with [sibling], but it’s been really hard.”

“What about support for us as parents navigating this? Life doesn’t prepare you for this if you didn’t grow up with it.”

“I see [partner] struggling, but I don’t know how to help besides just being there. But this is different than the usual life stressors.”
Results: Categories of Key Takeaways

• Sibling relationship (past and current)
• Earliest memories of autism
• Family planning decisions
• Participation in future research
• Research topics of interest/How can we help
• Spousal/Partner perspectives
• Advice for younger self and new generation of siblings
• “Be open about your needs and don’t be afraid to ask for help.”

• “Ask the questions and be part of the conversations. No secrecy.”

• “Learn strategies to connect with your autistic sibling in their unique way – be creative!”
Advice for Younger Self and New Generation of Siblings Video
Special thanks to the incredible study participants, the research team, our funders, and Dr. Cathy Lord for making this presentation possible!
Questions?

Contact Information:
Nicole Rosen, M.A.
nrosen@mednet.ucla.edu
Are you or your child Spanish/English bilingual AND have autism (or think they may have autism)?

You may be eligible for a research study at UCLA that will administer the following autism assessments in your home or community:

- ADOS-2
- Caregiver Interview
- Cognitive testing
- And more!

You can receive up to $100.00 in compensation!

For more information email mtafolla@mednet.ucla.edu

Tu o tu hijo tienen autismo (o piensan que tienen autismo) y son bilingüe en Español-Ingles?

Puedes ser elegible para una investigación científica en UCLA donde recibirán las evaluaciones de autismo siguientes en su casa o en la comunidad:

- ADOS-2
- Entrevista al cuidador
- Evaluacion Cognitiva
- Y mas!

Puedes recibir hasta $100.00 en compensación!

Para recibir mas info manda correo a mtafolla@mednet.ucla.edu
*Participants do not need to be actively involved in an intervention to participate.*