

Growing up with Autism: Brothers and Sisters Speak Out

A Panel Presented for the
National Autism Conference
August 5, 2009
By the
PA Bureau of Autism Services, DPW

Introductions

- PA Bureau of Autism Services
- Moderator
- Panelists
- Audience

Background Information:
What have other siblings said about
having a brother or sister with autism?

*A quick overview of research and self-
reports*

What is it like to grow up with a brother or sister with autism?

- Questions experienced by siblings
 - Why is that happening?
 - What is autism?
 - Can I catch it?
 - Did I cause it?
 - Am I the only person in the world with a sibling like this?
 - How can I handle peers?
 - Am I allowed to tease? To Misbehave? To excel?
 - How can I get my parent's attention?
 - How can I keep my homework safe?
 - What is my role ?
- *The above experiences are influenced by age, sex, birth order, and family composition, as well as severity/visibility of the disorder.*

How does growing up with a brother or sister with autism affect a sibling?

- Gained new emotional skills?
- Gained new behavioral skills?
- Too perfect? Too upset? Too much acting out?
- Life choices? Career? Family planning? Locations?
- Long term responsibilities?
- Differences across development?

How can we support siblings of individuals with autism?

- Share information
- Make alone time for siblings
- Include siblings in special activities
- Connect to other siblings
- Plan with siblings
- Provide freedom to make choices
- Recognize own barriers in hearing what siblings have to say

Siblings Speak for Themselves...

- BUT, remember...
- If you've met one sibling of an individual with autism, you've met one sibling of an individual with autism!
- There are many ways to be a terrific sibling. Everyone can choose their own path.
- *Note: Questions from the audience will be taken prior to intermission, and at the end of the presentation.*

What are your favorite things about your brother or sister with autism? Do you have a favorite memory or favorite thing to do together?

How were you first told about your sibling having autism? And at what age? What advice would you offer to parents deciding when and how to share information with typically developing siblings?

How did your family handle outings (e.g., church or other religious activities, going out to dinner, going to the supermarket, riding in the car, etc.). Do you have suggestions for parents or siblings for what “worked”?

How did you communicate with your sibling with ASD as a child? As a teen? As an adult? If your brother/sister was non-verbal, or has limited language, what unique “language” did you come up with?

Siblings of individuals with special needs report varied feelings about their brother or sister, some positive, such as pride or affection, and some more challenging, such as guilt or anger. What feelings have you experienced, and how have others (parents, teachers, counselors, friends) helped you work through your feelings?

Are there any personality traits or value systems that you feel that you developed (or are developing) because of your sibling with autism that you might not otherwise have developed?

Do you feel that your family dynamics (how everyone relates to one another) would be different if you had not had a sibling with autism? Do you feel that your role in relation to your sibling is different than it might have been (or is) with a typically developing sibling? If so, how?

Some of you have siblings who are very severely affected by autism, and some have high functioning" siblings. What are your thoughts about how severity affects your experience with autism?

Did your parents' philosophy on cause and/or treatment affect your outlook on autism and the interventions used? Do you share their philosophy/beliefs about cause and treatment? Has this impacted relationships among family members?

Has the experience of having a sibling with autism affected your career choices? Has the experience of having a sibling with autism affected other life choices that you have made?

As a child, how have peers responded to your sibling? Has this impacted your relationships?

As an adult, how have peers responded to your sibling? Has this impacted your relationships?

What are the most helpful strategies that your parents utilize(d) to help you manage the challenges associated with a sibling with autism?

Has anyone had the experience of having their sibling move outside the home (e.g., group home, institution)? As a child or as an adult? If so, please describe the transition and strategies/events that were helpful or stressful in this situation.

Does anyone have the experience of an adult sibling continuing to live at a parent's home? Or at an adult sibling's home? How have you felt about this?

What has your role been in terms of long-term planning for your sibling? Is this the role you would have wanted?

How are responsibilities distributed among typically developing adult siblings? Does this change in response to the death of both parents? How can parents help prepare for this time?

How has your family handled communicating difficult information with your brother or sister with autism (e.g., a death in the family, a sibling going off to college, etc.)?

Do you have any tips for adult siblings assuming care-giving roles for their brother or sister with autism? Please include practical tips, such as securing/maintaining Medicaid funding, housing, etc.

Are there any "gifts" that come with having a sibling with autism?

Audience Questions