

# Communicating About a Genetic Diagnosis With Children and Siblings

Amanda Gerard, MS, CGC

Certified Genetic Counselor

Baylor College of Medicine/Texas Children's Hospital

## Conflicts of Interest

I do not have any conflicts of interest to disclose.

## Objectives

- Discuss communication strategies and resources for having conversations about medical and genetic information with children.
- Review information and support needs specific to unaffected siblings and available resources.

## Benefits of Familial Discussion of Medical Information

- Children are generally very perceptive and able to sense when information is withheld
  - May make up their own explanations for what they do not understand
  - May not ask questions for fear of upsetting parents
- Lack of communication/understanding can lead to jealousy and resentment between siblings
- Poor understanding of health and genetic information can lead to poorer care outcomes in adulthood

## Preparing for a Conversation

- Important to have your own support to be able to support others
  - Can include friends, family, counselors, religious organizations, etc.
- Find time for self-care where possible
- Utilize healthcare professionals, informational resources, etc. to have your own understanding of the condition
- Check in with yourself and your feelings

# Preparing for a Conversation

- Consider where and when to have the conversation
  - Think about whether you want to discuss with children together, where they will be comfortable, when you will have a quiet moment, etc.
  - Children might also start conversations on their own
- Think about the key points you want them to understand right now
- You do not need to have the answer for everything
  - Be honest when you don't know an answer and help the child find out the answer
- Consider the child's age/developmental status and the types of information they can understand

Age	Information Processing	What can you do to support their understanding and coping?
<p>Preschool (ages 3-5)</p>	<ul style="list-style-type: none"> <li>• Asks lots of questions</li> <li>• Can understand simple explanations</li> <li>• Has trouble with multi-step directions or elaborate explanations; short attention span</li> <li>• Has some understanding of time – mostly in terms of routine rather than hours/minutes</li> <li>• Physical comfort and soothing is important</li> </ul>	<ul style="list-style-type: none"> <li>• Use simple words, books, pictures, or objects to explain information</li> <li>• Tell them when in their routine an appointment or procedure will occur (after you wake up in the morning, after this TV show)</li> <li>• Be a “secure base” for your child and have a trusted adult stay with them as much as possible</li> <li>• Encourage your child to play and engage in normal activities when possible and offer comfort/distraction with toys and fun activities</li> </ul>

Age	Information Processing	What can you do to support their understanding and coping?
School-age (6-12)	<ul style="list-style-type: none"> <li>• Obtain knowledge from TV and other life experiences</li> <li>• Has a better understanding of time</li> <li>• Attention span gets longer, but kids may still have trouble understanding multi-step directions and explanations</li> <li>• Usually thinks in concrete, literal terms and has trouble thinking abstractly</li> </ul>	<ul style="list-style-type: none"> <li>• Use simple words, books, pictures, or objects to explain information</li> <li>• Provide simple explanations about medical procedures and treatments (what will happen and when)</li> <li>• Encourage questions and help your child get answers from doctors or nurses if you cannot answer a question</li> <li>• Encourage children to interact with friends, go to school, and go to school events when able</li> </ul>



Age	Information Processing	What can you do to support their understanding and coping?
<p>Teens (13 – 18)</p>	<ul style="list-style-type: none"> <li>• Likely to want to know how diagnosis will interfere with daily activities, such as school, sports, spending time with family</li> <li>• Have developed abstract reasoning; able to think more deeply about the impact of their diagnosis now and in the future</li> <li>• May want to be involved in treatment decisions</li> <li>• Do not have a long track record of handling complex issues, so it is important for parents to remain involved in decision-making and treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Be honest about the condition and possible symptoms when they ask</li> <li>• Be open when discussing their diagnosis</li> <li>• Encourage your teen to talk with you or a trusted friend or healthcare professional regarding their feelings about their diagnosis. If they prefer not to talk, encourage them to express their feelings through writing, art, or music. Online or in person support groups and networks may also help.</li> <li>• Encourage them to interact with friends and to complete their school work</li> <li>• Give them privacy to the extent that you can</li> </ul>

## Navigating a Conversation

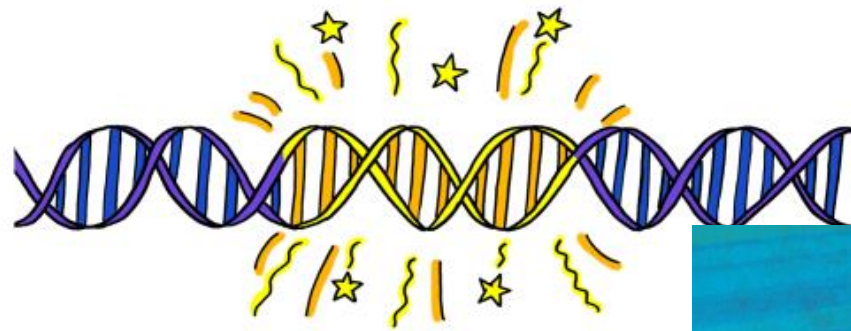
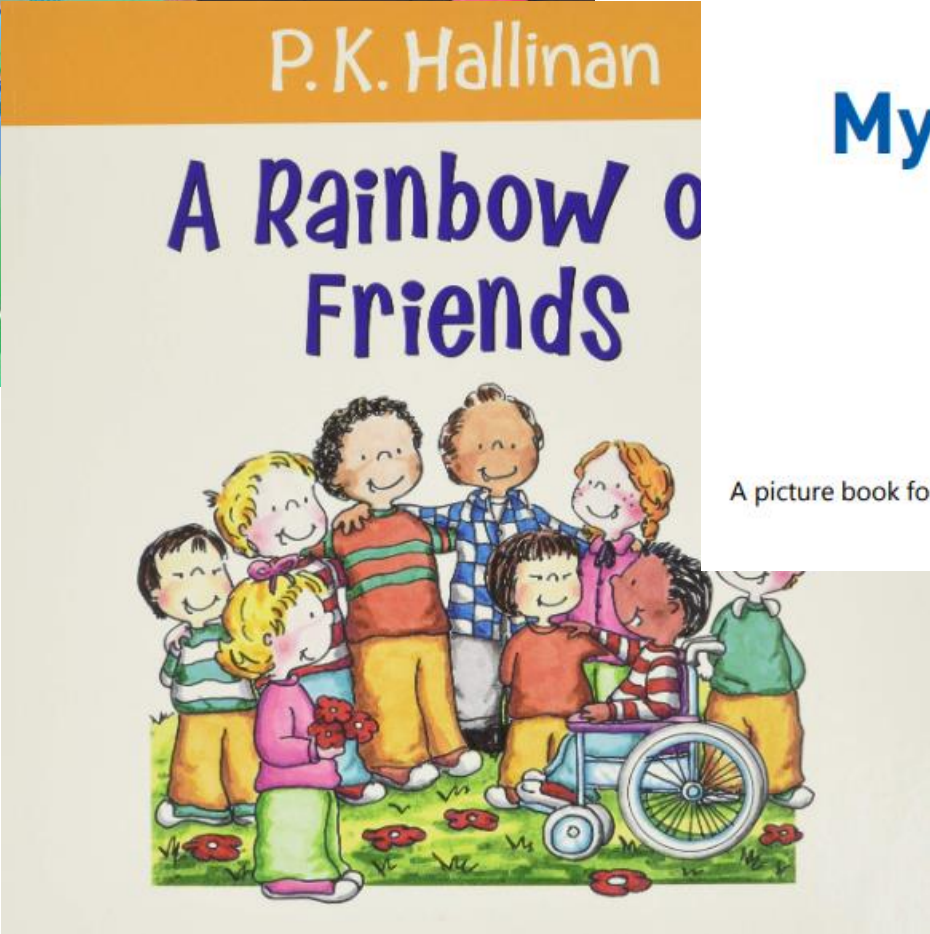
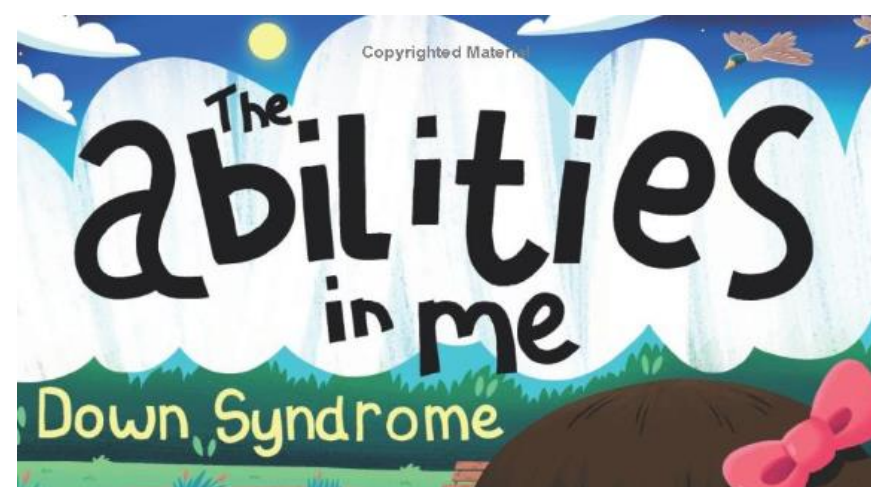
- Assess how much they know, affirm truths, and correct misinformation
- Consider how much information to share that isn't overwhelming
- Help the child understand basic facts and what to expect in the medical process
- Encourage the child to express emotions and to ask questions
- Offer messages of hope, support and love – despite difficulty and uncertainty

## Additional Tips

- Use open-ended questions to gauge their understanding and questions they have
- Ask the child to repeat what they understood back to you
- Consider helping children make an “elevator pitch” or role-play questions they might receive from friends/strangers
- Reassure children and siblings that they did not cause the condition
- Conversations will happen over time
  - Not necessary (or feasible) to discuss everything at one time
  - Young children in particular may need to hear something multiple times
  - Keep open lines of communication, as feelings and questions will evolve over time

## Helpful Resources

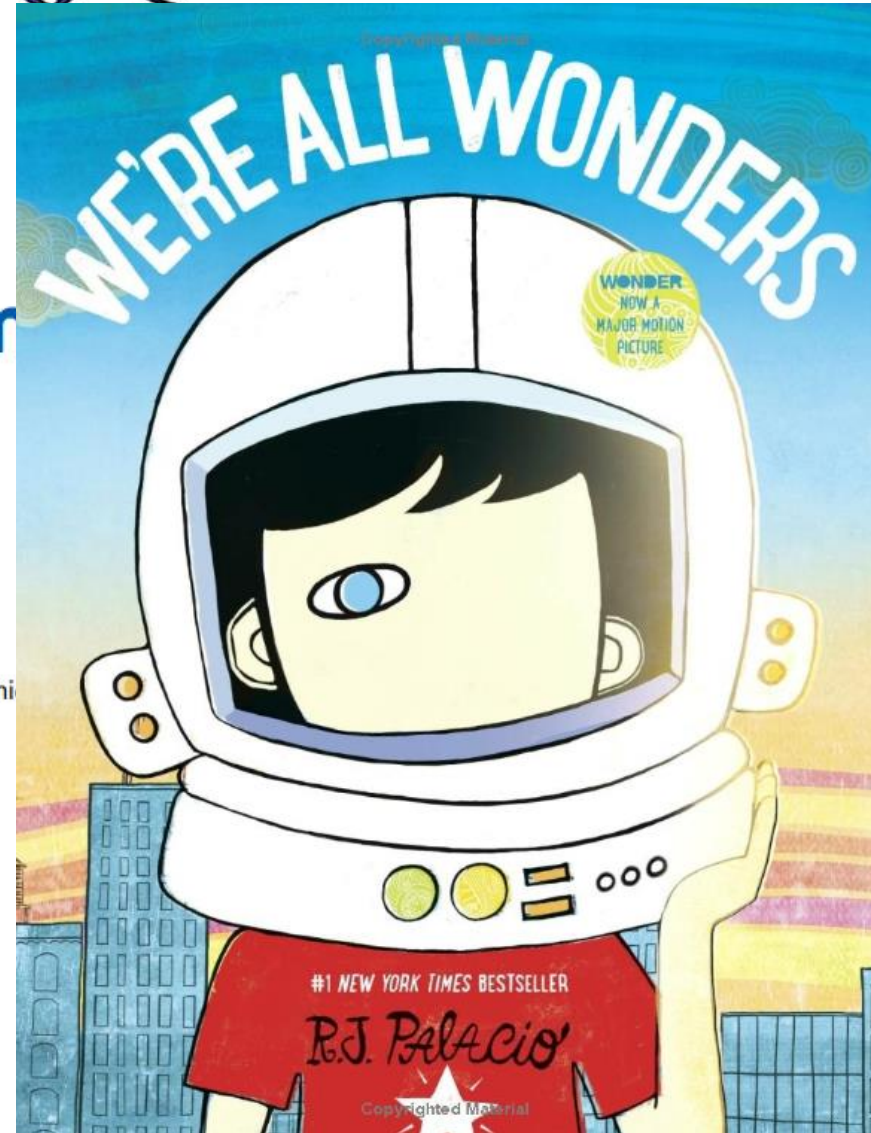
- Children's books
- Video resources
- Websites
- Movies
- Healthcare professionals



## My Chromosome Story

By Seonaid Beaumont

A picture book for children with a chromosome 1 q 21.1 mi





# Sibling- Specific Needs



Photo: <https://www.sowetanlive.co.za/good-life/2017-03-28-parents-playing-favourites-paying-more-attention-to-sibling-causes-forgotten-child-syndrome/>

## Parents' Communication with Siblings of Children Affected by an Inherited Genetic Condition

Gillian Plumridge · Alison Metcalfe · Jane Coad ·  
Paramjit Gill

Received: 2 September 2010 / Accepted: 8 March 2011 / Published online: 19 April 2011  
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**Abstract** The objective of this study was to explore parents' communication about risk with siblings of children affected by an inherited genetic condition, and to ascertain what level of support, if any, is required from health professionals. Semi-structured interviews were conducted with affected and unaffected children and their parents. Families were affected by one of six genetic conditions representing different patterns of inheritance and variations in age of onset, life expectancy and impact on families. Interviews were analysed using constructivist grounded theory and informed by models which focused on three different aspects of family communication. Interviews with 33 families showed that siblings' information and support needs go largely unrecognized by health professionals and sometimes by parents. Some siblings were actively informed about the genetic condition by parents, others were left to find out and assimilate information by themselves. Siblings were given information about the current symptoms and management of the genetic condition but were less likely to know about its hereditary nature and their own potential risk. When siblings were fully informed about the condition and included in family discussion, they had a better

understanding of their role within their family, and family relationships were reported to be more harmonious. The information and support needs of siblings can be overlooked. Parents with the responsibility for caring for a child affected by a genetic condition may require support from health professionals to understand and respond to their unaffected children's need for more information about the genetic condition and its implications for the children's own future health and reproductive decision-making.

**Keywords** Sibling · Inherited condition · Genetic risk · Family communication · Support · Genetic counseling

### Introduction

There is a body of literature considering the experiences of siblings of a disabled or chronically ill child, which suggests that these children face potential difficulties (Houtzager et al. 2004, 2005; Sharpe and Rossiter 2002; Williams 1997). Fewer studies have focussed on the impact for siblings of



# Article Summary and Key Points

- Interview-based study of families of children with several different types of genetic conditions
- Siblings reported a lower degree of knowledge than parents expected
  - More likely to learn about current symptoms/management or day to day manifestations
  - Specific information about carrier status/genetic risk not discussed until teens
  - Several children worried about their personal genetic risk earlier but did not ask their parents
- Siblings were generally open to receiving information and valued ongoing discussions
- No participants (adult or child) suggested any regrets of information disclosed
- Resources for siblings are limited; immediate family was the primary source of sibling support



ORIGINAL ARTICLE

# Communication practices of parents and unaffected sibling needs in families impacted by a diagnosis of Angelman syndrome

Abigail Turnwald<sup>1</sup>  | Talia Thompson<sup>2</sup>  | Kelly Nori<sup>3</sup> | Jessica Duis<sup>4,5</sup> 

<sup>1</sup>Program in Genetic Counseling, University of Colorado, Aurora, Colorado, USA

<sup>2</sup>Section of Developmental Pediatrics, Department of Pediatrics, Children's Hospital Colorado, University of Colorado School of Medicine, Aurora, Colorado, USA

<sup>3</sup>Children's Hospital Colorado, Aurora, Colorado, USA

<sup>4</sup>Section of Genetics & Inherited Metabolic Disease, Department of Pediatrics, Children's Hospital Colorado, University of Colorado, Aurora, Colorado, USA

<sup>5</sup>Special Care Clinic, Section of General Pediatrics, Department of Pediatrics, Children's Hospital Colorado, University of Colorado, Aurora, Colorado, USA

## Correspondence

Jessica Duis, MD, Section of Genetics & Inherited Metabolic Disease, Special Care Clinic, Section of Pediatrics, Department of Pediatrics, 13123 E 16th Ave, Education 2 South, Aurora CO, 80045, USA.  
Email: [jessica.duis@childrenscolorado.org](mailto:jessica.duis@childrenscolorado.org)

## Abstract

Angelman syndrome (AS) is a rare neurodevelopmental condition affecting approximately 1 in 15,000 individuals. To date, limited research elucidates how parents communicate about AS with unaffected siblings and their needs. This study aimed to understand if, when, and what parents are communicating with unaffected siblings. The study also evaluated unaffected siblings' knowledge of AS and their perceptions of their siblings with AS. Recruitment took place through social media platforms and a multidisciplinary Chromosome 15 clinic. Families were eligible for the study if they had a child diagnosed with AS and at least one unaffected sibling age five years or older. Two novel surveys, one for the parent and one for each of the unaffected siblings, were created based on a detailed literature review and input from AS professionals. Eighty-two families met the criteria and completed the required surveys. The majority of parents (94%) discussed AS with the unaffected siblings, but despite these discussions 41% of unaffected siblings still had unanswered questions. This study highlights the need for improved communication between parents and the unaffected siblings and emphasizes the importance of educational materials for unaffected siblings.

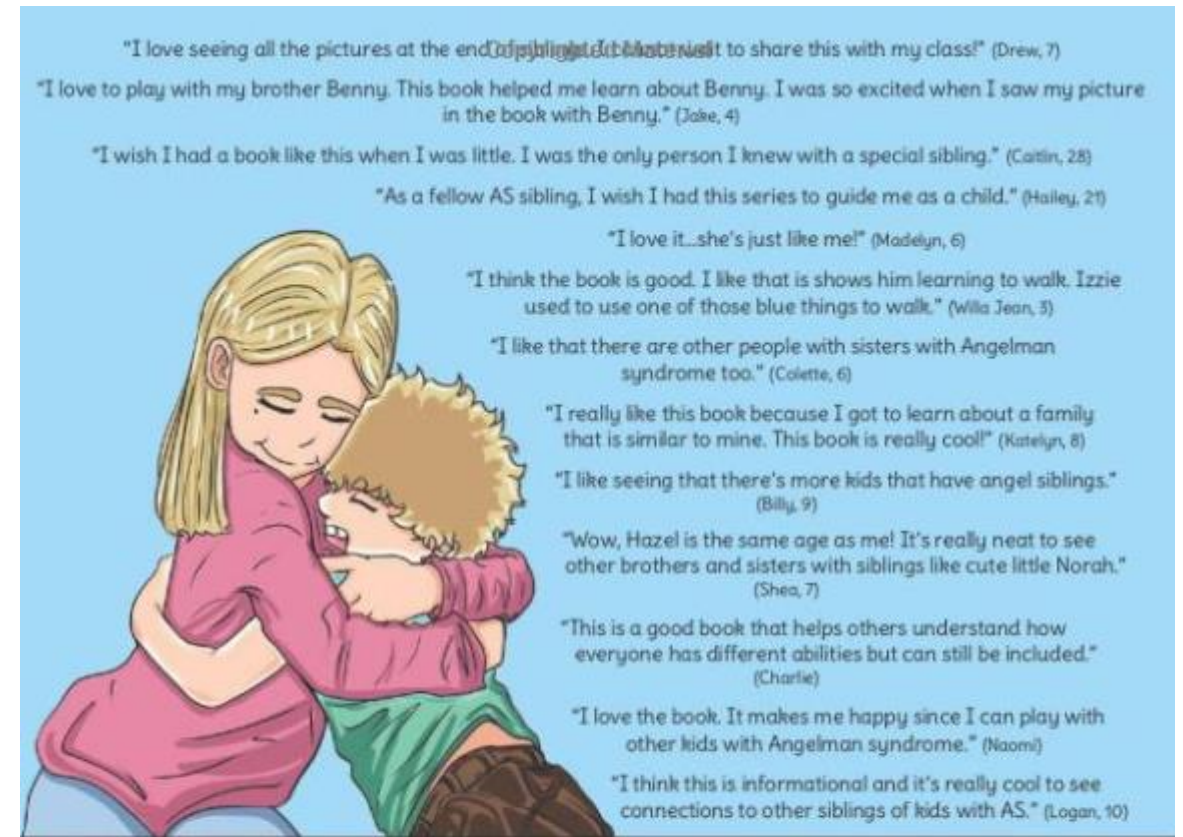
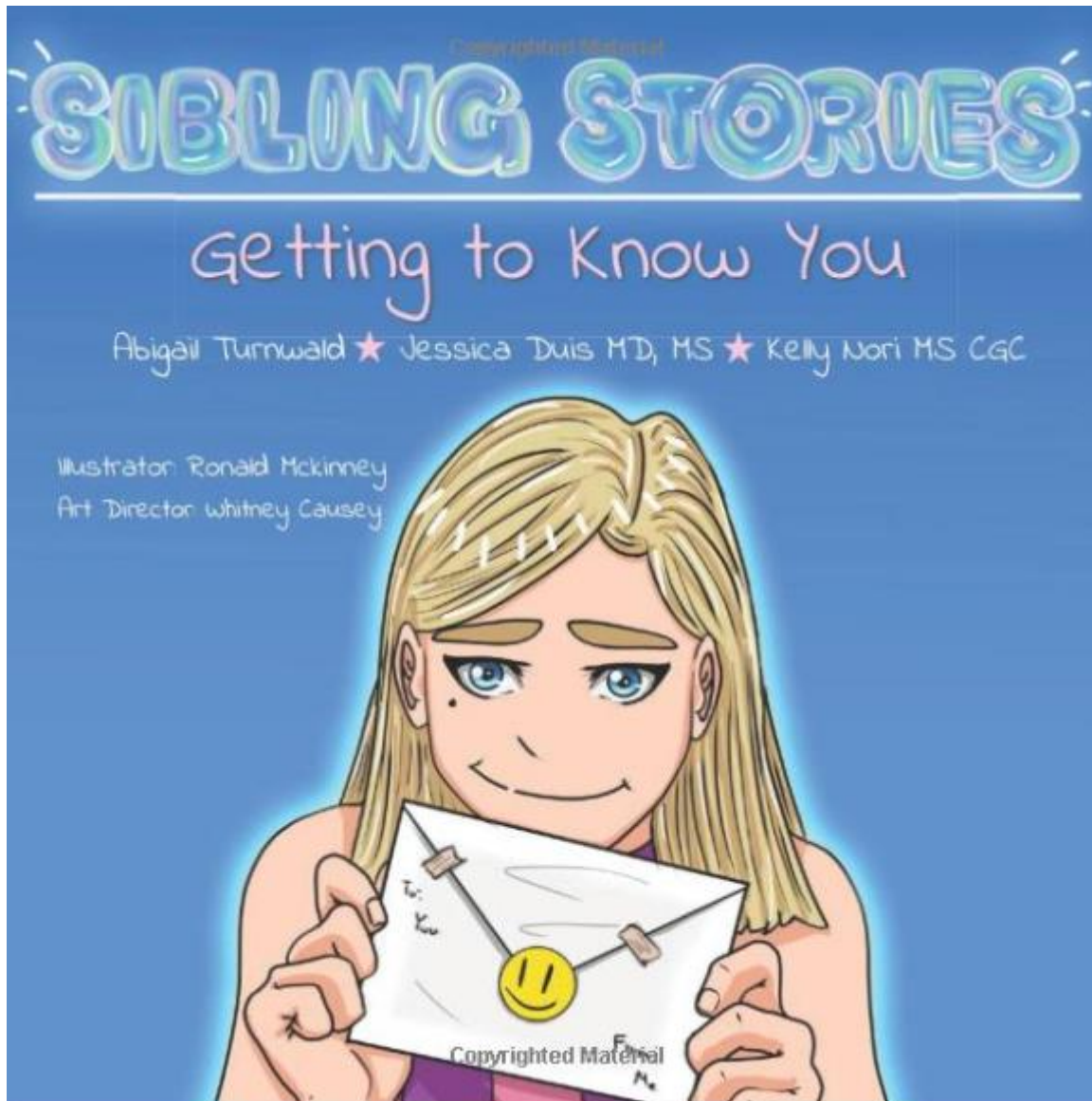
## KEYWORDS

Angelman syndrome, parent communication, rare disease, sibling experience

# Article Summary and Key Points

- Survey-based study of families of children with Angelman syndrome (AS)
- Half (49%) of siblings answered all informational questions about AS correctly, and 86% said they still wanted to learn more about AS
- Siblings reported a variety of emotions associated with the diagnosis
  - Parents often overestimated the frequency of feelings of sadness
- Few parents (13%) reported that a healthcare professional talked with them about disclosing the diagnosis to unaffected siblings
- Parents and siblings endorsed a need for more informational resources for children/siblings (videos, websites, children's books, sibling support groups/meetings)





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# The Abilities

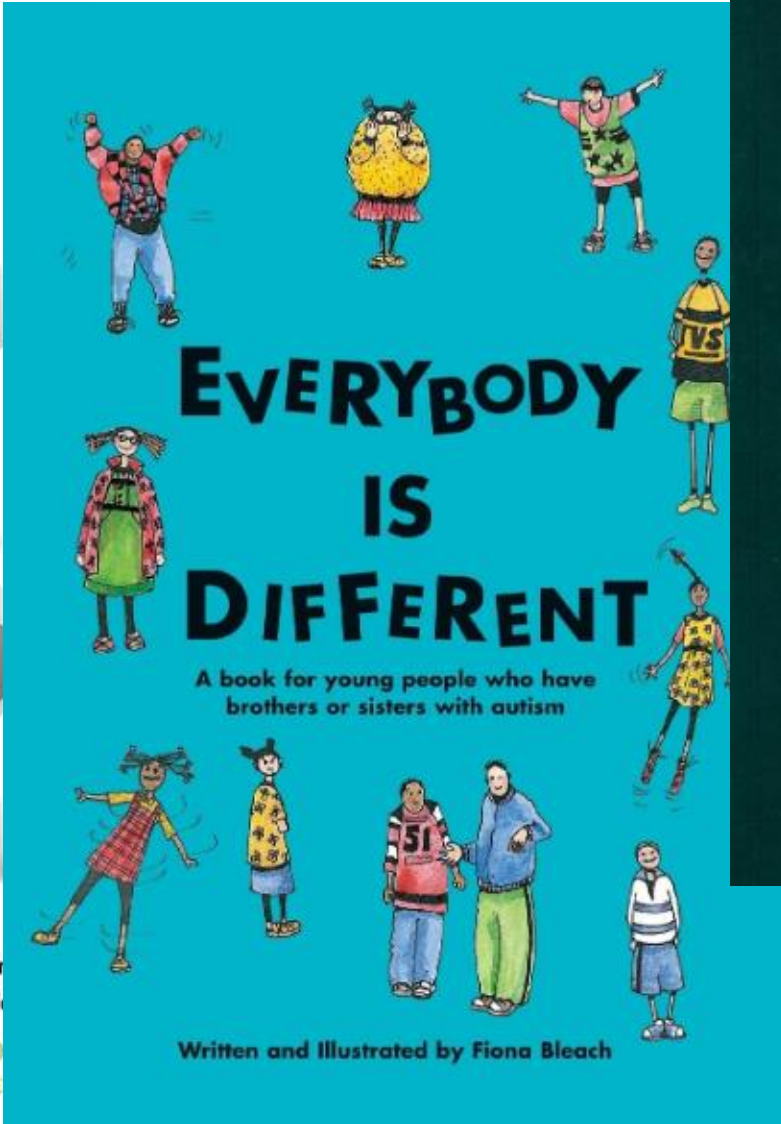
## By Siblings, For Siblings

siblings of people with disabilities supporting  
other siblings of people with disabilities

NATALIE HAMPTON & NICOLE HAMPTON  
Illustrated by NICOLE HAMPTON



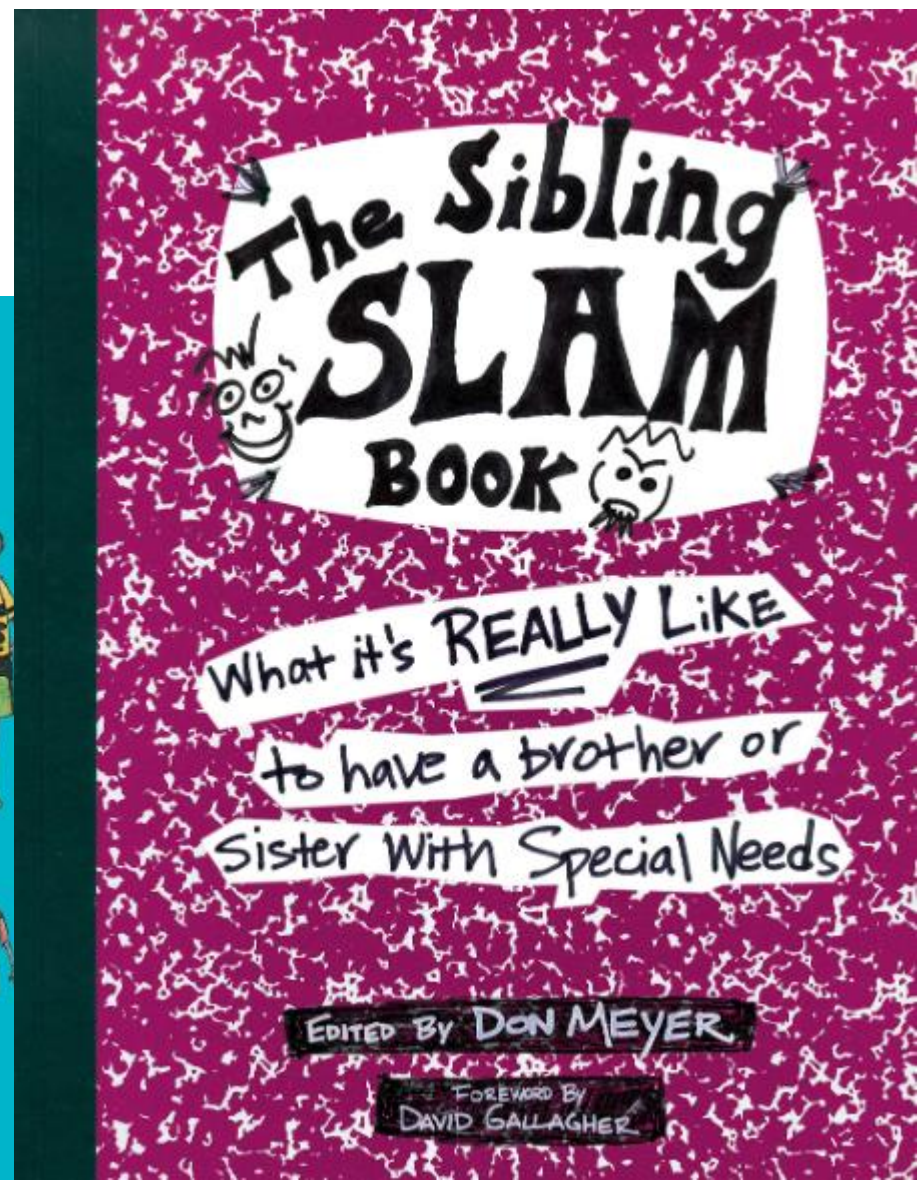
Gemma



# EVERYBODY IS DIFFERENT

A book for young people who have  
brothers or sisters with autism

Written and Illustrated by Fiona Bleach



# The Sibling SLAM BOOK

What it's **REALLY** LIKE  
to have a brother or  
Sister With Special Needs

EDITED BY DON MEYER

FOREWORD BY  
DAVID GALLAGHER

## Sibling Resources and Support

- Try to make special time for siblings
- Specifically consider information needs of siblings and encourage open/honest discussion
- Look for specific support groups for siblings (but we need more of these!)
- Sibling-specific children's books
- Sibling support organizations
- Sibshop

# Sibshops

- Working with Sibs
  - Locally and nationally
- Partnering with MTF2F
- Helping Sibs find a community
  - In person and virtually
- Sib Story

## Resources

- <https://siblingsupport.org/sibshops/>
  - SibNet
  - Sib20
  - SibTeen
- <https://siblingleadership.org/>

## Contact

Abbey Guza, LCSW

(406) 546-2665

abbeyguza22@gmail.com





# References

- American Psychological Association. (2015). How to talk to children about difficult news. <https://www.apa.org/topics/journalism-facts/talking-children>
- CureSearch for Children's Cancer. (2017, April 13). Normal at different ages – developmental and disease differences: Curesearch. <https://curesearch.org/Normal-at-Different-Ages-Developmental-and-Disease-Differences>
- enCourage Kids Foundation. (2023, January 10). Tips For Talking about a Difficult Diagnosis with a Child. <https://m.facebook.com/photo.php?fbid=493457552913835&set=pb.100067487844144.-2207520000.&type=3&rdr>
- Gallo, A. M., Angst, D., Knafl, K. A., Hadley, E., & Smith, C. (2005). Parents sharing information with their children about genetic conditions. *Journal of pediatric health care : official publication of National Association of Pediatric Nurse Associates & Practitioners*, 19(5), 267–275. <https://doi.org/10.1016/j.pedhc.2005.05.008>
- Plumridge, G., Metcalfe, A., Coad, J., & Gill, P. (2011). Parents' communication with siblings of children affected by an inherited genetic condition. *Journal of genetic counseling*, 20(4), 374–383. <https://doi.org/10.1007/s10897-011-9361-1>
- Ruiz, S. (2023, May 30). How to have hard conversations with your children - choc - children's health hub. <https://health.choc.org/how-to-have-hard-conversations-with-your-children/>
- Turnwald, A., Thompson, T., Nori, K., & Duis, J. (2022). Communication practices of parents and unaffected sibling needs in families impacted by a diagnosis of Angelman syndrome. *American journal of medical genetics. Part A*, 188(7), 2110–2118. <https://doi.org/10.1002/ajmg.a.62751>



Additional resources are available in  
the presentation handout.

Questions?

Amanda Gerard, MS, CGC  
agerard@bcm.edu