2017 Texas Symposium on DeafBlindness
The “Truth” About Siblings
Saturday, 10:15-11:45 AM
March 3-4, 2017

Presented by
Elizabeth Lewis, M.A.
Texas Center for Disability Studies
Department of Anthropology, UT Austin
emlewis@utexas.edu

Developed for
Texas School for the Blind and Visually Impaired
Outreach Programs
“Siblings of people with disabilities share most of the concerns that their parents experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs, including resentment, peer concerns, embarrassment, and pressure to achieve. Yet, compared to what is available for parents, services and supports for siblings are almost non-existent.”

(Meyer and Fish 2008, 20)

Guiding Questions:
1) What are some key themes, findings, and gaps in current studies on siblings and their experiences?
2) What are some common assumptions about sibling experiences and outcomes? Are these accurate?
3) What affects do challenging or aggressive behaviors have on the experiences of typically developing siblings?

Why Look at Siblings?
- Duration of the sibling relationship.
- A neglected topic in research.
- Unique experiences and perspectives.
- Roles across the life course.
- Why not???
Siblings and Disability: Social and Historical Context

- Increasing lifespans of people with disabilities
  - Caregiving across the life course
- Community living and de-institutionalization
- Social Media
  - Networks, support, information

Existing Literature: Issues & Inconsistencies

- Lack of attention to siblings
- Assumption: having a sibling with disabilities is negative.
  - Based on what evidence?
- Question: What is an “ideal” sibling relationship?
- Causation/Correlation
  - Is disability the cause? How can we know?
- Researcher bias
  - Positive sibling outcomes not prioritized in research

Slide7

“Generally siblings across the lifespan often regard their experiences as a sibling positively. Siblings report affection and positive regard for their brothers and sisters with disabilities, attribute high levels of empathy and altruism as deriving from their relationship with sibling, and on the whole, appear to be as well adjusted and successful as individual who have typically developing brothers and sisters”

(Heller and Kaiser 2008, 7)
Siblings: What We Know

- Siblings largely “indistinguishable” from their peers (Stoneman 2005)
- There is no causal link between negative outcomes among siblings and the general presence of disability in the family.
- Diverse information sources: research, firsthand accounts, memoirs, blogs, etc.
- Takeaway: Don’t pathologize the sibling experience!
  - Families and experiences are incredibly diverse.

What We Know, cont.

- Question: Why do some siblings have negative outcomes while others do not?
  - Possible areas for research, support, and intervention?
- Reminder: Ambivalence is okay.
  - High highs, low lows.
- A Closer Look: Possible link between challenging behaviors and negative sibling experiences.
  - Impact on peer relationships
  - Calls for further study.

Disability and Sibling Relationships

- Relationships described as positive, nurturing
  - Variation from childhood to adulthood
- Conflict
  - Siblings have the right to have conflict!
  - Expect some of the bumps of all sibling relationships
- Play and Bonding
- Difficult to Generalize
  - Age, family structure, other factors
Disability and Family Roles

- Role Asymmetry
  - Siblings assuming greater childcare roles than their peers
- Case of younger siblings
- Positive Effects: Empathy, flexibility, understanding
- Possible Negative Effects: Strain, trying to do too much

But research indicates that siblings want to be involved!

**siblings, disability, and social worlds**

- Impact on Peer Relationships
  - Mixed. Not noticeably negative
  - **possible roadblock**: behavioral challenges
- Right to Independence and Self-Determinism
  - Siblings have the right to their own interests and challenges
  - **possible roadblock**: Care, schedule needs, family supports
- Role of Sibling Communities and Support Groups
  - Networking, sharing, connecting
  - Long-term impact!
  - **possible roadblock**: Lack of attention to sib experience
Research: Key Themes and Patterns

- Sibling Self-Concept: No significant difference.
  - Mixed findings for impact on self-control, self-efficacy
- Behavior Problems: Findings are mixed
  - Behaviors can be external (aggression) or internal (e.g., anxiety)
  - Even when typical siblings have behavioral issues, they tend not to be clinically significant
- Depression and Loneliness
  - Limited research available. Why?

Slide 14

“Siblings of people with disabilities share most of the concerns that their parents experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs, including resentment, peer concerns, embarrassment, and pressure to achieve. Yet, compared to what is available for parents, services and supports for siblings are almost non-existent.”

(Meyer and Fish 2008, 20)

Additional Factors to Consider

- Individual characteristics
  - Race, ethnicity, gender, spacing between children, type of family, adoption, socioeconomic status, geography, support system.
  - Key: Behaviors
- Voice and Perspective
  - What do siblings say about themselves?
- Theoretical Awareness
  - How can we move beyond social stigma and assumptions to build a better understanding of siblings’ experiences?
The Takeaway: General

- Siblings must be included in “family.”
- Disability ≠ outcomes and experience.
- Disability ≠ explanation (necessarily)
- Like parents, siblings need and deserve access to a community of peers.
- We need more – and better – research!

The Takeaway: Parents

Siblings need:

- Self-determinism and independence.
- High (but reasonable!) expectations.
- To know that they do not have to “make up for” their brothers or sister with disabilities.
- The right to a complex relationship with their sibling.
- Age-appropriate communication and information.
- Opportunities to meet peers.
- Celebrations, acknowledgment of successes.
- Different types of support throughout the life course.
- Modeling from parents!

The Takeaway: Professionals

- Siblings want to be involved.
- Siblings will likely become primary caregivers. Develop processes to smooth out this transition.
- Siblings have a wealth of knowledge about their brothers and sister.
- Siblings have a different perspective than parents or professionals. Use this.
Areas for Future Inquiry

- Role of race and ethnicity on sibling experiences
- Research on larger families (beyond the 2-sibling dyad)
- Comparative studies among different diagnostic groups.
- Use of social media to alter the sibling experience.
- Focus on siblings across the life course.
- Behavioral challenges, dual diagnoses, low-incidence diagnoses, and other “atypical” cases.
GENERAL RESOURCES ON SIBLINGS AND DISABILITY

Key National Groups for Siblings:

Sibling Support Project (http://www.siblingsupport.org)
A fantastic sibling-led and –founded organization that has active Facebook and Yahoo groups for siblings of different ages. The Sibling Support Project also conducts SibShop trainings to help siblings and allies around the country start formal sibling programs in their communities. Finally, this organization has an extensive list of publications and recommended resources on its website.

Sibling Leadership Network (http://siblingleadership.org)
The SLN focuses on advocacy and policy issues for siblings. Its website offers extensive information regarding policy, scholarly research, and general support. The SLN has multiple committee opportunities for siblings to volunteer, network, and build their knowledge of and public impact regarding specific aspects of the sibling experience.

General Resources:

“What Siblings Would Like Parents and Service Providers to Know”
(Sibling Support Project)
http://www.siblingsupport.org/publications/what-siblings-would-like-parents-and-service-providers-to-know


“Sibling Issues” (Center for Parent Information and Resources)
http://www.parentcenterhub.org/repository/siblings/

“When a Sibling is Disabled” (Lawrence Kutner)
http://psychcentral.com/lib/when-a-sibling-is-disabled/0001262
“Siblings of Children with Special Needs” (The Child Study Center, NYU)
http://www.aboutourkids.org/articles/siblings_children_special_needs
“Sibling Talk.” Blog from BLOOM.
http://bloom-parentingkidswithdisabilities.blogspot.com/search/label/Sibling-talk
http://issuu.com/hollandbloorview

Advocacy and Policy:
“Sibling Advocacy Toolkit” (Sibling Leadership Network)
http://siblingleadership.org/policy-advocacy/sln-advocacy-toolkit/

What Not to Read
Be wary of anything that pathologizes the sibling experience or assumes a negative long-term impact. These are based on dangerous and outdated assumptions, and are not necessarily backed up by data. Don’t fall into the doom-and-gloom narratives of the past!

Need More?
I’m happy to offer any insights based on my research with families and my own experience as a sibling, and also to provide suggestions for additional resources. Please feel free to email me at emlewis@utexas.edu.
Disability in Fiction, Popular Non-Fiction, and Film

Many of these books are well known and can be found at libraries, and almost all should be available via Amazon.com. For a more extensive list of resources, please refer to the Sibling Support Project’s book list found at http://astore.amazon.com/thesibsuppro-20.

Fiction
Doerr, Anthony. *All the Light We Cannot See*. 2014.

Non-Fiction


*Living with a Brother or Sister with Special Needs.* 1996.


* Focuses on or relates to sibling experiences
Films

The IRIS Center at Vanderbilt University has a searchable listing of films on disability themes (http://iris.peabody.vanderbilt.edu/films). Two other useful websites are Media and Disability Resources (https://mediadisability.wordpress.com/films-tv-documentaries) and http://disabilitymovies.com.

The Reelabilities Disability Film Festival website (http://www.reelabilities.org) is another great resource. Based in New York, Reelabilities holds disability film festivals in cities across the country, including Houston, and is a wonderful resource for learning more about disability in film. The Austin-based Coalition of Texans with Disabilities also holds a two-day film festival, Cinema Touching Disability, in Austin each year. You can read more at http://www.txdisabilities.org/news-events/film-festival/filmfestival-2014/about1.
Texas School for the Blind & Visually Impaired
Outreach Programs

Figure 1 TSBVI logo.

Figure 2 IDEAs that Work logo and OSEP disclaimer.

"This project is supported by the U.S. Department of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the authors and do not necessarily represent the position of the U.S. Department of Education."