

An Adult Sibling Talks to Parents



"Siblings are the people we practice on, the people who teach us about fairness and cooperation and kindness and caring, quite often the hard way."

– Pamela Dugdale

Kerry Voss Smith, Esquire

August 2018

"There may not be a more accurate one word description of the sibling relationship..."

"There may not be a more accurate one-word description of the sibling relationship than ambivalence. For many young brothers and sisters of all abilities, the sibling relationship is characterized by 'hugging and slugging'.... And when special needs are a part of the relationship, the ambivalence, if anything, is enhanced: the highs are higher, and the lows are lower."

The Sibling Survival Guide, Chapter 1

“But if I have time for only one message...”

“...it is this: *Brothers and sisters are too important to ignore because they will be in the lives of family members with special needs longer than anyone. Brothers and sisters will be there after parents are gone and special education services are a distant memory. However, if they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.*”

Don Meyer: *I'm Constantly Thinking About Bev and Her Future: Siblings Speak About Aging*”

“It is wonderful that you have had such positive experiences with your siblings, but I don't know that your experience is universal.”

-Unknown

(National Autism Conference attendee)



What are parental concerns about siblings?



Michigan, 1960s



1960



The State provides the first sheltered workshops for people with disabilities as part of an effort to increase "independent living".

From The History of the Arc of PA

1965



The Bureau of Education for the Handicapped is created - the precursor to the Office for Special Education Programs

From The History of the Arc of PA

1968



Parents become increasingly frustrated by the deplorable conditions at Pennhurst Hospital.

From The History of the Arc of PA

1968



The ground breaking exposé on Pennhurst called "Suffer the Little Children" is produced.

<http://www.preservepennhurst.org/default.aspx?pg=26>

As late as the 1970s, children could be excluded from school under these circumstances:

- ▶ A school psychologist has certified the child as “uneducable and untrainable”.
- ▶ Admission to school could be postponed indefinitely until the child reached a mental age of 5.
- ▶ A psychologist concluded that the child was unable to “profit” from school.
- ▶ Compulsory attendance was 8-17 years, but, in practice, the admission to school of children with intellectual disabilities was postponed until age 8 and/or they were “eliminate[d]” from public school at age 17.

343 F. Supp. 279; 1971 U.S. Dist. LEXIS 13874

1971: PARC v. Commonwealth of PA

The Plaintiffs decide on a “right to education” theory of the case, with the underpinnings from *Brown v. the Board of Education of Topeka*, 347 U.S. 483 (1954) (state laws establishing separate public schools for black and white students are unconstitutional).



1975

The PARC consent decree lead to P.L. 94-142 The Education for All Handicapped Act, which is now known as the Individuals with Disabilities Education Act (IDEA)



The Closing of Pennhurst -1987

▶ 1975

PARC joined the suit to close Pennhurst

▶ 1977

Judge Raymond Broderick ordered the closure of Pennhurst, finding its conditions violated the civil rights of its residents. The Commonwealth of PA was ordered to place residents into community living arrangements (CLAs).



The Legacy of Pennhurst

- ▶ Pennhurst Memorial & Preservation Alliance

<http://www.preservepennhurst.org/>



- ▶ I Go Home (nominated for a Mid-Atlantic Emmy Award)

<https://video.witf.org/video/witf-i-go-home/>

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- ▶ An i-go-home sequel is slated for release in late 2018



The Legacy of Pennhurst

- ▶ Pennhurst is now regarded as the epicenter for the modern disability rights movement.
- ▶ Pennhurst and its longitudinal study became a model for de-institutionalization efforts around the world.

Conroy, J.W., & Bradley, V.J. (1985). The Pennhurst Longitudinal Study: A report of five years of research and analysis. Philadelphia: Temple University . Developmental Disabilities Center. Bciston :Human Services Research Institute

<http://www.eoutcome.org/Uploads/COAUploads/PdfUpload/PennhurstLongitudinalStudyScannedV3Optimized.pdf>



From The History of the Arc of PA

The Litigation of the 1970s and 1980s...

- ▶ Resulted in far reaching changes in disability policy and procedure, with people with disabilities, both of school age and adulthood, coming out of the shadows, assuming a more prominent role in their schools and communities.
- ▶ Despite these historic gains in disability policy, the non-disabled sibling continued to remain invisible by clinicians.



"It would be comforting to be able to report that I had the foresight to realize that in these rapidly changing circumstances the roles of siblings would take on new significance. But the truth is that over the years we focused almost exclusively on the urgent needs of our parents and their [children with disabilities]. Yes, we dutifully recorded the names of siblings in our clinical charts, but rarely considered their needs in our service plans."

Gorelick, J. A Strong Sibling Network: Forgotten Children No more (1996, p. 7)

- ▶ As recently as the 1980s, the impact of disability on the non-disabled sibling was rarely explored in a systematic way.
- ▶ (Midlarsky & Hannah, *Helping as Coping by Siblings of the Disabled*, 1989)
- ▶ Siblings have been referred to as “forgotten children” (Gorelick, 1996)

- ▶ Yet historically, the study of family systems when a child is disabled has focused on the parent-child relationship, or the child-parent-school relationship, with little attention paid to the non-disabled sibling within the family.
- ▶ As one researcher has put it, non-disabled siblings have always been around, “yet somehow remained invisible”.

(Liska, V. *The Sibling: A Lifelong Journey of Care*. 1996, p. 3)

Siblings Come Out of the Shadows

A combination of factors forced attention to the role of siblings in the family system:

1. increased lifespan of individuals with disabilities;
2. the deinstitutionalization movement and return of disabled individuals to the communities;
3. The aging of parent caregivers;
4. The death of parent caregivers.

(Gorelick, 1996)

The Sibling Support Project

- ▶ Founded in 1990
- ▶ First national program dedicated to the "life-long and ever changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns".



<https://www.siblingsupport.org/>

Sibling and Leadership Network

- ▶ Inception in 2007
- ▶ Mission statement: To provide siblings of individuals with disabilities the information, support, and tools to **advocate** for their brothers and sisters and to **promote** the issues important to them and their entire families
- ▶ PA Sibling Support Network
<https://www.facebook.com/Pennsylvania-Sibling-Support-Network-INC-116499945114727/>

Characteristic Questions

- ▶ “Where will my sibling go if my parents pass away unexpectedly?”
- ▶ “Will my own family be open to having my brother or sister moving in with us-even for a short time?”
- ▶ “Have financial arrangements been properly made?”
- ▶ “If there is no financial ‘safety net’, how will I afford caring for my sibling?”
- ▶ “How will I deal with my grief while trying to support my sibling?”

Sibling Survival Guide, p. 144

Recommendations from the Sibling Support Project

1. Siblings have a right to their own life



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

2. Acknowledge siblings' concerns



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

3. Share your expectations for typically developing siblings



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

4. Expect typical behavior from typically developing siblings



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

5. Align your expectations for the family member with a disability as closely as possible to your expectations for the children without disabilities



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

6. The right to a safe environment



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

7. Provide siblings the opportunities to meet peers



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

8. Provide siblings the opportunities to obtain information



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

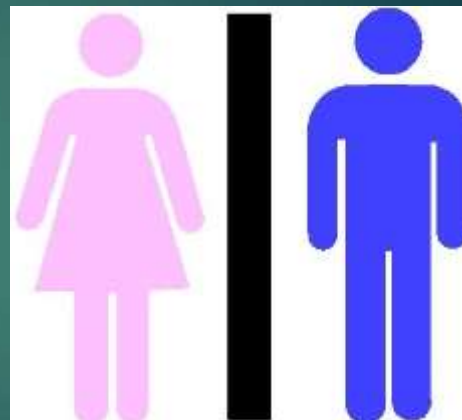
9. Discuss siblings' concerns about the future



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

10. Include both male and female siblings in discussion



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

11. Communicate,
Communicate,
Communicate



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

12. Have one-on-one time
with siblings



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

13. Celebrate every child's achievements and milestones, including siblings



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

14. Parents' perspective is more important than the actual disability



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

15. Include siblings in the definition of family



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

16. Actively reach out to siblings (service providers)

Out reach 

The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

17. Learn more about life as a sibling (service providers)



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

18. Create local programs specifically for siblings (service providers)



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

19. Include siblings on advisory boards and in policies regarding families (service providers)



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

20. Fund services for siblings (service providers)



The Sibling Survival Guide: What Siblings Would Like Parents and Service Providers to Know (2014)

Recommendations from the Sibling Support Project

How to Let Young Siblings Know You Care

Edited by Don Meyer, Cristina Breshears, and Patrick Martin

The Sibling Support Project

<https://www.siblingsupport.org/documents-for-site/how-to-let-young-siblings-know-you-care>

- ❑ A simple thank you
- ❑ Time alone with parent
- ❑ Acknowledgement of achievements big and small
- ❑ Acknowledgement of sibling assistance to brother/sister with a disability
- ❑ Acknowledging sibling's presence

Ideas to consider....



Ideas to consider....

Whatever your family structure, make it the healthiest it can be



Ideas to consider....

Parents set the tone within the family



Ideas to consider....

Siblings tend to protect their parents



Ideas to consider....

Siblings tend to be perfectionists



Ideas to consider....

Siblings may not be good at expressing their needs



Ideas to consider....

Siblings may need their own "social stories" to handle questions about their siblings

- ▶ "I knew there was something wrong with my [home]... But I didn't know how to explain what that was... I just didn't have the words." Graham Seaton. Now 30, Mr. Seaton said he realized that as a child, he felt he could not ask his parents for those words.
- ▶ NYTIMES Gretchen Cook April 4, 2006
- ▶ *Siblings of Disabled Have Their Own Troubles*

Ideas to consider....

- ▶ Strike the balance between watching over your disabled child with just letting them be a kid



Ideas to consider....

- ▶ Teach activities of daily living/self care to the greatest extent possible
- ▶ Include your child in household chores if possible (and however limited his/her contribution might be)



Ideas to consider....

No one will love your child
the way a parent does...
don't hold the sibling to this
impossible standard



Ideas to consider....

- ▶ Siblings may come in and out of their disabled siblings' lives



Ideas to consider....

- ▶ Siblings grieve too



Ideas to consider

- ▶ Understand the sibling's developmental stage



Ideas to consider....

- ▶ Avoid shaming siblings
- ▶ Don't hold them to a standard of perfection vis a vis their brother or sister—THEY WILL FAIL AT PERFECTION (even as adults) (and even if they are in the special education field!)



Resources

- ▶ The Sibling Support Project has published three books for younger siblings:
 - ▶ Views from Our Shoes: Growing up with a brother or sister with special needs
 - ▶ The Sibling Slam Book: What it is really like to have a brother or sister with special needs
 - ▶ Living with a brother or sister with special needs: A book for sibs

Resources - Adult

- ▶ For adult siblings:
 - ▶ Thicker than water: Essays by adult siblings of people with disabilities
 - ▶ The sibling survival guide: indispensable information for brothers and sisters of adults with disabilities
 - ▶ What about me? Growing up with a developmentally disabled sibling

- ▶ *Fiction for younger readers featuring sibling themes:*
 - ▶ Al Capone Does My Shirts by Gennifer Choldenko
 - ▶ Tru Confessions by Janet Tashjian
 - ▶ Rules by Cynthia Lord
 - ▶ Are You Alone on Purpose? by Nancy Werlin

Nonfiction and Memoir by Adult Siblings

- ▶ Riding the Bus with my sister by Rachel Simon
- ▶ **Special Siblings by Mary McHugh
- ▶ Being the Other One by Kate Stroh
- ▶ Check This Box If You Are Blind by Susan Meyers
- ▶ The Ride Together: A Brother and Sister's Memoir of Autism in the Family by Paul Karasik and Judy Karasik
- ▶ **How to Be a Sister: A Love Story with a Twist of Autism by Eileen Garvin
- ▶ That Went Well...Adventures in Caring for My Sister by Terrell Harris Dougan

Web-based Resources

- ▶ Best Buddies <http://www.bestbuddies.org/best-buddies>
 - ▶ This organization pairs volunteers from middle school age and up with individuals with developmental disabilities and intellectual disabilities for friendship, integrated employment, and leadership development.
- ▶ National Sibling Council <http://www.thearc.org/siblings>
 - ▶ The mission of the National Sibling Council is to ensure that siblings are educated about disability related policies and are engaged in national, state, and local advocacy efforts.
- ▶ Sibling Leadership Network <http://siblingleadership.org/get-involved/join-sln/>
 - ▶ The mission of the Sibling Leadership Network is to provide siblings the information, support, and tools needed to advocate for their family members and for issues important to their families.
- ▶ Sibling Support Project <https://www.siblingsupport.org/>
 - ▶ The Sibling Support Project was founded in 1990, as the first national program dedicated to the needs of siblings of brothers and sisters with special needs. The project sponsors sibling workshops where siblings can get together to discuss the joys and challenges of having a disabled brother or sister. There is a closed forum online, so that on siblings can post and read other entries.
- ▶

Workshops

- ▶ <https://www.siblingsupport.org/about-sibshops>
 - ▶ Sibshops are an opportunity for siblings to meet other siblings, and to discuss the challenges and contributions of having a disabled brother or sister.

SibShop University of Washington Survey Results

- ▶ Over 90% said the workshop had a positive effect on the feelings they had for their siblings
- ▶ The workshop taught coping strategies to over 2/3 of respondents
- ▶ Three quarters (3/4) of the respondents reported that the workshop affected their adult lives
- ▶ 94% said they would recommend sibshops to others
- ▶ (Results were not only positive, but enduring!)
- ▶ <https://www.siblingsupport.org/about-sibshops/university-of-washington-survey-on-sibshops>

Meeting Other Sibs Online

- ▶ SibNet (adult brothers and sisters)
 - ▶ SibTeen (teen brothers and sisters)
 - ▶ Sib20 (young adults, 18-early 30s)
- ▶ Some of us think that having a sib with a disability has enriched our lives, while others find having a sib with a disability a source of stress and even pain. And for many more, it has been a mixed bag, with "good stuff" and "not-so-good stuff" occurring simultaneously. All of these experiences are valid and all views are welcome on SibNet.

Conclusions

- ▶ EVERY relationship has its challenges.
- ▶ The sibling relationship has its own unique challenges (independent of any disability issues).
- ▶ Siblings of brothers and sisters with disabilities can have productive, supportive lifelong relationships.
- ▶ The fact that a child may have a sibling with a disability is just one of many factors that contribute to who the person becomes.
- ▶ While there are unique challenges to having a sibling with a disability, most non-disabled siblings do fine.

My Unofficial List of Sibling Characteristics

- ▶ We are funny (at least we think we are).
- ▶ We appreciate and tend to be more accepting of all kinds of differences.
- ▶ We have interesting stories to tell.
- ▶ We are less judgmental and less likely to jump to conclusions.
- ▶ We understand what is important in life.
- ▶ We are everywhere.



"Beth did email me, and everything she told me, sounds like my sister. It is so crazy how situations are so similar sometimes. Just when I think nobody could possibly know what it's like with a sister like mine, you tell me your story, and Beth tells me hers. It is so helpful to know there are people out there who are going through or have been through this. It is really teaching me to open up more about that area of my life that I once kept so secret."

(Friend's email to Kerry Smith)

“Sometimes I imagine meeting him wherever we go when we die, and he no longer has [an intellectual disability]. He tells me what it was like to live a life in which he understood that he wasn't like other people and wanted desperately to be like me, our father, or my husband. He tells me that he forgives me for not being a good sister to him many times....”

Special Siblings: Growing Up With Someone with a Disability (McHugh, 2003, p. 221)

Douglas H. Voss 1958-2017

His tender heart gave out too soon.

