

# The Sibling Experience, Sibling Support, & Sibshops

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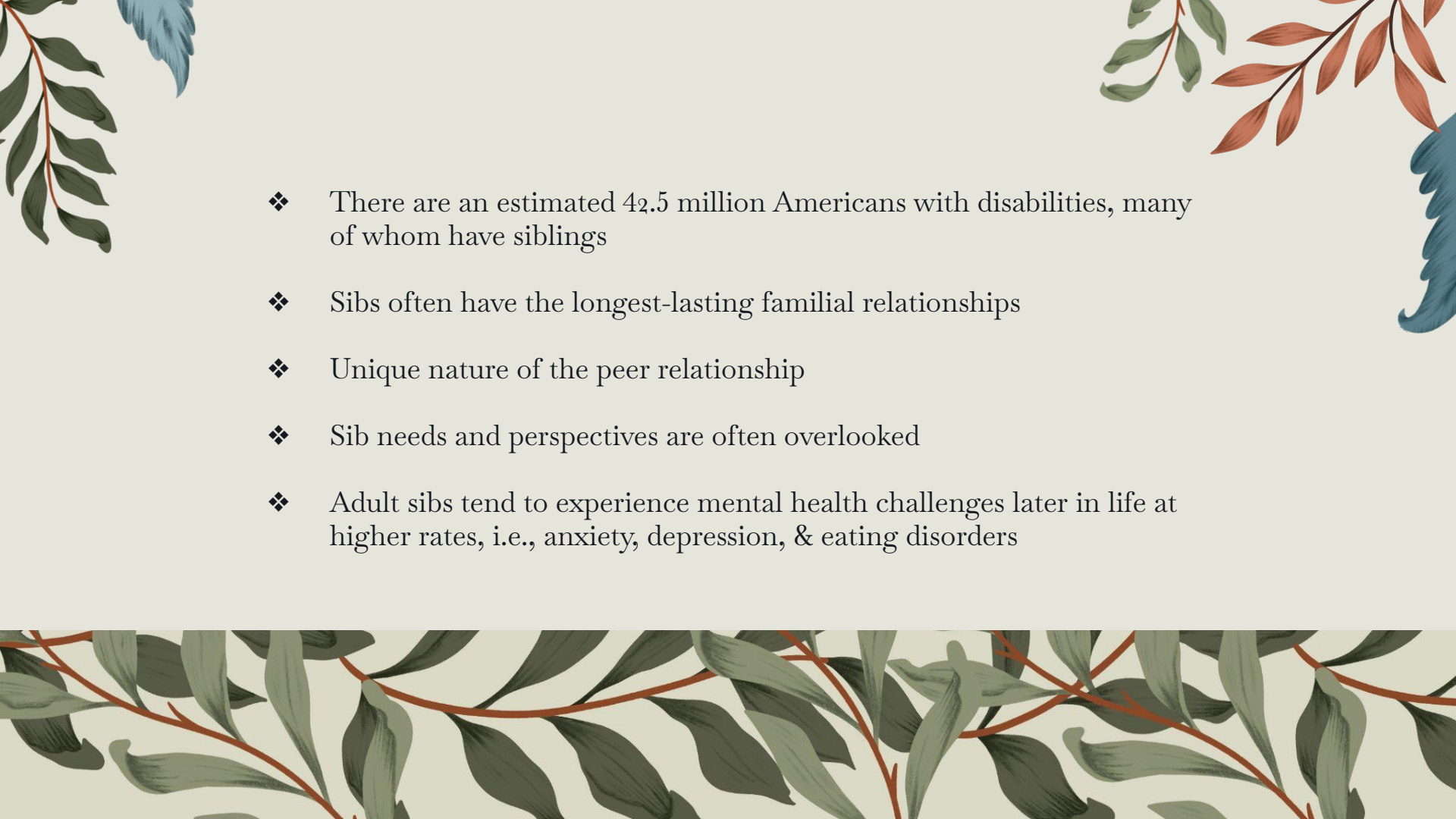
# What we will cover today...


- Introduction
  - Why Are “Sibs” Important?
- The Sibling Experience
  - Unique Challenges
  - Unique Opportunities
- Sibling Support
  - How Can We Maximize Unique “Sib Opportunities” and Minimize Unique “Sib Challenges”?
- Sibshops Programming
- Jess’ Sibling Story



The image features a light cream background with decorative floral and leaf motifs in the corners. In the top-left, there are dark green leaves and a single orange-red flower. In the top-right, there are blue leaves. In the bottom-left, there are dark green leaves. In the bottom-right, there are blue and reddish-orange leaves. The central text is in a black serif font.

A few of the many  
important reasons to  
talk about sibs...

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- The slide features decorative floral illustrations. In the top-left and top-right corners, there are branches with green and reddish-brown leaves. A large, detailed illustration of green leaves and reddish-brown stems runs horizontally across the bottom of the slide.
- ❖ There are an estimated 42.5 million Americans with disabilities, many of whom have siblings
  - ❖ Sibs often have the longest-lasting familial relationships
  - ❖ Unique nature of the peer relationship
  - ❖ Sib needs and perspectives are often overlooked
  - ❖ Adult sibs tend to experience mental health challenges later in life at higher rates, i.e., anxiety, depression, & eating disorders

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- The slide features decorative floral illustrations. In the top-left corner, there are green and blue leaves. In the top-right corner, there are red and blue leaves. A wide border at the bottom of the slide consists of a repeating pattern of green and red leaves.
- ❖ While support programs and services have been developed for individuals with I/DD and their parents, supports for sibs have traditionally been limited.
  - ❖ Sibs often become the next generation of caregivers
  - ❖ “Club Sandwich Generation”
  - ❖ There is a specific need for information on inclusive, future planning



# Unique Challenges...

Worry

Concerns About the Future

Resentment

Witness Stigma, Discrimination &  
Ableism Early and Often

Guilt


Embarassement

Frustration

Lack of Information

Loneliness

Parentification





# Ableism

## ABLEISM

a·ble·ism \ ăbə-,li-zəm \  
*noun*

A system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence and productivity.

These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism and capitalism.

This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily [re]produce, excel and "behave."

You do not have to be disabled  
to experience ableism.

a working definition by Talila "TL" Lewis in conversation with Disabled Black and other negatively racialized folk, especially Dustin Gibson; updated January 2020



# Pressure to Achieve

“Ever since I was a child, I have been put into that role - rescuer, perfect child, the one who would make everything right”.

- *David, in Leder, 1991*

"The Overachiever"

"The Perfectionist"

"The Good Kid"

**It is helpful for young siblings to understand that it is okay—and expected—to not get it right 100% of the time, and to know that they are unconditionally loved**



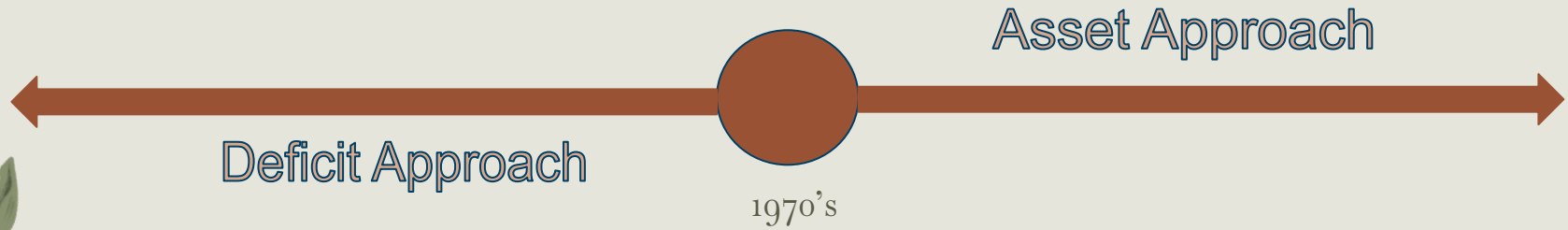
# The Sibling Experience & *Mental Health*

- Several studies have suggested sibs also tend to have higher rates of anxiety, depression and difficulty with peers, indicating the harmful effects of the internalization of their experiences.
- Low income families are especially vulnerable.
- The sibling support community can and should continuously strive to incorporate an **intersectionality lens** when conducting research on the sibling experience, developing sibling programming, and connecting siblings together.
  - Intersectionality is an analytical framework for understanding how a person's various social and political identities combine to create different modes of discrimination and privilege. Intersectionality identifies multiple factors of advantage and disadvantage.



# The Sibling Experience

*The Flip Side*



Sibling Research & Programming



Unique Opportunities...

**Maturity**

**Patience**

Protectiveness

**Pride**

**Strong Family Values**

**Open-mindedness**

Emotional Intelligence

**Empathy**

**Loyalty**

**Insight**

**Tolerance**





Unique Opportunities...

Gratitude

Appreciation

Resilience

Resourcefulness

Creativity

Social Adeptness

Mindfulness

Peacefulness





# Sibling Support



*What have we learned so far?*

**Sibs have...**

**Unique Concerns**

**Unique Opportunities**



*What can we do as sibling advocates to minimize siblings' concerns  
and maximize opportunities?*





# Sibling Support: Tips to Support Sibs





- Set aside special 1:1 time with sibs
  - Discuss disability and allow space for questions
  - Equal expectations (as best you can)
  - Be mindful of parentification - encourage kids to be kids!
  - Talk to them about the future
  - Active family life
  - Celebrate everyone's unique triumphs and successes
  - Reassurance - "A little validation goes a long way"!
  - Encourage your local service providers to include siblings and provide them with support
- 
- 



# Sibling Support: Tips to Support Sibs

Become curious with yourself, so you can extend the same curiosity to your sib





- Parent's interpretation of the disability is the single strongest factor affecting a sibling's interpretation of the disability
  - Model self-care as a parent:
    - Consider your own psychotherapy, self-care regimen, and support
    - Engage in stress-reduction activities, and include your family or designate a quiet time where everyone practices meditation, deep breathing, yoga, listening to music, etc.
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- 



# Sibling Support - Important Organizations to Know About



- Don Meyer
- First “Sibshop” launched in 1982 at UW
- In 1990, Don created the Sibling Support Project
- Current Director is Emily Holl (est. 2020)
- Only organization providing direct support to sibs through programming in this way
- Online communities such as SibTeen, Sib20, and SibNet (all closed Facebook groups) are wonderfully warm, supportive spaces where adolescent and adult siblings can receive information, resources, and validation 24 hours a day, seven days a week



<https://siblingssupport.org/>



# Sibling Support - Important Organizations to Know About



## **Mission:**

To provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.

## **Purpose:**

The purpose of the Sibling Leadership Network is to promote a broad network of siblings who share the experience of disability and people concerned with sibling issues by connecting them to social, emotional, governmental, and provisional supports across the lifespan enabling them to be effective advocates with their brother and sister, and to serve as change agents for themselves and their families



<https://siblingleadership.org/>

# Sibshops

- Sibshops provide young brothers and sisters with peer support and information in a lively, recreational setting.
- They are peer support groups that use play-based activities to help siblings of children with disabilities. Participants tend to be between 8 and 13, although some are as young as 6. While Sibshops may be therapeutic, they're not therapy. Sibshops are unapologetically playful.

<https://siblingssupport.org/sibshops/>





## The 5 Goals of Sibshops

1. Meet other siblings in a relaxed recreational environment
2. Discuss common joys and concerns with other siblings
3. Learn how others handle common sibling situations
4. Learn more about the implications of their brothers' and sisters' special needs
5. Teach parents and professionals about common concerns/opportunities experienced by sibs



- Meet other sibs (usually for the first time);
- Have fun;
- Talk about the good and not-so-good parts of having a sib with special needs with others who “get it”;
- Play some great games;
- Explore how other brother and sisters handle sticky situations sometimes faced by brothers and sisters;
- Laugh
- Learn about the services their brothers and sister receive; and
- Have some more fun!

The Sibshop curriculum is used throughout the United States and Canada and in Hong Kong, Japan, Mexico, New Zealand, Argentina, Ecuador, Iceland, Ireland, England, Italy, Malta, Singapore, and Turkey.



Matt (33)  
Jess (31)  
Nick (28)





## All About

Jessica Killian

1. I feel happiest when every body is very very happy.
2. I think I am good at taking care of my baby brother.
3. I care about every body
4. Two words that describe me the best are nice and friendly.
5. I help out at home by carrying in the groceries.
6. I know I am a good friend because I'm never ever mean.
7. I feel best about myself when I make every body happy.
8. I feel sad when every body is very very upset.
9. I am able to help out at school by helping clean up the room.
10. The thing I like best about me is very nice.





Contact Jess directly:  
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Thank  
You



# Resources

- The Sibling Leadership Network
  - <https://siblingleadership.org/national-siblings-day/>
  - <https://siblingleadership.org/sibling-leadership-network-mission-and-core-values/>
- The Sibling Support Project
  - <https://siblingsupport.org/history-2/>
  - <https://siblingsupport.org/sibshops/>
  - <https://siblingsupport.org/publications/>
- Support for Siblings of Special Needs Children. May 10, 2013. Contributed by Andrea Schneider, LCSW, Learning Difficulties Topic Expert Contributor
  - <https://www.goodtherapy.org/blog/support-siblings-special-needs-children-0510134>
- Avidan Milevsky Ph.D. Band of Brothers, and Sisters. Siblings of Children with Disabilities "What about me?" Enhancing the lives of siblings of children with disabilities.
  - Posted Jun 06, 2014
  - <https://www.psychologytoday.com/us/blog/band-brothers-and-sisters/201406/siblings-children-disabilities>
- Growing Up Alongside a Sibling With a Disability By Keren Landman, May 11, 2020
  - <https://www.nytimes.com/2020/05/11/parenting/children-sibling-disability.html>
- Sibling Studies:
  - <https://www.easterseals.com/explore-resources/siblings-study.html>
  - <https://pubmed.ncbi.nlm.nih.gov/23897909/>
  - <https://pubmed.ncbi.nlm.nih.gov/21204835/>
  - [https://www.researchgate.net/publication/265255618\\_Sibling\\_Involvement\\_in\\_Interventions\\_for\\_Individuals\\_with\\_Autism\\_Spectrum\\_Disorders\\_A\\_Systematic\\_Review](https://www.researchgate.net/publication/265255618_Sibling_Involvement_in_Interventions_for_Individuals_with_Autism_Spectrum_Disorders_A_Systematic_Review)
  - <https://pubmed.ncbi.nlm.nih.gov/16719637/>
  - [https://www.researchgate.net/publication/18341789\\_Siblings\\_of\\_retarded\\_children\\_A\\_population\\_at\\_risk](https://www.researchgate.net/publication/18341789_Siblings_of_retarded_children_A_population_at_risk)
- Getting Real About Resentment and Finding Small Ways. Feature article by Emily Holl in the parenting special needs magazine
  - [https://magazine.parentingspecialneeds.org/publication/?m=13847&i=700214&view=articleBrowser&article\\_id=3975336](https://magazine.parentingspecialneeds.org/publication/?m=13847&i=700214&view=articleBrowser&article_id=3975336)
- Article, "Young Siblings of Individuals with Intellectual/Developmental Disabilities: Common Experiences" Featured in the Impact Feature Issue on Siblings of People with Intellectual, Developmental, and Other Disabilities. Authors: Don Meyer & Emily Holl
  - <https://publications.ici.umn.edu/impact/32-2/young-siblings-of-individuals-with-idd>
- Intersectionality:
  - <https://researchguides.library.syr.edu/fys101/intersectionality>
- TL's Blog:
  - <https://www.talilalewis.com/blog/ableism-2020-an-updated-definition>