

What Adult Siblings Want Us to Know:

Understanding the evolving role of
siblings across the lifespan

Kaitlin McNamara
Sibling Leadership Network

Who Am I?

My Sibling Experience

- Oldest of four sisters
- Two of my younger sisters identify as women with disabilities
- Grew up navigating advocacy, systems, and lifelong sibling roles
- My lived experience shapes how I see disability, leadership, and family



My Education & Professional Path

- B.A., Political Communications, The George Washington University
- J.D., University of Wisconsin Law School
- Focused on disability justice and systems change
- Career in nonprofit leadership centered on civic engagement and systemic reform

The Big Questions

- What changes at 18+?
- The Unknown Future
- The Club Sandwich
- Becoming the Primary?
- Transitions across the Lifespan

74%

of siblings say this role profoundly shapes their identity and well-being

75%

feel pressure to make life choices around their sibling

Transitions aren't just about the person with a disability, it's about the whole family system.

What Happens at 18+

- Guardianship & decision-making
- Living arrangements
- Financial planning
- Benefits & eligibility
- Their own life trajectory

92%

feel caregiving pressure

90%

say that pressure comes from themselves

This is often when siblings move from “supportive sibling” to “future planner.”

The Young Adult Sibling

(Early 20s–30s)

Internal Monologue:

- “What will my role be?”
- “Will I have to move back home?”
- “How do I plan my career?”
- “When do I start learning the details?”
- “What happens when my parents can’t do this?”

85%

experience
anxiety

50%

find it difficult to
ask for help

‘Sibs’ talk to us about the anxiety about the unknown and limited connection to peers with similar experiences.

The Club Sandwich Generation

(30s–50s)

Balancing:

- Their own children
- Careers
- Aging parents
- Sibling with disability

Internal Monologue:

- “I’m next.”
- “There’s no backup plan.”
- “How do I juggle all of this?”



The Primary Caregiver Sibling

When Does this Happen?

- Parent illness
- Parent death
- Crisis event

83%

feel isolated

What's at Stake?

- Housing stability
- Medical decisions
- Employment/day services
- Navigating Medicaid & waivers
- Long-term sustainability

88%

struggle with
emotional expression

60%

report chronic stress

End of Life Transitions

What is Happening?

- Grief
- Role shift
- Intensified responsibility
- Changed family identity
- Logistics can crowd out space to grieve or heal
- Crisis moment if there was no plan, or sibling wasn't involved



Overnight shift in identity can be an isolating experience and lead to mental health concerns.

Other Considerations

Culture and Community

- Language & Interpretation
 - Translate complex systems
 - Interpret medical and legal terminology
- Navigate cultural expectations
- Carry additional emotional labor

37%

identify societal/cultural expectations as pressure

Disability, caring for family, and death are defined differently in different cultures.

What Adult Siblings Are Really Asking and Asking For

We Want to Ask:

- “Where do I start?”
- “Who else understands this?”
- “What if I don’t want to be guardian?”
- “How do I prepare without taking over?”
- “How do I have hard conversations with my parents?”

76%

want emotional well-being and community

What We Are Asking For:

- Practical tools
- Peer connection
- Clear pathways
- Validation

12%

feel great at asking for support

What Is Out There to Support Siblings?

Sibling Leadership Network

- Connecting siblings across the lifespan
- Policy & advocacy
- Evidenced-based Program Development
- Resources & education

SIBLING 
LEADERSHIP
NETWORK

Siblings are the longest-lasting family relationship. They need resources and support across their lives

Other Sibling Organizations



Find a sibshop near you for sibs ages 8-13 or become sibshop facilitator certified!

An international organization dedicated to support siblings who have brothers or sisters w complex health conditions.



For Sibs

SibThrive Next session runs Mondays, March 8 through April 13, from 6:00-7:30 PM PT.

Transform Your SibLife

6-Week Virtual Cohort for Sibs



"This program provided me with skills to better cope with feelings and issues that are unique to Sibs. I enjoyed the topics, community building aspect and having a safe space to vent feelings embedded in the program. I would recommend it for any Sib, especially those looking to build resilience and strength in relation to their roles."
SibThrive Graduate- Andrea Carpena

Program Highlights

- Story Sharing
- Boundary Setting
- Resilient thinking
- Community Building
- On-Going Support
- Holistic Approach

The **SibThrive program** offers adult siblings of people with intellectual and developmental disabilities a supportive, transformative space to connect virtually. Together, Sibs share their stories, explore caregiving boundaries, and reframe their journeys to embrace resilience, growth, and hope.

Scan the QR code or visit siblingleadership.org/resources/sibthrive/ to complete our **Interest Form** and get details on how to register.



Learn More at <https://siblingleadership.org/resources/sibthrive/>
Follow us on Instagram | Email us at SibThrive@SiblingLeadership.org

YOU'RE INVITED TO THE SLN'S

Virtual Sib Empowerment Meet-ups

Nobody gets it like another Sib. That's why we're starting these meet-ups. Take some time in a space designed just for you. Join us to reconnect and share!



07 MARCH 2026
11 AM -12 PM ET

EVENT HIGHLIGHTS

- Warm Welcome
- Community Building
- Topic of the Day
- Q&A Session
- Future Plans

The virtual meeting link will be sent through your e-mail

FILL OUT THIS FORM TO REGISTER

SIBLING LEADERSHIP NETWORK

A Midori Story Production

Sib as a Human



SIBLING LEADERSHIP NETWORK

SIBLING SELF-CARE TOOLKIT & WORKBOOK

Follow us on social media:

- The Sibling Leadership Network
- @sibleadership
- @siblingleadershipnetwork

Sign up to our newsletter to receive resources and connect with local chapters.
SiblingLeadership.org

THIRD EDITION

Sibshops

Workshops for Siblings of Children With Support Needs

Don Meyer
Emily Hill
Patricia Vadasy

Sibshops

RIGHT TO BE

FORMERLY HOLLBACK!

SIBLING LEADERSHIP NETWORK

BYSTANDER INTERVENTION TO SUPPORT THE DISABILITY COMMUNITY IN PUBLIC SPACES

THANK YOU!



For Organizations

Sibling Leadership Network's

NETWORK MEETING

VIRTUAL! HAPPENING QUARTERLY!

APRIL 14, 2026 | 07:30 - 08:30 PM ET

All partners are welcome to our **NEW** quarterly network meetings! Join us at these virtual meetings to hear updates on the SLN and connect with other organizations.

REGISTER HERE!

Email info@siblingleadership.org with any questions

Scan with phone to register!



What's Still Missing

- Structured transition planning that includes siblings
- Clear entry points for adult siblings
- Mental health supports specific to sibling caregivers
- End-of-life transition supports
- Culturally responsive sibling supports

Key Takeaways

Adult siblings are:

- Planning earlier
- Feeling pressure sooner
- Juggling multiple roles
- Asking for clearer pathways

If we support siblings early:

- We strengthen long-term stability
- We reduce crisis transitions
- We build sustainable family systems

92%

caregiving pressure

85%

anxiety

83%

isolation

50%

difficulty asking for help

Final Thought

Supporting siblings isn't optional.

It's creating preventative policy.

It's building family stability.

It's ensuring long-term systems sustainability.

Including 'Sibs' at the table prepares individuals and systems for the future.

Find ways to have the conversation with the 'Sibs' you know.

Stay Connected!



www.siblingleadership.org



@siblingleadership



@siblingleadershipnetwork



Sign up for our
newsletter!

Kaitlin McNamara

kaitlinmcnamara@siblingleadership.org