



What Adults with IDD Say about Sibling Support

Presented by Katie Arnold, Ph.D.

Katie's Siblings



BACKGROUND



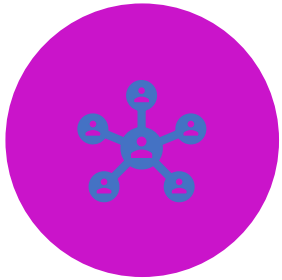
- Sibling relationships are often the longest of a person's life
- Sibs have an enduring bond
- The sibling experience is varied
- Siblings learn from each other
- Voices of people with IDD are missing in family support research
- Most research focuses on support people with IDD receive

OVERVIEW



- ▶ 30 virtual interviews were conducted using a dyadic interview method
- ▶ 10 adults with IDD and
- ▶ 10 Key Support People they chose
- ▶ Participatory Action Research approach was used involving 5 adults with IDD on a Community Advisory Committee.

FINDINGS



Companionship support such as how they keep each other company and help feel a sense of belonging.



Instrumental support such as how they provide help with healthy living and medical support as well as financial support and navigating services.



Emotional support such as how they show love and help handle emotions.



Informational support such as how they provide advice and guidance to make choices and plan for the future.

RESEARCH QUESTIONS



1. What types of supports do people with IDD receive from their families?
2. What types of supports do people with IDD give to their families?

METHODS

▶ Participants

▶ Eligibility:

- Adult with IDD (18 years or older)
- Live in Illinois with a family member
- Have at least one parent and sibling in their life

▶ 10 adults with IDD and

▶ 10 Key Support People they chose



Demographics for adults with IDD		% (n)
Age	20-29	40% (4)
	30-39	20% (2)
	40-49	30% (3)
	50-59	0% (0)
	60 and above	10% (1)
Gender	Male	80% (8)
	Female	20% (2)
Race/Ethnicity	White	50% (5)
	Hispanic	30% (3)
	South Asian	10% (1)
	Mixed	10% (1)

Participants:

- **10 adults with IDD**
- 10 Key Support People they chose

Demographics for adults with IDD		% (n)
Legal Guardian Status	Yes	60% (6)
	No	40% (4)
Key Support Person Relationship	Mom	50% (5)
	Dad	30% (3)
	Sister	20% (2)
Lives with	Parent(s)	80% (8)
	Sibling	20% (2)



Theme 1:
Social-Emotional
Support:

- A. Companionship support
- B. Emotional Support

Theme 2:
Independent Living
Support

- A. Instrumental Support
- B. Informational Support

Theme 1.A. Companionship Support:



Received from family:

- Over half of people with IDD liked spending time with their siblings the most
- Siblings provided peer support
- Siblings helped develop friendships

“Sister because she is easy to talk to.”

-Brian

Theme 1.A. Companionship Support (cont.)



Gave to family:

- Keeping Company
- Helpful
- Sibling Support: Role as Aunt/Uncle

“My brother, he, I think he tends to come to me first for a lot of his, like if he need to like vent. I’m really really happy that he can like get things out there and get things off his chest. Recently with his relationship stuff, I think I did that.”

-Sam

Theme 1. B. Emotional Support:



Received from family:

- Love
- Handling Emotions
- Grieving

*“I started crying and I hugged Aria.
And I know she’s there.”*

-Erin

Theme 1. B. Emotional Support



Gave to family:

- Express Love
- Being asked to Help
- Helping feel better

“Sometimes like my brother, uh sometimes like he’s, he’s crying before, and I told him you know it’s okay and then I hugged him.”

-Judah



Theme 1:
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Support:

- A. Companionship support
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Theme 2:
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Support

- A. Instrumental Support
- B. Informational Support



Theme 2. A. Instrumental Support:

Received from family:

- Medical
- Health
- Financial support
- Navigating Services

“Like the medicine. And going to the doctor...My sister helps me out with medical. Becky helps me out with doing the medicine and everything that is diabetes. She, she helps me out with putting the medicine in order and I put them in the strip.”

-Joey



Theme 2. A. Instrumental Support:

Gave to family:

- Physical help
- Healthy Living

“I remind my parents to take their pills every day.”
-Brian



Theme 2. B. Informational Support:

Received from family:

- Guidance
- Advocate
- Sibs in Future Planning

“She if I ever have a problem with something, I know I can always count on her to be there for me, ya know.”

-Nelson

Theme 2. B. Informational Support



Gave to family:

- Shared information

“I do, I do give people good advice.”
-Erin

IMPLICATIONS



Families

- Family Culture of Support

Professionals

- People with disabilities are invisible contributors of support
- Families provide more than physical support

Research & Policies

- More research with people with IDD
- Policies that take into account support people with IDD provide

Limitations & Future Research

Questions?

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