

Sibling Strengths and Supported Decision Making: Updates on Sibling Research

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This webinar is jointly sponsored by AAIDD and the Sibling Leadership Network.





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.**

www.siblingleadership.org

SIBLING
LEADERSHIP
NETWORK

Research

**Policy &
Advocacy**

**Support &
Information**



By joining the network you will:

- ❖ Become connected to the larger sibling movement happening across the country.
- ❖ Help strengthen the sibling voice so together we can effect even more change.

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Presenters



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STRENGTHS AND SOCIAL CONNECTIONS OF SIBLINGS WITH AND WITHOUT DISABILITIES

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SIBLING RELATIONSHIPS

- Sibling relationships are generally the **longest lasting relationships** in a person's life
- Sibling relationships **change across the lifespan**
- Sibling relationships that include an individual with disabilities are **not so different** from sibling relationships that do not include an individual with disabilities
- The **views of siblings matter**

WHAT PRIOR RESEARCH TELLS US ABOUT SIBLING RELATIONSHIPS

Research addressing the amount of time siblings spend together have provided mixed results (Seltzer, Greenberg, Orsmond, & Lounds, 2005)

Sibling relationships between individuals with and without developmental disabilities are generally positive (Floyd, Purcell, Richardson, & Kupersmidt, 2009; Hodapp & Urbano, 2007; Hodapp, Urbano, & Burke, 2010; Stoneman, 2005)

WHAT PRIOR RESEARCH TELLS US ABOUT STRENGTHS

- The literature tends to focus on deficits, challenges, and departures
- Few studies have addressed the strengths and positive qualities that individuals with intellectual disability and autism possess
- Most such studies have focused on the vantage point of parents (Carter, Boehm, Biggs, et al., 2015), educators (Carter, Brock, & Trainor, 2014), or staff (Woodard, 2009)
- The strengths and positive qualities people possess can provide points of connection to communities and relationships

RESEARCH QUESTIONS

STUDY 1

How do young adult siblings spend time with their brother or sister with IDD?

What factors are associated with the variety and number of activities siblings engage in together?

How do siblings perceive the quality of their relationship?

What expectations do siblings hold for their brother or sister with IDD?

STUDY 2

How do siblings assess the strengths of their sisters and brothers with IDD?

What factors are associated with the ratings of these siblings?

PARTICIPANTS AND RECRUITMENT

167 siblings for strengths analyses

- Ages 18-30 ($M = 23.2$ years)
- 78% sister, 22% brother
- 87% White, 7% African American, 3% Hispanic, 3% other
- 63% have more than HS diploma
- 77% single, 23% married
- 11% with children
- 34% live in same house
- 46% live within two hours

159 siblings for activities analyses

Fifty-nine organizations distributed information about the study:

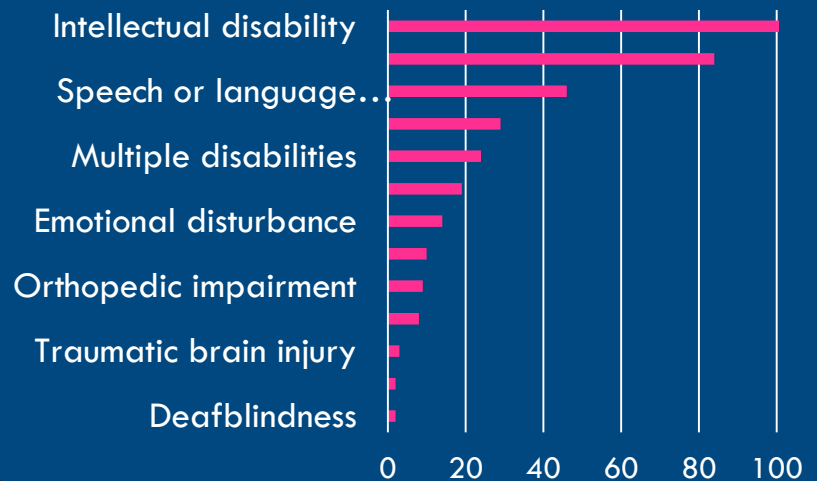
- 38 sent out emails
- 14 added information to a newsletter (electronic or paper)
- 11 shared it on social media
- 4 posted information on their website
- 3 organizations handed out information directly to family members

Arcs, Autism societies, Down syndrome associations, Special Olympics chapters, TABS, and smaller organizations

SIBLINGS WITH DISABILITIES

- Ages 1-46 (M = 21 years)
- Ranged from 16 years older to 29 years younger
- 61% ID, 50% ASD, and 14% MD
- 75% used speech, 16% limited words, 2% AAC, 8% no communication
- 95% get around without assistance
- 40% *sometimes* and 10% *often* engage in challenging behavior

Additional Disability Descriptions



MEASURES

1. Demographic information about the siblings and their family member
2. Activities they do with their family member
3. Expectations for their family member's future
4. Quality of their relationship
5. Strengths of their family member

REDCap web application (www.projectredcap.org)

Drawing for one of twenty \$25 gift cards

SHARED ACTIVITIES

Adapted from Carter et al. (2010)

Frequency of participation in 16 activities with sibling in the past year

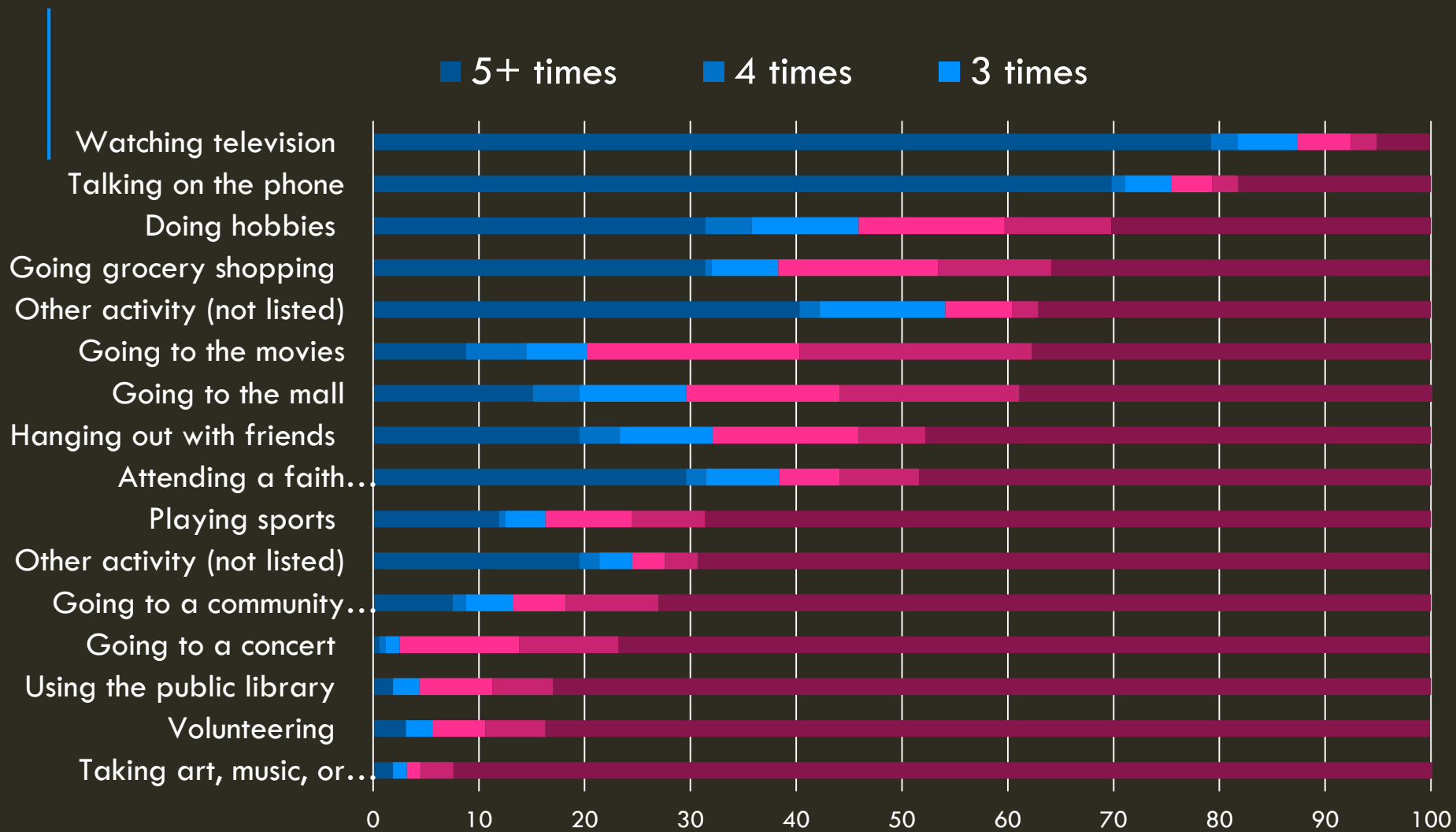
- 0 times, 1 time, 2 times, 3 times, 4 times, or 5 or more times

Others who participated

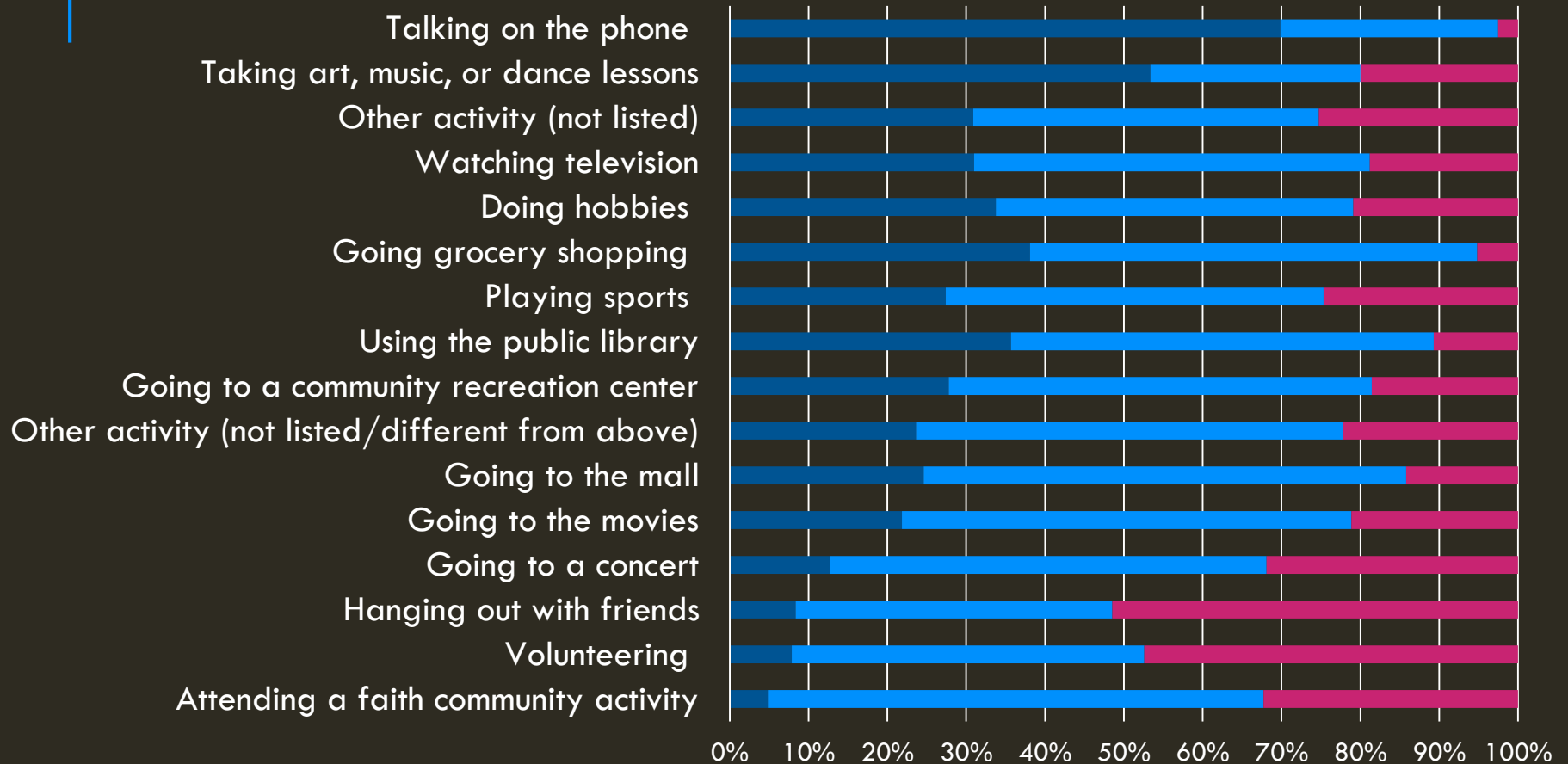
- with family, with friends, with others, or just the two of us

Below is a list of common activities siblings might do together. Please tell us how often you have done any of these activities **with your brother or sister with a disability**. Also tell us who else participated.

Activity	How often have you done this activity with your sibling in the last year?	With whom did you and your sibling do this activity? (Check all that apply)
Going to the movies	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Going to the mall	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Going to a concert	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Doing hobbies	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Hanging out with friends	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Playing sports	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Taking art, music, or dance lessons	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Volunteering	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Attending a faith community activity	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Using the public library	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Going to a community recreation center	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Going out to eat	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Watching television	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Going grocery shopping	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Going to an amusement park	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Talking on the phone	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 or more	<input type="checkbox"/> Family <input type="checkbox"/> Friends <input type="checkbox"/> Others <input type="checkbox"/> Just the two of us
Other:	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	<input type="checkbox"/> Family <input type="checkbox"/> Friends



■ Only the siblings ■ Also with family ■ Also with Friends or Others



FACTORS CORRELATED WITH FEWER ACTIVITIES

Communication

Siblings of brothers or sisters who were not able to communicate using speech participated in significantly fewer total activities with their brother or sister with disabilities ($t = 3.24, p < .01$)

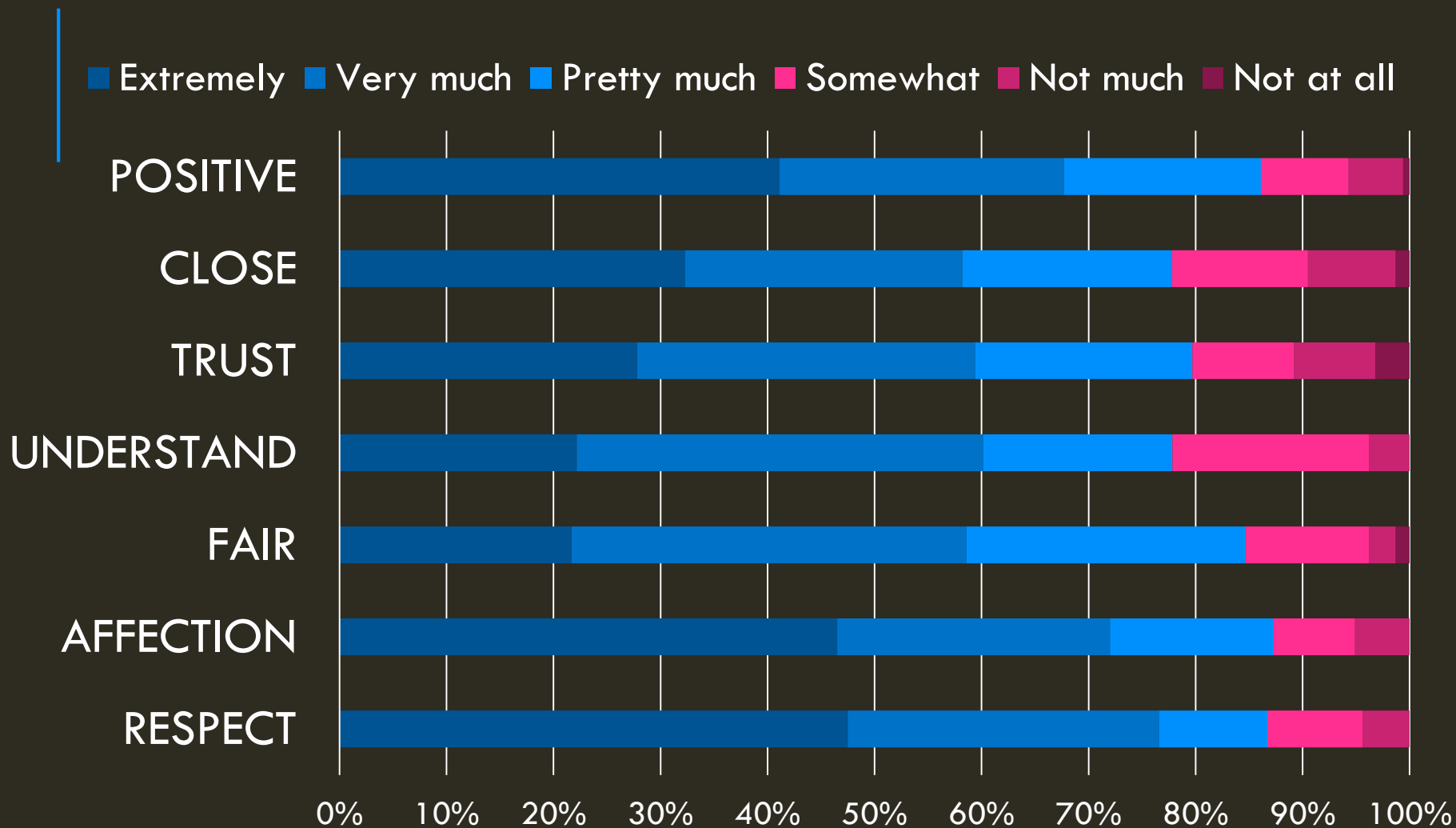
Mobility

Siblings participated in significantly fewer total activities when their brother or sister with disabilities was not able to get around without assistance ($t = 2.01, p < .05$).

ASD

Total number of activities participated in together were significantly lower when the brother or sister has ASD ($t = 2.27, p < .05$).

[illegible]



FACTORS ASSOCIATED WITH LOWER QUALITY RATINGS

Challenging Behavior

Siblings who reported their brother or sister with disabilities engaged in challenging behavior more frequently reported less positive quality relationships ($r = -.24, p < .01$).

FUTURE EXPECTATIONS

Adapted items (Carter, Trainor, Ditchman, Swedeen, & Owens, 2011; Chambers, Hughes, & Carter, 2004; Griffin, McMillan, & Hodapp, 2010)

Expectations across 8 areas:

- 1 = *definitely no*, 2 = *probably no*, 3 = *probably yes*, 4 = *definitely yes*

Cronbach's alpha = .61

Think about your sibling's future.	1 ▼	2 ▼	3 ▼	4 ▼	5 ▼
I expect my sibling to live with family members.	<input type="checkbox"/> Definitely yes	<input type="checkbox"/> Probably yes	<input type="checkbox"/> Probably no	<input type="checkbox"/> Definitely no	<input type="checkbox"/> Currently is
I expect my sibling to live independently.	<input type="checkbox"/> Definitely yes	<input type="checkbox"/> Probably yes	<input type="checkbox"/> Probably no	<input type="checkbox"/> Definitely no	<input type="checkbox"/> Currently is
I expect my sibling to live with others in the community	<input type="checkbox"/> Definitely yes	<input type="checkbox"/> Probably yes	<input type="checkbox"/> Probably no	<input type="checkbox"/> Definitely no	<input type="checkbox"/> Currently is
I expect my sibling to have a paid job in the community.	<input type="checkbox"/> Definitely yes	<input type="checkbox"/> Probably yes	<input type="checkbox"/> Probably no	<input type="checkbox"/> Definitely no	<input type="checkbox"/> Currently is
I expect my sibling to have a volunteer job in the community.	<input type="checkbox"/> Definitely yes	<input type="checkbox"/> Probably yes	<input type="checkbox"/> Probably no	<input type="checkbox"/> Definitely no	<input type="checkbox"/> Currently is
I expect my sibling to go have a job at a sheltered workshop.	<input type="checkbox"/> Definitely yes	<input type="checkbox"/> Probably yes	<input type="checkbox"/> Probably no	<input type="checkbox"/> Definitely no	<input type="checkbox"/> Currently is
I expect my sibling to go to college.	<input type="checkbox"/> Definitely yes	<input type="checkbox"/> Probably yes	<input type="checkbox"/> Probably no	<input type="checkbox"/> Definitely no	<input type="checkbox"/> Currently is
I expect my sibling to get married.	<input type="checkbox"/> Definitely yes	<input type="checkbox"/> Probably yes	<input type="checkbox"/> Probably no	<input type="checkbox"/> Definitely no	<input type="checkbox"/> Currently is

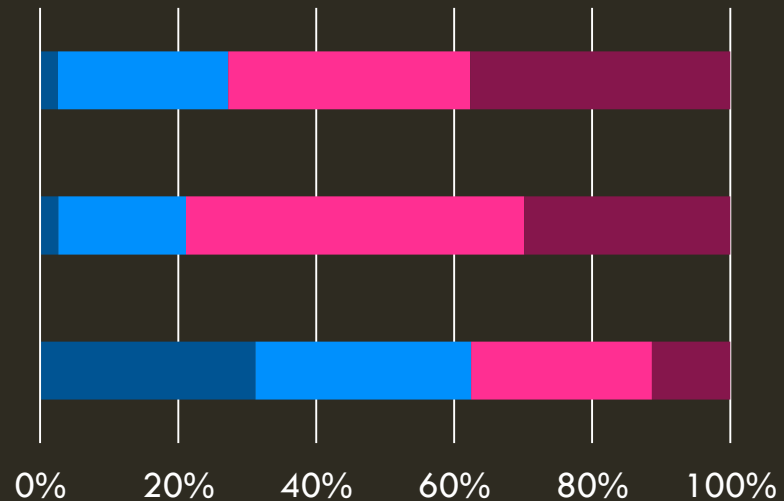
RESIDENTIAL EXPECTATIONS

■ Definitely yes ■ Probably yes ■ Probably no ■ Definitely no

I expect my sibling to live in a group home.

I expect my sibling to live independently.

I expect my sibling to live with family members.



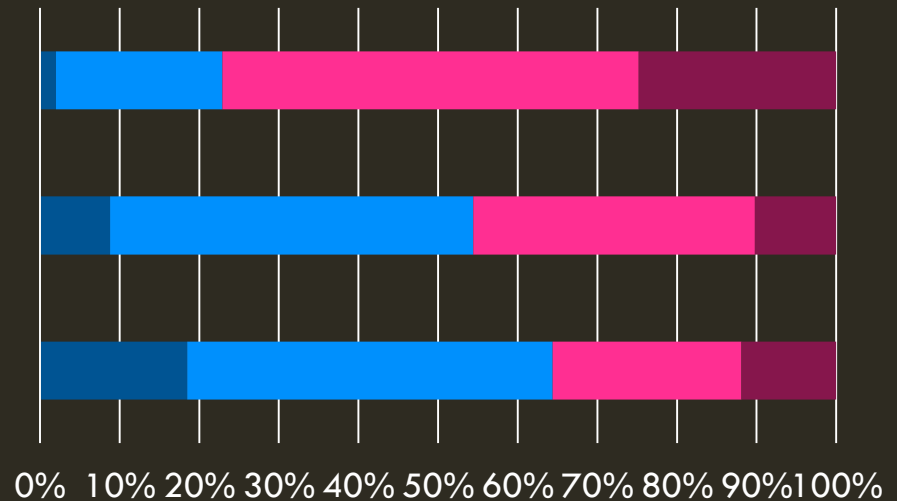
EMPLOYMENT EXPECTATIONS

■ Definitely yes ■ Probably yes ■ Probably no ■ Definitely no

I expect my sibling to go have a job at a sheltered workshop.

I expect my sibling to have a volunteer job in the community.

I expect my sibling to have a paid job in the community.

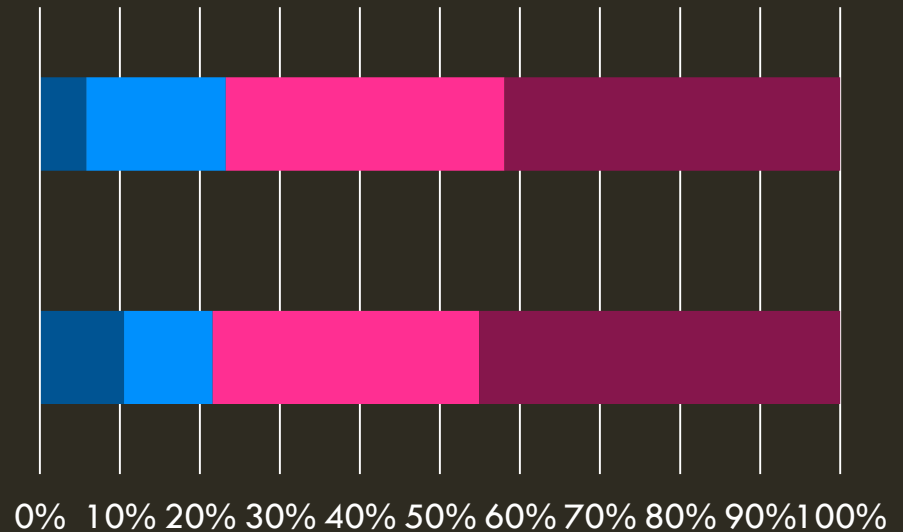


OTHER EXPECTATIONS

■ Definitely yes ■ Prbably yes ■ Probably no ■ Definitely no

I expect my sibling to get married.

I expect my sibling to go to college.



ASSESSMENT SCALE FOR POSITIVE CHARACTER TRAITS-DEVELOPMENTAL DISABILITIES

Adapted from Woodard (2009)

26 items across 10 domains or 4 sections

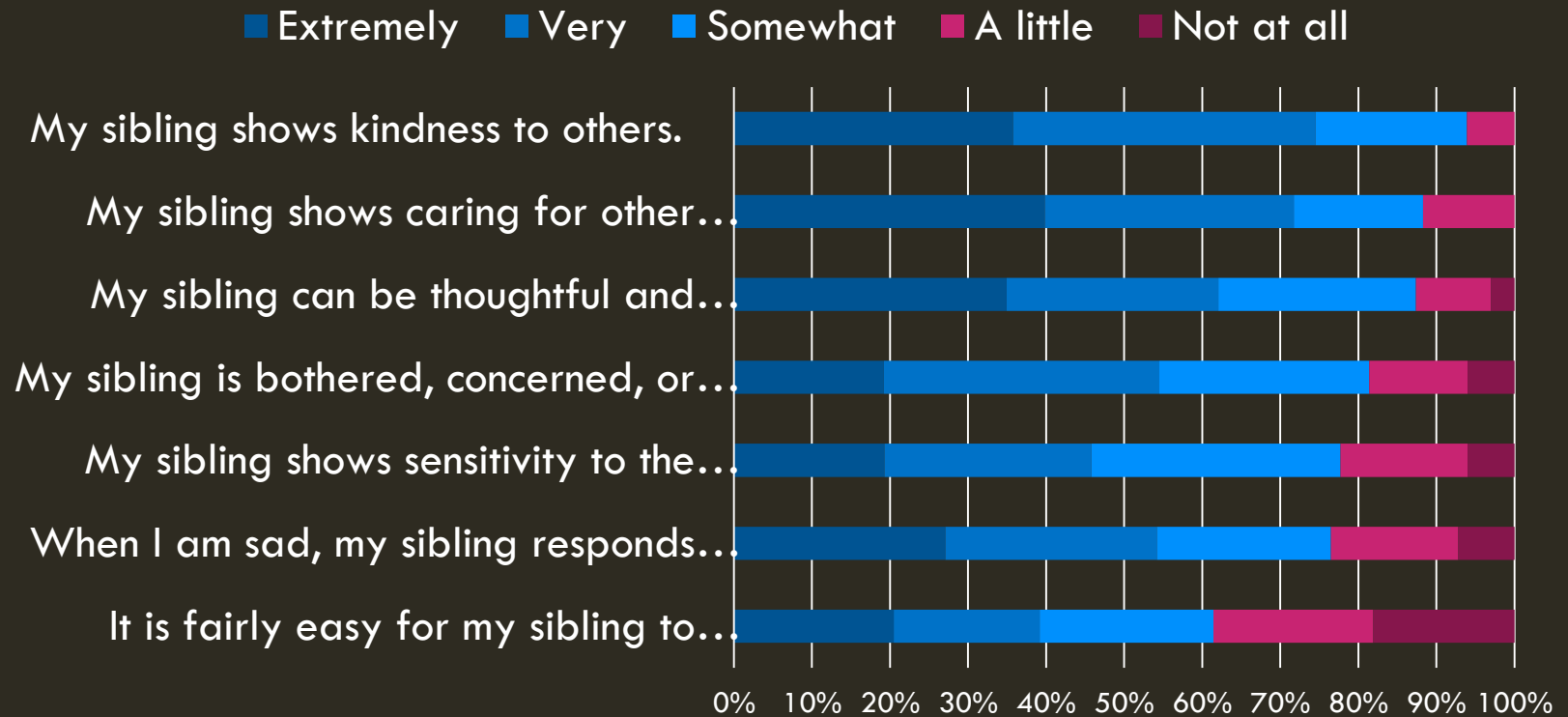
Rate the degree to which each trait is characteristic of their brother or sister

- 1 = not at all characteristic; 2 = a little characteristic; 3 = somewhat characteristic; 4 = very characteristic; 5 = extremely characteristic

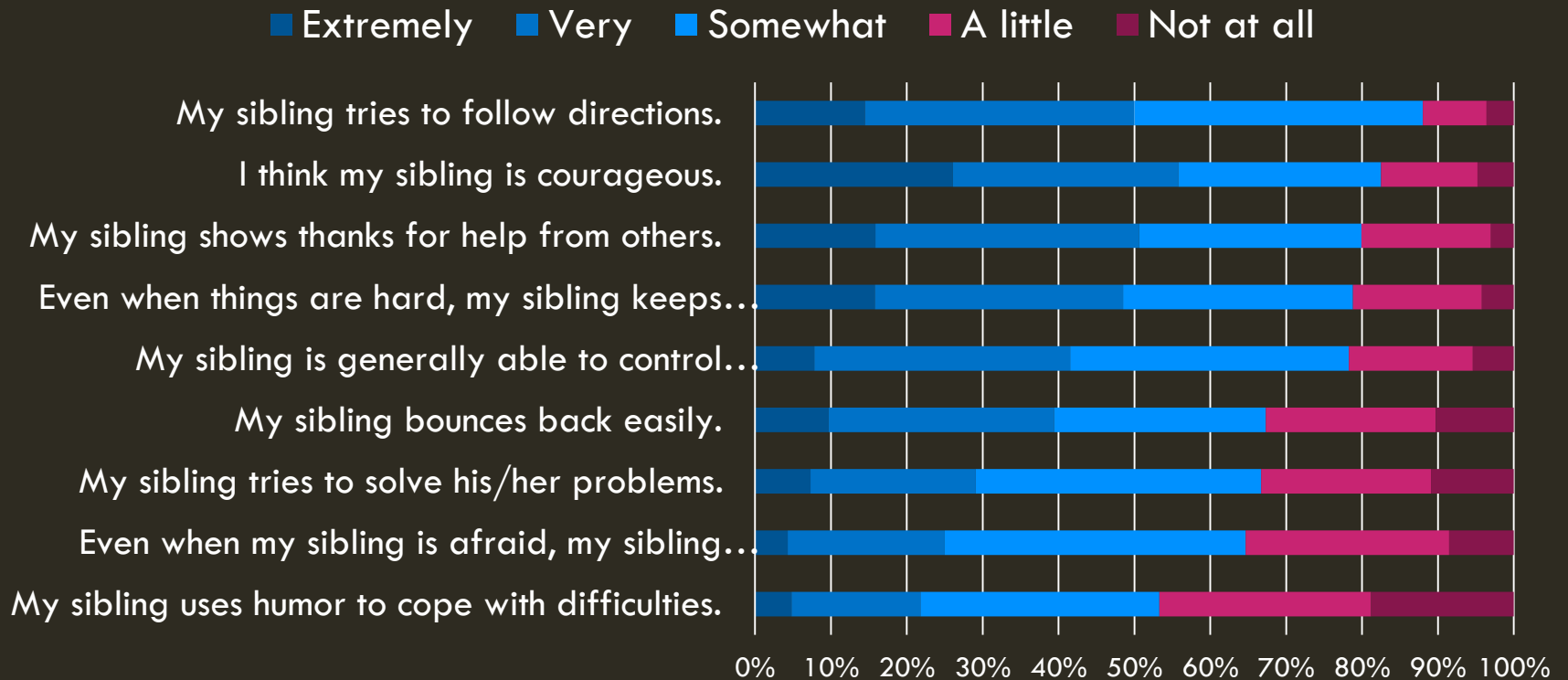
Cronbach's alpha ranged .66 to .87

How much is each trait characteristic of your sibling?	Not at all	A little	Somewhat	Very	Extremely
	1	2	3	4	5
I think my sibling is courageous.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling is bothered, concerned, or upset when someone else is uncomfortable or distressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling has a nice sense of humor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling can be thoughtful and helpful to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling does not hold a grudge against others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling shows caring for other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling can accept when he/she has made a mistake.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling shows kindness to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I am sad, my sibling responds to my feelings with concern.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling tries to solve his/her problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling does not lose his/her temper.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Even when my sibling is afraid, my sibling tries to do what is right or expected of him/her.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling shows sensitivity to the needs and feelings of others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling 'bounces back' easily.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling is generally able to control himself/herself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my sibling generally expects good things to happen to him/her.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling uses humor to cope with difficulties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling shows thanks for help from others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my sibling is happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Even when things are hard, my sibling keeps on trying.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling tries to follow directions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling seems to enjoy life and is thankful for life's simple pleasures.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling gets over his/her mistakes in a reasonable amount of time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling does not try to retaliate or get back at others who have hurt him/her.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My sibling usually thinks things will go his/her way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is fairly easy for my sibling to make new friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

POSITIVE RELATIONS



ACTIVE COPING



ACCEPTANCE COPING

■ Extremely ■ Very ■ Somewhat ■ A little ■ Not at all

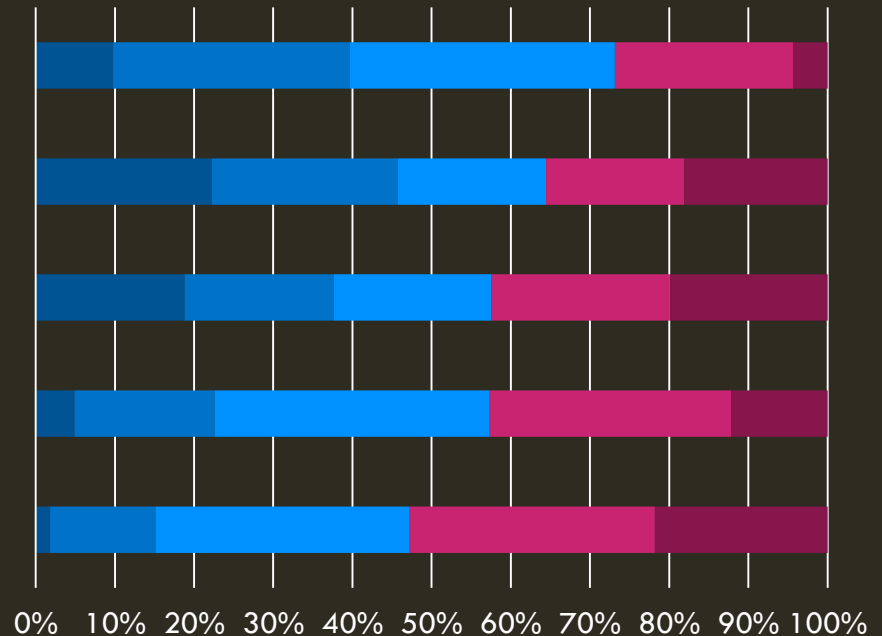
My sibling gets over his/her mistakes in a reasonable amount of time.

My sibling does not try to retaliate or get back at others who have hurt...

My sibling does not hold a grudge against others.

My sibling can accept when he/she has made a mistake.

My sibling does not lose his/her temper.



POSITIVE OUTLOOK

■ Extremely ■ Very ■ Somewhat ■ A little ■ Not at all

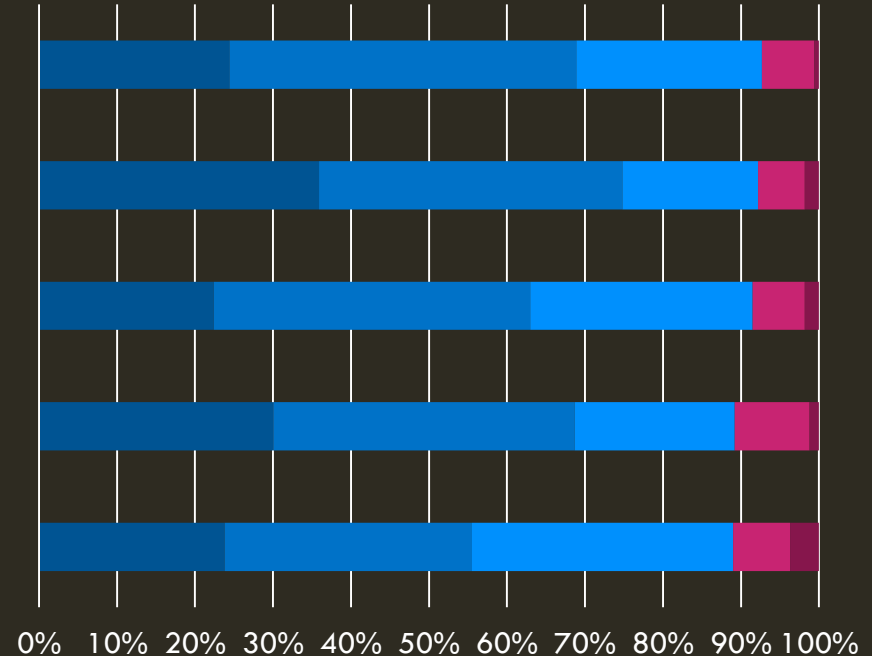
I think my sibling is happy.

My sibling has a sense of humor.

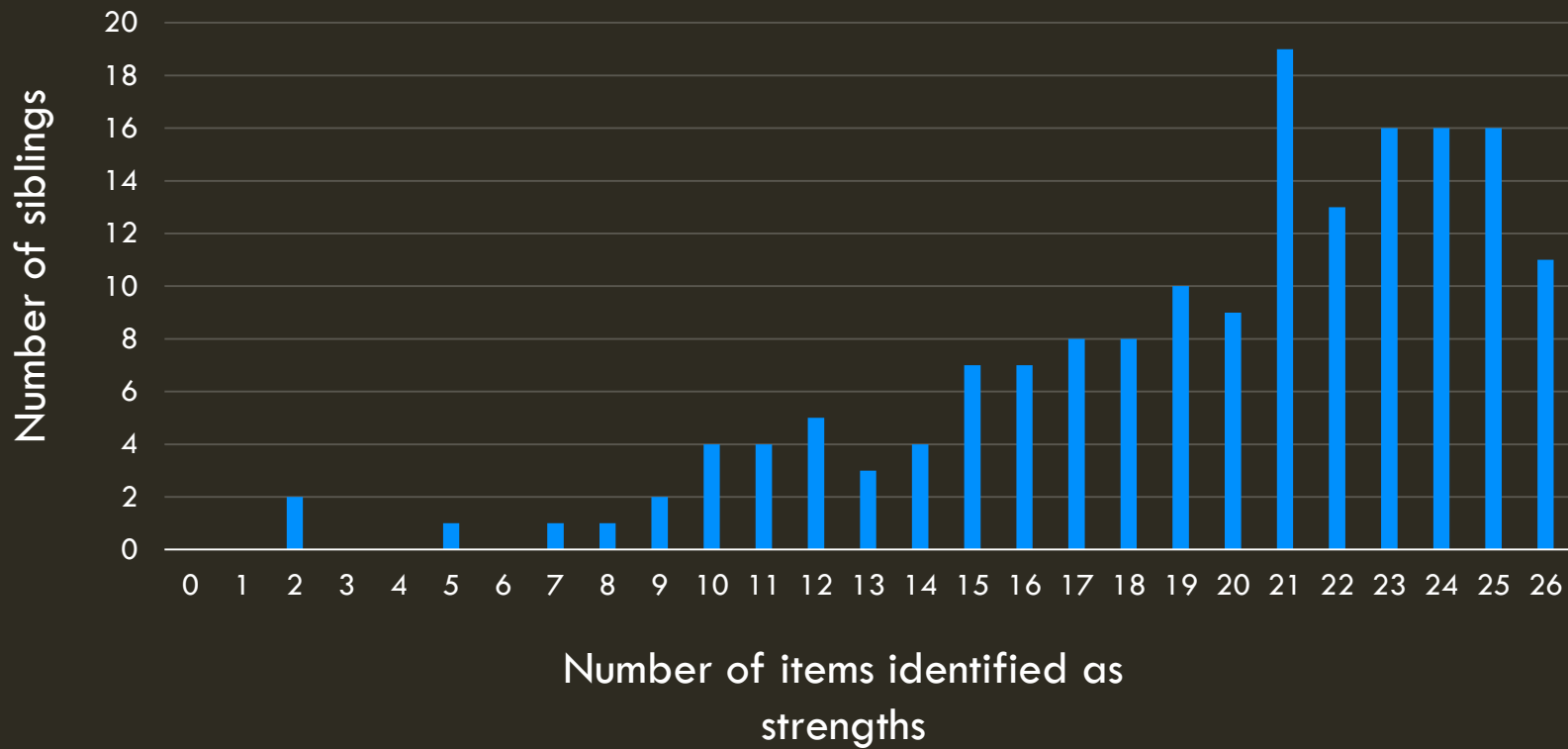
I think my sibling generally expects good things to happen to him/her.

My sibling seems to enjoy life and is thankful for life's simple pleasures.

My sibling usually thinks things will go his/her way.



NUMBER OF DIFFERENT STRENGTHS



SUMMARY FINDINGS

- Siblings with and without IDD spent substantial time together, participating in a wide range of activities
- Presence of ASD, limited mobility, and non-verbal communication were all associated with fewer activities participated in together
- Most siblings viewed their relationship with their brother or sister with IDD positively
 - More activities participated in together was correlated with high-quality relationships
- Future expectations were mixed
- A clear portrait of strengths emerged from the perspectives of siblings
- This portrait was very individualized; some group differences were evident

FUTURE DIRECTIONS

- Studies are needed to assess sibling knowledge of resources and supports that already exist
- Important to know where resources are housed
 - If resources are housed mostly in urban areas, community participation in rural areas may be more difficult for sibling dyads
- Future studies should collect more information about other factors that might shape participation in activities
 - Financial/economic resources, geographic locale, access to transportation
- Studies examining strengths from multiple perspectives—including those of the individual with disabilities—are needed

Enacting Self-Determination: Decision Making by Adult Siblings with and without IDD

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What is Self-Determination?

- **Self-determination refers to the attitudes and abilities required to act as the “primary causal agent in one’s life and to make choices regarding one’s actions free from undue external influence or interference” (Wehmeyer, 1992, p. 305).**
- **Being self-determined means making things happen in a person’s own life, instead of having others do things to, or for, them.**

Self-Determination, cont.

An individual with IDD, with assistance:

- has the ability and opportunity to make choices and decisions;
- has the ability and opportunity to exercise control over services, supports, and other assistance;
- has the authority to control resources and obtain needed services;
- has the opportunity to participate in and contribute to their communities;
- has the support, including financial, to advocate, develop leadership skills, become trained as a self-advocate, and participate in coalitions and policy-making.



Importance of Sibling Roles

- **As individuals with IDD are beginning to outlive their parents, siblings without IDD are often expected to fulfill caregiving roles (Burke et al., 2012; Orsmond & Seltzer, 2007).**
- **Yet, most research only focuses on perspectives of siblings without IDD, excluding the viewpoints of siblings with IDD (Taylor, Burke, Smith, & Hartley, 2016).**

For example...

- **60% of siblings without IDD report anticipating living with their brothers and sisters with IDD (Freedman, Krauss & Seltzer, 1997).**
- **Siblings without IDD report trying to secure employment for their brothers and sisters with IDD (Kramer, 2013).**
- **Siblings without IDD report advocating for their brothers and sisters with IDD (Burke, Arnold, & Owen, 2015).**

Need Perspectives of Siblings with IDD

- **People with IDD are experts on their own lives.**
- **Perspectives from both siblings with and without IDD are needed to understand their relationship and interactions (Burke, Lee, Hall, & Rossetti, 2019; Rossetti, Lee, Burke, & Hall, 2020).**
- **Considerations in research design and supports are needed for full participation by people with IDD (Hall, 2013).**

Purpose of Our Study

To understand how sibling pairs make decisions related to living arrangement, employment, and self-determination

Research Questions

- 1. How do siblings with and without IDD make decisions related to living arrangement, employment, and self-determination?**
- 2. Which variables influence decision making—and self-determination—of adults with IDD?**
- 3. What self-determination attitudes and abilities do adults with IDD use in decision-making?**

Method

	Ages	Education	Race	Disability
1. Eli	44	Some college	White	Down syndrome
1. Nicole	47	Some college	White	---
2. Emma	38	Some college	White	Down syndrome
2. Anna	41	Graduate school	White	---
3. Roy	24	Some college	White	Down syndrome
3. Jane	29	College	White	---
4. Jason	49	High school	White	Down syndrome
4. David	55	College	White	---
5. Mallory	19	High school	White	Down syndrome
5. Cara	22	Some college	White	---
6. Neil	56	High school	Black	ID
6. Tashelle	57	Graduate school	Black	---
7. Aaron	33	High school	White	ASD
7. Rachel	30	Graduate school	White	---
8. Cameron	21	High school	White	ASD
8. Allison	30	College	White	---
9. Anthony	36	High school	White	ASD
9. Sara	30	Graduate school	White	--

Methodology

Dyadic interview process with sibling pairs:

- 1. Interview with the sibling without IDD**
- 2. Interview with the sibling with IDD**
- 3. Interview with siblings with and without IDD**

Procedures

- Demographic sheet and interview**
- Interviews lasted:**
 - 45-75 minutes for the sibling without IDD**
 - 25-60 minutes for the sibling with IDD**
 - 20-45 minutes for the sibling dyad**

Interview Accommodations

- **Establish rapport**
- **Plain language interview protocol**
 - Short/concrete questions, rephrase, extra response time
 - Used info from the sibling interview to create probes
- **Use of pictures**
 - Created pictures for the interview protocol
 - Participants could bring in their own pictures
- **Offer a support person**

Hall, 2013; Mactavish et al., 2000

Analysis

- **Constant comparative analysis (Creswell, 2013; Strauss & Corbin, 1990)**
 - Compared all data to emerging codes
 - Created a codebook
 - Grouped codes into categories and themes
 - Conducted within-sibling dyad analysis
 - Conducted cross-case analysis of the dyads
- **Trustworthiness (Brantlinger et al., 2005)**
 - Triangulation of data sources
 - Member checking
 - Multiple coders
 - Researcher reflexivity

Findings

Decision-Making Process (Hickson & Khemka, 2013)

Identifying courses of action

Determining the probability of respective consequences

Choosing and implementing the best course of action

Identifying Courses of Action

Parents and siblings identified courses of action *for* their brother and sisters with IDD.

- **Roy (23-year-old with Down syndrome) discussed decision-making about housing:**

Researcher: So, who will help you decide where to live?

Roy: Really, it is really my parents.

Researcher: What did you do to learn about your living options?

Roy: I don't know. I just know it from my mom.

- **"I don't know how much they [parents] get his [Anthony's] input...it's not a group decision. It's their decision and I have some input."
–Sara (30, Anthony's younger sister)**

Identifying Courses of Action, cont.

- **“Yeah, me, my mom and my sister we all kind of really made decisions together. ... presented it in a light where he [Aaron] would think it would be a good idea.”**
–Rachel (30, Aaron’s younger sister)
- **“It’s probably more of, um, like us trying to brainstorm things for her, and then having her try them, and I guess, like, seeing how she [Mallory] reacts.”**
–Cara (22, Mallory’s older sister)
- **“So, I called and made the appointments, and set them up. And then, the typical kind of road show is me, Emma, and my mom, would go together, and talk to different agencies.”**
–Anna (41, Emma’s older sister)

Determining the Probability of Respective Consequences

Decisions were based on sibling perceptions of the person-environment fit.

- **“I love my job. [The grocery store] is a big place and [I] meet new people.”
–Emma (38-year-old with Down syndrome)**
- **“I like having my own room and having my own privacy.”
–Aaron (33-year-old with ASD)**
- **“He was an intern at a bank before. And he was an intern with a teacher. He really liked the bank one. We are having trouble looking for another internship for him.”
–Jane (29, Roy’s older sister)**
- **“The challenge is making that happen. There’s so many systems to navigate, and waiting lists, and paper work, and finding the right person. It’s tricky for us.”
–Anna (41, Emma’s older sister)**

Choosing and Implementing the Best Course of Action

Siblings reported active involvement in making the final decision by advocating for their brothers and sisters with IDD within the family, advising parents, and attending service meetings.

- **“My mom tried to answer and I was like, ‘No, no, give her [Mallory] a second,’ and sure enough, she did [answer] eventually. So I was like, ‘See, you just have to give her a minute to think and then it’ll be fine.’”**
–Cara (22, Mallory’s older sister)

Variables Impacting Decision-Making

- **Family Dynamics**
- **Sibling Relationship Characteristics**
- **Individual Skills and Characteristics**
- **Services and Supports**

Shogren & Wehmeyer, 2015

Variable- Family Dynamics

Decision-making—and self-determination—were affected by the composition, perspectives, and involvement of family members.

- **“Because my mom’s his guardian, a lot of things aren’t his decision... We all have very different views on things. ... I think because I spent day in and day out doing this, I know that he’s capable of more.”**

—Rachel (30, Aaron’s younger sister)

- **“Eli will say ‘I just don't wanna go.’ So it's like ‘Ok.’ And that's a new behavior for my mom. Because she is like, ‘Oh no. You gotta go. Come on! You said you are gonna go, you gotta go.’ And I'm like, over the past three or four years, ‘Mom, when the man doesn't wanna go, don't make him go.’ You know?....Yeah. Absolutely, there is conflict.”**

—Nicole (47, Eli’s older sister)

Variable- Sibling Relationship

The sibling relationship influenced the sibling involvement, the process for making decisions, and the final decisions.

- **“If I have a problem, I do really go to my sister.”
–Emma (38-year-old with Down syndrome)**
- **“Well, you know, he talks to me. When he wants to make changes, he works with me for the changes. ... I’m not the parent, right? And I don't make decisions like a parent would make a decision for their kid. You know, I let him go. If he's gonna fail, he's gonna fail. Just a part of living, right? You gotta know what failing is like and know what winning is like.”
–David (55, Jason’s older brother and guardian)**

Variable- Sibling Relationship, cont.

Siblings supported self-determination through advocacy.

They also provided encouragement and direct support to help their brothers and sisters make decisions.

- **“I just think it so incredibly important to at least ask the questions. We can’t assume. How are we gonna know if we don't ask?”
–Nicole (47, Eli’s older sister)**
- **“When my parents started a group home thing, I was kind of shocked. I was like, ‘Have you asked Roy what he wanted?’ because Roy doesn't want that.”
–Jane (29, Roy’s older sister)**

Variable- Individual Skills and Characteristics

The abilities, personalities, and perspectives of adults with IDD and their siblings influence the process and types of decisions made.

- **“I clean dishes, I pick up. And mop and sweeping the floor. I wash clothes. I do it all by myself.” –Neil (56-year-old with ID)**
- **“He wants to be seen as an adult, and he sees what we’re doing and he wants to do the same thing.”
– Allison (30, Cameron’s older sister)**
- **Researcher: “How do you think self-determination applies to Aaron?”**

Rachel (30, Aaron’s younger sister): “It doesn’t. I don't think he is aware enough to make decisions...Well, he will make decisions, but he has no idea what he is determining. They are bad decisions.”

Variable- Services & Supports

The type of decisions made were dependent on the services available and/or known to families, and the support families receive from friends, family, and community members.

- **“All my staff helps me a little bit. ...Grocery store, do my laundry, helps with my diet.” –Jason (49-year-old with Down syndrome)**
- **“[Name of grocery store] is a great place to work...they have been really enthusiastic about helping people with disabilities...and the support group there it is just amazing.”
–Anthony (36-year-old with ASD)**
- **“Limited in terms of what your options are and confines of your waivers and your locality.”
–David (55, Jason’s older brother and guardian)**
- **“I don’t want to wait until it’s upon me, but in the near future, I need to think about, you know, life after work.”
–Tashelle (57, Neil’s older sister and guardian)**

Decision Making and Self-Determination- Opportunities

Individuals with IDD tended to make daily choices but not formal decisions (e.g., employment, housing).

- “Well, as you can tell, the clothes I wear and I choose what I eat for breakfast and I choose what I eat for lunch.”
–Aaron (33-year-old with ASD)**
- “I want him to speak his mind more because I think a lot of times he just gets frustrated and goes with the flow. I want him to actually tell us what he wants.”
–Jane (29, Roy’s older sister)**
- “He can definitely make his own decisions and do stuff, but execution might take another extra support”
–Allison (30, Cameron’s older sister)**

Decision Making and Self-Determination- Communication

Self-determination was supported by how sibling pairs communicated, as well as how siblings encouraged their brothers and sisters with IDD.

- **“So, we’ll talk on the phone maybe twice a week. Because I like to do check-ins just to make sure he’s doing okay.”**
–Tashelle (57, Neil’s older sister and guardian)
- **“I just give him these little props.”**
–David (55, Jason’s older brother and guardian)
- **“Making sure that she has enough time that, um, she feels like she can think through it is important.”**
–Cara (22, Mallory’s older sister)
- **“She has good advice.”**
–Emma (38-year-old with Down syndrome)

Communication Support from Siblings

- **Repeating/rephrasing questions**
 - **Making the question more concrete/specific**
 - **Making the question more personally relevant**
 - **Breaking down the question**
 - **Asking the question in multiple ways**
- **Confirming yes/no answers**
- **Asking new questions**
 - **Questions for prompts (answer known)**
 - **Questions for conversation (curious to know the answer)**

Individual interview	Accommodations	Dyadic interview
<p>R: And what do you and Rosie like to do together?</p> <p>SWD: Nothing too much, just hang out.</p> <p>R: Hangout? Do you go out to eat?</p> <p>SWD: Mhm</p>	<p>Asking question to prompt response</p> <p>Making the question more personally relevant</p>	<p>R: What other things do you like to do with [sibling name]?</p> <p>SWD: Just hang out</p> <p>R: Just hang out. Going out to eat kind of things, hanging around here kind of things</p> <p>SWD: Mhm</p> <p>S: <i>What were we going to do before we started getting into organizing?</i></p> <p>SWD: Oh, we were going to play a game of cards.</p> <p>S: <i>And remember when you were at The Meadows, we haven't done it here, but what did we build a lot when you lived at The Meadows?</i></p> <p>SWD: Oh, Legos and puzzles.</p>

Individual interview	Accommodations	Dyadic interview
<p>R: And what do you and [sibling name] like to do together?</p> <p>SWD: She's in Seattle</p> <p>(R asks about Seattle and where sibling lives)</p>	<p>Making the question more concrete/specific</p> <p>Asking the question in multiple ways</p> <p>Asking question to prompt response</p>	<p>R: What do you and [sibling name] like to do together?</p> <p>SWD: What do you do together?</p> <p><i>S: What do you like to do with me when we hang out?</i></p> <p>SWD: You going to laser....</p> <p><i>S: What else do you like to do? What else do you like to do with me when we hang out? What do we do?</i></p> <p>SWD: What do you do? So...where did you go with you movies?...</p> <p><i>S: What did we do yesterday, [sibling name]?</i></p> <p>SWD: To the downtown to the Macy's to see the Holiday Christmas Tree Nutcracker.</p>

Individual interview	Accommodations	Dyadic interview
<p>(SWD has been answering every yes/no question with “yes”)</p> <p>R: Do you like living with [sibling name]?</p> <p>SWD: Yes</p>	<p>Repeating and rephrasing the question</p> <p>Asking the question in multiple ways</p> <p>Confirming yes/no answer</p>	<p>S: Do you like living at the house with me?</p> <p>SWD: Yes</p> <p>S: <i>Can I stay at the house?</i></p> <p>SWD: Yes.</p> <p>S: <i>Should I move out?</i></p> <p>SWD: What? You stay at the house.</p> <p>S: <i>Should I move out or should I stay at the house?</i></p> <p>SWD: Who stay at the house?</p> <p>S: Me. <i>Should I stay living at the house or should I move out and find an apartment?</i></p> <p>SWD: You stay in the house.</p> <p>S: <i>Want me to stay at the house?</i></p> <p>SWD: {sibling name}, where do you live?</p> <p>S: I live at the house right now. <i>I’m asking do you want me to stay at the house?</i></p> <p>SWD: Stay at the house</p> <p>S: Or do you want me to move out and find an apartment?</p> <p>SWD: I think you stay at the house.</p>

Individual interview	Accommodations	Dyadic interview
<p>R: I want to learn about you and Nancy and what you like to do together, okay?</p> <p>SWD: Mhm.</p> <p>R: What do you do for fun? Do you like sports?</p> <p>SWD: Mhm</p> <p>(R ask questions about hobbies and sports)</p>	<p>Asking the question in multiple ways</p> <p>Breaking down the question</p> <p>Asking question to prompt response</p> <p>Asking question to prompt response</p>	<p>R: So [name] what do you and [sibling name] like to do together?</p> <p>SWD: Uh. [sibling name]. With her...</p> <p>S: <i>What do we do together me and you? What is some of the stuff we do together?</i></p> <p>SWD: Columbus...</p> <p>S: <i>Where do we go every year? What concerts?</i></p> <p>SWD: Toby Keith.</p> <p>S: We go to Toby Keith every year. <i>And what's our favorite restaurant?</i></p> <p>SWD: I like pizza.</p> <p>R: Pizza.</p> <p>S: I was gonna say something else. How about the red? How about red....red...</p> <p>SWD: Red</p> <p>S: <i>Red...Where we go to eat?</i></p> <p>SWD: The Red Lobster.</p>

Decision Making and Self-Determination- Conflicts

Regarding the level of agreement in decision-making, there were several instances in which there were conflicting viewpoints.

Emma: “Actually, me and John [boyfriend] want to be together and John has been talking to me about finding an apartment to be together.”

Anna: “Oh, I didn’t know that you guys are talking about that.”

Emma: “And he also...in the future, he wants to call me his wife. It is almost two years, next November.”

Anna: “Two years. Yeah. I know you always think about your future right?... Well I guess we’ve never really talked about that, Emma. I guess it is new information to me. So I guess we have to think about it....Cause I don’t know if you are sure.”

Decision Making and Self-Determination- Self-Advocacy

- **“I want to teach them [other individuals with disabilities] to be a strong advocate. Um, stop putting yourself down, and also, to make their own choices....instead of relying on their parents.”**

–Emma (38-year-old with Down syndrome)

- **“I think it’s good that she’s her own guardian. I think she should be her own guardian. I think when we’ve had concerns about major life decisions we’ve been able to help her through conversation, instead of some sort of legal proceeding.”**

–Anna (41, Emma’s older sister)

Discussion

Key Findings

- Major decisions were made for adults with IDD ($n= 7$).
 - Siblings reported trying to facilitate inclusion of their brothers and sisters with IDD in decision-making.
 - This was usually with daily choices and recreation rather than formal decisions (e.g., independent living and employment).
- Major decisions were made by adults with IDD ($n = 2$)
 - When individuals with IDD made their own decisions, their siblings were directly involved.

Key Findings, cont.

- **Individuals with IDD advocated for themselves.**
- **Siblings recognized the importance of self-determination in decision-making.**
- **Sibling dyads were not always in agreement about decisions, thus siblings were not always engaging in supported decision-making.**
- **Decision-making also depends on available supports and services.**
- **Sibling support is often different than parent support.**
- **Dyadic interviews provided an opportunity for siblings with and without IDD to converse and learn new things about each other.**
 - **“Really? I didn’t know that...”**

Future Directions & Implications

- **More individuals with IDD can and should participate in research.**
- **A need to develop and test a supported decision making intervention.**
- **A need for longitudinal research examining family lifespan transitions.**
- **Interviewers can and should provide the supports siblings did.**
- **Sibling support may be an effective accommodation in studies that involve individuals with IDD but not their siblings.**
- **Include siblings in supported decision making, though not as a proxy for individuals with IDD.**
- **Consider impact of services (e.g., quality, availability) on supported decision making.**

Resources

Zach Rossetti – zsr@bu.edu

- Burke, Lee, Hall, & Rossetti (2019). Understanding decision making among individuals with intellectual and developmental disabilities (IDD) and their siblings. <https://doi.org/10.1352/1934-9556-57.1.26>
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Hilary Travers - hilary.travers@vanderbilt.edu

- Carter, Carlton, & Travers (2020). Seeing strengths: Young adults and their siblings with autism or intellectual disability. <https://doi.org/10.1111/jar.12701>
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