

Stress and Coping in Siblings of Individuals with IDD's

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Background & Research Questions

Background:

- In the United States alone, approximately one in every six children and adolescents are living with intellectual and/or developmental disability (IDDs) (Cogswell et al., 2022)
- Impacts of caring for a child with IDD can include increased overall stress and anxiety, adjustment problems, worsened physical health, increased problem behaviors and mental health struggles, financial difficulties, and more (Marquis et al., 2020)
- In one study, sibling of individuals without IDD reported lower levels of anxiety towards the target child compared to siblings of individuals with IDD (Shivers and Dykens, 2017)
- Siblings of individuals with ASD often report feeling secondary to their sibling with ASD (Leedham et al., 2022)
- Factors contributing to sibling outcomes include type of IDD, sibling characteristics, family income, birth order, and neighborhood characteristics (Marquis et al., 2020)
- Barriers within healthcare systems often contribute to a limited provision of services for siblings of individuals with IDDs (Bronson et al., 2022)
- Coping mechanisms utilized by adult siblings of individuals with IDDs remain understudied warranting future research to better understand their support needs and experiences

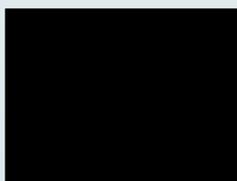
Research Questions:

- What are the coping mechanisms of adult siblings of individuals with intellectual and developmental disabilities?
- What associations may exist between sociodemographic factors and coping mechanisms in this population?
- How do adult siblings of individuals with IDD perceive the impact of their siblings' disability as adults?

Objectives

To explore and better understand the coping mechanisms and stressors of adult siblings of individuals with intellectual and/or developmental disabilities (IDDs) in order to identify opportunities for better supporting this population.

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Methods

- Mixed methods online survey design with optional semi-structured interviews
- Participants recruited through Facebook groups, the Vanderbilt University Medical Center, the Organization for Autism Research, the Vanderbilt University Psychology Department's Research Sign Up System (SONA), and the personal social media profiles of researchers

Instruments:

- Coping Resources Inventory (CRI); (Marting & Hammer, 1988)
- The Brief Coping Orientations to Problems Experienced Inventory (Brief COPE); (Carver, 1977)
- The Perceived Stress Scale (PSS); (Siqueira Reis et al., 2010)
- Optional Semi-Structured Interview utilizing an inductive content coding system; (Boles et al., 2017)

Participants

Inclusion Criteria:

- Age 18+
- One or more siblings with intellectual and/or developmental disability
- English as a primary language

Demographics:

- 27 total participants (24 completed the CRI; 26 completed the Brief COPE; 27 completed the PSS; and 13 participated in optional interviews)
- Participant gender: 22.2% male, 77.8% female
- 29 siblings of participants (individuals with IDDs)
- Sibling gender: 58.6% male, 41.4% female
- Mean participant age: 25.41

Results (Qualitative)

Throughout semi-structured interviews **participant responses highlighted four major themes:**

- Caretaking across the lifespan**
 - "My mom was made to do it alone, everything alone." (participant 43)
 - "I couldn't do anything because everyone had to take care of my brother" (participant 7)
- Parental transparency about sibling diagnosis**
 - "my parents were a little less focused on me per se" (participant 14)
- Negotiating normalcy inside and outside the household**
 - "He would run around the house making noises and flapping or clapping his arms... so I was confused when I was in trouble for doing a cartwheel in the house" (participant 41)
- Reframing the sibling experience**
 - "I don't wish everyone had a disabled sister, but I wish people could step into my shoes and see how beautiful their lives are, and how much they teach you. It is really incredible" (participant 48)

Results (Quantitative)

Figure 1; Coping Resources Inventory

Coping Type	Primary	Secondary	Tertiary
Cognitive (COG)	0.00% (n=0)	4.17% (n=1)	25.00% (n=6)
Social (SOC)	20.83% (n=5)	75.00% (n=18)	4.17% (n=1)
Emotional (EMO)	75.00% (n=18)	4.17% (n=1)	4.17% (n=1)
Spiritual/Philosophical (S/P)	0.00% (n=0)	4.17% (n=1)	54.17% (n=13)
Physical (PSY)	4.17% (n=1)	8.33% (n=2)	12.50% (n=3)

Figure 3; Perceived Stress Scale

Perceived Stress Level	Frequency	Proportion	Range	Mean
High	7	25.93%	27-35	31
Moderate	15	55.56%	14-26	19.4
Low	5	18.52%	3-12	8.2

Coping Resources Inventory (CRI):

- 75% of participants (n=18) identified that emotional coping resources were their most utilized coping resources
- 75% of participants (n=18) identified that social coping resources were their second most utilized coping resources
- 54.17% of participants (n=13) identified that spiritual/philosophical were their third most utilized coping resources
- See Figure 1

Brief Coping Orientations to Problems Experienced Inventory (COPE):

- The three most common coping mechanisms utilized were Self-Blame, Instrumental Support, and Acceptance
- The three least common coping mechanisms utilized were Behavioral Disengagement, Denial, and Substance Usage
- More than half of the participants demonstrated a regular use of Religion, Humor, Distraction, Planning, Positive Reframing, Self-Blame, Instrumental Support, and Acceptance by scoring a 2 or higher in those scales
- See Figure 2

Perceived Stress Scale (PSS):

- 55.56% of participants (n=15) demonstrated moderate stress levels
- 25.93% of participants (n=7) demonstrated high stress levels
- 28.52% of participants (n=5) demonstrated low stress levels
- The mean score was 20.33, which falls in the moderate stress level category
- See Figure 3

Results (Integrated)

- Many interviewed participants highlighted the importance of community support when caring for their sibling with IDD, in congruence with the quantitative data from the CRI and Brief COPE
- Throughout participant interviews, it was clear that many participants used positive reframing as an approach to their relationship with their sibling even though positive reframing was not one of the top 3 coping mechanisms seen in the Brief COPE data
- Similar to the moderate stress levels reported in the PSS, many participants stated that aspects of their lived experience with a sibling with IDD were a source of stress at times

Figure 2; Brief COPE

Coping Style	Mode	Mean	Median
Behavioral Disengagement	1	1.5	1
Denial	1	1.63	1
Substance	1	1.73	1
Emotional Support	2	2.5	2.5
Religion	1	2.52	2.75
Active Coping	2	2.52	2.5
Humor	3	2.58	3
Venting	2.5	2.65	2.5
Self-Distracton	3	2.67	3
Planning	3	2.77	3
Positive Reframing	2	2.83	3
Self-Blame	4	2.87	3
Instrumental Support	4	2.87	3
Acceptance	4	2.92	3

Conclusions

- From caretaking responsibilities to unique stressors and increased life perspectives, this population faces challenges and experiences unique to their relationship with their sibling
- Common stressors include caring for their sibling across the lifespan, negotiating normalcy inside and outside the household, and parental transparency about sibling diagnosis
- Participants in this study highlighted Self-Blame, Instrumental Support, and Acceptance as commonly utilized coping mechanisms, with emotional and social coping resources most often used by this population
- Many siblings also reported gratitude for their sibling and all they have learned from them.
- Healthcare providers, teachers, and other professionals can better support siblings by recognizing the negotiation of normalcy that siblings experience and in which they live
- Future research can further explore the implications of siblings utilizing specific coping strategies, as well as the factors that influence which strategies are utilized, in order to continue building resources and interventions to better support siblings and their families

Author Contributions

MA: Designed poster, generated data in Figures 1, 2, & 3
JB: Contributed to the designing and execution of study, oversaw project design and execution

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References

- Begum, G., & Blacher, J. (2011b). The siblings relationship of adolescents with and without intellectual disabilities. *Research in Developmental Disabilities, 32*(5), 1580–1588. <https://doi.org/10.1016/j.ridd.2011.01.056>
- Boles, J., Winsor, D., Mandrell, B., Gattuso, J., West, N., Leigh, L., & Grissom, S. (2017). Student/patient: the school perceptions of children with cancer. *Educational Studies, 43*(5), 549–566. DOI: 10.1080/03055698.2017.1312288
- Boulet SL, Boyle CA, & Schieve LA. (2009). Health Care Use and Health and Functional Impact of Developmental Disabilities Among US Children 1997–2005. *The Archives of Pediatrics & Adolescent Medicine, 163*(1), 19–26. doi:10.1001/archpediatrics.2008.506
- Braconnier, M. L., Coffman, M. C., Kelso, N., & Wolf, J. M. (2017). Sibling relationships: Parent–child agreement and contributions of siblings with and without ASD. *Journal of Autism and Developmental Disorders, 48*(5), 1612–1622. <https://doi.org/10.1007/s10803-017-3393-9>
- Brosnan, P., Davis, K. A., Mazzenga, M., Oberoi, A. R., Sharkey, C. M., Buchbinder, D., Alderfer, M. A., & Long, K. A. (2022). Psychosocial care providers' perspectives: Barriers to implementing services for siblings of children with cancer. *Pediatric blood & cancer, 69*(2), e29418. <https://doi.org/10.1002/pbc.29418>
- Carver, C.S. (1997). You want to measure coping but your protocol' too long: Consider the brief cope. *International Journal of Behavioral Medicine, 4*, 92–100. https://doi.org/10.1207/s15327558ijbm0401_6
- Carver, C.S., Scheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267–283. <https://doi.org/10.1037/0022-3514.56.2.267>
- Cogswell, M., Coil, E., Tian, L., Tinker, S., Ryerson, B., Maenner, M., Rice, C., & Peacock, G. (2022). Health Needs and Use of Services Among Children with Developmental Disabilities — United States, 2014–2018 *MMWR Morbidity and Mortality Weekly Report 2022; 71*, 453–458. <http://dx.doi.org/10.15585/mmwr.mm7112a3>
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A Global Measure of Perceived Stress. *Journal of Health and Social Behavior, 24*(4), 385–396. <https://doi.org/10.2307/2136404>
- Critchley, E., Cuadros, M., Harper, I., Smith-Howell, H., & Rogish, M. (2021). A parent-sibling dyadic interview to explore how an individual with autism spectrum disorder can impact family dynamics. *Research in Developmental Disabilities, 111*, 103884. <https://doi.org/10.1016/j.ridd.2021.103884>
- Dervishalija, E., & Murati, E. (2014). Families of children with developmental disabilities: perceptions and experiences of adolescent siblings of children with developmental disabilities. *European Scientific Journal, 10*(2). <https://doi.org/10.19044/esj.2014.v10n2p%25p>
- Glidden, L.M., Billings, F.J. & Jobe, B.M. (2006). Personality, coping style and well-being of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research, 50*, 949–962. <https://doi-org.proxy.library.vanderbilt.edu/10.1111/j.1365-2788.2006.00929.x>
- Glidden, L.M. & Natcher, A.L. (2009). Coping strategy use, personality, and adjustment of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research, 53*, 998–1013. <https://doi.org/10.1111/j.1365-2788.2009.01217.x>
- Hesse, T., Danko, C., & Budd, K. (2013, September 1). *Siblings of children with autism: Predictors of adjustment*. Research in Autism Spectrum Disorders. Retrieved January 22, 2023, from <https://www.sciencedirect.com/science/article/pii/S1750946713001505>
- Leedham, A. T., Thompson, A. R., & Freeth, M. (2020). A thematic synthesis of siblings' lived experiences of autism: Distress, responsibilities, compassion and connection. *Research in Developmental Disabilities, 97*, 103547. <https://doi.org/10.1016/j.ridd.2019.103547>
- Mandleco B, Olsen SF, Dyches T, Marshall E. (2003). The Relationship between Family and Sibling Functioning in Families Raising a Child with a Disability. *Journal of Family Nursing, 9*(4), 365–396. doi:10.1177/1074840703258329
- Marquis, S., McGrail, K., & Hayes, M. V. (2020). Using administrative data to examine variables affecting the mental health of siblings of children who have a developmental disability. *Research in Developmental Disabilities, 96*, 103516. <https://doi.org/10.1016/j.ridd.2019.103516>
- Marting, M. S., & Hammer, A. L. (1988). *Coping Resources Inventory (CRI)* [Database record]. APA PsycTests. <https://doi.org/10.1037/t06455-000>
- McHale, S.M., Updegraff, K.A. and Whiteman, S.D. (2012), Sibling Relationships and Influences in Childhood and Adolescence. *Journal of Marriage and Family, 74*: 913–930. <https://doi.org/10.1111/j.1741-3737.2012.01011.x>
- Moss, P., Eirinaki, V., Savage, S., & Howlin, P. (2019). Growing older with autism – the experiences of adult siblings of individuals with autism. *Research in Autism Spectrum Disorders, 63*, 42–51. <https://doi.org/10.1016/j.rasd.2018.10.005>
- Petalas, M. A., Hastings, R. P., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioral adjustment in siblings of children with intellectual disability with and without autism. *Autism, 13*(5), 471–483. <https://doi.org/10.1177/1362361309335721>
- Plano Clark, V. L., & Creswell, J. W. (2018). *Designing and Conducting Mixed Methods Research*. SAGE Publications.
- Ross, P. & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability, 31*(2), 77–86. 10.1080/13668250600710864
- Rossetti, Z., Lee, C. E., Burke, M., & Hall, S. (2020). Perspectives about adult sibling relationships: A dyadic analysis of siblings with and without intellectual and developmental disabilities. *Research in Developmental Disabilities, 96*, 103538. <https://doi.org/10.1016/j.ridd.2019.103538>
- Seltzer, Marsha Mailick, Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011, November 1), Midlife and Aging Parents of Adults With Intellectual and Developmental Disabilities: Impacts of Lifelong Parenting. *American Journal on Intellectual and Developmental Disabilities, 116*(6), 479–499. <https://doi.org/10.1352/1944-7558-116.6.479>
- Shivers, C. (2019, July 20), *Empathy and perceptions of their brother or sister among adolescent siblings of individuals with and without autism spectrum disorder*. Research in Developmental Disabilities. Retrieved January 22, 2023, from <https://www.sciencedirect.com/science/article/pii/S0891422219301180>
- Shivers, C. M., & Dykens, E. M. (2017, January 1). Adolescent Siblings of Individuals With and Without Intellectual and Developmental Disabilities: Self-Reported Empathy and Feelings About Their Brothers and Sisters. *American Journal on Intellectual and Developmental Disabilities, 122*(1), 62–77. <https://doi.org/10.1352/1944-7558-122.1.62>
- Shivers, C. M., Krizova, K., & Lee, G. K. (2017). Types of strain among family members of individuals with autism spectrum disorder across the lifespan. *Research in Developmental Disabilities, 68*, 42–51. <https://doi.org/10.1016/j.ridd.2017.07.003>
- Siqueira Reis, R., Ferreira Hino, A. A., & Romélio Rodriguez Añez, C. (2010). Perceived stress scale. *Journal of Health Psychology, 15*(1), 107–114. <https://doi.org/10.1177/1359105309346343>