


**Intellectual and Developmental Disabilities: Considerations for Caregivers' and Siblings' Mental Health**

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**Learning Objectives**

- Demonstrate knowledge of the currently known impact that IDD's can have on families.
- Identify care considerations of family members with a child with an IDD.
- Demonstrate knowledge of specific diversity considerations.
- Describe known impacts of COVID-19 related to family mental health of a child with an IDD.

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**Overview**

Past Research Information

- Families
- Parents
- Siblings

Interventions

Additional Cultural Considerations

COVID-19 Considerations

Discussion

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**Disclaimer**

- Much of this literature does not fully encompass the global situations of families or even cultural differences. The literature has historically focused on English-speaking, high-income countries and contexts.
- Focus on children

Families Special Interest Research Group of IASSIDD, 2013

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**Importance**

Bidirectional effects  
 Potential impacts on family members  
 Families being active in intervention process  
 Questions and concerns of families



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**Background Information**

- Intellectual Disability
- Developmental Disability
- Prevalence
- Examples



Centers for Disease Control and Prevention, 2023

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## Strengths



Improved social support      Seeing life from different perspective      Advocacy      Appreciating small things in life      Siblings more caring

Confidence      Increased compassion      Self-esteem

Unexpected achievements      Increased Sense of Purpose      Parenting = Rewarding

Determined      Good luck charm

Increased spiritual growth      Learning about yourself      Confronting Challenges

More tolerant and patient      Caregiving as a sense of duty      Closer family relationships

Enjoying being with the child      Less judgmental

Helping other families      Beighton & Wills, 2019

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## Concerns



High caregiver demands  
Stigma  
Financial strains  
Depression and anxiety  
Strained marriages  
Sibling adjustment  
Physical health concerns

Karste & Van Hecke, 2012;  
Scherer et al., 2019

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## Autism Spectrum Disorder



ASD PREVALENCE PER 1,000 8-YEAR-OLD CHILDREN

**Prevalence Overall**  
Overall: 27.6 | Lower Ct: 26.9 | Upper Ct: 28.3

**Prevalence By Race/Ethnicity**  
Non-Hispanic White: 24.3 | Lower Ct: 23.4 | Upper Ct: 25.2  
Non-Hispanic Black: 29.3 | Lower Ct: 27.9 | Upper Ct: 30.9

**Prevalence By Sex**  
Boys: 43 | Lower Ct: 41.9 | Upper Ct: 44.2  
Girls: 11.4 | Lower Ct: 10.7 | Upper Ct: 12

Asian/Pacific Islander: 33.4 | Lower Ct: 30.5 | Upper Ct: 36.4

\*ADDM estimate = the total for all sites combined.

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## Autism and Families

- Interference with family relationships and activities
- Stress – misconceptions and understanding of ASD in the community
- Background intersects with the caregiving experience
- Parent experience influenced by the “system”

Guite, 2004; Iadarola et al., 2019

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## Family Systems Approach



Cridland et al., 2014

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## Sibling Experience



Leedham et al., 2020; Mandleco & Webb, 2015; Simpson et al., 2021

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**Neurotypical Sibling Experience (ASD)**

- Impact on self and personal development
- Interactions with their sibling with ASD
- Interactions with others
- Experiences of Coping

Watson et al., 2021

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**Neurotypical Siblings At-Risk?**

- Worse internalizing problems, overall psychological functioning, **negative sibling relationships**, impaired social functioning
- No differences in adjustment, coping, ADHD symptoms, or externalizing problems
- No differences from parent reports vs sibling report

Shivers et al., 2019

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**Sibling comments**

What is good about having a brother or sister with a disability?  
 "Everything" "Nothing" "You look after them"  
 "Funny" "Cute" "it gives you another view of the world we live in, and makes you appreciate things more"  
 What would you change?  
 "Nothing" "Make her more kind" "not having a disability"  
 "to be able to talk and tell us what is wrong"  
 "her shouting and getting her own way"

Carter et al., 2016

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**Angelman Syndrome & Prader-Willi Syndrome**

- Initial diagnosis
- Dissatisfaction with disclosure process
- Practical and emotional support
- Time for personal needs
- Coping strategies

Thomsen et al., 2016

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**Families At-Risk**

- Child:
  - Maladaptive problem behaviors
- Parents:
  - Lack of coping strategies
- Parents with ID
- Income
- Government Planning and Policy Development

Families Special Interest Research Group of IASSIDD, 2013

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**Cross-Cultural Aspects**

- Communication Barriers/ Cultural Pragmatics
- Views on Relationship Skills
- Negative Views of the Child
- Lack of Support

Jegatheesan, 2009

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## Protective Mechanisms for Parents



Lindo et al., 2016

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## What Helps?

Combination of behavioral parent training (indirect) and coping skills interventions (direct) mitigate stress

- CBT
- Respite care/case management

Behavioral methods:

- Decreasing problem behaviors and increasing positive behaviors
- Parent Training

Group training for parents

- Cost effective and practical

Parent-to-Parent support models?

Families Special Interest Research Group of IASSIDD, 2013; Lindo et al., 2016

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## Care Considerations



American Psychological Association; Ennis-Cole et al., 2013; Sapiets et al., 2021

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## Care Considerations

- Impact of income on service accessibility
- Need for rural professionals/services
- Parental/community awareness/knowledge
- Knowledge of IDD including early for all professionals
- Increased training surrounding cultural norms/considerations
- Practical support
- Coordinated appointments

Sapiets et al., 2021

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## Sibling Interventions



Jones et al., 2020; Tudor & Lerner, 2014; Zucker et al., 2021

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## Advocacy



Ennis-Cole et al., 2013

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# COVID-19 Considerations



Doody & Keenan 2021; Neece & Fenning, 2020; Willner et al., 2020

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# Research Recommendations



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# References

Brighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities, 32*(5), 1255-1279.

Carter, S., Cook, J., Sutton-Boulton, G., Ward, V., & Clarke, S. (2016). Social pedagogy as a model to provide support for siblings of children with intellectual disabilities: A report of the views of the children and young people using a sibling support group. *Journal of Intellectual Disabilities, 20*(1), 65-81.

Centers for Disease Control and Prevention. (2023, March 23). *Autism data visualization tool*. Centers for Disease Control and Prevention. Retrieved March 26, 2023, from <https://www.cdc.gov/ncbddd/autism/data/index.html>

Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism, 18*(3), 213-222.

Ennis-Cole, D., Durosoyov, B. A., & Harris, H. L. (2013). The impact of culture on autism diagnosis and treatment: Considerations for counselors and other professionals. *The Family Journal, 21*(3), 279-287.

Guile, J., Lobato, D., Kae, B., & Planie, W. (2004). Discordance between sibling and parent reports of the impact of chronic illness and disability on siblings. *Children's Health Care, 33*(1), 77-92.

Jogatheesan, B. (2009). Cross-cultural issues in parent-professional interactions: A qualitative study of perceptions of Asian American mothers of children with developmental disabilities. *Research and Practice for Persons with Severe Disabilities, 34*(3-4), 122-136.

Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families. *International journal of developmental disabilities, 65*(1), 20-30.

Leedham, A. T., Thompson, A. R., & Freeb, M. (2020). A thematic synthesis of siblings' lived experiences of autism: Distress, responsibilities, compassion and connection. *Research in Developmental Disabilities, 97*, 103547.

Lindo, E. J., Kilmann, K. R., Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations, 65*(1), 207-224.

Mandicco, B., & Webb, A. E. M. (2015). Sibling perceptions of living with a young person with Down syndrome or autism spectrum disorder: An integrated review. *Journal for Specialists in Pediatric Nursing, 20*(5), 138-156.

Sapiets, S. J., Tolsika, V., & Hastings, R. P. (2021). Factors influencing access to early intervention for families of children with developmental disabilities: A narrative review. *Journal of Applied Research in Intellectual Disabilities, 34*(3), 695-711.

Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS One, 14*(7), e0219888.

Simpson, W. (2021). Siblings of people with intellectual disability: Relationships and decision-making across the life span. *Shivers, C. M., Jackson, J. B., & McGregor, C. M. (2019). Functioning among typically developing siblings of individuals with autism spectrum disorder: A meta-analysis. Clinical child and family psychology review, 22*(2), 172-196.

Thomson, A., Glasson, E., Roberts, P., & Bitles, A. (2017). "Over time it just becomes easier...": parents of people with Angelman syndrome and Prader-Willi syndrome speak about their carer role. *Disability and Rehabilitation, 39*(6), 763-770.

Watson, L., Hanna, P., & Jones, C. J. (2021). A systematic review of the experience of being a sibling of a child with an autism spectrum disorder. *Clinical Child Psychology and Psychiatry, 26*(3), 734-749.

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**DISCUSSION**

- What barriers seem the most pertinent for the families you work with regarding having a child with an IDD?
- What comments (strengths or concerns) have siblings of a child with an IDD do you have?
- Any specific cultural considerations you have encountered while working in the area of IDD.
- How has COVID-19 impacted the families you work with?

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