

Kelsey Walker, MS Munroe-Meyer Institute Predoctoral Intern

> University of Nebraska Medical Center

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## **Learning Objectives**



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- Demonstrate knowledge of the currently known impact that IDDs 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

## 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



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**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

Stren	-		Appreciating small things in life			
support	Seeing life from different perspective	Advocacy	Siblings more caring			
		Self-esteem				
Confidence	Increased compassion		Parenting = Rewarding			
Unexpected achievements Increased Sense of Purpose						
Determined			Good luck charm			
Increased spiritual						
growth			Confronting Challenges			
More tolerant and patient		Caregiving as a sense of duty	Closer family relationships			
Enjoying being with		Less judgme	Less judgmental			
the child	Helping other families		Beighton & Wills, 2019			

#### Concerns

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

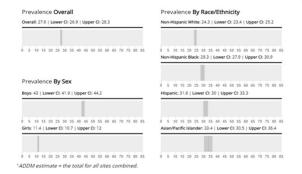
> Karste & Van Hecke, 2012; Scherer et al., 2019

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# Autism Spectrum Disorder ASD PREVALENCE PER 1,000 8-YEAR-OLD CHILDREN





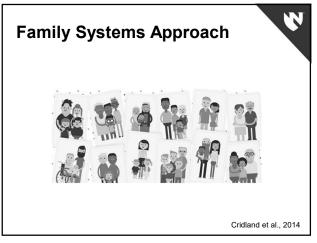
## **Autism and Families**

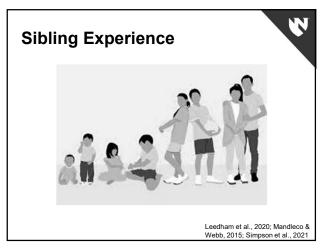
- Interference with family relationships and activities
- Stress misconceptions and understanding of ASD in the community
- Background intersects with the caregiving experience
- Parent experience influenced by the "system"

Guite, 2004; ladarola et al., 2019

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Neurotypical Sibling Experience (ASD)	2
Impact on self and personal development	
Interactions with their sibling with ASD	
Interactions with others	
Experiences of Coping	
	Watson et al., 2021

# 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

# Angelman Syndrome & Prader- N 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

Cross-Cultural Aspects	2
Communication Barriers/ Cultural Pragmatics	
Views on Relationship Skills	
Negative Views of the Child	
Lack of Support	
	Jegatheesan, 2009



# 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



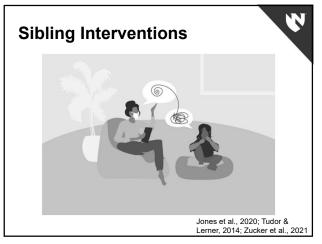
# **Care Considerations**

- · 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
- Increased training surrounding cultural norms/considerations
   Practical support
- Coordinated appointments

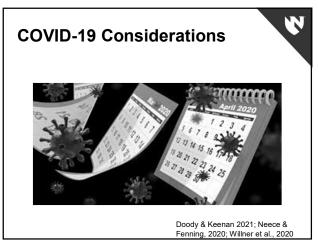
Sapiets et al., 2021

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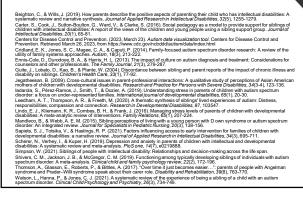








#### References



## DISCUSSION

• What barriers seem the most pertinent for the families you work with regarding having a child with an IDD?

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- 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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