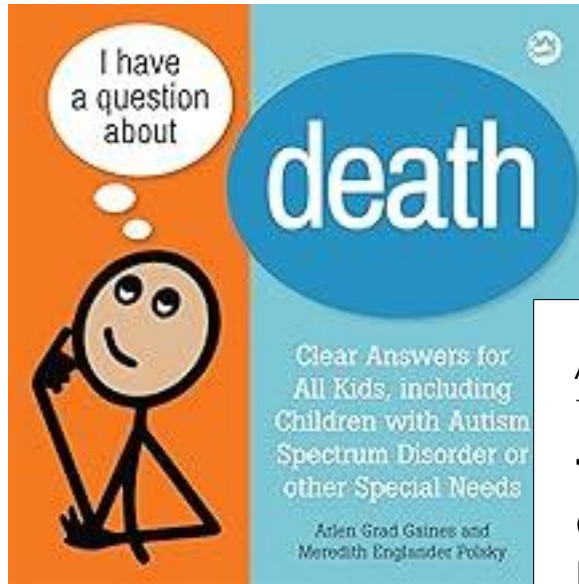


Caring through Loss: Supporting Grieving Children with Intellectual Disabilities

Caring Matters
December 2, 2025


Arlen Gaines, PhD, MSW, LCSW-C, LICSW, APHSW-C
Arlen.g.gaines@medstar.net



Article

The Grief Experiences of Children with Developmental Disabilities: A Narrative Literature Review

Arlen G. Gaines¹ 

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Original Manuscript

Caring Connections: A Grounded Theory Study of the Grief and Bereavement Experiences of Children With Intellectual Disabilities

Arlen G. Gaines¹ , Patricia M. Wright², Jaime Goldberg³,
Elizabeth M. Ducey⁴, Mary L. McPherson⁵, and John G. Cagle⁶

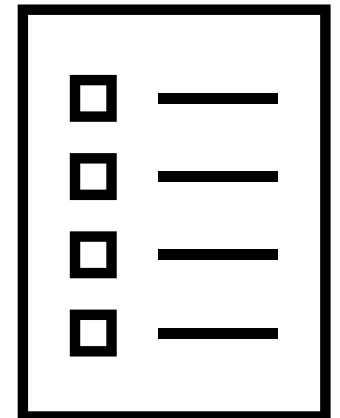
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Objectives:

Describe ways that children with Intellectual Disabilities (ID) understand and process a loss

Identify examples of how children with ID engage in Caring Connections

Demonstrate developmentally inclusive grief support strategies

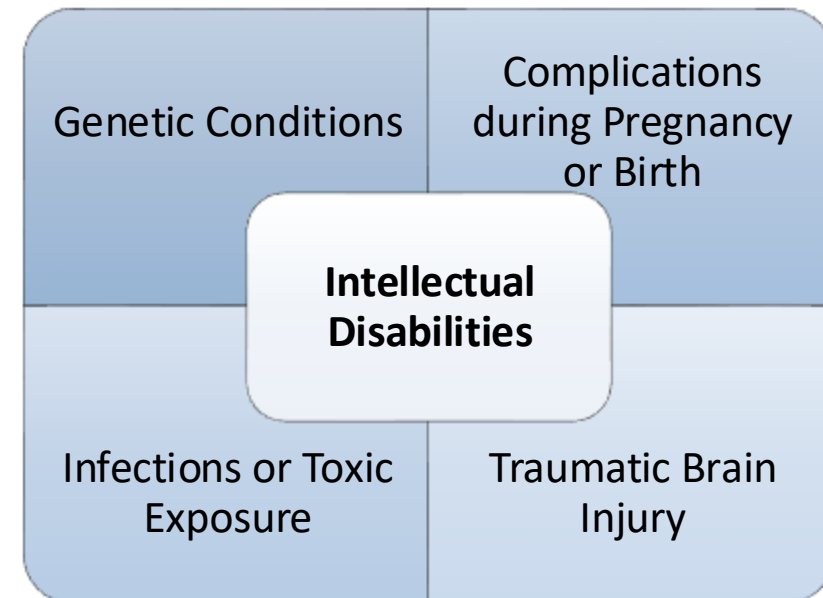


What are Intellectual Disabilities (ID)?

Subset of developmental disabilities

Impact intellectual and adaptive functioning

Varying levels of systems of supports



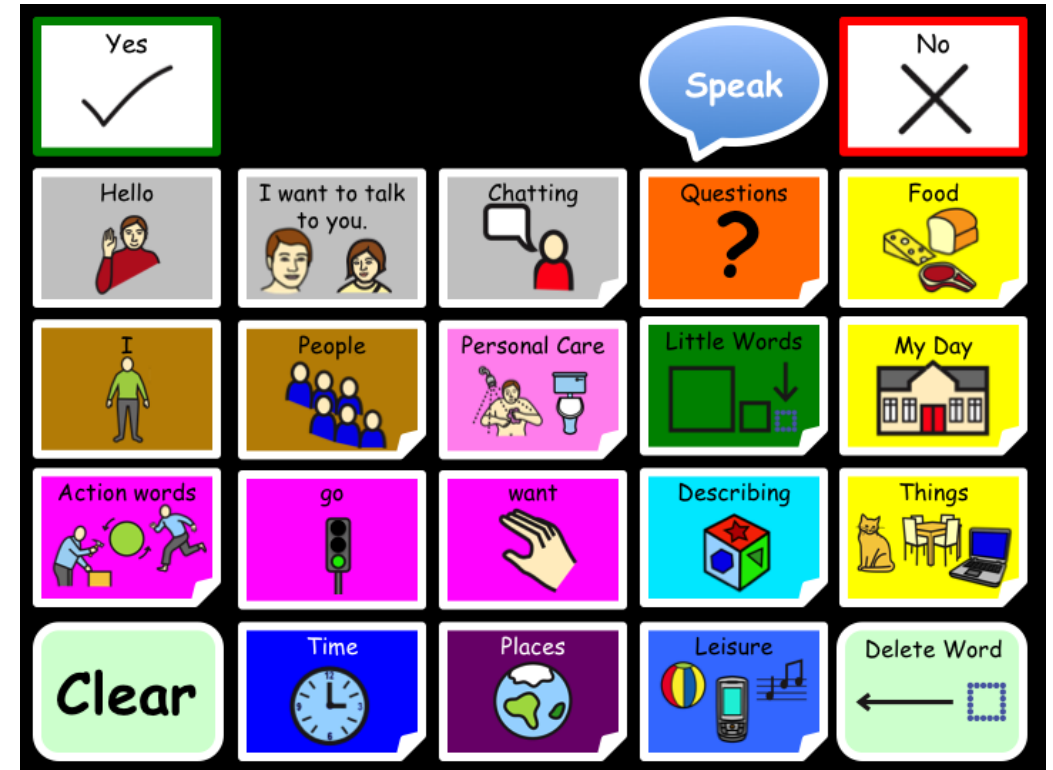
Examples of Causes of Intellectual Disabilities

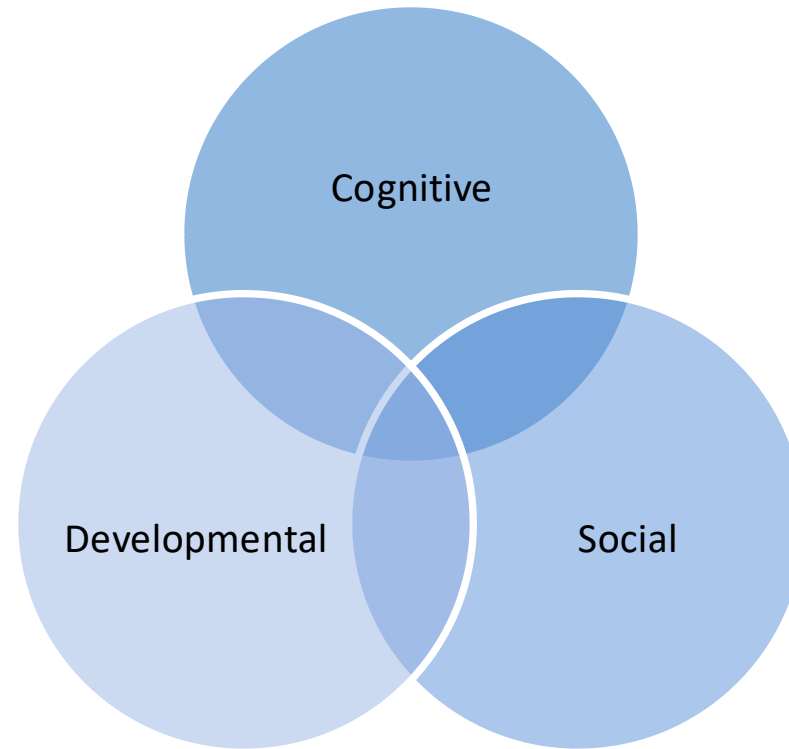
Language and Communication

Range of communication modes

Receptive and/or expressive
language delays

Social communication
considerations





Children with ID have a range of **cognitive**, **developmental**, **social** differences that have been minimally explored in relation to grief and loss experiences

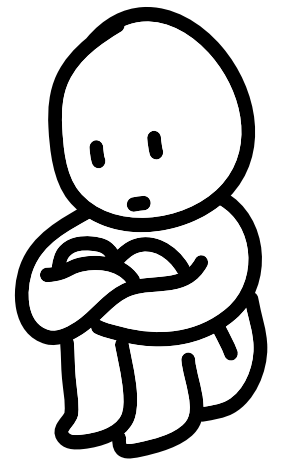
What do we know about neurotypically developing children and grief?

What we knew before this study about grieving children with ID:

- VERY limited research on grieving children with ID
- Children with ID may not fully understand death but experience the impact of the loss
- Range of emotional reactions
- Disenfranchised grief

But there were lots of gaps:

- Lack of research from family perspective
- Lack of a framework to guide support for grieving children with ID



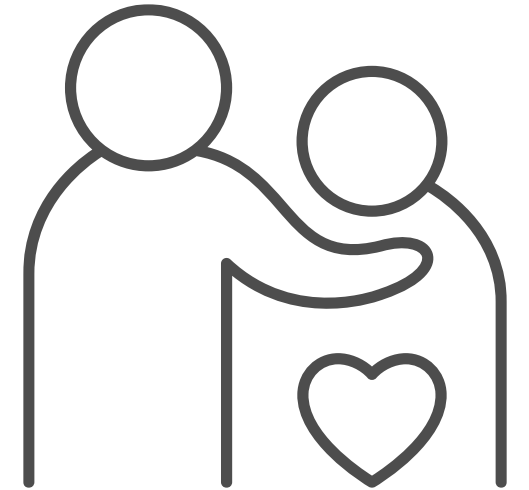
Research Aims

- To understand the grief and bereavement experiences of children with ID
- To develop a model that supports developmentally inclusive grief support



Methods

- Qualitative grounded theory research
- Inclusion criteria: Primary caregiver of a child ages 5–17 with ID who experienced the death of a significant person in their life
- Optional inclusion of child in the interview





UNIVERSITY of MARYLAND
BALTIMORE



**Has your child with an
intellectual disability
experienced the death of
someone in their life?**



Looking for parents/guardians for
important research study

We are conducting a study to understand more about how children with intellectual disabilities grieve after the loss of someone in their life. If your child has experienced such a loss, we invite you to participate in this study to help us learn how to support other children in similar situations.

Participants will be interviewed for approximately one hour and will receive a \$25 gift card as a token of appreciation. Interviews will be conducted by video or phone.

Your child may optionally join for a short portion of the interview.

Please email arlengaines@umaryland.edu or call 240-242-7424 for more information.

Who may be eligible?

- Parents/guardians over 18 who have a child with an intellectual disability
- The child was between the ages of 5-17 when they experienced the death of someone significant in their life (such as a parent, sibling, grandparent, or friend)
- The death was at least 6 months ago and no longer than 3 years ago



Recruitment Strategy

- Reached out to ~350 disability organizations in US
- 19% of orgs/contacts shared the information
- Participants never directly targeted

Who participated:

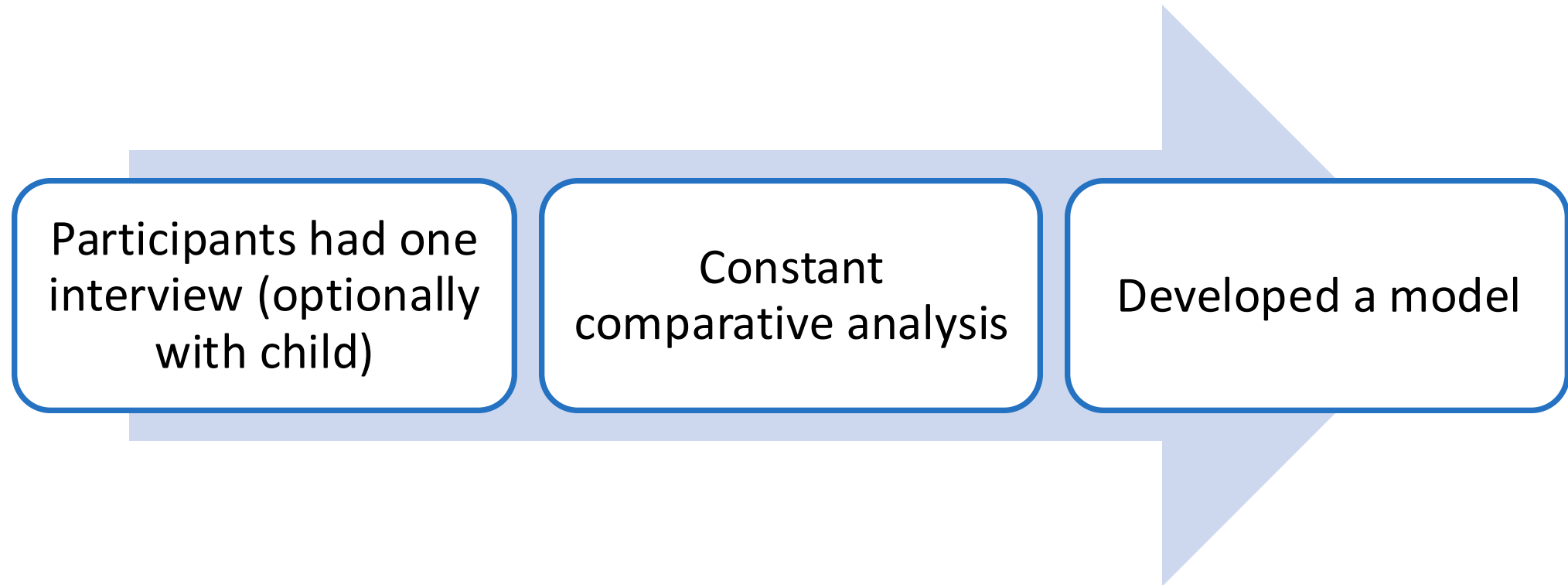
- 25 participants (n=19 adults and n=6 children with ID)
 - From 15 states from all 4 US geographic regions
 - 8 self-described faith orientations
 - 89.5% White, 10.5% Non-White
-
- 19 adults represented children ages 5-17 with
 - 4 conditions (Down syndrome, Fragile X, Other)
 - Range of communication modes

Demographics Related to the Loss

	M	SD
Age of decedent at time of death (years); range 21-104	63.0	19.4
Length of time since loss at time of interview (years)	1.5	0.8
	N	%
Circumstances of the death		
Expected death	11	45.8
Unexpected death	13	54.2
Decedent's relationship to the child		
Parent	7	29.2
Grandparent/great-grandparent	14	58.3
Other	3	12.5

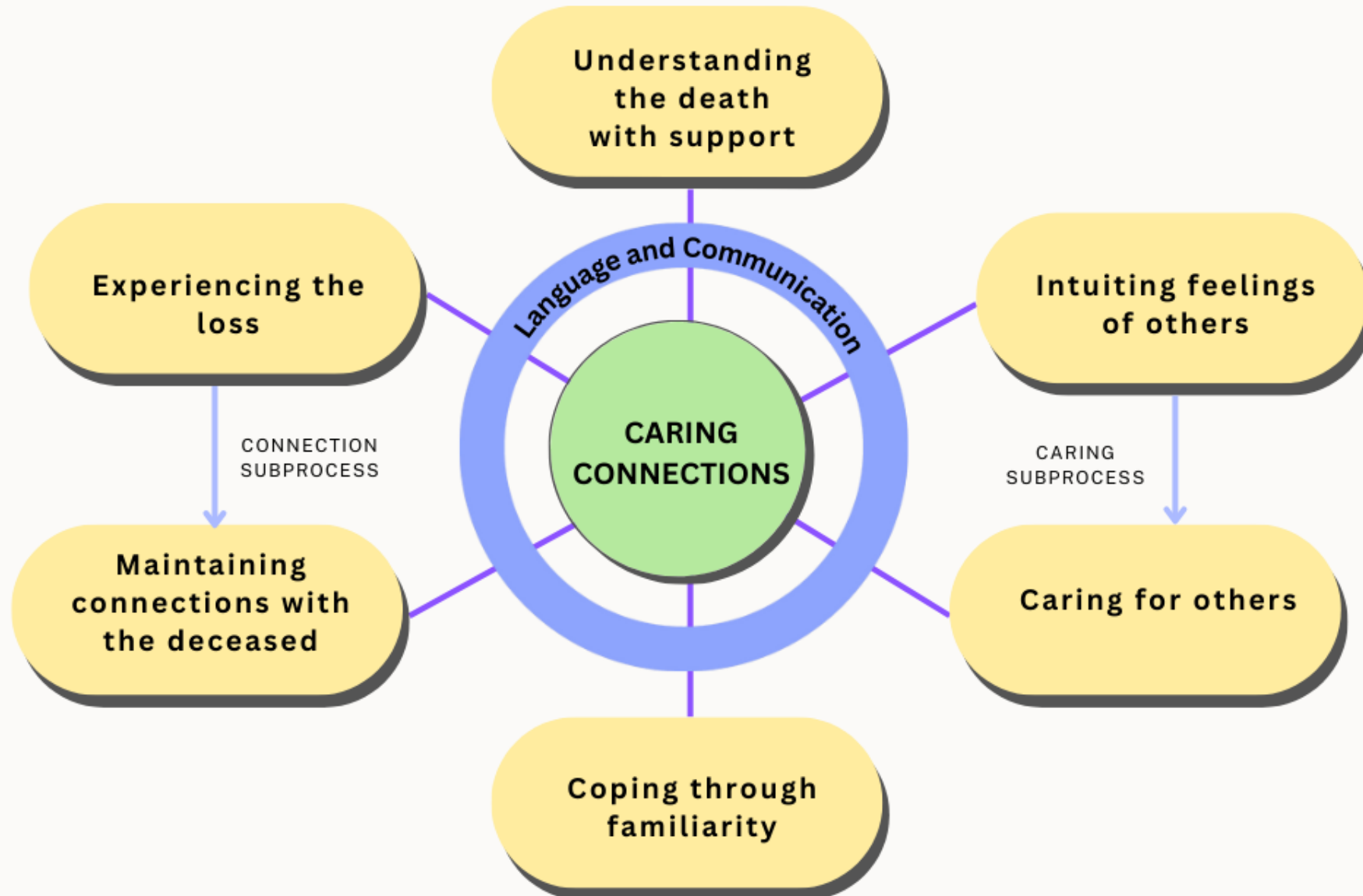
Note- there were 24 losses for the 19 families in the specified time period

How the process worked:



Results

Caring Connections Theory of the Grief and Bereavement Experiences of Children with ID



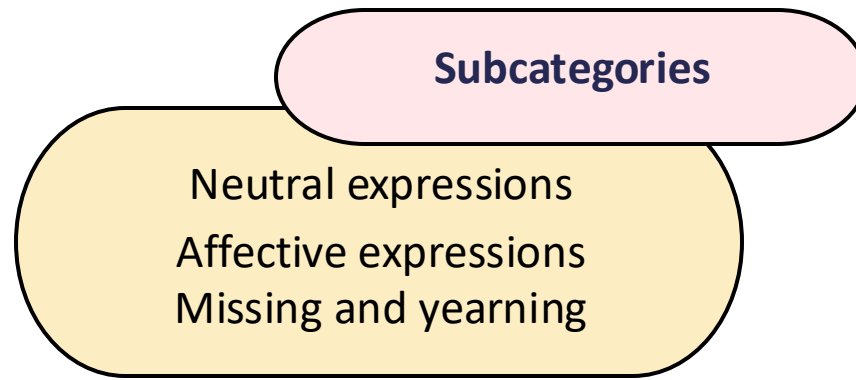
Understanding the Death with Support

Subcategories

Absorbing the concept of death
Processing the loss concretely
Beliefs about the loss

“I think understanding she’s cognitively really soaking it in and paying attention and attuned to so much, even though verbally there’s not a mirroring of that.” - Parent

Experiencing the loss



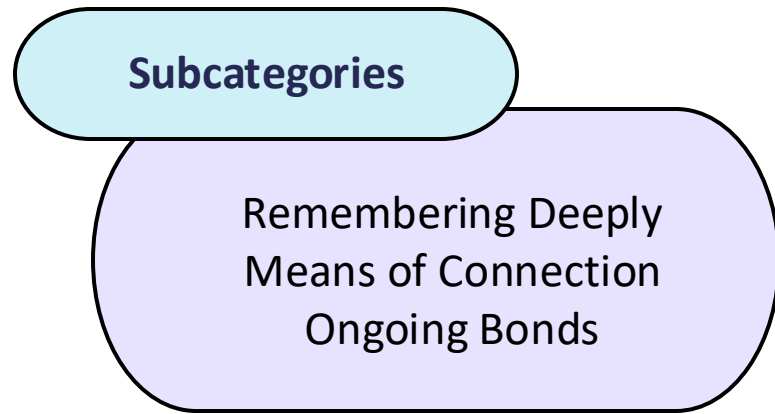
“They have that range of emotions. They're not always happy kids by any means...They feel that grief. They feel that hurt and anger.”

- Parent

“I wish Daddy be here with me in all years. I hope Daddy has not died.”

- Child

Maintaining Connections with the Deceased



“He is in the habit if he is up early that he goes out and says that he hugs the sky. And he sees Daddy in the moon and in the sky...And he just walks out there with his arms out, hugging the sky, and then he comes in and tells me I hug Daddy this morning. I saw daddy.” - Parent

Maintaining Connections with the Deceased



“It’s me and my dad cooking mac and cheese”- Child

Intuiting feelings of others

Subcategories

Feeling on a Deep Level
Being Attuned to Emotions of Others

“So she understood that other people were experiencing sadness and her response to that was she would cry and then she would go hug them...She felt like...if she was getting hugged when she was sad, she felt like extending that to another person was going to make them feel better.” -Parent

Caring for others

Subcategories

Nurturing
Having a Role

Coping through familiarity



The diagram consists of a large yellow rounded rectangle containing three lines of text. A smaller light blue rounded rectangle is positioned at the top right of the yellow rectangle, overlapping its top edge. The blue rectangle contains the word 'Subcategories' in bold dark blue text. The yellow rectangle contains the following text in black: 'Family Bringing Comfort', 'Continuity and Support from Community', and 'Routine and Repetition'.

Subcategories

Family Bringing Comfort
Continuity and Support from Community
Routine and Repetition

“I think as much as we could do the things that she was familiar with. Eating the same foods and watching the same shows and family around and people to play with. But not too unusual, like not strangers to play with.” - Parent

What we've learned:

The grief and bereavement experiences of children with ID do not fit neatly into existing models of grief

- Typical models using ages/stages don't hold up!
- But other models to hold up---continuing bonds
- Highlights importance of empathy and grief
- First model that takes into account language and communication considerations

What we've learned continued:

The grief and bereavement experiences of children with ID have aspects related to self and others

- Self-processes: experiencing the loss and maintaining connections
- External processes: intuiting feelings and caring for others
- Interplay of self and others throughout the model

What we've learned continued:

Children with ID are not necessarily disenfranchised in their grief

- Children in this study did not appear disenfranchised in their grief
- Being in a loving, supportive family with opportunities for care and connection may mitigate disenfranchised grief
- Future research needed with other groups

In Summary

Range of self-processes

(experience the loss, maintain connections)

Experience external processes

(care for others)

Opportunities for care and connection may
prevent disenfranchised grief



Research

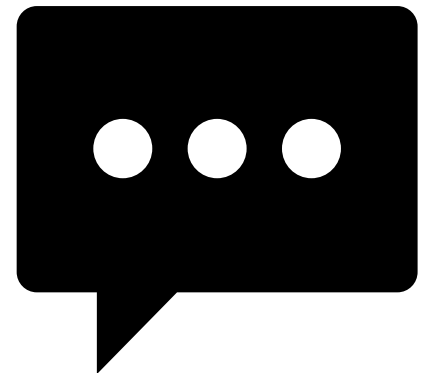
Practice

Support understanding of death through concrete language

- Honest conversations
- Concrete language, avoiding metaphors

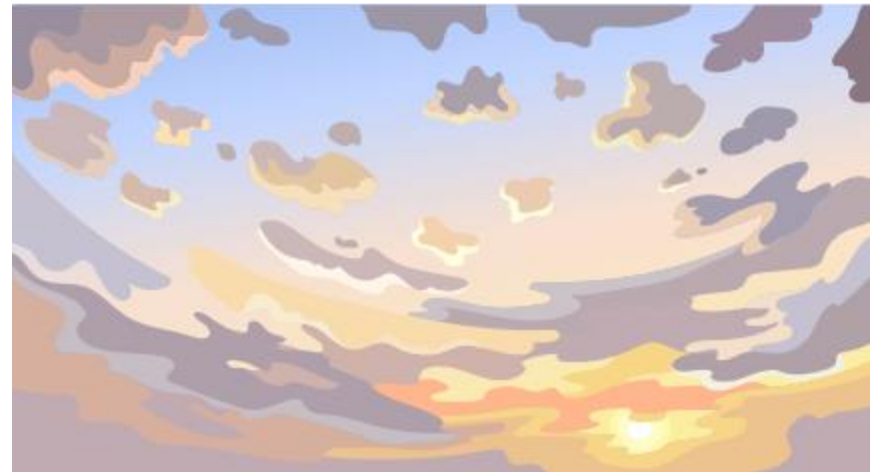
She has died.

Her body is no longer working.



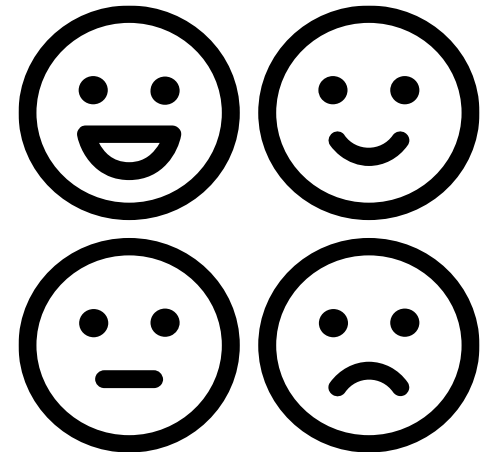
And...support understanding through belief systems

- Sharing spiritual beliefs
- Faith perspective
- Cultural beliefs



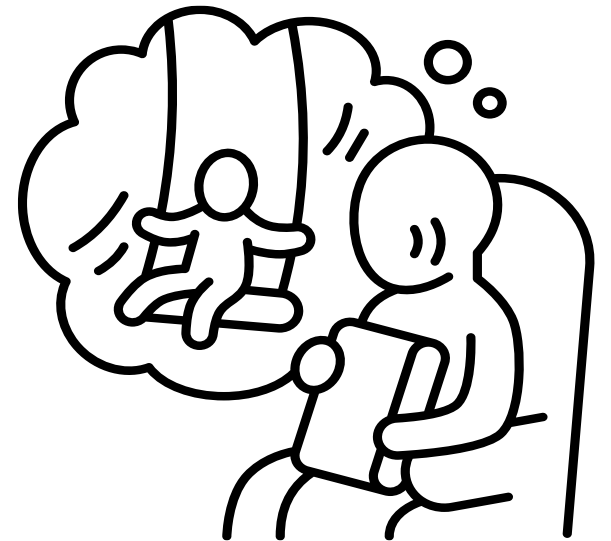
Recognize and accept children's grieving process

- Ways that missing and longing are expressed
- Potential for increased anxiety
- Possibility of behavioral changes as grief response



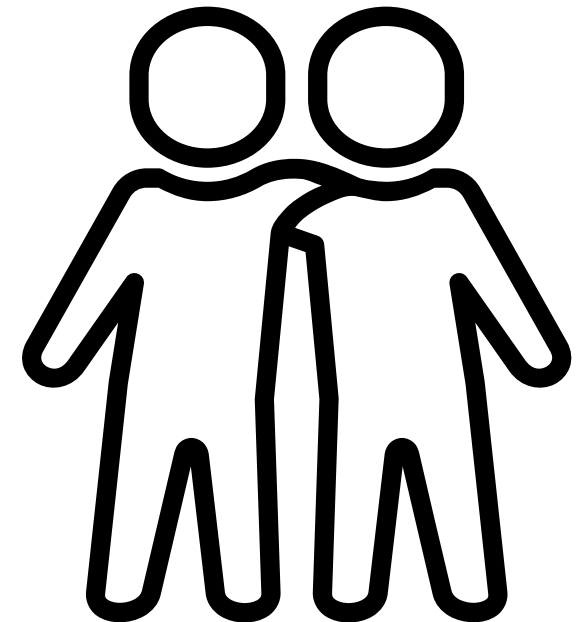
Foster opportunities to remember and share

- Looking at photos
- Having access to comfort objects
- Sharing stories
- Connecting through nature
- Having picture on AAC devices



Foster opportunities for children to care for others

- Offering a role, but not forcing
- Helping with the person's care
- Can comfort others who are grieving
- Can have a role at the service



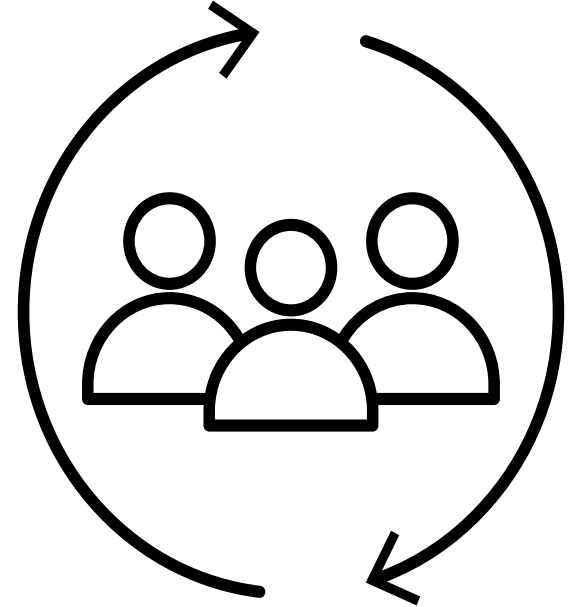
Leverage the support system

- Bolstering time with familiar support system
- Partnering with teachers, therapists



Provide reinforcement and reminders

- Expecting matter-of-fact questions
- Remind what they can and can not do
- Tell the story again
- Maintaining routines as possible



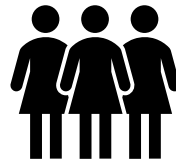
Example of Social Story



We will get dressed



We will go to
the memorial
service



There will
be a lot of
people.



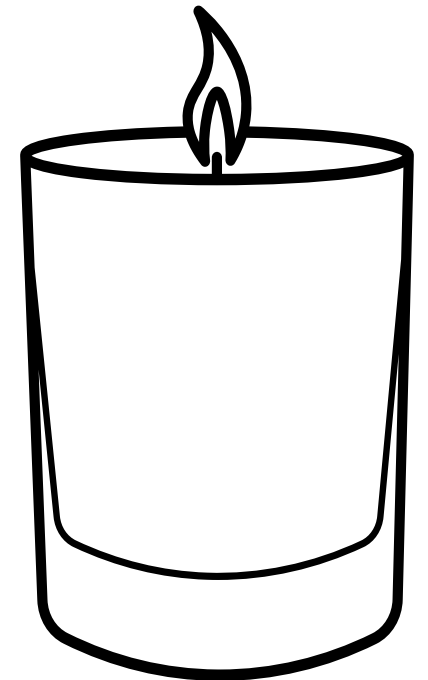
I can take a
break



We will go
home

Include children with ID in the loss experience through:

- Conversations about the death
- Community remembrances
- Talking about the person



Final thoughts

“The main thing that I've taken away from all of this is that [child] wants to be a part of the things that are going on in the family, in the community, in life and also in death. For him, and it may not be true for every person, but for him being included in those spaces, being included in the conversations, being included in the rituals has been really powerful and important for him and for everybody else.”

(Mother of a child with ID)



Co-Investigators:

John G. Cagle, PhD, MSW, Principal Investigator, University of Maryland, Baltimore

Patricia Moyle Wright, PhD, MBA, MSN, CRNP, ACNS-BC, CNE, CHPN, CPH, FPCN, University of Scranton

Jaime Goldberg, PhD, MSW, LCSW, University of Wisconsin, Madison

Elizabeth McAdams Ducey, PhD, Sonoma State University

Mary Lynn McPherson, PharmD, PhD, BCPS, FAAHPM, University of Maryland, Baltimore

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Questions?

Ethical Considerations

Potential risks and how they were mitigated

Risk of emotional distress

- Could take breaks
- Stop interview at any time
- Given resource sheet

Interacting with a grieving population

- Lead researcher and PI backgrounds in HAPC/ bereavement social work informed sensitivity

Demands of caregiver role

- One interview to minimize burden on their time
- Flexibility in scheduling

Protections needed for children

- Optional inclusion of children
- Parents asked questions of their children
- Assent process in place