

Grief and Individuals with Autism Spectrum Disorder and/or Intellectual and Developmental Disabilities

Understanding, Supporting, Empowering

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START Model

The START (Systemic-Therapeutic-Assessment-Resources-Treatment) model is an evidence-informed model of integrated community crisis prevention & intervention services for individuals ages 6 and older with intellectual and developmental disabilities and mental health needs.

START was first developed in 1988 by Dr. Joan B. Beasley and was cited as a best practice in the 2002 US Surgeon General's report and by the National Academy of Sciences in 2016.

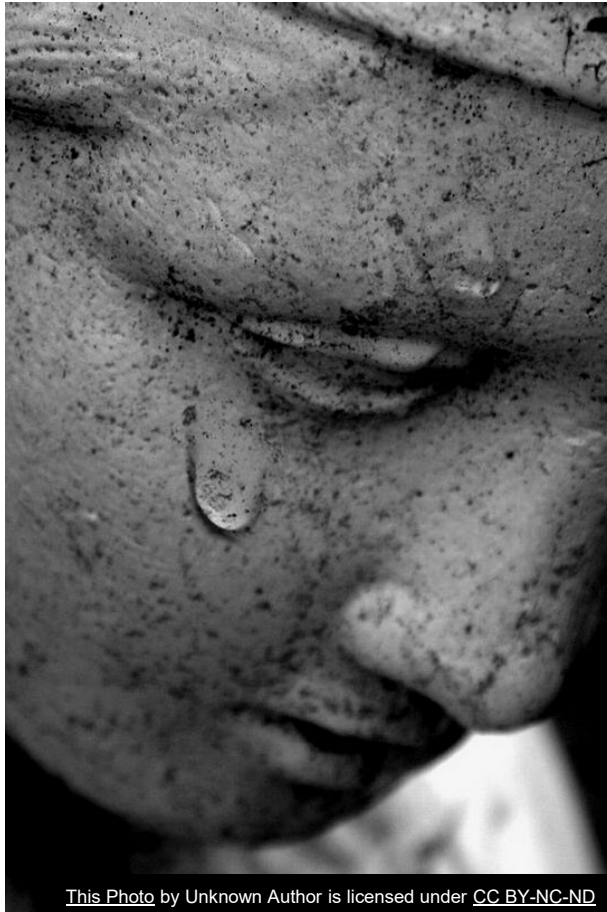
The **National Center for START Services** at the UNH Institute on Disability oversees the development, measurement and quality of START programs across the country.

Objectives

1. Review current understandings of grief and differentiate from depressive disorders, PTSD, or Separation Anxiety.
2. Distinguish Prolonged Grief Disorder and specific risk factors, specifically PTSD.
3. Discuss the trajectory of grief and how it is processed and experienced differently in the ASD/IDD population with attention to the influence of cultural norms and values defining this trajectory.
4. Provide interventions and strategies to discuss and process grief with individuals with neurodevelopmental differences such as IDD and ASD.



What is Grief?



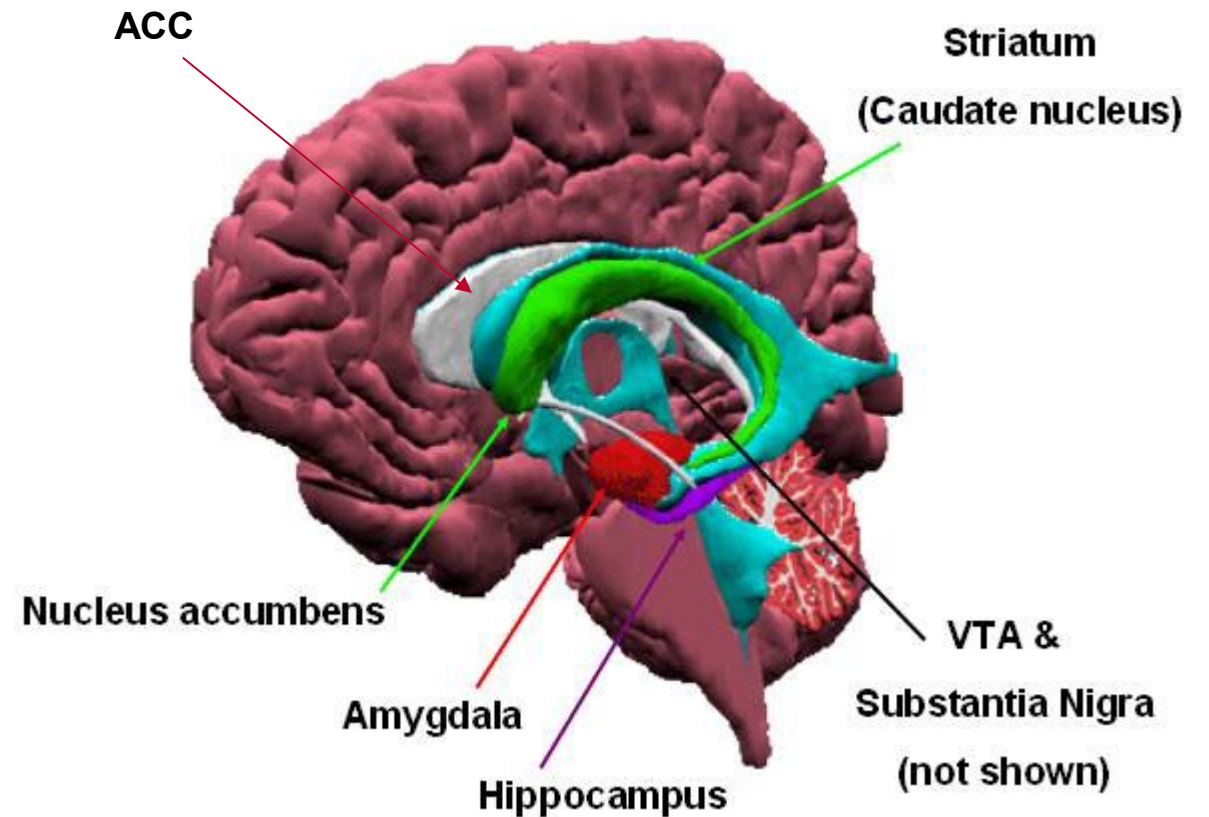
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- Definition
 - The emotional experience in response to a death or the loss of someone important.
- Misconceptions
 - It's a state of sadness
 - Grieving is a linear process
 - People with disabilities don't experience grief

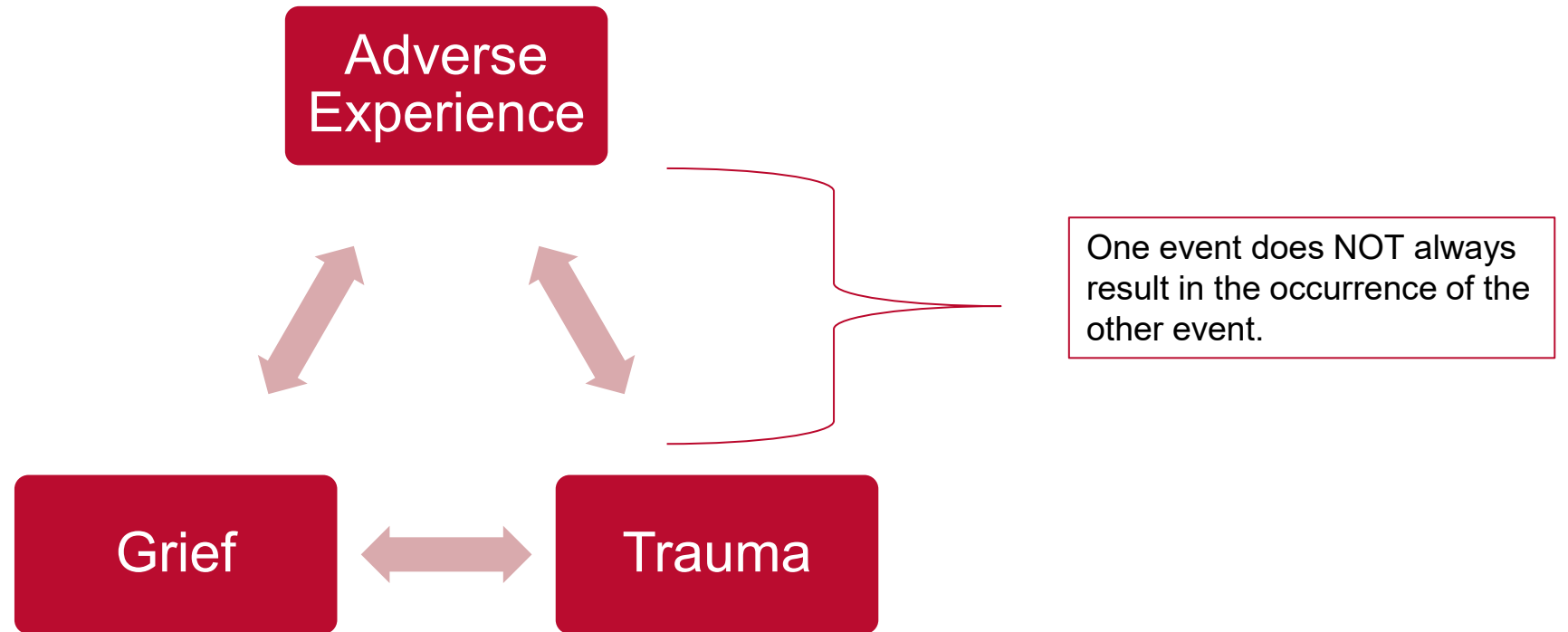
Grief and the Brain

- Nucleus accumbens: Reward and motivation
- Hippocampus: Long-term memory
- Amygdala: Emotional processing, memory formation, and activation
- Prefrontal cortex: Executive functioning and emotional regulation.
- Anterior cingulate cortex: attention, emotion regulation, and decision-making

Chen, et al, 2020; Huberman, 2022



Trauma and Grief



Developmental Disabilities and Grief

Children and adults with disabilities may experience grief differently due to:

- Developmental differences and challenges with thinking
- Social-emotional responses
- Reactions of those around them



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Conceptual Differences: Understanding Death

- Piaget's theory often doesn't align with comprehension for those with IDD.
 - Object permanence
 - Magical thinking
- Challenges with abstract thinking and metaphoric language.
 - "He passed away."
 - "They're at peace."
- Concrete teaching methods (e.g. visual aids, repetition) found most effective.

Social Emotional Responses



- Differences in emotional insight and expression
- Manifestations: crying, anxiety, regression, new behaviors (e.g. hitting, withdrawal, clinginess), increases in frequency or intensity.
- Challenges include rigidity, routine disruption, non-verbal communication.

Disenfranchised Grief



- People with disabilities are often excluded from rituals or shielded from truth.
- Misunderstood expressions may lead to lack of support.
- Lack of validation increases risk for prolonged or complicated grief.



Complicated Grief (CG)

Persistent, acutely distressing, and functionally impairing grief reaction that goes beyond what is considered a typical mourning process. (O’Riordan, 2022)

May result from misattribution of behaviors and diagnostic overshadowing.

Complicated Grief, cont.

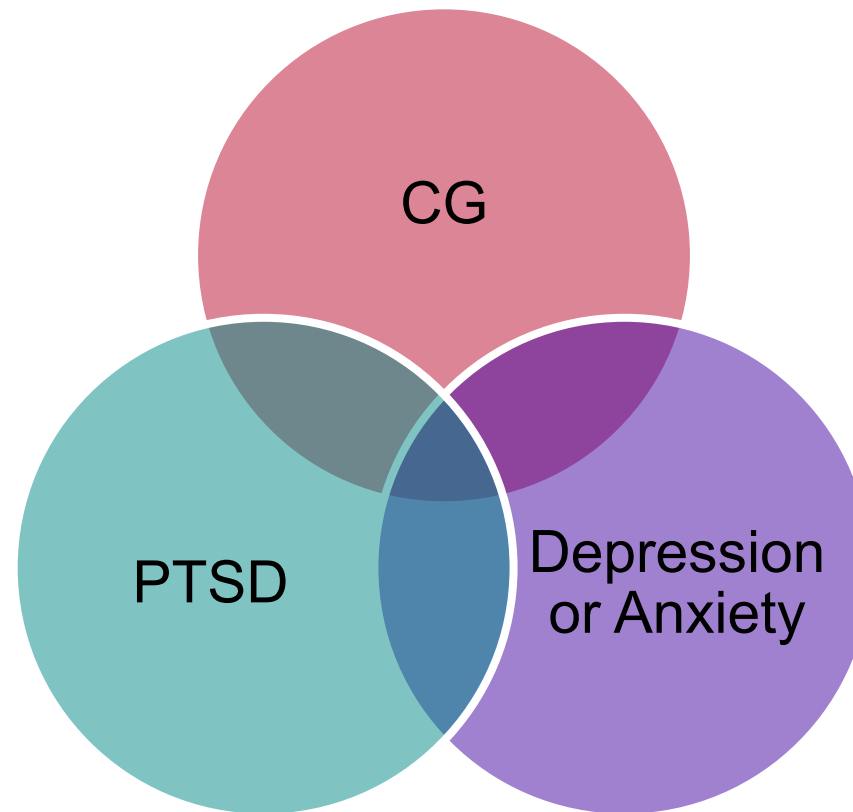
Prolonged/ Complicated grief and delayed onset common.

High prevalence: ~33% in ID vs. ~9.8% general population.

Separation distress more frequent than traumatic grief.

Self-report tools reveal more symptoms than proxy reports.

PTSD, Complicated Grief, or Other?



Protective Factors



Anticipated loss and bereavement education.



Involvement in rituals—if properly prepared.



Support from trained caregivers and consistent environments.

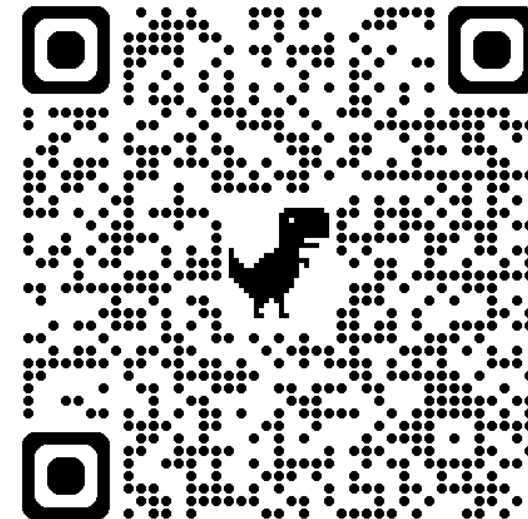


Reliable assessments and tailored interventions.

Key Takeaways

- Grief is experienced even if cognitive understanding is limited
- Individualized, concrete and honest approaches are essential.
- Maintain routine and stability as well as possible. Understand the risks of secondary loss (e.g., routine disruption, caregiving changes, etc.)
- Recognize and address challenging behaviors and seek specialized support.

<https://tipsheets.vkcsites.org/helping-people-with-intellectual-disabilities-cope-with-loss/>





Assessment- Understanding of Grief

ANNEX I

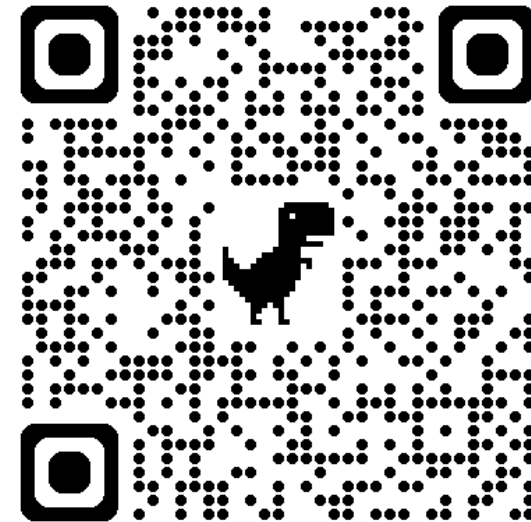
Inventory of grief and coping strategies in intellectual disability (IGCS-ID)

Understanding of the concept of death

1. The individual understood the concept of death	1	2	3	4
2. The individual understands the possible causes of death	1	2	3	4
3. The individual understands that when a person dies their body cannot come back to life	1	2	3	4
4. The individual understands that their life-defining functions (e.g., breathing, seeing) cease after death	1	2	3	4
5. The individual understands that all living beings (including themselves) die	1	2	3	4

Coping with the loss

6. The individual expressed their emotions	1	2	3	4
7. The individual was informed in advance that the significant person was going to die (if it was anticipated)	1	2	3	4
8. The individual was informed when the significant person died	1	2	3	4
9. The individual saw the significant person shortly before the death	1	2	3	4
10. The individual was able to attend the funeral	1	2	3	4
11. The individual had photos and mementos of the significant person	1	2	3	4
12. The individual was able to visit the grave of the significant person after the death (if there was a grave)	1	2	3	4



Assessment- Stressors



I-START Program
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Mason City, IA 50401
Phone: 641.525.0401 | Fax: 641.201.3992
Email: istart@countysocialservices.org
www.countysocialservices.org

UMASS Recent Stressors Questionnaire

Individual's Name:		ID:	
Completed upon:	<input type="checkbox"/> Initial <input type="checkbox"/> Review <input type="checkbox"/> Crisis	Date:	

Please check YES or NO for each item and describe any item answered YES. Please give details, dates if possible.

Which of the following have occurred in the past six months?

Changes in residential staff ☐ Yes ☐ No

Changes in school or day/vocational staff ☐ Yes ☐ No

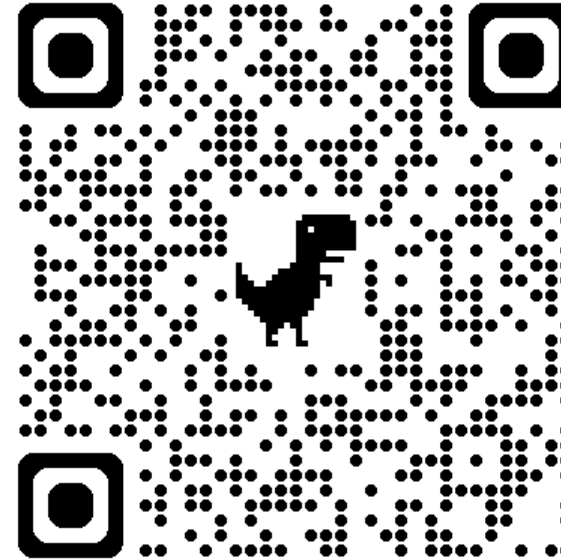
A move to a new living situation ☐ Yes ☐ No

A change in day program, job, or schools/classroom assignment ☐ Yes ☐ No

Changes in the level or rate or type of contacts with family or significant people ☐ Yes ☐ No

Illness of a loved one, caretaker, friend, or peer ☐ Yes ☐ No

Death of a loved one, caretaker, friend, or peer ☐ Yes ☐ No



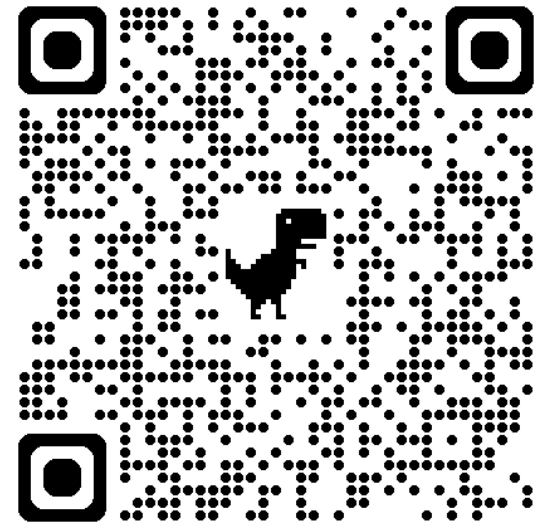
Supports and Tools

RUTGERS
Robert Wood Johnson
Medical School

THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES
New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service
New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program

RESPONDING TO GRIEF REACTIONS OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

ADAPTED FROM ROBERT L. MORASKY, PHD



References and Resources

Chen G, Ward BD, Claesges SA, Li SJ, Goveas JS. Amygdala Functional Connectivity Features in Grief: A Pilot Longitudinal Study. *Am J Geriatr Psychiatry*. 2020 Oct;28(10):1089-1101. doi: 10.1016/j.jagp.2020.02.014. Epub 2020 Mar 9. PMID: 32253102; PMCID: PMC7483593.

Huberman, A. (Host). (2022, May 30). The Science & Process of Healing from Grief (No. 74) [Audio podcast episode]. In Huberman Lab. Scicomm Media.
<https://www.hubermanlab.com/episode/the-science-and-process-of-healing-from-grief>.

O’Riordan, D., Boland, G., Guerin, S., & Dodd, P. (2022). *Synthesising existing research on complicated grief in intellectual disability: Findings from a systematic review*. *Journal of Intellectual Disability Research*, 66(11), 833–852.