The Caregiver Toolkit Coping with Grief and Loss as a Caregiver

Meeting Objectives

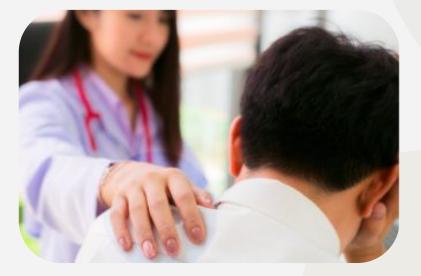
- 1 Understand the definition of grief
- **2** Discuss the 5 stages of grief
- **3** Review caregiver reports about grief
- **4** Understand the re-occurring process of grief
- **5** Discuss solutions to experiencing grief

Defining Grief

- "Deep and poignant distress caused by or as if by bereavement." ~Merriam-Webster Dictionary
- ✤ Grief is the experience of coping with loss
- An intellectual disability diagnosis has been associated with feelings of grief and loss in caregivers/parents
 - 5 Stages of Grief:
 - 1. Denial
 - 2. Anger
 - 3. Bargaining
 - 4. Depression
 - 5. Acceptance



"It was like I didn't expect it... I thought at the time that the physician was wrong. How was he going to know so soon that my son was not well."



1. Denial

- The initial diagnosis produces shock and disbelief in caregivers or parents of children with IDD
- A belief that the diagnosis was wrong or not so serious and that their child was going to be fine
- Denial is also demonstrated by hiding the diagnosis from family and social circles



"It was, why us, how did this happen, how is it caused... and they had no answers."

2. Anger

- Loss of personal dreams for the parent or caregiver and the individual
- Limited practical and emotional support
- Societal, financial, or geographical constraints that limit access to information or resources
- ✤ Comparison

"I got no care (from doctors) at all. I feel like guilty for not having done more and maybe things would have gone better. I trusted the doctors that saw me... I miss that. Because I feel that if I'd gone ahead of the doctors I would have helped my daughter more..."

3. Bargaining

- "If only" or "what if" thinking
- Grief in caregivers or parents arise with reminders of "what might have been"
- Thinking about what they "should have done differently"



"It [grief] was layering basically from the first diagnosis... there became a deep sadness within me and the sadness you can always see now in my eyes."



4. Depression

- Loss of hope about the future
- Feeling directionless, lost or confused about your life and the individual's life
- Difficulty concentrating
- Difficulty making decisions

"It's taken me to places I would never ever have wanted to go and I wouldn't wish on anybody but I think it has made me a different person... it's made me more compassionate for others... I have got an inner strength through this."

"Now I think that having a child with a disability is the best thing God has given me."

5. Acceptance

- The sadness and sense of loss or grief may never fully fade
- Adjusting to the new reality, starting to move on
- Sense of hope, healing, and integration
- Ability to allow sorrow and joy to live alongside one another



How Long Does Grief Last?

- There is no set timeline for grief
- The 5 stages do not always occur in an orderly sequence
- Grief repeats itself when a family's child experiences or should experience key milestones or transitions
- Grief described as an "emotional rollercoaster"



Solution

- Avoid the "tough it out" mentality
- Experiencing and sharing the grieving process is the solution, not the problem
- Benefits of yielding to the grieving process:
 - > Develops inner strength and external support
 - ➢ Fosters creation of new dreams
 - ➤ Reassesses sense of significance and impact
 - > Redefines criteria for capability

Questions?

Activity Time!



Questions?

Satisfaction Survey

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References

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