

# 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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