Honoring and Supporting Grief and Loss in the Lives of Persons with Intellectual and Developmental Disabilities and their Families

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People with IDD and Grief: How things have changed!!

People were never told

Death was out of sight

"People with IDD don’t express grief."

People did not know how to support people with IDD in grief.

Belief that grief support had to be “specialized.”

Focus on “chronic grief” of parents
In Old Systems of Care: Death an Indicator of

- Loneliness and loss of connection
- Injustice, no power, at hands of system, professionals, family
- Abandonment
- Family wounds
They usually did not participate in rituals of mourning. Why?

- Others being protective. (of whom?)
- "They would not understand."
- “They would get upset.” Or “They would upset the funeral, etc.”
Now.....

- Live in a world full of losses. We see them every day. TV, staff changes, friends come and go, moves, etc.
- Recognition that unexpressed grief can act itself out.
- Society as a whole is not good with planning ahead or coping.
- Too often rely on “Bring in the professional (i.e. specialized) grief counselor.”
- With COVID, huge awareness of the tragedy of isolation and loneliness.

- If inclusion and belonging is key, why not here as well?
New Challenges and Crises

Death as “double injustice”
Disability enough to deal with, why this?
Aging, disability, death=curses
Anger by staff and others at
- Family (and vice versa)
- Other staff
- Losses
Pressures and Paradoxes
- “They don’t understand” vs. “Move on quickly.”
- Pressure to fill the empty slot, bed, or place at the table
- Highlights the importance of relationships, not program or plan.
- “They don’t seem to get over it.”
Currents in DD systems and care is toward growth, development of potential, new life. End of life not in the plans.

When it happens unexpectedly, it becomes “critical incident report,” too often assumed to be someone’s fault. Paperwork and investigation compounds grief.

Currents in health care toward healing, cure, fix, death too often enemy and disability evidence of failure.

Hospitals too often dangerous places for people with severe disabilities.
Critical Role for Hospital Chaplains

Person in the hospital connected to larger networks, including families, service providers, friends, and community members, even if none are there.

While patient, may have direct care staff assigned to be in the room to facilitate communication and understanding. Hospital may be a scary place for them as well.

For families, hospitalization may resurface traumatic experiences with health personnel.

Communication issues may be paramount for staff.

"Quality of Life" issues may impact attention and care.
Critical Roles for Chaplains (continued)

- Modeling presence and respect for everyone involved.
- Connector between networks involved along with others.
- Awareness of resources for individuals with intellectual and developmental disabilities, families, and other caregivers.
- Connections with clergy and faith communities may not be there.
- Dealing with loss and grief may be new for agency staff.
- Wide diversity of religious and cultural backgrounds.
So, what to do?

Recognize:

Loss and grief will be there, whatever the level of disability.

Losses come in many forms: deaths, end of relationships, staff change, caregiver change, moves, change of valued routines, loss of pets, friends.

Supports need to be inclusive, but also person-centered and family-centered, in their cultural and religious context.

“They” are often better at sharing grief than “we” are.
Is God in nature?

My Mom died.

My Pop-pop died.

I don’t like to think about Woodbine.

I miss my friends at Woodbine.

I really, really miss them.

What is cancer?

Where do people go when they die?

Why does cancer kill a person?

I’m so sad.

How can I see my friends from New Lisbon?

I can’t talk to my friend in Ancora.

I don’t like to think about Woodbine.

My best friend doesn’t live here anymore.

My best friend died.

I need a friend to sit with.

My Mom’s in Heaven.

I can’t live alone anymore.

Where is Heaven? I need a place for my kids.
Reverse the questions. When asking about how to support someone, how would you support anyone else?

None of us completely understands what death means, but we all experience loss.

We all act our grief, usually but not always in family and culturally accepted ways.

Non-verbal supports may be more important than verbal. Participation beats understanding.
Guiding Principles (continued)

Pull in the people who have been supports in the past and present. Support the supporters.

The power is in the community of mourning and support. Your ministry is one of them.

It takes time for everyone.

Think of grief as circles, not straight lines. We live through it, not “get over it.”
What we can encourage others to do.

Planning ahead

- **Know**
  Know what a person or family’s traditions are for handling loss.

- **Use**
  Use teachable moments from TV stories, everyday experiences, to talk about the normalcy of grief and loss.

- **Help**
  Help people prepare: Visits to funeral homes and cemeteries, pictures, etc. Possible topic for religious education programs.

- **Build**
  Build anticipatory support teams: clergy, staff, relatives, others through shared conversations and resources.

- **Provide**
  Provide opportunities and rituals for closure: Saying thank you, love you, goodbye.
Key Strategies for Grieving

- First, recognize it and welcome it. “Grief delayed is grief denied and grief denied is grief delayed.”
- Create a safe place for it. A sanctuary.
- Be alert for behavioral expressions.
- Assist in appropriate behavioral expressions, e.g., cards, photos, letters, talking about feelings and memories, sending flowers, taking food, etc.
- Involve “their” community: friends, housemates, staff, teachers, coaches, others in programs, congregations, etc.
Key Strategies for Grieving

- Accurate and honest information and support to process questions/feelings
- Enable maximum involvement in the social and spiritual activities surrounding death, including planning.
- Keep connected with key supportive relationships: Who would you turn to?
- Maximize opportunities for expression of grief and condolences.
- Jeffrey Kaufman: Helping Adults with Mourning
Creative Strategies

- Talk with other families, staff, etc. about what they have seen.
- Individualized rituals of loss and celebration in addition to main ceremony.
- Pre-visits to places where rituals will take place.
- Involve person with IDD in some way in the planning and leadership of services.
- Plan a variety of individualized ways of remembering and memorializing: pictures, photo albums, memory boxes, favorite foods or places, anniversaries, and more
Paradoxes of Roles

- Staff, family, and/or friend
- “Be with” as well as “do for”
- “Care for needs” as well as “celebrate gifts.”
- Specialized supports vs. “give it away”
- Know what we don’t know, and use that to invite others in.

Lessons in Grief and Death: Supporting People with Developmental Disabilities in the Healing Process. By Linda Van Dyke,


Website for one of the authors of a number of the Books Beyond Words: http://www.tuffrey-wijne.com

Talking End of Life
...with people with intellectual disability

MyGrief.ca

http://www.aging-and-disability.org

L'Arche

THINKING AHEAD
My Way, My Choice, My Life at the End

Accessible Planning Tool
Glancing Back Planning Forward
Getting more specific: Autism

Autism is a neurological disorder characterized by deficits in both language and communication.
Autism & Grief

Supporting autistic adults in grief and loss

Grief is a Spectrum Too
Stories About Grief and Autism

Autistic adults describe their experiences of grief and loss in this compelling six-minute video by Exceptional Minds, a Hollywood studio that trains and employs animation artists on the autism spectrum.
DSM-5: Autism Spectrum Disorder

- Persistent deficits in social communication and social interaction
- Restricted, repetitive patterns of behavior, interests, or activities
- Symptoms are present in early childhood
- Symptoms limit or impair everyday functioning or relationships

(Tierney, 2015)
Common Behaviors in ASD

- Decreased eye contact
- Uneven development of skills
- Resistance to changes in routine
- Marked hyperactivity and/or extreme passivity, which may alternate
- Less demonstration of typical signs of affection
- Odd body movements or postures (flapping, spinning, etc.)

(Challman, 2015)
So what might that look like?

- Looking down, instead of at you when you speak
- Not answering questions, or not answering right away
- Not wanting to be touched
- Repetitive rocking, swaying or bouncing
- Walking only on toes
- Flapping hands
- Making noises that are not words
Universal Dimensions of Grief

- Very individualized...highlighting importance of knowing and adapting strategies to each autistic individual
- No universal stages of grief
- Rollercoaster, not a timeline.
- Multiple kinds of losses, e.g., loss of support staff, routine, home, pet, etc. Social circle may be more limited
- Physical and cognitive symptoms, as well as emotional and spiritual
For People with Autism

- There may be no outward change in behavior, which does mean lack of understanding or sadness. Assume competence.

- Too often assumed that they will not understand, or should be protected from loss..."disenfranchised grief," grief that is not recognized or respected.

- Can cause regression, anxiety, and stress...disconnect from feelings.

- Sometimes increase in behaviors used to soothe sensory overload.

- Uncertainty about social and cultural rituals related to grief and mourning.
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<td>Be clear, explicit and deliberate with your words. No euphemisms, e.g., “passed away,” “sleeping,” etc.</td>
<td>Repeat as needed. No blame for this happening</td>
<td>Be clear about what will happen next and offer choices about how to proceed in sharing news and coping with loss. (e.g. Books Beyond Words)</td>
<td>Provide reassurance and openness about your own feelings, i.e., model.</td>
<td>Address sensory challenges, e.g., visit to hospital, funeral home, etc. Provide companion who is trusted and known.</td>
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The Importance of Ritual

- Remember the importance of rituals, social, cultural, religious, and personal.
- Rituals and customs are expectations and traditions that have developed over time as ways of living out, and “acting out” our grief.
- As possible, help an autistic person learn about those rituals as they come up in daily living, what happens, etc.
- Give choices in what to attend while also educating others about the importance of their doing so. EG, help clergy or funeral directors know what to expect in terms of a person’s typical behavior and reassure them it is all right.
- Help in development of personal rituals of remembrance.
In other words:

- **Educate and explain**
- **Communicate about typical behaviors, in “both” directions.**
- **Model and demonstrate responses and interactions**
- **Choices about what they want to do, ways they want to participate and options for comfort or leaving if needed.**
- **Provide choice about who they would like to accompany and support them.**
- **Reflecting and processing afterwards...at their speed.**
Other Online Resources

- https://www.autismspeaks.org/family-services/resource-library/bereavement-and-grief-resources
- http://www.grieftspeaks.com/id96.html
- http://benziesangmassocialstoriesforautism.blogspot.com/2013/05/when-someone-dies.html
2023 Resource List re: End of Life, Grief, and Loss. Email: Bill.Gaventa@gmail.com

One chapter in the book expands the ideas in this webinar on Aging and End of Life issues. (Baylor University Press)

Feedback on the Autism and Grief website welcome, and stories.

Thank You!