# What is Spiritual Health?

What does this mean for people with I/DD?

# Stone Belt



# Myths about spirituality in I/DD population

# People with I/DD...

- are unable to be spiritual
- can't understand the concept of God or greater power
- are okay with staff being their only friends
- do not think about "the big questions"

# Spiritual Health

# Core human needs:

- Love
- Friendships
- Connection
- Belonging
- Feeling valued
- A sense of worth

#### Spiritual Questions Most People Ask:

- Who am I?
- Who are you?
- What comes after life?
- Where did I come from?
- Is there God?
- What is God?
- Why do bad things happen?
- Why do I have a disability? Is it a punishment from God?
- I feel left out or different. Why?

# Think about the individuals you provide support?

Who spends time with them every day?

Are the paid to be with them?

Do they have friends?

Do they have friends other than other people with disabilities in their home, day program, and classes? How would you feel if most of the people you shared your life with, were paid to be with you?

> How would you feel if you didn't really have much choice who your friends were?

# Grief Training

Understanding and helping people with I/DD cope with grief

# Stone Belt



# Myths about grief in I/DD population

## People with I/DD...

- are unable to understand
- should not be included in grieving rituals (or even informed when a loved one dies)
- only experience grief when someone dies

# The truth that breaks down these myths:

- People with I/DD *do* grieve -may need enhanced support to understand
- People may show an increase in "behaviors". This is normal to the grieving process for anyone.
- People who are not informed or included in rituals (memorials, funerals, etc.) often feel added loss

"What happens a lot within the organization ... is that you might have a staff working in an area for a long time and they move out and weeks later they might move back ... and the next thing a client is moved to another area without you consulting with your other clients, and I am sure they don't know the difference a lot of the time between death and people having moved on or retired."

- Quote from participant in McEvoy study

# The Grief People Don't Talk About: Secondary Loss & Cumulative Grief

# **Cumulative Loss**

# Why?

- Increased life expectancy
  = more exposure to loss
- Within the last 20 years, individuals with I/DD are outliving their parents on average

Cumulative Loss can be:

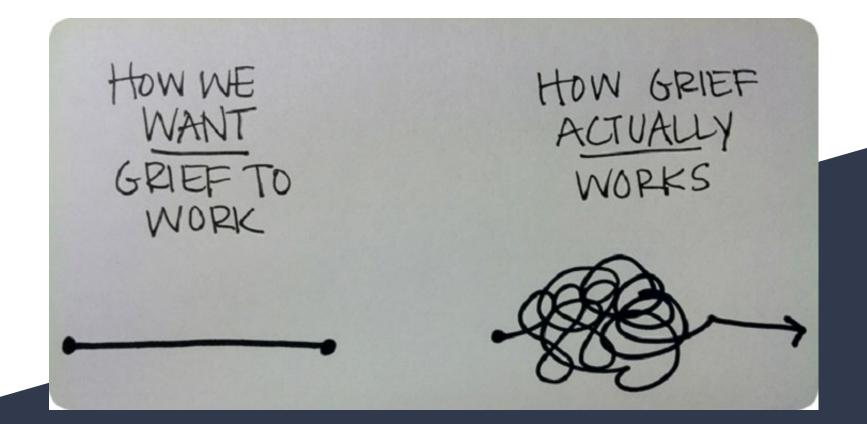
- TRANSITION
- Death of family member, friend, caregiver, roommate, pet, etc.
- New caregivers or staff
- Move to new home/apartment
- Perceptions of others (feeling less valued)
- Reduced independence
- Feeling lack of control
- Loss of employment

# What is grief? 7 Stages of Grief

- **Shock and denial**. This is a state of disbelief and numbed feelings.
- **Pain and guilt.** You may feel that the loss is unbearable and that you're making other people's lives harder because of your feelings and needs.
- Anger and bargaining. You may lash out, telling God or a higher power that you'll do anything they ask if they'll only grant you relief from these feelings.
- **Depression.** This may be a period of isolation and loneliness during which you process and reflect on the loss.

- The upward turn. At this point, the stages of grief like anger and pain have died down, and you're left in a more calm and relaxed state.
- Reconstruction and working through. You can begin to put pieces of your life back together and carry forward.
- Acceptance and hope. This is a very gradual acceptance of the new way of life and a feeling of possibility in the future.

While there are stages of grief, this will look very different for each person. People may go back and forth between these stages.



Things to consider:

- Individual differences in the grieving process
- How grief expression is impacted by the person's disabilities/diagnosis (verbal, non-verbal, level of functioning e.g., mild, moderate, severe)?

**Everyone grieves differently** and level of functioning will impact the grief process as well as ability to communicate, BUT will commonly include these functional areas:

- behavioral (e.g., social withdrawal)
- cognitive (e.g.confusion and helplessness)
- emotional/affective (e.g., anger, sadness)
- physiological (e.g., sleep disturbance, loss of appetite)



# *I.* Behavior Changes

- Aggression, self-injurious behavior (especially when verbal communication is limited)
- Has work productivity changed?
- Is this person withdrawing from social activities?
- Has their personality changed?

- Changes in mood (See emotional/affective)
- Increased crying, hyperactivity, inappropriate speech
- Challenging behavior/mental health problems such as depression, mania and psychosis.

# II. Cognitive

*Cognitive abilities* vary greatly from person to person. This can make it difficult to assess those diagnosed with profound or severe intellectual disabilities.

- Decrease in congitive abilities
- Increase in confusion
- Decrease in ability to do tasks they once were able to accomplish

### *III. Emotional/affective*

*Emotional/affective* states may not be expressed in a manner others think of as "typical". Look for indicators of their true feelings, such as behavior and use of non verbal means to help express emotions.

## III. Emotional/affective



### Emotional/Affective

- Anxiety
- Hyperactivity
- Agitation
- Depression
- Sadness
- Distress

# *IV*. Physiological

- Have sleeping patterns changed?
- Have eating habits changed?
- Has there been an increase in complaints of pain or illness?

Stress from grief may suppress immune response and you may see an increase in sickness. You may see an increase in "somatic" complaints as well:

- Chest pains
- Headaches
- Stomachaches
- Dreams



# Words associated with death:

- Passed away
- Lost
- Turning up daisies
- Resting
- Asleep
- Gave up the ghost
- Gone

- These words and phrases are very confusing for people with I/DD!
- It is **NECESSARY** to use clear language such as: died, death, dying, etc. You are not being rude, you are being clear and honest.
- If the person cries, it is NOT due to the language, but the natural emotions of grief.
- Using clear language can actually HELP a person move toward the stage of acceptance.
  - It is refreshing (honest)
  - o It is affirming
  - o It is clear



# How to help

- **Be open and honest**. Its okay to use the words died, dying, dead, death.
- Important to be proactive with interventions/strategies as well.
- Work with the team Communicate! (Behavior clinician, spiritual support coordinator, direct support staff, guardians, therapists, psychiatrist) to provide the best level of care for the client.
- **Crying is okay:** allow a person to cry. Often we are taught to try and cheer a person up. But allowing a person to cry is a part of the process.

# How to help:

What NOT to say:

- "Everything will be okay": this does not validate the person's feelings, and right now, things do not feel okay.
- "It's God's will" or "it was for the best": it is up to the person grieving to figure out how they want to understand their loss.
- "Don't be sad/mad/worried, etc)": this completely de-validates these emotions that are completely natural and healthy.
- Stay away from any "fixer" language. "I know what will make you feel better..,"You do not have to fix them or their emotions. Its okay to have these feelings and it's a process that never really goes away.

### How to Help

#### What to say:

- "I'm here for you if you want to talk"
- "I am sorry"
- "I've been thinking of you"
- Affirm their thoughts/emotions (ie. "It sounds like you are feeling...")

- Listen to what they telling you with their works or actions
- Be willing to just sit with them and keep them company (if they want you to): you do NOT have to say anything
- Recognize that grief is a lifelong process: there are the initial feelings, but grief never goes away completely. It can arise days or even years later.
- Accept deity-talk (ie: God, creator, Allah): Death brings up many faith based beliefs. You don't have to agree, this is what THEY believe.





Wake, Funeral, Celebration of Life, or other ceremonies

- Prep a person let them know what to expect
- Dead body vs. live body "live bodies move, breathe, hearts beat, organs work, etc. Dead bodies do not move or breath, hearts don't beat, and organs don't work."
- What is going to happen next?
- State the truth and state it clearly. Clearly is not mean or brutal, it's the truth. The truth is calming and helps. Unknowns are scary and provoke anxiety.

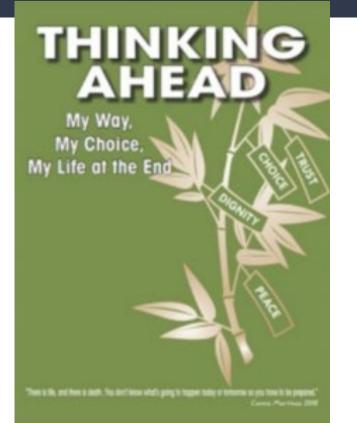
# A person has the RIGHT to grieve

A person has the RIGHT to decide how they want to die

Human Rights!

- Human rights: guardian or emancipated
  - Every person has the right to know what is going on with their body and their health
  - Learn about your states guardianship rules and a person's individual rights (where are the boundaries)
- Emancipated:
  - If a person with I/DD is their own guardian, often family, support agency, etc tend to try and make health decisions for the person – YOU CAN HELP PROTECT A PERSON'S RIGHTS
  - Informed Decision Making- some people may need to take extra time to learn about all possible options, what those options mean, consequences of those options, etc. before making an informed decision. - THIS IS A HUMAN RIGHT.

# End of Life Planning



- If a person doesn't have a WILL and/or an end of life plan. Help them write this out!
- You may be the only person willing to give them this opportunity and have this conversation.

# Planning

How can I help?

- Communication:
  - Assume Intelligence! YOU are likely the one that doesn't understand
  - Any communication tools?
    tablet, sign language, writing, speech, slow to respond, pictures, etc.
  - Choices using right or left hand to point/look to



#### Resources

Check in your communities: who offers grief counseling?

Make connections with your local Hospices:

They often host grief support groups

Have grief support resources

Sometimes have caregiver support group

Books:

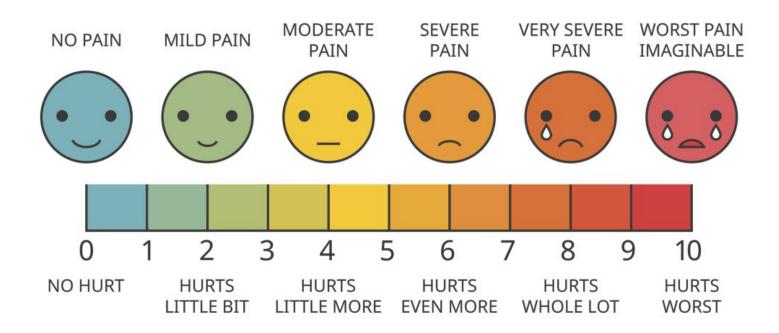
Spiritually Sensitive Caregiving: A Multi-Faith Handbook by Janice Harris Lord, Melissa Hook, Sharifa Alkhateeb, Sharon J. English

The Perfect Stranger's Guide to Funerals and Grieving Practices: A Guide to Etiquette in Other People's Religions Ceremonies Edited by Stuart M Matlins

Helping People with Developmental Disabilities Morn: Practical Rituals For Caregivers by Marc A. Markell, Ph.D.

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

## Pain scale



# Feelings Chart

#### **HOW DO YOU FEEL?** 11 00 36 0.0 happy confused anxious embarrassed angry 100 1000 6 frustrated excited content annoyed scared 10 100 and sick. disappointed silly confident



stressed

funny



247

100 Tax

tired

\* \*

· · · · ·

worried





loved.

-

insecure.





. .

hurt





guilty





. .

**lonely** 





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