>> Shelly Christensen: Welcome to the Seasons of Grief video series brought to you by the Religion and Spirituality Interest Network of the American Association on Intellectual and Developmental Disabilities. This series explores concepts of grief through the lens of disability, offering insights and free resources for individuals, caregivers, and communities. I'm Shelly Christensen, Senior Director of Faith and Spirituality at the disability-led nonprofit Disability Belongs™. Our mission is to fight stigmas and advance opportunities so people with disabilities can fully participate in all aspects of community. Disability Belongs™ has partnered with Karis Disability Services and Heritage Christian Services to make this video series possible.

>> Keith Dow: Hi, I'm Keith Dow, President of the AAIDD Religion and Spirituality Interest Network, and Manager of Organizational and Spiritual Life with Karis Disability Services. The Religion and Spirituality Interest Network celebrates the vital role of faith and spirituality in the lives of people with intellectual and developmental disabilities. The search for meaning and comfort during grief is universal, and everybody deserves supports, understanding, and the right to authentically express a range of emotions. Grief is deeply personal, and people with disabilities experience and process loss deeply, just like we all do. When grief is overlooked, it can lead to anxiety, depression, and emotional distress. This series explores how grief connects to meaning and spirituality, offering practical strategies for direct support professionals, service providers, faith leaders, and those supporting a loved one. You'll also hear from presenters of diverse faith and spiritual backgrounds sharing perspectives on grief, loss, and meaningful rituals or traditions that provide comfort.

>> Shelly Christensen: As a disclaimer, the information provided throughout this series is meant to be used practically to help remove barriers around talking about tough topics like grief. We are not grief counselors or providing any medical or mental health recommendations throughout the series. If you or a loved one needs further support, please seek professional support from licensed professionals. We want to thank everyone for being here.

>> Keith Dow: We're grateful to Karis Disability Services and Heritage Christian Services for sponsoring this series. Karis Disability Services' vision is that people with disabilities belong to communities in which their god-given gifts are valued and celebrated. And Heritage Christian Services fosters inclusive communities where all people are respected. Thank you for joining us. We hope the series offers guidance, encouragement, and meaningful ways to support people through grief and loss.

>> Jess Jankowski: Hello everyone, my name is Jess Jankowski. I'm a white young adult with short brown hair and glasses wearing a blue collared shirt. I use they/them pronouns. I am a licensed clinical social worker, and I work at JCFS Chicago. My presentation today is called Grief 101. I'll be talking to you about the basics of grief. We'll be looking at -- and answering several questions about grief, including things like what it is, what it looks like, and what to do about it. The first question I want us to think about and answer is "what is loss?" I bring loss up before grief, because grief happens as a result of loss. We can't talk about grief without talking about loss first. Loss is when something has changed and can't be changed back. Loss and grief are things that everyone experiences many times throughout their lives. It's important to note too that while loss and grief are universal, everybody experiences them a little bit differently. I think for many of us hearing the word loss, we might first think of a death -- a loved one has died and we have lost them. A death loss is certainly a loss, however, I also want us to keep in mind that a loss doesn't necessarily have to be because of a death. We experience loss in many ways. For example, some common non-death losses are a friend moving away, a change in physical or mental ability, being fired from a job, parents getting a divorce, getting a divorce ourselves, and many many more. These types of losses happen much more often than death losses. I said earlier that everyone experiences loss and grief a little bit differently. What's important to remember is that the size of a loss, or in other words how big the loss feels to someone, depends on the person experiencing it. For example let's think about the death of a family pet. Everyone in the family will be sad about the loss, but the loss might feel bigger to a family member who was closer to the pet than it feels to other family members. If someone experiences a loss and other people dismiss their feelings because the loss doesn't seem so bad to them, or because the loss is stigmatized, that person will experience what is called disenfranchised grief or unvalidated grief. It may be harder for the person to get support while they're grieving because either other people don't know about it, or other people don't think that the loss is a big deal. Some examples of losses that often lead to unvalidated grief are the death of a pet, a loved one dying of suicide or overdose, it's experiencing a miscarriage, or a loved one being diagnosed with something like dementia. So at this point you might be thinking, Jess, you said we were talking about loss, but you're starting to get into grief. And I hear you. So let's move on to a different question. What is grief? Grief is a normal natural process that occurs in response to a loss. It helps us adapt to and integrate the loss, or in other words -- grief helps us handle loss so that we can keep going. Grief is experienced differently depending on the circumstances of a loss and the resources that someone has to cope with it. There isn't clear end to grief – it's a dynamic ongoing adjustment to loss. I also want to be clear that we don't get over a loss, rather, we learn to live with it and most of us get better at living with a loss over time. Many of you may have heard people talk about stages of grief, and might be wondering why I haven't mentioned them yet. I wanted to share this graphic you'll see here while I talk about theories of grief -- in other words, how psychologists and other professionals think about and talk about grief. You'll see the left side of this graphic says "early theories of grief." Below that text is a u-shaped line with a few arrow heads on different parts of the line going in the same direction, down the left side of the u-shaped line and then back up the right side of the u-shaped line. Following the path of the arrow, there's text that reads "loss, shock, numbness, denial, overwhelming sadness, hopelessness, confusion, anger, panic, feeling low, loneliness, stress, continue with everyday tasks, difficulties readjusting, take on tasks from the person who died, do some social activities again, reinvest in life," and finally, "acceptance." The right side of the graphic says "the reality." Below that text are the same series of words as on the left in that u shape, but instead of a neat, u-shaped arrow of progression like on the left, the line here on the right is a big scribble. Early theories of grief discussed stages that people passed through until reaching acceptance. A famous one you may have heard of is Elisabeth Kübler-Ross' five stages of grief. Kübler-Ross created this model based on her work with terminally ill people and studying their grief process. Unfortunately, when taken out of context, her five stages model hasn't always been helpful when thinking about other types of loss. People were often judged or critiqued if they didn't go through these set stages or didn't go through them in the right order. People had a similar experience with other stage-oriented theories of grief. For those of us who have experienced loss, we know that grief isn't cut and dry. It's messy, it's surprising. One day you might feel all right and run some errands. The next day you might see an ad for toothpaste that somehow reminds you of your loss and requires you spend the day on the couch. One writer calls these surprises "grief landmines" – reminders of the loss that you don't necessarily think will trigger your grief. We now know that grief is a process where there's oscillation, officially called the dual process model. We go back and forth while grieving between tending to grief and tending to recalibration and restoration, in other words, tasks of grief. This brings us to the other prominent current grief theory called Worden's tasks of grief, the four tasks being accepting the reality of the loss, processing the pain of grief, adjusting to a world without the deceased, and helping the survivors to find an appropriate place for the deceased in their emotional life. The grief process is not the same for everyone, and there don't appear to be specific stages that everyone must go through. Instead, bereaved people show different patterns or trajectories of grief reactions across time. Here is another graphic I wanted to show you called "cartography of grief" which text you'll see across the top. It's drawn like a map. There's a heart-shaped outline which has waterways and landmarks on it. The waterways are labeled "river of love" and "waterfall of tears." Nearby is the "cave of safekeeping," "mountain of tissues," "beauty outlook," "republic of memory," "unexplored territories," "fog banks of the future," "hopes and fears railway," "library of meaning," "pockets of peace," "valley of the unexpected," and "grief landmines." The sea surrounding the heart also has a few points of interest, such as "I don't care a toll," a ship labeled "kindness" and "sea serpent of toxic positivity." I like this graphic a lot as a representation of grief, because as you'll notice, there are no stages. There's no path to follow. There's no definitive beginning or end. How you traverse the land, so to speak, and the sea of the cartography of grief is up to you. And different people will make their own ways. There's no reason you can't return to certain landmarks to visit, or stay in one place for a while. There's no correct way, in other words, to navigate through grief. This is all true to real life as well. What can grief look like? I've alluded to this a bit with the graphics that we've seen, and now I want to focus more directly on this question. While grief is a universal human experience, grief may look different from person to person. Grief can cause physiological changes, like changes in appetite, low energy, changes in sleep, suppressed immune response which can cause higher susceptibility to illness. Grief can cause emotional changes, like experiencing feelings of distress, guilt, despair, longing, sadness, anger, and anxiety. Grief can cause cognitive changes -- changes in how someone thinks, like problems with concentration and memory, preoccupation with the loss, and magical thinking, which is the belief that certain thoughts or actions can cause real world events, even when there's no logical connection. An example of magical thinking would be a person whose pet has died thinking, "if I had loved my pet better, if I had done xyz differently, my pet would still be with me." There are social aspects to grief. Someone might withdraw from friends and family. Someone else might focus on talking about their grief to others. People might engage in cultural practices related to loss and grief, and remembrance rituals. For a death loss, the grieving individual eventually returns to daily activities, but still maintains a symbolic attachment to the person who died. There can also be spiritual aspects to grief. Someone might turn to religion and spirituality for comfort during grief. Someone might question why a higher power would allow the loss to happen. In summary, grief can look like any combination of these things. Again, it varies person to person, and it's influenced by a person's supports and resources. Is there anything different if an individual has an intellectual or developmental disability when it comes to grief? The short answer is not really, but since we've got some time left, let me give you a longer answer. Why do some people think there's a difference in how people with IDD experience grief compared to people without IDD? Firstly, there are a lot of myths about people with IDD and grief. You may be aware of some of them, like the myth that people with IDD don't experience grief, people with IDD can't handle grief or it's too much for them, people with IDD need to be protected from loss and grief. The fact is that none of these are true. We culturally have a lot of discomfort around grief and loss. This can lead to using euphemisms when talking to people with IDD about grief. For example, saying somebody went to sleep instead of saying someone has died. This can also lead to avoiding the topic of loss and the person's emotions over it, withholding information from the individual, or trying to rush grief -- in other words, trying to make the person get over it faster. Another reason people might think people with IDD experience grief differently is due to something called diagnostic overshadowing. This is when people mistake symptoms of a mental health experience, like grief, for symptoms of someone's IDD. For example, let's say a person with IDD experiences the loss of a friendship. This person begins destroying their belongings. Their family members think that this new behavior might be because of the person's disability, when in fact, this new behavior is a sign that the person is grieving the loss of the friendship. Finally, communication differences have a huge impact on how people without IDD interpret people with IDD's experiences with grief and loss. Let's say a person with an IDD's parent dies. Staff notice that the person does not cry at their parent's funeral, and think that the person must not feel sad. This person begins spending most of their time in their day program drawing pictures of themselves with their deceased parent. This person is grieving the loss of their parent, but communicating it or expressing it in a way that support staff might not expect. What is the impact of these factors on people with IDD experiencing grief? Remember from a few slides ago that if grief isn't properly acknowledged, it becomes disenfranchised grief or unvalidated grief. For an individual with IDD whose support system, say, avoids talking about a loss, that individual experiences disenfranchised grief. Another way to think about this is the phrase "grief denied is grief delayed." Avoiding grief and related feelings does not mean that a person is protected from grief. It means that they'll experience it later on. When they do, the grieving process will be much more difficult and more prolonged than it might have been otherwise. It's also emotionally harmful for the grieving person. In summary, people with IDD don't experience grief differently from people without IDD. They simply may express or communicate it differently. It's important that they're given the supports and space to grieve losses like anyone else. How do I support a person who's grieving? It can be hard to know what to do to support someone who's grieving. We might easily fall into using cliches, which can actually feel bad for the grieving person, even if we have the best of intentions. Avoid statements like "you'll get through this," "just don't think about it," "everything happens for a reason," "they're in a better place," "be strong," and "I know exactly how you feel." Statements like this often feel really invalidating and unhelpful to someone who's grieving. Now that we've discussed what not to do, let's talk about what to do. Use phrases that are validating, like "I'm so sorry for your loss." Acknowledge that words don't feel like they're enough to convey sympathy and express support for the person. Like I said on the previous slide, it's hard to know what to say. Nothing we say is going to fix someone's grief, and it's okay to acknowledge that. Validate the person's feelings. "Of course you're sad right now," "it's okay to feel angry." Actively listen. This means listening to the person without planning what you'll say next and being present with them while they share their thoughts and feelings. Offer practical help. Sometimes a person who's grieving might not know what support they need. Offer to drop off meals, to run errands, to take care of pets. Provide suggestions or simply make an open offer, like "if you need help with anything, please text me. I'm happy to help however I can." When talking to someone about their loss, particularly a death loss, share your memories of the person who has died and encourage the grieving person to share their own, too. Finally, be accepting when someone refuses help, and continue to offer help in the months to come. Grief can be an intense and overwhelming process, and a grieving person might not initially be able to accept help. An incredibly common challenge that bereaved people talk about is that after the loss and a rush of support, think about a funeral, people offering help immediately after a loss, the rest of the world keeps going while they're still grieving months and years later. Check in regularly. This can make a huge difference for someone who might feel like they should be over it, or doesn't know how to ask for support months later. Continuing our conversation about support, I want to talk next about grief rituals, or in other words, tasks that someone performs individually or in community to process their grief. As mentioned on the last slide, asking about someone's memories of a deceased loved one can be helpful and healing. Additionally, engaging in creative arts like painting, writing, music, dance, sculpture, you name it, can be helpful for a grieving person to express and process their feelings in a different way. A client once shared with me that her day program created and performed a memorial play for a deceased participant. Another shared that they decorated the locker of a deceased classmate. Still another person told me about a personal ritual of writing a letter to his deceased parent and burying it in his garden. Another person continues to write stories about her deceased parent years after this parent's death. Someone might enjoy creating a memory book about a loss, making memory sharing into a tangible item that can be revisited. Giving people opportunities to grieve by creating spaces of remembrance can be helpful. One day program I know of holds a yearly event called "Blue Christmas" during which participants gather together to talk about and memorialize people they miss during the holidays. When supporting a grieving person, also check on cultural, spiritual, and religious rituals relevant to them. As a reminder, grief is a healthy and adaptive response to loss, not a disorder. This is from Harris, 2023. Most people who are grieving don't need professional help like psychotherapy or psychiatry. Grief is not meant to be treated. It's meant to be supported. When should I get professional help? Again, I want to emphasize that most grieving people get better on their own without any kind of professional help. As previously mentioned, the grief process, while it may be uncomfortable to experience and to watch another experience, is natural and normal. Rarely, someone may need to access professional help or treatment rather than supports. Treatment meaning, like, seeking psychiatric medications or formal psychotherapy, whereas supports meaning things like what we've talked about so far today, plus things like grief counseling or grief support groups which some find helpful. Again, most people don't require professional treatment for grief. It is important to seek professional help if new psychotic symptoms occur, if someone experiences new or increased suicidality or self-injurious behavior, or if the grief continues to be overwhelming or gets worse 6 months after the loss has occurred. Thank you for your time. Once again, I've been Jess Jankowski from JCFS Chicago. If you'd like to connect, feel free to contact me at JessJankowski@JCFS.org.