

# Episode 28: Part Two of an Interview with Margaret Gilbride

Summary Keywords: people, grief, loss, developmental disabilities, disability, resources, ritual, death, support, talk, tradition, chaplaincy

Speakers: Alex Schiwal, Margaret Gilbride, Tatiana Perilla

## **Alex Schiwal 00:00**

\*Music\* Hi, and welcome to the Mental Health Crossroads podcast, where we explore the intersection of mental health and developmental disabilities. This is part two of our interview with Margaret Gilbride from the Boggs Center. She talks about grief and loss in individuals with intellectual and developmental disabilities. Part one of her interview is available wherever you get your podcast, if you'd like to listen to that first. We hope you enjoy the second part of our conversation with Margaret. \*Music\*

## **Tatiana Perilla 00:36**

How can grief and loss affect different areas of life?

## **Margaret Gilbride 00:40**

Loss affects absolutely any area of our lives, whether we have a disability or not. Just naturally, moving through life, we experience multiple losses, good losses, bad losses, big losses, small losses. We experience them individually, we experience loss as we age of our own health, of our own mobility. There's lots of ways we experience loss through life, whether we have a disability or not. Those losses they do carry with them grief. They do sometimes inspire us to have natural grief reactions, such as those that I mentioned earlier including anger, confusion, sadness, physical distress, regression, and guilt. Many of us have the would'ves, the could'ves, the should'ves, for relationships that have changed and moved on, or for people who have changed and moved on totally out of our lives through death. It's impossible, I think, to just say, in this period of life, somebody will not experience loss or grief.

## **Margaret Gilbride 02:14**

I think the secret is for us to talk about it more, to acknowledge it more, to use teaching moments for anyone and all of our children, people with disabilities, kids with disabilities. It's the art of having goldfish and recognizing that when the goldfish dies, it doesn't come back. A lot of people think that if you have an intellectual or developmental disability, you can't understand death, for instance. There's really only two elements to understanding death. One, something or someone that was working, that was functional, that was alive, isn't anymore, isn't functional, isn't alive, isn't working. The body doesn't work anymore, just like a broken watch, or a broken mug, or glass. It can't be put back together, it's not going to work. That is

the one concept, something's broken and can't be fixed. The second concept is that it's forever, that it's not going to change. Those are two hard things for some people to understand. But I've never met anybody who was too intellectually or cognitively compromised, to be helped to understand those two concepts. Sometimes we think people aren't going to understand, or we think we're doing them a favor by not telling them of somebody's death or of a change that's going to happen that's out of their control. But people always prefer to have information, whether they have a disability or they don't have a disability.

**Tatiana Perilla 04:30**

You talked about how it can affect someone with their employment. Have you seen other situations where it's affecting other parts of their life, such as like maybe their school life or their social personal life?

**Margaret Gilbride 04:45**

Yes, people have lost residential placements, because of what was perceived as behavioral issues. Let me talk about one gentleman who almost lost his residential setting. He was a gentleman that was pretty well liked by everybody, never met anybody who he didn't get along with. He was held in high regard. He was a gentleman that was positive, happy-go-lucky. But what happened is, the way residential staff described it was, he became surly and negative, and nothing was good enough. He criticized everybody and everything, and it was constant. Truly, it became absolutely constant. It got to the point where nothing [was good enough], staff, his housemates, anybody at work, anybody in employment, at the day services, anybody at the Y, nothing. And if by chance, was good enough, the guy was just impossible. And people were like, 'Well, if he's this unhappy, we need to find another residential provider.' And they had actually talked to the support coordinator. They were getting everything in motion to make that happen.

**Margaret Gilbride 06:24**

As it turned out, the guy's birthday was coming and everybody decided they were going to do what they always do for everybody. Sing Happy Birthday, carry out the cake, and do all that for this gentleman. They carried out the cake, everybody sang. He took one look at the cake, and he became instantly angry, and he yelled about it. He actually knocked the plate, the cake went flying, the table went flying, and he yelled at the top of his voice, 'That's not right. Nothing has been right. Nothing, nothing, nothing. Nothing has been right since my mom died. And then he just broke down sobbing. He had not cried in months, and months, and months. He had not talked about his mother in months, and months, and months. He was the gentleman whose mom always made Boston Cream Pie instead of a birthday cake. When he saw the cake, it was the last straw. He didn't have the words to tell people what he was feeling, so it was coming out in his surliness, in his anger, in his negativity. One study recently showed that in 77% of the instances where a person with an intellectual or developmental disability suddenly changed in

their personality, and in their behaviors, had a marked significant change... In 77% of the instances, they had experienced the death of a significant loved one, within 16 months prior.

### **Margaret Gilbride 08:18**

This gentleman had gone to the funeral for his mom, he was involved, he did know she was deceased. But after everything, essentially, the ritual was over. He didn't have a vehicle to talk about, to process, all those emotions and what he was feeling about the loss of his mom. After this incident, with the birthday cake and the sobbing, and staff realizing what the situation was, he was able to get some grief counseling. They hung more pictures of his mom. Initially, the pictures were causing him to cry so they didn't have out a lot of pictures and mementos. But what oftentimes happens with many of us is, the very things that initially make it harder to process our loss are the very things that bring us comfort a little later. So for this gentleman, to bring out some of the pictures of his mom, and doing the things that they loved to do together, and setting up a little spot in his room where that could be, it really helped him talk, process and move through that grief. But that was a gentleman that almost lost his residential setting.

### **Margaret Gilbride 09:39**

I've had people that when staff or family did talk to them, out of kindness they used euphemisms or nice expressions. We need to be very careful when we're talking with a number of people with intellectual and developmental disabilities, that we use very concrete and precise language. For instance, the gentleman that almost got kicked out of school, he was doing absolutely everything he knew he wasn't supposed to do. All of a sudden, he's pulling fire alarms. He is knocking people over in the hallway, he's stealing things out of the faculty room. Now, by this time, he was about 20. He was in his last year of high school eligibility. And he'd never done any of these things before. And the school was beside themselves. He was about to get suspended. Then it dawned on... I don't even remember, to be honest, who it dawned on. But what had happened was, this young man's sister had died and in their faith tradition they believe in heaven, and they talked about angels. What was explained to this young man was that his sister was so good, that she was too good for this world, and Jesus wanted her with him because of her goodness. That was supposed to bring comfort, and for the people in the family who had that faith tradition, who understood that, it did bring comfort to them. But what this young man heard was, 'if you're really good, Jesus is gonna want you.' So he did everything he could think of to be bad, so that Jesus wouldn't want him.

### **Margaret Gilbride 11:51**

One of the things we need to be careful of... That do lead to sometimes behavioral communication, that we see as negative adjustment, which is actually really good communication. It's the direct result of using, if you will, bad language. Things like grandma didn't suffer, she went to sleep and she didn't wake up. I've seen that lead to people refusing to go to bed, doing anything to stay awake, because they think that that will cause their death. When we use language, when we're talking to people, we want to use concrete words. We

want to avoid euphemisms, even to say that somebody has passed, instead of saying somebody has died, it doesn't work. If we say somebody went to heaven, sometimes people believe that's like saying Judy went to Cincinnati. What's the difference between Cincinnati and heaven? They assume that if somebody went there, they're coming back. So we do need to watch our language, because it does lead to people not understanding. People can't voice their lack of understanding, so that gets translated into what we call behaviors. Those behaviors translate into job losses, residential losses, school losses, suspensions, across the board.

**Tatiana Perilla 13:24**

So I have a question that is a little bit vague, though. It sounds like depending on the individual and how it happened, there's a lot of factors that maybe some people respond to some forms of support better than others. But just in general, if someone is listening to this, and they're wondering, how and when should I start preparing? Like if someone's about to experience a loss, and there's going to be changes in supports and routines. Do you have any sort of general recommendations or things for them to keep in mind?

**Margaret Gilbride 13:57**

What's most important is to know the individual, him or herself, that you support and what works or what doesn't work. We all know some people that anticipation is hard because they don't necessarily have a good grasp on time. So if we say this is going to happen in the future, the future is too ambiguous, it's too abstract of a concept. We can begin with tv shows with earliest recognitions of people who are ill, or people who are dying, or of losses, or you know somebody's going to be graduating, or going to be doing this or going to be experiencing any kind of loss, you can be with the person, anticipate it, prepare him. We use social stories, talk about other people who go through change, be there to support the person. You have to know the individual, him or herself, and what the change is going to be.

**Margaret Gilbride 15:08**

But a lot of people, that 15%, are left out of wakes or funerals or whatever acknowledgement ritual that a family has. One of the reasons given is that the family doesn't think the person will have the supports they need because the family members themselves, who are in grief, can't trust themselves to be fully present. But we as providers of service, that shouldn't be a fear that family have. We should be able to learn what the ritual is going to be, what is going to be expected, walk the individual we support through it, prepare them, support them, and be there. It's really not more complicated than that. Some of the resources that I can share with you later, or tell you about later, that people can access... There's a number of things that can help unlock what's being communicated by some behaviors. They're at least worth a try if they are grief related.

**Tatiana Perilla 16:22**

I was gonna ask you about the resources, like if just off the top of your head there's a couple that you would recommend for someone experiencing grief and loss? What would those be?

**Margaret Gilbride 16:32**

My shameless plug would be, I work at the Boggs Center and there are four things that I have on there that are good resources. One of them is actually a resource about resources. If you don't want to go to the resource about resources, there is a book by Mark Markell, that I highly recommend, that's called *Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers*. There are a number of resources and books. But if you do go to the Boggs Center website, the one that I'm referring to is called *Resources: Intellectual/Developmental Disabilities, and Grief, Death and Dying*. That resource guide also has a section on resources specific to planning for the death of a person with disabilities, or the death of someone a person with disability loves. There's a resource there called *Responding to Grief Reactions of People with Intellectual and Developmental Disabilities*. I think that would be most helpful to a number of folks listening to this, because it's essentially two columns. On the left is the situation or the behavioral communication, the grief drama that you might be observing. And then to the right of each of those, are strategies to assist the person in processing whatever might be leading to that. There's a handout called *Ritualizing Grief with People with Intellectual and Developmental Disabilities (IDD)*. It tells you how to plan a ritual, it gives you suggestions on symbolic items or gestures, objects that you can use in a ritual that really help people with IDD in their expression. And then there's just a simple handout for helping people process grief. Based on a person's age, based on their experience, based on their loss history, different tools will be needed at different times, if that makes sense.

**Tatiana Perilla 18:50**

I think that makes sense. That was awesome. Thanks for listing those. We'll see if we can put some of them in the show notes. My very last question for you is, if someone's interested in working in this topic area, but they're not sure where to start, what would your advice be to them? And how can they learn more?

**Margaret Gilbride 19:07**

There's always tons and tons of resources. For general death education, it's called ADEC, the Association of Death Educators and Counselors. They're the ones that typically certify people in death education as a certifying body. But there's also a number of schools and colleges that you can approach. There's Hospice of the United States or Hospice In Your State. They have great educational programs, and they have lots of resources. There's an association called Good Grief that is filled with resources. Whatever your faith tradition might be, there's often grief and loss groups specific to somebody's faith tradition. They might be able to guide you as well if this was an area you wanted to get involved in. But hospital chaplaincy, there are two national organizations, but there's also hospital chaplaincy or pastoral- you work with people in hospice or palliative care oftentimes. Some folks go through their faith tradition for that. I did not do that, I went through hospital chaplaincy. Because it was nondenominational. Essentially, you work in a hospital, you work with families, you learn about all the different faith traditions and non faith traditions. There are ways to assist people if they do not have a faith tradition, that

are just as important to exercise. So those are some resources that people could explore. If they're at a university setting, there's a number of UCEDDs, University Centers for Excellence on Disabilities, every state has to have one, I happen to work at New Jersey's, but very often these UCEDDs could direct you to a special interest group on aging that includes grief and loss.

**Tatiana Perilla 21:31**

Thanks. Those are great points and directions to point people in to learn more about it. I've really appreciated talking with you today. Is there anything that you wanted to add before we finish?

**Margaret Gilbride 21:42**

I would just like for people to build an awareness that they're in very powerful positions to support people through multiple experiences of loss. To acknowledge the significance of losses in their lives is huge, to be willing to be a compassionate person who sits with people in their pain. If we could get more folks like that in the field and out of the field, who will sit with people and assist them, listen to them as they process their pain, and however that looks, it would go a long way in healing folks with and without labels.

**Tatiana Perilla 22:24**

Thank you, Margaret.

**Alex Schiwal 22:25**

\*Music\* Thank you for listening to this episode of the Mental Health Crossroads podcast. We hope you enjoyed it. All of the resources mentioned by Margaret in this episode are linked in the show notes. You can also find more resources and trainings at [mhddcenter.org](http://mhddcenter.org). And you can follow us on social media @MHDDcenter. Thanks for listening. \*Music\*