

Episode 27: Part One of an Interview with Margaret Gilbride

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Speakers: Alex Schiwal, Margaret Gilbride, Tatiana Perilla

Alex Schiwal 00:00

Music Hi, and welcome to the MHDD Crossroads podcast where we explore the intersection of mental health and developmental disabilities. In this two part series, we interview Margaret Gilbride from the Boggs Center at Rutgers University. She talks to us about grief and loss and populations of people with intellectual and developmental disabilities. Watch for part two, two weeks from the publication of this first episode. We hope you enjoy. Thank you for listening.

Music

Tatiana Perilla 00:38

Hi, everyone. Thanks for joining us on the Mental Health Crossroads podcast. Today I'm joined by Margaret Gilbride, who graduated from the Indiana University of Law and is a Certified Thanatologist. Thanatology is the study of death, dying and its associated losses and mechanisms of coping. Margaret is currently the Director of Transition, Employment, and Aging and Disability at the Boggs Center on Developmental Disabilities at Rutgers University. To start off, Margaret, can you tell our listeners a little bit more about yourself and your other professional roles?

Margaret Gilbride 01:11

My other professional roles, as if they haven't already heard a long list. I have a little over 30 years of experience in the disability field, primarily around employment of people with the most significant intellectual and developmental disabilities. But I've also dipped my toe into residential services, day services, respite. In addition, I am a death and grief educator. I also work as a hospital chaplain, and sit on a number of bioethics committees for area hospitals and health services, and have been on end of life advisory councils for the governor of New Jersey and others.

Tatiana Perilla 02:01

Wow. So it sounds like you've done a lot. I'm excited you're going to talk to us about this topic. Do you mind me asking you what led you to specialize in grief and loss? And how did you end up doing this work with individuals with intellectual and developmental disabilities?

Margaret Gilbride 02:18

As with so many other things in my life, I somehow just fell into it. I was touring Cincinnati Children's Hospital, Project SEARCH their site, and I was looking forward to seeing the work being done by one of their employees who has Down syndrome. Her position is incredibly complex. I really wanted to see her in action and get a sense of the work that she was doing. But prior to being able to tour her division in the hospital, her job coach explained that we would not be going by to visit that particular worker. The reason was because she was actually nearing about the 10th anniversary of her mother's death. The job coach explained that, predictably, around that anniversary time, this particular employee was more easily distracted, more easily taken off task, and her accuracy in her work could fail. And so, as part of the increased supports around the anniversary time for her mom's death, it was just advised that she should not be distracted further by tours and such.

Margaret Gilbride 03:40

But as the job coach was explaining about this particular worker's situation, I had an epiphany moment. I think, in part, the reason I had that epiphany was because it was only then, at my point in life experience, that I had experienced the death of a parent. As the person speaking was describing the employee with the disability's reaction to grief and how it affected her work performance, I had a thought about all the other people with intellectual and developmental disabilities with whom I've worked. Periodically, we could predict when they would need more work supports *inaudible* but never quite could identify why. It got me thinking, the combination of the pattern of support needs with my own hard learned knowledge of grief, and the reality of death and loss, and what that looks like and feels like in a person, that it piqued my interest to begin doing more research around loss and around grief and how it manifests in folks. Then, in particular, how it manifests in people with intellectual and developmental disabilities.

Tatiana Perilla 05:03

Thank you, that actually leaves me with a couple questions. First, though, I just want to ask, I noticed that you say grief and loss. Do you mind explaining why that is, and if there's different types of loss?

Margaret Gilbride 05:17

As I started to really think about anybody's life, because it's not a disability issue, per se, we talk about death a lot. And we assume that death is the only loss that people grieve. But the way I think about it, death is the ultimate paradigm for loss and for grief. But if you look back and you think about any significant life change, you've had, even the positive ones, like job promotions, or moving from one state to another, or a marriage, any kind of major change tends to involve a loss. You're moving from the familiar to the unfamiliar. Unfamiliar, you're leaving behind that which is known to venture forth into the unknown. But when you start really thinking about the kinds of things we lose in life, whether we have a disability label or not, we might lose our jobs, lose our homes, lose trust in other people, we might lose our way, lose our confidence. There

are so many losses that we incur during the course of a lifetime. As matter of fact, if you think about it, it's why very often culturally, we have ceremonies or rituals that acknowledge life changes. You do have a ceremony for your wedding, where tons of people come and they celebrate that, or you do have a graduation ceremony, where you do have a bat mitzvah or a baptism, any kind of rite or ritual, a housewarming party even, to acknowledge the significance of a life change.

Margaret Gilbride 07:12

When we start looking at losses, and the fact that any kind of change or significant loss is a stress period, we start to think about how many losses people with intellectual and developmental disabilities incur that, in fact, are never acknowledged and never respected. Losses in their residential settings, in their friendships, in their jobs, in their day services. We move people from one residential setting to another, oftentimes, with little input from them, driven oftentimes by funding issues. But we don't give people the opportunity to say goodbye, we don't acknowledge the difference in their life, from one day to the next. If you just look at the turnover rate, people who are intimately and significantly involved in people's lives come and go at an average rate of 45% to as much as 82% turnover within a year. So folks with disabilities, they experience loss frequently. They experience significant losses at the same time, oftentimes, and they experience losses that in themselves have significant, what's called, secondary losses. And it's a lot to process and incur and adapt to, particularly in people for whom adaptation is not often a natural trait that they have.

Tatiana Perilla 08:59

That was a great answer. I think you explained it really well. It does sound like an abrupt transition, and especially harder if you're not prepared for it at all. And I think you're right with those turnover settings. We don't always let people know ahead of time that their staff is going to change or their caregiver is going to change. Would you say some individuals with intellectual or developmental disabilities communicate their grief or loss differently than if someone does not have a disability?

Margaret Gilbride 09:29

Most definitely, oftentimes. I just wish to be clear that loss is the experience. Grief is the reaction or the feelings about those losses. People with disabilities, intellectual and otherwise, and people without disabilities, we all have similarities in the losses we experience, in the grief that those losses engender in us, in the fact that there are certain things that we need to do to healthfully move past them. Part of it is to acknowledge the significance of the event, to feel the feelings, to take those feelings and sit with them initially, but then eventually channel them into positive directions. These are real typical things where people with disabilities oftentimes have differences from their peers without disabilities when it comes to processing loss and experiencing grief. Very often, they're disenfranchised grievers. The significance of the event isn't acknowledged. The pain isn't acknowledged. We see change so often in the lives of people

with disabilities, that it's become routine. We have a tendency to routinize it to the degree that we don't even recognize it. As a job coach, for instance, somebody would lose their job and the typical reaction would be, 'That's okay, we'll find you another job. Come on, we'll help you look for a job that you like even better.' Without a true acknowledgement that there were meaningful relationships, that there was an identity, that there was a certain sense of competency. All of those things lost, when that job went away.

Tatiana Perilla 11:37

I feel like you touched on this a little bit when you were talking about the individual you met and how it was affecting her employment. Can you elaborate on how grief and loss can affect an individual's mental health?

Margaret Gilbride 11:53

Absolutely. Loss and the grief that it engenders in itself can lead to what are called natural grief reactions. Those include things that we're familiar with, like anger, confusion, the inability to think clearly, regression is often a natural grief reaction, somatic distress, actually getting ill as a result of loss of sleep, the confusion, the stress around loss. There's typical sadness. There's even depression, these are all typical grief reactions, that we would consider, for lack of a better word, normal grief reactions. For people with intellectual and developmental disabilities, they can experience what's called complex or complicated grief. As a result of not processing the losses, not feeling the feelings, not having them acknowledged by people outside, not ritualizing the ability to say, 'This is what was. This person was in my life. This person is no longer in my life. This place where I went to school and had friends was important to me. That phase of my life is gone. I need to move into a new phase.' By not doing those kinds of things and not allowing people to process the change and feel supported in the change, we essentially contribute to unhealthy grieving or complicated, complex grieving that really can exacerbate into mental health issues above and beyond what is typical depression or situational sadness.

Margaret Gilbride 14:00

People with intellectual and developmental disabilities can feel the intensity of initial grief that fades or shifts in the typical population in three to five years. People with IDD can be feeling that kind of grief, the intensity of the newness of it, 10 to 15 years later than the initial loss. Part of that is because if it's a significant loss that's not acknowledged, the person carries that. In addition to that loss, every other loss accumulates, the feelings of grief build. Whenever we experience a significant loss, with or without a disability label, we are reexperiencing to a degree the previous losses and the previous grief feelings that we've had. For those of us that have more resources available to us, more counseling available to us, more support structures in meaningful relationships available to us, more language available to us- We're talking about folks with intellectual and developmental disabilities who oftentimes do not have the language with which they can process and express the feelings that they have, so those feelings build up. Oftentimes, they build up to the point that folks communicate in the only way they truly have

available to them, through grief drama. What I would see as grief drama, what somebody else might see as behavioral outbursts, increased compulsivity, anger directed at either themselves or at others, outbursts, feeling the need to control absolutely anyone or anything over which they think they can have any kind of control. Some people might begin to become more clingy, other people might begin to withdraw. A lot of people end up on behavioral plans or with negative reputations, as a direct result of long term grief reactions that have accumulated through a lifetime of unacknowledged, unresolved, unaddressed loss and grief.

Tatiana Perilla 16:42

As you were describing all the ways that it can affect someone's mental health and the very lasting impact it can have up to 10-15 years later, it made me realize that I don't think everyone always realizes how much their response can play an effect on somebody. Maybe sometimes we're minimizing without meaning to be. Is there-

Margaret Gilbride 17:07

I'm sorry, I just wanted to... I would have to say the biggest difference between how people with intellectual and developmental disabilities oftentimes experience loss and grief and those who do not have intellectual and developmental disabilities, has nothing to do with the individuals themselves and everything to do with how they are treated. Having an intellectual or developmental disability is certainly not the same as having an emotional disability. Right now, research shows, and it's remained steady over the years, that about 15% of all people with intellectual and developmental disabilities are left out of any kind of grief ritual that is held for somebody who is important to them: a mother, a father, a sibling. 15% of the times, the person with the disability is not included. They're not told about the death. They're not told about the rites and rituals. They don't get to gather in community and acknowledge the significance of what has changed in their life.

Margaret Gilbride 18:34

If somebody with an intellectual disability has visited with their parent, let's just say they don't even live at home anymore which is that they're living in a residential setting, but once a week they go home or they go to Dairy Queen. They have a meal with their parents, and then all of a sudden that stops. Most people with intellectual and developmental disabilities do what really any of us would do. If a significant person in our life suddenly started not showing up, they think they did something wrong. They think that the person has just left. They begin to fill in the blanks of noninformation. It tends to turn into feelings of abandonment. If somebody you love ceases to come and see you, and nobody ever explains to you what has transpired, what are you left to think but that you're not worthy. You've been abandoned. You did something wrong. You can't make it up to the person. These are the things that contribute to poor mental health, to stress, to people not being able to process what's going on in their lives. It's what leads to people becoming what we tend to think of as non-compliant, or people who elope.

Margaret Gilbride 20:16

Oftentimes, we're thinking people are trying to elope from their day services. When I've worked with people that started to run away, it was like they were running towards something not away from something. They were trying to get back to their familial home to find out why their dad was not visiting them anymore. This one person I'm thinking of, her dad used to pick her up every Friday from the day program. They would go to Steak and Shake, and they would have a lovely meal. Then he'd bring her by their parental home and she would get to see her mom who had health issues and couldn't really leave the house. But then one day, the father died. And nobody told this young woman. In her mind, he just stopped showing up. Unfortunately, he died about three weeks after he had had to make the decision to move his wife into a nursing home in the Alzheimer's unit. He had not yet told his daughter with a disability that his wife had moved. This young girl, about eight months after his death, she was about to be kicked out of her day program because she kept, in their words, eloping. It was because the day program was about six blocks from the home she grew up in. She was hoping she could run home, find her way, and talk to her parents and find out what she had done wrong that they weren't visiting her anymore and that she couldn't go home and visit them. A lot of times when we think we're being kind to people by sparing them, by not telling them about a loved one's death, in fact, we're doing them far more harm.

Tatiana Perilla 22:26

Yeah, I can see how people might think it's also uncomfortable to have that conversation, but I think it's like you said, you're doing a lot more harm by not telling them. And those behaviors and those emotions, that's exactly, what I'd expect. It sounds like a natural reaction when you're just left in the dark about what happened. How would you say that families and friends can better support people with intellectual and developmental disabilities who are experiencing grief and loss?

Margaret Gilbride 22:54

Part of it is to understand that as humans, we all experience loss, we all experience grief. The one thing that actually sets humans apart from some of the other animals, who many of whom also grieve the death of a loved one, is that we can also grieve in anticipation of something. We already begin grieving- if you think about somebody you care about who is out driving and it's horrible, terrible weather. And they were supposed to get to your home at about 9:00. By 10:30, you're already calling all of the police. You've got in your mind every horrible, terrible bad thing that could have happened to that individual. That's anticipatory grief. That's anticipatory stress. That's anticipating worst case scenario. That's kind of unique to us. So when we think about supporting people with intellectual and developmental disabilities, we should support them in getting the information they need before a change, before a loss, before a death to really explain in as clear and concise a way as possible what to expect, what's happening. Allow them to have the information and process the information, with our support. In the anticipation, we should do this. Through the experience, we should do it. We talk to the

person, we acknowledge the significance. We actually can put words to the feelings. We can model. We can say, 'I feel sad, because...' or 'I miss...' Sometimes we can provide the words.

Margaret Gilbride 24:55

There's also many other strategies. For folks that are older who have had a life's accumulation of unacknowledged losses, there are many different strategies that we can do. Some involve different rituals. By ritual, I mean, as simple as at a holiday having an empty chair, or toasting people who aren't there, or talking about the qualities that you miss in somebody. These are all things that we can easily do to support folks. There's tons of resources that are available. The biggest thing is to listen, to acknowledge the significance of something that has changed, and to provide people the opportunity to identify their feelings whether that's by symbolic gesture, by color, by assisting them with words, and moving them through.

Margaret Gilbride 26:04

One of the popular myths of our culture is that grief is something you actually move through and get over or that loss is something you get over. In fact, it does damage to the typical population thinking that way, as well as the folks that we support who have intellectual and developmental disabilities (IDD). For instance, in our culture, we have a tendency to think there's a right way to grieve when there isn't. It's as individual and as culturally and as *inaudible* and as experientially defined for each person, person to person. But when we start talking about timelines... The intense grief, it does tend to fade in the typical population. But it takes almost three years, three to five years, depending on the relationship, the nature of the relationship, for that to truly begin to fade. And there's differences between was it a loss or death? Was it a violent death? Was it an expected death? Is there grief? Unresolved words said? Is there guilt feelings? There's lots of things that can play into the typical person and the person with IDD in that timeline for the intense feelings of loss.

Margaret Gilbride 27:45

Part of the theory as to why people with IDD might experience loss and the intensity of it longer is because, particularly when it comes to significant relationships... For many people, the number of significant people in their lives with whom they do fun things, go camping, go to restaurants, experience joy, feel totally loved and supported [by] that number of people tends to be smaller for the population that we're talking about than for their typical age peers. A loss of a parent or grandparent is difficult for anybody, but if that parent was also your confidant, your bridge to socializing, your source of transportation, your financial bolster, if that person is intrinsically involved in your life and that person is done then it's a natural reaction to be uncertain. Who was going to do this? Who will love me? Who will know that I like Boston cream pie for my birthday instead of a traditional birthday cake? Who knows my history? Who will love me unconditionally? When you have less people of that importance in your life and you lose them, it is that much more significant than if you have a host of healthy, really involved people in your life who you know will champion you.

Alex Schiwal 29:46

Music Thank you for listening to this episode of the MHDD Crossroads podcast. We hope you enjoyed it. Watch for part two of our interview with Margaret coming out in two weeks. If you want more resources, please visit our website at mhddcenter.org, follow us on social media @mhddcenter, and check out our show notes. Thanks for listening. *Music*