

## **GRIEF IN THE SHADOWS: EXPLORING LOSS AND BEREAVEMENT IN PEOPLE WITH DEVELOPMENTAL DISABILITIES**

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*A greater understanding of how developmentally disabled people cope with loss and bereavement is needed to improve assessment and intervention for these individuals. Misconceptions exist about how effectively developmentally disabled persons can articulate their perceptions and feelings about traumatic experiences, death, and the subsequent impact of the events that follow. The lived experience and expression of grief may differ for the developmentally disabled population. As a result, their reactions may not be adequately recognized, interpreted, or managed therapeutically, compounding their distress. Three case reports of developmentally disabled individuals who experienced a loss are presented, along with helpful guidelines regarding assessment and intervention.*

Like all individuals, those with developmental disability are not immune to loss and may have losses that only they will have to face. Some people with disabilities cannot verbalize their thoughts or feelings completely, which makes discovery about traumatic events even more

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difficult (Focht-New, 1996). As a result, it is not uncommon for health care providers, parents, or other primary caretakers to assume that people with developmental disabilities do not “really” understand the concept of death or its subsequent impact (Moddia & Chung, 1995; Read, 2001).

Determining the cause of behavior changes and presenting symptoms in a person with absent or limited communication skills can be confusing and difficult (Focht-New, 1996). Additionally, some people with developmental disabilities may not grieve immediately or in the same way as expected by others. Because of limited communication skills, their reactions may not be noticeable or even interpreted as grief responses. As a result, grief may not be recognized, addressed, or promoted, creating yet another loss. In essence, the individual may be left to grieve in the shadow of the loss and in the darkness of the lack of education, support, and guidance.

Loss is at the root of many experiences for all people and can resemble an emotional wave that disrupts daily life routines and functions (Clements & Henry, 2001; Clements et al., 2003). People with developmental disabilities may have cumulative losses, beginning with others’ perceptions of their value. Therefore, the death of a loved one may compound the interpretation of and response to the loss, as it is piled atop a lifetime of losses and devaluing experiences. “For many years, people with a disability have had forgotten deaths, forgotten grief and have often become forgotten people when it comes to meaningful support over the death of a loved one” (Read, 1997, p. 5). Often, in apprehension of eliciting disturbing behaviors and unpredictable reactions, it is more common for people with developmental disabilities not to be informed of the death of a loved one in a timely manner. In turn, they may receive minimal, if any, support, guidance, or promotion of grief and may not even be permitted to attend the funeral of a loved one for fear that it “might upset them” (Crick, 1988).

There is a paucity of scholarly literature on grief and bereavement in people with developmental disabilities as well as on clinical anecdotes and strategies for intervention. Subsequently, there is most likely frequent misinterpretation of atypical behaviors that are not recognized as normal grief responses in the developmentally disabled. These seemingly “senseless behaviors” might be disturbing to health care providers and may result in the provider’s failing to identify pathological grief, leading to additional developmental and emotional disruption and derailment (Clements, 2004).

This article explores the underlying factors of loss, grief, and bereavement and examines how they relate to assessment, understanding, and intervention in developmentally delayed individuals.

The following are three case reports that illustrate the importance of communication, support, and guidance when a person with a developmental disability experiences a loss.

### **CASE 1**

James is a 36-year-old man with moderate mental retardation. He is able to communicate most of his needs and desires verbally, although his vocabulary is limited. Two months ago, James moved from his family's home into a community living arrangement with one other man. He recently had a physical examination, during which the physician discovered an arrhythmia believed to be an iatrogenic effect of a medication prescribed by the psychiatrist. On the way home, James told the staff person that he did not want to go to sleep that night. That afternoon, James attended a biweekly problem-solving support group. With further exploration and encouragement, James was able to communicate to the staff that his grandmother died of a heart attack in her sleep two years earlier and now James was afraid that the same thing would happen to him, that perhaps going to sleep would mean never waking to face another day. Interventions included helping James to understand that his medical problem was different from his grandmother's, that the psychiatrist would specifically evaluate the medication in two days, and that the staff was available for James so that he could explore and express his increased anxiety. Staff availability was important in promoting adaptive coping.

With assessment and evaluation, it became clear that James did not initially receive enough information about his grandmother's death, nor was he able to express worries about his own death after that time because of his limited vocabulary and intellectual disability. He also did not understand the nature of his diagnosis, which is not uncommon when a person's ability to understand is not taken into account and information is shared directly and solely with the caretaker. This creates the potential for a significant knowledge deficit for the developmentally disabled individual when, in contrast, a simple straightforward explanation, perhaps using pictures, might clarify for clients what they need to know and reduce the resulting worry.

### **CASE 2**

Sabrina is a 46-year-old woman who lives in a community residence with several people with varying levels of intellectual disabilities. Sabrina's diagnosis is mild mental retardation, and she is able to clearly articulate most of what she thinks. Her mother was diagnosed with a

debilitating disease when Sabrina was very young. As a result, Sabrina went to live with her grandmother until she moved to the community where she currently lives.

Three years ago, Sabrina's grandmother died. Recently, Sabrina required additional assessment and planning to address multiple issues. During the development of a therapeutic relationship, it became evident that there were issues most important to Sabrina to work on initially. A housemate was often up at night, and Sabrina could not sleep, wondering if he would come into her bedroom. In addition, there were children in the house who sometimes cried at night, and this bothered Sabrina. As a result, a move was imminent to another home within the community. Addressing the aspects of transitioning was a priority. Over the next six months, Sabrina would periodically begin to talk about her grandmother's death and become withdrawn. On the anniversary of her grandmother's death, she finally broke down and, while sobbing, revealed that she had thrown away a photo of her grandmother because it was too painful to keep it in her room.

Sabrina did not understand or accept that what she was experiencing was common to most people who are grieving. Her grief was postponed by the difficulty she had accepting and experiencing her feelings. This situation was perpetuated when other people dismissed the possibility of feelings about such things in a person with mental retardation. In addition, many developmentally disabled people have a limited number of friends, if any, with whom they can discuss personal struggles.

It was determined that the primary goal for adaptive coping and effective grieving was to communicate and promote the normal grief responses and affective disturbances that are common to most other people. Once accomplished, Sabrina would be encouraged to explore and express her feelings surrounding the loss of her grandmother within a framework of support and guidance. Both her grandmother's death and her mother's ongoing illness needed to be focused on and explored during therapeutic interactions. One method used to promote this exploration was the reading together of a book about grief and loss.

Initially, exploration was slow and painful for Sabrina, resulting in avoidant and affectively charged response patterns. However, she demonstrated the intrapsychic flexibility to express compassion and understanding for other people's losses. Using the book allowed for a transition from relating what was read about other's experiences to Sabrina's own experience and feelings. The change in Sabrina was slow; however, effectiveness was noted, as every week Sabrina is certain to remind the counselor to bring the book for the next therapeutic session.

### **CASE 3**

Jose is a 9-year-old boy with mild mental retardation. His grandparents, with whom he had always lived and called Mom and Daddy, brought him in for psychological assessment and therapy. He was displaying oppositional and verbally aggressive behaviors related to the anticipated loss of his Daddy, who was in the last stages of hepatitis C liver disease. Jose and his family had known for a long time that Daddy's illness was terminal, but Jose continued to emphatically deny that his Daddy would die and refused to discuss the issue. As his Daddy's death became imminent, the boy insisted that if his Daddy was going to die, so would he.

On assessment and examination, it was clear that Jose had no realistic or viable plan for suicide; he just wanted so much to go with his Daddy. After his Daddy's death and subsequent funeral, Jose wrapped himself in his Daddy's robe, slept in his bed, and stated that his Daddy talked to him, telling him to take care of everybody after he was gone and that it was now "Jose's job." In this manner, Jose articulated a desire to remain close to the memory of his Daddy and displayed an alliance in character and conscientious loyalty by "taking care of everybody." Although Jose would cry and talk about his Daddy at home, he initially avoided the painful feelings of grief and loss in session, preferring to play with army men and wage wars inside a toy house. This play may have been representative of his own battle within to address his difficult and painful feelings. His mother was encouraged to remain supportive and patient with his crying until he was able to trust that he could express these feelings with his therapist.

Although Jose has been able to lay his Daddy's robe aside and he no longer hears his Daddy's voice or wants to join him in death, he still struggles with wanting to sleep in his bed. It is anticipated that progress will remain slow, with occasional reworking of the feelings of loss surrounding his Daddy and his death.

### **COMMON LOSSES AND RESULTS**

These cases provide only a glimpse into the myriad universal and unique losses that regularly appear in the lives of individuals with developmental disabilities.

A diagnosis of a developmental disability in infancy and early childhood has a profound effect on the family unit, often changing the pattern of their lives. Family grieving may begin with the diagnosis or prior to this event, when parents suspect their child is not meeting normal

developmental milestones. Their emotions can potentially be communicated to the child through interrupted bonding, which can cause yet another layer of loss and guilt at being an imperfect parent. If this is their firstborn, parents may struggle over whether to ever have another child, and some determine they cannot handle the uncertainty of possibly having another child with a developmental disability. If there are other children in the family, their needs are often usurped by the needs of the child with the developmental disability, possibly creating jealousy and feelings of neglect.

Often, the diagnosis requires medical and psychological testing. This may introduce the child to the medical model, in which the health care provider may view the child with developmental disabilities through a distorted lens of flaws and deficits. This can be communicated through the quality of the parents' interactions with the provider and can exacerbate the loss they are already experiencing. Traumatic experiences are a greater possibility because the disability increases the individual's vulnerability. In addition, the actual disability contributes to the person's difficulty to adequately process information. As the infant grows into a child, then into a teen, and eventually into an adult, the developing sense of self is altered. Eventually, the individuals may begin to integrate the negative beliefs of others, having heard often that maybe they cannot move as well, speak as clearly, think as fast, or progress through school as well as everyone else. They may then begin to grieve the loss of a positive sense of self.

Although many people with developmental disabilities continue to live at home with their parents or adult siblings and have very productive and happy lives, there is a group of individuals who experience institutionalization. Separation from family in itself is a traumatic loss for all involved. Families make the best decisions they can based on what is happening at the time. However, individuals who are institutionalized subsequently lose the daily contact with family members, family rituals, and routines that contribute to a sense of security. This loss may result in persistent grieving, with a desire to return to the primary family unit.

People who live in a group home or other residential setting may potentially experience additional loss through diminished individual privacy and continual staff turnover. People with the most severe disabilities often require assistance with daily activities, such as bathing and toileting. The construct of a residential setting requires individuals to share living space with a number of other people, limiting their privacy. An important part of the staff's role is the development of therapeutic relationships. However, staff members arrive at work without notice

and “disappear” routinely, allowing no transition time for the individuals living in the home. With each change in staff comes the change in each staff person’s therapeutic style and expectation of the individuals they work with, creating a sense of anxiety. This potentially contributes to a loss of power and control of the individual’s decision-making process.

It is not uncommon for individuals with developmental disabilities to be unprepared for death, given the typical approaches to working with them. They receive little, if any, information, or inaccurate information (e.g., “the person went on vacation”) and may possess minimal experience in recognizing and working through the normal feelings experienced by people in general. Many times, the person is not told about a death until well after the fact and may not be included in the funeral or other related activities. This may result in a delayed and ineffective grieving process.

## **ASSESSMENT AND INTERVENTION**

Moddia and Chung (1995, p. 38) identified six factors to take into account during assessment and planning for successful progression through bereavement:

- ego strength;
- age;
- degree of dependency;
- emotional closeness;
- circumstances of the death (sudden versus unexpected); and
- capacity to cope with anxiety and stress.

Developmentally delayed individuals have emotions and need support and guidance, just like everyone else, although their needs may be manifested, and subsequently interpreted, in various ways. Goal-setting should be a concrete and reassuring method of stress reduction during the chaotic aftermath of death. It provides direction, with realistic and mental health-promoting tasks on which to focus. This allows for an underlying message of future orientation as well as some sense of control over an otherwise seemingly out-of-control life event (Clements & Henry, 2001; DeRanieri, Clements & Henry, 2002).

Bearing in mind that the client is the expert on his own grief, it is the role of the health care professional to use expertise in guiding the client along the continuum of adaptive coping and functional grieving, taking into account any cultural or religious tenets that might require consideration for treatment planning and support (Clements, Vigil, Manno,

et al., 2003). Identification and commitment to small, short-term goals can provide a sense of accomplishment, a sense of control, and a sense of “getting better.” It is critical to validate that any “grief work” toward accomplishment of these goals will most likely be painful and that this pain may manifest itself in many different ways. Many clients and care providers fear the reality that the only way to get to the “other side” of grief is to “go all the way in and all the way through” (Clements & Henry, 2001). During this early phase of the grief process, it is important to mourn the loss by allowing a full range of emotions while avoiding the minimization of what the loss means in an attempt to please others. Although tears are not necessary for functional grieving, crying should be validated as a typical and acceptable form of expression (DeRanieri, Clements, & Henry, 2002).

Many grieving clients may become deeply introspective and devolve into a state of loneliness. Clients can experience problematic beliefs of uncertainty and inadequacy, perceiving the world as dangerous and feeling an overt lack of control (Vigil & Clements, 2003). Encouraging clients to express their needs to their supporters and to communicate how they can help can be a significant conduit for adaptive coping and bereavement. The pain and emotion that accompany loss and grief can be mitigated when emotional support is readily available and utilized. At the same time, many “well-wishers” may recommend major changes or decisions as a method of coping or “getting over it.”

In general, it is suggested that health care providers keep in mind the following points, outlined in *Helpful Insights on Listening to the Bereaved* (American Association of Retired People, 2004), when they approach the client:

You are not listening when:

- You say you understand when you haven’t had the same experience.
- You have an answer for clients’ problems before they have finished telling you what the problem is.
- You interrupt clients before they finish speaking or you finish their sentences for them.
- You tell clients about your experience, making theirs seem unimportant.
- You are communicating to someone else in the room (such as a parent, primary caretaker, or other health care provider), talking as if the client is not even present or able to hear.
- You refuse a client’s “thank you” by saying you really haven’t done anything.

You are listening when:

- You really try to understand clients even if they are not making much sense.
- You grasp the expressed point of view even when it goes against your own sincere convictions.
- You realize the hour the client took from you has left you a bit tired and drained.
- You allow clients the dignity of making their own decisions, even though you think they may be wrong.
- You do not take clients' problems from them, but allow them to deal with the problems in their own way.
- You do not offer clients religious solace when you sense they are not ready for it.
- You give clients enough room to discover for themselves what is really going on.
- You come quietly into clients' private worlds and let them be just exactly who they are.

## **SUMMARY**

Assessment and intervention for developmentally disabled individuals can be difficult when attempting to explore and understand traumatic events. It is important to address such issues with the understanding that, although perhaps "different" or "unusual," people with developmental disabilities may "really" understand the concept of death and the subsequent changes. Some people with developmental disabilities may not grieve immediately or in the same way as expected by others. Awareness that their reactions may not be noticeable or even interpreted as grief responses due to their limited communication skills can provide for enhanced monitoring and assessment by the health care professional. Otherwise, grief may not be recognized or addressed. If functional grieving is not supported, yet another loss for the individual with developmental disability may be suffered.

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