Individuals with intellectual disabilities: Struggling with loss and grief

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Introduction

One of the most significant trends for the past forty years has been the increasing longevity of individuals with intellectual disabilities. Medical advances in both the understanding and the treatment of intellectual disabilities, and deinstitutionalization from the larger facilities where individuals with intellectual disabilities were generally warehoused have increased life expectancy. Most individuals with intellectual disabilities, with exception of Down's syndrome now have a near-normal lifespan and even persons with Down's syndrome may expect to live well into midlife.

Along with the trend toward increased longevity, there have been significant strides in normalizing the lives of individuals with intellectual disabilities. Many of them now live within the community in group-homes, with family members, in special assisted living facilities, or even on their own. They have, as other persons do, created and sustained attachments to a variety of persons – family members, fellow residents and consumers, staff members, co-workers, members of their faith communities, and other friends.

One of the prices of such attachments is that individuals with intellectual disabilities experience loss, as do all others. They are now likely to outlive parents. Loss inherently is a part of communal living as staff members and other residents relocate or die. In fact, individuals with intellectual disabilities may experience significant secondary losses that may complicate grief. The death of a parent or caregiver, for example, may necessitate a change in residence leading to a range of losses that might include friends, neighbors, and employment.

In short, individuals with intellectual disabilities experience grief.

Some more highly functioning members of this population may even experience a sense of grief and loss over their disabilities – a lingering sense of loss over the fact that they are perceived as different from others. Grief is a reality of life for all persons whether or not they experience intellectual disabilities.

Families of individuals with intellectual disabilities experience grief as well. Certainly they may experience a deep sense of grief and loss when a family member with intellectual disabilities dies. They may even experience an ongoing sense of loss over the disability itself. Roos (2002) identified *chronic sorrow* or a continuing sense of loss that may surge at different moments. For example, parents may experience a profound sense of loss when they learn the child has an intellectual disability – sometimes even prior to birth. This sense of loss continues throughout the child's life possibly spiking when non-disabled peers experience transitional events such as graduations or weddings. It is as Bruce and Schultz (2001) note a continuing or *nonfinite* loss.

A basic and welcome assumption of this book is that effective end-of-life needs to address the ongoing reality of loss. The chapter begins by exploring grief reactions in individuals with intellectual disabilities, their families, and staff. A second focus of the chapter reviews the ways to individuals with intellectual disabilities and significant others in dealing with loss. The chapter then concludes by addressing the possibilities and need for grief education.

Grief Reactions in Persons with Intellectual Disabilities

There is a Buddhist proverb that states, "*We are like all others, some others, no others.*" That is an excellent way to think of the grieving reactions of individuals with intellectual disabilities. Individuals with intellectual disabilities generally grieve in the same ways as others who experience a loss. That is part of our common humanity. Yet, the nature of intellectual disabilities can create unique issues as individuals with intellectual disabilities experience grief – hence there may be characteristics of the grieving process that are shared by others with similar deficits. Finally, every experience of grief is unique – based upon the characteristics of the person and the relationship to the person who died.

Like all others, individuals with intellectual disabilities experience physical, cognitive, emotional, behavioral, and spiritual manifestations of grief. Grief reactions can be experienced on a physical level. Grieving individuals may convert grief into a range of physical reactions such as nausea, headaches, or other bodily aches or pains. This is especially true with individuals with intellectual disabilities. Here emotional manifestations may easily be converted and interpreted as physical symptoms. Anxiety for example, might be expressed as stomach pains. Moreover physical symptoms elicit care and concern – support – from others at a distressing time. In working with individuals with intellectual disabilities during a time of loss, it is essential to continually assess their physical state.

In addition to physical responses, there is a range of affective responses to loss. These can include such emotions as anger, guilt, jealousy, anxiety, sadness, or regret – among many others. Some deserve special mention. It is not unusual that other residents, consumers, or staff members can be the focus of displaced anger. Guilt, too, is a common reaction. Again this is especially true in populations of individuals with intellectual disabilities; as such individuals may have limited understanding of causality.

There also may be cognitive reactions. In the initial phases of grief, people may be in shock – disbelieving or denying, unable to process information. Throughout the grieving process, individuals may find their concentration or span of attention is impaired. They may process information less effectively. It is not unusual for health professionals or others to be asked the same question or to provide certain information repeatedly. Individuals may experience impaired judgment. In persons with impaired cognition, these changes can be profound. In some cases, such as after the loss of a guardian, it is critical to temper any assessment of an individual with intellectual disabilities with recognition that such an assessment will likely be affected by the loss.

Behaviors may be influenced as well. Grieving individuals may seem lethargic or hyperactive. Life pattern such as sleeping or eating may change. For example, it is not unusual that individuals with intellectual disabilities might experience sleep disorders. They may engage in risky behaviors such as substance abuse. They may seem angry, lashing out to others, or withdrawn. There may be acting out behaviors. In short, grieving individuals may behave in quite uncharacteristic ways. Individuals with intellectual disabilities may become quite resistant to any changes in routine – protesting if someone, for example, sits in their regular seat. When significant changes occur, individuals often become resistant to the minor changes that they can control. This may result in compulsive behaviors where they become rigid in trying to keep whatever they can from becoming unstable. Such changes in regular behavior then ought to be included in assessments of grief.

Finally, individuals can have a range of spiritual reactions. They can struggle with profound spiritual questions. Guilt or anger can have a cosmic focus as persons vent their anger at their idea of a Deity or feel the disease or death is a punishment for some supposed sin.

There is no timetable to grief. Over a period of years, most individuals find a lessening of painful cognitions and emotions and a return to their previous levels of functioning. In fact, some individuals may even do better in time as their loss creates a developmental push – creating needs to learn new skills or insights. However, this does not preclude that fact that even over time individuals may experience surges of grief perhaps at special times such as holidays or anniversaries or at events in which the presence of the deceased is profoundly missed. Nor is there any particular sequence or stages within the grieving process. Current models tend now tend to see the process of grief as a series of very individual processes or tasks (Worden, 2008; Rando, 1993; Stroebe & Schut, 1999).

While these reactions are generally common to all people, researchers and clinicians have identified particular manifestations of grief that may be found in individuals with intellectual disabilities. Individuals with intellectual disabilities often have limited or distorted emotional expressions (Todd & Hymes, 1999). One client, for illustration, would giggle whenever she was anxious. In recounting the story of her beloved father's death, she would giggle in this nervous fashion – sometimes confusing less empathic relatives. They also may have a positive bias – that is a generally optimistic view of the world that may be inherent to the disability or a consequence of reinforcement (Todd & Hymes, 1999). This means that individuals with intellectual disabilities may appear and report they are happy. Such a perspective may mask the deep feelings of anxiety, dependency, ambivalence about the dependency, and abandonment that may be generated by the loss (Kaufman, 2005).

Since cognitive processes are impaired, individuals with intellectual disabilities may have difficulty in comprehending death. Lipe-Goodson and Goebel (1983) found that their sample of individuals with intellectual disabilities was able to understand death. However, the ability to understand death was not dependent on IQ but rather chronological age suggesting the critical importance of experiential learning. Because of these intellectual deficits, individuals with intellectual disabilities may need to spend considerable processing the implications of death and loss. Moreover their limited coping repertoire might restrict their abilities to effectively respond to the loss (Lavin and Doka, 1999).

In addition, others may disenfranchise the experience of grief of individuals with intellectual disabilities. *Disenfranchised grief* refers to situations where an individual experience a loss but that loss is not openly acknowledged, socially supported, or openly mourned (Doka, 2002a). In short the person experiences a loss, but has no socially sanctioned right to grieve.

The grief of individuals with intellectual disabilities is often disenfranchised (Lavin, 2002). There may be many reasons why such grief is disenfranchised. Caregivers may feel inadequate in addressing grief in individuals with intellectual disabilities and hence ignore their needs. Others may feel the presses of time inhibit opening topics they feel ill equipped to handle. There may be a sense of over-protectiveness that creates a reluctance to upset individuals with intellectual disabilities that results in attempts to limit exposure or discussion of death, loss, and grief. In other cares, there may be erroneous conceptions that individuals with intellectual disabilities are incapable of sustaining attachments, retaining attachment if the person is no longer present, or understanding grief (Duetsch, 1985; Lavin, 2002). Since individuals with intellectual disabilities may manifest grief in some distinct ways, others may not always recognize that grief. However just because an individuals grief may not be understood by other; it does not mean that the individual does not understand and experience the loss.

This sense of disenfranchisement can often extend to families of individuals with intellectual disabilities. There may be disenfranchisement of their own loss in having children with a disability. Since individuals with intellectual disabilities may be less valued by the larger society, others may disenfranchise even the death of such a child. Clients who have had a child with intellectual disabilities have often noted that others will often suggest that such a death should be perceived as a "blessing" or "relief" thus disenfranchising the parents own sense of profound loss.

Counseling Individuals with Intellectual Disabilities

Prior to discussing counseling individuals with intellectual disabilities, it is important to reaffirm that individuals with developmental disabilities are not homogeneous. They share the same differences in terms of background as other groups. Levels of cognitive disability can vary from mild to severe. Living conditions can also vary: some may live independently, others with their families or in-group homes, still others in institutions. Levels of social and psychological impairments can also differ, and may not neatly correspond to cognitive impairments. Thus an impaired person's age may not be predictive of developmental level or behavior.

Lavin (2002) describes certain characteristics typical of individuals with developmental disabilities. They often have an external locus of control, lack confidence in their own ability to solve problems, find it difficult to think abstractly, have limited ability to transfer skills from one level to another, and have poor short-term memory skills.

Because of these limitations, developmentally disabled persons may have a very difficult time coping with abstract concepts such as "disease," "dying," or "death." Some research has suggested that these concepts may be easier for developmentally disabled persons to master as they age. Chronological age, rather than cognitive level, may be a factor, since it provides a rough index of the developmentally disabled person's level of experience with dying and death. Often family and staff may exacerbate these conceptual difficulties if they try to overprotect the developmentally disabled client, effectively disenfranchising the client from any role in the treatment.

In grief counseling with individuals with intellectual disabilities, Lavin (2002) makes a number of points that can be applied to counseling such individuals in any crisis. First, she emphasizes the need for caregivers to be patient and clear with their clients. Comfort and continued reassurance may be particularly important throughout the crisis. Second, Lavin emphasizes that caregivers will have to teach coping skills throughout the crisis. This begins by analyzing what behaviors and skills will be necessary at each phase. Lavin then suggests that a four-step process can facilitate learning:

1. *Preparation* – Here the goal is to prepare the person with developmental disabilities to be exposed to the experience. Counselors may wish to begin by talking about the individual's previous experiences with illness. This will provide an opportunity to draw upon these experiences in later times.

2. *Direct Instruction* –The counselor can teach skills that may be useful to the person, providing constant reassurance and reinforcement. For example, he or she may have to go over circumstances in which the individual should notify an appropriate caregiver about changes in health, carefully explaining the symptoms the person might monitor.

3. *Modeling* – In this approach someone models the expected behavior for the individual. The counselor may help to interpret the event (for example, "He is going to tell the nurse what's bothering him"). The person with developmental disabilities can then attempt to copy the behavior with the encouragement and support of the caregiver.

4. *Emotional Support* – Throughout the crisis, persons with developmental disabilities may have to be helped to understand and express their emotions. Directive questions such as, "Are you scared?" or "How do you feel when you are scared?" may help such individuals to recognize their emotions. Counselors may need to provide considerable support throughout the crisis of illness. Nonverbal behaviors such as reassuring touch may provide that needed and welcome presence.

Counselors may find that counseling individuals with intellectual disabilities requires considerable flexibility in approach. Depending on the level of disability, the present crisis, and the person's previous experiences, caregivers may have to continually adapt approaches to each person. But these clients still share the same needs as other nondisabled individuals, including the need for autonomy, control, and respect.

These basic approaches may be applied at any point in the illness process. Certainly intervention should begin as the significant other is dying. There are two major reasons for this – especially with individuals who have intellectual disabilities. First, grieving begins with the illness. In recent years, Rando (2000) has redefined the anticipatory mourning. Rando's redefinition emphasizes that anticipatory mourning is not simply a reaction to an event projected at some future time. Rather it is a response to all the losses, encountered in the past, present, and future, within the illness experience. For example, the individual with intellectual disabilities may already begin to grieve the losses associated with the illness such as the parent visiting less or being less available to the client. The client no longer is able to visit. All these changes are secondary losses due to the illness and may generate grief within the client.

Second, the dying process can become a significant learning process. As stated earlier, individuals with intellectual disabilities often benefit from experiential learning (Lipe-Goodson and Goebel, 1983). Involving the individual with intellectual disabilities early within the illness experience can assist in helping the person eventually understand the fact that other individual is very sick, and perhaps even assist the individual with intellectual disabilities with eventually comprehending the death.

For these reasons, it is important to begin assisting individuals with developmental disabilities to cope with loss at the onset of the illness process. Rather than protect individuals with developmental disabilities from the illness process, this should be an opportunity for supportive learning. Individuals with developmental disabilities should have opportunities to visit relatives in hospitals, hospices, or home care so they can see the inevitable deterioration that the illness causes. Naturally, individuals with developmental disabilities need retain a sense of control and choice as to what their role should be. Insuring that individuals with developmental disabilities are fully informed in an understandable way about what they are likely to observe best does this. Such an educational approach should build on past experiences and may even include books or pictures illustrating what they might see as many individuals with developmental disabilities learn visually. Second, individuals with developmental disabilities will need options. Do they wish to visit or would they rather call? Would they wish to go to the hospital or wait till the person returns home? Finally, individuals with developmental disabilities need support. There should be someone whose prime responsibility is to care for the individual with developmental disabilities – offering respite if the visit becomes uncomfortable and patently asking (and soliciting) any questions or concerns that are likely to emerge.

Continued involvement within the illness allows individuals with developmental disabilities to comprehend the illness and avoid the shock of a death that is unexpected. Throughout the illness, questions should be answered in an honest yet supportive way. For example, early the illness when the prognosis is still unsettled any question of whether the ill person might die may be answered in a way that allows the possibility even if it stresses the ongoing medical care. "Momma is very sick but the doctors are doing all they can to see if she gets better." Once the prognosis is terminal, an honest answer may be that: "Momma may die but her doctors are doing all they can to help her feel comfortable." Again, books and videos may be good adjuncts to the learning process. While involvement is essential, caregivers also need respect that individuals with developmental disabilities, just like others, may choose moments to avoid or deny the illness. A response, for example, like "I know Momma will get better" might be answered with a simple "I hope so too but even if she does not, your brother and sisters will take care of you."

At the time of death, individuals with developmental disabilities should have the same opportunities for presence and involvement. Again the rubrics of education, options in making choices, and support remain critical. At the time of death, it is also important to avoid, if possible, any rapid change. For example, if the individual with developmental disabilities is living at home but cannot remain there, it might be better if someone can stay with them for a short time or that the individual stay in a familiar and comfortable place of respite until an effective transition can be made. While effective permanency planning ought to have been complete prior to the death of a caregiver, if it is now necessary, care should be taken in assessment. The fact that grief is likely to be manifested in a range of dimensions including the cognitive and behavioral, any assessment done in the aftermath of the death is likely to significantly underestimate the capabilities of the individual with developmental disabilities. That fact should be taken into consideration. At the very least, placements ought to be considered tentative and the individual with developmental disabilities should be reassessed at least six months later.

The question of whether individuals with developmental disabilities should funerals also needs to be addressed within the immediate period following the death.

Funeral's are therapeutic. They offer a time to be with others and to share memories and support. They allow opportunity to do *something* at a time that seems so disorganized and stressful. Funerals reaffirm the reality of death while providing an outlet for emotions. They even help individuals understand the death – to hear the ways that their own faith systems speak to the loss.

The value of the funeral does not cease simply because an individual has intellectual disabilities. Funerals are liminal events – that means that they touch individuals at the very edge, the threshold of consciousness. All can benefit from participation in meaningful ritual. Yet, individuals with intellectual disabilities may need a little extra assistance as they prepare to participate in a funeral.

As before, it is critical that individuals retain choice regarding funerals. Often others may suggest that choices be made for the person. There may be a feeling that the event is too upsetting or an individual may not be able to understand what is occurring. Rather than arbitrarily deciding whether or not an individual should attend, it is helpful to allow the person to make his or her own choices. Explain what the funeral will be like in words that an individual can understand. Sometimes, even books can help describe the setting or funeral directors can arrange a tour so the individual becomes familiar with the layout.

Sometimes individuals may choose to only attend part of the funeral. Most funerals have numerous parts – a visitation, a funeral service, a committal, and perhaps even a meal or gathering. A person may select to attend only some of the events. In such cases, the individual may be offered another meaningful role. One client attended the visitation, but believed it would be too sad to be at the cemetery interment. Instead, he helped prepare food and set the table for a reception that would follow the cemetery ceremony.

One of the most valued aspects of a funeral is that it offers support. It is important that special efforts be made to provide support for all members of the family. It is easy for more vulnerable members of the family to get lost in the activity of the moment.

This can be done in a number of ways. For some it may mean allowing the individual with intellectual disabilities to invite their friends such as other individuals with whom they work or reside. Staff can sometimes have a useful role serving as a supportive other at the time of the funeral – especially important as immediate family is likely to otherwise engage and unlikely to be as available as they might wish. In other cases, members of the extended family or family friends well know to the individual with disabilities can play that role – answering questions and if necessary offering respite allowing the individual with intellectual disabilities the opportunity to leave for a while if the experience becomes overwhelming.

Training can be a form of support. Many people pick up cues on how to behave by watching others. If one enters a room and sees everyone talking quietly and somberly, one behaves in similar fashion. Individuals with intellectual disabilities may need specific instruction. For example, they may find it useful to "practice" what to say when people offered condolences. Providing that extra assistance also is a critical part of support.

Following the death, individuals with intellectual disabilities will continue to need support. Staff should continually assess, over the next months, any manifestations of grief including anger, withdrawal, regressive behaviors including increased dependency and clinging behaviors, heightened compulsivity, or somatic distress. While somatic distress can be a manifestation of grief, naturally any such physical symptoms should be medically evaluated. Individuals often experience increased morbidity and mortality following a significant loss; hence health should always be monitored (Williams, 2002). Staff should be particularly observant around times that may trigger grief. This can include days or the week or times that the deceased individual might visit or call as well as significant dates such as birthdays, holidays, or around the anniversary of the death. Even with some individuals with intellectual disabilities who may not remember or process dates events around the date can trigger grief. One client with intellectual disabilities, for example, would have anniversary reactions around Easter since he associated the time with his mother's death.

Expressive therapies often work very well with individuals with intellectual disabilities since such persons generally less verbal. Music, play, art, and even dance are among modalities that can be used. Therapeutic ritual also can be effective. Rituals can be created at different points within the grieving process to mark events such as anniversaries or to allow bereaved individuals to feel a sense of continuity, note transitions, affirm the relationship or even create a reconciling act (Doka, 2002b). Rituals can be extremely useful in that they allow individuals with intellectual disabilities the opportunity to take meaningful actions to express grief. Even a simple ritual like placing memorial ornaments on a Christmas tree can address the feelings of loss inevitably associated with the holidays. In another case, an individual client would take messages to his mother that he would play at appropriate times in the chapel. Luchterband and Murphy (1998), for example, offer multiple strategies for both using expressive approaches and crafting therapeutic rituals.

Group support often is an effective mode of bereavement support. Grief support groups can offer a sense of validation in a shared community thus easing a sense of isolation. They can help model and teach effective coping and offer hope. Groups that utilize expressive approaches can be an especially effective modality with individuals with intellectual disabilities. In one support group, it became the group practice to sing songs associated with the person who died. Each person would suggest a song and tell a story of how the song was associated with the individual who died. One young man, for example, suggested *Danny Boy*, since his name was Danny and his deceased mother would often sing that to him. One of the lower functioning members of the group would insist that he group joined him in *Take Me Out to the Ballgame*. He could not, though, verbalize a connection, leaving staff members wondering whether he was processing the exercise. Later when a brother visited, they asked the brother if there was any connection to the death of his Dad. The brother recounted that his father was a baseball scout, he often take the boys to games, especially his younger brother since schools in the late 1940's had little to offer children with intellectual disabilities. They would sing the song on every outing.

Another interventive approach may be to create a memorial place such as a wall or garden. This should be in a location that individuals can choose to go to rather than one that they will inevitably pass. Such as a "sacred place" can be both an area for ongoing rituals as well as a spot for reflection and remembrance.

It is important to remember two things when working with grieving individuals with intellectual disabilities. First, because of deficits in processing information, individuals with intellectual disabilities may ask to have information continually repeated and re-explained. Often such repetition is useful to assist them, as they comprehend the difficult and abstract realities of death and illness. Second, an experimental approach is necessary when assisting individuals with intellectual disabilities in coping with loss. There is comparatively sparse research on this population to offer the possibility of evidence-based practice. One should continue to assess then, even on an individual basis, the efficacy of varied approaches.

Beyond that intervention strategies and grief support need to be crafted individually. Like other mourners, individuals with intellectual disabilities will have their own unique issues and concerns as they cope with a particular loss.

Acknowledging Other Mourners

In discussing grief support for individuals with intellectual disabilities, it is also important to acknowledge other mourners. Family members particularly may need support. Often, the death a an individual with intellectual disabilities can be disenfranchised by others, that is the loss of an adult child with intellectual disabilities may not always be acknowledged by others (Doka, 2002a). Memorial services at group homes or residences and at sheltered workshops can have much value. They can bring together a community of mourners that includes family members, staff, and friends, fellow consumers, and co-workers. Such remembrances reaffirm the individual worth of the deceased, reaffirming the inherent value of the deceased's life. This is particularly important when the larger community may view such a loss more ambivalently. Family members also may be invited to participate in any subsequent memorialization at such facilities. In addition, it may be effective education to encourage the deceased's fellow consumers, co-workers, and residents to acknowledge the loss to the family through cards, drawings, or video tributes. Families often treasure such items.

Grief support should also be extended to staff members. Staff members can create strong bonds with individuals with intellectual disabilities. In some cases these bonds can last over years. These losses can be cumulative especially as residents age in place. Moreover, the deaths of clients can result in numerous secondary losses. For example, meaningful contact with family members is likely to cease once a resident dies. The loss of a resident may have complicating factors as well. Staff members, for example, may disagree with ethical decisions that have been made or otherwise feel that end-of-life care was inappropriate or unsuited to the nature of the individual's disability. It is unrealistic to expect staff to develop close bonds with clients, and support other individuals with intellectual disabilities at the time of the loss if their own needs for grief support are not met. The result of such unrealistic expectations is that staff members are either likely to experience a sense of occupational stress or burnout, or become wary of bonding to residents as closely in the future (Papadatou, 2000).

Effective grief support generally involves individual strategies of self-care. These include acknowledging and validating loss, finding effective methods of respite that allow one to manage stress, and developing a personal and spiritual stance that allows a staff member to find an overarching framework for attributing meaning to life and death as well as finding satisfaction in one's own work (Doka, 2006). However, research also has emphasized that organizations play a large role in effecting support. Effective organizations have both formal policies and informal procedures that validate loss. Formal policies can include time off to attend funerals or debriefings after death. Such can set the tone that creates an environment within the work setting where supervisors and other employees can be both validating and supportive of grief. In addition effective organizations offer both ongoing education and rituals that marked significant deaths (Vachon, 1987).

It is also important to acknowledge that not all losses involve death. Other losses such as when residents or staff members leave also can engender feelings of grief and ought be marked by ritual.

Implications for Training and Education

The previous section emphasized the tasks inherent in offering grief support for individuals with intellectual disabilities. Central to that process are implications for training and education. Naturally, individuals with intellectual disabilities would benefit from education about loss and grief. Life-cycle education that emphasizes that living things are born, develop, and eventually die offers a basic foundation that may useful when individuals face illness or loss. In addition, visits to hospitals, funeral homes and cemeteries often are best done in a non-crisis atmosphere. Such field trips provide a basic familiarity that may very well be useful when such facilities need to be used. Resources that offer education about death and loss in simple ways but with pictures of adults, especially individuals with intellectual disabilities, can fill a present void. Often the only educational resources that are available (with the exception of some lifecycle books such as *Lifetimes* or *The Fall of Freddy the Leaf*) characterize children thus demeaning adults with intellectual disabilities.

Staff also should have opportunities for training on loss and grief. This both assists in self-care and helps generate a sense of competence that might presently impair staff receptiveness to reach out toward grieving individuals with intellectual disabilities (Schwebach, 1992).

Moreover, systems of care for individuals with intellectual disabilities should see their role not only in educating their clients and staff but reaching out to other populations as well. Schwebach (1992), for example, found that parents and siblings of individuals with intellectual disabilities often disenfranchised such individuals by trying to shield them from the illness or inhibiting such individuals from attending family rituals. Providing education about grieving processes in individuals with intellectual disabilities in support groups or educational programs for communities again can best be done in non-crisis situations and open dialog between family, staff, and individuals with intellectual disabilities about loss, illness, and grief.

Systems of care for individuals with intellectual disabilities also may offer training to or in collaboration with other organizations. The philosophy of inclusion and normalization means that many individuals with intellectual disabilities may end their lives in facilities such as hospices or nursing homes. Shared trainings can offer opportunities both to open dialog and to mutually collaborate. Presently there is a program in NY State between the Young Adult Institute, a group established to assist individuals with intellectual disabilities, and the New York Hospice Association to improve end-of-life care for individuals with intellectual disabilities. In these trainings, the Young Adult Institute can offer education about developmental disabilities and the needs of their clients while learning from hospice staff the generic issues that face the dying.

Perhaps though, this shows a larger need to revisit the ways individuals with intellectual disabilities are educated. Often there is an emphasis on learning by rote and routine. Yet that same system contributes to a lack of flexibility that may impair coping. As persons in systems of care for individuals with intellectual disabilities seriously consider ways to educate and to prepare clients to cope with illness, grief, and loss, it might create a need to re-evaluate training and to emphasize ways to train individuals with intellectual disabilities to cope with the inevitable transitions that are a natural part of life.

Conclusion

Like other populations, individuals with intellectual disabilities as they age will inevitably have to cope with loss and grief. While one cannot protect individuals from such loss, one can prepare and support individuals as they mourn. Such support begins even before the illness experience. It ends only with death.

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