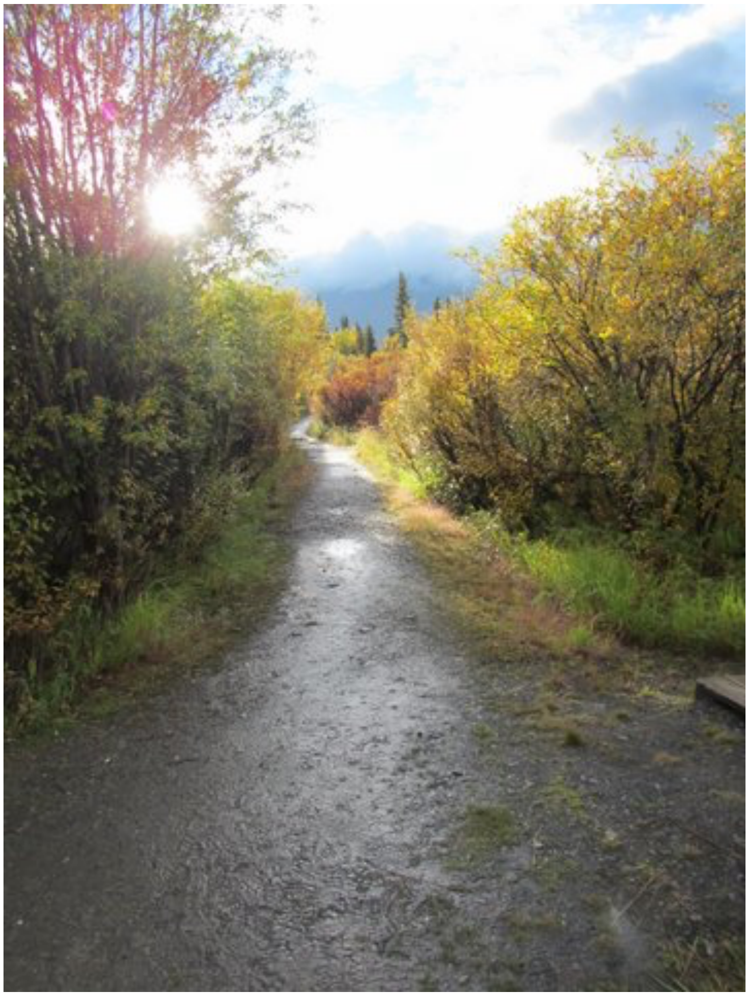

Grief Support for Adults with Intellectual Disabilities:

A Guidebook for Residential Caregivers

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Author's Note:

This guidebook is an abridged version of one I prepared as a Pathway project— part of completing my master's degree in social work through Memorial University.

Throughout this guidebook I will be referring to people who are labelled as having "intellectual disabilities" (IDs). This is the language and structure (referring to people first and then the label) favoured by People First of Canada. People First is a self-advocacy organization that strives to ensure that those with IDs are fully acknowledged and are included in all aspects of community life (People First of Canada, n.d.).

Preferences for particular labels are different across the world and change over time. For instance, literature from the United States tends to refer to individuals with "mental retardation", while in the United Kingdom (UK) the term "learning disabilities" is more common. The term "intellectual disabilities" is used internationally. "Developmental disabilities" is also widespread, particularly within North America. Any quotations from books or articles will maintain the term used within the source document.

People First is an organization that was formed because some of the people in our communities felt that they were not considered as people first. They felt talked about, talked to, thought about, and treated according to the disabilities that others labelled them with (People First of Canada, n.d.).

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Introduction

Loss is a shared human experience. We lose jobs, friends, partners, and pets. As we age or become ill, we may lose our mental faculties, our physical abilities, and our independence. Any significant change in circumstances, even those we look forward to, will often bring losses as well as blessings. Most of us manage such losses by coping in idiosyncratic ways that we have developed over the course of our lives. And when more significant losses occur, such as the death of someone we are especially attached to, we typically need time to grieve in our own way before we are able to adapt to the ripple of impacts that loss usually brings.

Many of those who have lived through the multiple impacts of de-institutionalization in the 1970s and 1980s are now aging and dying in community-based settings. When a significant loss does occur those with IDs naturally look to others around them for emotional comfort. In some cases residential care providers are the only people in the position to provide this kind of support.

Even with support people with IDs may have particular difficulty coping with and adapting to loss. This guidebook has been created primarily as a resource for agency and professional caregiving staff who may not be fully prepared to meet the emerging needs of an aging, sometimes grieving, population of adults with lifelong disabilities. The first part of this guide includes some of the themes that have emerged within the bereavement literature for people with IDs. With these themes in mind, the next section offers general guidelines for bereavement support within the context of residential care. These guidelines may also be of interest to service providers in vocational and other community-based settings.

Part 3 explores opportunities for meaningful collaboration between caregivers, hospice workers, mental health clinicians, and others who comprise the circle of care for grievers with IDs. It is the underlying premise of this guidebook that by learning from each other and collaborating in mutual respect for differences in perspectives, we can significantly improve the mental and emotional health outcomes for some of the most vulnerable members of our community.

Part 1: A Brief Overview of the Literature

Within the research for typical populations "bereavement" is the term applied to the situation of having lost someone significant through death. The term "grief" is most often applied to the emotional reactions people have to the loss of a loved one.

Grief can manifest as a variety of psychological (cognitive, social, behavioural) and physical (physiological-somatic) experiences and expressions. Symptoms of grief vary considerably from one bereaved person to the next, from one culture to another, and even within individuals over the course of time. "One person's grief may be dominated by intense feelings of loneliness, another's by anger at being abandoned…. one person may show a few signs of grief early on but intense reactions later, whereas another person may manifest the opposite duration-related effects" (Stroebe, Hansson, Schut & Stroebe, 2008, p. 5).

The primary concern of bereavement research is to "better understand and to try and relieve the suffering of bereaved people" (Stroebe, Hansson, Schut & Stroebe, 2008, p. 5). The research literature concerning grief support needs for adults with IDs indicates this population may be at particular risk of cumulative and unresolved losses. Reasons for this tend to cluster along the following lines:

- Systemic barriers (e.g., inadequate resourcing of services; social attitudes and ideological approaches that preclude consideration of grief needs);
- Inherent complexities of community-based residential care (e.g., prioritizing "managing behaviour" when emotional and /or behavioural expressions are experienced as disruptive to staff and/or other residents);
- Unique intellectual differences that have implications for working through grief in healthy ways.

All of the points above are implicated in the following key finding: people with IDs who are living with loss are more likely than their non-disabled peers to suffer *disenfranchised grief*— a disregard for an individual's need and/or capacity to grieve, and *diagnostic overshadowing*— "behavioural problems" or emotional distress attributed exclusively to the disability itself. The consequences of serial loss can have a significant effect on an individual's psychological and emotional well-being. Unresolved loss in particular is associated with the development of mental health and other health-related disorders.

Post-Deinstitutionalization: Consequences and Challenges

By the late 1970s, family members and other advocates within the disabilities community had managed to apply enough pressure on various levels of Canadian governments to initiate deinstitutionalization of people with IDs. These advocates, armed with ample evidence of the harm done to those living and working in institutions, kick-started a shift in social policy and social change, the effects of which continue to ripple in the lives of many. Along with these blessings there have also been challenges. Just how well "the community" has been able to meet the unanticipated demands that deinstitutionalization brought to its collective doorstep is a matter for debate. In measures of mental and emotional well-being, it is worth noting that in both the United Kingdom and in Canada researchers have found that people with IDs who are living in community care settings are more likely than their typical peers to develop mental disorders. According to the literature these disorders frequently go undetected, and thus, untreated.

Complicating matters in the context of bereavement care is the established risk that service providers and caregivers may mistake loss reactions for either psychiatric or behavioural disorders that are not associated with loss. This is understandable given that for some people with IDs:

- Grief reactions such as depression, anxiety and distress, particularly among individuals less able to express themselves verbally, do manifest as behavioural difficulties, and;
- Angry and even aggressive reactions to loss may also occur, but be so delayed that no relationship to the loss is recognized.

It is also important to acknowledge that people can have a mental disorder or challenging learned behaviour, *and* may be grieving all at the same time. It is no easy task to untangle the individual's disability, a potential psychiatric disorder, and an acute response to loss. It makes sense that we might look to those with mental health expertise to help sort it through. In North

America mental health services are typically guided by a “medical model” approach to understanding and treating acute emotional distress.

This approach can be traced back to the mental hygiene movement, an approach to public health that found its way to Canada by the turn of the 20th century. The aims of the movement emphasised prevention, early intervention, evidence-based treatment, and health promotion through public education—components that are still evident and largely taken for granted as part of our current approach to public health. While the movement emerged in the context of psychiatric care and treatment, it was a perspective soon lauded and adopted by social workers, sociologists, politicians, and others who were seeking scientific means for addressing social ills. The movement was also a primary driver of institutionalization and eugenics programs within and outside of North America.

One needs only to consider co-morbid health-related impacts of disability to recognize how vital medical expertise is in ensuring appropriate care and treatment for people with developmental disabilities. Heart abnormalities associated with Down Syndrome is just one example. But the “medical model” approach has also been criticized on multiple counts, including challenges by advocates within the disabilities community that the “medicalization of intellectual disabilities” perpetuates stigma. Post-modern critiques of the medical model rightly challenge its focus on assessment of “deficits” and for “pathologizing” expressions of distress. This is arguably one way to understand why the study of capacity of individuals with IDs to experience loss has dominated the research literature thus far (Dodd, Dowling & Hollins, 2005). In comparison, little research has been done in the areas of needs assessment and therapeutic care for bereaved adults with IDs.

> The “medical” model of disability attacks one’s relationship with oneself because the assumption is made that the impairment is the enemy, but in reality the impairment is part of the person, and only the person can themselves choose to separate them without feeling torn apart. So uninvited intervention, however well meaning, is a form of violence to the inner being.
>
> ~ Micheline Mason, author & activist.

Developmentally Challenged Research

Historical and social influences inevitably shape both the design and focus of research. And while research efforts have increasingly endeavoured to be more inclusive, these too have been hampered by the nature of disability itself. Studies have commonly relied on participants with strong verbal skills. Researchers have also depended largely on the perceptions of caregiver or service provider informants. As a result, "best practices" with regards to what helps are most commonly gleaned from relatively small, unrepresentative groups of research participants, anecdotal evidence, and opinion-based clinical experiences rather than direct input from the bereaved.

A review of the literature at the time this guidebook was originally prepared found that recommendations arising from existing research are far from definitive. Some were also strikingly contradictory. For instance, exclusion from funerals and other bereavement rituals was considered by some to contribute to the distress people experience following loss. And yet other researchers asserted that automatic inclusion might prove to be insensitive, if not hurtful to the bereaved, by strengthening "separation distress-type symptoms" (i.e., longing and searching for the deceased), as well as exacerbating the symptoms of more acute distress (e.g., somatic reactions).

It remains to be seen if increased distress following grief counselling or participation in death related activities such as funerals is evidence that these activities are truly harmful, or are simply a natural outcome when the required emotional and social space for grief to emerge is actually provided. It is worth considering that researchers' concerns may not only be a matter of unconscious over-protection but a red flag for the potential for iatrogenic harm. Given our collective social history, Clute's (2010) finding of attitudes of over-protection and of disenfranchisement of grief among bereavement counselors working with people with IDs is certainly not surprising.

The apparent inconsistencies make clear that there is much we simply do not know. Obviously, these findings *may or may not apply* to the person you are companioning through grief. Critical evaluation of any research is as crucial as ever. To this end, the list of reference materials used in the preparation of this guide has been included at the end of the document.

May it continue to grow and be enhanced through thoughtful critique and substantive contributions to research literature.

Signs of Change

The values of community inclusion, equality, and social justice that have long been at the heart of “community living” are also emerging within the academic literature. There has been growing interest in the systemic barriers people with IDs face in accessing timely and appropriate bereavement support. Individuals with IDs are also increasingly recognized as having a wide spectrum of abilities as well as disabilities. This is shown in the apparent expansion of research concerns from a preoccupation with the question of *capacity*, to more “strengths-based” approaches to providing emotional care and support. For example, it was suggested that exploring with the bereaved individuals their previous experiences of loss may not only shine a light on current coping skills, it may reveal other intrapersonal and interpersonal resources that would otherwise go untapped. More recent research findings also affirm what we already know: persons labelled with an intellectual disability have emotional needs like the rest of us, and they can and do benefit from emotional care and psychotherapy.

> We are at a fork in the road in terms of our approach to disability and disabled people. One road continues trying to alter disabled people from the "outside", whilst society in general stands aside and waits for the miracles to happen. The other road moves towards accepting the fact of disability as part of ordinary life, and works to help society value and include disabled people as they are”.
>
> ~ Micheline Mason, author & activist.

Part 2: General Guidelines

Many individuals with IDs recover from grief in much the same way that their typical, non-disabled peers do—eventually adapting to the loss, sometimes with tears and usually with the passage of time. As with the rest of us, most individuals with intellectual disabilities have a “typical” course of grief that usually lasts about a year. This may well include periods of more acute distress.

We may take for granted that people with IDs living in community-based settings have access to many of the resources they need. And yet research findings highlight many of the systemic and attitudinal barriers people with IDs meet in accessing timely and appropriate grief support. Offering the kind of environment most people with IDs require to grieve in healthful ways is not so difficult. The difficulty may well depend upon our capacity to honestly and objectively confront the systemic and intrapersonal barriers that perpetuate suffering of the bereaved individuals we care for.

> **…**rare is the client with mental retardation who is brought for therapy because he or she seems to be merely unhappy...pressures on the residential system are such that if residents are withdrawn or crying...as opposed to acting out, nothing will be done about it...but if a resident's behavior contributes to a crisis for the household that resident's behavior gets attention (Natter, 1995, p. 194).

Signs and Symptoms of Grief for People with IDs

Historically it was assumed that people with IDs were unable to understand the meaning of death and therefore did not have the experience grief. Research has helped us understand that even if an individual has no concept of death they may still feel distress in response to the absence of the person who has died. Here are some typical expressions of grief you might see in the bereaved person, regardless of their cognitive or developmental capacities**:**

- Changes in sleeping patterns
- Change in eating habits
- Change in "functioning" (i.e., needing more help with things they could do before).
- Social withdrawal
- Increased somatic symptoms (e.g., complaints of stomach upset, headaches, fatigue).
- Change in behaviour or personality
- Resistance or aggressive behaviour to self or others

The pain of typical grief is often eased with time and informal support through friends, family and other caregiving companions. Grief can also be “complicated” and more intractable. For some people the intensity of their distress not only seems to last longer than expected, but continues to significantly impact many aspects of their health and well-being. In such circumstances it may be necessary to secure additional, more specialized supports. These will be discussed in further detail in Part 3 of this guide, “Widening the Circle of Support.”

Additional Risk Factor: Unrecognized Cumulative Loss

People with IDs are thought to vulnerable to complicated grief. As noted earlier, this can be the result of cumulative losses that are not apparent to others, and therefore remain unresolved. It may be necessary to refer these individuals to a bereavement counsellor and/or for mental health services, in addition to providing a nurturing and supportive environment in daily life. Still, the beliefs, attitudes, skills and knowledge of caregivers and service providers inevitably shape the interventions offered to those in acute emotional distress.

> When we work with a client with mental retardation we must never assume that he “doesn’t know” about the loss and the experience of grieving…we must, in fact, proceed on the assumption that he knows about the loss, that he feels it emotionally, and that it affects his physical body and his spiritual centre (Howell, Gavin, Cabrera, & Beyer, 1989, pp. 328-329).

How much do we really know about the inner experiences of those we support? Take a moment to reflect on the people you know who are labelled with IDs. How well do you know their life stories? How well documented are their histories, so that future caregivers or support workers are aware of the significant events that have shaped their lives? Are the individuals you know encouraged to share their feelings and experiences?

In 2009 my colleague and I offered a workshop to self-advocates as part of the BC Association for Community Living. One participant talked about how she knew her father was dying, but relayed that “people stopped talking about it” the moment she came into the room. She described feeling disregarded, isolated in her own grief—emotionally abandoned by her family, without (I assume) their conscious awareness that this was the case. A middle-aged man shared that after his last surviving parent died the family home was sold and its contents distributed amongst his siblings. “I didn’t get anything”, he said, “because I was in a group home. My sister said I didn’t need anything. I just wanted something to remember my parents by”.

Death of siblings, friends, and pets, loss of homes, friends that moved away—everyone, it seemed, had a story of loss. But by far, stories of the death of parents were most potent amongst the workshop participants. For many adults with IDs, parents are the most constant presence in their lives. Not only do parents possess the knowledge of the individual’s personal history, “the lifetime primary caregiver may be the only person to whom they can effectively express their needs and desires” (Brickell & Munir, 2008, p.6).

The sudden death of an aging caregiver can also initiate a series of changes and accompanying secondary losses that are unknown or unrecognized as such. For example, Oswin (1991) found it was not unusual for individuals with IDs to be moved four or five times in the year after a major bereavement, such as the death of a primary caregiver. Individuals caught in these circumstances may also experience disruptions in contact with other family members, suffer a loss of familiar surroundings, routines, personal belongings and other household objects that for all of us lend a sense of security and symbolize “home”. Once established in a more permanent placement, residents may find themselves confronted by sudden, often inexplicable (to them) loss of support workers to whom they may have become attached. Group home living can also bring further loss experiences when other residents leave or die. For individuals with limited expressive language difficulties, effectively communicating the experience of having had multiple losses must be particularly hard.

> “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.” (Clements, Focht-New & Faulkner, 2004)

A strengths-based approach to bereavement support acknowledges and enlists the unique capacities the grieving person brings along for the journey. Before this can happen, primary caregivers and others must first of all be able to *recognize* signs of grief, and then be willing to find ways to support the bereaved person to experience and express their loss in their own way.

Ways and Means

Bereavement support tends to fall into two main categories: general support and formal interventions. Common informal support includes: empathetic listening, providing transitional objects (e.g., mementos), and facilitating memorialization activities (e.g., planting a tree in honour of the person who died). Formal interventions refer to specialized professional support such as bereavement counselling, art therapy, and grief groups. One of the fundamental assumptions repeated in the literature is that most individuals with IDs need only a supportive environment to deal with grief, but not formal intervention.

Kaufman (2005) summarizes what he calls the four most important ingredients in providing bereavement care to someone with an ID:

1. Provide information and support the processing of this information.
2. Enable maximum involvement in the social environment surrounding the death;
3. Maximize a sense of security, nurturing relationships, and opportunities for meaningful connectedness, and;
4. Maximize opportunities for self-expression.

Whether or not we are providing informal or formal support to someone who is grieving, most of us will remember to:

- ✓ Offer closeness. Just being there for the other person can be profoundly comforting.
- ✓ Truly listen to the person who is bereaved. Invite questions, check for understanding. Provide the space to talk through any misunderstandings or concerns they may have about the events that have occurred.
- ✓ Use concrete language in explaining why the body was no longer able to sustain life.
- ✓ Use visuals and stories to educate about the grief process and what to expect. Even for those who have great verbal abilities, visual information may be easier to take in, particularly during times of stress.
- ✓ Validate that grief work is often painful, that the pain may be expressed differently in different people, and that the intensity of grief will likely diminish with time.

- ✓ We often use “modelling” to help people with IDs to learn. Consider sharing your own experiences with grief. And if the current loss also affects you, consider showing the bereaved person that you too have feelings about it.
- ✓ Avoid minimizing what the loss means to the bereaved person, in an attempt to please or appease others.
- ✓ Explore with the individual, and if possible with their family, the cultural and religious traditions that may have special meaning for them.
- ✓ Expect all of the above to take time and repetition**.**
- ✓ Let go of worrying too much about saying *just the right thing*. In the sage words of Phillip Stanhope Earl of Chesterfield, "Many a man would rather you heard his story than granted his request."
- ✓ Be aware of your own grief issues and listen for these in colleagues and other helpers. A new loss will not only stir up unprocessed grief experiences from the past, but may trigger loss experiences in others who are around the bereaved person.

No doubt we can agree that each bereaved person has individual needs, strengths, capacities, and challenges that must be considered in the context of the environment. It is equally vital that we develop our own capacities as helpers in order to respond skilfully and ethically to the needs of this particular population of grievers. The next section of this guide will explore in more detail some of possibilities for and risks of informal support within a residential setting.

Grief Support in Residential Care

Within the context of residential, community-based care, two primary factors have been identified as barriers for provision of appropriate support at a time of loss. The first relates to the personal impact caregivers are anticipating (or avoiding?) for themselves— including being reminded of personal experiences of loss and/or confronted with their own mortality.

> Can I see another's woe, and not be in sorrow too? Can I see another's grief, and not seek for kind relief?
>
> ~ William Blake, English poet, painter & printmaker.

Bereavement Care Begins with You

We humans are wired to avoid pain. It is just as natural to avoid exposure to the pain in others. We should never underestimate the power of the urge to deny grief (Kauffman, 2005). Feelings of anger towards the bereaved person, a raise in our own anxiety level when we are witness to their suffering, the urge to control, to pathologize, to emotionally withdraw—all are within the range of human responses to grief in other people. Our responsibility as helpers is not to squash these reactions, but rather, to endeavour to be conscious of this potential in ourselves so we can act in ways that are sensitive and respectful to all involved. The call to provide support at a time of loss requires *fearless self-reflection*. As you tune your "third ear" to your own responses, some thoughts and feelings you may find helpful to listen for include:

- Minimizing the impact the loss is having on the person. (e.g., "He's not crying so I guess he's not grieving").
- Focussing on actions intended to "fix" the person (e.g., "We're going to the graveyard so she understands her mom is dead").
- The urge to push them along in their recovery from grief (e.g., telling people they've grieved long enough and it's time to "get over it").
- Shutting down or otherwise redirecting conversations or feelings that are related to the loss.
- Internalized ableism (e.g., he's too disabled to notice they're gone).

> Compassion is the *courage* to face the denial of grief and death in oneself. This compassion, or courage, is the basis of skill in providing grief support, counselling, or psychotherapy (Kauffman, 2005, p.4).

The second factor is the level of support available within the person's living situation. Ask yourself: does their environment encourage expression of feelings, validate experiences and allow the full range of emotions**?** *If not, what are the barriers and how can these be addressed?*

> An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives, and their day to day decisions. An institution is not defined merely by its size (People First of Canada, n.d.).

In residential settings where institutional culture affirms compliance and redirects emotional expression, service providers and other caregivers may be vulnerable to prioritizing containment at the expense of the individual's needs. This is understandable for residents who are already prone to having physically aggressive outbursts, or who are considered to be at risk of self-injury. Bereavement counselors understand that feelings of anger, irritability, and frustration are common reactions to grief. Ignoring, minimizing, or trying to medicate or "program" grief can have unanticipated impacts on the bereaved person. Within the literature the point is repeatedly made that behavioural interventions intended to restrict emotional expression may actually increase the risks associated with unresolved, cumulative loss.

As noted earlier, the inherent complexities of community-based residential care can exacerbate idiosyncratic difficulties in coping with loss. Sensitive and well supported caregivers are in a key position to help others make sense of behaviour in the context of grief, and also to collaborate in facilitating a resident's meaningful participation in rituals and other activities associated with the loss. Those of us who have worked directly with individuals in residential care are well familiar with needing to act as advocates within the broader community. And, in some instances, we are advocating within the residential system itself. Botsford (2000) references the following vignette to illustrate behavioural issues resulting from unresolved grief, and as an example of advocacy on the part of paid caregivers in a residential setting:

> When a man in his 40s, living in a group home, was admitted to a hospital, everyone in his home thought that he would soon recover and return to them. However, his health steadily declined, and after a month, he died in the hospital. Immediately after his death, several older residents in the home displayed ''disruptive'' behaviors both in

their work program site and in the group home. This continued for several days. The supervisor of the home told the staff that they would have to tighten controls to eliminate these troublesome outbursts. Staff analyzed the problem differently and contacted a chaplain experienced in working with people with developmental disabilities. He organized a house meeting that would include a ritual of remembrance for the man who had died. The meeting began with a discussion of the facts of his death and people's feelings about the facts. Art media were used for the expression of feelings, since many of the people living in the home were nonverbal. The discussion moved to a sharing of memories prompted by displaying personal objects that the man had kept in his room. Following this, scriptures were read, prayers were offered and a candle was lighted. One older woman whose brother had died earlier in the year was encouraged to hold a candle in memory of him. Simple songs were shared and the gathering concluded with a special meal arranged by the staff. Within one day, all ''disruptive'' behaviors of the older people in the home had disappeared (Botsford, 2000, p. 43- 44).

In the vignette above, thoughtful staff members considered the behaviours in the context of bereavement. A variety of verbal and non-verbal sensory-based approaches were employed to support meaningful participation in mourning, as well as individual expressions of grief, in residents with a range of intellectual strengths and capacities. Furthermore, workers were able to collaborate with resources outside of the residential setting to mitigate systemic barriers. As a result, the behavioural issues were reduced and ultimately resolved.

Part 3: Widening the Circle of Support

> Disability implies a loss not just at the moment of acquiring a disability, but repeated insults and ''losses'' at every turn, when an unaccommodating society causes renewed obstacles and suffering (Blotzer & Ruth , 1995).

The final section of this guidebook highlights some of the experts in with various disciplines that may be enlisted in providing bereavement support. In my own experience, bereaved persons with complex needs have better outcomes when loved ones, caregivers, bereavement counsellors, and clinicians with expertise in developmental disabilities come together to develop a plan of care. Needless to say, not every community is so resource-rich. As a result, those committed to providing the best care possible to bereaved adults with IDs may be required to engage in some self-directed “capacity building”, coupled with consultation with practitioners in other communities.

Home Support Workers and Other Professional Caregivers

The use of social stories, visual and communication aids such Picture Communication Symbols, and other alternative means of facilitating understanding and communication are typically familiar to most community and home support workers. Bereavement counsellors, hospice volunteers, or mental health workers may wish to draw upon this expertise to develop something that will be consistent with the capacities and needs of a particular client. Such materials may be especially helpful in assisting individuals attending bereavement counselling, or for those preparing to participate in activities such as a memorial service. Some bereavement books for adults with IDs are available, such as “When Somebody Dies” (Hollins, Dowling, & Blackman, 2003). This and other picture books for people with intellectual disabilities may now be obtained on-line through *Books Beyond Words*, a non-profit enterprise that has assumed publishing of this series, originally developed through St. George’s, University of London (http://www.booksbeyondwords. co.uk/welcome). These books may not be appropriate for every client but they are well worth considering as part of an agency’s resource library.

If you are working in a residential program that hasn’t done so already, consider developing a process and template for collecting historical resident information. Such a template may be useful for summarizing and tracking significant events, anniversaries of death dates, and relevant client strengths and needs. Adapted to the particular requirements of the setting, this type of file information may help to mitigate the issue of “unknown losses”.

Developmental Psychologists

Expressions or reactions to loss must first be understood in the context of the individual's unique developmental and cognitive challenges. Clinicians with expertise in developmental disabilities may be able to offer caregivers the opportunity to explore alternative interpretations of behaviours before intervening with medications or behavioural programs. Some authors have also examined the ways in which intellectual and socio-emotional age influence how people with IDs handle death and mourning (Meeusen-van de Kerkhof, van Bommel, van de Wouw & Maaskant 2006). Without understanding grief in the context of developmental delay, caregivers are more likely to miss attuning to the grief response simmering below the surface, or misread reactions from strictly a behavioural perspective.

Mental Health Worker

Some responses of grief can be particularly disturbing to caregivers. For example, most bereavement counsellors have heard from the bereaved that they experience the presence of the deceased. A person with an ID may strongly assert that their loved one is not only alive but has been visiting. Similarly, the bereaved person may seemingly resist accepting that their loved one has died, and instead claim they are at some other place and "not coming" because they are angry or upset.

Depending on one's ideological orientation, responses to such expressions can vary significantly. Is the griever, for instance, delusional? Or are they perhaps "attention-seeking"? Ideally, mental health clinicians working with people with IDs would understand mental disorders in the context of intellectual and socio-emotional age. Such expertise could greatly help caregivers distinguish between typical responses to loss, manifestations of developmental delay, and the kinds of mental health issues that require further assessment and /or treatment.

Bereavement Counsellors and Hospice Volunteers

In addition to providing emotional support to the griever who has an intellectual disability, bereavement counsellors and hospice volunteers working in residential settings may be called on to act as advocates and educators for caregivers. Bereavement counsellors and hospice workers well know that a caregiver's own experiences of loss may re-emerge simply by being in the presence of one who is actively grieving. Enabling caregivers to recognize and respond appropriately to their own needs, and ensuring that program administrators are also sensitized to this reality, may not only reduce the risk for burnout of caregivers, but also provide some protection against any unconscious interference in the grieving process of persons in their care.

The Role of Social Work

Social workers may become involved through a variety of avenues—as bereavement counsellors, mental health clinicians, managers of group homes, team members for palliative care and home hospice programs, case managers for adults with disabilities, and so on. Through each of these pathways, each with a particular role and associated responsibilities, there are opportunities for deepening our collective understanding of how best to support individuals with disabilities who are living with loss.

As a social worker for what was then British Columbia's Ministry for Children and Family Development—Community Living Services, I was required to place adults with IDs in the appropriate residential setting. As a former group home worker, I was also well aware of how challenging a mismatch between the person and their environment could be. One of the key pieces of learning for me in working in end-of-life care has been a deepening understanding of the impact of bereavement on "daily functioning"—for typical folks as well as those with IDs. Based on my own experiences in practice, further borne out in the research, I offer the following observation: Behavioural and functional changes are to be expected and ideally would be accommodated without undue disruption. Any formal assessment of the individual's support needs following a major bereavement, if it cannot be delayed, should be at very least informed by the understanding that, particularly during acute grief, the individual may present as less able than they are. I recommend that a review of care needs be scheduled, at minimum, within one year of a major loss.

There is another aspect to the role of social work that is relevant in this context. Canadian Social Work Social Code of Ethics (2005) articulates a commitment to social fairness and the equitable distribution of resources. We promote actions aimed at reducing barriers and expanding choice for all persons, "with special regard for those who are marginalized, disadvantaged, vulnerable, and/or have exceptional needs" (p. 8).

Within the context of bereavement support services to people with IDs there is a need to critique and address gaps that hamper access to grief support. I believe that such analysis, coupled with action, could greatly enhance the accessibility and the quality of support services currently available to people with IDs who are living with loss.

In Closing…

The literature is continuing to evolve, but there are still many important questions to be answered. Nevertheless, there is ample evidence that a supportive environment, supplemented as needed with interventions such as grief support groups, and individualized bereavement counselling, effectively reduce distress associated with loss. Until there is further empirical research that provides the basis on which to argue for or against a particular model or theoretical framework, the following general recommendations are offered for the consideration of all who comprise a person's circle of support:

1. Begin with yourself. Reflect on how your own experiences of grief may influence your capacity to be fully present for the person you are there to support.
2. Spend time with, and be truly present for, the person who is grieving.
3. With more "verbal" individuals, check their understanding of what has occurred and invite questions. Answer with simple, concrete terms in response and avoid the confusion that can result from explanations like the person has "gone to heaven". For if they can go somewhere, can they not return?!
4. Look at photos together. Simple words and images coupled with a compassionate and attuned presence can breach the loneliness that often accompanies loss, and models doing so for others.
5. For those labelled as profoundly disabled, loss may be expressed in behaviour, such as restlessness or resistance. Use sensory stimulation to create an atmosphere of remembrance. Favourite foods, particular scents, even favoured objects can be revisited and acknowledged in the context of shared remembrance.

6. Familiar patterns in daily life, respectful touch, and moments of special care can be soothing to someone who needs more time to understand that the person they are missing is not returning.
7. Work to strengthen relationships and facilitate “cross pollination” of perspectives between the disciplines and with family members. Particularly for those individuals who are expressing their loss in ways that are disruptive to others, an open dialogue that explores the potential for diagnostic overshadowing may be illuminating for many, and may further clarify risks and benefits of potential interventions.

We cannot take away the emotional distress that often accompanies living through loss. Nor should we, for feelings of loss can only emerge after we have also experienced connection and love. At the very least, however, those times of loss need not be lived in punishing isolation.

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