«Catechetica ed Educazione» 9 (2024) 1, 79-89.

Accompanying Persons with Disabilities and their Friends through Grief, Loss, and End of Life

William Gaventa*

► **ABSTRACT**

The article begins with a critical look at the practice of, and the importance given to, accompanying persons with disabilities and their friends in experiences of grief or loss. It goes on to present the challenges that emerge as progress is being made in the field and points out the lessons that are being learned from researches carried out and from the best practices that can be identified. It offers then a set of principles that can guide these practices, keeping in line with the challenges outlined, and reflects on the need to address the exigencies of planning this all-important service and the paradoxes involved in it such as the we-they discrepancies and the difficulties involved in the practice of labelling, with regard to accompanying persons with disabilities.

► **KEYWORDS**

Accompanying; End of Life; Grief; Loss; Persons with disabilities.

***William Gaventa:** Reverendo, Direttore del Summer Institute on Theology and Disability (Texas, USA).

Introduction

One of the hardest yet most sacred experiences in anyone's life is coming alongside a person who is grieving and/or facing the end of one's own life. There is nothing that reminds us more of our own mortality, than the fact that this is a journey all of us face.

Our first task on the way to learning is to do what I call "Reversing the Question". When someone asks how we should help a person with Down Syndrome to deal with the death of a parent or friend, or how to accompany someone with a physical disability as they face the end of their own lives, our answer should be another question: "How would we do that with anyone else?". Start from what we know already about coping with death and grief and assume commonality instead of difference. There may be communication issues, but those can be dealt with. There may be questions about the ability of a person with an intellectual disability to understand what is happening to them, or what has happened to a parent, but the truth is that all of us have difficulty understanding the death of parent or friend, much less our own. Sometimes there are no explanations. But there are personal, spiritual, and cultural ways of facing the grief and loss and mourning.

One reason we do ask the questions is because the lives and deaths of people with disabilities are too often overlooked, unseen, or devalued. That is where this paper will start, with issues in the past that are carried into the present. The newer, more just ways of working with people with disabilities carry new challenges and questions as social policy and caregivers recognize the value of community inclusion and their right to self-determination. They have the right to make choices and preferences known. Thankfully, there has been significant attention to grief, loss, and end of life issues for people with disabilities in recent years.

My focus will be on people with intellectual and developmental disabilities, partly because that is where most of my experience lies, and partly because I think that they teach us about what is most fundamental in accompanying anyone through loss, grief, and death.

1. Looking Backwards

During the last half century, there have been major changes in services and supports for people with disabilities in the United States and in other western countries. My first job was as a chaplain in a large state institution in upstate New York. Many people had been admitted because the professional advice to families was that institutionalizing a child was the best way to care for them. For many families, of course, that was a traumatic decision and event. Not long after I arrived there, a family came to the center wanting to see the gravesite of their teenage daughter. She was Protestant, so it was my task to accompany them to the beautiful countryside institutional cemetery. Beautiful, except for the fact that

there were no gravestones with people's names, only numbered round stone markers. Both parents almost collapsed with grief when they saw that, asking me and the universe, "Is this the only sign left of our daughter?".

Deaths in institutional care were also too often related to forms of institutional abuse or neglect. Looking for those cases became a hallmark of investigations of institutional care. But if not abuse, death was often a very lonely affair in a lonely place. I led a funeral for a man in the small Protestant chapel to which five people came. Four were other residents paid five dollars each to be pallbearers, the best paying job on campus. The other was a staff assigned from the ward where he lived. Otherwise, no other residents, no staff, no family, no friends. Funerals are really for the living, so it almost made no sense to me, but my anger at those circumstances led to a feeling of "let's do this right" as a matter of justice.

The social workers also occasionally received calls from relatives informing them that a resident's mother or father had died. I was asked to tell a young man named Dale that his mother had died. He struggled with language, so I tried to use simple words, some gestures, and whatever I could. Then, it was clear, he understood. He said, "Mum-Mum", hit his chest over his heart (indicating heart attack), gestured falling over, then put his hand above his head running his fingers in circles (flashing lights and siren) and then pointed towards heaven. He clearly understood. Unfortunately, the staff and I did not realize we could have done more, such as try to get some pictures, or find out from the family where the cemetery was, or encourage them to come visit him.

2. Challenges that Come with Progress

As people with intellectual and other disabilities became more visible because of community based services and supports, another kind of phone call and story emerged. A family member might call a social worker or other staff person and inform the agency that a parent or relative had died, but they did not want the person being served by the agency to come to the funeral. Usually, they were not sure he or she could "understand", or because they were afraid it would be too upsetting, and lead to behavioral outbursts. It is what grief scholar Ken Doka calls "disenfranchised grief", grief that is not recognized nor is it given any expression. We know that unrecognized and unsupported grief can express itself in a behavior that is difficult for others. (That is perfectly true of everyone). Pastoral theologian Granger Westberg once said, «Grief denied is grief delayed, and grief delayed is grief denied».[1] A caring circle involving a service agency, chaplain, pastor or others can address that by talking with someone's family long before the inevitable deaths happen, so that plans are made with a person or those who know them best about how to provide support when a close relative dies.

[1] Cf. G. WESTBERG, *Good grief: A constructive approach to the problem of loss*, 35th Anniversary edition, Fortress Press, Minneapolis 1997.

There are also online tools for adults with intellectual and developmental disabilities to think through their own preferences about care and supports as they face the end of their own lives.[2]

In the last fifty years, a core belief and assumption underlying changes in the services and supports with people with intellectual disabilities is that children and adults can learn and grow, both from effective educational strategies and from being included with other children and adults in classrooms and other learning environments. For many parents and professionals in the field, a strong sense of social justice has fueled commitment to growth and learning. Many of us have been fortunate to bear witness to remarkable growth by individuals and their becoming able to lead flourishing lives in communities, including faith communities.

People with intellectual and other disabilities are now also living longer. That means they also face the trials of old age and the loss of capacities that come with old age. None of them likes hospitals. While even the public thinks "hospitals are where you go to die", the hospitals pose unique problems for people with disabilities, especially people with multiple disabilities. Hospital staff may not have much experience working with people with intellectual disabilities or autism, for example, communication issues necessitate care to slow down, which is hard in a busy medical environment. It is far too easy for health care professionals to see the major problem of a multiply disabled person, as one of "quality of life", rather than the illness or injury that that made them a patient. Too often it becomes imperative for a parent or staff person to stay in the hospital simply to help the staff understand. Said another way, most of us appreciate having a family member or someone who knows us well, to be a presence and advocate when we are hospitalized. The *Health Care Passport* is a tool designed to help that communication, a person-centered description of who a person is, what they like and don't like and other ways of letting medical staff know who someone is.[3] One agency I knew in New Jersey used to write short phrases about their non-verbal clients on a balloon to tie to the end of their hospital bed, thus trying to personalize the patient, and help hospital staff to know that there is a community of people who care about, and value the person who is in that bed.

Even so, when the inevitable happens, and people begin to lose capacity because of illness, old age, and injuries, the community of care and support must shift to one of journeying with people as their limitations grow and as they move toward the end of their lives. That may be a difficult shift when so much energy has been put into helping people flourish. It is not a failure of rights, growth, and care, but rather a time to change goals from accomplishments to presence, care, and support. It also brings new roles, such as helping friends, families, and staff to deal with their own sense of grief and loss as someone they love is dealing

[2] Cf. California Department of Human Services and With Foundation, *Thinking Ahead. My Way, My Choice, My Life at the End*, (2006). Retrieved February 19, 2024, from <https://coalitionccc.org/common/Uploaded%20files/PDFs/Thinking-Ahead-2022-Web.pdf>.

[3] *Health Care Passport*. <https://healthservice.hse.ie/filelibrary/onmsd/hse-health-passport-for-people-with-intellectual-disability.pdf>.

with pain, illness, and loss. Clergy and religious communities can be an invaluable support not just by being present on that journey, but also by supporting the people who are the primary friends and caregivers in that person's life.

In the United States, for example, it has taken several decades for community-based service providers to realize they need to work along with hospice and health care providers. I have heard agencies say, "No one in our care dies", because death was so often interpreted as abuse in the older institutions. What it meant in practice is that an agency would transfer someone out of their residential care to a nursing home or hospital because they did not believe they could handle the death of a person they supported. However, people then began to realize that a person who had been in their care would lose all sense of home and long-standing relationships. A disabled person has both a need and the right to choose where they want to die. Now, collaborative relationships with hospice organizations can help agencies care for someone in the environment in which they have always lived. Clergy and congregational members can have two important roles here: being part of the support team for an individual and staff, and advocating, if need be, for an individual's choices and preferences as they move toward death.

To provide that kind of home-based support, care providers also must understand that the staff who are the closest caregivers may come from many different cultural and religious backgrounds. In parts of the United States, many of them are immigrants. That means a wide variety of beliefs about death and the cultural practices that cope with mourning and loss. It means that agencies who provide care, need to have clear policies and training about how to handle terminal illness or unexpected death of the people they serve. For example, at one workshop I led in New Jersey with several staff from the same agency, two homes had experienced recent deaths. One said their supervisor said crying by staff was unprofessional. Another said they had been told it was fine to do so.

Differences in belief and practice about what one should do when someone is dying or has died, can occur even in the same culture or same family. Health care professionals and clergy know far too well how relatives of a dying person can differ in opinions about how care should be delivered. One way that some agencies have addressed this, is to form "Grief and Loss Teams" composed of staff from a variety of disciplines, community clergy, hospice staff and others who can be called in to help the people with disabilities, their staff, friends and relatives when a person has died, or, better yet, before, to help everyone become more confident in their ability to journey with a person who is dying.

Community based residential systems, such as group homes or supported living, also face enormous waiting lists for their services. That can lead to significant pressure to fill a "slot" in their programs quickly after someone has died. Agencies only get paid if someone is there. That means that others in the living environment do not have time to experience the empty bedroom or place at the table. I have known of situations when other residents got angry at a new person coming in because they were taking their friend's room. We believe that people with intellectual and developmental disabilities can learn to handle grief and loss, but as with other learning, it may take more time. But the pressure in both

the care systems and in the general culture is for grieving people to move on quickly, to get over it, and return to "normal".

Once again, "normal" might not be so healthy.

3. Lessons Being Learned from Research and Practice

In the face of the challenges and issues of providing person-centered care so that a person is lovingly accompanied as they move to the end of their lives, there are some core lessons being learned about "best practices". They include:

- Seeking to help a person maintain relationships that are important to them and bring together those relationships into a "community of support" during serious illness or end of life. Who does a person trust? Who are their friends and family? Who have they turned to for support in the past? Asked another way, who might they want to say "good-bye" to, or who would like to be involved in saying "good-bye" to them.
- When a common policy value in disability services is self-determination, we need to give people choices about what they would like, as well as take seriously the opinions of close caregivers (of any role) who know a person very well, especially if they have problems in communicating. "*Supported decision making*" is a legal term for that process, recognizing that people who have been close to someone can often interpret behavior, including gestures and limited speech, to know what someone prefers. As people move toward the end of their life, can care-givers intentionally seek to expand that circle of support by inviting hospice staff, community clergy, and/or others in the community. One example is the organization *Compassio* in Porto, Portugal,[4] an NGO dedicated to ensuring that no one dies alone.
- We not only need to learn from people with intellectual and other disabilities about what is important to them, but also recognize that many people with disabilities are much more experienced in sharing and dealing with grief than "we" are. As stated earlier, they live in a world where relationships are primary (we all do, but don't always recognize it) and where they have had to deal with many losses. People with all forms of disability can also support others, and indeed help and teach anyone providing care.

4. Principles to Guide Practices

- Loss and grief will be present, no matter the level of disability or cognitive ability;
- Understanding death does not equate with cognitive ability. None of us really understands, and meanings vary, but we all experience it;

[4] <www.compassio.pt>.

- Losses come in many forms besides death: end of relationships, caregiver changes, moving, changes in valued routines, loss of pets, and more;
- We all "act out" our grief. Sometimes caregivers worry that a person with an intellectual or developmental disability will "act out" their feelings of grief, sorrow, or confusion in ways that are not "typical". That also happens with people who not disabled. But we need to recognize that our cultural and religious traditions and ceremonies of mourning, funerals, and burials are all ways of "acting out" our feelings of grief, our desire to be a comfort to others, and to mark the sanctity of life and its ending;
- Non-verbal supports may be more important than anything we say. Being present, and participating in a community of mourning, is more critical than cognitive ability. I heard someone say once that "when we cannot find the right words, it means that your thoughts and/or feelings are so important that words cannot carry all the meaning";
- There are many ways to provide support and presence, but remember it is crucial to help and let people "mourn". Jesus did not say, "Blessed are the comforters". Rather, "Blessed are they who mourn, for they shall be comforted". Trust that mourning itself is a human and holy experience, through which comfort may come;
- There is no timeline for grief. Our journey continues with memories, feelings, memorial days and ceremonies, holiday remembrances, and more, sometimes when we least expect.

5. Planning and Learning Ahead

In the United States, and perhaps in Italy as well, "typical" people are notorious for their reluctance to make plans for what they would like to happen towards the end of their lives. Making plans, through such processes as powers of attorney, one's wishes for end-of-life care, and funeral wishes can all help conversations to happen that avoid crisis and conflict when a person can no longer speak for themselves. What are some ways we could help this to happen?

- When an adult with an intellectual or developmental disability comes under care of an agency, an agency could ask both the individual and family about their own grief traditions and experiences. The family might wonder why, but an agency can do so proactively as a way of sharing its belief about the importance of addressing grief and loss with love and care as well as the importance of the disabled person's being involved in those experiences with families. A family might be uncertain, but the agency can say "we will also help when those times come";
- Caregivers and others who work with adults with intellectual and developmental disabilities can use moments from television when death is being talked about as "teachable moments" for answering questions about death and loss;

- As part of learning about the community, and about what happens at the end of life, an agency could help people visit a funeral home, talk with a pastor and church where funerals take place, visit the cemetery and so on, to take a bit of the unknown out of what happens. This may be particularly important with people on the autism spectrum to help them know what will happen in the multiple social situations involved in mourning and loss;
- There are now on-line tools for helping an adult with an intellectual disability or anyone else think and plan. One was mentioned earlier: *Thinking Ahead: My Life, My Choice, My Life at the End*. There are others;[5]
- There are also a growing number of online resources to assist individuals with disabilities, family members, staff, caregivers, and community friends. One of them on *Aging and Disability* notably comes from L'Arche of Canada.[6] *Talking End of Life … with people with intellectual disabilities* includes short interviews, care strategies and resources from Australia.[7] *My Grief.CA* is a virtual hospice with a section devoted to people with intellectual disabilities;[8]
- The Hospice Foundation of America sponsors a website called *Autism and Grief*,[9] with portals for autistic adults, family and close caregivers, and clergy and other professionals. This may be particularly helpful for people on the spectrum who have difficulty in social situations, managing intense feelings, and for whom ritual activities are important ways of relieving anxiety and self-control;
- One of my favorite resources are the *Books Beyond Words* coming out of the United Kingdom.[10] They are adult oriented social story books of pictures about a variety of life situations, with a possible text, but intended for a caregiver to "read" with an adult, or adults, with an intellectual disability and talk about the pictures as they go through. Several of them focus on the death of parents, friends, getting older, dealing with dementia, and healthcare. One does not have to be able to read English to talk about the story in pictures, assuming that the pictures are understandable in different cultures.

6. When the Time Comes

When a person with a disability experiences a loss or death of someone close to them, best practices in some ways boil down to the Golden Rule, "Treating others as you would want to be treated". In more detail, they include:

[5] *Accessible Planning Too: Glancing Back, Planning Forward*. Three versions, one for individuals, one for caregivers, and one serving as guide for the other two. From the excellent Trinity Center on Ageing and Intellectual Disabilities. University of Dublin, Ireland. <https://www.tcd.ie/tcaid/accessibleinformation/index.php>.

[6] <https://aging-and-disability.org>.

[7] <https://www.caresearch.com.au/tel/>.

[8] <https://www.caresearch.com.au/te5>.

[9] <https://www.autismandgrief.org>.

[10] <https://booksbeyondwords.co.uk>.

- Recognize feelings, welcome them, and provide safe spaces where people can grieve, with people they trust. With permission, you can call for a "grief professional", but they may not have much experience with people with disabilities and they will be a stranger to the person grieving;
- Be alert for behavioral signs of distress such as anger, sadness, confusion, fear, lack of appetite, and sleeplessness;
- Assist individuals who are grieving to do what is traditional in your community, such as send condolence cards, flowers, go through old pictures and talk, taking food to the family, going to the wake and funeral, etc. Customs of "acting out grief" in habitual ways vary between cultures, religions, countries and even communities in the same country;
- If needed, think about leading a memorial service in a work center or other places where the individual may have spent their days in addition to the funeral at the church. This may provide more ways and time for friends to help plan, talk, and remember;
- Help create individualized ways of remembering and memorializing someone, such as a photo album, memory boxes, memorial activities like a favorite meal, going to a favorite place, contributing to a memorial garden, or visiting the cemetery.

Jeffrey Kauffman, a social worker in the United States, named four primary strategies:

1. Provide honest an accurate information and support to questions and feelings. Do not avoid them. For many, including people on the autism spectrum, that means being concrete and clear. Do not use euphemisms such as "passed away", "went to sleep", or even "went to be with God" unless you take the time to explain what you mean about heaven and God's love. Otherwise, someone may hear "Let's go to Mass to be with God" and begin to wonder, "Am I going to die?";
2. Enable maximum social involvement in the social and spiritual activities surrounding death, and, if possible, help individuals to be involved in planning those activities;
3. Keep people connected to people they trust, for support. Support those supporters;
4. Maximize opportunities to express grief and condolences.[11]

7. The Paradoxes of Accompaniment

Whatever role and experience you bring to supporting people with disabilities, their families, friends and caregivers in their grief journeys and journey toward their own death and new life with God, there is often no one "correct"

[11] Cf. J. KAUFFMAN, *Guidebook for helping persons with mental retardation mourn*. Baywood Publishing Company, Amityville, NY 2008.

way or person to do something. It can be a process of balancing what seem to be contradictory attitudes or practices and finding what feels right in a particular time or context. These are some of them I have felt and experienced:

1. The boundaries between roles get blurred between staff, family members, professional caregivers including clergy, and friends. The key is support by people who are trusted. People at the end of their lives deserve us at our most human and flexible;
2. Directly related, care is sometimes just "being there" rather than "doing for". Trying to fix or explain the unfixable and unexplainable often hurts more than helps, builds barriers rather than bridges;
3. These are times for meeting people's growing limitations, but also celebrating their gifts. No matter who you are or your role, the final days are times to thank people for their gifts. How will people who are dying know that they have been important to us unless we tell them?
4. Professional caregivers can provide specialized services, but they can also empower others to be more present to someone by giving away what we know so that others can accompany their friend or family member more successfully;
5. One of most important professional skills, especially at times like these, is to know what they don't know, and thus be willing to invite others with needed experience or expertise (such as in a different culture or faith) in to help. Saying you don't know but can help find out does not enhances your expertise rather than diminishing it.

8. We Not Them: It is About All of Us

The most profound paradox and lesson I have learned over the years is that by trying to learn what I can to help or accompany people with disabilities in their grief and end of life journeys, or trying to support others who alongside them, is that in the end, the lessons learned are not just about "them", but about all of us. Re-read these pages and tell that you do not think the suggestions do not apply to what you might want for yourself or loved ones. I know that for me, when I have tried to do my best in accompanying others in my care, or when I have heard profound stories from others doing the same, I end up thinking "I hope that happens for me and those I love" or "I hope that *never* happens to me or someone I love".

Once again, it is the paradox of labels. Naming a disability or difference can be very, very helpful for individuals and families who are searching for answers and in them finding how help has been provided to others. But labels can be harmful when we assume differences in areas where we are all more alike than different. Assumptions of differences in accompanying people with disabilities just because they have a disability, disempowers both parties. Remember the strategy of "reversing the question" at the beginning of this article. Sometimes I end up wanting to ask a health care professional, chaplain, priest, and caregivers in other roles who are uncertain that they have to offer someone with a disability: "What gifts do you bring in your care to others without those labels? Start there.

Trust what you can do and learn. But first, be there, first, and you may find yourself being blessed and taught in ways you had never expected". We are all at some level strangers to one another, In the hospitality of accompaniment. As we learn repeatedly in the Bible, it is often God who shows up.

Accompagnare le persone con disabilità e i loro amici attraverso il dolore, la perdita e la fine della vita

► **SOMMARIO**

L'articolo inizia con uno sguardo critico alla pratica e all'importanza data all'accompagnamento delle persone con disabilità e dei loro amici in esperienze di dolore o perdita. Prosegue presentando le sfide che emergono man mano che si compiono progressi nel settore e sottolinea gli insegnamenti tratti dalle ricerche condotte e dalle migliori pratiche che possono essere individuate. Offre quindi una serie di principi che possono guidare queste pratiche, in linea con le sfide delineate, e riflette sulla necessità di affrontare le esigenze di progettazione di questo importantissimo servizio e i paradossi che esso comporta, come le discrepanze noi-loro e le difficoltà che comporta la pratica dell'etichettatura, per quanto riguarda l'accompagnamento delle persone con disabilità.

► **PAROLE CHIAVE**

Accompagnamento; Dolore; Fine vita; Perdita; Persone con disabilità.

bill.gaventa@gmail.com