Deep in the shadows of loss: An exploration of grief, mourning, and intellectual disability

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Deep in the shadows of loss: An exploration of grief, mourning, and intellectual disability

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Dissertation
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Deep in the shadows of loss: An exploration of grief, mourning, and intellectual disability

Abstract

This qualitative research project explores grief and mourning experiences of people labelled/with intellectual disabilities subsequent to the death of someone important in their lives. The primary research question was: in what ways do people labelled/with intellectual disabilities experience grief after the death of a significant person in their lives? The need for a project of this kind is grounded in the lack of research and social work practice literature related to better understanding grief, mourning, and support experiences after a death from the perspective of people labelled/with intellectual disabilities. The dual purpose of this research is to better understand (and help others understand) the complex experience of grief after a death for bereaved people labelled/with intellectual disabilities, and, from this understanding, develop ideas for how social workers (and other professionals and support people) can provide sensitive, timely, and meaningful grief support over the lengthy time where they may have a range of grief reactions. To achieve this dual purpose, the research methodology of interpretive description was used within a care ethics framework of engaging with ‘vulnerable’ populations. Individual interviews were conducted with people labelled/with intellectual disabilities (N=14) from different locations in Ontario. In addition, support people (N=4), and key informants (N=5) were also interviewed. The interviews were followed by thematic analysis of the data collected. Participants provided insights relevant to the research question and pre-existing literature on the topic that have implications for understanding the intersection of grief and disability, and for practice. The findings demonstrate that although many of the grief reactions experienced by the bereaved participants are similar to those of the neurotypical population there remain significant differences in a number of areas, such as limited choice, exclusion, significant loss histories and
trauma, and gatekeepers monitoring grief expression, that have implications for practice and education. Notably, bereaved people labelled/with intellectual disabilities indicated that rather than always being only the recipients of bereavement support, they want to use their experiences to help others - their bereaved peers, family members, and paid staff. This project contributes valuable practice insights and points to the need for better education for social workers (and other professionals in developmental services) in the intersecting topics of thanatology and disability studies.

**Accessible Abstract:**

- 14 people labelled/with intellectual disabilities shared what it was like for them after someone important to them died.

- They shared that they had many different feelings, thoughts, reactions in their bodies, and questions after the person died.

- The people labelled/with intellectual disabilities said that it is important to have the choice of whether or not to go to a funeral or the cemetery. They do not want people to keep secrets from them. They want to hear the bad news and be supported when this news is shared.

- Many shared that they had a lot of losses in their lives (living away from home, many staff that come and go, and people who died) and some had lots of trauma experiences too.

- Bereaved people labelled/with intellectual disabilities told me that they want to help other bereaved people (family, friends, paid staff) because they have learned so much from their own experiences.
Acknowledgments

My PhD journey has been long and fascinating and would not have been possible without the support and encouragement of many people. My process toward completion may have been different from many of my colleagues, but the richness of my learning and enhancements to my practice (both clinical and teaching) would not have been possible if I had not given myself the time I needed while also attending to my family, friends, and work. I had the pleasure of working with two supervisors over the years. Dr. Eliana Suarez agreed to be my supervisor after the retirement of Dr. Gary Cameron, and I am very grateful for her support, expertise, and enthusiasm for my dissertation topic. She has provided valuable insights, ongoing encouragement, and offered suggestions that have been exceptional. I would also like to thank my wonderful committee members who have remained engaged through the years: Dr. Michelle Skop (co-supervisor); Dr. Ann Fudge-Schormans; and Dr. Eunice Gorman. It has been an honour and privilege to learn from all of you and to have my work shaped through your unwavering support.

I have been fortunate to develop friendships with many doctoral student colleagues, professors, and staff during my time as a doctoral student, and I appreciate their unwavering support. Thankfully none of my doctoral colleagues had ‘meltdowns’ at the same time as me, and we shared our struggles and triumphs through text messages, phone calls, and over lunch many times. Thank you, Samantha Clarke, Dr. Karun Karki, Dr. Todd Adamovich, Dr. Bibi Baksh, Amilah Baksh, and Lin Haag. Thank you Zaida Leon, Peggy Freymond, Dr. Michael Woodford, Dr. Magnus Mfoafo-M’Carthy, and Dr. Deena Mandell. Thank you also to my wonderful research assistant, Nadeem Momenzadeh, who helped connect me with potential participants during a pandemic and transcribed all of the research interviews.
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Dedication

The human soul doesn’t want to be advised, fixed, or saved. It simply wants to be witnessed, seen, heard and companioned exactly as it is. When we make that kind of deep bow to the soul of a suffering person, our respect reinforces the soul’s healing resources – Parker J. Palmer (2016)

This dissertation is dedicated to the wonderful people who participated in this research project. I appreciate your trust, honesty, and that you shared with me some of your treasured memories and difficult experiences. My hope is that I have honoured your experiences through this work and that your contributions will help others beyond this paper – that your words and suggestions will help the healing of other grieving human souls. You have inspired me to continue to share your stories and what you have taught me in ways that educate, influence practice, and support others through loss and in grief. Thank you!
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Chapter 1: Introduction

For well over 150 years in Canada, people labelled/with intellectual disabilities\(^1\) have been socially excluded and experienced inhumane treatment. They have been subjected to multiple forms of harm, including, but not limited to, institutionalization, exclusion from education, sterilization, and denial of personhood (Malacrida, 2012, 2015; Rossiter & Rinaldi, 2019). The exclusion and mistreatment of people labelled/with intellectual disabilities coincides with Western medical and capitalist institutions becoming more death-denying and death-defying in end-of-life practices in the past century, to such a degree that the inevitable human experiences of death and grief have been increasingly medicalized and pushed to the margins of everyday life (Granek, 2016; Harris, 2009; Kastenbaum & Moreman, 2018; Wittkowski & Menzies, 2021). As Western capitalist society has become more individualistic and focused on economic growth, with medical advances aimed at the manipulation of genetic material to prevent or alter disability to achieve ‘perfection’ of the human body (Bérubé, 2013) and defying death, disability and death have become the “ultimate failure of medical science” (Hadad, 2009, p. 6), while impairments, grief, and mourning are increasingly measured against medical definitions of what is ‘normal’ and ‘abnormal’ (Bérubé, 2013; Malacrida, 2015; Rogers, 2016; Zachar et al., 2017). Despite the more contemporary move by researchers and authors such as Kübler-Ross (1969), Wolfelt (2005, 2016), and Neimeyer (2012) to make death and dying discourse more visible beyond the field of thanatology, dying people tend to remain hidden away

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\(^1\) In this dissertation I use the terms intellectual disability and people labelled/with intellectual disabilities. There is no one agreed upon term to speak of intellectual and/or developmental disability. I refer to people as being labelled/with intellectual disabilities to reflect both having a label imposed on oneself and disagreeing with (rejecting) it, and, for some, the acceptance of the label while maintaining a people first orientation, as preferred by some self-advocates (Fudge Schormans et al., 2019; Spagnuolo, 2016). I have chosen not to shorten the terms to acronyms as I believe this further diminishes an already oppressed and marginalized group of labelled people.
in hospitals and long-term care facilities, and are often subjected to intrusive and sometimes destructive medical procedures in the effort to sustain hope and prolong life, all the while potentially increasing suffering (Northcott & Wilson, 2016; Zucker, 2007). This parallels the treatment of people labelled/with intellectual disabilities in Canada who were institutionalized on a large scale, and, both in and outside of institutions, have been subjected to intrusive, destructive - and typically unnecessary - medical procedures (Malacrida, 2015; Rossiter & Rinaldi, 2019). More recently, even with the deinstitutionalization movement, people labelled/with intellectual disabilities remain largely absent from the everyday life of communities.

Given the long-term marginalization of people labelled/with intellectual disabilities, and the wide-held view that they cannot contribute to capitalist neoliberal systems financially and intellectually, the dominant able-bodied society does not value the lives and deaths of socially disabled bodies (Butler, 2006; Malacrida, 2015; Rogers, 2016). Furthermore, people labelled/with intellectual disabilities are often shielded from knowledge about end-of-life issues and excluded from knowing about death and participating in rituals for reasons such as infantilization (assuming the person has a child-like understanding of the world), denial of personhood, and worry that their behaviour will be ‘difficult to manage’ (McCord et al., 2021; Rogers, 2016; Tuffrey-Wijne et al., 2017).

The focus of many professional helping relationships, including those related to treatment of grief, has become about measuring outcomes and levels of recovery, rather than on individualized healing presence and flexible clinical process (Harris & Winokuer, 2021; McGann et al., 2021). In Canada, this is related to neoliberal restructuring of health and social services as well as the move to demonstrate efficiencies using evidence-based, short-term practices and
interventions (Baines, 2018; Preston & Aslett, 2017; Smith, 2017). There has also been long-standing debate about what a ‘neurotypical’ (understood as ‘acceptable’) grief process involves for the bereaved, which opens the door to pathologizing grief. As Foote and Frank (1999) note, “grief, like death itself, is undisciplined, risky, wild” (p. 170), and in a society that prefers predictability, clear trajectories, answers, and ‘resolution’, unique grief and mourning expressions are not always well tolerated socially (Hadad, 2009; Kastenbaum & Moreman, 2018). Thus, when individuals do not follow socially acceptable “grieving rules – that attempt to specify who, when, where, how, how long, and for whom people should grieve” (Doka, 1989, p.4) their grief and mourning is viewed as problematic, and potentially pathological. This is particularly challenging for bereaved people labelled/with intellectual disabilities who are viewed by many as being outside of socially acceptable ways of being (Kauffman, 2005; Malacrida, 2015). Furthermore, as will be expanded on in following chapters, people labelled/with intellectual disabilities are often not viewed as capable of understanding death or experiencing grief reactions, leading to their exclusion from participation in rituals surrounding death and not always receiving social support for their grief and mourning needs (McCord et al., 2021; Morse et al., 2016; Tuffrey-Wijne et al., 2017).

The prominent grief theories and models that will be explored in this dissertation tend to describe both typical and pathological grief expression and mourning behaviour, with little in between. Despite this, thanatologists are advancing clinical knowledge regarding the grief process, from theories of decathecting (detaching emotional energy from the deceased) (Freud, 1917), to stages of grief (Kübler-Ross, 1969), to current theories and models that recognize the individuality of grief after a death and the complex factors influencing grief and mourning experiences (Blackhall & Gyalsten, 2021; Doka & Chow, 2021), while encouraging the
development of continuing bonds with the deceased and meaning-making from the loss (Gilbert & Macpherson, 2021; Kosminsky & Jordan, 2016; Neimeyer, 2006). Within these theories and models, researchers have also studied particular groups of mourners – for example, widows (Parkes, 1996), bereaved parents (Buckle & Fleming, 2011; Calderwood & Alberton, 2021), and children/teens (Balk, 2009; Goldman, 2013; Webb, 2010) – proposing special considerations for each group, typically through an ableist lens.

This acknowledgement of the diversity of grief expression and mourning practices has yet to fully extend to exploration of how grief reactions are understood and how helpful support can be practiced with people labelled/with intellectual disabilities (Morse et al., 2016; Read, 2014; Tuffrey-Wijne, 2013; Tuffrey-Wijne et al., 2017). In comparison to the other populations studied within thanatology, there exists a significant gap in the current literature and research regarding best practices for understanding grief and providing appropriate support for people labelled/with intellectual disabilities who are grieving the death of a significant person in their lives. Thus, the following overarching research question guided the process of this dissertation research: in what ways do people labelled/with intellectual disabilities experience grief after the death of a significant person in their life?

To examine this question and significant gap in research and practice knowledge, this dissertation starts by exploring contemporary grief literature and practices, relevant disability literature, and the intersection of how bereavement related issues are understood and support is practiced with individuals with an intellectual disability. The review of these bodies of literature will demonstrate that there is no one model of grief and mourning applicable across losses and populations (Harris & Murray, 2021), and that there is little focus on the loss experiences, subsequent grief expressions, and support of people labelled/with intellectual disabilities,
particularly from the perspective of those with lived experience. The significant omission of 
literature informed by people labelled/with intellectual disabilities grieving a significant death 
influenced my research questions, methodological approach, and interpretation of the data.

My research interest is grounded in my professional experience over the past three 
decades in community-based bereavement support services and failing to see people 
labelled/with intellectual disabilities referred to bereavement support programs and counselling 
that are available to the neurotypical population. This led me to wonder if these referrals were 
not evident because support persons did not believe people labelled/with intellectual disabilities 
grieve and thus saw no need for bereavement related support, or if it was because they were 
receiving support somewhere else in the community, or if the services I was providing in the 
community were not sufficiently inclusive. Pondering the absence of mind/body difference in my 
bereavement practices led to my interest in exploring the grief experiences of people 
labelled/with intellectual disabilities through a formal research process. I want to be cautious 
against ‘othering’ in this process, meaning that at the outset of my research I did not expect the 
grief and mourning needs of people labelled/with intellectual disabilities would necessarily 
appear vastly different from those of the neurotypical population. However, I was wondering if 
the expectations about, expressions of, and understanding of grief and mourning, along with 
related supports, would look dissimilar, particularly considering the varying theoretical lenses 
through which one can view grief and mourning, and disability.

**Guiding Beliefs & Questions**

We are all differently positioned within society and social systems when it comes to 
navigating the complexities of life. We have differences along inter-personal, socio-economic, 
intellectual, physical, spiritual, and regional/cultural/racial spectrums and resources, to name a
few. We are also differently situated, socially and within an ableist perspective, when it comes to grief and mourning in response to loss (McCord et al., 2021; Morse et al., 2016). Grief affects individuals across various life domains, including the emotional, behavioural, cognitive, social, physical, and spiritual realms (Calderwood & Alberton, 2021). Grief and mourning are also influenced by factors such as the quality of relationship with the deceased, preparation for the death, cause of death, the person’s previous loss history, the role of the deceased in the family, other stressors (financial, interpersonal, etc.), inclusion or exclusion from death rituals, cultural differences, and any outstanding unaddressed issues (Doka & Chow, 2021; Victoria Hospice et al., 2017; Worden, 2009).

People labelled/with an intellectual disability are a heterogeneous group, with wide ranging strengths, desires, and support needs, which requires attention to the nuances of individual experience within social contexts in the investigation of the literature in both the thanatology and disability fields. Yet it is essential that I acknowledge my core belief that grieving a loss does occur regardless of a person’s cognitive and communication abilities, because as humans we all share the need to be in relationship with others for support, approval, and love (Bowlby, 1960; Lord et al., 2017). It is through these relationships and attachments that we define ourselves and create the narratives of our lives. Thus, when people in our lives die, we suffer the loss of not only the person who died, but also of our co-constituted worlds and the many secondary losses attached to that lost relationship (Corr et al., 2019; Morse et al., 2016; Rando, 1993). These interconnected losses, how they affect people labelled/with intellectual disabilities and the types of grief support they have access to, are at the core of exploring the nuances and complexities of the grief and mourning experiences of the people who will engage in my research.
My Motivations

Death is intrinsic to human experience. We may try to cram it into a dark closet and shut the door. There it stays until, bursting the hinges, the door flies open and death is forced upon our awareness. For some, death may be like a mysterious stranger at a costume ball, whose mask conceals the face beneath. Perhaps the disguise is more terrifying than the reality, yet how can we know unless we risk uncovering the face hidden beneath the mask? Learning about death and dying helps us to identify attitudes and behaviours that keep us from lifting the mask and confronting death in a way that is meaningful for our own lives. (DeSpelder & Strickland, 2007, p. 39)

When I think back to my days in elementary school in the 1970s, I remember having many friends with varying backgrounds, abilities, and beliefs. In this small community school, just outside of Montreal, there was a separate class for children labelled with varying intellectual disabilities (at the time, it was called a special education class). Although these children did not join us in our daily classes, we were encouraged to play together on the playground at recess and at lunch. So, my early memories include children from the special education class with whom I played tetherball and four-square and slid down ice slides at Carnival. We had such fun together as friends, not distinguishing our differences in the segregated ways the adults had in terms of our educational opportunities. For the remainder of my middle and high school years (spent in five different schools in three different provinces), people deemed to have differing intellectual and developmental abilities were absent from my life. I do not even recall any more ‘special education’ classes in these subsequent schools.

Fast forward to my studies at Toronto Metropolitan University in the Bachelor of Social Work program, where two very significant experiences occurred that, to this day, shape my
academic and social work practice interests. First, I had a second-year field placement at an institution where people labelled/with intellectual disabilities lived. I had the opportunity to experience the negative aspects of institutional and segregated living for these adults, but I also encountered many caring employees who worked hard to meet the needs of the residents of the institution, and some family members who remained involved in the care of their loved ones.

During this field placement, I remember a young staff member (I will call her Gayle) whom I had observed several times while she facilitated a craft group with some of the residents of the institution. One day, she died on her way to work. Although other staff and employees knew of her death, I do not remember anyone sitting down and talking to the group members she had worked with about her death or facilitating their possible grief reactions in any way. She was just gone. Another employee took her place in the group and the craft activities carried on. This left me to wonder if institutional management had purposefully decided not to tell the group members (thus not acknowledging their personhood and abilities to have meaningful relationships with others) or if the group members were viewed as non-persons incapable of the grief experience due to their disability. Perhaps management and staff were uncomfortable talking about death and did not know how to speak to the group members and manage their possible grief reactions.

While still engaged in this field placement, the second event occurred, one so personal and traumatic that it changed my life forever. Very early one morning, I was woken up by my mother screaming for me to call 911. My father had stopped breathing in his sleep. I tried to save him. I ran to wake up neighbours to help me do CPR, and he was taken to the hospital where we were told upon our arrival that he was dead. He had been healthy, vibrant, and only fifty years old. I knew nothing about how to handle my reactions to this event, or how to manage in my new
grieving family. I entered an unfamiliar world without the foundation of my father, and with intense emotional, cognitive, spiritual, social, and physical reactions that I had never before experienced. I did not realize that I had also been traumatized by what I witnessed and by my failure to save my father. I needed the space to grieve, and I needed understanding and support, but I had exams to write, courses and field placement to return to, and a widowed mother to look after, so my grief was crammed into the dark closet with the door tightly shut, as DeSpelder and Strickland (2007) so vividly describe above. Yet no one noticed. I believe most people were relieved that they did not have to deal with my grief, but it did creep out through the small cracks and began to affect my overall health and relationships.

Years later, after recognizing and working on my trauma and grief reactions, which included attending a bereavement group for young adults, I started volunteering as a facilitator of children’s bereavement groups. This was one way to honour my experiences and ongoing relationship with my father, and to give back to others in need of support. I also had the professional and personal experience needed to be an effective facilitator. Having said this, I do not believe that one must have the same personal experiences as the people one works with to be effective in the work being done together. I work with compassion, respect, and a willingness to not be the expert. I have now had the privilege to develop and facilitate countless mutual aid bereavement groups for children, teens, and young adults through my professional work. My dedication to this work comes from a personal passion rooted in my father’s death and my experiences of not being educated about death and grief at a younger age, and not seeing grief socially recognized in many situations. The absence of my father’s physical presence in my life has influenced who I am today as much as the time I had with him before his sudden death.
As I reflect on my journey in my PhD studies, my passion for studying grief related to death remains, and my interest turned specifically to researching grief related to death in the lives of people labelled/with an intellectual disability. Just as people labelled intellectually disabled became invisible in my educational experiences growing up, they have remained invisible in my extensive and long-time work in grief support. As community living staff, school board staff, and other professionals increasingly sought my professional advice about how best to support bereaved people labelled/with intellectual disabilities, I became even more curious about the lack of information related to grief and people labelled/with intellectual disabilities and what research and literature had to say about this important topic. I came into my PhD studies with a very strong foundation in social work practice, grief counselling, and death education. I wish I could say that I learned about thanatology and/or disability studies during my previous degree programs, but there is a significant lack of education in both fields (never mind their intersection), and my education in these areas has come through long-term personal and practice experience, and significant continuing education pursuits.

I have maintained a social work focused applied purpose throughout my comprehensive and dissertation work, as I believe it is important to better understand how social workers, in terms of practice knowledge and supportive interventions, can be helpful to bereaved people labelled/with intellectual disabilities. Social workers are uniquely positioned with skills to examine human challenges at all levels – micro, macro, and mezzo – using generalist and humanistic approaches, as well as with specialized training, to explore human conditions beyond the individual, considering historical factors, anti-oppressive practice, and wider system social influences (Burton et al., 2022; Finn, 2021). Social workers are also trained collaborators who
work alongside clients to reach client goals, and many also act as educators, sharing clinical knowledge and skills beyond solely the counselling role (Ruffolo et al., 2016).

My personal and professional belief is that death and dying are topics that need to be talked about and taught more broadly, and that coming together in compassion and companionship should not be dependent on intellectual or physical ability. As noted death and dying researcher and author Elisabeth Kübler-Ross wrote in 1969, “I am convinced that we do more harm by avoiding the issue [of death and dying] than by using time and timing to sit, listen, and share” (p. 142). This leads me back to the story of Gayle and her group members. Although I do not know the effect that Gayle’s absence due to her death had on the group members (and others who knew her), I do believe that a more respectful and compassionate approach would have been to sit, share, and listen as a group of humans all affected by the sudden death of a community member.

**Overview of the Organization of Chapters**

This dissertation is ordered in chapters, each providing separate yet interconnected content that is related to the primary research question: in what ways do people labelled/with intellectual disabilities experience grief after the death of a significant person in their lives? This introductory chapter has provided context for my interest in this topic and a brief preliminary discussion of the intersecting areas of thanatology and disability studies. In chapter 2, I provide a detailed overview of the relevant literature in both thanatology and disability studies; looking at how both bodies of literature view grief and intellectual disability historically, while landing on contemporary theories and practice approaches that informed my research approach and interpretations of findings. Given that I am examining two large bodies of literature, thanatology and disability studies, as well as how they intersect, Chapter 2 is organized into sections. This is
an effort to make the large amount of material more digestible, while also distinguishing the two bodies of knowledge that I needed to engage with both separately and together while also considering contemporary social work practice. In Chapter 3, I explain the chosen methodology of interpretive description along with the process of my research project. Interpretive description is a qualitative approach to research developed to address human “…experience[s] from holistic, interpretive and relational perspectives” (Burdine et al., 2020, p. 336), an approach well suited to exploring the intersecting topics of thanatology and disability studies, as it seeks to generate broader understandings of nuanced and complex human experiences that inform support and professional practice (Thorne, 2016).

Chapter 4 introduces the research participants and the key findings that emerged from data analysis. The key themes emerging from the interviews with participants include reactions to a death, background context (personal and interpersonal), coping with loss, meaning reconstruction, and organizational contexts. Within each of these overarching themes, sub-themes emerged that will be illustrated through participant quotes. My reflexive process is also discussed in this chapter, providing an overview of what was occurring for me subjectively, how my beliefs and assumptions might be informing/interfering with data collection, and how my understanding was being affected in light of what I was learning from the research participants. Chapter 5 provides a discussion of my interpretation of the findings within existing literature and practice, the implications of the findings, and how this research deepens and extends the current knowledge related to grief in the lives of people labelled/with intellectual disabilities. The experiences and needs of the bereaved participants labelled/with intellectual disabilities inform the concluding comments made in the final chapter related to practice, education, and inclusive support.
Chapter 2: Literature Review

The purpose of a literature review within an interpretive description methodology (further described in Chapter 3) is to situate the researcher “substantively, theoretically, and within a disciplinary orientation” (Thorne, 2008, p. 55). Thus, for this research project, literature from the fields of thanatology and disability studies, particularly from a social work lens when available, was explored to determine relevant theories, approaches, and considerations for bereaved people labelled/with intellectual disabilities. It is also important to always be attentive to the key research question(s) when conducting a literature review across intersecting topics – such as death, grief, and disability – so that efforts to seek and review large bodies of literature are focused and relevant. The primary research question guiding my examination of the thanatology, disability, and research literature is: in what ways do people labelled/with intellectual disabilities experience grief after the death of a significant person in their lives? The literature review conducted for my dissertation research related to this question also needed to best support the chosen methodology of interpretive description. To do this, I focused on literature that “grounds the study within the existing knowledge, offers critical reflections on what exists and what does not, and offers commentary on the strengths and weaknesses within the overall bodies of knowledge” (Thorne, 2008, p. 61).

Subsequently, the following questions guided the theories, models, and interventions explored in this literature review:

1. What are the current theoretical models of bereavement, grief, and mourning that can inform exploration of bereavement in the lives of people labelled/with intellectual disabilities?
2. What are the current theoretical models in disability studies, and what do they have to say about the experience of being labelled/with an intellectual disability?

3. Are there best practice models and interventions in the grief literature that are inclusive of individual difference?

4. Given that I am exploring a specific population with a specific life event, are thanatology and disability studies communicating with one another academically and/or in practice?

5. What does the literature say about social workers working with grievers who are labelled/with intellectual disabilities?

To address these questions and share the literature that informs my research, it is necessary to define the terms being used before I explore theories and models of grief and mourning within the neurotypical community, and intervention models recommended for particular populations. Next, I will present a discussion of relevant literature from the field of disability studies to consider perspectives I will utilize in looking at the intersections of grief, mourning, and disability. Following this will be an exploration of best practices for supporting people labelled/with intellectual disabilities who are grieving the death of a person in their lives. The following table outlines how this chapter organizes this information, which is not intended to be in any order of importance of one section over another, rather it is a means of organizing the information for the reader:
Table 1: Organization of Chapter 2

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A) Defining Terms

Defining the key terms that will be used throughout this dissertation is an important task, particularly in relation to the thanatology literature, as some terms are used interchangeably.

*Bereavement* refers to the objective fact that a loss has occurred. According to Corr et al. (2019), there are three elements necessary to be bereaved: “(1) a relationship or attachment with some person or thing that is valued; (2) the loss – ending, termination, separation – of that relationship; and (3) an individual who is deprived of the valued person or thing by the loss” (p. 218). One can be bereaved for a variety of losses beyond the death of a significant person. Losses can be developmental (e.g., maturation), situational (e.g., relationships, employment) or symbolic (e.g., loss of dreams, hopes); (Doka & Martin, 2010; Harris & Winokuer, 2021). The bereaved participants in my research have experienced the death of a significant person or persons in their lives, which also comes with related secondary losses which will be discussed later in this chapter.

The terms *grief/grieving* are used to describe our personal, subjective reactions to a bereavement, including reactions that are emotional, behavioural, cognitive, social, physical, and spiritual (Corr et al., 2019; Doka & Chow, 2021). Table 2 provides examples of grief reactions across these domains; reactions that will be unique to everyone depending on many factors (e.g., individual temperament, relationship with the deceased, cause of death, social support, etc.). Grief in response to a loss is viewed by many researchers and practitioners as an adaptive process which encompasses our reactions across these domains (Corr & Corr, 2007; Gilbert & Macpherson, 2021; Harris & Winokuer, 2021).
Table 2: Examples of Possible Grief Reactions Across Multiple Domains

<table>
<thead>
<tr>
<th>EMOTIONAL</th>
<th>PHYSICAL</th>
<th>COGNITIVE</th>
<th>SOCIAL</th>
<th>BEHAVIOURAL</th>
<th>SPIRITUAL</th>
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<tr>
<td>Sadness</td>
<td>Tired</td>
<td>Blaming</td>
<td>Support</td>
<td>Changes in activity level</td>
<td>Religious affiliation</td>
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<tr>
<td>Anxious</td>
<td>Upset stomach</td>
<td>Confusion</td>
<td>network</td>
<td>Withdrawal</td>
<td>Religiousity</td>
</tr>
<tr>
<td>Nervous</td>
<td>Appetite changes</td>
<td>“I’m crazy”</td>
<td>Perceived role of deceased</td>
<td>Changes in sexual activity</td>
<td>Challenges to faith</td>
</tr>
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<td>Guilt</td>
<td>Shakiness</td>
<td>Poor decisions</td>
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<tr>
<td>Anger</td>
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<td>Disbelief</td>
<td>(stigma)</td>
<td>Change in ability to communicate</td>
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</tr>
<tr>
<td>Despair</td>
<td>Agitation</td>
<td>Poor concentration</td>
<td>Relationship with the deceased</td>
<td>Increased substance use (alcohol/drugs)</td>
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<td>Panic</td>
<td>Rapid heart rate</td>
<td>Memory problems</td>
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<td>Sleep</td>
<td>Assumptions about life/death</td>
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<tr>
<td>Fear</td>
<td>Thirst</td>
<td>Nightmares</td>
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<td>Relief</td>
<td>Headaches</td>
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<td>Antisocial acts</td>
<td>Symbolism</td>
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<tr>
<td>Uncertainty</td>
<td>Blurred vision</td>
<td>Changes in thinking</td>
<td></td>
<td>Intensified startle reflex</td>
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<tr>
<td>Depression</td>
<td>Vomiting</td>
<td>Suicide ideation</td>
<td></td>
<td></td>
<td>Beliefs</td>
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<tr>
<td>Longing</td>
<td>Teeth grinding</td>
<td>Values</td>
<td></td>
<td></td>
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<tr>
<td>Overwhelmed</td>
<td>Weakness</td>
<td>Beliefs</td>
<td></td>
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<tr>
<td>Irritability</td>
<td>Dizziness</td>
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<td>Loneliness</td>
<td>Insomnia</td>
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<td>Helplessness</td>
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<td>Hopelessness</td>
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Adapted from: DeSpelder & Strickland (2020); Hadad (2009); Mitchell & Everly (2003).

*Mourning* has been described both as the “intrapsychic and interpsychic processes of coping and learning to live with loss and grief” (Corr & Corr, 2007, p. 131), while also being described as the public or social process of expressions of grief in response to the bereavement (e.g., lowering a flag to half-mast; in some cultures, women wear black clothing to indicate their status as a grieving widow) (DeSpelder & Strickland, 2020; Kastenbaum & Moreman, 2018).

Mourning is an essential process for coping with grief and can provide ways for the bereaved to integrate the loss(es) into their life moving forward (Corr et al., 2019).

My research examines bereavement, grief, and mourning in the context of death; nonetheless, I acknowledge that people face numerous losses throughout their lives which trigger grief responses and mourning behaviours (e.g., end of a relationship, moving, ageing, changes in support persons). People labelled/with intellectual disabilities can face compounding losses
related to the social construction of and social responses related to their labelled disability including, but not limited to, loss of personhood, loss of independence, loss of support persons, and loss of autonomy, which typically leads to experiences of discrimination, oppression, and marginalization.

Intellectual disability, a term devised by professionals to describe people who are understood, from a statistical and medical perspective rooted in dichotomous ideas of ‘normal/abnormal’, to “function and behave in ways that seem to be different from the majority of people” (Brown et al., 2017, p. 4). Intellectual disability is categorized as a neurodevelopmental disorder in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR), (American Psychological Association [APA], 2020). The DSM-5-TR defines intellectual disability as having an onset during development (prior to age 18 years) with deficits in intellectual functioning (including reasoning, problem solving, planning, abstract thinking, judgment, academic and experiential learning), and social and practical areas of functioning (such as, communication, culturally defined social skills, personal independence, school or work functioning) (APA, 2020). Intellectual functioning deficits can be confirmed by various standardized tests of intelligence, and are categorized by the DSM-5-TR in groupings as follows (and in comparison to ‘neurotypical’ people – people without a developmental disorder diagnosis): mild to moderate – individuals placed in this category (approximately 95% of people diagnosed with an intellectual disability) (Reynolds et al., 2013) are considered to have adequate communication and self-care abilities but they may require extra teaching and daily support; severe – the individual so labelled is understood to have major delays in development, tends to have limited expressive communication skills and typically requires more intensive support in a family or group home setting; profound – this term is used to describe the smallest proportion of
people medically diagnosed with intellectual disability who are typically understood to have, along with very limited cognitive and communication abilities, co-occurring physical and sensory disabilities, and to require 24-hour care (Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders, 2015; Reynolds et al., 2013).

The literature in the field of intellectual disabilities tends to use developmental disability interchangeably with intellectual disability, and I have noted that recently they have been combined by professionals in the developmental services, some of whom use the label ‘intellectual developmental disability’. Statistics Canada defines a developmental disability or disorder in medical terms as “cognitive limitations due to the presence of an intellectual disability or disorder, such as Down syndrome, autism or mental impairment caused by a lack of oxygen at birth” (Cossette & Duclos, 2001, p. 10). Community Living Ontario (2015) resists using an impairment- or deficit-based definition due to the stigmatizing labels and understanding of intellectual disability that can arise from this practice; however, they do put forth this definition:

A developmental disability is a life-long condition, usually present at birth or originating in the early years of childhood, which interferes with one’s ability to learn at the same pace or to the same extent as others. Individuals may have difficulty understanding abstract concepts or adapting to some of the demands of daily life…the nature and extent vary greatly between individuals and may or may not be accompanied by other physical conditions. As with any individual, people who have a developmental disability are capable of many accomplishments, and simply require an opportunity to be included in the daily life of their community in order to make their unique contribution. There are
more than 200 known causes of intellectual disability; thus, the nature and extent vary greatly between individuals, and may or may not be accompanied by other physical conditions. (para. 1)

Moving away from a purely medical definition, Community Living Ontario’s definition represents a more person-centred and ability-focused perspective which informs my research, as it is rooted in my strong beliefs regarding inclusive environments for grief expression and support. From a social work perspective, the description developed by Community Living Ontario also adheres more closely to concepts of inclusion, social justice, anti-oppression, and respect for human dignity (Sandys, 2017; Sheafor & Horejsi, 2012).

Language is an essential consideration when exploring literature regarding the lives of oppressed groups of people (Withers, 2013). In the field of disability studies, researchers and academics do not present an agreed upon approach to naming the different groups who have been socially constructed as disabled by the dominant able-bodied majority (Rogers, 2016), categorized medically as differently impaired (Oliver & Barnes, 2012). In this dissertation I use the terms intellectual disability and people labelled/with intellectual disabilities. I refer to people as being labelled/with intellectual disabilities to reflect both having a label imposed on oneself and disagreeing with (rejecting) it, and, for some, the acceptance of the label while maintaining a people first orientation, as preferred by some self-advocates (Fudge Schormans et al., 2019; Spagnuolo, 2016). I have chosen not to shorten the terms to acronyms as I believe this further diminishes an already oppressed and marginalized group of labelled people. The language around how to describe the majority, typically functioning members of society within which people with intellectual impairments live, is a murky area. Words such as neurotypical, able-bodied, and non-disabled are all present in a review of the literature (Bigby & Frawley, 2010;
Rogers, 2016; Shildrik, 2012). For the purposes of this dissertation, the term neurotypical will be used.

According to the 2013 *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario*, there are approximately 66,000 Ontarians, aged 18-64, with a developmental disability, and nearly half of these adults have a coexisting mental health diagnosis, which is labeled as a dual diagnosis (Community Networks of Specialized Care (CNSC), 2015).

*Ableism*, from which oppression and marginalization of the disabled originates, is defined by Campbell (2001) as,

A network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human. (p. 44)

Ableism enforces a mind/body norm against which humans are measured and disability is defined, which leads to disabling social notions and practices towards people with mind/body differences. Loja et al. (2013) state that this in turn creates two distinct consequences for people with disabilities: “the distancing of disabled people from each other and the emulation by disabled people of ableist norms” (p. 192). Disablism, discrimination against disabled people due to genuine or assumed differences (Campbell, 2001), follows from ableism – it is the result of ableist construction of who is and who is not human. Consideration of the influences of ableism and disablism on thanatology and disability studies research and literature, as well as the clinical interventions reviewed, will be important in recognizing the effects they have on these bodies of knowledge and practice.
B) Death, Grief, & Mourning

Of all human experiences, none is more overwhelming in its implications than death. Yet, we tend to delegate death to the periphery of our lives, as if it can be kept ‘out of sight, out of mind’. A first step toward gaining new choices about death is to recognize that avoiding thinking about it estranges us from an integral aspect of human life. (DeSpelder & Strickland, 2020, p. 3)

Life and death are inexorably linked, and yet we pay so much more attention to the meaning of the former in our daily lives, relegating the latter, as stated above, to the periphery. However, the deaths of people we love and the subsequent grief reactions that can emerge from these losses are something most people will undergo, in their own unique way, throughout their lives (Zachar et al., 2017). As previously stated, grief and mourning are experiences that affect individuals on emotional, behavioural, cognitive, social, physical, and spiritual realms. The death of a significant person in our lives can cause tremendous change and upheaval but having a compassionate social support network is known to mediate some of the challenges brought on by death and grief and can also allow for personal growth (Doka & Chow, 2021; Corr et al., 2019; Neimeyer & Jordan, 2013; Tedeschi & Calhoun, 2004). Social support can come from a variety of sources, including family, friends, neighbours, and religious communities, to name a few. As death and dying have moved more into institutional settings and are less visible in our daily lives, changes in memorialization after a death are also noted due to increasingly diverse religious and cultural communities who have varying end-of-life practices (as a reflection of Canada’s multicultural population) (Northcott & Wilson, 2016). The COVID-19 pandemic caused further social disconnection with the dying and has resulted in countless memorial rituals being postponed while also drastically reducing social support for grievers, the long-term effects
of which are yet to be understood (Hoy & Harris, 2020). Furthermore, the neurotypical bereaved population tends to be given little time to adjust after a death, with, for example, workplaces legislated to provide three paid days of bereavement if the deceased is an immediate family member leave (in Canada, and only if you have three consecutive months of continuous employment with your employer), and this does not include workers who may be precariously employed part-time or on contract (Government of Canada, 2021).

**B1) Religion and Spirituality**

Finding purpose and meaning about life and death are at the core of many world religions. DeSpelder and Strickland (2020) explain that religion shapes beliefs, provides “answers to the ‘big questions’ about human existence and purpose” (p. 531), and forms moral attitudes, values, and expected behaviours in relation to death. While there is no one definition of religion or spirituality, Stevenson (2007) provides a distinction that is useful in conceptualizing both:

…Religion is defined as a *set of beliefs*, and related practices, which can provide meaning, while spirituality is defined as an ongoing *quest to find meaning*. …in simple terms, one can say that religion is *external*, while spirituality is *internal*. (p. 317)

While religion can include teachings on the meaning of life, and the process of death and necessary rituals (and an afterlife depending on the religion), spirituality encompasses the individual’s beliefs and understandings about the meaning life and death, which may or may not adhere to their religion’s teachings or relate to an organized religion at all (Thompson, 2016). For many people, death, grief, mourning rituals, and coping are interwoven with their religious and/or spiritual teachings. While overall rates of religious adherence are falling, the 2011 National Household Survey found that, in Canada, 108 religions were identified by respondents.
The results of this survey show the largest religious affiliation is Christianity (67.3% of the population), followed by people who do not identify with a religion (23.9%), and then followers of Islam (3.2%) (Statistics Canada, 2011). The diversity of religious adherence and practice provides both opportunities and challenges for grief support. There are many traditions and rituals available to mourners, which may be helpful, but may also prove to be distancing from helpful support if strict observance to religious practices is not upheld and differences in ritual is not sanctioned by one’s religious community. Affiliation with a religious faith or involvement in spiritual practice are often considered to provide a framework from which can emerge better health outcomes, more robust social support, and meaning creation within rituals and beliefs from loss due to death (DeSpelder & Strickland, 2020; Klass, 2007; Thompson, 2016).

However, for some people, their religious or spiritual lives do not provide sufficient coping tools to manage their grief and their shattered assumptions about how their world should look (Doka & Chow, 2021; Klass, 2007; Lee et al., 2013). A crisis of faith may also result after a death. For example, from a Christian perspective, someone may question why their God took a person too early, or had that person suffer so much prior to their death. It is important to keep in mind different religious and spiritual teachings about death, and rituals related to death and mourning, particularly as they relate to the inclusion and/or exclusion of people labelled/with intellectual disabilities, while at the same time acknowledging that exploring the myriad religious beliefs and practices related to death are beyond the scope of this project.

B2) Gender

Although past research has included the consideration of gender in differences in grief and mourning expression, Doka and Martin (2010) argue that the differences are based in style of expression as opposed to gender qualities. The acceptable norms surrounding grief and mourning
tend to be that emotional expression, such as crying, is acceptable (for a short period), and seeking support after a period of what others deem as too much emotion is encouraged. Societal norms related to gender and expression of emotions tend to favour women, with the commonly held belief that men are strong and unemotional (Hadad, 2009; Matheson, 2007). The two styles of grieving identified by Doka and Martin (2010) are intuitive and instrumental. An intuitive griever would tend to experience and express emotional reactions using coping strategies to express affect; an instrumental griever is less likely to display emotion, instead focusing physically on “practical matters and problem solving” (Corr et al., 2019, p. 239). These two styles rest at opposite ends of an “adaptive grieving style” continuum along which unique individual grieving styles are included (Gilbert & Macpherson, 2021, p. 296). Generally, women are characterized as intuitive griers, while men are considered to be instrumental griers (Doka & Martin, 2010; Gilbert & Macpherson, 2021). However, with consideration of differences in personality, life experience, values, and beliefs, along with society’s broadening understanding of gender, aspects of both styles can be seen across gender identities, at different times and in varying contexts (Corr et al. 2019; Doka & Martin, 2010; Gilbert & Macpherson, 2021; Hadad, 2009). Although grieving styles and gender differences are not considerations found in the literature regarding bereavement and people labelled/with intellectual disabilities, this remains an important construct to keep in mind in terms of exploring supportive interventions along the spectrum of grieving styles.

**B3) Age**

Just as within the dominant able-bodied population, people labelled/with intellectual disabilities will live to different ages and die from varying causes, some related to the labelled disability and others unrelated (Thorpe et al., 2020). As people labeled/with intellectual
disabilities moved from institutions to the community, with access to improved medical care, expanded social support, and more enriching life experiences with expanded social networks, it has been noted that they are living longer than previous generations (Thorpe et al., 2020; Tuffrey-Wijne et al., 2017). Issues related to ageism (stereotyping attitudes about and discrimination against older adults [Bernstein et al., 2022]), in the context of the intersecting topics of thanatology and intellectual disability, were not present in the literature reviewed. However, issues related to infantalizing people labelled/with intellectual disabilities is present. Infantalizing of people labelled/with intellectual disabilities occurs when the dominant able-bodied community does not treat them as adults, but rather as “…‘eternal children’ in need of control, management and spiritual guidance (Smart, 2009, p. 329). Infantilization occurs at individual, community, and systems levels, and impacts all aspects of the daily lives of people labelled/with intellectual disabilities. For example, limits are placed on personal choice and opinions, intimate relationships, access to education and employment, and not allowing/encouraging independence (Rogers, 2016; Smart, 2021). Within the context of grief and mourning, I have found that many professionals assume that research and practice literature that is related to children’s grief is also applicable to all people labelled/with intellectual disabilities (irrespective of age) without any consideration of the appropriateness and potential harms of this practice.

C) Prominent Theoretical Perspectives: Grief

Anyone who is capable of loving, of being in a relationship, is also capable of grieving when that relationship ends due to death. However, it is more recently being noted that people labelled/with intellectual disabilities have long been excluded from being legitimized as griever (Kauffman, 2005; Lord et al., 2017; McCord et al., 2021; McEvoy et al., 2012; Rando, 1993;
Tuffrey-Wijne et al., 2017). There is an increased risk of social isolation if people labelled/with intellectual disabilities are left out of knowing about a death, participating in rituals, and are pathologized for not following the social norms of grief and mourning expression (Lord et al., 2017; Morse et al., 2016). Grief is also not solely an intellectual exercise. Thus, most people labelled/with intellectual disabilities, because they are in relationships with others, are very capable of understanding aspects of death and experiencing grief reactions, despite differing cognitive abilities. People labelled/with intellectual disabilities have emotional selves, are capable of reflection, and have reactions to loss even though they may be expressed differently than neurotypical society may expect (Lord et al., 2017; Todd et al., 2013). It is essential that the grief experiences of people labelled/with intellectual disabilities are further explored and heard within the social work and thanatology fields, because their voices have been ignored for so long and their grief is often disenfranchised and often dismissed as behavioural disturbances (Condillac, 2020; Morse et al., 2016).

Bereavement theories originate from many different disciplines and epistemological perspectives, resulting in numerous theories and models, with no one comprehensive and generally applicable theory of bereavement, grief, and mourning (Gilbert & Macpherson, 2021; Kastenbaum & Moreman, 2018; Rothaupt & Becker, 2007). Many early prominent writers in thanatology focused on the notion that one resolves or gets over grief to then rejoin the world as a productive and so-called normal person again after doing their grief work (Worden et al., 2021). Butler refers to this as the Protestant ethic of grief (Butler, 2004) - the message being that hard work and discipline will lead to resolution of the problem (grief). Related to this is the dominant narrative of achieving closure and getting over it as the end goal of our grieving. It is not uncommon for me to receive referral calls from people to see their family member through
my practice soon after a death because they believe their loved one is not over their grief yet, and their ongoing grief and attachment to the deceased are uncomfortable for those around them. This view of an ending to grief in a well-managed way precludes the mourner from having ongoing feelings, and reactions related to the death, never mind having an ongoing relationship with the deceased (Berns, 2011).

Literature and research in the field of thanatology tends to originate from the fields of psychology and medicine (Kübler-Ross, 1969; Doka, 1989, 2010; Jordan & Neimeyer, 2007; Kauffman, 2005; Zachar et al., 2017), is focused on the clinical treatment of cognitively and physically abled grievers, and often excludes those who do not fit into the assumed proper ways of being bereaved (Harris, 2009; Morse et al., 2016; Pine, 1989). Contemporary research and writing in the field aim to scrutinise and alter previous theories in order to expand on the knowledge base and enhance the clinical practice of those working with the bereaved. The grief literature and research findings tend to be written from a predominantly Western cultural and medical perspective, and, most significantly, for my project, through an ableist lens.

To date, I have found little grief literature solely from the perspective of social work within a Canadian context. However, I have made a concerted effort to find writing and research from differing perspectives (Attig, 2004; Harris, 2009; Harris & Border, 2016). Additionally, bereavement and disability related education is sorely lacking in most social work educational programs, with death and grief only being an elective in some schools of social work, and critical disability courses are even less common (Burghardt et al., 2021). Furthermore, even within disability literature and education, there is typically less attention paid to people labelled/with intellectual disabilities, positioning them as the “left behind of the left behind” (People First of Canada, 2020). Thus, in many areas of social work practice, we bump up against the limits of
what we know. Given this lack of general bereavement and disability education, it should come as no surprise that opportunities for death education and grief support for people labelled/with intellectual disabilities is “…all but non-existent” (Morse et al., 2016, p.155).

**C1) Severing Bonds: Freud**

Many of the contemporary theories of bereavement and models of grief and mourning can trace their genesis to the writings of Sigmund Freud (1917) while he was developing his early approach to psychoanalysis. Freud put forth a model of mourning where, for healthy resolution of mourning, a person must work through the loss with the outcome being the detachment of emotional energy from the relationship with the deceased (the process of decathexis), and letting go of all hopes for a future relationship with that person, thus freeing up emotional energy to invest into new attachments (Jordan & Neimeyer, 2007; Kastenbaum & Moreman, 2018; Worden et al., 2021). Failure to withdraw emotional energy from the deceased, to let go of the attachment, was considered by Freud to be a pathological outcome resulting in ongoing misery and dysfunction (Kastenbaum & Moreman, 2018; Rothaupt & Becker, 2007).

Subsequent to Freud’s theories on the nature of mourning, Lindemann (1944) described characteristics of acute grief (which was grief beyond the expected social norm), including “…somatic distress, preoccupation with the image of the deceased, guilt, hostility, and alterations in usual patterns of conduct” (Jordan & Neimeyer, 2007, p. 133). This added considerations of cognitive, physical, and behavioural dimensions to grief, beyond solely emotional concerns, in a way that described these aspects as abnormal (Kastenbaum & Moreman, 2018). Lindemann (1944) coined the term _grief work_, similar to Freud’s notion of decathexis, in that the process requires the bereaved to acknowledge that the person is permanently gone from their lives, while also confronting and acknowledging their feelings and
memories of the person who died (Rothaupt & Becker, 2007). The goal of grief work was to sever the emotional bonds to the deceased so that new relationships could be undertaken. Thus, unhealthy resolution of grief would be the result of delaying or distorting grief reactions (Jordan & Neimeyer, 2007).

**C2) Stage Model of Grief: Kübler-Ross**

Likely the most widely known model of grief and mourning is Kübler-Ross’ five stage model. Through her research with dying patients, and subsequent book, *On Death and Dying* (1969), Kübler-Ross theorized that dying persons go through five emotional stages upon diagnosis of a terminal disease: denial, anger, bargaining, depression, and acceptance (Kastenbaum & Moreman, 2018; Kübler-Ross, 1969; Worden et al., 2021). Kübler-Ross’ work with dying patients was revolutionary for the times, and her plea for more humanistic treatment of the dying was a key message in her work (Kübler-Ross, 1969; Doka, 2007). Her work became a touchstone for ongoing research related to the grieving process and was taken out of the context of dying patients and into the grief process of bereaved individuals (Calderwood, 2011). Her model also became popularized in mainstream Western culture and has for decades served as a linear model against which grieving individuals (as often seen in my practice) and their support system hold themselves up for comparison of how they are progressing in their grief. The resolution of grief, using this model, occurs once one has reached acceptance that the person has died (Rothaupt & Becker, 2007). This model does not provide consideration for other life domains that may be affected by the death, such as cognitive, behavioural, physical, social, and spiritual, nor does it address the grief of people not considered normative. Contemporary thanatology researchers have called for Kübler-Ross’ stage model to be “relegated to the past” (Stroebe et al., 2017, p. 456) as it is not supported with empirical evidence, and it may also cause
harm to grievers when applied by clinicians in therapy (Kosminsky & Jordan, 2016; Worden et al., 2021).

One significant emotional state was left out in the popularization of Kübler-Ross’ work, and that is hope. Hope appears throughout her work and is significant because “it is this glimpse of hope which maintains [the patient] through the days, weeks, or months of suffering. It is the feeling that all of this must have some meaning …if only they can endure it for a little while longer” (Kübler-Ross, 1969, p. 139). This conceptualization of hope is also applicable to people who are grieving the death of a significant person. In fact, the finding of creating meaning from suffering and loss is quite compatible with contemporary models to be explored later in this paper (Tedeschi & Calhoun, 2004; Neimeyer et al., 2014).

**C3) Attachment Theory and Grief**

Bowlby’s (1960) model of childhood attachment to a child’s mother (or primary support person) and the nature of that attachment is relevant to the study of grief and mourning given that the sense of psychological safety many people develop in childhood (or do not develop) continues into adult relationships and is reflected in attachment styles: secure, anxious-ambivalent, disorganized, or avoidant (Kosminsky & Jordan, 2016; Worden et al., 2021). This model also provides a way to conceptualize the need in humans to seek emotional bonds with others to survive and to examine the aftermath when bonds are severed by death (Worden et al., 2021). Bowlby believed that a person’s instinct toward attachment relationships continued throughout the lifespan, contributing to the construction of beliefs about whether the world is safe or threatening (Harris & Winokuer, 2021), and suggested that early attachment style affected later grief and mourning reactions (Kosminsky & Jordan, 2016). Bowlby described a process of mourning which encompassed initial numbing, then yearning and searching
behaviour, followed by disorganization and despair, leading to a reorganization within one’s world (Harris & Winokuer, 2021). According to an attachment-based viewpoint, grief is an instinctually based response that occurs when a significant attachment is threatened. When one loses a person with whom there is an attachment, there will typically be separation distress reaction and when reunion with the deceased is not achieved, a range of related behaviours will occur (such as protest, seeking, avoidance, despair) in an effort to rebuild one’s worldview post-loss (Harris & Winokuer, 2021; Kosminsky & Jordan, 2016).

Parkes (1996) utilized Bowlby’s work on early life attachment as he observed adults in his practice who were experiencing what was considered to be problematic grief and he worked to make a connection between attachment and loss. He extended Bowlby’s work to include the “assumptive world – a strongly held set of assumptions about the world and the self, which is confidently maintained and used as a means of recognizing, planning, and acting” (Parkes, 1975, p. 132). Parkes set forth the theory that “…a person’s bereavement was impacted by two sets of factors: those related to the nature of the bereaved’s relationship with the deceased, and those related to the nature of the death” (Kosminsky & Jordan, 2016, p. 7). Bowlby’s attachment theory has also been used in studies attempting to link bereavement outcomes and attachment styles (Richardson, 2006) and has seen a resurgence in considering interventions from an attachment-informed lens (Kosminsky & Jordan, 2016). Attachment theory does not make an appearance in much of the disability literature reviewed for this paper. However, Simcock & Castle (2016), writing about disability from a social work perspective, state that “impairment per se is not associated with insecure attachment; however, research findings suggest that higher numbers of disabled children than non-disabled children are insecurely attached” (p. 111). Given the history of institutionalization of people labelled/with intellectual disabilities, ongoing
segregation in education and community (Spagnuolo, 2016), de-humanizing treatment, and frequent placements out of their family homes, issues of attachment could very likely influence expression of grief and mourning for this population.

C4) Task Models of Grief

Researchers and practitioners began to develop task and process models starting in the 1980’s as there was little empirical evidence to support previous linear stage models of grief and mourning (Rando, 1993; Worden, 1982, 1991, 2002, 2009). Worden’s task model of mourning highlighted a level of “…individuality and autonomy not often seen in stage models” (Doka, 2007, p. 23) and he also viewed mourning as an active and healthy process that must be engaged in by the mourner (Corr et al., 2019; Worden et al., 2021). Although the tasks are laid out in a progressive manner, Worden (2009) stressed that an individual would complete the tasks in their own way, in their own timeframe, and could choose not to address some of the tasks. The four tasks of Worden’s model are: (1) to accept the reality of the loss; (2) to process the pain of grief; (3) to adjust to a world without the deceased (internally, externally, and spiritually); and (4) to emotionally relocate the deceased and move on with life (Corr et al., 2009; Worden, 2009; Worden et al., 2021). Worden later re-worked his fourth task to now state, “[to] find an enduring connection with the deceased in the midst of embarking on a new life” (2009, p. 50), which better reflects contemporary views in thanatology on continuing bonds. Worden’s fourth task suggests movement toward the bereaved reconstructing their life and identity without the deceased present any longer, while also restructuring their relationship with the deceased person. Worden’s fourth task is also a focus in some of the models to be discussed shortly. Clinically, Worden’s model had the potential to be a helpful tool for grief counsellors as they could educate clients about the tasks, find out what tasks may be challenging for them, and assist the grieving
client as they worked on the tasks (Doka, 2007; Worden et al., 2021). However, task models can also be problematic when clinicians and the bereaved interpret the model too literally without consideration of the context of the person’s life and their individuality, while also believing there are so-called normal and abnormal reactions to loss, grief, and mourning that are then subject to therapeutic intervention (Foote & Frank, 1999).

Rando (1993) also describes the mourning process as a series of tasks that the mourner undertakes in an active way, and she termed her model the “Six R Processes of Mourning.” Using Rando’s model, these processes of mourning must be undertaken by the mourner for healthy mourning to occur, but the mourner can move between the processes in a nonlinear way (Rando, 1993; Corr et al., 2019). The six R’s of mourning are as follows: (1) recognize the loss; (2) react to the separation and identify and mourn secondary losses; (3) recollect and re-experience the deceased and the relationship; (4) relinquish old attachments to the deceased and the old assumptive world; (5) readjust to move adaptively into the new world without forgetting the old; and (6) reinvest in new relationships and activities (Rando, 1993; Worden et al., 2021). According to Rando, healthy mourning requires the mourner to transform their relationship with the deceased into “…something more appropriate to the loved one’s new status” (1993, p. 50). The mourner must relinquish their attachment to the old assumptive world where the deceased once existed and only once this has been accomplished can the mourner create new attachments based on the acknowledgement of the reality of the person’s death (Rando, 1993). This is not a perspective or experience that I agree with, as Rando’s assumptions include the binary notion that there is only the potential for normal and abnormal (pathological) mourning, based on the mourner relinquishing attachment to the deceased and the world in which the deceased existed with them. In fact, as will be discussed shortly, grief and mourning are currently being
conceptualized as including ongoing attachment to the deceased (e.g., Klass’ 2006 articulation of continuing bonds), and meaning making from the primary and secondary losses associated with the death of the person (Gilbert & Macpherson, 2021; Neimeyer, 2001; Neimeyer et al., 2014).

There are two aspects of Rando’s model that do have relevance to my research focus, and those are secondary losses and the assumptive world. A *secondary loss* is conceptualized by Rando (1993) as “…a physical or psychological loss that coincides with or develops as a consequence of the initial loss” (p.20). For example, an empty chair at the table, loss of emotional support person, loss of an identity, loss of financial provider, etc. According to Rando (1993), a further grieving and mourning process begins with each of the individual’s secondary losses, which may or may not be similar in nature to the reactions to the primary loss. This is relevant to keep in mind for people labelled/with intellectual disabilities because they have historically been given little control or autonomy in their lives, while also often experiencing numerous support persons who come and go, thus exposing them to multiple potential primary and secondary losses on an ongoing basis (Lord et al., 2017).

To illustrate the above, I return to my experience as a BSW student working in the institution for people labelled/with intellectual disabilities when their craft group worker was killed on her way into work. The members of the craft group were excluded from the knowledge of Gayle’s death, yet they experienced secondary losses related to her death and her subsequent absence from their daily lives. The members of the craft group had no opportunity to say goodbye to her, they had a new worker to facilitate their craft group without any explanation, and there was no consideration of the relationship and attachments they had made with Gayle. Perhaps she had a special way of interacting with each of them as individuals or perhaps they were also used to seeing her at other times during their week, and these aspects of her loss were
never addressed. This is an extreme example because the group members were not even told about the nature of the primary loss, so the secondary losses are, on my part, assumed (and perhaps less dramatic than I imagine if they were used to high staff turnover). Unfortunately, it has not been unusual in my clinical practice to come across examples of exclusion of people labelled/with intellectual disabilities from knowing and experiencing the realities of loss through death, and being excluded from mourning rituals, and importantly, with their reactions to secondary losses more likely to be viewed as poor behavioural choices rather than grief reactions appropriate for the circumstances (Condillac, 2020).

The assumptive world (Parkes, 1988) is an organized schema containing everything a person assumes to be true about the world and the self developed based on previous experience (Harris, 2016; Parkes, 1988, 1996; Rando, 1993). As further conceptualized by Rando (1993), the assumptive world is viewed as being fueled by the individual’s experiences, memories, and needs, and confirmed through experiences, behaviour and interaction patterns, and relationships. Janoff-Bulman (1992) extends the concept of assumptive world and discusses three primary categories of assumptions people make about the world:

1. the world is benevolent – that there is more good than bad in the world and that people are generally trustworthy;
2. the world is meaningful – that good and bad events are distributed in the world in a fair and controllable manner;
3. the self is worthy and has value. (p. 10)

Thus, when the assumptive world is shattered through a death, a person will question the myriad assumptions from which they previously lived their daily lives. The death of a person to whom one has an attachment “…violates the mourner’s specific assumptions about the loved one’s continued interactive presence and violates the countless expectations the mourner held for
that person’s forming a significant part of the world” (Rando, 1993, p. 51). Moreover, the mourner must resolve the world as it is now with the world that they thought and believed existed before the loss, and Rando argues that the grief process assists with this rebuilding to a new and revised assumptive world (Rando, 1993; Harris & Winokuer, 2021). This is relevant to consider in my work because I believe people labelled/with intellectual disabilities also develop assumptions about their worlds, whether they can verbally communicate them or not. For example, I have come to the opinion that the craft group members assumed that they would see Gayle each day, have an opportunity to get out of their residential area to the sunny craft room, and experience their own unique interactions with Gayle. I believe that opportunities to process, discuss, and/or emotionally express and adapt to their changed world was not provided. The combination of the lack of knowledge of Gayle’s death, lack of acknowledgement of the effect of her loss and the associated secondary losses, combined with the changes in their assumptive worlds, may have made the craft group members more at risk for a complicated grief situation (to be discussed below) under Rando’s model.

Foote and Frank (1999) critique these ‘grief work’ task-based models. They utilize Parsons’ (1951) sick-role theory to suggest that the bereavement role is similar to that of a sick person in that the role places the person into particular expectations that are structured by society: “…first, that illness is not the sick person’s fault; second, that the sick person is excused from normal responsibilities; and third, that the sick person has an obligation to seek medical treatment, comply with that treatment, and get well” (p. 168). Foote and Frank (1999) argue that the social ideal of bereavement is that the role is temporary; that certain behaviours are appropriate, and others are pathological; and, that the above entitles professionals to intervene in grief, and based on the task model used, to determine what is clinically appropriate or what is
pathological. Parsons (1951) did not separate chronic and acute illnesses in his work (Oliver & Barnes, 2012). Thus, the bereaved who do not get well with treatment in a specified time frame and people labelled/with intellectual disabilities who fail in the sick role, are further socially excluded and pathologized.

**C5) Continuing Bonds: A Paradigm Shift**

As contemporary models began to move away from the notion that a resolution to grief needed to occur through relinquishing emotional connection to the deceased and leaving the past behind, research began to indicate that many bereaved actually hold the deceased in their memories for long periods, often for the rest of their lives, in healthy, non-pathological ways (Gilbert & Macpherson, 2021; Klass et al., 1996). This phenomenon was theorized by Klass et al. (1996) to be continuing bonds. They found that bereaved people who maintain a continuing emotional and relational bond with the deceased can have “positive outcomes in their grief process” (Gilbert & Macpherson, 2021, p. 284). The deceased may continue to be a source of guidance in the bereaved’s life through values, beliefs, and morals shared while they were living. The bereaved may sense the presence of the deceased, may seek closeness through linking objects (e.g., jewelry, clothing, other belongings of the deceased, memories, photos), and may have dreams or visions of the person who died. Continuing the bond with the deceased in these ways is not unusual but could be (and often is) interpreted as maladaptive and/or pathological from a Western medical model perspective when using older models of grief and when measured against social rules of how grieving should unfold (e.g., time-limited, get over it, move on, etc.) (Harris, 2009).

Following this theory, it is not unusual for the bereaved to maintain an inner representation of the deceased, one which is dynamic, interactive, and evolving throughout the
life of the survivor, even though the person is physically absent in their life (Klass et al., 1996).

As this theory has evolved, continuing bonds have also been considered within broader social and cultural contexts, and as a “collaboratively co-constructed [social] phenomenon” (Gilbert & Macpherson, 2021, p. 284). For example, in what ways was I still a daughter without a father alive in my life? The government reframed me as an orphan – providing me with orphan’s benefits as long as I remained in school. If I identified as an orphan while still having a mother alive, could this be considered pathological within the context of Western norms of mental health? McRitchie et al. (2014), when conducting one of the few qualitative explorations of grief experiences with people labelled/with intellectual disabilities, noted that their participants experienced comfort from being able to maintain an ongoing relationship with the deceased person (continuing bond) while moving on with their lives.

In many non-Western cultures, maintaining connections to the deceased is encouraged through ritual and celebration. For example, Día de los Muertos (Day of the Dead) in Mexico, which is a public and socially accepted means of connecting with the dead (Gilbert & Macpherson, 2021). When considering continuing bonds in my research with bereaved people labelled/with intellectual disabilities, it will be important to explore whether this ongoing relationship with the deceased is evident, encouraged, or recognized by the bereaved and the people in their social circle.

**C6) Dual Process Model of Coping**

A further model for consideration is that of the dual process model of coping with grief developed by Stroebe and Schut in 1999 (revisited in 2010). This model (see Figure1) was proposed as an alternative to grief work models, instead suggesting that coping with grief and mourning involves three aspects: loss-oriented coping; restoration-oriented coping; and
oscillation between the two (Gilbert & Macpherson, 2021; Kastenbaum & Moreman, 2018; Richardson, 2010). Loss-orientation refers to “the painful dwelling on, even searching for the lost person, a phenomenon that lies at the heart of grieving” (Stroebe & Schut, 2010, p. 277). The focus is on the deceased, the cause of death, and feelings such as longing and yearning for the deceased person. The restoration-orientation refers to the secondary stressors that accompany a bereavement, such as loneliness and role changes, reflecting the efforts to re-orient oneself in an altered world without the deceased (Stroebe & Schut, 2010). Oscillation refers to the movement between times when the bereaved will confront aspects of their loss or their restoration tasks, and times they will avoid them, thus helping the individual adjust without the need for constant grieving (Stroebe & Schut, 2010). They also recognize that there are time-outs when the person is not actively grieving but is engaged in their daily tasks. Contrasted with stage/process models, Stroebe and Schut’s model includes the assertion that mourners learn that “…over time to ‘compartmentalize’ and intermittently turn away from grief is as much a necessary part of the mourning process as moving toward, and through, the grief” (Kosminsky & Jordan, 2016, p. 56). Thus, they can, for example, return to work and assume daily responsibilities, all while taking breaks from their grief in order to cope. The risk associated with these grieving time-outs is if the individual does not make time to re-orient to the active grief process and continues to compartmentalize. Stroebe and Schut’s model may work well in application to people with an intellectual disability, as it may reframe those times when the person is not grieving as grief time-outs as opposed to the view that they are not grieving at all. For example, using this model, it is expected, and in fact encouraged, that individuals take time off from their grief and during this time they have the opportunity to participate in social activities with family and friends (Gilbert & Macpherson, 2021; Richardson, 2007). Providing understanding and support during
the adaptation (loss and restoration-oriented coping) and oscillation process, while also considering individual differences and needs, has the potential to be a sensitive and comprehensive approach when working alongside people with an intellectual disability.

In 2016 Stroebe and Schut added the concept of overload to their model as they came to recognize that some bereaved people perceive they have “more than s/he feels able to deal with - too much or too many activities, events, experiences and other stimuli” (p. 100). This includes the possible perception that in these moments coping is not possible. Overload may lead to feeling worried, pressured, anxious, tired, and distressed and can be diminished through, for example, the bereaved being open with others about their needs, seeking meaningful social support, and mindfulness training (Stroebe and Schut, 2016).

**Figure 1: Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999)**
C7) *Post-Traumatic Growth, Transformation, and Meaning Making*

The more current literature on grief and loss also includes the concept of post-traumatic growth. Posttraumatic growth is defined as “…positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004, p. 1). The growth does not come solely from the experience of the event itself, but from the individual’s subsequent struggles with the event in their new reality. It can be difficult for many people to imagine that growth and transformation could be an outcome for people after the death of a loved one. What Tedeschi and Calhoun’s (2004) study suggests is that what makes these experiences transformative is that they have “…an affective component, so that the lessons learned are not merely intellectual reflections” (p. 2). I understand this to mean that one’s intellectual ability is not the only measure of how one’s life is transformed by a significant loss. Although psychological processing of the event (loss) is necessary in their concept, this can be done through a variety of interventions. The research notes that not everyone experiences a painful process of depression and mourning after a loss and argues that “…traditional models of grief have underestimated the resilience of people’s capacity to adapt to loss and trauma” (Jordan & Neimeyer, 2007, p. 215).

For some people, this growth can include becoming involved in a charitable cause related to a disease (e.g., Canadian Cancer Society) or involving oneself in an activity enjoyed by the person who died. Tedeschi and Calhoun (2004) also emphasize that significant good and meaning can come from human suffering as people struggle with trauma through a variety of coping mechanisms that develop and grow over time, but do not necessarily have acceptance of the event. Furthermore, the loss and suffering, which may result in tremendous learning and
growth, can come at a high cost. In his own reflections about post-traumatic growth after the death of his son, Rabbi Kushner poignantly shares the following:

I am a more sensitive person, a more effective pastor, a more sympathetic counselor because of Aaron’s life and death than I ever would have been without it. And I would give up all of those gains in a second if I could have my son back. If I could choose, I would forego all of the spiritual growth and depth which has come my way because of our experiences …But I cannot choose. (Viorst, 1986, p. 295)

As noted by Rabbi Kushner and in the work of Neimeyer (2002, 2014), meaning reconstruction is a fundamental process many bereaved individuals will undergo (Gilbert & Macpherson, 2021; Worden, 2009). Personal growth and meaning reconstruction after a death can occur as we review narratives of our previous life with the deceased person, explore new narratives without them, and start to reconstruct the new world without the person’s physical presence (Neimeyer, 2001, 2014). For example, part of my meaning reconstruction process after my father’s sudden death was to offer support to other bereaved people, specifically children, through mutual aid groups – this not only honoured my ongoing relationship with my father but provided me with some meaning from his death through companioning others who were where I had once been. Through choosing to consider the possibility of “…something positive occurring after the negative life event, individuals may be able to assign meaning to their experience, which helps to rebuild the foundation for one’s assumptive world that is positive again” (Harris & Winokuer, 2021, p. 36). The concepts of post-traumatic growth and meaning making, although somewhat different in nature, require the person to redefine themselves, and relearn their world and how to engage in it without the deceased person physically present (Currer, 2007). This is perhaps where my earlier reference to the absent presence of my father in my life has created
meaning within a world deeply different than it was prior to his death, and an ongoing relationship that has endured beyond his death. It is not possible for the individual to return to how they were functioning in the world when the deceased was alive, however, they can nonetheless create a meaningful life (this can be linked back to Worden’s third task discussed above).

**C8) Social Constructionist Perspective**

A social constructionist view of grief moves away from a solely psychological explanation and individual focus of grief and mourning. The focus is on grief and mourning in a social and community context, in that the narrative processes through which meaning is created occur as much between people in interaction with one another as they do within the individual (Gilbert & Macpherson, 2021; Neimeyer et al., 2014). Furthermore, Neimeyer et al. (2014) remind us that although death and grief are universal, “…both the story of the death and our changed relationship with the deceased are personally narrated, socially shared, and expressed in compliance with or contradiction to widely varying communal rules” (p. 486). As grievers, the social context of our experience determines how our grief and mourning are enacted publicly, telling us when and where to show or not show certain amounts of emotion, and how one should respond or is expected to respond (Doka, 1989; Foote & Frank, 1999; Harris, 2009; Zachar et al., 2017), which in turn influences our internal process of adapting to the loss. Thinking critically about emotions Harris & Winokuer (2021) describe that in Western society the social expression of emotions is viewed as “weak, irrational, pathetic…an indication someone is out of control” (p. 116). Those who are analytical, contain their emotions, and remain stoic in the face of loss are viewed as coping more appropriately and behaving rationally – they are considered to be *strong*. This has implications for people labelled/with intellectual disabilities who may not possess the
acceptable type and degree of emotional regulation skills or disciplined behaviour and thoughts society expects them to demonstrate, but rather share their grief and adaptations to the loss through different behaviours and emotions in ways others are uncomfortable with and/or pathologize.

The social constructionist perspective of grief and mourning suggests it is the stress linked to the process of coping and adapting to the loss within the constraints of the social milieu that is the main reason why people seek counselling support rather than the loss itself being the primary cause (Kalich & Brabant, 2006). Parkes (1971) suggests that some losses are more difficult for bereaved people when they encounter profound changes in their social environments. Parkes (1988) coined the term *psycho-social transitions* to describe possible social changes of the bereaved. A failure to revise their assumptions about the world, experiencing lasting rather than transient change, and having little preparation for change are all factors that may contribute to problems for the bereaved individual within the social milieu (Currer, 2007). Fredman (1997) further suggests that people are more likely to attend counselling because the people around them cannot cope with their grief, not because they cannot manage it themselves.

The social constructionist perspective of grief and mourning has a significant connection with disability studies and will be an important consideration in this work, as it affects not only both the social experience and expression of grief, but also how a griever labelled/with an intellectual disability is viewed socially. For example, many bereaved people labelled/with intellectual disabilities are excluded from attending funerals (if one is held) because support persons may believe they need to be protected from the realities of death, or they worry that the bereaved person may act out emotionally or behaviourally in a way that is considered socially inappropriate (Oswin, 1991; Read, 2014). I recall being at the funeral of my cousin’s father-in-
law when her sister-in-law labelled/with and intellectual disability began a very close examination of her father’s body, which was in an open casket. Fortunately, she was able to express her wishes to be at the visitation, to touch him, hold his hand, speak out loud to him, and spend as much time as she needed with his body without anyone interfering, which aided her in her subsequent grief and mourning processes.

**C9) Disenfranchised Grief**

Doka’s (1989) concept of disenfranchised grief rests within a social constructionist view, where the grief of certain people or their losses are not socially sanctioned or recognized. The grief of intellectually disabled individuals, when mentioned, is almost exclusively referred to in the thanatology literature as being disenfranchised: “Disenfranchised grief refers to situations where an individual experiences a loss, but that loss is not acknowledged, socially supported, or openly mourned” (Doka, 2010, p. 263). According to Doka (1989), there are three ways a loss can be disenfranchised: the type of loss is not socially sanctioned (e.g., miscarriage, abortion, loss of body part, dementia, disability); the type of relationship is not socially sanctioned (e.g., secret relationship, past relationship, same-sex relationship); the grievers are not socially sanctioned (e.g., not recognized as persons who are entitled to experience grief or have a need to mourn). When disenfranchised, the griever will typically receive insufficient or even no social support, and can experience social stigma (Harris & Winokuer, 2021). Loss for people labelled/with intellectual disabilities often lies within the third category, but can also fall into the others simultaneously, depending on an individual’s relationships and experience of loss. As a result, family, friends, and support persons may not acknowledge that a death will affect the person or know how to respond, so they ignore or do not recognize the person’s needs. McRitchie et al. (2014) note that disenfranchisement of grief for people labelled/with intellectual
disabilities is rooted within beliefs that they are incapable of “(a) forming attachment relationships, (b) understanding the concept of death, or (c) processing death in the same way as [neurotypical] adults” (p. 180). Morse et al. (2016) concur, stating that disenfranchisement occurs for people labelled/with intellectual disabilities when they are “profoundly underestimated in terms of awareness of what is going on around them, while their internal and emotional lives are often trivialized or simply ignored” (p. 159). This creates what Pine (1989) refers to as “an underclass of griever” (p. 13), people who are not recognized as legitimate grievers with needs for support and understanding.

Morse et al. (2016) critique the social model of grief for those labelled/with an intellectual disability when it is only viewed as disenfranchised, as this classification neglects the need for death education (for support persons and people labelled/with intellectual disabilities) and for inclusion in death rituals. Some professionals and family members may err on the side of over-protectiveness, excluding the person labelled/with an intellectual disability from knowing certain information and participating in key rituals. This may be because the individual labelled/with an intellectual disability is viewed as not understanding death or because they worry the individual will act out behaviourally in a way that support persons cannot support (Blackman, 2002; Clements et al., 2004; Lord et al., 2017; Oswin, 1991). This results, “in essence, the individual [being] left to grieve in the shadow of the loss and in the darkness of the lack of education, support and guidance” (Clements et al., 2004, p. 800). As stated earlier, social support is known to be an important protective factor for grieving people, however, the experience of disenfranchised grief excludes one from social support, forcing the grief to remain private (Doka, 1989). This potentially puts the griever labelled/with an intellectual disability at risk for further isolation, and lack of opportunities for social support and expression in their
grief. This demonstrates that it is not always true that people labelled with intellectual disabilities are always disenfranchised in their grief and mourning simply by nature of the label of intellectual disability, rather they are at risk of disenfranchisement in their loss experiences due to social factors such as lack of education, exclusion, and marginalization.

Although they agree that there exist social feeling rules surrounding grieving, Foote & Frank (1999) challenge the concept of disenfranchised grief as creating yet another group of people as candidates for clinical grief intervention. In their opinion, using a lens of disenfranchised grief extends bereavement to all manners of loss, thus implying that every loss must be grieved and subsequently described in clinical terms (normal and abnormal responses), open to assessment, and intervention at the site of the individual – making grief the individual’s personal problem to be “overcome” (Foote & Frank, 1999, p. 167).

C10) Pathologizing Perspectives of Grief

There is a fine line between working to understand the grief of those who are disenfranchised and perhaps in complicated situations, and pathologizing the grief experience, which I do not want to do as I believe that grief is a healthy response to loss. Using a critical perspective, Foote and Frank (1999) critique grief therapy and some of the current models underpinning grief therapy (for example, Rando’s work in complicated grief) and conclude that these models only examine the bereaved through a therapy lens and thus the bereaved are shaped primarily by “therapeutic knowledge” (p.163). This is then used to determine what constitutes normal and abnormal (pathological) grief. Foote and Frank (1999) provide a concise overview of what the dominant discourse of grief looks like in Western society based on some of the early theories discussed above:
The fundamental narrative of this discourse is that ‘normal’ grieving is short term and follows a linear trajectory from acute to moderate to a thing of the past. Even during the most intense periods of grieving, mourners are expected to restrain their displays of grieving to appropriate times and places…time is expected to heal. When people are not healed after a ‘reasonable’ period of time, the mourning is judged to be ‘complicated’ and pathologized. (p. 172)

Expanding upon this, Poole & Ward (2013) challenge the Western expression of grief (tame, controlled) and suggest that Mad grief, grief that “breaks open the bone” (p. 95) and exposes the real pain, is not in fact pathological, but is healing, accepting, and can connect us to others. Thus, perhaps people labelled/with intellectual disabilities who show their pain through what some people classify as behavioural disruption and acting out instead need people who will “allow grief simply to exist” (Poole & Ward, 2013, p. 104). Poole and Ward’s notion of sitting with grief and connecting with others through opening our wounds and sharing our stories is compatible with Wolfelt’s companioning model (2005, 2016) and a narrative, meaning-making approach to grief interventions (Neimeyer, 2014). Unfortunately, many people labelled/with intellectual disabilities have restricted social networks, and this is often highlighted at times of loss and grief (Blackman, 2002; Morse et al., 2016), when what is needed is the space to share and receive emotional, physical, spiritual, and social support. This restricted social network can expose some risk for people labelled/with intellectual disabilities who are grieving because, as mentioned earlier, social support is a key protective factor for grieving people (Doka, 1989; Balk, 2007).

Foote and Frank (1999) (much like Wolfelt, 2016) argue that the bereaved’s stories and understandings must be at the forefront rather than the expertise of the therapist who “claims
some truth for clients and works to move clients toward that truth” (p. 179). They are not the only academics and researchers questioning the role of therapy in the lives of the bereaved (Jordan & Neimeyer, 2003), however, they do appear to be the most critical in calling-out the pathologizing of some grievers. The proposition then becomes that clinical efforts should instead be concentrated toward high-risk mourners, who could include some individual mourners labelled/with an intellectual disability (Brickell & Munir, 2008), rather than only neurotypical mourners (Jordan & Neimeyer, 2003). This suggests the need for support persons to be further informed about grief and mourning for people with an intellectual disability, and how best to support them through typical reactions to loss, while also having the ability to recognize if someone is a high-risk mourner in need of greater attention.

A controversial psychological disorder developed within the field of psychiatry and thanatology, Persistent Complex Bereavement Disorder (previously known as Complicated Grief or Prolonged Grief Disorder), was approved as a psychological diagnosis in 2020 by the American Psychiatric Association in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DMS-5-TR). This diagnosis is assigned to individuals who experience a remarkably disabling or protracted response to bereavement beyond a twelve-month period since the loss (Prigerson et al., 2021). For consideration of Persistent Complex Bereavement Disorder an individual would, for example, be demonstrating a sense of meaninglessness in life, experiencing intense yearning for the deceased, feeling disbelief that they have died, and have considerable isolation from others marked by loneliness (Prigerson et al., 2021). In part, this means that identifying the research and literature regarding effective interventions for diverse grief experiences will be important in differentiating between grief expressions that are complicated by certain factors (e.g., cognitive ability, communication
ability) and grief that may be diagnosable as Persistent Complex Bereavement Disorder (Boelen & Prigerson, 2012; APA, 2020).

Rando (1993) considers intellectual disability a predisposing factor for complicated grief (Persistent Complex Bereavement Disorder):

When death education has been nonexistent, the person will likely be bewildered at the disappearance of a loved one. Individuals with mental retardation (sic) also often experience inherent difficulties in comprehending the abstract concepts involved in death and putting into words the myriad emotions mourning engenders. Indeed, their reactions to loss appear similar to those of young children [emphasis added], who experience pathological responses that contribute to further maladjustment. (p. 189)

Rando (1993) additionally states that the disenfranchisement of grievers labelled/with an intellectual disability further contributes to the potential diagnosis of complicated grief (Persistent Complex Bereavement Disorder). There are many aspects of Rando’s conceptualization of people labelled/with intellectual disabilities and their predisposition to complicated grief (Persistent Complex Bereavement Disorder) that are very troubling. Although I agree with the challenges posed by a lack of death education (supported in the research of Lord et al., 2017) and the differences in conceptualizing death (McEvoy et al., 2012), I do not agree with her statement regarding the childlike nature of the reactions of this population, nor her characterization of children experiencing pathological responses to grief. Rando’s description of complicated grief in people labelled/with intellectual disabilities appears to suggest that the majority of people in this population could be diagnosed with a pathological response to bereavement simply by the limitations she suggests they face, leading to troubling interventions such as medication to dull the individual’s assumed maladaptive responses.
The above theories and models are specific to adult, neurotypical grievers. Compared to the amount of recent research and literature available for groups such as children, adolescents, and ageing adults, there has been less focus on the grieving needs of those labelled/with an intellectual disability (whether youth or adults). In my experience, people labelled/with intellectual disabilities are often viewed as childlike (infantilized) within the thanatology field, leading to the assumption that the children or youth bereavement literature and research are applicable and appropriate for this group of grievers, which I believe is inaccurate and patronizing. In my search for literature regarding grief and mourning support techniques for working alongside people labelled/with intellectual disabilities, for example books for individuals to read (with or without support), I have typically been directed to children’s literature, which is inadequate and inappropriate for work with adults within this population. For example, although there are some children’s books about death and grief that can be used with older populations - such as The Fall of Freddie the Leaf, or Tear Soup - these books often have symbolic or metaphor-based messages that may be difficult for some people labelled/with intellectual disabilities to grasp. On the other hand, simple language books such as those using Sesame Street’s Elmo (Something small: A book about remembering) or Arthur, an eight-year-old Aardvark cartoon character (How dinosaurs die), can be infantilizing.

Summary

The above review of prominent theories, models, and perspectives in thanatology highlights that there remains no one way to conceptualize and describe the grief experiences of the bereaved, and that numerous considerations for individual factors must be taken into account. This knowledge now leads us to an exploration of various approaches to practice for professionals (and lay people) who work with the bereaved.
D) Grief Support Techniques

It is important to acknowledge that, for most people, there is a tendency for grief reactions and adaptations to improve with or without professional intervention based on research with neurotypical griever who have developed effective coping skills and have sufficient social support (Doka & Chow, 2021; Harris & Winokuer, 2021; Jordan & Neimeyer, 2003; Wolfelt, 2016; Worden, 2009). Professionals need to keep in mind that satisfactory support for individuals within their family and friend systems, in their community, and/or at work is an important mediator during the grief and mourning process. When counselling intervention is sought, the professional (e.g., social worker, psychologist, clergy member) needs to first develop a therapeutic relationship with the bereaved person prior to any type of grief-related support being offered. Presence is an important component of the therapeutic encounter, and this is about being with (or companioning) an individual instead of focusing on doing to and doing for them. Neimeyer (2012) considers this to be the “…broader relational framework that provides a ‘container’ not only for our client’s grief, but also for the specific procedures we offer to express, explore and ease the experience of loss” (p. 3). Core relational and engagement skills (such as listening, presence, nonjudgmental stance, open-ended questions) act as both “…an intentional process and an ongoing commitment” (Finn, 2021, p. 189) within the therapeutic relationship from a social work perspective. In order to develop a therapeutic relationship with a client, the therapist must construct a space of respect, care, and hope within which difficult conversations and expressions of grief can occur. It is then within the well-constructed relationship that specific interventions can be suggested and enacted (Neimeyer, 2012).

A key component of grief counselling that distinguishes it from mainstream counselling is that the focus is not necessarily on what is wrong, but rather what is adaptive about how the
individual is experiencing grief in response to a death. The focus, whether through traditional talk therapy or expressive interventions using, for example, art and/or music, is to “…facilitate the healthy unfolding of this adaptive process rather than upon its containment” (Harris & Winokuer, 2021, p. x). When the adaptive aspects of grief unfold in the presence of compassion, the bereaved individual can begin to incorporate the loss experience and the changes it demands into their new life. This is not a quick process. As professionals working with the bereaved, cultivating therapeutic presence, compassion, and the ability to sit with the person and their grief (Harris & Winokuer, 2021) can be very intense and time consuming. This is important to keep in mind in terms of people labelled/with intellectual disabilities who live in community living settings where their lives are typically highly organized around routines, potentially leaving little room for the unfolding of grief and adaptation to loss. Furthermore, to work with the bereaved in a manner that respects difference and aims to reduce suffering, clinicians require flexibility in their thinking and actions that are informed by “(a) clinical research and experience, (b) [client] concerns and well-being, and (c) best practice” (Cacciato & Flint, 2012). This is challenging with bereaved people labelled/with intellectual disabilities because they remain a group who are paid little attention in clinical thanatology literature.

**D1) Therapeutic Interventions**

There are numerous therapeutic interventions suggested in the literature in relation to supporting neurotypical griever (Neimeyer, 2012, 2022; Neimeyer et al., 2011; Servaty-Seib & Chapple, 2021). There are also standardized measures used by some clinicians to determine levels of, for example, post traumatic stress (Impact of Events Revised – IES-R), anxiety and depression (Hopkins Symptoms Checklist – HSCL), grief expression (Brief Grief Questionnaire - BGQ), and levels of prolonged grief (Prolonged Grief-13 scale -PG-13), all of which, once
completed with the bereaved person, can be used to guide the choice of clinical interventions (Cacciatore & Flint, 2012; Prigerson et al., 2021). Worden (2009) laments that there remains a one-size fits all tendency in grief counselling that does not fully account for the uniqueness of individual grief experiences. Neimeyer (2012) disagrees with Worden’s critique of grief therapists, citing his own experiences of working with professionals who are aware of and attentive to recent research and practice advances, and are adjusting their interventions accordingly to client needs using a vast array of “…research-informed treatments for specific problems (e.g., traumatic responses, attachment issues) to creative adaptations of narrative, artistic and ritual forms” (p. xvi). Despite Neimeyer’s observations, I suggest that an ableist lens clouds grief practice and research, to the detriment of people labelled/with intellectual disabilities (among other groups). As with the theories explored earlier, most therapeutic interventions are intended for use with neurotypical individuals or groups, and those developed for use with people labelled/with intellectual disabilities (to be discussed below) are adaptations of those used with the neurotypical population (usually based in interventions geared toward children) rather than having origins in the field of intellectual disability and/or being informed by bereaved people labelled/with an intellectual disability.

D2) Theoretical Perspective Influences Therapeutic Approach

The type of therapeutic grief support (or intervention) that is offered to a bereaved person depends largely on the theoretical perspective and professional affiliation of the clinician, the context of where they work, and consideration to the type of loss (e.g., parent, child, cause of death). Clinicians who prescribe to a psychoanalytic or stage model of grief will see their role as assisting the client to complete their grief work through expression of emotions that leads to a detachment and moving on from the relationship with the deceased, with emotional energy
instead being focused on new and existing relationships (Jordan & Neimeyer, 2007; Worden et al., 2021). There would be no consideration for ongoing attachment or relationship with the deceased past a certain time frame since the death. Popular culture, borrowing from some cultural and/or religious practices, has adopted a six month to one year tolerance for the grieving process related to these stage models (Rosenblatt, 2007).

**Attachment-Informed Grief Therapy.** In contrast to grief work models, Kosminsky & Jordan (2016) provide the following definition of an attachment-informed grief therapy model: “Grief therapy is a concentrated form of empathically attuned and skillfully applied social support, in which the therapist helps the bereaved person reregulate after a significant loss by serving as a transitional attachment figure” (p. 100). Using their model, the grief therapist positions themselves as a secure yet transitional attachment figure and then assists the bereaved to experience and tolerate feelings of grief, while also learning and integrating new information, developing new intra-personal skills, and creating a new life narrative that includes an ongoing attachment to the deceased post-loss (Gilbert & Macpherson, 2021; Kosminsky & Jordan, 2016). The ultimate goal of attachment-informed grief therapy is “integration of the loss on a psychological and neurological level” (Kosminsky & Jordan, 2016, p.100). How this goal is achieved with people of different psychological and neurological capabilities is not addressed in their current work. Therapeutic techniques using this model are aimed at adaptation to the loss through meaning-making and include therapeutic conversation, writing, visualization and enactment, and retelling and reworking the death narrative (Kosminsky & Jordan, 2016).

**Task-centred Approach.** Task-centred models of grief and mourning set forth a process for resolution of grief, which can be used to educate people about what their grief process might look like in order to achieve this resolution, while also suggesting clinical interventions to
support this process for clients. Worden (2009) provides suggested clinical interventions that can be used with individuals or in group settings – including using photographs of the person, evocative language (“your son died” p. 105), writing, artwork, cognitive restructuring – all of which are focused on adapting to the loss and reinvesting in a new life without the presence of the deceased. Rando (1991) speaks to the bereaved directly in her book, How to go on Living When Someone You Love Dies, to educate the bereaved and engage them in activities that specifically move them through her Six R process, as described earlier, in order to resolve their grief. Some of the “resolution” suggestions offered by Rando (1991) include:

(1) Give yourself permission to feel your loss and to grieve over it; (2) accept social support and tell others what you need; (3) be realistic in your expectations of yourself as a griever; (4) give some form of expression to all of your feelings; (5) remember the deceased and review your mutual relationship; (6) identify and work to resolve your secondary losses and unfinished business; (7) yield productively to the grief process, taking care of yourself as you do it; and, (8) accommodate to the loss of your loved one. (pp. 241-260)

These suggestions are not overtly inclusive of the relationship with the deceased continuing in the bereaved person’s life in some form (i.e., continuing bonds, ongoing attachment). However, Rando (1991, 1993) coined the term STUG – sudden, temporary upsurges of grief – to describe those moments when grief reactions occur when the bereaved are not expecting them. For example, birthdays, anniversaries, and special holidays are when the bereaved might expect the grief to be more present. STUGs can also occur at random, seemingly unrelated times, such as seeing the deceased’s favourite cereal at the grocery store, hearing a
song on the radio, or recognizing a familiar smell. Educating bereaved clients and their supportive network about STUGs can be a normalizing and validating practice.

**Companioning the Bereaved.** Wolfelt (2005, 2016) has developed a model of care for the bereaved that he calls *companioning*. Wolfelt has moved his model of bereavement support out of the medical model, refusing to create treatment for grief, and instead advocates a philosophy of companioning people through their grief and pain. This perspective makes the person the expert in their own grief, while honouring their spirit and being wholly present in a way that the professional is not there to fix the person (Wolfelt, 2016). This model seems quite compatible when working with people labelled/with intellectual disabilities, as the focus is not on intellect, articulation of minute feelings, or progressing toward a certain outcome. It is also a model that Wolfelt has used extensively to train lay people in how to companion the bereaved in community-based support groups and may be useful in educating support persons of people labelled/with intellectual disabilities because of its ease in adopting for practice. “Companioning the bereaved is not about assessing, analyzing, fixing or resolving another’s grief. Instead, it is about being totally present to the mourner - even being a temporary guardian of her soul” (Wolfelt, 2016, p. 10). Wolfelt’s model also encourages the bereaved to maintain a relationship with the deceased, moving the person from a place of physical presence to a place of memory and ongoing connection. He points out that this is compatible with many cultures other than Western society, where individuals and groups are encouraged to have enduring relationships in some form after death. In fact, he points out that “…many cultures provide bereaved people with rituals to encourage an appropriate relationship of memory, such as Mexico’s “Day of the Dead” (Wolfelt, 2005, p. 7). Wolfelt (2004, 2009) has also developed several guided journals available to the bereaved which provide them with the opportunity for narrative reflection and meaning
making, however, these are intended for a neurotypical griever. The companioning model is appealing in its foundation rooted in compassion and humanity. However, to be used effectively and responsibly with bereaved individuals the professional support person requires general knowledge about the field of thanatology to be able to recognize possible limitations of the companioning model. For example, knowing when further clinical intervention may be required for depression, suicidal ideation, or self-harm. Wolfelt’s “Tenets of Companioni ng the Bereaved” can be found in Appendix A. The companioning model resonates with me because, as a clinician who has worked with the bereaved for over thirty years, this model of care acknowledges that compassion, non-judgmental acceptance, hope, tenderness, and providing relational space for people in their deep grief are also valuable interventions (Neimeyer, 2012; Wolfelt, 2016).

Meaning-making and Continuing Bonds Approach. When using a meaning-making and continuing bonds perspective in grief counselling (Gilbert & Macpherson, 2021; Neimeyer, 2001, 2014), the therapist will strive to acknowledge the changes and adaptive processes that a bereaved person must engage in after the death of the significant person and will actively encourage the bereaved to have an ongoing relationship with the deceased at a level comfortable for them. Therapeutic activities in counseling sessions could include empty chair work (Neimeyer, 2012; Worden, 2009), letter writing (Harris & Winokuer, 2021), metaphors, exploration of dreams, bibliotherapy, and use of linking objects (Potash & Handel, 2012). There are also self-help books (Rando, 1991; Wolfelt, 2004) and clinical literature (Neimeyer, 2012, 2016, 2022) aimed at facilitating creative grief expression and continuing bonds tailored to the individual needs of the bereaved person. Once again, most of the available literature for creative expressions of grief are aimed at neurotypical grievers.
**Dual Process Approach.** Using the dual process model of coping (Stroebe & Schut, 2010), a clinician can work with their client to identify coping behaviours that are loss-oriented and restoration-oriented and identify the coping strategies that the client feels are helpful, while also identifying areas of everyday life that may be a challenge for the client. When a client is finding it difficult to continue to oscillate, to switch focus between the loss and the restoration, an exploration regarding overload can be helpful. This allows for the exploration of the bereaved feeling they cannot cope when the stressors are experienced as too much/too many to deal with. This overload may result in the bereaved feeling anxious, pressured, distressed, and exhausted (Stroebe and Schut, 2016). Furthermore, in the context of the COVID-19 pandemic, I have found it helpful to explain this model to clients because the pandemic-related social restrictions have inhibited mourners’ ability to oscillate as needed toward restoration-oriented activities, thus making it more difficult to cope with their grief.

**Psychoeducation.** An important aspect of grief support, regardless of the theory or model preferred by the clinician and/or the bereaved person, is to normalize and validate the grief experiences of that unique person. Educating people (psychoeducation) about what is typical to experience, based on the literature and research done with other bereaved people, can be a relief for some people when their reactions are being minimized or pathologized by the people around them (Payàs, 2016; Spence & Smale, 2016). Social workers have a teaching role with clients around identifying feelings, thoughts, behaviours, and physical reactions associated with their grief, and how they can express these to others through words and actions (Ryan, 1989). Being aware of supportive community resources (such as bereavement support groups, walking groups, social media/websites) for people who are grieving a death, effectively evaluating the appropriateness of the resource(s) for the individual, and facilitating connection to these
resources is also a key role for a social worker. Empowering the bereaved to acknowledge, speak about, and act out their grief can create opportunities for healthy expression and meaning-making that can also provide them with approval to share their grief and to mourn in a way that is liberating. Reimagining and advocating for communities where all grief, no matter the bereavement, can be openly expressed and socially validated is an important role for social workers (McCord et al., 2021; Ryan, 1989).

**Mutual Aid Groups.** Grief expression and support can also occur in a group format, facilitated by clinicians and/or lay people who are bereaved themselves and have received training in group facilitation and grief support. For example, Bereaved Families of Ontario (BFO) is an organization with affiliates throughout Ontario that provides mutual aid bereavement support groups to bereaved parents and children. Although very few control group studies have been undertaken to examine the clinical effectiveness of mutual aid groups (Neimeyer & Jordan, 2013), in my personal and clinical experience, participants tend to report that meeting other people – who are also grieving, in a safe, supportive atmosphere, where they can share in a more socially uninhibited manner – is validating, normalizing, and often healing.

**Mindfulness Practice.** Mindfulness practice interventions in bereavement care are gaining popularity as this model of practice, which originates from Buddhist meditation tradition, is increasingly entwined with social work practice (Turner, 2009) and clinical interventions, such as Dialectical Behaviour Therapy (DBT) (Linehan, 2015). Mindfulness as a practice involves “…focusing attention on internal and external stimuli (e.g., sensations, thoughts, feelings, sights, sounds) as they arise from moment to moment in a non-reactive, non-judgmental way” (Chapman & Mitchell, 2013, p. 168). Cacciatore & Flint (2012) have developed a mindfulness-based model that clinicians can use with clients who have experienced the traumatic death of a
significant person. Their model, ATTEND (attunement, trust, therapeutic touch, egalitarianism, nuance, death education), includes a primary focus on clinicians developing their own mindfulness practices, which they then bring into the therapeutic relationship with the client. This leads to teaching and encouraging the client to begin their own mindfulness practice in an effort to foster healing, hopefulness, meaning making, and post-traumatic growth (Cacciatore & Flint, 2012). There is little research evaluating the use of mindfulness approaches with people labelled/with intellectual disabilities who are bereaved. A study by Chapman and Mitchell (2013) analysed the experiences of intellectually disabled adults who took part in a group mindfulness workshop for stress reduction (which included an explanation of mindfulness practice, a 20-minute body scan activity, and a mindfulness CD to take home). Although there are several limitations identified in their study, they found that mindfulness practice can be helpful in reducing stress when it is presented and practiced in an accessible way that meets the needs of people labelled/with intellectual disabilities. Thus, including mindfulness practice may need to be a consideration in my future work with bereaved people labelled/with intellectual disabilities and their support persons. Incorporating mindfulness practice into education about possible grief and mourning reactions and therapeutic support will be in line with current therapy model practices in social work practice (e.g., DBT).

**Summary**

The above exploration of bereavement interventions highlights that there is no one way to support and work alongside people who are bereaved by the death of a significant other. Nonetheless, being aware of and knowledgeable about the myriad techniques and interventions available when working with people through such a multidimensional experience, assists the clinician in providing appropriate, ethical, creative, and adaptable support to the bereaved.
E) Disability Perspectives

E1) Brief Historical Background: Institutionalization and People labelled/with intellectual disabilities

People labeled/with intellectual disabilities have long been excluded from meaningful participation in their communities, experiencing institutionalization, sterilization, segregation, oppression, abuse, and separation from their families (Ben-Moshe, 2013; Lemay, 2009; Liegghio, 2013; Malacrida, 2012, 2015; Rossiter & Rinaldi, 2019). Thus, it is critical to examine some of the historical aspects of the treatment of people labelled/with intellectual disabilities to have a context for contemporary practices and theoretical lenses in this field of study. Reviewing some of the literature regarding institutionalization (and the losses related to this experience for older adults labeled/with intellectual disabilities who are still alive and now living in community settings) and the ensuing de-institutionalization movement provides a background for the exploration of citizenship issues, social exclusion, and critical disability studies. However, as Malacrida (2015) points out, it has been very difficult for disability historians to capture a realistic and detailed historical picture that reflects the treatment of people labelled/with intellectual disabilities because many people no longer officially exist in remaining institutional records, their stories have been told through the lens of people who had authority over them, and/or their perceived lack of value made their lives less valuable and important to understand. Despite this, there remains enough information and firsthand experiential knowledge to confirm that people labelled/with intellectual disabilities institutionalized in Canada, from the 1830s on, experienced systematic dehumanizing, abusive, and traumatic treatment (Malacrida, 2015; Panitch, 2008; Region of Waterloo, 2017; Rogers, 2016; Rossiter & Rinaldi, 2019).
In 1876, Canada’s first Asylum for Idiots was opened in Orillia, Ontario (later renamed the Huronia Regional Centre) (Burghart et al., 2015; Rossiter & Rinaldi, 2019). Upon the birth of a supposed deficient child, many parents were told by the medical community to institutionalize their child and sever ties with them. People labelled/with intellectual disabilities were placed in institutions because they were viewed through a medical and social lens as deviant, feeble-minded, unproductive, burdensome, disposable, and defective (Carey, 2009; Malacrida, 2015; Rossiter & Rinaldi, 2019). As societies became industrialized, people with disabilities were considered unable to contribute to the capitalist system, and in fact were feared as deviants to the norm and the assumption was that they may procreate and burden society with more ‘deviants’ (Carey, 2009; Malacrida, 2015; Panitch, 2008; Rossiter & Rinaldi, 2019). This dehumanizing of a particular group of people made it possible - and even justifiable - to segregate them from able-minded and able-bodied society, which in turn was used as reasoning to subject them to oppressive practices such as exclusion from communities, removal from families, institutional oppression, and forced sterilization. Collectively, these practices were part of the eugenics movement (Malacrida, 2015; Panitch, 2008; Rossiter & Rinaldi, 2019). Through interviews with former residents of the Michener Institute in Alberta, family members and former staff, and by reviewing institutional records, Malacrida (2015) determined that, for some residents, it was a lack of educational support and being born into what were considered to be troubled families (poverty, abuse, single mother) that sent them into institutions, not necessarily a diagnosed intellectual disability. Malacrida (2012, 2015) singles out the formalized education system whose role became to identify children as feeble-minded and thus more likely to be removed from mainstream education, their peers, and even families. She notes that the survivors’ stories were consistent regarding why they went into the Michener Institute: “…they went because they or
their families were told that life inside the institution would be better for them than life outside” (Malacrida, 2015, p. 46). This is echoed by siblings of people who were institutionalized as children at the recommendation of health professionals. Little consideration, care, or interest was paid to the potentially devastating effects of loss for these families. As shared by an adult sibling whose sister who was born with Down syndrome and placed in an institution at age two, not only did the children and adults in these institutions experience loss, pain, and fear but so did their families:

> Even now, more than 50 years later, I can’t begin to express the rage I felt, the bitter sense of loss. I was never able to speak it then; I swallowed it down, was a good girl, denied my pain to lessen the pain of others. I did this out of love for my parents, but also out of fear, for if my parents did not love Martha, perhaps they also only pretended to love me. Perhaps one day I would also be sent away to some awful place. I had not just lost Martha, then; I had lost the security of my parents’ love. (Burghart et al., 2015, p. 111)

Another sibling states:

> Robert was denied humanity. He experienced inhumanity. He was just ‘one of them’. He was put ‘over there’. Whenever that happens, people are harmed. …Robert missed everything: flavours, sunshine on his face, music, toys, movement, snow, plants and animals, love, a future. (Burghart et al., 2015, p. 107)

The efforts aimed at dehumanizing people labelled/with intellectual disabilities permitted these inhumane treatments and isolation from their communities. Malacrida (2012, 2015) outlines three outcomes from the systematic dehumanizing of a group of people: the dominant group determines the acceptable “actions, behaviours, and attributes of those being
dehumanized” (p. 60) in a way that an individual’s personal traits are eradicated and they are placed into a group pre-determined to be not fully human; it justifies the maltreatment and discrimination by the powerful neurotypical group toward the less than human group by normalizing their “outsider status” (p. 62); and, the dehumanized group becomes viewed as “scourges and dangers to the cleanliness, decency, and health of the modern social body” (p. 62).

The socially and politically sanctioned dehumanizing of people labelled/with intellectual disabilities (and people presumed to have an intellectual disability) and the movement to institutionalize them in large scale institutions, away from the neurotypical public occurred for well over one hundred years in Ontario (Rossiter & Rinaldi, 2019).

As the horrific conditions of these institutions where children, siblings, and community members were living became more apparent to the outside world, a movement began to challenge them, and organizations such as Associations for the Mentally Retarded (later changed to Community Living) sprang up across Canada starting in the late 1950s (Burghart et al., 2015; Malacrida, 2015; Region of Waterloo, 2017; Rossiter & Rinaldi, 2019). Advocates (particularly mothers) lobbied for people in these institutions to be moved into community-based homes, closer to their families, where they could live in better conditions and their families or community members could have more involvement in their care (Burghart et al., 2015; Panitch, 2008). However, this needed to coincide with government funding and assistance to provide needed community-based supports. This does not mean that all families were in favour of moving their family members out of institutions. In fact, the normalization movement – to make the everyday lives of people with disabilities as closely reflective of those of people without disabilities – had many detractors who argued that only institutions had adequate services and programs, and that community-based living may be less safe for those people who were marked
as vulnerable due to their disability (Bigby, 2012; Carey, 2009). Nevertheless, the deinstitutionalization movement gained traction in the 1970s as parents, self-advocates, and community allies brought forth to the general public the dehumanizing treatment of people in institutions (Rossiter & Rinaldi, 2019). They encouraged the notion of *individualization*, which sees the individual (person labelled/with an intellectual disability) as someone with unique abilities, interests, needs, and who has a right to be part of the planning that affects their life. Not only did the move for deinstitutionalization seek to transfer individuals out of large-scale institutions to community-based homes, but the goal was also to create a system of social inclusion and autonomy where the person labeled/with an intellectual disability had a role in making decisions about their own life.

Inclusion of specific human rights for people with disabilities in Ontario legislation did not come into effect until the early to mid-1970s. Legislation was aimed at preventing discrimination toward people labelled/with intellectual disabilities, and it was not until 1982 that people labelled/with intellectual disabilities were included in the Canadian Charter of Rights and Freedoms (Region of Waterloo, 2017).

The legacy of loss and harm experienced by people placed in institutional care continues to resonate today for survivors, for families, and for those now entrusted with the day-to-day support and care of people labelled/with intellectual disabilities. For people working with individuals who have experienced institutionalization, there is typically a lack of information about loss and trauma histories, making it difficult to address cumulative issues of loss in their lives (Kauffman, 2005; Rossiter & Rinaldi, 2019). It is interesting to note that, just as people labelled/with intellectual disabilities are on the margins of thanatology research and writing, they are also on the margins of disability studies, with few books dedicated solely to the exploration
of intellectual disability and how being labelled/with an intellectual disability is experienced socially and individually in a different way than physical disability (Bigby, 2012; Rogers, 2016). Interestingly, although there is wide acknowledgement that people labelled/with intellectual disabilities are “the experts on their own experiences, these individuals have been largely omitted from the disability discourse” (Coons & Watson, 2013, p. 14). Consequently, I have worked to find literature specific to intellectual disability in an effort to bring intellectual disability discourse in from the margins. What follows is an exploration of theoretical perspectives in disability studies in general, with a subsequent exploration of intellectual disability specifically.

**E2) The Medical Model**

Similar to the field of thanatology, *disability studies* is also a fairly new specialized area in academia. The origins of disability studies can be traced to “the organizations of disabled people whose voices emerged in the late 1960s and who shared ideas drawn from those of other previously excluded groups” (Roulstone et al., 2012, p. 3). Disability studies literature tends to refrain from a medicalized approach to categorizing people specifically based on the type of disability they embody, instead focusing on the social, political, and institutional structures present in society (Panitch, 2008). However, it remains relevant to acknowledge that the diagnosis of a disability (necessary for access to services) requires medical and psychological tests that are carried out and interpreted by medical professionals, with disabilities viewed through a biomedical lens of individual defects and deficits (Bach, 2017; Clements et al., 2004). The medical model continues to be used in clinical practice (through diagnosis and intervention selection) and presumes that the responsibility for change rests with the individual through professional help (Oliver & Barnes, 2012).
**E3) Social Model of Disability**

Disability scholars in the 1980s, in search of moving beyond the medical model of cognitive impairment being solely based in biology and individual deficit (in comparison to societal norms of intelligence and functioning), conceptualized a social model of disability which drastically transformed ideas of how disability can be understood (Bach, 2017; Rogers, 2016). This model puts forth a particular interpretation of how society, through ableist normative ideas as to who does and does not count as a valued person, has created discrimination and disadvantage for people with disabilities and excluded them from full participation (Bach, 2017; Shakespeare, 2013). Two key elements of the social model include “the distinction between disability (social exclusion) and impairment (physical limitation)” (Shakespeare, 2013, p. 215), which means that both the physical and social environment becomes disabling for people with physical and/or intellectual disabilities, limiting their social participation through disablism. This is reflected in the Fundamental Principles of Disability (UPIAS, 1975) which states (with regards only to people with physical disabilities):

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our [physical] impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (p. 4)

People with disabilities, using a Western social model, are no longer viewed solely in relation to their medical diagnosis and impaired body/mind but, rather, in terms of how social, physical, and political structures create exclusion and oppression which lead to the discrimination and limitations faced by the disabled (Bach, 2017; Baines, 2012; Roulstone et al., 2012; Shakespeare, 2013). Withers (2010), a disabled individual and organizer, adds that the
social frameworks of the powerful who create disability are always changing and are thus dependent on the period, culture, and milieu. Extending these views to people with an intellectual disability, for earlier theorists, people born with “extreme mental deficiency” or who were “abnormal” experienced unsuccessful socialization from “biological accident” (Berger & Luckmann, 1966, pp. 165-170). This means that people became disabled because of social stigma (Oliver & Barnes, 2012) and exclusion which occurred intrinsically due to cognitive impairment. In terms of remaining marginalized and oppressed, “as long as such individuals…do not form a counter-community of their own, both their objective and subjective identities will be predefined in accordance with the community’s institutional program for them. They will be [mentally deficient] and nothing else” (Berger & Luckmann, 1966, p. 166). However, this returns to the personal tragedy view of impairment without looking at how a disabling society can - and should - be eliminated (Oliver & Barnes, 2012). This form of oppression, with efforts aimed at silencing an entire group of people (Rogers, 2016), is in part what fueled the removal of intellectually disabled children from their families and communities to be placed in institutions.

People labelled/with intellectual disabilities remain “one of the most socially disadvantaged groups of people within society” (Read, 2014, p. 33) due to the challenges they pose for neurotypical bodies and minds, and the Western ideal of perfection. This is not meant to suggest that all members of neurotypical communities will oppress and reject people with an intellectual disability. However, due to oppression and marginalization, people labelled/with intellectual disabilities “experience profound and multiple losses across the lifespan, many of which are invisible, and therefore go unnoticed, unrecognized, and unsupported” (Read, 2014, p. 33).

Goodley (2013) notes that the social model of disability in the 20th century severed the causal link between the body and disability by scholars who instead “…relocated disability to
social, cultural, economic and political registers” (p. 634). Thus, the focus was not on what a person’s body is limited by; instead, it was what is done within a social context to the person, situating the disability within the social and political environment (Bach, 2017; Lang, 2007). This view seeks to understand societal structures, institutions, attitudes, and beliefs of what others people with disabilities through disablism and ideas of what normal should look like (Roulstone et al., 2012). Baines (2012) summarizes the social model perspective as “…a tool with which to provide insights into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication” (p. 18). Furthermore, Anastasiou and Kauffman (2013) believe that the biological and cognitive characteristics of people labelled with a disability are “only social illusions fully determined by the social context and social values” (p. 445). They fully separate impairment (loss or lack of some functional part of the body) and disability within a society that discriminates, disadvantages, and excludes people with impairments.

Historically, having a disability was viewed as the problem of the individual and as a tragedy preventing the disabled person from full participation in life (Hughes, 2012), and being labeled disabled was viewed through materialistic and capitalist lenses as an inability to contribute while also being a dependent within society (Bach, 2017; Baines, 2012; Titchkosky, 2011). Alternatively, Oliver and Barnes (2012) suggest that when disability is defined as “social oppression” (p. 14), the person with a disability will be viewed through the lens of an uncaring society, rather than as a personal tragedy, which can lead to changes in social policy aimed at lessening oppression. Hiranandani (2005) adds that within a social model of disability, the environment is seen as the primary target of intervention. Social barriers have, for many decades, isolated people with disabilities from meaningful employment, education, housing, and care,
excluding them from inclusion in mainstream activities enjoyed by the neurotypical majority (Baines, 2012; UPIAS, 1975). The Union of the Physically Impaired Against Segregation (UPIAS), although an organization solely of people with physical impairments, advocates for inclusive practices (that can be considered in relation to people labelled/with intellectual disabilities as well) and cautions neurotypical professionals who wish to be allies in their efforts:

We know that as a small, weak, minority group, disabled people cannot achieve a fully human life by their own efforts alone. We need and welcome the help of sympathetic able-bodied people. But the basic problem we face is our exclusion from full social participation. It follows that this oppressive situation can be put right only by disabled people actually taking a more active part in society. The efforts of professionals and other able-bodied people are therefore really constructive only when they build on and encourage the self-help and activity of disabled people themselves. (2012, p. 11)

A critique of the social model is that it discounts biological impairment as a problem (Shakespeare, 2013) and the embodiment of disability: “how the body operates in the world at the intersections of the corporeal and institutional” (Goodley, 2012, p. 316). Moreover, while the social model assumes oppression (which it is also trying to prove), it does not take into account the challenges of distinguishing the effects of impairment (e.g., chronic pain) from those of social barriers, and critics argue that a “barrier-free utopia” (Shakespeare, 2013, p. 219) is just not feasible. Rogers (2016) extends the critique to include people labelled/with intellectual disabilities: “In understanding intellectual disability…certain difficult behaviours and day-to-day occurrences, whether for the intellectually disabled person, or for the one caring, are not eradicated via the social model of disability” (p. 27).
**E4) Critical Disability Studies**

This is where critical disability studies extends the social model to develop an interdisciplinary expanded perspective (Oliver & Barnes, 2012). Critical disability studies is not a rejection of the social model of disability, rather, it is a critique and extension of thinking based on the social model not being adequate to fully explain the experience and oppression of the disabled. Tom Shakespeare’s (2006) argument, as summarized by Goodley (2013), is that consideration of impairment is important because “…some are static, others are episodic, some degenerative and terminal. Hence, a social model can only explain so much before we need to return to the experiential realities of ‘impairment’ as object(s) independent of knowledge” (p. 634). There are some impairments that are disabling in society, such as intellectual disability, that cannot be fixed solely by addressing accessibility and inclusion issues. Shildrik (2012) questions embodiment, identity, and agency as they affect all living beings, critiquing power and binary thinking, while asking what it is that underlies and motivates the move of excluding others from mainstream society. She extends this into consideration of bodies as “performative entities” (Goodley, 2013, p. 635) with the non-neurotypical body as a challenge to neurotypical notions of what a body should be and demanding consideration of alternative responses to impaired bodies (Shildrik, 2012). Critical disability scholars consider the individual impairment within the social and political systems that continue to impede movement toward more equitable conditions for the disabled (Bach, 2017; Shildrik, 2012). Newell (2010) notes that neurotypical culture (the dominant culture of the oppressor) does not want to trouble itself with human frailty and mortality. He calls disability the “dangerous other in the form of terror on wheels, and on crutches, and most disturbingly in a world where intellect is all, in the form of a disturbed mind” (p. 173).
For people labelled/with an intellectual disability, who have been deemed as less than human (Malacrida, 2015; Oliver & Barnes, 2012; Rogers, 2016), Liegghio further argues that being socially constructed as mentally “incompetent” and “dangerous” becomes a powerful means of being deemed ineligible as knowers (epistemic violence), corresponding to forms of discrimination and prejudice that are faced daily by people deemed “mentally different” (2013, p. 125). Furthermore, to restore someone’s epistemic existence - in this case, to bring into being a griever labelled/with an intellectual disability - this restoration “…requires conscious acts that construct, support, and give legitimacy to the person as someone with legitimate ways of knowing and, ultimately, legitimate ways of being” (Liegghio, 2013, p. 127). This means that the individual and their biological impairments are not the target of change, but rather, institutional structures and processes that deny the existence of the grieving intellectually disabled person are examined and changed (Liegghio, 2013).

**E5) Psycho-emotional Disablism**

An additional element of exploration in disability studies is that of psycho-emotional disablism, the disregard for the emotional well-being of disabled people who experience exclusion, discrimination, and oppression (Hughes, 2012; Thomas, 2007). This is in addition to structural social disablism and constitutes emotional well-being issues as a result of social exclusion and from “hurtful” interactions with neurotypical society (Thomas, 2007, p. 72). Hughes (2012) suggests that in everyday life “disabled people experience attacks on their existential security” (p. 68). He identifies three emotions central to the “emotional infrastructure of ableism” (Hughes, 2012, p. 68) – fear, pity, and disgust. The focus of this perspective is on the emotions experienced by neurotypical society in their aversion toward impairment and disability and their lens of tragedy when looking at the lives of people with impairments. The effect of
society’s feelings toward the disabled in turn challenges the emotional well-being of those who are living in a disabiling society, affecting their self-esteem, confidence, and daily interactions (Thomas, 2007). As noted by Shakespeare et al. (1996) “dealing with anger, self-loathing, and daily experiences of rejection and humiliation are among the hardest aspects of being a disabled person” (pp. 42-43).

**E6) Care Ethics Model**

Rogers (2016), proposes a ‘care ethics model’ of disability which encompasses three spheres of care-full, interrelated work: “The emotional caring sphere – where love and care are psycho-socially questioned; the practical caring sphere – where day-to-day care is carried out relationally; and the socio-political caring sphere - where social intolerance and aversion to difficult differences are played out” (p. 2). See Figure 2. This model advocates for care-full contemplation before action in the ‘everyday.’ Rogers (2016) suggests that human difference should be embraced rather than attempts aimed at normalizing, as all humans are intrinsically distinctive and denying this “…is inhumane and care-less” (p. 5). These care-full spheres of work are important to consider when engaging in research and when working with people labelled/with intellectual disabilities who are bereaved. No matter the level of intellectual ability, the person will be in relationship with others involving all three spheres of caring and will inevitably experience some level of disruption when the relationship ends (Morse et al., 2016; Rogers, 2016). Rogers (2016) stresses that the experience of both giving and receiving care highlights the humanity and vulnerability in relationships that must always be conducted in care-full ways so as not to be care-less in our interactions and caregiving. Given the lengthy history of care-less treatment toward people labelled/with intellectual disabilities (Rossiter & Rinaldi, 2019), a care ethics approach is a valuable addition for consideration in exploring grief support
for people labelled/with intellectual disabilities. As I learned about loss and grief from my research participants labelled/with intellectual disabilities, attending to a care-full approach in my process was essential as I navigated entering, staying, and leaving their lives.

**Figure 2: Care Ethics Model (Rogers, 2016)**

A care ethics approach is not only helpful in engaging in my research, but also for social workers (and other professionals) engaged in support with people labelled/with intellectual disabilities as it guides individual practices while also considering the effects of broader social relationships and social policy (Baines, 2018).

**F) Intellectual Disability**

As defined in various ways earlier in this paper, intellectual disability is distinct from other types of disability because the individual experiences challenges in cognition that are life-long, and that are in variance from the societal norm, thus affecting their daily functioning in countless ways. The key element to an intellectual disability (although sometimes accompanied
by physical or other impairments) is cognitive ability that is understood to be different from the norms determined by standardized tests and diagnostic criteria (Bach, 2017; DSM-5-TR, 2013; Malacrida, 2015). This medically based classification is what society uses to determine the knowledge and participation abilities that people labelled/with intellectual disabilities possess. In addition, parents’ movements and some ally organizations became responsible for creating the image of the “special child” – one who is dependent, innocent, and an eternal child (Carey, 2009). This infantilization only served to further other and distance people labelled/with intellectual disabilities from recognition as holders of knowledge because they were viewed as childlike regardless of their age. Adults labelled/with intellectual disabilities are still infantilized, which also plays out when a death occurs and they are often protected (excluded) from the realities associated with a loss from death and treated like children, which means they can be excluded from this innately human experience (McCord et al., 2021; Robey, 2006).

What the DSM-5-TR does not capture in its diagnostic criteria are the multiple meanings of being diagnosed with an intellectual disability. Ivan Brown (2020) argues that it is important to understand intellectual disability across the following four domains: personal, public, critical, and definitional. The personal meaning of intellectual disability is diverse across individuals and is meaningful in varying ways across their lifespan. Only the individual labelled/with an intellectual disability who lives with the complexities and nuances that accompany their experience can describe it from their own perspective. Thus, understanding of the ‘lived experiences’ of someone labelled/with an intellectual disability can only come through care-full observation, communication, and listening to their point of view (Brown, 2020). As previously discussed, in the past, the personal meaning and experience of living with the label of intellectual disability has tended to come from professionals rather than from individuals and groups
labelled/with intellectual disabilities. This was very important to keep in mind in my research process, as I work to prioritize the grief experiences of people labelled/with intellectual disabilities from their unique personal perspective while facilitating the telling of their stories in an effort to further inform support for others in the future.

The *public* meaning of being labelled/with an intellectual disability is often different from that of people labelled/with intellectual disabilities and is informed through the media, workplaces, cultural and religious institutions, and policy/government (Brown, 2020). The general public gains their understanding through these means rather than as a direct result of knowing someone labelled/with an intellectual disability. Public meaning of intellectual disability “emerges as a consequence, and a confluence, of two main factors: the public’s understanding of the literal meaning of the term, and the sociocultural meaning associated with it” (Brown, 2020, p. 6). Brown (2020) describes the literal meaning of developmental (intellectual) disability, as understood by the public, as the way a person develops over time that leaves them unable to participate and accomplish certain things in their life. The literal meaning can also be connected to the definitional meanings as used by medical professionals in making the diagnosis of intellectual disability. The social-cultural meaning of intellectual disability is embedded in what the larger social group considers what people *should* be able to do (within differing cultural contexts) and when someone does not have the ability to perform or participate in ways the broader group thinks is typical (e.g., writing, banking, communicating, self-care) this lack of capacity is understood as a disability (Brown, 2020). The public, literal, and sociocultural meanings of intellectual disability have tremendous influence on an individual’s personal experience of being labelled/with an intellectual disability and how they make meaning
of this label. The *critical* and *definitional* meanings of intellectual disability have previously been discussed.

**F1) Social Exclusion**

People labelled/with intellectual disabilities have long been excluded from social participation and recognition, with far less writing and research existing in this area of impairment and disability (Rogers, 2016). Growing up, people born with an intellectual disability “…learn the standards against which they are judged and society’s responses to their devalued and disadvantaged status. Growing up with an impairment can often be an isolating and lonely experience, [without] strong supportive role models to look up to” (Oliver & Barnes, 2012, p. 110). Citizenship and all its inherent rights (in a Western sense), as explained by Carey (2009), places preference on those who are intelligent, independent, and contribute to the economic and social well-being of a community and country. In contrast to this “ideal citizen…people [labelled/with] intellectual disabilities tend to be characterized by their deficiencies…[appearing] unworthy, at best, and a threat to the nation and himself or herself, at worst” (Carey, 2009, p.1) and are thus not recognized as citizens in the same ways as their non-disabled counterparts. Furthermore, Carey (2009) extends the argument such that, whether an intellectual disability is fixed or fluid, whether rooted in biology or social construction, whether they are similar or different from other people, we cannot “…locate people on the poles of such dichotomies…[T]here can be no consistent or correct placement of people [labelled/with] intellectual disabilities” (p. 15). Recognition is needed that people labelled/with intellectual disabilities are not “a homogeneous group” (Bach, 2017, p. 42), but rather, are individuals who differ across gender, race, culture, interests, and abilities.
**F2) Epistemic Violence**

People labelled/with intellectual disabilities have historically been segregated from mainstream education and work opportunities (Rossiter & Rinaldi, 2019), which has excluded them from being holders of knowledge within neurotypical society. This is referred to in the literature as epistemic violence. Liegghio (2013) discusses epistemic violence in relation to psychiatric patients, but the position she takes and the application of the concept, is useful with the experiences of people labelled/with intellectual disabilities. Epistemic violence occurs when “…certain persons or groups in society are disqualified as legitimate knowers at a structural level through various institutional processes and practices” (Liegghio, 2013, p. 123). People labelled/with intellectual disabilities often remain silenced while segregated in group homes and sheltered workshops, being cared for by staff who are not likely specifically educated in recognizing and supporting grief and mourning expression. The concept of epistemic violence is very relevant in relation to whether people labelled/with intellectual disabilities are recognized as capable of having their own knowledge of loss and grief. This is evident once again in the story of Gayle, her death, and the exclusion of the members of the craft group from knowing about her death. How can you try to make sense of and meaning from something you have not even been told about? As Liegghio states, “it is the very denial of a person’s legitimacy as a knower – their knowledge and their ways of knowing – that renders the person out of existence, unable to be heard and have their interests count” (2013, p. 124). Thus, how can a person labelled/with an intellectual disability enact their grief and mourning when they are often excluded from the very knowledge of death and feelings related to loss (McCord et al., 2021)?

Taking this a bit further, I draw on Poole and Ward (2013) who assert that modernist assumptions create preference for reason and rational thinking, maintain binaries of what is
understood to be normal and abnormal (in-group/out-group), and determine who decides what
groups or individuals contribute to the formation of knowledge; and, particularly relevant to this
discussion, what can be known about grief by whom. This suggests that people labelled/with
intellectual disabilities cannot know grief because they are constructed as lacking in reason and
rationality – but where is the acknowledgment of differing cognitive abilities, emotion,
attachment, and relationship in this? Thus, when a death occurs and the griever is already in a
position of social vulnerability in our competitive society where human weakness is not well
tolerated, so much of the grief experience is disenfranchised and must go underground (Harris,
2009; McCord et al., 2021). Vorhaus (2016) argues that when the concept of capability is
explored across human abilities, one cannot conclude that all humans inherently have the same
capabilities regardless of impairments, as “there is more to what is valuable about a person,
including what they can offer other people, than is likely to be revealed in an audit of their
capabilities and functioning” (p. 38-39). This plurality of human qualities and abilities is, in part,
why we must explore numerous viewpoints and experiences of being human in both thanatology
and disability studies.

**F3) Grievable Lives**

When a life is not considered to be fully human, and an entire group of people are
consequently socially excluded and oppressed, does society even consider their lives worthy of
grief? Butler (2004) argues that lives that are already socially dead cannot be grieved as they
have already been lost. What Butler (2004) is suggesting (specifically regarding violence and
war, but extendable to the lives of people labelled/with an intellectual disability) is that Western
society’s way of thinking renders certain people out of existence, making them invisible because
they are not understood to be socially alive. The necessary work then is to bring people into
being, so they are visible and humanized. Life is more precarious for those who are not recognized as human - in this instance, people labelled /with intellectual disabilities - because the necessary social and economic resources afforded to neurotypical people are not as accessible and abundant for those rendered invisible (Butler, 2016). Goodley (2013), referring to the work of Ghai (2006), states that “disabled bodies risk becoming dis-embodied because of constructions around them that threaten to create total invisibility of the disabled individual” (p. 635). The grievability of certain lives is an important construct to consider when exploring the death of people labelled/with intellectual disabilities and how they are remembered and valued by others in their lives.

**F4) Intersectionality**

The concept of intersectionality is present in the examination of the literature in disability, but less so in the field of thanatology. For Davis (2002), disabled people are the ultimate intersectional subject through which exclusion and resistance can be examined. This is, in part, because disability can be found across all other social categories. Poole and Ward (2013) describe intersectionality as “how aspects of social identity – such as race and madness, for example – intersect with oppressions such as sexism and heterosexism” (Poole & Ward, p.96). Using this concept, one could look at the social model of people with an intellectual disability, how they are oppressed through social, political, and economic means, and how this affects their individual grief experiences. The concept of intersectionality can also be applied to explore if there are any significant race, gender, class, and sexuality issues intersecting with the experience of grief for people with an intellectual disability (which is also lacking literature and research at the intersection of thanatology and disability studies).
G) Integrating Bereavement, Grief, and Mourning in Relation to Intellectual Disability

Having previously noted that both thanatology and disability studies are fairly new academic fields, and that they rarely seem to intersect in their research and writings, it is not a stretch to say that there is not a vast interest in exploring bereavement, grief, and mourning related to death for people labelled/with intellectual disabilities. This could be, in part, related to institutionalization and the historical and contemporary removal of people labelled/with intellectual disabilities from communities in which research and academic enquiry were taking root. Hidden away in institutions, stripped of personhood, and subjected to inhumane treatment in the name of eugenics (Rossiter & Rinaldi, 2019), many people labelled/with intellectual disabilities had no opportunities to integrate into families and communities. According to Todd et al. (2013),

Institutionalization could be characterized as a form of death, ‘social death’. Hidden and removed from society, their social death preceded their biological one, sometimes by many decades. It is interesting to note that the wider and more general interest in the social dimensions of death occurred at the same time as the de-institutionalization of people intellectual disability. The deaths of people labelled/with intellectual disabilities became more public and hence less easily overlooked. (p. 183)

However, this does not fully explain why people labelled/with intellectual disabilities were, and continue to be, deemed not worthy of being told when a death of a significant person occurred. Once again, this happened in my placement when Gayle died, and the members of her group were not told of her death. Whether this occurs from the infantalizing standpoint of needing to shelter people from bad news, the notion of ‘ignorance is bliss’ and/or that people labelled/with intellectual disabilities will not understand, or whether individual staff-related/other
factors also affect such choices, such as challenges faced by those telling with managing their own emotions, and lack of education and/or experience with death, the result is the same – the person is excluded as a knower and disenfranchised as a griever (Lord et al., 2017; McCord et al., 2021). From a developmental perspective, using Piaget’s (1973) framework of cognitive development, death as a concept becomes better understood as one’s cognitive abilities develop, allowing for understanding key concepts such as: cause, finality, cessation of bodily functions, universality, and finality of death (Balk, 2021; Lord et al., 2017). Although it has been found that many people labelled/with intellectual disabilities may only have a partial understanding of the concept of death, expression of emotions, thoughts, and behaviours related to loss and grief are not dependent on a complete understanding of death as a concept, nor necessarily the ability to communicate this verbally (Lord, et al., 2017).

There are further considerations when looking to determine best practices in bereavement care and people labelled/with intellectual disabilities. Reviewing aspects of Butler’s queer theory, with the focus on human ethics and the questioning of whether our Western ways of thinking make certain people in our society not exist, is very relevant to this discussion. The concepts of invisibility, livable world, and grievable lives apply beyond the study of violence, gender, and sexuality. Butler (2004) discusses human vulnerability, grief, and our responsibility for each other’s lives. Butler asks:

…what makes, or ought to make, the lives of others bearable? Somewhere in the answer we find ourselves not only committed to a certain view of what life is, and what it should be, but also of what constitutes the human, the distinctively human life, and what does not. (2004, p. 18)
How are people labelled/with intellectual disabilities brought into being within our communities after so many years of suffering, segregation, and dehumanizing treatment (Rogers, 2016)? Much of our learning comes through socialization – how to behave, ways of thinking, beliefs, values, roles, identity formation, how to grieve. For people labelled/with intellectual disabilities, who may not have broad opportunities for socialization, this learning and development of perceptions of who they are is shaped through their treatment by others (Oliver & Barnes 2012). The field of thanatology has not engaged fully in exploring the unique needs and challenges faced by bereaved people labelled/with intellectual disabilities (Morse et al., 2016; Read, 2014). As noted, people labelled/with intellectual disabilities remain marginalized from mainstream bereavement support and thanatology research. Additionally, issues of bereavement, grief, and mourning due to the death of a significant person are not often taken up in disability studies literature. It is troublesome when this is not acknowledged because people labelled/with intellectual disabilities also may have limited coping skills, and display behaviours when dealing with the death of a loved one that may be difficult for others in their environment to understand and support (Morse et al., 2016). As mentioned earlier, people labelled/with intellectual disabilities likely experience cumulative losses, related not only to tangible losses such as death, or loss of a staff member who has changed jobs, but also related to the perceptions of others in their communities as to their value and worth – a loss of personhood (Clements et al., 2004).

Poole and Ward (2013) argue that the pathologizing of grief, when applied to oppressed and stigmatized groups, leads to issues separating people into power-up and power-down groups: “this factional splitting ensures a lower standard of service for the power-down group and allows the power-up group to judge, reframe, and belittle the power-down group in pathological terms”
This relates to the earlier discussion of the pathologizing of grief using the new DSM-5-TR Persistent Complex Bereavement Disorder diagnostic criteria. Furthermore, as a group deemed as ineligible ‘knowers,’ many people labelled/with intellectual disabilities are unprepared for death in their midst, having received no death education (as discussed earlier), little accurate information, and experiencing exclusion from death rituals (Clements et al., 2004; McCord et al., 2021). This, combined with restricted socialization, can make it difficult for people labelled/with intellectual disabilities (and the people around them) to recognize their grief reactions, which may delay or impede their grieving process, or they may be labelled as pathological grievers (Clements et al., 2005).

Butler’s (2004) concept of performativity (of our identities through language, gestures, bodily enactment of reality) is brought into disability studies by Shildrick (2009), and Goodley (2013) notes that this “…demands us to think about the ways in which non-neurotypical bodies are performative entities … [which challenges] neurotypical ideas of disabled bodies” (p. 635). Performativity can extend into grief as well. For example, concerning grief, we can ask: am I performing grief properly? Do people labelled/with intellectual disabilities, as human beings, enact grief differently from neurotypical society? Is there only one way to perform grief? Does a bereaved person labelled/with an intellectual disability enacting their grief challenge societal norms about grief expression and who can grieve?

In my work with community living agencies, front-line workers often share that they have little understanding and training in how to react when a death affects the people they work/live with (McCord et al., 2021). Often, emotions and behaviours related to grief are instead viewed as acting out, inappropriate, and are managed as such rather than with compassion and informed by knowledge about grief and mourning. This is an outcome of diagnostic
overshadowing, where the diagnosis of intellectual disability is the only factor considered, making grief reactions an impossibility for consideration (Mason & Scior, 2004). Moreover, exclusive use of a behavioural management approach toward the grief reactions of people labelled/with intellectual disabilities is not a helpful practice as the focus is on correcting or redirecting unacceptable behaviour rather than considering root causes and connections to emotional, cognitive, social, and spiritual influences (Clements et al., 2004). Instead, with mutual education and understanding, people labelled/with intellectual disabilities and their caregiving community can provide appropriate and individualized support, meaning-making activities, and continuing bonds with the deceased that demonstrate how people important in their lives are grievable, valuable, and important.

With an understanding of the individual’s loss history (often difficult to access, but often including separation from family) (Clements et al., 2004), any issues related to the death (such as disruptions in their environment), and interpersonal resources, it is possible to assist people labelled/with intellectual disabilities to link the situation with their feelings, thoughts, and behaviours (Clute, 2010; Parkes, 1996). Kauffman (1994) discusses the importance of creating a loss assessment before working with a person labelled/with an intellectual disability who is bereaved to create a story of the losses the person has experienced, note the reactions they have experienced related to loss, and how they have engaged in adaptation to the loss. Appendix B outlines the areas of enquiry and the purpose of the loss assessment prior to grief interventions being undertaken. The goal of intervention is “not to fix the hurt, but to facilitate the mourning process: to recognize or acknowledge the loss and support the expression of grief” (Kauffman, 1994, pp. 11-12). Furthermore, if a framework of normalization is strictly applied, a denial of disability may occur as supportive others expect the bereaved person labelled/with an intellectual
disability to grieve, cope, and develop grief reactions as they are assumed (incorrectly) to affect the neurotypical population (Clegg & Lansdall-Welfare, 2003).

People who were institutionalized (or who live in other forms of institutionalized care), may have an extensive loss history – loss of rights, loss of family, community, home, loss of privacy, numerous support persons – rooted in the social and systemic treatment of people labelled/with intellectual disabilities prior to the deinstitutionalization movement and continuing into community living. However, much of this loss history has vanished – either through lack of documentation, missing records, or neglect – so a historical picture of who a person has lost through death and how a person has coped with these losses is lacking. Thus, the lack of knowledge about loss history hinders a good understanding of how a current loss may affect a person’s grief reactions (Kauffman, 2005). Those who have lived at home or in group homes also experience multiple (often unrecognized) losses as support persons come and go from their lives, family members die, and they are excluded from important decision-making about their own lives.

Oswin (1991) undertook a study to determine what bereavement looks like for people labelled/with intellectual disabilities. Based on the findings of her study, she provides guidelines for how support persons should provide support to these bereaved individuals. In the book Oswin (1991) wrote to share her study findings, the methodology of her study is not clearly articulated, but it appears she undertook interviews with staff and residents of long-term care homes, as well as with people labelled/with intellectual disabilities living in the community with family or in supported living homes. Oswin’s work was grounded in the concept of normalization (Clegg & Lansdall-Welfare, 2003), which problematically frames bereavement and grief reactions in comparison to neurotypical populations only. This study (among others) highlights one of the
inherent challenges of undertaking research with people who have *varying levels of intellectual and communication abilities* – only those able to speak or share in a way that Oswin could understand contributed to her understanding of bereavement for people labelled/with intellectual disabilities, thus leaving out the voices of those with more extensive communication impairments and, one could argue, disabling them further through exclusion from the study. The outcome of Oswin’s study was the creation of seventy-three recommendations and suggestions for supporters of people labelled/with intellectual disabilities who are bereaved. The broad categories for these recommendations include: learning of the death, breaking the news of a death, going to funerals, acknowledging and respecting grief, remembering, better planning and kinder services, and recognition of different forms of loss (Oswin, 1991). Limitations of the study were not addressed in the book. Clegg and Lansdall-Welfare (2003) critique Oswin’s study based on her conclusion that people labelled/with intellectual disabilities grieve in very similar ways to the neurotypical population, stating that her study was “…developed when mourning was commonly conceptualised to follow a universal sequence of stages. Despite many challenges to this view in subsequent bereavement research, recommended interventions in intellectual disability are commonly framed by stage theory” (p. 72). Moreover, Oswin’s focus on the skills that support persons and professionals needed to support bereaved people labelled/with intellectual disabilities meant that little attention was paid to the nuances of emotional, behavioural, and social differences between people (Clegg & Lansdall-Welfare, 2003; Kauffman, 1994). It also continues to frame people labelled/with intellectual disabilities as non-knowers of their own experiences by only creating recommendations for others to *do* interventions to the bereaved person.
Emotional development and attachments are now being considered as quite separate to intellectual development (Blackman, 2002), leading to the conclusion that people labelled/with intellectual disabilities do grieve, in multiple and vastly individual ways, and that it is critical to work understand, listen to, witness, and support their various grief reactions. It is important to note that although there is a wide range of potential grief reactions for bereaved people labelled/with intellectual disabilities, like with the neurotypical population, there is also risk for additional issues particularly when the death of the significant other results in profound changes for the bereaved, such as a move of residence or change in primary support person (McEvoy et al., 2012). Inclusion in rituals surrounding the death, death education, opportunities to express grief reactions, and a supportive environment are all understood to be protective factors, nevertheless, complications in the grief process can occur requiring more intense professional intervention (Kauffman, 2005; McEvoy et al., 2012). Death is an abstract concept for some people to understand and consider, and confusion about where their significant other went, how they will eat and breathe now that they are dead, and worry that they caused the death, are all examples of factors that can complicate the bereavement experience of a person labelled/with an intellectual disability if left unexamined and unattended to. However, this does not mean that the grief process needs to be pathologized in these situations. Instead, working together to understand how the person labelled/with an intellectual disability is processing the loss, what they may need for support, and how they might express their grief are all key areas to address in collaboration with the individual through conversation and/or creative activities with support persons and/or a trained clinician. What this collaboration can look like and how it can be beneficial to the bereaved are questions explored in my research and shared in subsequent chapters.
Although contemporary thanatology research recognizes that the dead continue to have a social, emotional, and cognitive presence for the bereaved, how people labelled/with intellectual disabilities modify their relationship(s) with deceased significant others is not addressed in the literature beyond advice of keeping a picture visible, and maintaining some physical linking objects (Oswin, 1999; Todd et al., 2013). The possibilities for post-traumatic growth and meaning making, as discussed above, are virtually absent from the intersecting literature of thanatology and disability studies. Wolfelt’s (2016) companioning model of grief support may provide a perspective more conducive to grief support within a practice and/or group home setting in that his model normalizes the experience of grief and discourages the professional from taking an expert stance, is not so dependent on cognitive abilities to conceptualize death, and appears to be more accepting of a broad range of grief reactions.

H) Summary of Chapter

Healing found in brokenness and community, when suffering may still be present, is a wonderful paradox. (Newell, 2010, p. 178)

As more people labelled/with intellectual disabilities live longer, they will experience more deaths of significant people in their lives, making this area of research both timely and valuable (Doka, 1989; Kauffman, 2005; Thorpe et al., 2020; Tuffrey-Wijne et al., 2017). My hope in engaging in this research was not to find the one way that people labelled/with intellectual disabilities grieve, but rather, to learn from people labelled/with intellectual disabilities the myriad ways in which grief enters their lives, and how it affects them and the people around them. People labelled/with intellectual disabilities are not a homogeneous group. They vary in age across the lifespan, possess differing intellectual and communication abilities, live in a variety of settings, have different cultural backgrounds, and may or may not have
physical and/or psychiatric impairments as well. This is a multifaceted population of varying intellectual, emotional, social, physical, and spiritual abilities and needs who are facing a complex human experience: loss, death, and grief. The literature specific to grief for people labelled/with intellectual disabilities is mostly about what to do to and for people, rather than how to be with them. Newell (2010) encapsulates my interest in further exploring a companioning philosophy (Wolfelt, 2005) rather than a treatment model when he states:

> There is also a need to create a space so that we may listen to the still voice of those with disability. Not only our lives and bodies, but also even a lack of voice and communication capacity, may speak loudly. Otherwise, those who live without life-limiting impairment speak about rather than listen and be with. (p. 174)

I am also left wondering if the grief experience for people labelled/with intellectual disabilities is more than disenfranchised grief. When people labelled/with intellectual disabilities have historically been socially, economically, and politically excluded from daily life in Western society, then they are already marginalized, leaving me to wonder if it is possible to be labelled disenfranchised in one specific experience when you are already disenfranchised in your life in general. Would this be a ‘double disenfranchisement’ or is this thinking too binary? Or is it an experience of exclusion from being recognized as people, people who experience love, joy, pain, and grief in life, thus being rendered as non-human and thus incapable of the experience of grief (psycho-emotional exclusion)?

Before we can encourage continuing bonds, meaning-making, and post-traumatic growth through a loss experience, the legitimacy of people labelled/with intellectual disabilities as people and grievers must first be established. My research undertaking is not about giving voice to an experience of a particular group; rather, it is about listening, learning, and companioning.
Sara Ryan, the mother of an eighteen-year-old son who died in a bathtub while in an assessment unit facility in the United Kingdom, summarizes the issue of voice well:

I can’t stand this ‘give people voice’ crap. It’s so patronising and offensive it makes my ears weep. People have voices (or other ways of communicating). They don’t need to be given them. The problems here don’t lie with learning disabled people not having ‘voices’. They lie with people not listening. Not understanding. And not caring…I don’t think people will really start to care properly until they see learning disabled people as full and valued members of society. (Rogers, 2016, p.88)

When we fail to put forth people labelled/with intellectual disabilities as experts in their own lived experiences and continue to exclude their valuable knowledge and insights from literature and research (Fudge-Schormans et al., 2020), we can never have a fully person-centered approach to grief support that is more inclusive and mutual. Support persons have a crucial role in companioning people labelled/with intellectual disabilities who are grieving, and I suggest that the reverse is also true – bereaved people labelled/with intellectual disabilities have a role to play with support persons and others labelled/with intellectual disabilities as companions and role models through times of grief.

The extensive review and application above of the thanatology and disability studies literature provides a great number of possibilities for determining an approach to further research in this area. The current thinking in disability studies which is inclusive of both social and bodily considerations (Bach, 2017; Oliver & Barnes, 2012; Rogers, 2016; Shakespeare, 2013) complements the thanatology models of continuing bonds, meaning-making, attachment-based approach, and companioning (Balk, 2007; Kosminsky & Jordan, 2016; Neimeyer, 2012; Neimeyer et al., 2011). As stated above, the concepts of secondary losses and changes in the
assumptive world will also be of consideration moving forward. Identifying secondary losses and exploring their relationship with the primary loss will be informative as the bereavement process will be affected by all levels of perceived loss. The assumptive world is also a significant consideration to determine what sense of self in a disablist world looks like for people labelled/with intellectual disabilities and how their assumptions about themselves and their communities might affect their grief and mourning processes. Given that the models and interventions discussed above related to grief are aimed at neurotypical populations, and that the goals of contemporary interventions are aimed at adaptation to loss primarily at the levels of cognition and feeling, how meaning-making and continuing bonds are achieved with people of different psychological and neurological capabilities requires careful attention. Rogers’ (2016) three spheres of care ethics is also a perspective I carried into my research process, as care-full implementation of my research plan is necessary along with a care-full entry into people’s lives for the purpose of extracting information from them for my own gain.

A theme echoing throughout my work, although not always explicit and clear, is that of hope. Not in a way that says, “everything will be ok”, but rather hope that the complexities of loss and grief will be acknowledged, in ways where we can companion one another through difficult times, express and accept different experiences, ease suffering, and create inclusive environments. Rogers (2016) discusses the centrality of hope in loss stories: “we need hope as a survival mechanism, and I assert that it is a human trait, an irrefutable part of being human. Indeed, it is arguably necessary in life after suffering” (p. 97). As mentioned earlier, hope was a key theme in Kübler-Ross’ (1969) work, but it was overshadowed by the stage-model she created. My hope is to continue to make death a topic that can be shared, and the subsequent variety of grief reactions also made visible, supported, and accepted. This can be done through
examining the importance of psychoeducation in relation to death, grief and mourning, and the intersection with disability studies. I envision the psychoeducation and supportive aspects of grief care as essential for both support persons and people labelled/with intellectual disabilities, carried out in partnership, so that grief care that does not require professional clinical intervention is not pathologized unnecessarily. This is a complex task. There is little tolerance for grief and mourning behaviours that go beyond the existing social rules governing acceptable behaviour, time frames, and outcomes in the neurotypical population, never mind for people labelled/with intellectual disabilities already excluded from many areas of social life.

Creating an environment inclusive of differences in intellect, communication, and grief reactions, where hope, belonging, wisdom, tolerance, and mutual learning exist, would be my ultimate goal at the intersection of thanatology and disability studies. Contributions from this dissertation research and my future research may help to move one step closer to this inclusive healing environment.
CHAPTER 3 Methodology

Purpose

The purpose of my research was to engage with people labelled/with intellectual disabilities who have been bereaved by the death of a family member, close friend, or support person to gain a better understanding of what happens (emotionally, cognitively, physically, behaviourally, socially, spiritually) for them as individuals when they are grieving and mourning. I was interested in gaining a better understanding of the phenomena of grief and mourning through the eyes of the research participants within their social contexts. This research was not an attempt to discover the way all people labelled/with intellectual disabilities grieve, but rather to explore the complexities and variances of this experience for participants of differing intellectual and communication abilities. To accomplish the purpose of this research project, the qualitative research approach of interpretive description was used as this approach allowed for an exploration of the phenomenon of grief and interpretations of the meaning of grief experiences (due to death) in the lives of the research participants (Creswell & Poth, 2018). This research aims to inform future best practices for social workers, social service workers, developmental service workers, and support persons supporting people labelled/with intellectual disabilities who are grieving and mourning a death.

The primary research question guiding this project was:

• In what ways do people labelled/with intellectual disabilities experience grief after the death of a significant person in their lives?

Subsequent and related questions include:

• What are some of the grief reactions of participants?

• In what ways are these participants receiving support for their grief?
• How is loss through a death approached within organizations that provide support to people labelled/with intellectual disabilities?

The interview guide questions were open-ended and exploratory (based on previous answers), while also being concrete so that they were easily understood and provided clarity about what is being asked (Coons & Watson, 2013). These qualities made the questions suitable for a qualitative approach with people labelled/with intellectual disabilities. (See Appendix C for the interview guides for all participants).

**Context and Rationale**

As demonstrated in the literature review, both in research and in practice, there is little intersection of theories of grief and disability specific to intellectual disability. There is also a scarcity of contemporary practice literature informing work to support people labelled/with intellectual disabilities who are grieving. Prior to this research, in my clinical practice, many support persons repeatedly told me they lacked the confidence, knowledge, and tools to best support the people they work/live with when a death occurs. This can lead to both paid support workers and family members being unsure of how and what to tell the person about the death, uncertain about what grief expression might look like, and how to provide helpful and compassionate support. One way to be better informed about best practices in this area was to learn about grief experiences (across the life domains noted above) from grievers labelled/with intellectual disabilities, their support persons, and organizational management. Gaining a better understanding of what has been helpful and not helpful within the context of contemporary grief and disability research and literature could lead to practical and person-centred guidelines/suggestions for best practice.
**Who am I in This Research?**

My epistemological lens is informed by social constructivism and systems viewpoints in that I collected and analysed participant data within Western socially constructed beliefs about grief and disability within their individual contexts that exist within systems of care. A social constructivist lens stresses that there is no one reality, rather that multiple realities and sense-making are subjectively and intersubjectively created within social relationships (Berger & Luckman, 1966; Gilbert & Macpherson, 2021; Thorne, 2016). Collaboration and the co-construction of meaning is encouraged from this perspective, “…inviting us to reflect on our assumptions and practice, and most importantly, to construct new forms of understanding and new ways of conducting our lives together” (Gergen, 2009, p.28). Thus, meanings related to the death(s) experienced by individuals and subsequent reconstruction of meaning occurs within past and present experience, while reconstructing objective reality without the deceased person(s) occurs in the context of the social setting (Gilbert & Macpherson, 2021).

My beliefs about inclusion, the nature of human difference in complex life situations (‘disability’ as variance on a continuum of ability dependent on social/systemic limitations rather than as a deficit), and employing care-full positioning were important in the practice of this research (Creswell & Poth, 2018; Rogers, 2016). The goals of the research included developing an understanding of grief experiences while recognizing that my background (personal and professional) will influence some of the interpretation of the data while striving to remain true to the participants’ constructions of meaning (Creswell & Poth, 2018). I worked to address credibility in this area through reflexive journaling (further discussed later), consultation with my dissertation committee members, and checking back with participants when required. My work was informed by an anti-oppressive practice (AOP) lens in that the participants were centered as
experts in their experiences, and issues of power, oppression, identity, disenfranchisement, and marginalization were of note within the context of the research (Baskin & Davey, 2017; Finn, 2021). Being trauma informed within the research process is related to AOP as I maintained awareness of the potential of past harm and trauma in the lives of participants (e.g., past institutionalization, abuse) and worked to minimize harm and/or re-traumatization while engaging as participants in this research project (Brown, 2020; Rossiter & Rinaldi, 2019). I did this by acknowledging and believing past harm when shared by participants, while also monitoring for any emotional upset related to this disclosure and checking in regularly regarding their feelings of well-being while in the interview.

As a social work clinician, I have an applied interest in this research. I am neither seeking to create a theoretical understanding nor a theoretical framework from which to examine the grief of people labelled/with intellectual disabilities; rather, I sought to hear from people labelled/with intellectual disabilities (and their support persons) about their grief experiences and to examine these experiences with the purpose of informing future supportive practice in this area. My clinical experience, collegial consultations, and review of the related literature have informed me that despite the best overall care and intentions, death and grief in the lives of people labelled/with intellectual disabilities have remained often taboo and challenging topics.

I am a bereaved person, having experienced the deaths of many significant people in my life, but I am deemed neurotypical and do not depend on others to hold knowledge or interpret events for me which positions me as an outsider in this research process. I believe that anyone in relationship with other people will experience loss and subsequent grief reactions to an extent dependent on many factors (as outlined in the literature review), and I believe this is true along the spectrum of human ability, regardless of how reactions to the loss are expressed (through
language, behaviour, physical expressions, etc.). Undertaking this qualitative research project fit well with my high level of professional competence in conducting interviews, working with people labelled as *vulnerable*, noticing and supporting emotional upset, and working collaboratively with family members and professionals (Thorne, 2016).

**Research Methodology: Interpretive Description**

The research method chosen for this project is the qualitative approach of interpretive description. Given that this research has an applied purpose and that the goals included collecting data that captures the complexities and diversity of loss and grief experiences of the participants, this qualitative approach is “…especially amenable to obtaining straight and largely unadorned answers to questions of special relevance to practitioners” (Sandelowski, 2000, p.337).

Interpretive description is a research methodology with roots in the nursing profession where the human client is seen within the context of theorizing, but the practical information and knowledge gained through the research process about human complexity and frailty is used to inform the best care possible for people within their unique environments (Thompson Burdine et al., 2020; Thorne, 2016). Hunt (2009) shares that interpretive description is “a noncategorical methodological approach to developing clinical understanding [of] complex experiential questions that are relevant to…health disciplines, but which are not easily answered by traditional qualitative methodologies” (p. 1285). Sandelowski (in Thorne, 2016) notes that interpretive description evolved from an effort by Thorne to create a method that fits for varied research participants within disciplines such as nursing, medicine, and other health professions that wish to learn more to better serve their “respective social missions” (p. 12). Thorne (2016) notes that interpretive description differs from other popular health sciences methodologies such as grounded theory (purpose is to build theory) and phenomenology (“seeks to understand the
essential nature of a thing”, p. 29) in that it extends beyond theory and description into applied use of the information “in the everyday world of practice” (p. 34). Thorne (2016) describes the genesis of interpretive description as coming from the “tension between theoretical integrity and utility” (p. 34), while including exploration of issues from “holistic, interpretive and relational perspectives” (Thompson Burdine et al., 2020, p. 336). This method of research suits my area of interest, my epistemological lens, and my professional ethics as there is a dual purpose of understanding theory which informs the research, and a focus on what is known (currently in practice) and not known (areas for future research) centred on information provided by participants.

Qualitative research methods such as Interpretive Description are:

…characterized as inductive, emerging, and shaped by the researcher’s experience in collecting and analyzing the data. The logic that the qualitative researcher follows is inductive, from the ground up, rather than handed down entirely from a theory or from the perspectives of the inquirer. (Creswell & Poth, 2018, p. 21)

A qualitative approach was appropriate for this research as there is a demonstrated need to advance social work knowledge in the area of grief experiences of people labelled/with intellectual disabilities. This is because little is known about themes, patterns, and experiential elements of this complex phenomenon; how meaning-making and continuing bonds may be present (Buckle et al., 2010; Gilbert & Macpherson, 2021); and, how thanatology, disability theory, and subjective experiential context may or may not be linked (Thorne, 2016). Interpretive description is an approach that facilitates the exploration of questions based on the existing empirical and practice evidence (and gaps in that evidence) to determine what else may be integral to the understanding of the experience(s). Thus, it creates the “…potential to deconstruct
the angle of vision upon which prior knowledge has been erected and to generate new insights that shape new inquiries as well as ‘applications’ to practice” (Thorne, 2016, p. 35). As noted above, there is a need to increase knowledge about the experience of loss through death and grief in the lives of people labelled/with intellectual disabilities to best suggest multiple approaches of providing care and support. Furthermore, this inquiry requires more than solely reporting on the loss and grief experiences of the participants. The data analysis must be situated within the field of practice with considerations of the complexities that surround the experience, which includes the immediate and broader social systems as well as organizational contexts and relational influences (Thompson Burdine et al., 2020; Thorne, 2016). Thus, the approach to obtaining participants, the interviews, and to subsequent data analysis was to allow for a multi-layered understanding of the phenomenon of grief and mourning in the lives of people labelled/with intellectual disabilities, primarily through their lived experiences but also with consideration of how support people and organizations did or did not understand and support their losses, grief, and mourning.

The thorough review of the literature and previous research documented earlier demonstrates that there is no one theory or model of either grief or disability that can incorporate the myriad realities of grief in the lives of people labelled/with intellectual disabilities. Thus, utilizing a research methodology such as interpretive description allows for data to be collected within the familiar environment of participants, while attending to their subjective, individual, and experiential knowledge as fundamental in informing clinical insight and future practice (Thorne, 2016). The inclusion of support persons in the interviews (as needed and/or requested by the bereaved participant) allowed for comfort of the participants and the ability to include people who communicate in ways other than through spoken words (the support person could
instruct the researcher as to what the participant was saying or interpret for me when communication devices or sign language were used). Support person inclusion also allows for subjective data collection providing a different perspective on the same event.

Although experiencing the death of important people in our lives is a universal experience, this research methodology allows for individual experience and various reactions to be shared within consideration of social and system contexts, providing a multi-layered understanding. This approach also recognizes “…the inseparable relationship between the knower and the known, such that the inquirer and the ‘object’ of that inquiry interact and influence one another” (Thorne, 2016, p. 74) which required that I employ reflexive writing throughout the research process to examine issues such as researcher/participant interactions, biases, emotional reactions, assumptions, power issues, and other issues as they arose (Probst, 2015). My reflexive writing process is discussed in more depth later in this chapter. This research is potentially rife with contrasting values, beliefs, and practices (e.g., based in religion, culture, socio-economic status, attitudes toward dying and death, assumptions about abilities, etc.) that required me to be aware of and continually examine my own values, beliefs, and practices while gathering information from participants and later analyzing that data (Creswell & Poth, 2018). This research undertaking is not about giving voice to an experience of a particular group; rather, it has been about listening, observing, learning, and exploring multiple realities to inform future best practices of support.

**The COVID-19 Pandemic**

Before I proceed to discuss ethical considerations, participant sampling and recruiting, data collection methods, reflective practices, and data analysis strategy, I must discuss the context of planning for this research prior to the COVID-19 pandemic and the numerous
challenges and changes that followed once isolation and lockdowns were in place in Ontario (starting in March 2020 and continuing into 2022). My plans for in-person interviews had to change which meant modifications to my Wilfrid Laurier Research Ethics Board (REB) application approval, with changes to plans for recruitment, data collection, and use of technology. Although the pandemic required changes to my research plans, upon reflection, using virtual means of connecting with organizations and conducting participant interviews allowed me to reach a broader geographical area in Ontario, including rural low population areas and urban centres, as well as participants who may have not been comfortable with face-to-face interviews. The multiple effects of the pandemic were evident in the sharing of all participants in this project and had a significant impact on their day-to-day lives. I worked to maintain the focus of the research as outlined by the research questions, however, the pandemic, and related deaths and other losses cannot be ignored or separated from all the data collected and will be evident in this and subsequent chapters.

**Ethical Considerations**

Principles of ethical research require that respect for the individual’s rights, choice, and well-being are upheld. Careful consideration of ethics when working with ‘vulnerable’ populations is essential; not only to uphold human rights and to ensure no harm, but also to ensure the quality and outcomes of the research undertaken (National Disability Authority (NDA), 2009). Not only was ethical approval granted through Wilfrid Laurier’s REB but also through the ethics committees or procedures of the various organizations approached to identify potential participants for this project. I distinguish between the ethics of the procedures of the research and the ethics that applied to the interactions with individuals participating in the project. The professional ethics and standards of social work practice as outlined by the Ontario
College of Social Workers and Social Service Workers (OCSWSSW, 2008) were attended to throughout the research process. When “ethically important moments” (NDA, 2009, p.14) arose in the research process, consultation with my Dissertation Advisor and/or Laurier’s REB were sought to maintain the well-being of participants and the integrity of the research process. For example, Laurier’s REB approved virtual interviews using Microsoft Teams technology, but many participants were only familiar with Zoom thus approval was sought to use the Zoom platform to improve accessibility and comfort for participants.

I refer back to Chapter 2 and the discussion of Rogers’ (2016) Care Ethics Model. This model provided me with much to think about and consider for my research. I adapted this model to ‘care-fully’ guide my thinking and preparation for entering into researcher/participant relationships prior to engaging with grieving people labelled/with intellectual disabilities. The reality that, over their lifetime, people labelled/with intellectual disabilities may have had hundreds of people in caregiving roles in and out of their lives led me to adapt the care ethics model from disability studies to my research project. In fact, my reflections and interpretation of this model for my research led to a presentation (2019) with social work students where I discussed social work skill sets, research ethics, and care-fully engaging in research with people classified as vulnerable through research ethics bodies, legislation, and/or professional practice. Figure 3 illustrates my interpretation of Rogers’ care ethics model and identifies the specific areas that I believe needed to be care-fully considered in my researcher/participant interactions.
Creating this care-full approach to my research was essential in clarifying for me that I needed to be very clear about my role and purpose – meaning that I positioned myself as a transitional person whose purpose was to listen to participant stories of loss and grief; I was a researcher meeting with them once (only meeting with them more than once if needed for shorter interviews over several sittings); and, I was not providing any clinical counselling support but was sensitive to the emotional challenges of talking about death and grief. I was also highly aware of the potential to cause harm to participants deemed vulnerable by the nature of their labelled disability, potential past harms, and past exclusion due to differences in communication and judgments of ability. Furthermore, gaining access required first developing relationships.
with organizations that act as gatekeepers to accessing my participants. This required me to be care-fully aware of organizational contexts and openness to collaboration.

**Consent to participate**

Concerns have been raised related to the question of informed consent when involving people labelled/with intellectual disability in research. Of interest is whether individuals were fully informed of the purpose and nature of the research, of their role (and that of the researcher), and their rights as research participants when they agreed to participate. The concern is that for this group of participants, the realization of consent can often be in question (Calveley, 2012). Debate as to the competence of people with intellectual disability to make independent decisions continues. Yet what is becoming increasingly apparent is that, given careful explanations, many people labelled/with an intellectual disability can understand and make informed decisions, including the decision to participate in research (Santinele Martino & Fudge Schormans, 2018).

I utilized what Knox et al., (2000) refer to as *process consent*. This process requires the use of plain language documents (read by or to the participant) and plain language verbal discussion; information given in smaller increments but with more repetition; and the provision of time for thought and questions. The use of process consent – and the importance of repeated opportunities to request information, ask questions, express concerns, and reaffirm/withdraw consent – was a priority with all participants. Another priority was an ongoing evaluation of the participant’s ability to understand the nature of the research and the potential risks/benefits. This is done through checking in with the participant when it appears they have forgotten the purpose of the interview and/or are exhibiting undo emotional distress. For example, checking in on how a participant is feeling throughout the interview, whether they need breaks, and providing opportunities to ask me any questions.
Consent to engage in this research was first sought from collaborating organizations who then identified possible bereaved participants, and their support persons (or substitute decision maker (SDM) as appropriate). This provided all parties with an opportunity to assess the potential participant’s suitability for the project, while also making them aware of the activities involved in the project, the types of experiences that may be discussed, and any possible upset that may arise from discussions. Once identified and their interest confirmed, bereaved participants (and their SDM if appropriate) were provided with the plain language Informed Consent form via email, and verbal assent was obtained at the start of each interview by reviewing the form together (see Appendix D). As mentioned, consent was an ongoing process in my research rather than a one-time event and this involved ongoing check-ins with participants during interviews to ensure they were wishing to continue. Consent was explained in plain language in such a way that participants understood the purpose of the research and interview, the process of the questions, and the benefits and risks of their participation (discussed below). Consent and assent were voluntary, and it was explained that it could be withdrawn by the participant (or primary support person) at any time. Reviewing the informed consent emphasized to participants and their primary support person(s) that they were free to decide not to participate, to stop participation at any time, to take a break during any research activity, or to refuse to answer specific questions or discussions they found too sensitive. Consent included that the information shared would be confidential, and their identity would remain anonymous within the project findings. Participants were given the opportunity to choose their own pseudonym during this process (those who did not choose a pseudonym were later assigned one using an online name generating program). Given both the nature of the sensitive topic being discussed and the varying abilities of the participants, care was given to establishing rapport and creating a
comfortable relationship during the process of sharing the above prior to initiating the discussion of their personal grief experiences (Roller & Lavrakas, 2015).

It is important to note here that each bereaved participant (N=14) was provided with a $25 Tim Hortons gift card in gratitude for their participation in the research. The gift card was provided to scheduled bereaved participants, regardless of whether they completed the interview or not. All participants were able to complete the interview process. Gift cards were mailed to the bereaved participants with a thank you card shortly after their interview. The bereaved participant (N=1) who also attended an interview as a key informant was provided with a second gift card in recognition of their additional time and contributions above and beyond the individual interview they had previously engaged in. The inclusion of this bereaved participant labelled/with an intellectual disability as a key informant alongside a paid staff member provided important information about their experiences of providing grief education and support to others (a unique experience within the sample of bereaved participants).

*Emotional/psychological risks*

It was essential to acknowledge that being asked about the death of a significant person and personal experiences of grief can be a sensitive and potentially upsetting process. To provide the bereaved participants (and other participants) with a choice of whether to participate or not, I was clear about the purpose of our meeting, the potential benefits and risks, and the ability to end the interview at any time without consequence. I included support persons in interviews with bereaved participants when needed or requested (with clear instructions as to their role in the interview), inquired if participants needed breaks, and ensured there was support for the participant after the interview if needed. Furthermore, participants were able to choose the person/people and experience(s) they wanted to talk about and were comfortable sharing.
To mitigate potential emotional and psychological risks, I discussed in detail the purposes and nature of the research activities with support persons and/or potential participants during our first contact (first through email initiated by the participant or support person/SDM and followed up with a telephone call to schedule the interview). This provided an opportunity for me and potential participants to assess their comfort level with what was proposed, and to ensure that participants were aware of the activities associated with the research, the types of issues they may be discussing, and the possible upset that may arise from the discussions. Potential participants were also informed that they could have a support person of their choice available to them during and/or after the interview(s). We determined the availability of emotional support for the participant either with the support person or someone else identified during this initial contact.

In the event that a participant became upset because of discussions taking place during an interview, I could offer immediate support by pausing the interview, asking if the participant would like to take a break or stop the interview, or asking if there was anyone the participant would like to contact for support - this mitigated the chances of blurring the boundaries between myself as researcher and as a registered social worker.

**Social Risks**

Participants were informed that they had the right to say “no” to being interviewed and that they could end an interview at any time without consequence. It was stated to participating organizations and participants that there should be no link between involvement in the research interviews and the services they provide/receive through their care organizations. Some concrete examples of this were to assure participants that my research project had no links to the organization providing them support, their family/support worker, or any of the activities they
engage in. Support people were informed in the research information letter that if a potential participant declined involvement this needed to be respected. None of the participants chose to not be interviewed after the Informed Consent was reviewed verbally together, and none asked for the interview to end prematurely. Care was taken so that the relationship between the participant and their support person was not affected in a negative manner (NDA, 2009).

Attention was paid to social-desirability – meaning that a participant may have answered a question based on what they thought the interviewer (or support person present) wanted to hear or answer without really understanding the question (Flicker, 2004). This was achieved through monitoring responses to questions, restating questions, and at times through the support person rephrasing the question in a way they knew the bereaved participant might better understand. In an effort to develop rapport with participants I used gentle humour, answered any questions they had, and let the narrative of their stories flow at their own pace, without interrupting, asking questions in such a way that allowed expansion of their experiences across multiple domains and to capture the complexities of their experiences (Roller & Lavrakas, 2015). I was very clear with bereaved participants regarding my role, paying particular attention to the one-time nature of our interview and my involvement in their lives. This was informed through the literature review, my previous practice knowledge, and an experience shared by my very first bereaved participant, Fraser, who still wonders why a counsellor he saw 20 years ago did not answer his email suggesting they get together for coffee once their sessions had ended. In addition, given experiences of isolation and decreased social contact related to the restrictions in place during the COVID-19 pandemic, being clear about my role and our contact being limited to the focus of the research addressed the risk of creating an expectation on the part of participants for lasting relationships with me (as an ongoing clinical support and/or friend).
**Possible Benefits**

Having the opportunity to discuss the person/people who died, how they have experienced grief, and what support has been helpful or not helpful, can be empowering and healing for individuals (Buckle et al., 2010). A few recent studies conducted regarding grief in the lives of people labelled/with intellectual disabilities point to the existence of continuing bonds with the deceased and that talking about the deceased can be one of the ways to maintain an ongoing relationship (McRitchie et al., 2014; Thorpe, Stedman, & Lloyd, 2017). Thus, through participation in this research, participants are not only contributing to knowledge in this field and helping others, but they may also experience the benefits of being able to share their stories, experiences, and ongoing bonds with the deceased (Neimeyer, 2001; Neimeyer et al., 2014). Moreover, sharing the overall purpose of the research – to create change in how service providers, support persons, etc. understand and support people labelled/with intellectual disabilities when they experience loss – may be of benefit to participants as they consider that their contributions will change understanding and support for others labelled/with intellectual disabilities in the future. Thus, through participation in this research, participants will not only be contributing to knowledge in this field and helping others, but they may also experience the personal benefits of being able to share their stories and experiences.

Understanding more about the diversity of lived experiences of grief and mourning directly from people with intellectual disabilities is important, as it will potentially counter enduring cultural stereotypes (e.g., that people labelled/with intellectual disabilities do not understand death, they do not grieve, they are eternally childlike, etc.) and will add to the sparse research literature regarding the experiential aspects of grief and mourning. As well, through gathering rich qualitative data, the project will provide insight into the varying viewpoints,
needs, and capacities of a diverse group of intellectually disabled grievers which in turn can enhance future supportive efforts by professionals and lay people involved in the lives of this population. While this may not necessarily result in any immediate benefits to participants, adding to and expanding existing knowledge may have benefits more broadly. Furthermore, this research is fundamentally anchored in the disability movement slogan of *nothing about us without us* (extended to, no research about us without us) through honouring, first and foremost, the voices and experiences of those with intellectual disabilities who are bereaved (Santinele & Fudge Schormans, 2018).

**Participants: Sampling, and Recruitment**

**Sampling Strategy**

I received approval to proceed with my research from Laurier’s REB (with COVID-19 protocols in place) on October 27, 2021 (REB #6428). My approach to sampling was purposive, meaning that I approached organizations that I knew provided support and/or care to people labelled/with intellectual disabilities and thus had access to the specific individuals whose participation I was seeking (Creswell & Poth, 2018; Thorne, 2016). A combination of purposive and convenience sampling strategy ensured that “…the eventual findings [produced] have the potential of ringing true or seeming reasonable to [the] audience” (Thorne, 2016, p.91). As mentioned previously, these organizations act as gatekeepers in terms of protecting access to people labelled/with intellectual disabilities with lived experience who could inform this research (Lennox et al., 2005; Santinele Martino & Fudge Schormans, 2018). Thus, the purposive sample of bereaved people labelled/with intellectual disabilities had to come through interaction with these organizations (sites) and the staff developing trust in me and my research project which then led to contact with a sample of bereaved people labelled/with intellectual disabilities
interested in participating in the research. I sought to recruit approximately 18-20 research participants overall: 10-12 bereaved participants for this research project from Ontario-based organizations that support adults with intellectual disabilities (e.g., Community Living organizations, Christian Horizons, L’Arche); as well, key informants (3-4) such as primary support persons (e.g., primary worker in a group home, parent/guardian), and one organizational manager per agency to be interviewed for further contextual understanding. The primary source for understanding the experience of grief after a death is the sample of bereaved participants labelled/with intellectual disabilities, with their narratives centered because they are so rarely provided with the opportunity to speak for themselves within systems of care. This sample size was congruent with an interpretive description methodological framework as I was seeking a more in-depth exploration of a phenomenon that occurs for all humans (death of someone important to us and subsequent grief) within the context of being labelled/with an intellectual disability and receiving care/support from others. The proposed sample size and the sample achieved (N=24), are congruent with the research question(s) and are sufficient for exploring this subjective interpersonal experience within the time and resources available for dissertation research (Thorne, 2016).

Bereaved participants needed to be adults (over age 19 years) who had previously been identified as intellectually disabled. I was seeking a sample of bereaved participants who identified as a person labelled/with an intellectual disability (which included a range of intellectual disability labels, for example, Down syndrome, Fetal Alcohol Spectrum Disorder, Global Developmental Delay, Autism Spectrum Disorder, etc.), and come from varying socioeconomic, cultural, and ethnic backgrounds. I sought an inclusive approach to sampling that could accommodate people who may not use spoken words to communicate. This could include
voice-synthesized speech, picture symbol communication, and typed or written communication. These alternative forms of communication are designed to facilitate the person communicating with people who use speech or to be interpreted for me through a support person familiar with the communication strategy, and thus typically do not require any type of specialized training or knowledge on the part of the researcher. Participants were confirmed to be labelled with intellectual and disability by virtue of their involvement with the support agencies that agreed to facilitate recruitment of bereaved participants. Potential participants were bereaved through the death of someone they identified as significant to them, and the death could have occurred at any time.

**Connecting with Organizations**

I was fortunate to work with an MSW student Research Assistant (RA) who compiled a list of organizations in Ontario that provide support and care to adults labelled with intellectual disabilities, and we began to send out emails with an introductory letter explaining my research, and the potential benefits to their organization for participating (sharing of findings, development of support tools and training, etc.). The organizations were asked to share the research request with organizational staff who could then identify potential bereaved participants and share the information. Organization representatives were offered the opportunity to speak with me over the telephone or virtually to further discuss the research project, ask questions, and begin to identify potential participants (bereaved, support persons, and managers). This outreach, as well as connections facilitated through my committee members, resulted in contact with several people, including people labelled with intellectual disabilities who are self-advocates and could provide their own informed consent, support persons who could assist bereaved participants in being
interviewed, support persons willing to be interviewed (parents and paid carers), and
organizational managers.

**Recruiting Bereaved Participants**

Initial contact with potential participants included emailing them the letter describing the research and the informed consent documents. Initial telephone calls with some bereaved participants assisted in screening (e.g., determining they were bereaved through a death) and scheduling interview dates and times. Other participants were scheduled using email as per their preference. With care-full (Rogers, 2016) attention to how I entered the personal spaces of the participants and gathered their stories, between December 2020 and May 2021, I interviewed 14 adults labelled/with intellectual disabilities who had experienced the death of a significant person in their lives; 4 support people/support persons; 3 key informant managers; and, conducted one interview with two key informants (one a manager and the other a person labelled/with an intellectual disability) who had co-facilitated teaching about death and grief to college students and were involved in a grief support group for adults labelled/with intellectual disabilities.

Deciding on a stopping point for participant recruitment and sample size is not an exact science (Thorne, 2016). The total sample size I was able to achieve (N=24) provided me with ample data that accounted for some interviews which provided less information than others and provided sufficient data across the research questions and from different points of view (bereaved participant, support person, organizational manager). Please see Table 3 in the Findings Chapter for information about the bereaved participants. Descriptive paragraphs introducing each bereaved participant follow Table 3. These descriptions were created through a reflexive process that included consideration of the losses they had experienced, personal interests and
achievements they had shared, and aspects of their grief experience they had emphasized during their interviews.

**Recruiting Support Person Participants**

Recruiting and interviewing the support persons/parents/guardians of some participants was important as they work and live alongside the person labelled/with an intellectual disability on a daily basis and often know deeply personal information about them; they likely have knowledge of how the person expresses emotion, distress, etc.; they will possess communication tools the researcher does not; and they can provide details about their own comfort in talking about/providing support for grief and mourning reactions. The support persons/parents/guardians were interviewed separately from the person labeled/with intellectual disabilities they supported or who was their adult child. I had previously met three of the support persons/parents/guardians when they supported the interview with the bereaved participant they supported, and the remaining support person was someone I had met professionally who has worked in the field of developmental services for many years and has an interest in grief. Support persons/parents/guardians can have a crucial role in companioning people labelled/with intellectual disabilities who are grieving, and this research suggests that the reverse is also true – people labelled/with intellectual disabilities have a role to play with support persons/parents/guardians as companions and models through times of grief. In fact, approaching sites and individual participants in a way that privileged stories and experiences while explaining that participation in the research would likely help someone else who experiences a death in the future, was an empowering and inclusive approach. See Table 4 in Findings Chapter for information about the support person participants.
Recruiting Key Informants

I sought to interview at least one person in a managerial position at each organization that participated in the research to gain a contextual understanding of how death and grief are understood and approached from an organizational and systems perspective. This can be considered gathering data from a key informant. Three key informants in managerial positions were interviewed, as well as two key informants who collaborated on grief education and support. The rationale for interviewing key informants within the project is that these people are often in a position where the phenomenon being studied has been observed and considered before within an organizational context rather than having lived the phenomenon (Thorne, 2016). The key informant can “…provide you with access to what is happening and why it is happening” (Thorne, 2016, p. 91). The information collected in these interviews provided important context for the individual experiences shared by the bereaved participants. See Table 5 in the Findings Chapter for information about the key informants and the organizational missions for their workplaces.

Data Collection Methods

Research interviews can offer rich narratives, and with enough participants and depth of discussion, one can achieve a thick description about the experiences of loss and processes of grief shared by the participants. As previously mentioned, the grieving participant determined who they talked about (sometimes more than one person had died); this is not something I determined through criteria I created, as relationships and attachments are subjective and personal. Research interviews occurred virtually using Microsoft Teams or Zoom for participants with access to technology (and support, when needed), and over the telephone for those who either did not have access to technology or preferred the telephone. There were some challenges
with accessing good internet connections at the height of the COVID-19 pandemic lockdowns when internet providers were overwhelmed with users thus affecting connectivity for some of the interviews. Nonetheless, this issue was manageable throughout the interview process. At times I was challenged in understanding what participants were sharing due to my own hearing loss issues, becoming accustomed to different pronunciation patterns, and the quality of the internet and/or telephone connection.

The data collected in this research project derived from virtual online and telephone interviews using a narrative approach of broad, open-ended questions that allowed for a semi-structured exploration of grief-related experiences across multiple domains of living which are methods consistent with interpretive description as informing methodology. A benefit of a semi-structured interview protocol “…has been found to be successful in enabling reciprocity between the interviewer and participant, enabling the interviewer to improvise follow-up questions based on participant’s responses, and allowing space for participants’ individual verbal [and non-verbal] expressions” (Kallio et al., 2016, p. 2955). However, Coons and Watson (2013) noted that open-ended questions may result in inadequate answers and thus some concrete, more structured questions may also need to be included. During the interviews I paid attention to how I was framing questions and worked to be clear, concrete, and concise. The presence of support workers/parent/guardian in some interviews (N=10) was helpful as these people were able to know when the bereaved participant was not understanding my question(s) and could tell me this or rephrase the question themselves. For example, my first interview included the bereaved participant’s circle of care of a parent, a paid support person (present in the room with the bereaved participant), and a long-time member of the circle, as the bereaved participant did not use words to communicate. The other people present in this interview assisted with
communication interpretation and shared further information with me when asked to do so by the bereaved participant. This support facilitated the inclusion of this person in the research. Support people and/or parents/guardians were present in several other interviews to assist with technology, provide emotional support, and/or assist with staying focused. Others present during the interview were asked to allow the bereaved participant to answer for themselves and/or to provide clarification if asked to do so by the bereaved participant. Four support persons/parents agreed to separate interviews.

The interviews (N=23, as one interview included two people) were conducted using open-ended questions in a semi-structured format. This created space for participants to describe and reflect on their losses and experiences in a way that they may not have in their daily lives. Sharing stories of the person/people who died, how they reacted to the loss(es), and their experiences since the death(s) can be helpful to not only acknowledge grief that may be disenfranchised, but it also provides opportunities for personal reflection, meaning making, and education of the researcher in interpreting their experiences (Charmaz, 2006; Doka & Chow, 2021). Data collection in this research project included “service users’ own values and aspirations and provide[s] more holistic and contextual understandings of clinical practice” (Warner & Spandler, 2012, p. 14). This in turn provided data that can further explore, challenge, and inform both clinical and frontline practice alongside grievers labelled/with intellectual disabilities.

Given the move to virtual online interviews I was able to record both audio and video of most of the interviews. Interviewing participants virtually in their homes or location of their choice allowed for observations of their non-verbal language and their physical surroundings. Video technology has the benefit of capturing rich data inclusive of interactional and contextual
information, while also allowing me to be more present in the relational aspect of the encounter while not worrying about noting or remembering important details of the interaction beyond the words spoken (Miller Scarnato, 2019). Five interviews were done over the telephone due to online connectivity issues or lack of access to online technology, and only audio was recorded for these interviews.

Keeping in mind that I am a social work clinician with many years of experience in the field of thanatology, it was extremely important that I worked to maintain a separation in my role during this research. I worked to maintain awareness of my “disciplinary preconceptions” (Thorne, 2016, p.99) and to suppress my clinical mind that is trained to listen and react in a particular therapeutic and active manner. However, my clinical knowledge and experience was of importance and benefit in gauging the comfort of participants, applying open-ended inquiry, and working to mitigate emotional upset related to the interview content. For example, when one participant became focused on describing themselves in negative ways I was able to purposefully counter this behaviour by sharing positive qualities I had noted through their generous sharing of some difficult experiences.

Interpretive description methodology includes elements of “concurrent data collection and analysis” (Thorne, 2016, p. 99), meaning that the researcher is starting with the assumption that parts of the reality being studied are socially constructed requiring “ongoing engagement with the data…to confirm, test, explore, and expand on the conceptualizations that began to form as soon as you enter the field” (Thorne, 2016, p.99). I understood this to mean that analysis of the data would not be an activity that only happened once all the data was collected, rather, ongoing analysis occurred during, after, and between interviews such that meanings, patterns, and newly discovered aspects of the experience could be considered throughout the data
gathering process. This inductive, non-linear, and meaning-making process was noted throughout the data gathering process using field notes and reflexive writing.

**Reflexivity**

Reflexivity is generally understood as awareness of the influence of the researcher has on the people or topic being studied while simultaneously recognizing how the research experience is affecting the researcher. [Reflexivity] promotes an ongoing, recursive relationship between the researcher’s subjective responses and the intersubjective dynamics of the research process itself (Probst, 2015, p. 37).

It is essential for all researchers to pay attention to situating prior knowledge and experience with the topic being researched. Given the inductive process of data analysis in the interpretive description approach, it was necessary to carefully document what went on subjectively and conceptually for me as the researcher throughout the data gathering and analysis process (Thorne, 2016). Reflexivity is an ongoing, conscious practice for many social workers and involves paying attention to issues of privilege, oppression, power, and marginalization in relation to one’s own positionality (Béres & Fook, 2020; Finn, 2021). Reflexive writing includes what one is experiencing during the research process in relation to these issues and others, as well as observations being made, hunches about what is emerging from the data, and/or reactions from participants during interviews (Creswell & Poth, 2018). These reflexive writings can inform the research process by highlighting any biases, personal/professional values, and subjective experiences that may affect interpretations, emerging themes, findings, and conclusions (Creswell & Poth, 2018).

The use of reflexive writing in this research project recognized that as a clinician researcher I sought “…to discover associations, relationships and patterns within the
phenomenon that has been described…searching for underlying meanings that might further illuminate what is happening and develop a deeper appreciation toward what would ultimately be the optimal clinical response” (Thorne, 2016, p. 50). I engaged in reflexive writing immediately after each interview and at any other time during the process that I was considering issues, relationships, connections/disconnections, and gaps throughout the research process. The reflexive notes were formatted using a template provided by Roller and Lavrakas (2015). A copy of the format can be found in Appendix F. The areas for reflection after each interview included broad takeaways such as reflecting on what I thought I knew from the participant, how I arrived at the knowledge, and whether the knowledge changed or supported earlier assumptions/beliefs; and specific reflections such as assumptions made, examination of values and beliefs, emotional connection and reactions, and the physical environment in relation to possible effects on the data gathered. For example, my reflections from my interview with Fraser (Bereaved Participant 1) noted similarities in our loss stories and an emotional connection that I needed to pay attention to for possible emotional reactions and biases in myself. My reflexive notes from my interview with Margaret (Bereaved Participant 6) indicated that issues of family dynamics and estrangement were significant for her, and thus needed further contemplation and inclusion in inquiry for future interviews. This reflexive writing was utilized to provide deeper insights and connections as I analysed the data, developed my findings, and reached conclusions. Examples and interpretations of my reflexive notes are shared in Chapter 4.

**Data Analysis Strategy**

As stated above, data analysis began to some extent from the first interview onward and was documented through reflexive writing and interview memos noting important aspects emerging from that particular interview and in relation to previous interviews. As the interviews
of the research project participants proceeded (bereaved participants, identified support persons, and key informants) audio recordings were transcribed verbatim from video and/or audio recordings by a Research Assistant funded through Laurier’s Faculty of Social Work for later analysis. Zoom generated transcripts were not used as they are often inaccurate. Once the audio transcripts were completed, I viewed video recordings alongside the transcripts in such a way that interactional, contextual, and non-verbal data was woven in to add depth and richness to the audio data (Miller Scarnato, 2019) and any errors were corrected. Further analysis of the data in written, audio, and video formats “…allows for stronger validity of findings through multiple viewings and interpretations by researchers, with enhanced ability to focus on detail and honor participants’ voices and self-representations” (Miller Scarnato, 2019, p. 393). This process also provided me with the opportunity to begin informal coding and noting of participant experiences related to the research questions.

**Thematic Analysis:**

Formal thematic analysis of initial groupings began once all data had been transcribed, and the interactional and non-verbal data included so that qualitative coding could begin using the entirety of the data. As described by Thorne (2016), within an interpretive description methodology, the data pieces needed to be examined carefully and independently reviewed before being sorted into patterns or themes. Thematic analysis is a data analysis strategy not tied to any particular qualitative methodology and it “provides a flexible and useful research tool which can potentially provide a rich and detailed, yet complex, account of data” (Braun & Clarke, 2006, p. 78). Thus, it is a suitable approach to this research topic and process. I engaged in an inductive, open, and exploratory process to code data, with a ‘code’ being a short phrase or word that “assigns a summative, essence capturing portion of language or visual data” (Saldaña,
The approach was latent in that it was aimed at capturing underlying ideas, patterns, and assumptions related to the research question. The goal of developing the codes is to provide rich description and involves the purposeful effort to avoid trying to fit data into a preconceived coding framework (Braun & Clarke, 2006). The purpose of using a thematic analysis approach is to work toward a description of themes shared by participants and to proceed to an interpretation which highlights the significance and meanings of the themes in relation to the literature, research, and current practice (Braun & Clarke, 2006; Saldaña, 2016; Sandelowski, 2000; Thorne, 2016).

Thematic analysis occurred in phases once the data was transcribed and organized. Suggested phases of a thematic analysis process include: becoming familiar with the data through multiple reads of the interview transcripts and views of video data; generating initial codes (features of the data that can assist in organizing into groups); searching for themes (sometimes also referred to as categories - sorting codes into potential themes based on relationships, patterns); reviewing and refining themes in comparison to the data set; defining and naming themes (explaining the essence of each theme, the story it tells, and how it relates to the overall research question); and, producing the written findings which include evidence of the themes in the data, examples, and how these relate to the overall research questions and purpose (Braun & Clarke, 2006; Roller & Lavrakas, 2015). NVivo software was used for the further reading of the transcripts, generating initial codes while sorting them into potential themes, and then refining the themes. Defining and naming the themes occurred after this process and these findings will be presented in the next chapter. At this point in the data analysis, I used a mind mapping program to provide me with an initial visual representation of the emerging themes,
which was a helpful tool for then sorting out primary themes and secondary topics within the themes.

The findings will be primarily linked to practice (rather than theory or framework development), meaning that the findings will also be interpreted within literature, the lived experiences of grief, and the contexts of participants to suggest best practices for supporting grieverse based on the data collected (Warner & Spandler, 2012). This process preserves the method of interpretive description in that empirical, practice, and participant evidence (and gaps in that evidence) will be considered when analysing the data to determine a better understanding of the phenomenon (Sandelowski, 2000; Thorne, 2016).

Member checking occurred through emailing participants excerpts of their transcripts (the direct quotes related to the initial themes) rather than the full transcripts. This decision was made to minimize the length of the material needing review for participants, particularly those labelled/with an intellectual disability. Participants were invited to respond to me should they wish any of the information changed based on errors at my end or their wish to exclude certain portions. Only one support person/parent/guardian wished some details to be changed for further anonymity and I complied with their wishes. All participants were advised that their names had been changed (either to the pseudonym they chose during the interview or through a random name generator program) and any identifying information had been removed from the transcripts.

**Summary**

In this chapter I have outlined the purpose of my research, the key research questions, and the rationale for the research, along with situating myself in the context of this research. I have provided a description of the methodological approach of interpretive description and why
it is well suited for capturing the complexities, intricacies, and individual realities of the lived experiences of bereaved people labelled/with intellectual disabilities. Ethical considerations are important in any research endeavor, and I reviewed my efforts to engage in ethical research practices and care-full interactions with a population of people deemed to be vulnerable. The data collection period of this research occurred within the context of the COVID-19 pandemic, and this was noted as it provides further context for some of the changes that had to occur in the data collection plans. I have provided information about my research participants and how I engaged with the data gathered in interviews through an inductive process which resulted in the themes I will now present in my Findings chapter.
CHAPTER 4 Findings

Within the research methodology of *interpretive description*, sharing the findings of the project first requires that the data have been organized thematically and conceptualized with the ‘audience’ (i.e., social workers, social/developmental service workers, health care professionals) in mind, so that the nuanced and complex experiences of bereaved people labelled/with intellectual disabilities are presented in a way that enhances professional capacity to understand this phenomenon (Thorne, 2016). The focus of this chapter is therefore, to share the findings from the research interviews - interviews with the bereaved participants (N=14), the support person/parent participants (N=4), and the key informants (organizational managers) (N=5). These interviews lasted between 30 minutes and one and a half hours in length. The length and depth of each interview was determined by the participant, and the interviews ended when questions were answered to their level of comfort, and they felt they had nothing further to add. As discussed earlier in this dissertation, the approach to recruiting the participants, facilitating the interviews, and analysing the data was to develop a multi-layered understanding of the complex phenomenon of grief and mourning in the lives of people labelled/with intellectual disabilities. For me, this approach requires that the experiences shared by my bereaved participants are positioned as my primary sources of findings. The data gathered from the interviews with support people/parents informs how the needs of bereaved people labelled/with intellectual disabilities may be met by people in the support/parenting role. For further context, the data gathered from the key informants situates the data from my bereaved participants within systems of care that may or may not be meeting the diverse needs of bereaved people labelled/with intellectual disabilities. I want to be clear that I did not engage in triangulation of the data through “corroborating evidence from different sources to shed light on a theme or
perspective” (Creswell & Poth, 2018). This process, although important in many qualitative research projects, would have served to put into question the experiences of the bereaved participants. I did not want this to happen, not only because people labelled/with intellectual disabilities rarely have the opportunity to have their authentic voices heard, but also because it is their experiences that I want centered for informing practice in grief support.

I will first introduce you to each bereaved participant, followed by an introduction to the support people/parents, and key informants prior to sharing the findings of the experiences and reactions of the bereaved participants labelled/with intellectual, and relevant findings from the support people/parents and key informants. I will then share my reflexive process through providing examples of some of the questions that emerged and connections I was making during the interview and data analysis processes. This reflexive engagement demonstrates how I was making sense of both the content and process of the interviews and data, situated in the intersections of my subjective experiences of the research, the literature, and my practice experience.

**Bereaved Participants**

I had the pleasure and privilege of interviewing 14 bereaved individuals who have been labelled/with intellectual disabilities and, by virtue of their involvement with developmental services organizations, were deemed suitable participants. This included people who identified as self-advocates, people living in congregate care, and living in group homes or independently with some support. For reasons of maintaining anonymity, I have chosen not to disclose their individual ages, however, the average age of the bereaved participants is 43.6 years. In terms of gender, 8 participants identified as male, and 6 as female. The deceased people that participants chose to talk about included parents (biological and adoptive), grandparents, extended family
members, siblings, and friends. Pseudonyms were assigned to every research participant using a random name generator, except for four participants who chose their own pseudonyms. I will first provide a table outlining the bereaved participants followed by a brief introduction to each person.

**Table 3 – Bereaved Participants**

<table>
<thead>
<tr>
<th>Bereaved Participant #</th>
<th>Gender</th>
<th>Pseudonym</th>
<th>Who died?</th>
<th>Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>male</td>
<td>Fraser</td>
<td>Father Friend</td>
<td>Cancer Sudden</td>
</tr>
<tr>
<td>002</td>
<td>female</td>
<td>Butterfly</td>
<td>Paternal grandmother</td>
<td>Unsure</td>
</tr>
<tr>
<td>003</td>
<td>female</td>
<td>Esther</td>
<td>Grandmother Foster mother</td>
<td>Heart attack Heart attack</td>
</tr>
<tr>
<td>004</td>
<td>female</td>
<td>Julia</td>
<td>Paternal grandfather</td>
<td>Health complications</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Maternal grandfather</td>
<td></td>
</tr>
<tr>
<td>005</td>
<td>female</td>
<td>Aleta</td>
<td>Cousin</td>
<td>COVID-19</td>
</tr>
<tr>
<td>006</td>
<td>female</td>
<td>Margaret</td>
<td>Parents Sister-in-law and 2</td>
<td>Cancer Sudden accident</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>kids Boyfriend</td>
<td>Car accident</td>
</tr>
<tr>
<td>007</td>
<td>male</td>
<td>Layton</td>
<td>Parents</td>
<td>Bleeding ulcer Heart attack</td>
</tr>
<tr>
<td>008</td>
<td>male</td>
<td>Simon</td>
<td>Parents Dog</td>
<td>Cancer Unsure</td>
</tr>
<tr>
<td>009</td>
<td>male</td>
<td>Arthur</td>
<td>Mother</td>
<td>Heart issues</td>
</tr>
<tr>
<td>010</td>
<td>male</td>
<td>Ron</td>
<td>Mother Grandmother Grandfather</td>
<td>Mental health Cancer Cancer</td>
</tr>
<tr>
<td>011</td>
<td>male</td>
<td>Gilbert</td>
<td>Parents</td>
<td>Stroke Aneurysm</td>
</tr>
<tr>
<td>012</td>
<td>male</td>
<td>Wayne</td>
<td>Brother</td>
<td>Car accident</td>
</tr>
<tr>
<td>013</td>
<td>female</td>
<td>Isabella</td>
<td>Parents</td>
<td>Aneurysm Cancer</td>
</tr>
</tbody>
</table>
Fraser

Fraser is a talented artist who has many long-term friends. He experienced the death of his father to cancer 20+ years ago. Fraser does not use many words to communicate. He uses some sign language, and I was assisted in the interview by a worker who was with him in his space sharing what images he was indicating in his communication book, by his mother who would ask him if he wanted her to expand on his experiences, and a long-time member of his circle of care. As Fraser shared about his father, his mother, Laura (also interviewed at a later date, see below) stated, “Fraser remembers details [of his father’s death] as if it was still, as if it was still happening”. Fraser shared that it is important to him to be able to support other people in his life.

Butterfly

Butterfly is very aware of multiple losses in her life and trusted me enough to share many of them. Butterfly feels she has lacked connection to helpful support over the years as she has dealt with past abuse, trauma, mental health challenges, and the foster care system. What she wished she had access to is:

Lots of compassion, understanding, no judgments, um we can cry, I think at least you don't have suicide thoughts I think you're okay, like you should be able to talk, like I don't think like it's a bad thing to talk about suicide because like you're there to support the person and at the same time they should be able to talk about it but at same time you have to do the security point.
Regarding the death of her grandmother Butterfly shared “when she died, I felt like a relief because she wasn’t suffering anymore”. Her grandmother kept her family “together” and her death caused further discord in the family.

**Esther**

Esther is a strong advocate for choice and inclusion: “just because you have an intellectual disability, and you need some support, it doesn't mean that those choices could be made for you”. The choices she was referring to included being told or not about a death, attending a funeral, and what is shared amongst staff about her personal information. Esther likes to talk about her grief and wishes more people would listen. Like Butterfly, Esther grew up in the foster care system and also lamented the lack of access to counselling: “when you’re, when you’re a system child, you get lost in the system. So therefore, when somebody dies, there's no. You know there's no counselling, or there's no bereavement [support]”. Regarding grief support and education Esther shared this important insight: “there’s not a lot of support out there when it comes to grief. Grief is a subject that really needs to be out, get out there more because a lot of people hide grief because they’re scared of what people's reaction is gonna be”.

**Julia**

Julia has close relationships with her family, and they included and supported her when her grandparents died. Seeing her grandparents in their caskets during their funeral viewings was difficult for Julia because it was a new experience for her, but it also started her wondering if everyone was going to die eventually. Julia shared that she dreams about her grandparents, and in her dreams, they are alive and have “come back”. She shared that “when I go to my parents or my aunt’s house, I see their pictures on the walls. Good memories that way”.
**Aleta**

Aleta presented as quiet but is very clear that personal choice is most important to her. It is important for her to have the choice whether to attend a funeral and to view any documents related to the person who died. When her cousin died in another country, she had the opportunity to join the funeral over social media but chose not to, a decision supported by her family. Regarding her personal beliefs, Aleta shared that “[I] believe that there is a heaven and um...People go to a better place when they pass away”. Aleta finds it helpful to play hymns on her piano when she is missing someone who has died.

**Margaret**

Margaret has a beautiful smile, and she highlighted the many challenges of family estrangements after a death. Margaret experienced the deaths of several close family members in a tragic accident more than 30 years ago, and this event remains a source of significant grief and anxiety for her. Since the deaths of her parents, her siblings have become estranged from one another. Margaret does not fully understand the situation but shared: “when my mom passed away, they were my two [siblings] were fighting over something. . .I'm in the middle [nervous laugh], I don't like it too much”. Margaret shared that it is important to her to be able to visit the cemetery where her family members are buried on special days such as birthdays, Mother’s and Father’s Day.

**Layton**

Layton is a “man of few words” but a deep thinker who shared regrets he has about his past relationship with his deceased parents: “at times I was kind of bad to them…I used to call them names…wish I never did”. Layton also highlighted the common situation of people labelled/with intellectual disabilities being dependent on others to facilitate their involvement in
funerals and other death-related rituals. He shared: “there was a funeral [for dad] but I didn't go. I wish I did. I couldn't get a ride. [It was] kind of upsetting”. In contrast, when his mother died, Layton chose not to attend her funeral. Since the deaths of his parents, Layton has become estranged from his siblings.

**Simon**

Simon has experienced numerous losses that have affected his self esteem, but he is generous, caring, and a great artist. After our interview his support person sent me a photo of a picture he had coloured for me. When Simon’s parents died, he not only lost them but also his home, his dog, and all of his personal possessions when he had to move into another home with a paid support person. Simon highlighted the effects of cumulative losses (or *overload* as discussed earlier in relation to the Dual Process Model of Coping [Stroebe and Schut, 2016]) - when everything became unfamiliar to him and the losses so widespread, it is hard to know what/how to grieve. Simon and his support person (who was also present for the interview) emphasised the wide range of emotions he experienced and the difficulties he had in expressing them verbally, so many came out in harmful and destructive behaviours. Simon shared:

> with all the stress and weight, and I was just, almost at the point where I had a meltdown, a mental breakdown. I was worried, confused, angry, hurt, and I was most of all upset. And I was just beside myself because I couldn't even cry.

**Arthur**

Arthur has a wonderful sense of humour and was very open in sharing past trauma related to being institutionalized from a young age into adulthood. The past trauma of institutionalization in general, the specific abuse he endured, and his sense of self and others significantly impacted his grief after his mother died. Arthur shared a dream about his mother
that was very significant in his grief journey – he had been blaming himself for her death and in the dream, she told him it was not his fault: “I got to see her…and… I said, will I ever see you again mom? And…and she just said, you would always, 'I'll be always with you.' And…I feel good about that”. Arthur is involved in teaching about grief and intellectual disabilities as well as supporting others in a bereavement group setting. Regarding his first impressions of the grief support group, Arthur shared: “once I got to know them then I spoke up. But it took me a long time to do that. And I just listened to others and look at them, and that's how I listen and learn from them”.

**Ron**

Ron is a hard worker who has experienced many losses that he wanted to share for this “intriguing” research. The death of his mom (primary support person) brought on a complete change in Ron’s life – he no longer had parents (his dad had not been in his life), he was an only child, and he lost his home. Ron frequently stated that his mom died 21 years ago but the effects of the changes and losses still affect him: “it was my first death to experience and um...I kinda took it pretty hard”. After his mother died, Ron moved into a “community of people”, and he found it helpful to be surrounded by friends. “Sometimes it's good to talk about grief. Because I know that...If I just keep grief to myself only, then...because it won't help me to overcome it”.

**Gilbert**

Gilbert has close relationships with his siblings, and he really enjoyed sharing a special memory of his father. Gilbert was included in the funerals for both of his parents and this inclusion led to conversations with his siblings about his own end-of-life (EOL) wishes. “I don't want to be cremated. I want to be buried, so they have a place at the cemetery for me, when I
die”. Gilbert talked about how his siblings shared information with him, but also about times they made decisions without him (e.g., delay in being told about his mother’s death).

**Wayne**

Wayne makes friends wherever he goes and has many life-long friends. His brother died suddenly 15+ years ago. He misses his brother but also has a spiritual connection with him.

Wayne shared that the physical aspects of early grief surprised him, for example, throwing up and hitting his head against the wall right after he was told that his brother had died. “You never know how we're going to react when you lose a loved one”. Wayne also shared that thinking about his mom dying is hard and he gets “obsessive” thoughts about this. He and his mother, Giselle, shared that open communication about his worries and pre-planning in the event of her sudden death is helpful.

**Isabella**

Isabella feels an ongoing love and connection to her parents. Their love and care for her inspires her to help others in need.

I would have given up my heart and my soul for my dad, but it was just kind of traumatic for me. You know, to find out that my dad had passed. I had all kinds of emotions. Like upset sad, worried I guess for his widow and all that? I had feelings like that it was my fault...that my dad died. Like I kind of blamed it on myself.

Isabella shared that she has seen the spirits of her parents and that has made her feel “Happy, I guess that he wasn't like hurting anymore. And he was, but also like upsetting because he's no longer here”.
**Raju**

Raju is a fan of hockey and wrestling. He thinks that keeping secrets from people labelled/with intellectual disabilities causes more problems than solutions. Since the deaths of his parents, he feels his siblings have “moved on” and “forgotten”, which makes it harder for him to share his experiences and reactions while continuing to hold his parents in memory. Raju shared that his faith community is helpful: “the people at my Mosque are really understanding, they knew my parents…they’ve known me since I was a kid…it helps to go see them and listen to the Imam and stuff like that…they try to keep my spirits up”.

**Support Person/Parent Participants**

I was able to interview four participants in a support or parent role with people labelled/with intellectual disabilities. Two parents were interviewed, the parents of Fraser and Wayne. I first met them in the interviews I did with their sons, as they were acting as supporters during these interviews. I interviewed each parent separate from their adult child after the interview with the adult child. This had provided me with some prior information from which I could ask any clarifying questions, although I also followed the interview protocol for Support People participants as outlined in Appendix C. Of the two paid support people I interviewed one was employed as a worker with Margaret, while the other was a support worker I had met years ago when they approached me to develop training for staff about grief support – she had maintained an interest in this topic and was interested in being interviewed for this research project. Table 4 provides brief information about these participants, including their role and a general location of where they live/work. The two paid support workers each had 10+ years of experience working with people labelled/with intellectual disabilities.
Table 4 – Support Person Participants

<table>
<thead>
<tr>
<th>Support Person</th>
<th>Pseudonym</th>
<th>Role</th>
<th>Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent of Participant 001</td>
<td>Laura</td>
<td>parent</td>
<td>GTA</td>
</tr>
<tr>
<td>Parent of Participant 012</td>
<td>Giselle</td>
<td>parent</td>
<td>Eastern Ontario</td>
</tr>
<tr>
<td>Support Worker of Participant 006</td>
<td>Phyllis</td>
<td>Paid worker</td>
<td>Southwestern Ontario</td>
</tr>
<tr>
<td>Former Support Worker</td>
<td>Carol</td>
<td>Paid worker</td>
<td>GTA</td>
</tr>
</tbody>
</table>

*GTA is the Greater Toronto Area

Laura

Laura is Fraser’s mother, and they share the loss of her husband (his father) over 20 years ago. Laura shared that there were many times she had to walk through what happened with Fraser, and that this could be exhausting especially while she was also grieving, but she knew it was what he needed for his process. “I think it's a challenge…for an individual who perseverates. You know, at what point does, how do you distinguish [grief from behaviour]?” Laura shared that Fraser worries about her dying, particularly when she had a serious illness diagnosed several years ago: “Fraser has been on pins and needles ever since. When am I gonna die? …He worries all the time…if I cough 'are you okay?' But that's been how many years now. I survived. It's almost as if I have to”.

Giselle

Giselle is Wayne’s mother, and they share the sudden loss of her son, Peter (Wayne’s brother), over 15 years ago. Giselle is Wayne’s primary emotional support person. Her faith is very important to her in her work and her personal life, and their faith-related community was a great source of support to her, and Wayne after Peter died. Giselle was very reflective and open in sharing her experiences of supporting Wayne while also grieving the death of her other son.

…the grieving was done mostly by talking…we did cry together… Probably a year after that where he wouldn't let it go. And then he would talk about it, …and I myself, you
know, I was grieving at the same time, so sometimes I became impatient with him, and I said, 'okay, [Wayne], we're gonna let it go for now and we'll talk about it later.' Okay, because it would drive me crazy. So, he had trouble expressing his feelings, but that didn't mean that he didn't have any, any feelings, um the reason I say this, is only much years later...he says 'mom, when is the pain gonna go away?' And then I understood. That just because he doesn't express it doesn't mean the pain’s not there.

**Phyllis**

Phyllis is a paid support worker who works with Margaret. Phyllis is educated as a Personal Support Worker (PSW) with no formal education related to grief and bereavement. Working for a small, rural organization there are limited resources for ongoing work-related training. Phyllis shared that she supports people experiencing grief through instinct and her personal style, and that knowing an individual’s loss history is important. “I believe that every single one of [people labelled/with intellectual disabilities]...can feel and grieve when they do lose somebody”.

**Carol**

Carol is someone I met through my clinical work many years ago. Her work has primarily been as a support person, and she is not employed by any of the agencies participating in my research. Carol shared that grief education (for people labelled/with intellectual disabilities and staff), and grief support is often initiated or identified as a need by an employee with an interest in that topic. In her experience at different organizations, it is not a topic that is typically addressed in education and staff training. Carol highlighted the long wait for community-based counselling for people labelled/with intellectual disabilities and that it is difficult to access counselling “for our individuals because it's not always affordable...[there’s] a three-year wait
list for people…and we weren't necessarily sure if it was counselling [needed] or just needing somebody to talk to…a staff that was comfortable with such a difficult topic”.

**Key Informants:**

As discussed in the Methodology chapter, I sought to interview at least one person in a managerial position at each organization that participated in the research to gain a contextual understanding of how death and grief are understood and approached from a systems perspective. Three key informants in managerial positions self-selected for participation in this research and were interviewed, as well as two key informants who collaborated on grief education and support. Interestingly, the key informants in managerial positions each had 20-30+ years experience in the field, and two are bereaved parents who link their interest in supporting people labelled/with intellectual disabilities experiencing grief not only to what they have witnessed in their work but also their personal experiences of loss. The data collected in these interviews provides important context for the individual experiences shared by the bereaved participants and, along with support person/parent data, allows for the multi-layered approach to understanding the grief and mourning experiences of people labelled/with intellectual disabilities. The overarching mission of each organization is included to provide further organizational context. See Table 5 for information about the key informants and the organizational missions for their workplaces.

**Table 5 – Key Informants**

<table>
<thead>
<tr>
<th>Key Informants Pseudonym</th>
<th>Role</th>
<th>Area</th>
<th>Organization Type</th>
<th>Organization’s Mission (paraphrased)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kathy</td>
<td>Education Manager – with agency 30+ years (including as a support worker)</td>
<td>Urban Southwestern Ontario</td>
<td>Ontario and International</td>
<td>Working together with people who experience disabilities to accomplish their goals and fostering communities where everybody belongs.</td>
</tr>
<tr>
<td>Name</td>
<td>Role</td>
<td>Location</td>
<td>Scope</td>
<td>Quote</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-------------------------------------</td>
<td>---------------------------</td>
<td>----------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Earl</td>
<td>Manager - with agency 30+ years</td>
<td>Semi-rural Southwestern Ontario</td>
<td>Local</td>
<td>Working to create authentic and meaningful participation through community connection, determined by individual choice. Community connection is at the centre of our work to ensure individuals with developmental disabilities are fully included in the communities where they live.</td>
</tr>
<tr>
<td>Evelyn</td>
<td>Program Coordinator</td>
<td>GTA - urban</td>
<td>Canada-wide and International</td>
<td>Enhance the abilities of people labelled/with intellectual disabilities, through mutually respectful relationships. Creating a community that responds to the changing needs people labelled/with intellectual disabilities.</td>
</tr>
<tr>
<td>Barbara &amp; Arthur</td>
<td>Retired – Barbara initiated grief support groups at her agency and co-presented with Arthur in DSW classes re: grief and loss</td>
<td>GTA - urban</td>
<td>Canada-wide and International</td>
<td>As directly above.</td>
</tr>
</tbody>
</table>

**Overview of Findings**

Table 6 presents the key themes and related sub-themes that emerged from the data, providing a brief description of each overarching theme as well as one quote that speaks to that theme. Following the table, each theme and subtheme will be discussed using participant quotes to illustrate the themes.
Table 6

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
<th>Description</th>
<th>Descriptive Quote</th>
</tr>
</thead>
</table>
| Encountering Loss: Grief Reactions to a Death | ● Emotional  
● Cognitive  
● Physical  
● Behavioural  
● Social  
● Spiritual | This links directly back to the primary research question: In what ways do people labelled/with intellectual disabilities experience grief after the death of a significant person in their life? What are the grief reactions of bereaved participants? | “You never know how [you’re] going to react when you lose a loved one” (Wayne) |
| Background Context Influencing Grief (personal and interpersonal) | ● Loss History  
● Trauma  
● Recognition as Grievers  
● Choice  
● Breaking Bad News | Factors that can influence individual grief and mourning | “And because I lived a lot of trauma, and a lot of rejection...It made me more confused and felt more lonelier...” (Butterfly) |
| Managing grief: Coping with Loss | ● Family:  
   ● Inclusion  
   ● Exclusion  
   ● Estrangement  
   ● Communication  
   ● Coping Strategies  
   ● Spiritual Practices  
   ● Circle of Support  
   ● Learning Lessons from Loss and Grief | Factors that assist and/or impede coping with grief reactions and mourning activities | “Grief is a subject that really needs to be out, get out there more because a lot of people hide grief because they’re scared of what people's reaction is gonna be” (Esther) |
| Healing grief: Meaning Reconstruction | ● Rituals of Remembrance  
● Dreams  
● Visions/Extraordinary Experiences  
● Continuing Bonds | In what ways (if any) are people making meaning of their grief experiences? | “I had a dream one night that she said, don't blame yourself for something you didn't do. And it felt so real to me that I woke up” (Arthur) |
| Organizational Contexts & Grief | ● Community Resources  
   ● Rural  
   ● Urban | Factors that influence an organization’s understanding of grief in the lives of people labelled/with | “They [staff]...need to realize that death is a hard thing, especially when you have a developmental disability.” |
1) Encountering Loss: Grief Reactions to a Death

Consistent with what was described in the literature review in Chapter 2, this research project’s findings show that the death of a significant person in the lives of people labelled/with intellectual disabilities and subsequent grief reactions include reactions across emotional, cognitive, physical, behavioural, social, and spiritual domains. There is a great deal of variability in reactions to a death with no two people, even in the same family, grieving and coping in the same ways. Differences can be influenced by personal temperament, the relationship with the person who died, cause of death, coping abilities, past loss history, and social support available, to name a few (McEvoy et al., 2012). Simon had experienced multiple losses because of the deaths of his parents: “everything has changed now…the past, present…[it] takes a huge toll on my health, on my mental health. And on my mental wellbeing”. This overarching experience of change and how it affects individuals labelled/with intellectual disabilities across the above domains was shared by all bereaved participants. Wayne highlighted how the experience of grief is unique to every individual: “you never know how we're going to react when you lose a loved one”. The bereaved participants shared further details about grief reactions across multiple domains which will now be shared separately with recognition that they are also interconnected.

**Emotional**

Bereaved participants described numerous emotional responses related to their losses, including feeling: sad, confused, abandoned, peaceful, scared, anxious, overwhelmed, left
behind, connection, “going crazy”, self-blame, worry, disbelief, relief, and loneliness. For some, a previous diagnosis of anxiety disorder and/or depression was related to their coping with their grief reactions. The numerous feelings associated with the death and related secondary losses was shared by Simon:

When a person dies it makes me feel overwhelmed…I have abandonment issues, that’s what I felt because I was left behind… I was worried, confused, angry, hurt, and I was most of all upset. And I was just beside myself because I couldn't even cry.

Feeling overwhelmed by numerous emotions that subsequently inhibited other reactions was described by Wayne: “There was a funeral for him, yes. And I was so sad. I just wanted to run right out of the church. I was very angry at everybody”. Isabella shared that she “had all kinds of emotions. Like upset sad, worried…I had feelings like that it was my fault...that my dad died. Like I kind of blamed it on myself”. The feeling of blame about the death was echoed by other participants as well, with no clear connection to why they thought they were at fault. Creating a clear distinction between thoughts and feelings was not always easy, for example, Arthur shared how they connected for him: “I thought I was the one that caused it to happen. And I blame myself for something I didn't do…making my mom die. 'Causing her to die young". Worry about someone else dying was shared by some participants, for example:

Wayne: I don't want my mom to die right, so I said to my mom, 'mom I want you to live to be a hundred and ten' my mom's like, ‘Wayne, I can't live to be that long’

Cara: Do you worry about her dying?

Wayne: Yeah

For Wayne this worry, when expressed to his mother, led to discussion of what will happen when she dies:
Wayne: My mom said ‘Wayne, if I was at home and I passed away, somebody would come and knock on your door and say, oh, by the way, Wayne, and umm your mom passed. I'm here to come and get you’ and my mom's sister or family would come and see me.

Cara: Ok, so…she's arranged that, and you know about that.

Wayne: Yeah. I always thought that, okay if my mom passed and nobody answered the phone then. And like, like, how would I know?

Evelyn, a key informant with over 25 years of experience, reflected on grief and emotions for people labelled/with intellectual disabilities, as well as the interrelation between feelings and behaviour:

…how does grief or loss, how does it manifest in a person with disabilities? I would say they have the same kinds of feelings as anyone. And go through similar phases or stages. The dilemma is that people may not have the means of expressing it. And so, it comes out oftentimes in behavior. And if you just are looking one dimensionally at the behavior in that moment, then you're missing the whole communication behind the behavior.

It is essential to have awareness of the numerous emotional reactions that a person may experience after a death, and the interconnectedness of these emotions to their relationship in life, their previous losses, and abilities to communicate their feelings (verbally, non-verbally, through assistive communication devices).

_Cognitive_

How someone thinks about death and dying, their beliefs, attitudes, and understanding, influences how they adapt to the loss (Kosminsky, 2017). As shared above, both Isabella and Arthur had feelings of blame which originated from their beliefs/thoughts that their parent’s
deaths were their fault or that they caused the deaths. Trying to describe why she thought her father’s death was her fault was difficult for Isabella:

   Isabella: I had feelings like that it was my fault...that my dad died. Like I kind of blamed it on myself.
   Cara: And how could it have been your fault? …how are you thinking that it could be your fault?
   Isabella: I wasn't thinking well, like, because maybe if I could have been a donor or something, you know, for my dad. Maybe he'd still be here. But like they did surgery on him. Like the first time. And then, I guess the surgery didn't work too well or something. And I wasn't able to go to the hospital to say goodbye to him or to the hospice or whatever. To say goodbye.

Butterfly shared that “it's a lot of stuff to think about and like I'm not there yet, but like it's scary, it's a scary world”. Two participants, Simon and Wayne, described their thoughts about the deaths as “obsessive”. Wayne and his mother, Giselle, discussed this:

   Giselle: For the longest time after Peter died, Wayne was obsessed with death.
   Wayne: I was obsessed with death after Peter died for the longest time.
   Giselle: And then I would get mad at him actually, I would be like Wayne ‘OK that's enough for now, we talked about it and everything, you've got to let it go and let’s go do something else.' Because he would [inaudible] over it and I figured after he had expressed it and talked about it and everything after telling him to stop it and let it go
   Wayne: Let it go. Yep.
   Giselle: …and let it go. Because that's all he talked about. So, it stayed with him, and it stayed with him for a very long time
This excerpt demonstrates the need to explore the origin of the thoughts the bereaved person may share (or need to be asked about) and to recognize that grief can last for a long time and require patience and caring from those people in support roles.

When someone important to them dies, some participants thought about their own mortality and then shared their thoughts about their own death and their end-of-life wishes with family. For Gilbert, after his mother died, he told his sibling: “I don't want to be cremated. I want to be buried’, so they have a place at the cemetery for me, when I die”. Julia shared that after her grandparents died “I also used to think about like, about other people like my parents, how they'll deal with it, like what happens to them. …sometimes something like, oh, 'how is it [death] gonna happen for myself’”.

Consistent with the literature (Calderwood & Alberton, 2021), several participants shared that they think about the person/people who died on the anniversary of the death (which for some is more related to a season or holiday than the actual date, as they could not remember the exact date), birthdays, and/or special holidays. Wayne shared that “every year on the anniversary, Peter loved, what treat was that Mom? Tiny little cinnamon rolls and 7up drink. Yeah. We do that to celebrate every year”. For Simon, being reminded about his losses is not a positive experience:

March, May, and January are often the anniversaries of my dog, my mom, and my dad. And I play it over and over again. I just want someone else to carry that burden. I've had that burden for too long and I've had to experience too much in my life. I had, between the things that come in the back of my mind it’s like a record.

For Fraser, his mother Laura shared that he “remembers details [of his father’s death] as if it was still, as if it was still happening”. Laura also shared that Fraser still thinks about a previous experience he had with a bereavement professional that was helpful. However, this
professional had not responded to Fraser’s request to get together for coffee; this event occurred over 20 years ago but remained on Fraser’s mind in such a powerful way that I, as the researcher, was very careful to explain that he would only see me this one time for our interview.

*Physical*

Physical reactions to grief can often be overlooked as most people are more familiar with grief as an emotional state. For some participants, these involuntary physical reactions after a death surprised them. Wayne shared that when he heard about the death of his brother “I banged my head against the wall. I threw up in the bathroom…I never thought I would do that”. Raju also experienced a strong physical reaction:

…he just said [to me] 'dad is dead.' And I went to the washroom and didn't say a word to anyone, they're like 'are you okay?' and I still didn't say a word. And I went to the washroom and I’m in there relieving myself and I threw up everything…because I was so nervous about the funeral and everything else.

Other physical reactions included having sleep disturbance. Gilbert remembered:

I had a little hard sleeping when my dad died, and I had a little bit hard times sleeping when my mom died because…when my dad died it was just on my conscience all the time. Just working, you know, I had dreams about them and I'm…wasn't sleeping very well and this and that and I wasn't sleeping very well after mom died, you know, but now it doesn't bother me to sleep.

Crying is a common physical reaction related to grief and Isabella shared that “[you] can't help it when you cry. It was super, super hard”. For Simon, who experienced multiple significant secondary losses in addition to his mother’s death, he shared:
…at that point I had already lost my home, I lost my car, I lost my mom and dad and my
dog, I lost everything I lost everything. And that killed me all the time, I'm surprised I
didn't even drop dead on the floor… It's like a pain in my heart and it's like someone
ripped out my heart and stomped on it”.

These excerpts demonstrate some of the physical reactions that the bereaved participants
experienced at the time of hearing about the death and over time.

**Behavioural**

As discussed earlier in this dissertation, behavioural reactions by people labelled/with
intellectual disabilities, when not understood within the context of grief and mourning, can be
treated as misbehaviour, and managed as such with, for example, behavioural modification
techniques, admonishment, and redirection. These responses to grief and mourning-related
behaviour preclude the opportunity for compassionate and sensitive support of the grieving
person. Esther sums this up through this statement:

People experience grief so differently. And the staff have to be aware of their
actions…they have to be aware of their behavior. It's not, it's not because they're bad and
they don't listen, and they're not listening, they have to be aware of their behavior and try
their best to help them…Like swearing, emotional, you know, hitting, whatever, you
know, not eating, you know.

Butterfly shared that seeing her grandmother dying in the hospital was difficult for her: “when I
see somebody in pain, I don’t like it and it makes me very sad and upset and all that”. This upset,
if not viewed in the context of Butterfly recently seeing her dying grandmother, could be taken
out of context within her living environment and treated as negative behaviour. Simon shared
how his support worker assists him in these situations:
I just lose control of my situation and it's just, you know, it's like, it's like I can't deal with it, or I try to put it off or I just walk away. And then if I have to, I talk to someone and then that person, that support worker, he normally calms me down, and then we go out for a nice drive somewhere or a ride somewhere.

For Aleta, being upset and acting differently relates to her frustration that so much has changed for her: “I’ve been having days where I'm upset because I just want things to go back to normal. And I just want things to be the way they used to be, but I know it won't go back to that”. Cathy, a key informant who currently works in management but has over 30 years of experience in varying roles within her organizations, shared the following:

They're [people labelled/with intellectual disabilities] going to react in the only way that they know how. And whatever that looks like for that…it's going to be different for each person because that's what we do, right? I know enough about grief is we're going to react in our own personalities. So, if you're generally acting out and throwing things well you're going to probably do it more, you know what I mean? And just telling someone that we support to just stop…it's not helpful.

These participants illustrate how grief includes behavioural reactions and how these reactions can be misinterpreted within systems of care and ‘managed’ as behavioural ‘disturbances’ rather than seen as components of their grief experience.

**Social**

It has been established that having social support that is meaningful and helpful to the bereaved person is a protective factor in grief (Doka & Chow, 2021). Ron recognized this and shared that: “sometimes it's good to talk about grief. Because I know that...If I just keep grief to
myself only, then...Because it won't help me to overcome it”. For Ron, sharing his grief makes it more manageable. Meeting others who have experienced loss is important for Butterfly:

And for a long time I felt alone and I found peace if you know some people that lived the same situation, doesn't mean that your problems will go away but at least you feel less alone...And they live the same situation too so they might have ideas to make you feel a bit better, doesn't mean that like you're better but at least you're not too much alone so that's what I'm trying to do.

Raju highlighted the lack of privacy and control over personal information for people labelled/with intellectual disabilities living in a group home or supported living situation. Raju shared that he is “…big on trust…so if I tell [staff] something personal or tell them I'm sad, I don't want them to go and tell the whole building or tell the other team members unless I say ‘okay you can’”. He also shared an experience with a staff member who repeatedly asked him about his parents, ignoring or forgetting that Raju had told him they had both died. This was very upsetting for Raju, and he believes that the staff “was trying to get some kind of reaction. And I wasn't giving him the reaction, so he just kept pushing”.

**Spiritual**

Spirituality means different things to different people. For some participants, their connection to a religion provided a structure or framework to assist them in their grief. Religion and spirituality can also be related to a person’s culture, but culture, as a specific influence on their grief reactions, was not overtly shared by participants. For Aleta, her religion informs her belief “that there is a heaven and um...People go to a better place when they pass away”. For Margaret, the ritual of going to the cemetery and prayer are helpful: “I say a prayer or something. To them [when at the cemetery]”. For Raju, the community of people at his Mosque have been
helpful: “…the people at my Mosque, are really understanding”. Whereas, for Butterfly, although initially her church community was helpful, “they were like a family to me, because if I had a bad day they would pray for me, if I needed support, they would sort of help me like [crying]”, once the person she was closest to at church moved away and she had to go there alone,

the church part like it's complicated, really really complicated. I find it's a lot about money and saying, like ‘oh you can do this this this, but you cannot do that that that’ and like... Not everybody is perfect and like in the same situation you know…they can talk about you, they can reject you, they can say whatever and I find it wasn’t fair at all. Cause I didn't choose my life, I didn't choose to have parents that couldn't take care of me... I didn't choose to have depression… I don’t want to be different, but I am.

Spirituality can also be related to a sense of connection to the person who died, a way of making meaning in life, and certain rituals. Wayne shared the following experience that he described as powerfully spiritual and meaningful for him:

And then one time when my mom and I went to the cemetery I wrote letters [to my brother] and put them there and all of a sudden, I look up and there’s a deer that came right towards me and I could reach out and pet him. So, the spiritual deer that came to the cemetery…It was letting me know that [my brother] was in heaven and that he was, okay. It made me feel at peace. And it made me cry. Oh, and I had goosebumps and shivers. I like I wrote the letters like telling [my brother] how much I love him and miss him and just put them out the just put them on like on the like on the tombstone there.
2) Background Context Influencing Grief (Personal and Interpersonal)

There are many factors that can influence an individual’s grief and mourning experiences. The personal and social/interpersonal contexts within which an individual experiences a loss and subsequent grief reactions were numerous for the bereaved participants (and were considered by the support people and key informants). After data was analysed, these contexts fell into the following five sub-themes: loss history, trauma, disenfranchisement, breaking bad news, and choice. As with the sub-themes above under Grief Reactions, although these sub-themes are presented separately, there is a need to acknowledge that there is some overlap and interconnectedness between the sub-themes. Kathy, a key informant, articulates some of these interconnections when she stated:

I think it's easy to forget as a staff person…the grief that this person has gone through and we're seeing occurrences all the time and they've been on the increase and…that's trauma, right? And when you're trying to hurt yourself and or you're trying to hurt others, it definitely stems from that trauma. For people we support there's all sorts of other trauma they have had to deal with. So, adding depth to the mix is [the loss] of someone that they love is just a significant source of trauma for sure.

Loss History

The history of losses in our lives informs how we view death and dying, our beliefs about what grief looks and feels like, and how we cope with grief and mourning after a death. For many people labelled/with intellectual disabilities, if they have previously lived in an institution and/or multiple settings, their loss history may not be known by the people in their current circle of care. Even when past losses are known, carers may not realize the significance of particular
losses (death and non-death related) that may be important to how an individual labelled/with an intellectual disability may react to a new loss. People labelled/with intellectual disabilities may have had numerous support persons and/or members of their circle of care throughout their lives. Carol, support worker participant, shared the following:

so many [people] in the group living situations, unfortunately get so used to staff coming in and out that we think there should be some kind of attachment when somebody moves on to a different role and then there isn't always, it's like 'yeah they don't stick around nobody sticks around.' So, there's that other kind of opposite reaction to the group living and staffing response too.

Butterfly was primarily sharing about the death of her grandmother but also shared about another significant loss - “my daughter didn't die but it feels like a loss too” – her daughter had been adopted at a young age.

Arthur shared, “the staff [at the institution] were hurting us and they were gonna do everything they can to hurt us…[lived in an institution] 20 years of my life. From the time I was 4 to the time I was 24”. This history of being in an institution for over 20 years meant that Arthur lost regular contact with his family, and for him, the abuse that he suffered affected his ability to trust people, which in turn affected his willingness to share his grief with others around him in his new community after his mother died:

Cara: [You felt you] couldn't trust people or open up to people?

Arthur: Not to anyone. I felt they didn't trust me so why should I trust them.

How others react after the death of someone significant to us can also affect how we cope with past losses and the current changes they bring about. Raju shared the following:
[After my mom died] I was like do you realize that you’re changing around everything, the dynamic of the household. And [my dad] was like 'no she's (step-mom) not' and I was like 'come on no you can't see it?' And my dad would be like 'Call her mom' and I was like 'No. There's no way I'm doing that. I'm not doing that.' And he would insist. And I’m not doing that. She's not my mom.

These significant changes in family dynamics were viewed as substantial further losses by Raju.

*Trauma*

Past (and current) experiences of trauma were shared by several participants as being significantly related to their grief experiences. I did not define what constituted trauma for the participants, this is language they used in their interviews. Margaret shared that the traumatic deaths of several of her family members in an accident over 30 years ago continued to have an impact on her in terms of often feeling anxious. When talking about her reactions after her grandmother died, Butterfly shared: “and because I lived a lot of trauma, and a lot of rejection, and [inaudible], and stuff like that. It made me more confused and felt more lonelier”. As shared above, Arthur’s history of trauma while living in the institution ranged from being separated from his family, physical and other abuse by institution staff, not feeling safe, and being separate from his broader community – “the staff were hurting us, and they were gonna do everything they can to hurt us. I was not allowed to talk to anyone. And and…I found that really hard”.

Simon described the following experience of trauma after his mother died and he lost his home and everything important to him:

…it’s like a shockwave that comes right through you. It’s like trauma, it’s like a whole tidal wave that comes and forces you away. It was like everything that was like, normal for me. And everything was like totally destroyed and I don’t think I can reclaim what
once was, like it once was because it’s like, I loved everything in my life truly and close
to my heart and I love everything that I missed. And now everything is gone. And like I’ll
never get anything back.

The depth and breadth of trauma and grief Simon experienced is clearly illustrated through this
poignant quote.

Recognition as Grievers

Lack of recognition as a griever occurs, in the context of grief, when a person is not
socially acknowledged as a legitimate griever and/or the loss is not deemed significant. For
people labelled/with intellectual disabilities this can occur because they are not viewed as being
affected by a death, not understanding the implications of a death, or a myriad of other reasons
related to personhood. Participants shared that when they were offered choice and provided with
timely and clear information about a death, they felt recognized, and their loss experiences were
acknowledged. Esther linked recognition and choice saying: “Just because you have a
developmental disability, and you need some support, it doesn't mean that those choices [should]
be made for you”. Furthermore, she stated: “When you're being, when you're being looked after,
it's not fair because they... You're not given a voice. This is like what the staff want, not what
you want, it's what the supervisors want, not what you want”. It appears that not being told the
information about the death or excluded from rituals or opportunities to mourn, are the primary
ways the participants experienced disenfranchisement from the experience of grief.

Choice

As Esther shared above, choice should be offered to people labelled/with intellectual
disabilities when it comes to how they want to be involved when someone is dying and any of
the rituals/gatherings after a death. Further to this, Esther shared: “For me, now that I live on my
own, I choose who I…want to keep in contact with…I let go of a lot of people…I want people that are going to be positive not negative”. This included people who would respect her privacy and communicate directly with her about difficult things such as death and grief.

Earlier, Aleta’s quote shared her choice to not attend the Facebook streamed funeral of her family member because she felt it would be too hard on her. But for Fraser, as shared verbally by his mother, Laura, being able to attend his friend’s funeral over zoom “…was so helpful…Fraser and I were here at the table with a computer and we just sat for the two hours, the whole time, and it was really really helpful”. This was during the COVID-19 lockdowns so in-person attendance at the funeral was not possible. Regarding choice about who knows personal information related to the death and the participant’s grief, Esther shared:

I live in a group home right…so they have to put everything, they have to jot everything down in a communication book for all staff to see. Let it be…Let it be more confidential. Don't put it in the book for everybody to read. Because maybe maybe I don't wanna go through that. You know what I mean? So, when somebody passes away, just let it be on a professional level, but let it be more confidential.

Cara: So, let you have more say on who knows about it?

Esther: Yes. Cause maybe I want to, maybe I don't feel comfortable with the staff that's working that night or whatever. Or maybe I feel more comfortable with the next staff that comes in the next day…It's all about respect. Yeah, so respect is, respect is so huge

Choice as related to who gets to know about the person/people who are dying or have died is linked to the next sub-theme, Breaking Bad News.
**Breaking Bad News**

How we share (or do not share) information can affect how a person reacts to bad news and their subsequent grief experiences. For Wayne, he remembers the police officers coming to his home to talk with his parents. When he was told that his brother was dead, “I was crying right away. It was the hardest thing my mom ever had to tell me”. His instantaneous physical reactions to this news were documented earlier under the Physical Reactions sub-theme. Esther remembers that her family members first contacted the group home supervisor rather than tell her directly that her beloved grandmother had died so that she would have support available, but also shared that she has previously been alone and received bad news without any support available.

Esther: Death is touch and go, it really is. It depends on the situation. It depends on who it is but like…You gotta be comfortable and you gotta be safe to talk about death. You can't talk about death with anybody, you have to be comfortable, and you have to feel safe. Especially if you live in a group home.

Raju shared that at first, he was not told that his father was in the hospital “because they [his family] didn't want me to know, because they thought I'd be too sad”. But when he saw his father in the hospital, he did not feel sad, “he looked okay, I mean he had, obviously he was sick because he was sick, but he looked okay. I was like you know what my dad's gonna to make it”. The following day, when his father did not call him as planned,

I had to go to school that morning and nobody told me anything. So, I got back to my foster dad and my… and was like 'your brother's going to call you in 20 minutes'…I was like what’s going on here, nobody’s telling me nothing. And I'm like what the heck is going on…then my brother calls me he didn't even say the word hello, or how are you, or anything, he just said, and I'll never forget this, he just said 'dad is dead.' And I went to
the washroom and didn't say a word to anyone, they're like 'are you okay?' and I still didn't say a word.

Finding out the news of his father’s death this way, and how other family members reacted, made Raju not want to talk to anyone at the funeral or afterwards. Carol, a support worker participant, shared that she was once asked by an organization to inform two adult siblings labelled/with intellectual disabilities, that she had only met once before, that their only surviving parent had died. This parent had been their primary support person for their whole lives and, although they knew this parent was in the hospital, they had not been allowed to visit or told that this parent was dying. This decision was made by their siblings.

Carol: The [other] siblings didn't want to tell them, I had only met them once, so they wanted me to tell them. [One sibling] that I had a meeting with, talked [to me] as if they weren't in the room…they acted like they didn't know or understand anything that was going on around them…But then in conversation with the [other sibling] they’d say well [they’re] doing this and it's kind of odd or [they] keep going to [parent's] room…it was clear they understood there was a different routine and something had happened because there was all these people now of course. They were [eventually told]…because I did make sure that they were told, I just didn't feel it should come from me. So, the [worker] who had been coming in, helping them with meals, and encouraging showers, and things like that while [parent] was in hospital had a bit better relationship with them to be able to facilitate that conversation with the sibling [who did not want to tell the siblings labelled/with intellectual disabilities]. I mean…as far as grief goes, they lost a family member then they lost their home.
In this circumstance, breaking bad news in a supportive and caring way required clear communication between family members, paid support workers, and organizations involved with this situation.

In some situations, family members direct staff not to inform the person labelled/with an intellectual disability that a family member has died (this also ties into the sub-theme of family exclusion). Kathy, a key informant, shared the following situation related to a person they supported and the death of their parent:

Kathy: Very sad. But the person supported is blind and deaf and poses significant behavioral challenges and doesn't use words to communicate. And then [their parent], [who] was quite active in [their] life. Like coming around like visiting [them] regularly. And then [the parent] passed away and [the client’s] family told the staff not to tell [them]. But, you know, [they] noticed that [their parent] wasn't visiting anymore. Like that's not going to be something [they don't] notice, right?

Cara: What did you see in [their] behavior, [their] demeanor that told you, [they] know?

Kathy: I think there was a lot of sadness, some increased self injury because [they’re] quite self injurious. And would the staff, maybe attribute that to grief? I don't know if they would, if they thought about it for any time they might, but they probably didn't. But they were quite upset that they weren't allowed to tell [them] that…[their parent] died. Those are very tough situations. And that's not the only one, depending on the person, sometimes the disability is significant enough that other family members will decide that they don't need to know that a loved one has died. Which I think is terribly sad…and they don't give enough credit to the person that we support that they will understand...what has happened. It's not uncommon that we receive those requests from family.
Both Carol and Kathy believe that bad news must be shared with people labelled/with intellectual disabilities in ways that is caring, compassionate, and provides some explanation of what has happened (in language and details appropriate for the person labelled/with an intellectual disability).

3) Managing Grief: Coping with Loss

There are numerous factors that assist and/or impede coping with grief reactions and mourning activities after a death. Just as our grief reactions are unique and individual, so are the ways we cope with life and mourn after the death of someone important to us. As professionals and support persons, knowing what can be helpful for a grieving person labelled/with an intellectual disability can be challenging. For example, Phyllis, Margaret’s support worker, shared about another individual she supports:

Phyllis: So, she'll talk to her [deceased sibling] every single day and look off in the corner and have like a conversation with [them].

Cara: OK. And just letting her do that seems to be helpful for her?

Phyllis: Yeah, Oh yeah. We don't encourage it per se, but…I'll communicate with [her] while she's communicating with her [sibling], and I'll ask her questions…'What is [sibling] saying to you?' And...I don't tell her not to do it for sure, because I feel like it is helping her. It's her, it's I think it's a coping mechanism for her. So yeah, that's absolutely fine.

Key factors affecting coping shared by participants include: family (inclusion, exclusion, estrangement, communication), coping strategies, spirituality, circle of support, and post-traumatic growth.
Family

The bereaved participants chose who they identified as family. For some participants this extended beyond biological and adopted family to include friends, members of their circle of care, and paid workers. I identified four family related factors that related to their coping: inclusion, exclusion, estrangement, and communication. Inclusion was identified as times when family provided the bereaved participant with information, choice, and support. Julia shared that she has been included in family deaths since she was young:

It was a little bit hard for me when it was the very first ones (funerals), 'cause experiencing as a child, kinda hard for me to hear. Yeah, I actually went to the funeral [for grandfather’s] viewing with my dad. Me and my sister went in from the very first one it was kinda hard for me 'cause I never experienced this before. As a little girl, like seeing someone who's passed and how they look, it was kinda hard for me to deal with, like that night after it happened, like I... Having nightmares about it because like being a child. It was kinda hard for me to see and then, and then like to think of it and stuff.

Although she still experiences some fear about attending funerals and seeing a dead body there, Julia further shared that “…they're not really there, like it was, the spirit of love”. Arthur shared that he could talk about his mother’s death and his grief with his sister rather than with his brothers.

In terms of exclusion from knowing about illness/death and rituals, Raju shared:

[My dad] I had no idea. And they made up a lie. They told my [step] mom to tell me a lie. And they told her to tell me that he's gone to a religious gathering in Toronto. And I was like no, he's been gone for too long, there's something going on. And I was like, I had a feeling something was wrong. But I didn't want to say anything.
Even though he suspected his father was not well, the lies told to him about the situation prevented him from being able to know what was really going on. For Gilbert, he was not told about the death of his mother until two days after she died. “I said to [sibling] ‘why are you holding it off so long to tell me that?’ And [they] said ‘oh well [other sibling] said oh I didn't want to tell you right away in case of you were up in case, in case if you were uptight or upset or whatever’”. Gilbert acknowledged that part of the delay was because his siblings wanted to tell him in person and to ensure he had support available to him after they shared the news. Carol, a support worker participant, discussed the inability to visit someone in hospital, and attend funerals and other gatherings due to COVID-19 restrictions:

There would be those kind of normal things that we as a society do [related to deaths, funerals, etc.]. And with COVID we've not been able to do that and how frustrating that is…on a normal developmental level and being able to understand that. Imagine if you were told, 'no, you don't need to go to the funeral because you might make a scene or you might whatever or you don't understand', right? So, you just get excluded from that whole process…and that's how folks with developmental disabilities who get left out of the process feel all the time. The things that we feel we're missing [during the pandemic], it's part of it that ritual is, could be how being left out in the regular times would feel of exclusion for people labelled/with intellectual disabilities.

Family *estrangement* after parents’ deaths was experienced by several participants. It was first brought to my attention by Margaret, and she identified it as a cause of anxiety for her. Her siblings had disagreements regarding the estate of their parents after they both died:
I hope someday they talk to each other. Hope someday. I hope so. Because yeah, you forgive, you forgive them. The person. And we move on. Yeah, I want them to do it, but I don't know if they're really gonna, but I hope they do that someday.

Margaret appeared very sad and teary when she talked about the estrangement of her siblings. Layton shared that after his parents died, he became estranged from both of his siblings and has not spoken to either of them in over 10 years. Layton shared that if his father was still alive, he would likely have “fixed” this situation. This was reiterated by Butterfly who shared that her family had not been very close prior to her grandmother’s death, but when her grandmother was not there to broker the relationships anymore, things became worse in her family:

…it was for the funeral it was like the family weren't close, so it was hard, like I felt like nobody liked each other…It was my grandmother that was making everybody be like together, so when my grandmother died it made like everybody more frustrated and everybody got to their own sides more.

Communication within families can be difficult when family members are mourning the same death in different and unique ways, and alternatively, effective communication can open important conversations such as those about end-of-life (EOL) wishes. As shared by both parent participants, supporting their adult child people labelled/with an intellectual disability in their grief while also grieving the loss themselves could be challenging (see Wayne and Giselle discussing this in Grief Reactions, under Cognitive sub-theme). Wayne’s mother, Giselle, shared the following about communicating about emotions:

[His brother] dying made him experience emotion that he didn't know to put the names to. Sometimes he had a hard time naming the emotion that he feels. And it's too easy for
me to tell him how he's feeling. So, I have to let him speak. Because if I tell him how he's feeling then he's going to immediately say, that's how I'm feeling.

For Fraser’s mother, Laura, she shared that since Fraser does not use words to communicate, “…he cannot articulate more specifically, it's just sort of hoping we're, I'm getting it right”, when she would guess at what he might be experiencing after his father’s death. She added further that “…because he's nonverbal we really have to be present and…tuned in. It takes a lot of extra effort”. Raju does not feel that he can communicate about his feelings related to his parents’ deaths with his siblings: “I like talking about it with other people. But I will not talk about it with my [siblings], they just move on. Whereas me, I can't to move on. I can’t move on…forget”. As mentioned in Gilbert’s introduction above, talking about his parents’ deaths with his siblings also led to talking about what his EOL wishes are: “I don't want to be cremated. I want to be buried, so they have a place at the cemetery for me, when I die…my sister brought up if I wanted to be buried or cremated”.

**Coping Strategies**

There are countless ways to cope with grief after a death and the coping methods will be unique to each person, their environment, and the loss. We try to cope with grief as best we can, with the resources available to us, and in ways that we hope will be helpful. For people labelled/with intellectual disabilities they may need others around them to facilitate their desired methods of coping. Participants shared multiple ways they try to cope with their grief reactions, including: sharing feelings, telling stories, and sharing worries with trusted others; walking/go ing out; talking to others who have had someone die; helping others; art; music; faith/church; work; and looking at photos. For Layton, “I just... Ahh...I just deal with it. Just, think about better things”. Simon shared that talking with his support worker and going for a drive helps him to
“calm down”. Ron tries to “…find other ways to keep me happy. That's my mom, that's what my mom would have wanted me to do…I do a lot of art”. For Gilbert, walking helps him to think about his mother: “I go for a lot of a lot of walks thinking about it. I'm thinking about all the times me and mom went for our walks. It just makes me felt like sometimes I miss her, sometimes I don't. It depends”. For Wayne and his mother Giselle:

Giselle: Wayne and I talk about [his brother] like he's living, like he's here, and he has something to say, and we talk about him all the time.

Wayne: And that's good though.

Isabella uses photos to remember her deceased family members and she also finds that crying helps her cope: “I have pictures that I look at…my [sibling] and [their partner] put together a photo album for me. My dad and my mom and everybody… I cry sometimes when I look at it…I do have memories of them”. This illustrates that an aspect of coping can include crying, something that can be wrongly pathologized when not considered an aspect of the person’s coping with their grief.

**Spiritual Practices**

Spirituality was discussed earlier under the Grief Reactions theme. For some participants spiritual practices such as going to church and/or the cemetery, their church community, and prayer were identified as helpful in their coping. Julia shared the following goal:

…yearly visits [to the cemetery], like once a year me…It's a little bit like not too bad for me, you know, because like they make it, they don't make it look so scary, they make it look more holy and more comforting, like they renovated the cemetery.

Margaret, who has experienced many deaths of family members over the years, shared that going to the cemetery is important to her.
Margaret: …every year I lay, I lay a flower put it on the stone, my mom's stone. Yeah, and I when I [visit] my [the children’s] stone so I put a flower there too. [Their mom] too.

Cara: And then when you're there, what sort of feelings are you having?

Margaret: All right, I say a prayer or something. To them and that.

Cara: So, is religion important in your life, are you part of a…?

Margaret: Yes. Yes. Catholic.

Several bereaved participants shared that due to COVID-19 restrictions they had been unable to attend in-person religious services for some time. As Raju shared in an earlier section, the people at his Mosque had known him and his family since he was young, and he found this to be helpful and comforting.

**Circle of Support**

Many people labelled/with intellectual disabilities have what is called a *circle of support*. This is a group of people who the person labelled/with an intellectual disability has chosen to assist them in different areas of their lives. Members of a circle of support can include family members, friends, paid workers, neighbours – anyone the person labelled/with an intellectual disability wants to have included. Some of the bereaved participants described having a ‘formal’ circle of support while others shared about people in their lives who provide them with important support. Laura, Fraser’s mother, shared that Fraser’s circle of support members were the most helpful part of supporting him to grieve and mourn his father’s death: “he had other people to talk to, he had relationships with other people". Isabella shared that “it was really nice to see a couple of my friends come to the funeral hall”. Butterfly specified the qualities of someone she would find helpful for support: “I would rather talk to somebody that has compassion, listens, no judgment”. Arthur shared that he came to the realization that “…there's certain things I'm gonna
need help with because I can't do it alone. I need friends that are willing to support me when I feel that way. And...How to really face that and to be open to it”. For him, friends in his grief group not only helped him face the death of his mother but also the longstanding effects of institutionalization:

[Grief group members] once I got to know them then I spoke up. But it took me a long time to do that. And I just listened to others and look at them, and that's how I listen and learn from them. So that I could do the same and go from there...By listening to others and trusting, that it’s helping. Helped me to trust myself. And someone believed in me. That's what helped me. All the garbage that was in me [from the institution].

For some participants, there were people who were not very helpful in their grief. Margaret shared: “[I] tried different counselling. Yeah. Yeah. Doesn't help”. Ron noted that “some people after [the death] weren't very supportive”. As I asked participants about what the people in their lives did to support them that was helpful and/or unhelpful, some made the point that they want to be seen as helpers for others as well, not always only as the recipients of help. For example, Arthur assisted in teaching a Developmental Services Worker (DSW) class about grief through sharing his story and co-facilitating a grief group with Barbara. Isabella summed this up saying:

I'm there for all of my friends who are like in turmoil like this, you know? I want to be an influence on them...I want to let them know that if they are thinking of suicide or whatever, don't do it because it's not gonna...be good.

Evelyn, a key informant, added “everybody [here has] a great capacity for compassion. They know what it's like to have struggled, to suffer so they know what loss is down to their very core” and thus wanting to help others can come from this personal suffering.
**Learning Life Lessons from Loss and Grief**

Several participants, like Isabella above, shared that they have gained some life lessons, or growth, from their experiences of grief and loss. Personal learning and growth was described by participants as a sense of improved self-awareness, a wish to help others, and a sense of meaningful connection to the person who died. It is important to note that post-traumatic growth is not a requisite for ‘good’ grief nor does every bereaved person experience growth through grief. For Arthur, as he reflected on his grief and mourning experiences related to his mother’s death, he shared: “…this year I said, I'm open to facing the fear as well as the good. And I couldn't believe I said that”. As mentioned earlier, Arthur’s sense of self and relationship with his mother was seriously affected by 20 years of institutionalization. Coming to the realization that he could hold fear and good together was an inspiring revelation for him and seemed connected to his opportunities to help others through his teaching and involvement in the grief group.

Isabella, using her experiences of loss and grief, tries to be a helpful support her friends through telling them: “talk about it. If they want to talk about it then talk about it…I'm there for all of my friends who are like in turmoil like this, you know? I will not, I don't leave anybody”. Wayne described growth related to feeling obsessed with death after his brother died:

Wayne: And then I realized being obsessed about death doesn't help anybody.

Cara: Okay. Was it interfering with you having a life? Like you enjoying things.

Wayne: It would interfere with me having a life and being a fuss about it.

Giselle: Yes.

Cara: Yeah, I just wonder if it you know stopped you from being happy and enjoying things and trying new things.
Wayne: Yeah, it did.

Cara: So that took a while to work through that.

Wayne: It did yes. I'm like, like, if somebody dies, like about grief is like everybody grieves differently, at their own time. ‘Wayne, he's not there, he's not in the ground, he's like nowhere' like I've heard people talk about different things like that. I say I'll grieve the way I want to grieve, and this person will grieve that way.

When given the opportunity and space to share, the bereaved participants in this research had many life lessons rooted in loss to share.

4) Healing Grief: Meaning Reconstruction

Meaning reconstruction is viewed as part of the natural grief process as it is how we make meaning of the separation from the person who has died, explore how the loss has changed our identity, and affected our sense of belonging in family and community (Gilbert and Macpherson, 2021). The previous themes and sub-themes inform the process of meaning reconstruction for participants, as it is directly linked to their grief reactions, the contexts of their loss, and how they are coping. At the end of my interview with Arthur, we had the following exchange, which powerfully highlights some of the meaning he gained from his experiences of loss and how they are expressed his new identity, and also how his participation in this research was meaningful for him:

Cara: Well, you've answered all, a lot of questions that I had, and I appreciate that. Do you have any questions for me at this point?

Arthur: Umm…Yeah, how did you feel about me talking about those things?
Cara: How did I feel? Umm…Thank you for asking. I felt honoured that you would trust me and share that with me. I really appreciate it. And I recognize that it’s been a long process for you. So, I feel honoured to learn from you, and I feel grateful to that you’re so, so generous to share both the fear and the good.

Arthur: Yeah

Cara: So that I'm grateful and honoured. Thank you for asking.

Arthur: You're welcome. It took me a long time to do that.

Specific sub-themes that are related to the meaning reconstruction process include: rituals of remembrance and linking objects, dreams, visions/extraordinary experiences, and continuing bonds.

**Rituals of Remembrance and Linking Objects**

Participants shared several ways they engage in rituals of remembrance and different objects they have that remind them of the person/people who died. As shared in earlier quotes, Wayne writes letters to his brother, takes them to the cemetery, and on the anniversary of his death, he and his mom take some of Peter’s favourite foods with them to the cemetery. Also shared above, Julia and Margaret find that going to the cemetery on special occasions such as the anniversary of the death, Mother’s/Father’s day, etc. is helpful for them. Layton shared that he has never been able to see the gravesites of his parents because he has no way to get there:

Cara: OK, would that be important to you to someday go to their graves at the cemetery?

Layton: Yeah, I thought about it…Yeah. I thought it would be nice to see their gravesite.

Cara: OK, so you think about going to see it.

Layton: Yeah.

Cara: OK. But haven't figured out a way to get there?
Layton: No.

Gilbert shared that he has jewelry that belonged to his mother and wearing it is meaningful for him. Margaret talked about having a family heirloom that links her to her mother and grandmother:

Cara: Were you able to get anything of your mom's that's important to you?
Margaret: Yeah, yeah. Some of my mom's stuff. Yeah. I got the clock, I got the grandfather clock, but I, it still works but it is broken little bit.
Cara: Does that remind you of your mom?
Margaret: Yes. [smile, laugh] My grandmother, it was hers too.

**Dreams**

Dreams of the deceased were shared by several participants as being an important aspect of their reconstruction of meaning after the death. Grief dreams are only recently receiving attention in research (Black et al., 2019) and it is interesting that participants shared this part of their experience. For Arthur, the dream he had of his mother helped resolve the blame he felt: “I had a dream one night that she said, don't blame yourself for something you didn't do. And it felt so real to me that I woke up”. For Julia, having dreams about her grandparents was like spending time with them: “And then sometimes I used to have dreams of seeing them at nighttime, like that they were alive, and they came back”. Gilbert talked about dreams and not sleeping well after the deaths of each of his parents: “I had dreams about them, and I wasn't sleeping very well...after mom died, you know, but now it doesn't bother me to sleep”. Gilbert then shared that he also has dreams of fun times he had with his father.
Visions/Extraordinary Experiences

In my experience, bereaved people are often hesitant to share their encounters of seeing or sensing what they describe as the person’s spirit or ghost after they have died. The worry tends to be that they will be considered crazy or not be believed. As Wayne shared so poignantly earlier under the Spiritual sub-theme of the Grief Reactions section, his experience seeing the “spiritual deer” while at his brother’s gravesite was a powerful and meaningful experience that helped him feel his brother was giving him a sign that he “was in heaven and was okay”. Wayne also shared a separate experience of seeing his brother’s spirit or ghost:

Wayne: One time, umm… I like after [Peter] passed I look like, like, I had a closet that had a little like curtain on it, and I went forward, and I see [Peter] standing there like a silhouette of him.

Cara: Okay. What did you do?

Wayne: I was just happy to see him. It was a sign that he was okay.

Isabella shared that she has sensed the spirits or ghosts of both of her parents:

Isabella: I think it’s not fair I lost both of my parents. Oh, yeah, yeah, his ghost appears to me sometimes… when my mom passed, I had her spirit that just swooped in like because I got, I was in bed and like I got cold all of a sudden. Like I felt like my window was open. And she floated in and sat on my bed.

Cara: And… could you see her, or just feel her?

Isabella: I just felt her. It did wake me up. You know, because of the coldness. And she floated in, I didn't like I didn't see it. I just felt it, And I think she just wanted me to know that she was okay, she was good. That she was up there, heaven and that she was okay,
she wasn't hurting anymore she, like…both of my parents were churchgoing, like church-going people so.

Cara: And you mentioned, so your dad, you've had some spiritual experiences with him too.

Isabella: Yes. Same thing. Just floating into my room. And telling me that he's okay. And he's not hurting anymore. And whatever.

Cara: And how did that make you feel?

Isabella: Happy, I guess that he wasn't like hurting anymore. And he was, but also like upsetting because he's no longer here.

The sharing of these experiences was not linked to a specific question within the interview protocol, the sharing emerged organically during the interview. I hope that being able to share their visions/extraordinary experiences without judgment and/or pathologizing within the space of the research interview was validating and helpful for the bereaved participants.

**Continuing Bonds**

As outlined in Chapter 2, continuing bonds with the deceased is now believed to be a healthy, typical component of grief, where the living maintain an ongoing inner relationship or representation of the deceased (Gilbert and Macpherson, 2021). This bond can be maintained in the ways described above such as through ritual, linking objects, and dreams, as well as through memories and lessons taught by the deceased that the living carry into their lives moving forward. Arthur remembers something his mother said that helps him remain connected to her: “I got to see her in the hospital. And...I said, will I ever see you again mom? And...And she just said, you would always, ‘I’ll be always with you.’ And...I feel good about that”. Gilbert likes to “remember the good memories of my father” and he shared some of them with me during our
interview. This kind of sharing of stories and memories with others can help to maintain the bond with the deceased. Isabella shared her ongoing love for her parents:

I love [my parents] so much. And I know that they’re still in my heart and everything and I see pictures, you know, but it’s not the same. No, it’s not the same. I thank them both…and I talk to them in some sense, I guess. And I just say I miss them both.

5) Organizational Contexts and Grief

Situating individual bereaved participant experience within the context of the organizations with which they are connected is important for understanding some of the potential influences in the care and support they receive when grieving. Bereaved participants were involved with five different organizations, within small rural areas in southern Ontario and larger urban organizations in the Greater Toronto Area (GTA) and Eastern Ontario. The organizational managers who participated in this research are outlined in Table 5 above. Three organizations were represented by individuals in managerial positions, two of which have a religious base to their service provision and mission (but provide services to people labelled/with intellectual disabilities from multiple faiths). Despite this theme coming last in this chapter, overall organizational context and the sub-themes identified influence all of the other themes and sub-themes when applying a systems perspective within my research process. Sub-themes identified include: community resources (rural and urban), frequency of deaths increasing, grief education, and staff experience (personal and professional).
Community Resources

The context of where organizations and their services are geographically situated plays an important role in the availability of grief support resources and access to counselling when needed.

Rural. For two organizations, represented by bereaved participants and one manager, lack of access to community-based bereavement and counselling resources were identified as related to where they were located geographically within Ontario. Rural or small urban-based developmental services organizations tend to be what is known as a stand-alone community living organization and do not have multiple locations such as larger organizations that are provincially and/or internationally situated. Earl, with over 30 years of experience working in the field, shared:

Because we're rural, we don't have a lot in this area, we have to kind of do it on our own. We have to wear many hats…We reached out to regional support associates, but the waiting list there is sometimes two years and with grief counseling you need...fairly soon we can't leave it too late, especially if it's a recent death in the family. Beyond that, we've tried to get other counsellors. Mind you, it's, there's an expense.

For Carol, a support worker in another small community, for her clients “there's a three-year wait list for people if they felt they needed counselling”. This is related to cutbacks to funding for community-based counselling agencies which increases their wait lists, as well as a lack of counsellors familiar with and/or trained to work with people labelled/with an intellectual disability.

Cara: Do you find that there are counsellors around who have experience working with folks with developmental disabilities?
Earl: Not locally, no. [Larger city] would be the closest for us, there isn't really anybody in this area…it is hard in our area for sure.

Urban. Key informants who work for organizations that are either in urban centres or have multiple locations of service, tend to have more potential for collaborative support – between different locations of the same organization or with other, close-by services. For example, Evelyn shared, “we lost [to death] four individuals in a very short span of time. And our resources were depleted. So, someone [from another location of the same organization]…came to help us process…sharing…support”. Both of the urban, larger organizations where two key informants worked had their own grief support programs for the people labelled/with intellectual disabilities that they support (described below under Grief Education).

**Frequency of Deaths Increasing and Ageing**

As shared in Chapter 2, people labelled/with intellectual disabilities are living longer now that institutions are closed, and medical care (access to and interventions) has improved. Thus, as the population of people labelled/with intellectual disabilities age (much like the current ageing issues within the neurotypical population) more people are outliving their parents, siblings, and friends. Earl shared that organizations are encountering grief and mourning “…more than we have before, because a lot of the people we support are getting older”. For those people labelled/with intellectual disabilities who live in group homes or congregate care, they may have had roommates in their lives for many years and have functioned much like a family over this time. Their grief and mourning can be exasperated when the organization must “fill the bed” of the person who died within a certain time frame based on government ministry regulations. Kathy shared “it is very difficult for them. I've heard of people we support just
wandering into the person's [who died] bedroom...just sitting there or just looking and when it's occupied by somebody else. How does that make you feel right?” Evelyn discussed the role for managers as advocates in this type of situation:

Evelyn: Someone died last December and their bedroom, we usually advocate to the Ministry now because the Ministry likes to fill the vacancies, but we advocate for a time where that bedroom remains uninhabited. So that there can be that sense of this was that person's space and then eventually we start to clean out. Give away the things that person treasured and that helps the people in the home to let go,

Cara: I suspect it would also help the next person coming in as well that it's not so quick and that the person's just erased and gone.

Evelyn: Exactly, you can welcome them a little more openly...we have had times where it was rushed. We were under pressure, and we had to rush it and then it became well you're in that person’s bedroom and that's not [ok]. It's tricky but we do our best, it used to be where you had more control over that but now...they do want you to fill the vacancy. And meanwhile we have advocated to the Ministry, and they have respected us. To recognize the reason for the vacancy and the effects it’s had on folks.

Carol, a support worker participant, discussed the link between waitlists for people labelled/with intellectual disabilities to move to a group home while living with ageing parents and the crisis that ensues when the parents die before a placement has been secured for the person labelled/with an intellectual disability:

The unfortunate part is that [this] is not really a unique situation as our population ages, right? People who have been looking for group living wait on waitlists for 20 years and end up in a family home where, you know, Mom and Dad are so elderly or health-wise
and something happens. And that's when they get their placement as opposed to having it be a nice transition to be able to, you know, go visit mom, and those kind of things, while the parents are still healthy enough to be able to support that transition and independence. Yeah, but group living vacancies are so few and far between that that's who gets the spots now [the people labelled/with intellectual disabilities in crisis].

**Grief Education**

Grief education of staff and for people labelled/with intellectual disabilities is sadly lacking. As Esther shared during her interview, “they [staff]…need to realize that death is a hard thing, especially when you have a developmental disability. Cause I take time to process things”. Carol works for the only organization (in this sample) that provides a one-day grief education workshop for their front-line staff – and it is optional, not required. As a follow-up to this one-day workshop, staff who work with a person labelled/with an intellectual disability who is grieving can attend 1.5-2-hour arts-based bereavement group together with other bereaved people labelled/with intellectual disabilities and their paid staff.

Oh, there's a lot of hands-on, we talk about the life cycle of a butterfly…as we’re colouring and as we're talking…oftentimes we'll just chat and we'll go through 'okay, what is it that you have experienced?' and I can contribute to that too right like what is it that you have experienced 'how, what have you done?' Like we have those conversations, it's very conversational but at the same time we're doing hands on stuff right? Coloring of the butterfly or drawing the mask or umm…what other things do we do? We do names name tags and just talk…it's very therapeutic just for people to just talk about it. And I've had participants who don't use words to communicate, but they’re still participating in the artistic piece of it and in are still very interested in what's going on because they could
have easily left the group and they didn't. So, I find that I think just opening up the
dialogue. However, that looks like for the person, is really good.

Many front-line staff at these organizations do not come with a formal education in
developmental services, social work, or social service work, never mind exposure to
contemporary grief theories and supportive practices for bereaved people labelled/with
intellectual disabilities. Earl shared that even workers who have a Developmental Services
Worker diploma (DSW) have not had education about grief and mourning. Phyllis, who is
Margaret’s support worker, is educated as a Personal Support Worker (PSW) at Earl’s
organization, and she shared that, lacking the opportunity for formal grief education, she
supports people experiencing grief through instinct and her personal style. Evelyn shared:

I find because [the organization] attracts young people…to work with individuals. I find
that the knowledge they gain is through the experience. For some, it may be their first
time to face the death of somebody or to even be in front of a loss. And it's very possible
that people come not having experienced the death of a significant [person]. So, there is
the need for support in particular ways…I've gone into teams and talked with people.

I became curious about whether key informants noticed any tension between staff trained
in Applied Behavioural Analysis (ABA) and how they might approach grief.

Cara: If people are trained [only in ABA], do they…miss that, emotional, spiritual,
physical grief, piece? Or make the connection [between behaviour and grief]?

Kathy: They certainly can miss making that connection. It's not always that way. It really
depends on the staff person and the kindness that they've experienced in their life. And if
they have a holistic view…then they're going to approach it holistically. But…lots of
people don't and then they're approaching it analytically instead of the whole picture. So, there is a tension there, it can work together well, if you approach it properly.

Grief education opportunities for people labelled/with intellectual disabilities and/or their families were not formalized in any of the organizations connected to the bereaved participants. Evelyn shared that in her organization there are traditions throughout the year to mark certain changes: “…for purposes of this particular topic around grief and loss…we have certain traditions in our community that we would follow, and that people would pretty much be able to connect with quickly” if they experience a death.

I had the opportunity to conduct a joint interview with Arthur and a key informant, Barbara. I arranged this interview as I had learned from Arthur, during his interview, that he and Barbara had provided grief education to DSW classes at an Ontario college on a few occasions. This came about because Barbara had a family member who worked in the program. Arthur and Barbara had first met through a grief support group she developed and facilitated within the organization that Arthur was connected to. Arthur wanted students to learn from his grief experience related to the death of his mother:

Arthur: It was hard but...yeah…they [my family] said it was too hard for me and...I said I’d rather face the pain than hide it. I can't believe I actually said that... It was like…I surprised myself and I was like, whoa. It surprised me... 'Cause I didn't think I was that kind of person.

Cara: The kind of person that…what?

Arthur: I'm learning to speak up for myself, which I couldn't do in the past. [Arthur was institutionalized from age 4-24]
Cara: So, you didn't think you were the kind of person who could say what you needed and mean it and have it happen?

Arthur: Yeah, it took me a long time to do that.

Arthur was clear in both of his interviews that helping others was meaningful for him and he wanted to share with students how he supported one of his workers after their sibling died:


Cara: What did you do?

Arthur: Um...I just stood next to him. I didn't know what to do, so I just stood next to him.

Cara: OK, to show your support?

Arthur: Yeah.

Barbara: You went to [name of city] with [worker], right?

Arthur: Yeah.

Cara: That's where his [sibling] was?

Arthur: Yeah. And [worker] answered all the questions. I kept my mouth shut on this one.

Barbara: And [worker] said it was very helpful 'cause you spent time with his mom and his dad.

Arthur: Yeah.

Cara: Was [worker] part of your presentation [to the students] as well?

Barbara: Yeah. I think as we talked about...one of the good things...[was] that it was important to be able to help other people too and not just to be helped all the time.

[Worker] is very articulate about how dear or important that was for him, you know. That
Arthur was there…I think it confirmed for both of you…the mutuality is affection. So, you could really help each other.

Arthur: Yeah.

Barbara: I think that solidified your relationship, eh?

Arthur: Yeah, and I also helped him with his...when he couldn't speak to his father and...I helped him in that too. They were gonna send [another worker] down...but they sent me instead. And I didn't know what to say to him. So, I just stood next to him and...

Barbara: Mostly what people need is just someone to be there, right?

Arthur: Yeah.

Barbara was quite talkative in our interview, and I worried that Arthur was not having as much opportunity to share his views about the education and support he has offered in partnership with Barbara, so the following conversation came at the end of our interview:

Cara: So, Arthur, to give you the final word. What else that we maybe haven't talked about would you add to your experience of teaching folks about your experiences of grief and loss? What was most important for you doing that?

Arthur: Um...Just getting to know others and...plus, getting to know who I am as a person.

Cara: Getting to teach others like you said.

Arthur: Yeah, which is something I always wanted to do [he wanted to be a teacher when he grew up]…it took me a long time to do that.

Cara: I suspect, though, the teaching that you've done…has helped these students go on to support so many other people and recognize…their needs and their strengths.

Arthur: Yeah
Cara: So, you made a big difference.

Arthur: As long as you live on this planet, you're not, you're never too old to learn. And if there's something...that I said that's hard...I always talk to the person that you're dealing with...that's another thing I learned.

Cara: Tell me some more about that. What do you mean?

Arthur: When I was younger...if I did something bad, they would go to someone else and talk to them...and that's just before I came here...you gotta speak to the person...the only way you can get to know people is just to spend time with them.

**Experience**

**Personal.** The key informant and support worker/parent participant sample is small, but it remains interesting that two of the four key informants identified as bereaved parents. Earl shared that when it comes to supporting people labelled/with intellectual disabilities who are grieving:

Personally, I've tried to help people when I can too...Certainly my faith has helped with the grief in our family...'cause I lost a [child] so I know...grief does come in waves, and you need something to help you through and my faith is certainly helped me. But because we're [a] small [agency] I can't help everybody [laughs].

Kathy also shared her personal loss experience during our interview:

When my [child] died, the people [labelled/with an intellectual disability] that I worked with many years ago, [staff] brought them to the visitation of my [child] and it was one, [laughs] one of the people I supported she went right up to the casket and touched [child], and looked at me and said 'dead?' You know...that's not something that they probably had ever experienced is seeing someone lying in a casket. So, it was an interesting
experience and I just remember that because it was significant, but the fact that they were
there even was pretty amazing and I give kudos to the to the staff, who brought them in
support [of me].

Personal experience with loss seems to enhance awareness in staff and management. As noted by
the bereaved participants, having people available to talk to who are comfortable talking about
death and grief is important and helpful. The grief support available in organizations often
depends on the support person’s ability to recognize grief apart from behaviour and their comfort
level talking about death and grief. When asked why she created the bereavement group at her
organization, Barbara shared:

…it was just something I personally was interested in…for whatever reason…[it] wasn't
like people said 'OK, you do this'. I think it was at a point when [organization was]
around for a while so there were a number of people [we supported] who were dying. A
lot of peoples’ families were dying, so…we were really in front of it, right. A lot of
people getting older right? And their needs changing. I think people were naming
grieving as a behavioral issue…they would name it as behavioral issues and not grief,
right? So [they] would approach it as something totally different…people are being really
anxious and they won't stop talking about it…they would set up programs to try to do
other stuff, right? But it's not…intentional, but just not making that connection [to grief].

Professional. All key informants have worked long-term in the field (25+ years each),
and they all identified the necessity to better recognize the grieving needs of the people they
work with. Their interest in this topic and gaining further information from participating in this
research to enhance their services was a motivating factor in engaging in my research. Working
for a long time in the field has provided the key informants with a broad understanding of shifts
in needs, areas to focus on in service provision, and how personal comfort in talking about grief relates to professional support of people labelled/with intellectual disabilities. Kathy shared the following in relation to the COVID death of a service user within her organization and the resulting complications for staff and subsequent service user grief:

I do find the [organizational] processes [for communication] get in the way in red tape and…that's very sad. And that causes the employee, you know, causes angst with employees as well. And if they don't feel supported and they're not feeling like they can grieve properly and then the spot becomes vacant and you have to fill it, you know, it's tough. Because the staff are inhibited with their own grief. How can they support people…who live in the home? How can they support them through their grief because they're all consumed with frustration and anger?

Kathy speaks well to systemic issues and how organizational policies (often linked to broader Ministry policies) and actions affect staff, which in turn affects the service user (people labelled/with intellectual disabilities) at a time when social support, good communication, and compassion are most needed for everyone affected by the death.

**Reflexive Journey: Making Space to Explore Emerging Tensions and Connections**

I am choosing to share parts of my reflexive journey in this chapter as they represent a separate, yet connected, piece of data, that for me, act as a bridge between the findings from the research participants and how I was navigating the research project and making sense of the data collecting and analysis process. Throughout the research project I maintained the practice of engaging reflexively with interview content and process, noting insights that came as I digested the interviews in consideration of the literature, my own practice experiences, and new
information that came to my attention. Documenting what was happening to me subjectively, how my beliefs and assumptions might be informing/interfering with data collection, and how my thinking may be changing became informative as my interviews progressed and as I engaged in data analysis, developing themes, and reporting on findings (Thorne, 2016). After each interview I completed a reflexive note (as discussed in Chapter 3, format can be found in Appendix F), all of which were revisited individually and collectively for consideration during the data analysis phase. As I reviewed interviews, transcripts, and engaged in thematic analysis, I noted my reflections on participant interviews as they were situated in the whole of the data, as well as broader connections I was making that act as a bridge, connecting the findings to the literature and practice. For example, noticing times when I experienced tensions between my role as a researcher and my identity as a social worker. I wrote the following after my interview with Butterfly:

I tried to bring the conversation back to the death of her grandmother, but she also needed space to share the loss of her [child] to adoption and her trauma history. I believe my clinical skills, trauma-informed approach, and comfort in engaging in difficult conversations allowed for appropriate disclosure while not completely going off topic. I found it important to validate and normalize reactions that she shared as I would do during any therapeutic conversation – was this wrong?

The reflexive process assisted me in maintaining attention to my research role, while also noting the importance of my clinical skills and therapeutic approach to a difficult topic, without crossing the boundary into therapy. The use of my clinical skills (e.g., active listening, validating, paraphrasing, use of self, warmth, acceptance, non-judgmental attitude) and subject matter knowledge (e.g., grief theories and models, disability perspectives, practice models and
interventions) in preparation for, during, and after interviews allowed for me to collect significant data while also causing no harm to the participants. In fact, none of my participants were unable to complete their interview due to being overcome with emotion, memories, or other challenges, and were in fact grateful for the opportunity to share their loss experiences and reactions. Simon enjoyed his interview so much his support person sent me a photo of a picture he coloured for me after our interview:

![Coloured picture](image)

I also made note of information that surprised me. For example, after my interview with Esther I reflected that she “shared that if a mutual support grief group were available to her, she would want it to include others [labelled/with intellectual disabilities] but they would need to be as ‘smart’ as her – I wasn’t expecting this type of exclusionary thinking”. Whether or not this reflection would influence my overall findings was unknown to me at the time I made this reflection. I did not have any other participants discuss the cognitive ability of others as being significant to whether they could share with them or not (in a group or otherwise).

Margaret brought forward the experience of family estrangement after the death of parents – something I had not previously considered but had played a significant role in her ongoing coping with grief related to the deaths of many family members. Reflecting on what Margaret shared and noting the effects of family discord in her grief journey resulted in this issue being explored with other participants (if relevant). My reflections then also became moments of
learning, which aligns well with my approach to this research – that first and foremost people labelled/with intellectual disabilities inform what others need to learn from their experiences in order to be better professionals, family members, and friends.

As I mentioned in my introduction to Layton, he is a “man of few words”. After our interview I made the following observation:

Layton is not emotionally expressive as he prefers to keep things inside and think about them. For me, this challenges the notion that grief includes notable behavioural and emotional expression and supports that all grievers (labelled/with an intellectual disability or not) react differently (related to personality? grieving styles?). This interview has me thinking about ‘emotional literacy’ related to grief and loss for people [labelled/with intellectual disabilities] - maybe Layton didn’t express emotions because he couldn’t connect descriptive words to his thoughts and feelings.

Whereas, after my interview with Simon, who experienced multiple losses after his mother died, I noted:

One thing that stood out for me after my interview with Simon was the effect of cumulative losses – when everything becomes unfamiliar and the losses so widespread, it’s hard to know what/how to grieve. However, he uses very descriptive language and metaphors when describing his grief. Without having any outlet to share and process his grief, Simon became “destructive”. In addition to the deaths of his parents and beloved dog, Simon also experienced the loss of his home, familiarity, the family car, neighbours, and other family members – he felt “abandoned”. He stated very early in the interview, “I have abandonment issues”. He (and his support person) shared that anger, frustration, and negative self image developed from these issues (I wondered if they had been there
previously as well given the challenging environment he had been living in). The interview with Simon highlighted the wide range of emotions he experienced and the difficulties he had in expressing them verbally, so some came out in harmful behaviour.

Once I had completed seven bereaved participant interviews, and reflected on colleague and Laurier’s Research Ethics Board (REB) worries that this research might be too upsetting for participants to engage in, I noted the following:

So far, after 7 interviews, this process hasn’t appeared to be emotionally overwhelming for any participant and I have not had any follow-up from support people to indicate that it was, either during or after the interviews. REB had numerous concerns about this (rightfully so) as did some organizations and other individuals who thought that it may be too sensitive a topic to explore with people labelled/with intellectual disabilities. Why might this be happening? Is there an assumption that people labelled/with intellectual disabilities can’t manage emotions of grief and loss? Is my preparation and clinical experience helping? Are frequent check-ins during interviews helping? Is it related to how people labelled/with intellectual disabilities (my participants) process the loss? I have found my participants, so far, to be very generous with their sharing, open and honest about their experiences, and quite wise and thoughtful.

Further to this, I want to acknowledge the compassion shown to me by the bereaved participants; some of whom checked in with me during the interviews, asking questions such as “have you lost someone?” and responding to my check-ins if they were “doing ok” while sharing, with asking me how I was coping with hearing what they were sharing.

After my interview with Arthur, I made some connections to trauma as expressed by participants before him, and his experience of being institutionalized:
Arthur highlighted for me that the past trauma of institutionalization in general, the specific abuse he endured, and sense of self and others significantly impact grief. Past abuse deeply affected Arthur’s abilities to trust, share with, and care about others. The loss of a parent or support person challenges feelings of safety and care that may already be tenuous.

Further to this reflection I noted: “past institutionalization, mistreatment, and lack of family contact ‘colours and flavours’ everything related to his loss experiences”, which I think was an important reflection related to loss histories, past trauma, grief reactions, and coping with grief. I also made notes regarding dreams and extraordinary experiences/visions as this became a topic shared by more and more bereaved participants. I noted that Gilbert brought forth that family communication about death and grief can also lead to discussion of the end-of-life wishes for the person labelled/with intellectual disabilities.

The practice in engaging in these reflexive notes provided space to start to make some connections between experience, context, and practice. For example, after my interview with Wayne, where he and his mother described one of his primary reactions to his brother’s death as becoming “obsessive”, I noted:

Wayne’s (and his mother’s) descriptions of the “obsessive” aspects of his grief made me wonder if it could be reframed as slower processing or reality checking. This could add knowledge to practice in that ignoring the “obsessive” thoughts/behaviours/feelings doesn’t stop the ruminating, rather, patience and ongoing dialogue with re-direct could be more helpful than ignoring the “obsessions” or fast re-directions. Can support people/practitioners acknowledge the “obsessive” thoughts/behaviours/feelings and re-direct without closing the opportunity for further discussion and processing?
A further connection between experience, context, and practice started to emerge in my reflections as many participants (across categories) were noting that people labelled/with intellectual disabilities want to help others who are grieving and not always only be the recipients of care. After my interview with Isabella, I wrote that her “desire to help others is based in her loss experiences and this also connects with other participants who find meaning in helping others”. This reflects directly back to the literature related to meaning making (Gilbert & Macpherson, 2021; Neimeyer, 2001; Neimeyer et al., 2014) and post-traumatic growth (Tedeschi & Calhoun, 2004) while demonstrating that people labelled/with intellectual disabilities can experience deep meaning and growth from loss in their lives.

Summary

This chapter has introduced you to the participants of this research, first through short descriptive paragraphs of the bereaved participants and support people, followed by a chart outlining the key informants and their organizations. I intentionally centered the losses and stories shared by the bereaved participants because, as I have stated previously, their lived experiences of loss, grief, and support need to be the basis for any type of informed support and/or intervention suggestions that come from this research. Of course, the context within which people labelled/with intellectual disabilities live and receive bereavement support is an important consideration, some of which was explored with the support people and key informants.

The themes and subthemes from the interviews were presented along with illustrative quotes from the research participants and were linked to the overarching research question while also emerging throughout the data analysis process. The overarching themes included: encountering loss; background context influencing grief; managing grief; healing grief; and
organizational contexts. These themes and their related sub-themes captured much of the rich descriptions of loss and grief within the lives of the bereaved participants. I chose to add examples from my reflexive notes in this chapter as I believe they are relevant as another data source from this research and document not only how I was processing the content and meaning of the data across time, but also how I navigated tensions in my roles, expanded my enquiry, and started to link my findings back to my research questions and the intersecting literature of grief in the lives of people labelled/with intellectual disabilities.

The next chapter provides the opportunity to discuss the findings within consideration of the literature presented in Chapter 2. The chapter will begin with an illustration of the interconnected complexities of the experience of grief followed by a discussion of my interpretations of the findings as related to theory, approaches, and practice. I will then explore the key implications of the findings, in general for the field of grief and intellectual disability, and then specifically for social work education and practice (and other professionals working within the developmental services field). Limitations of the research project will be discussed followed by a plan for sharing the findings and recommendations from this research (knowledge translation). I will share recommendations that emerged from engaging with my participants for improving the understanding and support of grief in the lives of people labelled/with intellectual disabilities.
Chapter 5: Discussion and Conclusions

The overarching question that guided this research is: In what ways do people labelled/with intellectual disabilities experience grief after the death of a significant person in their lives? The use of an interpretive description approach to this research question means that the interpretation of the findings is primarily for the purpose of application to practice, rather than theorizing (Thorne, 2016). The dual purpose of this research is to better understand (and help others understand) the complex experience of grief after a death for bereaved people labelled/with intellectual disabilities, and, from this understanding, develop ideas for how social workers (and other professionals and support people) can provide meaningful and helpful grief support. Developing a better understanding of this complex experience through this research is also an effort to bring loss, grief, and mourning out from the shadows of the lives of people labelled/with intellectual disabilities (Clements et al., 2004) and bring it out into the open where loss can be acknowledged, grief can be expressed, and mourning engaged in meaningfully with helpful support in place. Through individual interviews with people labelled/with intellectual disabilities, support people, and key informants (managers in developmental services organizations) and my qualitative analysis of the data collected, participants provided insights relevant to the research question and pre-existing literature on the topic that have implications for understanding the intersection of grief and disability for practice. This chapter aims to make sense of the findings, through re-examination and interpretation, within the context of the known literature, approaches, and practices previously discussed (Thorne, 2016).

This research project was aimed at better understanding the grief experiences of a group of people labelled/with intellectual disabilities – their individual reactions, the support they receive and/or need, and how loss and grief are understood and supported (or not) within the
organizations that support individuals labelled/with intellectual disabilities. It has been established that grief is an expected and adaptive process after a loss, yet there remains ongoing misunderstanding, stigma, and pathologizing of grief reactions for many people, regardless of ability (Corr & Corr, 2007; Gilbert & Macpherson, 2021; Lord et al., 2017; Morse et al., 2016; Winokuer & Harris, 2012). The findings of my project demonstrate that although many of the grief reactions (emotional, cognitive, physical, behavioural, social, and spiritual) experienced by the bereaved participants are similar to those of the neurotypical population (see Table 2, Chapter 2, Examples of Possible Grief Reactions Across Multiple Domains) there remain significant differences in a number of areas that have implications for practice and education. To illustrate the interconnected and complex nature of loss, grief, and mourning experiences, as shared by the research project participants and presented in Chapter 4, I have created the visual below (Figure 4).
Although there is a great deal of data that emerged from this research that speaks to the nuances of the experiences of grief, in this chapter I will discuss my interpretations and implications of the findings across three general themes: encountering death, living with grief,
and grief in the organizational context. Following this section, limitations of the research will be discussed as well as plans for knowledge translation. The chapter will end with my final conclusions and final words from one of the bereaved participants.

**Interpretations of the Findings**

It is essential to note that all the bereaved participants shared losses (death and non-death) that are inseparable from the death specific grief reactions they shared. Meaning that, as will be discussed, prior trauma and losses have a significant influence on grief after a death and need to be considered when observing, assessing, and intervening in the domains of the emotional, cognitive, physical, behavioural, social, and spiritual worlds of people labelled/with intellectual disabilities (Kauffman, 1995; Rossiter & Rinaldi, 2019). As I noted in my reflexive notes shared in Chapter 4, past experiences of trauma, abuse, and exclusion are integral considerations that influence grief when a death occurs.

**A) Encountering Death:** “You never know how [you’re] going to react when you lose a loved one” *(Wayne)*

**A1) Grief Reactions.**

People labelled/with intellectual disabilities are living longer and thus encountering the deaths of family members, friends, and staff in significant numbers (Thorpe et al., 2020; Tuffrey-Wijne et al., 2017). This, combined with the lack of grief education and awareness for many people labelled/with intellectual disabilities and their support people (Morse et al., 2016), can lead to increased pathologizing of grief reactions across multiple domains of life. As discussed by the paid support workers and key informants for this research, and echoed in the literature
(Lord et al., 2017; Morse et al., 2016), education about grief is not provided for people
labelled/with intellectual disabilities and their paid staff. The recognition of the role of grief in
the lives of people labelled/with intellectual disabilities seems to primarily occur due to a
personal experience and/or interest of staff rather than as part of their training. The lack of
awareness many support people have of the numerous and nuanced reactions that can accompany
loss, while also being unaware of the influence of past losses (Kauffman, 2005; Lord et al., 2017;
Morse et al., 2016), within the context of highly managed day-to-day life for many people
labelled/with intellectual disabilities, contributes to diagnostic overshadowing (Cheetham &
McMillan, 2020; Mullins, 2020). This means that rather than being seen as a person capable of
attachment relationships and grief related to the loss of the attachment, the different
emotions/behaviours demonstrated by the bereaved person labelled/with an intellectual disability
are not understood as linked to expression of grief or reaction to loss(es)/trauma but instead
treated as if they are manifestations of the disability. This leads to seeking professional
interventions/treatment/diagnosis rather than employing psychosocial approaches such as
listening, companioning, or validation. For example, Phyllis (support worker) shared the story
about an elderly person she works with who experienced the death of their only sibling (in
Chapter 4, p. 173). This person is aware that their sibling is dead, but often talks to the sibling
about their day as if they are in the room – this provides them with comfort and a sense of
connection. However, Phyllis shared that other staff will quickly redirect the elderly person in
fear that they are being delusional, which is upsetting for the elderly person trying to maintain a
connection with their deceased sibling. Thus, what is an act of mourning and an expression of
grief for this elderly woman is pathologized as inappropriate behaviour, shutting down what
could be a meaningful ongoing bond that could become part of this person’s adjustment to the
loss of their sibling’s physical presence. If this behaviour is not harming anyone, does it need to be managed and redirected? Furthermore, there is a risk that what may be considered delusions are medically treated as such, and medication is then prescribed intended to alter the delusional behaviour without consideration of the relationship of the behaviour to the elderly person’s grief and their continuing bond with their deceased sibling.

Even if people labelled/with intellectual disabilities are not reacting in overtly different ways than the neurotypical population and they are engaging in the adaptive responses related to their grief (Harris & Winokuer, 2021), how their reactions are responded to by those around them can be vastly different when they are in a system of care such as a group home or congregate care setting. For example, participants noted information being withheld from them, experiencing surveillance of their behaviours/reactions in communication books for others to read, and exclusion from mourning rituals. Bereaved participants’ experience, in this sense, reflects epistemic violence as discussed in Chapter 2. The bereaved participants describe being deemed ineligible as knowers of information vital to their own lives in an effort to ‘protect’ them from upset (Liegghio, 2013). Organizations have a responsibility, both to resist pathologizing intellectual disability and to restore epistemic existence, which will be discussed below (C1).

A2) Loss and Trauma History

The bereaved participants in this research, although expressing many reactions similar to those of the neurotypical population (as also illustrated in the literature), have notable differences in terms of trauma histories, cumulative losses (including secondary losses), and having gatekeepers of knowledge and controllers of expression (paid staff within particular environments) (Read, 2014). Past histories of institutionalization, abuse, trauma, loss of self, loss of many caregivers (paid staff), family estrangement, and loss of children to adoption were all
momentous past losses that influenced how the bereaved participants experienced the grief related to the person(s) who died. As noted in my personal reflections, this past loss history “colours and flavours everything” in the lives of people labelled/with intellectual disabilities.

When loss histories are unknown to current support people, individual reactions to a death may appear to be out of the ordinary and misjudged (Kauffman, 2005). Moreover, this led to some internalization of pathologizing language as participants described their grief reactions as, for example, becoming “obsessive” (Wayne) and creating “abandonment issues” (Simon). Kauffman (2005) suggests that a client loss assessment should occur with all new clients (service users) of an organization. The loss assessment, which includes deaths, lost relationships, and other changes (see Appendix B), provides a narrative of the past losses, the unique reactions, and the adaptive process(es) the person has experienced throughout their life which can then inform support people about these losses, how the person copes, and significant dates/times of year that may be difficult for them.

A3) Communication Abilities

The ability to communicate our feelings and experiences varies within the neurotypical population. This is also true for people labelled/with intellectual disabilities (Koudys & Spottiswood, 2020). All but one of the bereaved participants used spoken words to communicate and were able to share their thoughts, feelings, and experiences verbally. One bereaved participant used a communication book, sign language, and short verbal utterances to communicate. All bereaved participants had differing abilities to label, interpret, and articulate their experiences yet all were very clear that despite ability, their losses and grief require acknowledgment and compassionate support. Difficulties can arise when gaps in communication exist. As noted by Koudys and Spottiswood (2020),
Sometimes people are not able to request their preferred activities or items, or to reject non-preferred ones. Sometimes emotions or pain cannot be expressed, and meaningful social interactions cannot occur [leading to frustration]…frustration can lead to unwanted and challenging behaviours, such as kicking, biting, hitting, yelling, and throwing objects. (p. 481)

When these communication challenges arise, staff and support people need to consider the reasons the behaviour may be happening, what the person may be trying to tell them, and determine how they might be able to assist the person labelled/with an intellectual disability communicate their emotions and/or needs in a safer way (Koudys & Spottiswood, 2020). During the interview with bereaved participant Wayne (with his mother present for support) it was clear that, at times, he repeated what his mother shared rather than using his own words to describe his experiences. When she related this tendency to Wayne’s grief experiences after his brother died, his mother, Giselle, shared the following observation and approach:

[His brother] dying made him experience emotion that he didn’t know to put the names to. Sometimes he had a hard time naming the emotion that he feels. And it’s too easy for me to tell him how he’s feeling. So, I have to let him speak. Because if I tell him how he’s feeling then he’s going to immediately say, that’s how I’m feeling.

Providing time for people labelled/with intellectual disabilities to share their grief through whatever means they communicate is crucial for their well-being and sense of social support as they experience the layers of grief that accompany the death loss. Providing opportunities for sharing the narrative of the loss(es) is known to be helpful for many bereaved people as they adapt to the loss and engage in meaning reconstruction (Gilbert & Macpherson, 2021; Neimeyer et al., 2014). When bereaved people labelled/with intellectual disabilities, as
demonstrated by the bereaved participants in this research, are provided with space and time to personally narrate their stories in a social setting (whether one-on-one or a group), using whatever means they typically use to communicate, the bereaved can express ongoing grief reactions, explore their ongoing relationship with the deceased, and share their personal learning from the loss. This can occur using co-created approaches such as art, music, poetry, life story creation, photographs, memory box, watching a movie, and other ways that are meaningful for the individual labelled/with an intellectual disability (Read, 2014).

**A4) Grieving Rules**

An ableist lens looks at grief reactions as situated within the individual, with the individual having choices as to what/how to express (or not) within the context of social grieving rules such as, who is allowed to grieve, for how long, and acceptable expressions of grief (Harris, 2009). These social rules, when applied to the grief and mourning experiences of people labelled/with intellectual disabilities, need to be considered carefully. What are the social grieving rules within a system of care (e.g., group homes, congregate care) where behaviour is monitored, and routines and daily consistency are of high importance and usually determined by staff members? In what ways can organizations facilitate the inclusion of people labelled/with intellectual disabilities in mourning rituals for the deceased (for example, providing transportation to a funeral out-of-town)? I suggest that currently, there is little flexibility within the expectations of routine and behaviour monitoring for the unpredictability and potential messiness of grief, and that this is one contributor to the pathologizing of grief reactions that disrupt daily routine. Furthermore, financial constraints faced by organizations affect the ability to provide transportation and/or staff accompaniment for out-of-town visits to family and/or mourning rituals such as funerals.
A5) Disenfranchisement

In the context of this research, participants do not appear solely as disenfranchised griever (Doka & Chow, 2021) within their social circles/organizations, as they had people who recognized the experiences and implications of loss, grief, and mourning in their lives. As will be addressed in the Limitations section, the bereaved participants in this project can be assumed to be recognized as griever because they were provided with the information about the project through the organizations that I contacted. Nevertheless, aspects of their experiences can be considered disenfranchised, such as being protected from getting information about an illness or death right away (Read, 2014) and/or not having access to transportation to attend a funeral. However, the experience of disenfranchisement remains relevant for those not involved in this research project as they can be involved with family, support people, and/or organizations that do not recognize people labelled/with intellectual disabilities as griever. Key informants shared examples of people labelled/with intellectual disabilities not being told about the death of a parent. For example, when siblings decide they should not be told as the assumption is the person labelled/with an intellectual disability could not handle the news of the death and would become overly upset if told. Organizational staff must follow family wishes when family acts as the substitute decision maker, although it is organizational staff who then must manage with the daily effects of this decision. No consideration was made by family that the person labelled/with an intellectual disability would likely notice changes in visits and/or their environment and likely grieve this change despite not knowing the cause.

Considering a broader systems perspective, the ongoing marginalization and oppression of the population of people labelled/with intellectual disabilities will maintain disenfranchisement through a broader ongoing lack of personhood status and citizenship rights
(Carey, 2009; Clements et al., 2004). Disenfranchisement is related to disablism of grief when the physical/emotional/cognitive/behavioural/social/spiritual norms of grief against which the neurotypical population is measured (Harris, 2009) are misapplied without consideration of differences and variations for people labelled/with intellectual disabilities. Ableist attitudes and disenfranchisement impede the healthy unfolding of the adaptive process of grief (Harris & Winokuer, 2021), instead containing it and closing off the possibility of people labelled/with intellectual disabilities having rich and meaningful loss experiences, as well as being able to contribute knowledge and support to others who are bereaved about this essential human experience. Ableism entitles certain people (professionals/staff/families/community members) to be the holders of knowledge with powers to intervene in what are often typical reactions to a significant loss that are not fitting well within the context of care and control in many spaces of care. As illustrated by the findings from this research, people labelled/with intellectual disabilities have significant experiences of loss in their lives, from which they have learned noteworthy life lessons that can enrich the lives of others when they are recognised as legitimate grievers and provided opportunities to share and support others who are grieving.

B) Living with Grief: “There's not a lot of support out there when it comes to grief” – Esther

B1) Coping with Grief

To effectively cope with the myriad of reactions and changes associated with loss and grief (Corr et al., 2019; Doka & Chow, 2021), the bereaved first need to be recognized as grievers within their social environments (as discussed above). Research has demonstrated that when the bereaved have sufficient social support and they develop effective coping strategies, they tend to adapt to the loss without professional intervention (Doka & Chow, 2021; Jordan &
Neimeyer, 2003; Harris & Winokuer, 2021; Wolfelt, 2016; Worden, 2009). However, those who are disenfranchised will not receive effective understanding and support which may lead to individual challenges within an unaccommodating (or grief illiterate) environment as they try to cope with the myriad of reactions related to their experience(s) of loss. This elucidates the pathologizing of grief reactions for many people labelled/with intellectual disabilities and suggests attention must be paid to the environment within which they are trying to cope with grief rather than the focus being solely on the individual’s reactions and the subsequent quest for the professional treatment of these reactions.

As illustrated in the thanatology literature, just as everyone will have unique experiences with grief after a loss, the ways individuals cope and adjust after a death will vary. Furthermore, how the person labelled/with an intellectual disability has coped with challenging things before in their life needs to be considered before moving quickly to pathologizing reactions and seeking professional intervention. As shared by the bereaved participants, coping with their grief looked different for different participants at varying times in their journeys. Some tried to cope through re-visiting the loss, through destruction of objects, through painting, through talking, and through staying quiet. How a bereaved participant coped (adapted to the changes) appears connected to both their past coping abilities and the level of relational compassion and understanding in their current environment (Stroebe & Schut, 2010, 2016). For example, when Fraser needed to re-enact the day his father died, his mother was willing and able to walk him through the day whenever he needed as he tried to understand and cope with the death. On the other hand, for Raju, his siblings want him to “move on” and “forget” their parents, shutting down his attempts at coping aimed at continuing the bonds with his parents. Furthermore, Raju had lost trust in his relationships with some of the support people in his environment, which then limited his support.
network for coping with the deaths of his parents. The literature related to coping with grief has little to say about the application of the dual process model of coping with bereavement (Stroebe & Schut, 2010, 2016) to people labelled/with intellectual disabilities and does not provide other coping ideas specific this group of people. Besides one bereaved participant who attended a grief support group and learned some specific coping strategies from this group (e.g., mindfulness), the bereaved participants coped in ways that either they had used previously during challenging times and/or that people in their circle of care had suggested (e.g., colouring, walking, talking).

For people acting as supporters for the bereaved person labelled/with an intellectual disability, it is important that they consider ways of coping that are meaningful and accessible for the individual and promote acceptance of a variety of reactions.

**B2) Family**

As noted by Walsh and McGoldrick (2013), “death [of a family member] poses immediate and long term adaptational challenges for families” (p. 21). Family relationships prior to and after a death are significantly related to how a person labelled/with an intellectual disability will cope with their grief. Family systems and the relationships within that system, past and present, play a significant and complex role in how the bereaved person labelled/with an intellectual disability will respond to a loss and experience grief (Doka & Chow, 2021; Walsh & McGoldrick, 2013). For some participants, family relationships had been close and maintained throughout their lives, and this did not change after the death. This was evident for participants such as Fraser and Wayne, whose surviving parents have been highly involved throughout their grief journeys, including them in rituals and facilitating expression of ongoing grief as well as continuing bonds. For others, previously strained relationships grew worse, and family estrangement was evident for some participants. Some parents had acted as ‘relationship brokers’
between their children when alive and when this role was no longer fulfilled after their death(s) and family conflict ensued, this challenged how the person labelled/with an intellectual disability coped. For example, the estrangement between Margaret’s siblings causes ongoing anxiety that interferes with her daily living and coping with the deaths of her parents. I have not encountered literature that clearly addresses these significant issues that were raised by several of the bereaved participants.

Another important consideration within the family context is the strain that may occur between grieving family members as they grieve the same person, sometimes in vastly different ways (as illustrated by Raju). At times of death, rituals such as funerals, memorials, and other ceremonies can serve as a time for family to come together to share the loss and mourn together (Skinner Cook, 2013). These rituals and ongoing support following a death facilitate what Hemmings (1995) positions as an essential part of grief, “remembering, not forgetting” (p. 112). Some of the research participants shared how rituals were affected by the COVID-19 pandemic and creative ways in which they could still attend (e.g., over zoom, Facebook). The two parent support participants, Laura and Giselle, talked about the challenges of attending to their own grief while having the patience and understanding to also support their adult child labelled/with an intellectual disability with their own understanding and expression of their grief. Without extended social support from other family members and paid carers in the lives of their adult children, their grief and mourning could have been affected in negative ways (Skinner Cook, 2018; Walsh & McGoldrick, 2013).

It is important to acknowledge that family is not always someone with whom one has a blood relationship (Collins et al., 2013). For some of the bereaved participants, people who had been in their lives as paid support workers, teachers, friends, and in other roles feel very much
like members of their family. As Raju shared, “To me my staff are like my family, I know they're not supposed to be, but that's just the way I feel”. This needs to be recognized when, for example, a housemate dies, a staff member leaves, or a program closes (as happened during the COVID-19 pandemic, causing tremendous grief for some participants). Providing information about upcoming changes, when known, demonstrates respect for these important relationships and provides opportunities to communicate about what to expect and learn how the person labelled/with an intellectual disability feels about the changes (Kauffman, 2005; Tuffrey-Wijne, 2013).

**B3) Dual process model and overload**

The Dual Process Model of Coping with bereavement (Stroebe & Schut, 1999, 2010, 2016) is relevant when interpreting the findings related to how the bereaved participants engage in their grieving. When a death occurs, and the person labelled/with an intellectual disability is fully informed and included, they have the opportunity to engage in both loss-oriented coping and restoration-oriented coping. This means that they spend time experiencing the effects of the death of the person across multiple domains (emotional, cognitive, physical, behavioural, social, and spiritual) while also engaging in changes associated with the loss. As the dual process model illustrates, it is expected that people will oscillate between these two orientations and taking breaks from intense grief is in fact healthy (Stroebe & Schut, 1999, 2010, 2016). When a person labelled/with an intellectual disability is disenfranchised in their grief and/or diagnostic overshadowing occurs, the opportunity to engage in coping from a dual process perspective is not a consideration. This model of coping with bereavement has not, to my knowledge, been applied to the experiences of people labelled/with intellectual disabilities. However, the findings from my project confirm that using this model in practice with people labelled/with intellectual
disabilities can reframe those times when the person is viewed as not grieving as *grief time-outs* as opposed to the view that they are not grieving at all.

The addition to the dual process model of *overload*, having too much to deal with and feeling unable to cope effectively, is also evident in the findings and needs to be considered as to how it affects the ability to engage in oscillation between the loss-oriented and restoration-oriented efforts at coping (Stroebe & Schut, 2016). It is also important to note that expression of grief, in the loss-oriented sense, looks different for everyone. In my reflexive notes, I discussed the differences in expression between the experiences of Layton and Simon. Layton shared that he is not emotionally expressive as he prefers to keep things inside and think about them. In comparison, Simon, having multiple cumulative losses, is much more emotionally expressive, to the point of engaging in “destructive” behaviours. These differences can occur for a multitude of reasons – for example, personal temperament, loss and trauma histories, available support network, and emotional literacy (Kauffman, 2005). Layton’s response challenges the notion that grief always includes notable behavioural and emotional expression, furthering the need for flexible, educated, and compassionate grief support. Further research specific to the application of the dual process model, overload, individual differences, and people labelled/with intellectual disabilities is needed.

**B4) Meaning Reconstruction**

As demonstrated through the findings of this research, people labelled/with intellectual disabilities are capable of meaningful relationships, experiencing deep grief, and making meaning from their experiences of loss. The bereaved participants shared many ways in which they gained meaning and growth from experiencing the deaths of people important to them and their subsequent grief. For some, dreams and extraordinary experiences helped to resolve
feelings of guilt and blame, while fostering continuing bonds of love and care. Engaging in rituals such as attending a funeral, visiting the cemetery, and/or having linking objects (something that belonged to the deceased) were also meaningful for many participants. Without the opportunity to share their stories and these moments of insight, I wonder how meaning may be stifled for many bereaved people labelled/with intellectual disabilities. When provided with a space to share their narratives through this research the complexities and nuances of adaptation to loss were captured (Neimeyer, 1999), suggesting areas of meaning and growth that may not have occurred for people situated in disenfranchising environments.

I believe that a significant emergent finding related to meaning making/reconstruction after a death is that people labelled/with intellectual disabilities do not always want to be only the recipients of support. Given the depth and breadth of loss in their lives, several of the bereaved participants in this research project expressed that they would like opportunities to offer bereavement support, wisdom, and/or practical help to others who are grieving. Whether this support is for their peers, workers, or family members, they were clear that using their own experiences to support others can provide them with a sense of purpose, create additional meaning from their own losses, and foster a sense of belonging. This is an important finding to consider within the organizational context.

C) Organizational Contexts & Grief: “We've seen [death and grief] more than we have before, because a lot of the people we support are getting older” (Earl)

C1) Recognition of grief

Based on the information shared by all participants in this research project, recognition of grief in the lives of people labelled/with intellectual disabilities and resources available to
support grief by organizational staff is not guaranteed but rather seems to be dependent on, or influenced by, an employee with a specific interest in grief and loss, either through a personal experience of loss and grief, or through recognition of the effects of loss on the people they support. This can also be linked to personal and professional comfort in acknowledging and recognizing grief. It has been noted that people labelled/with intellectual disabilities are living longer (Thorpe et al., 2020; Tuffrey-Wijne et al., 2017), and given the potential for significant loss histories, death and grief, and other end-of-life issues, grief awareness needs to become a priority for organizations – for staff education, education for service users, and providing helpful and ongoing grief support. Training needs to include information about the life cycle, how to communicate about death and dying, grief across life domains, mourning activities, coping, and support strategies (Kauffman, 2005; Tuffrey-Wijne et al., 2017; Read, 2014).

C2) Organizational mission

Although the sample of organizations is small in this research project (N=4), there were some differences noted between organizations with a religious/spiritual mission and those identified as community living organizations without an overt religious/spiritual grounding. Participants (bereaved, support persons, and key informants) from two organizations that are connected to religion shared that their organizations have established rituals (e.g., memorial activities) and groups related to loss and grief for their ‘clients’. There is not enough data to say if this religious/spiritual organizational orientation influences the experiences of bereaved people labelled/with intellectual disabilities, but it remains noteworthy that traditions and rituals related to death and grieving have been established in these organizations and are demonstrated through other research to be helpful for many in their mourning (DeSpelder & Strickland, 2020; Hoy et al., 2021; Kauffman, 2005).
Implications and Recommendations

*Grief is about a broken heart, not a broken brain.* All efforts to heal the heart with the head fail because the head is the wrong tool for the job. It’s like trying to paint with a hammer – it only makes a mess. (James & Friedman, 2017, p. 5)

The above quote speaks to resisting efforts to try to make sense of grief solely through intellectual means. This directly challenges a behaviour management approach to correcting reactions related to grief, as significant loss through death creates instinctual responses and separation distress that is not a conscious choice (Kosminsky & Jordan, 2016) and thus not an appropriate target for either behaviour management or mandatory adherence to normative rules. Furthermore, focusing solely on whether a person labelled/with an intellectual disability understands death, or if they are acting out by choice fails to consider their broken heart – a heart that may have been broken repeatedly throughout their lives – and ways in which it can begin to heal (Tuffrey-Wijne, 2013). This adds to disenfranchisement and leads to considerations of the critical implications of this research.

**Implications for Social Work**

Learning from the bereaved participants in this research project, there is clearly a pressing need to acknowledge the presence of loss and grief in their lives and to move from disenfranchisement to enfranchise/empowerment. *Enfranchised grief* (Anderson, 2008) promotes validation that loss exists in multiple forms and that everyone has different and varying grief reactions and coping styles/tools, and encourages sharing, rituals, ongoing relationships, and expression of grief over time. To achieve enfranchised grief for people labelled/with intellectual disabilities, several changes need to occur. First, providing education related to grief and loss for people labelled/with intellectual disabilities (and their families/caregivers)
throughout their lives will assist in understanding and processing the ongoing nature of loss in life (death and non-death related). Second, mandatory education for paid and volunteer staff and social workers is needed through both formal education (courses on death, dying, and grief, and disability, as well as inclusion of these topics in core social work, social service work, and developmental services courses) and job-specific training. This type of education can promote understanding and recognition of loss, adaptive processes of grief, and coping skills, with attention to quality of care aimed at supporting and empowering people labelled/with intellectual disabilities to participate in mutual assistance and becoming more involved in decisions that affect them (e.g., attending a funeral, end-of-life wishes) (Payne, 2016). Next, moving accessible grief education for people labelled/with intellectual disabilities into daily practice is required and organizations providing services to this group bear responsibility for ensuring both grief education and daily supportive practices are in place. Grief education needs to further extend to include a multi-disciplinary audience, as people labelled/with intellectual disabilities typically interact with a broad range of professionals throughout their lives (e.g., medical doctors, nurses, social workers, developmental/social/personal service workers, physiotherapists, occupational therapists, case managers, etc.).

Social Work Education

Hemmings (1995) states that “loss is the core theme of social work” (p. 109) and yet social work education has very little to say about both grief and disability, never mind the intersection of grief and intellectual disability. Alarmingly, education in grief and disability is not required – together and/or separately – at both undergraduate and graduate levels of social work study. This type of education should not be aimed at practices to minimize grief, rather, education needs to maximize understanding of the complexities and nuances of grief in the lives
of all people - neurotypical, disabled, and labelled/with intellectual disabilities - while also critically examining the concept of care of marginalized and oppressed populations (Shuttleworth, 2018). Application of an ethics of care framework (Baines 2018; Rogers, 2016) within courses related to grief and disability provides a systems perspective and broadens grief and disability from being situated solely within the individual and provides consideration of multiple sources of influence on individual experience. Without the inclusion of grief education in social work programs, in practice, I have seen a hesitancy from social workers to approach issues of grief with service users. This hesitancy, or outright refusal, is heightened when the service user is also labelled as disabled which contributes to ongoing disenfranchisement of the grief of people labelled/with intellectual disabilities.

**Social Work Practice**

The skills valued by service users (i.e., presence, deep listening, validation) are devalued by the profession within the current neoliberal context of practice that is evidence-based, time-limited, and goal-directed (Finn, 2021). Counselling support for grief, requires creating a relational frame within which the service user(s) can share their deeply personal narrative of loss, explore their reactions, how they are coping, and how they might move forward in their new reality (Neimeyer, 2012). This is difficult to practice within organizational pressures which include time-limited sessions, clear goal development, and measurable outcomes (Finn, 2021) as fixing the grief related to loss is not on the table. Grief cannot be solved or fixed within 3-6 sessions; the deceased cannot magically be brought back to life. Grief in the counselling setting needs to be expressed, supported, and attended to in professional ways that are curious, respectful, compassionate – much like Wolfelt’s (2005, 2016) Companioning Model, with the social worker having the additional abilities to intervene with creative, individual skills and tools
aimed at assisting the service user(s) with adapting to the new world without the deceased. I have found that through inadequate social work education, organizational expectations, and service user beliefs about grief being something to be managed, social workers become very uncomfortable when the actual need is to bear witness and accompany the grieving person, rather than overtly having the answers and/or intervention to solve the so-called problem. Furthermore, it is crucial that social workers (and other professionals) engage in reflexive practice so that we are aware of how we, as outsiders to the lived experience of intellectual disability, interpret reactions based on our own beliefs, loss experiences, expectations, and attitudes (Béres & Fook, 2020). Reflexivity within social work practice and research requires that social workers make time to examine personal and professional assumptions, beliefs, and experiences in ways that enhance learning and understanding which in turn is intended to improve professional practice and research. As demonstrated through my reflexive notes kept throughout my research project, being aware of and unsettling the influence of my “whole self” within the research process assisted in appreciating “the link between language and power, …how personal experience is also social and political, and how individual beliefs can be changed in order to contribute to socially just change” (Béres & Fook, 2020, p. 3). Engaging in reflexivity during my research project allowed me to document how I was making sense (or not) of both the process and content of the research in a way that was non-linear, open, and questioning.

The sense-making and meaning reconstruction process for people after a death is often processed through the sharing of narratives (Neimeyer, 2012). It is vital to understand the value of these stories. Social workers working with the grieving person labelled/with an intellectual disability need to create space, time, and means for meaningful and accessible storytelling across different modalities (e.g., talking, music, art, memory books, photos) and for differing ways of
communicating (e.g., spoken words, sign language, communication books). These narratives can be created and shared in many ways, for example, verbally through storytelling, using communication tools (such as picture books, sign language), creating art, listening to or creating music, dance, and taking photos. This type of work can be done in various settings both individually and in group settings.

Being trauma informed as social work professionals and within organizations providing services to people labelled/with intellectual disabilities is essential. The goal of trauma-informed work is to minimize harm, not to treat trauma (Brown, 2020). Being trauma-informed within the context of this research topic and practice with bereaved people labelled/with intellectual disabilities means that efforts are made to determine the loss history of an individual, how trauma has played a role in their lives, and to engage with their grief and coping in ways that minimize any further harm. When working with people labelled/with intellectual disabilities it is important to consider it likely that they have experienced events they perceive as traumatic, and this will influence current reactions to loss. Considering current grief reactions with a trauma-informed lens will provide a better understanding of how an individual labelled/with an intellectual disability may be experiencing a loss and why they may be reacting in ways that are uncomfortable for them and/or the people in their lives. Working from a trauma-informed perspective will also require resistance to pathologizing grief. There will be times when trauma-specific therapy will be required, just as providing a psychiatric label may be needed for treatment and/or care. However, as noted by Rubin et al. (2013) “bereavement interventions [by professionals can] serve to provide social support even as they span a wide range from non-specific support to highly specialized interventions for specifically defined difficulties” (p. 271). For many people labelled/with intellectual disabilities, when their grief is enfranchised and
understood as adaptive within their personal history of loss, trauma, and inclusion/exclusion, and meaningful social support is available within which they can express and process their experiences, there is no need to pathologize their grief.

People seek grief counselling when their social environments do not support them, and they are experiencing ongoing stress related to loss in their environment (Kalich & Brabant, 2006). It is established that restricted social networks at times of loss and grief can increase the risk that the bereaved will experience challenges that are difficult for them to cope with (Balk 2007; Kastenbaum & Moreman, 2018). Beyond the loss experiences that brought them to participate in this research, the bereaved participants further noted that the social restrictions in place due to the COVID-19 pandemic were very difficult for them. They missed having in-person contact with family, friends, staff, and co-workers. As noted above, through providing the opportunity for bereaved people labelled/with intellectual disabilities to support others (peers, staff, family) who are grieving, organizations can expand their available resources. This could be particularly beneficial for rural/smaller organizations (and larger ones) that could offer in-house support without overreliance on community-based, professional counselling resources.

Furthermore, bereaved people labelled/with intellectual disabilities, once they have a sense of their own losses and how they cope with their grief, can provide comfort/help/support to the newly bereaved both informally (through social connections) and formally (as bereavement group co-facilitators).

As members of a profession with a stated commitment to the pursuit of social justice and inclusion (CASW, 2005), social workers can work to remove barriers to ongoing communication about loss and grief between family/staff and people labelled/with intellectual disabilities. To respect personhood and inclusion for people labelled/with intellectual disabilities, social workers
can assist family members/staff through educating them about grief and loss, as well as assisting them in sharing difficult information with the person labelled/with an intellectual disability and supporting them after the news is shared. Social workers can also play a role in enfranchising the griever labelled/with an intellectual disability through recognizing the complexities of the experiences, the myriad ways grief can be expressed and processed, while advocating for inclusion of the person in whatever ways the person wishes. For example, arranging for transportation to a funeral or a cemetery visit, having access to and/or support with technology for online rituals, and facilitating opportunities for people labelled/with intellectual disabilities to move into roles of supporter and not always being recipients of support. Additionally, social workers can advocate with the Ontario Ministry of Children, Community and Social Services to slow down the process of “filling the bed” after a death so that housemates and staff within congregate care living situations have time to process the loss, identify grief reactions, and engage in mourning rituals. This is not only helpful for the bereaved people labelled/with intellectual disabilities and staff, but also for the new person moving into the setting.

**Social Work Research**

This research demonstrates that people labelled/with intellectual disabilities have and can share knowledge that informs research and practice related to loss and grief. With appropriate measures in place to protect so-called vulnerable people from harm through participation in research, people labelled/with intellectual disabilities can (and should) participate actively and meaningfully to inform social work practice that directly affects their lives. Research, policy development, and practice interventions need to include people labelled/with intellectual disabilities, whether through direct participation or, at the least, as with this research, informed through their participation in research. Conducting research such as this project provides critical
information for social work education and practice from the lived experiences of service users. Furthermore, social workers are well positioned to engage in research with varying diverse populations as researchers. Social workers typically have strong interview skills, the ability to gauge emotional upset, a commitment to cause no harm, and an awareness of broader systems issues on the research subject and topic. These skills support the research participant while the interview occurs for the purpose of data collection.

Implications and Recommendations for Organizations

The organizations through which people labelled/with intellectual disabilities receive support services have varying mission statements that influence the way services are provided. The organizations represented by key informants in this research provide a variety of services, including community participation, employment supports, community residential care, and supported independent living. To do this work, organizations operate under a host of policies and procedures, some linked to religion for faith-based organizations. This research indicates that policies and procedures need to be developed, alongside people labelled/with intellectual disabilities, regarding how, when, and by whom news is shared about an illness and/or death with service users. The bereaved participants in this research are clear that they want to be informed of important information that affects them in a timely manner. Sharing this information, ideally, should be done by family and/or a person who has a relationship with the person labelled/with an intellectual disability.

Organizations need to recognize that there are often long-term relationships between service users and paid staff in the developmental services field, relationships that can feel like family bonds (attachments) for many people labelled/with intellectual disabilities. Staff turnover is an ongoing loss for people labelled/with intellectual disabilities, and as people labelled/with
intellectual disabilities live longer, there will be more people who will come and go from their lives. People labelled/with intellectual disabilities need to know when staff (or other important people in their lives) are changing roles, leaving the organization, or have died. Through sharing this information personhood and attachment are honoured, opportunities for goodbyes are provided, and recognition of associated grief occurs. Staff also grieve the loss of service users and may need organizational recognition and support for their grief. Staff may be actively grieving while also trying to support the friends/housemates of the deceased person labelled/with an intellectual disability and may need assistance in managing their role while grieving and supporting others. In these circumstances, having education about grief, mourning, and disability can assist the staff to respond effectively to bereaved people labelled/with intellectual disabilities. Creating rituals and/or traditions that will occur after a death allows for a predictable routine for what can/will happen after a death, while also providing a means for mourning and recognizing the accompanying grief.

Developmental services organizations may not realize they are resource rich with bereaved people labelled/with intellectual disabilities (service users) who can help others who are grieving (peers, family members, staff). It is not always necessary to professionalize grief support, especially when there are so few social workers and counsellors familiar with grief and intellectual disability, and for those who are, waiting lists and the costs of counselling are often prohibitive for timely support. Organizations can, with grief education and training, use the human resources they already have, bereaved people labelled/with intellectual disabilities, to provide mutual aid support. Boosting and nurturing these additional resources starts with identifying people labelled/with intellectual disabilities who have experienced a death, who are comfortable talking about their loss(es), have an understanding of their grief, and who want to
help others. Training in peer-to-peer grief support, from a Companioning Model (Wolfelt, 2005, 2016), can occur for staff and people labelled/with intellectual disabilities and a pilot mutual aid grief support project could be developed (either for 1-1 or group peer support).

**Limitations of this Research**

This exploratory research project highlights the grief and mourning experiences of the participants within the context of family and organizational care and support. The project did not require participants to disclose the nature of their intellectual disability nor the medicalized level of functioning they have been ascribed. Thus, the impact of severity of disability is not considered within the design and findings of this research. Although the project was designed to be inclusive of people with varying means of communicating, only one participant used means other than spoken words to communicate. This means the grief experiences of a broad number of people using means other than spoken words to communicate was not captured.

In terms of volunteer bias, the people who chose to participate in this research are comfortable talking about their loss(es) and grief, and believe it is an important topic to explore further. Those for whom the topic is difficult and/or disenfranchised were not fully represented in this research project. I wonder who was not included in the research because they were not considered by staff to be a griever, were not provided with the information about the project, or who was interested but did not have the support to contact me. Because of this, there are experiences, viewpoints, and insights that were missed. Further research in this area needs to examine how to reach and learn from disenfranchised grievers labelled/with intellectual disabilities without causing harm.
The organizations in developmental services act as gatekeepers. Organizational personnel are charged with the care of so-called vulnerable people labelled/with intellectual disabilities and thus they determine what information will or will not reach their service users. The limitations related to this include: (1) some organizations viewed this as an important topic/priority while others did not; (2) potential participants with varying stories, abilities, and experiences were left out because management (person who received the information letter/reach out) did not pass along the information or did not think the issue/research was important; and, (3) the effects of the COVID-19 pandemic and the demands on organizations to cope with the resulting limited resources/time meant they were unable to participate. Fortunately, despite these limitations, I was able to engage with bereaved participants, support people, and key informants in sufficient number to achieve the collection of significant and meaningful data.

**Knowledge Translation: How I am Sharing What I Have Learned**

I have been actively engaging in knowledge translation related to this topic since early in my PhD journey. In 2017, while in Winnipeg for training in Dignity Therapy, I met the Executive Director of Canadian Virtual Hospice (CVH). CVH has a website, mygrief.ca, dedicated to grief education across varying losses and populations. I used this meeting as an opportunity to talk about my research and the lack of accessible, free information regarding supporting bereaved people labelled/with intellectual disabilities. My pitch to add this content to the website was successful and five years of content development began. I was the Canada-wide team lead for the project which included team member (subject matter expert) recruitment, content development, and video content. The learning module launched in May 2022 and has
been well-received within the developmental services sector


I am also working with the developers of griefstories.com to improve the diversity of content on their website, which provides short video-based content of bereaved people speaking about their losses and grief experiences. Through the inclusion of videos by people labelled/with intellectual disabilities and lived experience of loss through death, we will be improving access to mutual aid in that people labelled/with intellectual disabilities who are bereaved and want to hear how others labelled/with an intellectual disability have coped with loss will have fast and free access to these stories from their peers.

I have presented my initial (undefended) research findings and/or research approach at the following conferences:

- Canadian Health and Wellbeing in Developmental Disabilities (CHWDD) Conference, Temerty Faculty of Medicine, University of Toronto, February 9, 2022. This was a multi-disciplinary, international virtual conference.
- PhD Research Colloquium, Faculty of Social Work, Wilfrid Laurier University, March 2, 2022.
- Faculty of Social Work Research Forum, Wilfrid Laurier University, October 11, 2019.
- Renison University College School of Social Work, guest speaker at 4th year BSW research class, June 9, 2022.
- Bereavement Ontario Network Annual Conference, presentation abstract accepted for October 24, 2022. This is a multi-disciplinary conference.

As a result of my presentation at the CHWDD Conference in February of this year, I was invited to become a member of a provincial (Ontario) multi-disciplinary working group creating the
grief and bereavement content of the Intellectual and Developmental Disability (IDD) Palliative Care Toolkit, which is intended to be the IDD supplement for Ontario's Palliative Care Toolkit through the Ontario Palliative Care Network (OPCN) and Secretariat. The working group includes front-line developmental services professionals, palliative care professionals, and researchers.

Future contributions to knowledge expansion in grief and IDD education and practice will include:

- Creating an accessible executive summary of my research findings and recommendations for developmental services organizations and interested professionals.
- Based on this summary, I can develop further documents and/or training workshops regarding grief and intellectual disabilities, and ideas for support, all informed by the bereaved people labelled/with intellectual disabilities participating in my research.
- Assist organizations to identify and train people labelled/with intellectual disabilities to do peer-to-peer bereavement support.
- I will continue to provide consultation and counselling services for people labelled/with intellectual disabilities and their support circles through my private practice.
- I plan to create journal articles from my dissertation work that contribute to scholarly knowledge and professional practice.
- I will present this work at future conferences, such as, Social Work and Hospice Palliative Care (SWHPN), Hospice and Palliative Care Ontario (HPCO), Ontario Association on Developmental Disabilities (OADD), Ontario Agencies Supporting Individuals with Special Needs (OASIS), Association for Death Education and Counselling (ADEC).
For my presentation at the CHWDD Conference in February 2022, I created an example of a tool (mnemonic) that support people and professionals can use as they practice ‘care-full’ entry and exit into the lives of the grieving people labelled/with intellectual disabilities they have the privilege to work alongside. I share this as an example of how my research findings and knowledge can be disseminated in easily digestible portions while providing an easy to remember practice approach:

- Compassionate presence
- Awareness of loss history and influence on current grief
- Respect for differences in reactions, expressions of grief
- Expression opportunities – art, music, walks, talks…

Facilitate inclusion and mutual support

- Understand that grief ‘bursts’ can happen at any time
- Learn more about death, dying, and bereavement
- Love never dies, relationships continue

A tool such as this demonstrates, in part, how I will share the findings of this research with people labelled/with intellectual disabilities, developmental services professionals, and organizations in order to facilitate better understanding of grief and grief support in the lives of people labelled/with intellectual disabilities.

Future research in this area that has emerged from my project, ideally using a co-researcher model alongside people labelled/with an intellectual disability, can include: the examination of the use of the dual process model of coping when working with bereaved people labelled/with an intellectual disability; the development and implementation of training for and
facilitation of mutual aid bereavement groups for people labelled/with an intellectual disability (and/or a mixed group including people who are neurotypical); the grief and mourning experiences of people labelled/with an intellectual disability who do not use verbal language to communicate; grief and mourning within the family system when one member is labelled/with an intellectual disability; the role of dreams and extraordinary experiences in the grief journey of people labelled/with intellectual disabilities; the effectiveness of grief education training for front-line staff in developmental services organizations; social work knowledge needed regarding grief and mourning in the lives of people labelled/with an intellectual disability to enhance practice.

**Conclusions**

The findings of this research demonstrate that people labelled/with intellectual disabilities have rich relationships within which they receive and express love, and through which they have also been caused harm. This means that they experience varied grief reactions after the death of someone they care about, which can be more complex due to the influences of past losses and trauma. The findings of this research shatter the notion that people labelled/with intellectual disabilities, because they may not understand the concept or permanence of death, do not experience grief in similar ways to the neurotypical population. In fact, several of the bereaved participants not only understood grief in relation to death, but they could also articulate their experiences, share their stories of grief and hope, and express their wish to help others who are grieving. My hope remains that the complexities of loss and grief will be better understood and acknowledged through the contributions of this research, in ways that acknowledge and embrace
different experiences, ease suffering, create more inclusive environments, and encourage companioning one another in difficult times regardless of ability.

Grief support and/or counselling for people labelled/with intellectual disabilities needs, first and foremost, to be informed by people labelled/with intellectual disabilities. The gatekeepers of knowledge (family members, staff, other professionals) need to share power and work alongside people labelled/with intellectual disabilities so that the human experience of loss and grief is a mutual, collaborative, and compassionate journey rather than one that is managed and shaped to meet the needs of systems of care (e.g., group homes, congregate care). This research project demonstrates that it is acceptable to not know how to intervene to make grief easier for a person. Rather, to companion through being with, listening to, learning from, and journeying together is powerfully supportive and healing.

I would like to give the final words to Arthur (a true expert), a bereaved participant who experienced the death of his mother and shared the challenges and wisdom related to this loss alongside other significant losses in his life. With a past that includes institutionalization, loss of self, and trauma, Arthur has not only participated in a mutual aid grief support group, but has also co-facilitated the group, taught Developmental Services Workers about his experiences of grief, and contributed to grief program development:

I got the feeling that my family didn't want me to be there [at the hospital with my dying mother] and so... It was hard but...yeah…they said it was too hard for me and...I said I’d rather face the pain than hide it. I can't believe I actually said that... It was like…I surprised myself and I was like, whoa. It surprised me... 'Cause I didn't think I was that kind of person. I'm learning to speak up for myself, which I couldn't do in the past. We're still learning about it [grief] and…helps to face the pain and...learn how to get it out...out
in the open [through the group process]. So that it doesn't stay in their bodies. It was something we had to face and get it...some do it by walking and some do it...by dreaming about something. For me it was a bit of both. It was the dream [of my mother] that helped me and...for others it was walking and...getting it out in the open...even if it meant just shake it off or... and it was a good way to get things out. Help me open [up] and...to really listen. 'Cause if you keep it in too long...it just gets...bigger and bigger. As long as you live here, you're going to face the good side and the bad side. As long as you live on this planet, you're not, you're never too old to learn. You gotta speak to the [bereaved] person. …The only way you can get to know people is just to spend time with them.
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Appendix A: Companioning the Bereaved

Dr. Alan Wolfelt’s Tenets of Companioning the Bereaved (2005, 2016)

Companioning is about…

1) Being present to another person’s pain; it is not about taking away the pain.

2) Going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.

3) Honouring the spirit; it is not about focusing on the intellect.

4) Listening with the heart; it is not about analyzing with the head.

5) Bearing witness to the struggles of others; it is not about judging or directing these struggles.

6) Walking alongside; it is not about leading.

7) Discovering the gifts of sacred silence; it is not about filling up every moment with words.

8) Being still; it is not about frantic movement forward.

9) Respecting disorder and confusion; it is not about imposing order and logic.

10) Learning from others; it is not about teaching them.

11) Compassionate curiosity; it is not about expertise.
Appendix B: Client Loss Assessment

(Kauffman, 2005, pp. 95-96)

The purpose of the loss assessment is to put into words: the story of the losses the person has experienced; the reactions; disturbances that have occurred in reaction to these losses; and the course of the adaptive process.

The purpose of the initial loss evaluation (done at intake) may include the following:

1) Gathering information;
2) Opening up discussion of loss and death topics may be beneficial simply through the act of having the loss recognized and being given meaningful opportunity to talk about losses – mourning is sanctioned through the expression of concern and the permission to talk about losses;
3) Relationship building – the discussion may strengthen the bond of trust and mutuality;
4) Educational opportunity to understand more about relationship issues, loss and death issues;
5) Talking about loss may help the mourning process and the adjustment process of change (in placement, employment, etc.);
6) Developing a written instrument that can be used in an ongoing evaluation process which tracks changes and helps staff to link behaviour and experiences over time;
7) Assists with decision-making, such as setting up advanced directives;
8) Heightens awareness of loss and mourning;
9) Develops a document for use by front-line staff in understanding psycho-social needs, grief vulnerabilities and behaviours of a client.
Appendix C: Interview Guides for all Participants

Interview Protocol: Bereaved Participant

Date:
Time:
Location:
Interviewer:
Interviewee:

Research Purpose & Questions: The purpose of the proposed research study is to better understand what happens (emotionally, cognitively, physically, behaviourally, socially, spiritually) for people with intellectual disabilities when they are grieving and mourning after the death of a significant person in their lives. This is to determine some key factors/influences, potential best practices for support, as well as to identify potential areas for further understanding.

Complete Informed Consent/obtain Assent. Provide time for questions regarding the research and the data collection process.

**How these questions are asked and the information gathered will be dependent on the communication abilities of the participant**

Guiding Questions:

1. Can you tell me about the person who died? Possible follow-up questions: who were they; what was your relationship; what did you enjoy doing together; how did they die; how did you find out they had died?

2. What has it been like for you since they died? (emotionally, cognitively, physically, behaviourally, socially, spiritually)

3. How have you been supported since the person’s (use name) death?

4. What has been the least helpful thing since the person died?

5. What has been the most helpful?

Debrief statement: Thank you for participating in this interview. What you shared will remain confidential, you will have the opportunity to review the transcript of the interview, and to see future research findings. (Guide participant to support person after interview if needed for emotional, physical, cognitive, spiritual, etc. support)
Interview Protocol: Bereaved Participant’s Support Person

Date:
Time:
Location:
Interviewer:
Interviewee:

Interviewee is Support Person to Participant #

Research Purpose & Questions: The purpose of the proposed research study is to better understand what happens (emotionally, cognitively, physically, behaviourally, socially, spiritually) for people with intellectual disabilities when they are grieving and mourning after the death of a significant person in their lives. This is to determine some key factors/influences, potential best practices for support, as well as to identify potential areas for further understanding.

Complete Informed Consent. Provide time for questions regarding the research and the data collection process.

Guiding Questions:

1. What are your beliefs about the ability of people labeled with an intellectual disability to experience grief after a death?

2. Can you tell me about the person who died in _____’s life (who were they; when did they die; what was the relationship like; what did they enjoy doing together; how did the person die; how did you find out they had died)?

3. From your perspective, what has it been like for _____ since they died? (emotionally, cognitively, physically, behaviourally, socially, spiritually)

4. Have you been facilitating anything in particular that seems helpful for _____ (i.e. looking at photos, talking about them, visit to cemetery)

5. How has it been for you to support _____ since the person died?

6. What has been the least helpful thing since the person died?

7. What has been the most helpful?

Debrief statement: Thank you for participating in this interview. Your responses will remain confidential, you will have the opportunity to review the transcript of the interview, and to see future research findings.
Interview Protocol: Managerial Perspective (Key Informant)

Date:
Time:
Location:
Interviewer:
Interviewee:
Position of Interviewee:

Research Purpose & Questions: The purpose of the proposed research study is to better understand what happens (emotionally, cognitively, physically, behaviourally, socially, spiritually) for people with intellectual disabilities when they are grieving and mourning after the death of a significant person in their lives. This is to determine some key factors/influences, potential best practices for support, as well as to identify potential areas for further understanding.

Complete Informed Consent. Provide time for questions regarding the research and the data collection process.

Guiding Questions:

1. Please describe the overall purpose of your organization and the core beliefs driving the work done here?
2. Historically, how has your organization understood death, loss, and grief in the lives of people with intellectual disabilities? Has understanding changed over the years?
3. What might grief and mourning look like for people with an intellectual disability in your organization?
4. How has support been practiced (or not provided)?
5. Have your staff members been provided with education about death, grief, and people with intellectual disabilities? If so, what has that entailed?
6. Describe a challenging situation related to the death of a ‘client’ or staff member that your organization has dealt with recently.
7. Describe a successful situation related to the death of a ‘client’ or staff member that your organization has dealt with recently.

Debrief statement: Thank you for participating in this interview. Your responses will remain confidential, you will have the opportunity to review the transcript of the interview, and to see future research findings.
Appendix D: Plain Language Informed Consent

Wilfrid Laurier University Informed Consent Contract (FOR BEREAVED PARTICIPANT)

Deep in the Shadows of Loss: An Exploration of Grief, Mourning, and Intellectual Disability

Researcher: Cara Grosset, PhD Candidate cgrosset@wlru.ca

Advisor: Dr. Eliana Suarez, Associate Professor, Wilfrid Laurier University, esuarez@wlu.ca

My name is Cara and I am interested in talking to you about what it’s been like for you to have someone important to you die and the reactions you have experienced. I am doing a school project that looks at experiences of people with intellectual differences when someone important to them dies, and what social workers/support people can do to be helpful when this happens.

When someone important in our lives dies, we feel lots of different feelings, we can act differently, and think about the person a lot – this is called grief. This is what I want to talk about. We will meet over the computer using a program called Microsoft Teams – we will be able to see and hear each other. I will ask you some questions about the person who died, what it’s been like for you since they died, and what sorts of supports you have found help or don’t help with your grief. Our talk will last about an hour, but we can break it into shorter times over more calls if you want to.

Sometimes it can be really hard to talk about our grief and the person who died, so I’ll make sure you have support if you feel sad, upset, or want to end the talk – you can have someone nearby who supports you or we can connect you with someone who can help. Sometimes it can help to talk about the person who died – to remember fun times together, to let our feelings out, and to share what has helped you. The information you share with me will also help other people – I will use the information to look at ways to help people in the future.

You can decide to end our interview and/or leave the project at any time and it won’t change the support you get from the agency/person who supports you. For meeting with me and sharing your experiences, as a ‘Thank You’, you will receive a $25 gift card for Tim Hortons coffee shop. You will get this card even if you have to end our talk.

Our interview over Microsoft Teams will be recorded – the video and the audio (the sound of our voices). This lets me have the interview written out on paper for us to look at later, and for me to watch us talking after our interview. Are you ok with me recording our talk?

Verbal Assent – Yes_____ No______ (if no, I will be taking notes as we talk so I don’t forget what you share with me)
What you share with me will become part of the written part of my school project (dissertation). I will not use your real name, where you live, the name of the person who died, or anything else that could tell someone reading the project that I’m talking about you – this means the information you share with me stays confidential. Someone who knows you really well might be able to identify you from my project, but I’ll change as much as I can to try to stop that from happening. I will meet with you again once our interview is written out to make sure that you agree with what is written.

If you have questions at any time about the project or what I’m doing, you can contact me, Cara Grosset at cgrosset@wlu.ca or by cell at (519) 717-0605. My faculty advisor is Dr. Eliana Suarez, and she can be reached at esuarez@wlu.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Jayne Kalmar, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 3131 or REBChair@wlu.ca.

When I write up my project (dissertation and articles), I will be putting together information from interviews with lots of people. I like to use the real words they used to describe their experience (quotes). Are you ok with me using your words (quotes) in my written project (dissertation and articles) and in presentations?

Verbal Assent – Yes _____  No ______

Now that we have discussed all of this, do you have any questions?

Do you agree to participate in my project (research study)?

Verbal Assent – Yes _____  No _____  Date: ____________________________

(This consent must be accompanied by signed informed consent, Appendix A, Informed Consent for Support Person)

I will check in regularly as we talk to see how you’re doing. Will you let me know if you feel upset at any point and need a break, some support, or want to end the interview?

Verbal Assent – Yes _____  No _____

Participant’s Name (please print): __________________________________________

Participant’s Signature: ___________________________  Date: ___________________________

Researcher’s signature: ___________________________  Date: ___________________________
Appendix E: Wilfrid Laurier University Informed Consent Contract – Support Person

(e.g., primary worker in a group home, independent living support worker, parent/guardian who is providing consent for participant)

Deep in the Shadows of Loss: An Exploration of Grief, Mourning, and Intellectual Disability

Researcher: Cara Grosset, PhD Candidate cgrosset@wlu.ca

Advisor: Dr. Eliana Suarez, Associate Professor, Wilfrid Laurier University, esuarez@wlu.ca

People you support are invited to participate in a research study to explore their experience of the death of someone close to them. This research is being conducted in the context of a doctoral dissertation at the Faculty of Social Work, Wilfrid Laurier University.

Information

The purpose of this research study is to engage with people with an intellectual disability who have been bereaved by the death of a family member, close friend, or support person in order to gain a better understanding of what happens (emotionally, cognitively, physically, behaviourally, socially, spiritually) for people with intellectual disabilities when they are grieving and mourning. I am interested in discovering and gaining a better understanding of the phenomena of grief and mourning through the eyes of the research participants within their social context. The proposed research is not an attempt to discover the way all people with intellectual disabilities grieve, but rather to explore the complexities and variances of this experience for a number of individuals of differing intellectual and communication abilities.

This study’s central question is: In what ways do people with intellectual disabilities experience grief? This question will be explored through an unstructured interview (approximately 1 hour, can be done over several interviews) where the researcher will ask initial questions about loss and grief experiences. With your consent, the conversation will be conducted over the Microsoft Teams online platform, recorded, transcribed, and analyzed. With the participant’s consent/assent, I would also like to interview you about your perceptions of the loss. Interviews will be transcribed by an individual other than me and this individual will be required to sign a confidentiality agreement. I will review a copy of the written transcript of the interview with participants and/or their support person (approximately 30 minutes) for you to ensure I have captured the discussion in a way you agree with. You and the participant will have the opportunity to correct any inconsistencies and clarify any information from your transcribed interview. The findings from all the participants interview will be written up into a dissertation.
Risks

As a result of participation in this study the person you support may experience some discomfort in terms of revealing their experiences related to the death of someone they cared about. The following safeguards will be used to minimize any discomfort: the recorded interview will be in a private location of choice, without the presence of anyone the participant does not wish to be present. The participant will be offered emotional support during and after the interview if needed by someone you have previously identified. Comments will not be linked to participants in any way in the research. Participation in this study will not affect any services received from the support organization.

Participants are free to leave the study at any time and to choose not to respond to any question without any consequence.

Benefits

The study is expected to explore what happens (emotionally, cognitively, physically, behaviourally, socially, spiritually) for people with intellectual disabilities when they are grieving and mourning. Additionally, I hope to have an enriched understanding of the supports that are helpful (or not helpful) to people with intellectual disabilities who are grieving, and to contribute to literature about the nature of support needed in this field of social work practice. This research may benefit participants by providing opportunities to reflect on experiences and to contribute to the learning of current and future practitioners, and also to other bereaved people with intellectual disabilities. Participation may lead to feelings of ongoing connection to the person who is deceased; the opportunity to express feelings, thoughts, etc. that may not have been previously shared; and to making some meaning from your experiences.

Confidentiality

The confidentiality/anonymity of participant data will be ensured by assigning a code or pseudonym to names so that participant names are not connected with their comments. However, knowing that the information participants provide and the stories they tell have the potential to identify them to family members, support staff, and other members of an immediate community, efforts will be made to change potentially identifying information in ways that do not alter the research findings. The data will be stored on a password-protected computer and on a password-protected recording device. Any identifying information will be stored separately from the data. All audiotapes, videotapes, and transcripts will be physically destroyed seven years after the final dissertation has been defended. The research results will be first published as a dissertation. Names of participants will not appear in any further research reports, presentations, or publications arising from the study. Any quotations used in the report and presentations will not include names or any identifying data to ensure confidentiality.
Compensation

Each bereaved primary participant will receive a $20 gift card from Tim Horton’s in appreciation of their time spent in participating in this research project. Completion of the interview is not necessary in order to receive the $20 gift card.

Contact

If you have questions at any time about the study or the procedures, you may contact the researcher, Cara Grosset at cgrosset@wlu.ca or by cell at (519) 717-0605. The researcher’s faculty advisor is Dr. Eliana Suarez, and she can be reached at esuarez@wlu.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Jayne Kalmar, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 3131 or REBChair@wlu.ca

Participation

Participation in this study is voluntary; participants may decline to take part without penalty. If you decide to participate, you may withdraw from the study at any time without penalty while the data collection process is occurring. If participants withdraw from the study, every attempt will be made to remove their data from the study, and have it destroyed. Participants have the right to omit the answers to any questions they choose.

Feedback and publication

I will review a copy of the written transcript of the interview with the participant and/or their support person to ensure I have captured the discussion in a way the participant agrees with. The participant and/or their support person will have the opportunity to correct any inconsistencies and clarify any information from the transcribed interview.

Findings of the study will be disseminated through the publication of the dissertation, academic journals, academic conferences, and community workshops. Participants will be provided with an executive summary of the findings by email at the completion of the study. Results should be available by or before December 2021. Publication will occur after the successful defense of this dissertation study.

Signed Consent

I have read and understand the above information. I understand the audiotapes, videotapes, and/or transcripts, and final report will not be used for any other purposes without my additional permission. I have received a copy of this form. I agree to participate in this study.

Support Person’s signature: ______________________________
Consent to be recorded (video and audio) on Microsoft Teams call(s)

I consent to the researcher audio and video recording Microsoft Teams interviews, and understand that participants can withdraw their consent at any time.

Support Person’s signature: ____________________________
Date _______________________

Consent to use quotations

I consent to the researcher including my quotes in the final report, after I have had the opportunity to review and approve the transcript of our conversation. Quotations will be de-identified to ensure confidentiality.

Support Person’s signature: ____________________________
Date _______________________

Researcher’s signature: ________________________________
Date _______________________
Appendix F: Reflexive Note Template (Roller & Lavrakas, 2015, p. 42)

Participant #: ____________________________  Date: ____________________________
Location: ____________________________  Time: ____________________________

**Broad Takeaways from the Interview, Focus Group discussion, or Observation**

What do I think I ‘know’ from this/these participant(s)?

How do I think I ‘know’ it?

At what point in the interview, discussion or observation did I arrive at that knowledge?

Does this knowledge change or support my earlier assumptions or beliefs?

Will this knowledge change the course of the research, in terms of objectives, methods, line of inquiry; and, if so, how?

**Specific Reflections on the interview, discussion, or observation experience**

**Assumptions:**

What assumptions did I make about the participants?

What assumptions did I make about comments/responses to my questions?

How did these assumptions affect or shape the questions I asked, the interjections I made, my listening skills, and/or my behaviour?

**Values, Beliefs, life story, social/economic status:**

How did my personal values, beliefs, life story, and/or socio-economic status affect or shape the questions I asked, the interjections I made, my listening skills, and/or my behaviour?

**Emotional connection to the participants:**

To what degree did my emotions or feelings for the participant(s) affect or shape the questions I asked, the interjections I made, my listening skills, and/or my behaviour?

How will my emotions or feelings for the participant(s) affect the analytical process and my ability to draw valid interpretations from the data?

**Physical environment and logistics:**

How did the physical setting/location of the research event alter how I related to the participant(s), and vice versa?

How did the physical setting/location impact data collection?

What were the logistical issues (e.g., in gaining access) that contributed to the ‘success’ or weakness of the outcomes?