A GROUNDED THEORY STUDY OF THE BEREAVEMENT EXPERIENCE FOR
ADULTS WITH DEVELOPMENTAL DISABILITIES FOLLOWING
THE DEATH OF A PARENT OR LOVED ONE:
PERCEPTIONS OF BEREAVEMENT COUNSELORS

by

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For the degree of Doctor of Philosophy

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(date) _______October 27, 2006_______

*We also certify that written approval has been obtained for any proprietary material contained therein.
DEDICATION

This dissertation and the work to fulfill the requirements for my PhD are
dedicated to the memory of my mother who never doubted my ability to finish anything I
started. She always wanted her PhD. She died before I achieved candidacy. This one is
for you, Mom.
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# LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CD</td>
<td>Cognitive Disability</td>
</tr>
<tr>
<td>CWRU</td>
<td>Case Western Reserve University</td>
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<tr>
<td>DD</td>
<td>Developmental Disability</td>
</tr>
<tr>
<td>DDD</td>
<td>Division of Developmental Disabilities</td>
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<tr>
<td>ID</td>
<td>Intellectual Disability</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>LD</td>
<td>Learning Disability</td>
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<td>MR</td>
<td>Mental Retardation</td>
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GLOSSARY

**Anxious Attachment** - One of Mary Ainsworth’s original categories of attachment; separation from the caregiver results in distress with distress continuing even after the caregiver returns.

**Anxious-Avoidant Attachment** - Separation from the caregiver results in no apparent discomfort but, when reunited with the caregiver, the child evades contact with the caregiver.

**Anxious-Resistant Attachment** - Separation from the caregiver results in visible discomfort and protest and, when reunited with the caregiver, the child is difficult to calm and reassure.

**Attachment** - Relational bond or feelings of closeness.

**Bereavement** - The period following a death.

**Bibliotherapy** - The use of books and stories as a therapeutic intervention.

**Boundaries** - Rules of social contact that include professional and client relationship expectations.

**Cognitive Disability** - Thought processes and intellect fall below normed standards.

**Concreteness** - A term applied to using words and explanations that can be visually or experientially demonstrated or described.

**Continuing Bonds** - Maintenance of feelings of closeness and attachment to someone that is deceased.

**Coping** - Managing stress and change in a manner that the person is not overwhelmed or unable to function due to distress.
**Developmental Disability** - Generally, a condition initiating before age 18 that may include physical, cognitive, social and emotional challenges creating difficulties in performing tasks of daily living without assistance.

**Disconnection** - Not feeling or being included; a state of being disjointed, as in thoughts, behaviors and feelings not in sync.

**Disenfranchised Grief** - Not being recognized as having feelings of typical grief that are shared by others; having unrecognized relationships with the result that when the relationship ends, no acknowledgement is given for the loss.

**Dismissing Attachment** – Avoidance of giving importance to a relationship.

**Egocentrism** - Seeing the world from one’s own perspective without incorporating the views or experiences of others.

**Fearful Attachment** - Avoidance of developing feelings of connection for fear of being abandoned or hurt.

**Generalization of Knowledge** - Being able to carry knowledge over from one learning experience to another.

**Grief** - Emotions and affect that result from loss or perceived loss.

**Growth** - Development of the physical, the psychological, the social or emotional aspects of personhood.

**Honoring** – Recognizing and giving validation to an individual’s emotions, thoughts and being.

**Hospice** - Holistic health care services providing care for the terminally ill or those with six months or less of life expectancy.
**Insecure Attachment** - Lack of a bond with another person that allows exploration and growth.

**Intellectual Disability** - Cognitive challenges; mental retardation.

**Learning Disability** - A broad category to include persons with challenges to understanding and retaining information; often used in Britain to refer to adults with mental retardation.

**Loss** - Having sustained damage or having something of importance removed or taken.

**Mediator** - A factor that influences the triggering of an event.

**Mental Retardation** - A term used to diagnose persons with IQ’s less than 70.

**Moderator** - A factor that influences the quality or direction of an event.

**Modalities** - Types of interventions.

**Mourning** - How grief is displayed; varies from culture to culture, family to family, and individual to individual.

**Palliative Care** - Holistic supportive services provided when medical conditions have no ultimate cure.

**Preoccupied Attachment** - Another name for anxious attachment.

**Secondary Loss** - Changes or damages that follow a death or major change.

**Secure Attachment** - A bond with another that is developed based on trust

**Secure Base** - A relationships that encourages exploration and growth.

**Stage Theorist** - A proponent of grief theory that believes grief can be explained in phases or stages.

**Stress** - Physical, psychological, social or emotional events or conditions that create discomfort or imbalance
A Grounded Theory Study of the Bereavement Experience for Adults with Developmental Disabilities Following the Death of a Parent or Loved One: Perceptions of Bereavement Counselors

Abstract

by

MARY ANN CLUTE

This study is a grounded theory inquiry into the experience of bereavement for adults with developmental disabilities (DD). Two research questions were asked. 1) How do bereavement counselors perceive the experience of bereavement for adults with DD? 2) What do bereavement counselors perceive as being helpful during bereavement for adults with DD? Data were analyzed from eighteen semi-structured interviews with bereavement counselors who have served adults with DD. Two major themes, Disconnection and Growth, are identified.

Disconnection is represented by the categorical concepts of Loss, Grief Response and Coping Challenges. Disconnection is described for many adults with DD. Countless unrecognized losses usually precede a current death loss. Grief responses are primarily behavioral, intense and are not always recognized as grief. Protection and dependence on caregivers limit development of coping skills. Coping often fails due to cognitive limitations and limited social support. An endless cycle of continued disenfranchised feelings about death, change, and loss may follow.
Bereavement counselors reported the belief that good counseling techniques can lead to growth for the adult with DD. The counselors’ comments reflected observations of client growth through the experience of being honored and being together. When counselors recognized and honored the feelings associated with grief and loss, counselors reported that clients experienced safety and that clients were able to share and explore the intensity of grief emotions. Counselors’ believed that clients with DD moved along the path of growth when they were assisted to connect with others and were helped to connect their feelings, thoughts and emotions about bereavement.

Multiple forms of loss are documented. Coping is viewed as challenged by misguided protection strategies. Dependence on caregivers moderates the bereavement experience. The study found evidence supporting attachment theory concepts of the helpfulness of a secure base. Connections were found with the stress and coping literature. The study generally supports the findings of existing bereavement literature on adults with DD.
CHAPTER ONE: BACKGROUND AND SIGNIFICANCE

Introduction

Research on bereavement for adults with developmental disabilities (DD), especially those with mental retardation, has been very limited (Kauffman, 2005). Studies do exist on the conceptual understanding of death for adults with DD (Kennedy, 2000; Kuekes, 1996; Levelle, 1997; Lipe-Goodson & Goebel, 1983; McEvoy, 1989), but little work has been done on the socio-emotional experience of bereavement for this population. Since “grief does not focus on one’s ability to ‘understand’ but instead on one’s ability to ‘feel’” (Wolfelt in Nolen-Hoeksema & Larsen, 1999, p. 122), it is irresponsible to ignore how adults with DD experience -- understand and feel -- bereavement after parental death. By continuing to presume that adults with DD grieve like adults without DD (Higgins, 1992), we assume this population views and experiences life without any exceptional differences. This assumption is untenable. The impact of parental bereavement, as stated by McLoughlin (1986), may be substantial and uniquely constructed:

In the mentally handicapped, particularly where the person has been looked after at home by relatives for many years, the degree of attachment and dependence may be very strong indeed. It could be argued that the mentally handicapped person, because of his reduced social sphere and the limitations that are often placed on him which restrict development of many different relationships, may have a much greater investment in a few highly significant relationships; the
breaking of those close bonds may be catastrophic for the life and that individual.

(p. 258)

The overall aim of this study is to explore from the perspective of bereavement counselors bereavement among adults with DD and concurrent cognitive disabilities (CD) or mental retardation (MR) who have experienced parental death or death of a loved one. The classification, DD, can include persons who have IQ’s above 70, but have extensive disabilities that require daily assistance. In this study, however, I will use the term DD throughout the text to refer to adults with developmental disabilities with concurrent CD or MR. In the literature reviews, DD is often also termed “intellectual disability (ID)”, “learning disability (LD)” or just DD. Grief and loss may manifest distinctively during bereavement for these adults. In this study, qualitative methods will be used to collect and analyze narratives of bereavement counselors who have served adults with DD for the purpose of developing a grounded theoretical explanation of their bereavement process. Two focused research questions are asked. 1) How do bereavement counselors perceive the experience of bereavement for adults with DD? 2) What do bereavement counselors perceive as being helpful during bereavement for adults with DD?

Plan for Chapter One

First, the historical background and significance of the problem of bereavement in general is explained. This concludes with a review of the general bereavement literature framed by two major theories: attachment theory and stress and coping theory. Second, the specific issue of bereavement after parental death is discussed in terms of existing knowledge and significance. Third, background information about adults with DD is
presented, and the imperative for exploration and understanding of bereavement after parental death specific to adults with DD is approached. Fourth, after laying the groundwork for understanding the issue and the population, a review of the literature on cognitive understanding of death for adults with DD and the scant literature on bereavement and grief for adults with DD is considered. Finally, an argument is made that, due to the current paucity of bereavement research for adults with DD in general and bereavement after parental death specifically, research focusing on this issue is past due. Qualitative research is presented herein as the most desirable means to capture the voices of the bereaved adults with DD. Specifically, grounded theory methodology is defended as the means to best explore the experience and build theory regarding the bereavement process for adults with DD after the death of a parent.

Background and Significance of Bereavement

Facing death is a formidable but an inevitable task that everyone, with a disability or without, will experience in the course of his or her lifespan. The Centers for Disease Control and Prevention reports that in 2001 there were 2,416,425 deaths in the United States, 13,074 more than the year 2000 (Anderson, Minino, Fingerhut, Warner & Heinen, 2004). Loss of loved ones can be due to advanced age, traumatic events, or to incurable disease. Worldwide disease, disasters, and war raise issues for treatment and policy on a global level (Stroebe, Stroebe & Hansson, 1993).

Before proceeding, it is necessary to define terms. Martin and Doka (2000) define the broad concept of loss as “being deprived of or ceasing to have something that one formerly possessed or to which one was attached.” (p. 12) Brown (1980) speaks of loss as “being deprived of something that provides a source of gratification.” (p. 8). M. Stroebe,
W. Stroebe and Hansson’s (1993) definition of bereavement, grief, and mourning states, “Bereavement is the objective situation of having lost someone significant; grief is the emotional response to one’s loss; and mourning denotes the actions and manner of expressing grief, which often reflect the mourning practices of one’s culture” (p. 5).

John Bowlby and Elisabeth Kubler-Ross, two well known theorists, employed stages to look at reaction to loss. Nolen-Hoeksema and Larson (1999) discuss grief by use of models that also utilize the concept of stages. Nolen-Hoeksema grouped symptoms for the earliest phase into cognitive, emotional, behavioral, and physical or somatic symptoms. The earliest phases include “slowed thinking, disorganized thinking, suicidal ideation, disbelief, appears unaffected” (p. 3) and are classified as cognitive reactions. Emotional responses include “psychic numbness, blunting, euphoria, hysteria, appear unaffected” (p. 3). Behavioral responses include “crying, weeping, sobbing, outbursts, talkativeness, hyperactivity, unaware of others, passivity, sighing, appears unaffected” (p. 3). Physical or somatic responses include “physical numbness, feeling of unreality, feeling outside body, dizziness, general physical distress” (p. 3).

Nolen-Hoeksema and Larson (1999) summarize the second or middle phase for cognitive reactions as “preoccupation with thoughts of the deceased, idealizing the deceased; searching; ruminating; dreams of the deceased; impaired concentration; impaired memory; meaninglessness; loss of interest; lowered self-esteem; worry; ‘I’m going crazy’; hears voice of deceased; ‘sees’ deceased” (p. 4). Emotional responses are described as “sadness, yearning, anxiety, fear, anger, irritability, guilt, depression, loneliness, apathy; anguish, relief” (p. 4). Behavioral reactions are inclusive of the earlier mentioned reactions and, additionally, “restlessness, accident proneness, psychomotor
retardation, withdrawal, support seeking, dependence, avoidance, lack of initiative” (p. 4). Physical or somatic symptoms may include “general physical distress, muscle weakness, muscle aches, headaches, stomachaches, chest pains, tightness in chest, heartbeat irregularity, shortness of breath, sleep disturbance, change in appetite, vulnerability to illness, nausea, and low energy” (p. 4).

The final or resolution phase includes cognitive reactions such as “realistic memory of deceased, pleasure in remembering, and new meaning in life” (p. 4). Emotionally, the bereaved have reestablished a “normal range of emotions” (p. 4). Behaviorally, the bereaved have returned to “normal functioning, new or renewed social relationships; new or renewed activities” (p. 4). Physically, restoration to previous functioning is noted.

Researchers are struggling to understand the grief process for the general population. Two major challenges regarding bereavement exist for social scientists and practitioners. The first is that typical grief reactions are difficult to define. Shuchter and Zisook (1993) outline multiple human dimensions researchers have found to be affected by bereavement, including: affect, cognition, coping, continuing bonds to the deceased, functioning, relationships, identity, and personal growth. Even the DSM-IV (American Psychological Association, 1994) states: “The duration and expression of ‘normal’ bereavement vary considerably among different groups” (p. 684).

Because of the intensity of the loss experience, the large number of people it affects, and the systematic variations with which its consequences are distributed across populations, bereavement has far reaching implications (Stroebe, Stroebe & Hansson, 1993, p. 3). The transitive nature of theoretical knowledge about grief sets the stage for
another challenge: the ability to predict and identify pathological grief. Much uncertainty exists for the public, as well as for practitioners, about what constitutes healthy grief. Neither group can be certain about when grief becomes unhealthy or what risk and protective factors exist for unhealthy grief. Researchers note that normal grief is not a pathological condition requiring treatment for the majority, yet 20-30% of bereaved display pathological distress that needs professional intervention (Maercker, Bonanno, Znoj & Horowitz, 1998; Ott, 2003). Depression, anxiety, and increase in mortality rates have been documented outcomes of pathological bereavement (Ott, 2003; Shuchter & Zisook, 1993; Stroebe, Stroebe & Abakoumkin, 1999). Martin and Doka (2000) summarize documented grief reactions into five categories. Physical reactions which include appetite loss, headaches, inability to sleep, noise sensitivity, body pain, nausea, fatigue, tension, and for females, irregularity of menstruation. Emotional responses include feelings of sadness, anger, guilt, jealousy, anxiety and fear, shame, powerlessness, relief and emancipation (pp. 17-18). Cognition is the third category. Changes in cognition due to bereavement are noted to include: “obsessive thinking, inability to concentrate, fantasizing, apathy, dreams, disorientation and confusion, continued thought about loss, rehearsing and reviewing the circumstances of the loss” (p. 18). In addition, the griever may feel the deceased’s presence while trying to grasp or “cognitively understand the loss” (p. 18). Fourth, spiritual responses to loss embrace the search for meaning and subsequent alteration in spiritual belief systems. Finally, behavioral changes are summarized as:

- crying
illness-related behaviors (such as observable symptoms or expressions of illness)

outward expression of emotion (anger or euphoria for instance)

observable changes in religious or spiritual behaviors and expressions

searching behaviors

avoiding or seeking reminders of the loss

obsessive activity

activities that provide some sense or continued connection to the loss (for example, visiting the cemetery)

physical activities (such as exercise, sports, gardening)

social withdrawal

absentmindedness

accidents

changes in pre-loss behavior

social withdrawal

increase in the use of alcohol, smoking, and other chemical use. (p. 19)

Martin and Doka also summarize variables that will affect the experience of grief. From a review of the literature, they note seven variables: the nature of the loss, the quality of the relationship of the griever to the deceased, the timing and other variables specific to the loss, the griever’s history of losses, personality factors, socio-cultural factors, and the griever’s own individual status in terms of wellness and coping skills.

Martin and Doka propose that people tend to grieve on a continuum from intuitive to instrumental. Intuitive grievers primarily experience the emotions of grief. They
display the tears and vocalizations of sadness and do best with interventions that allow the expression of feelings. Emotions may interfere with thinking, focus and organization. They may feel exhausted and anxious. On the other end of the spectrum, the instrumental griever react more cognitively. They think about the loss, but don’t really want to talk about it. Keeping control of themselves and the world around them is paramount. They may have periods of disruption of their thinking processes and their energy levels may fluctuate, but they do not identify this as related to the loss. Martin and Doka point out that most people have some of both patterns.

Risk factors that cause bereavement to be pathological need to be identified to enable early identification and intervention for those at risk. What is “normal grief”, and what causes pathological grief are questions that researchers have struggled to answer from a variety of theoretical frameworks. Almost 25 years ago, Bowlby (1980) noted two distinct problem areas in bereavement: (a) ideas regarding the nature of the mourning processes themselves and in what ways healthy and pathological processes differ, and (b) ideas regarding why some individuals and not others should respond to loss in a pathological way. (p. 23)

The broader literature on loss is also informative. Brown situates bereavement into the broader category of loss. She describes four major types of losses as “(1) loss of body image or some aspect of self, (2) loss of a loved one or significant other, (3) material loss, and (4) maturational loss” (p. 10). Brown’s four types of loss may be especially relevant when exploring bereavement in the cognitively disabled. Loss or reduced self-image, self worth, and social roles are examples that fit the first category. Loss of parents, family, friends or familiar others fall into category two. Losses of
possessions, home, or familiar surroundings apply to category three. The fourth category includes developmental changes that may be due to biology, such as the aging process or to family additions, losses or shifts. Brown states that one category of loss can build on another, thus triggering further losses.

Kauffman (2005) discusses losses that people with DD deal with in their daily lives. He includes loss of familiar routines and structure; loss of place; death losses; broken relationships; physical illnesses of those around them, as well as for themselves; damage to self efficacy; internalizing losses of parents or family members; loss of role or employment; and traumatic losses, such as loss of safety due to abuse or violence.

Rando (1993) states that all change involves a loss of some type. She describes developmental losses (biological); change related to typical social transitions associated with ages or stages, and competency based changes that involve efforts and attainment or lack of attainment of goals. She describes secondary loss as “a physical or psychosocial loss that coincides with or develops as a consequence of the initial loss.” (p. 20). It is logical to assume adults with DD experience the types of losses described by Brown and Rando. I suspect that their initial and secondary losses may be as great, or even greater than, the typical or normal adult loss experiences.

Literature Review

The following section includes historical and current literature on existing theories regarding general bereavement. What is already known about bereavement forms a basis for comparison to new knowledge about bereavement for the developmentally disabled. Two major theoretical frameworks, attachment theory and stress and coping theory, have guided much of the current bereavement research (Nolen-Hoekesema &
Larson, 1999). The historical development of bereavement theory and research supporting these two theories will be reviewed.

_Bereavement and Attachment Theory Review_

Most of the currently available literature on bereavement traces back to Freud’s *Mourning and Melancholia*. Freud viewed bereavement as psychological work to sever the ties to the deceased or disengagement of the ego’s energy toward the deceased (Stroebe & Stroebe, 1992). He believed energy must be withdrawn from the relationship to the deceased and transferred to a new relationship to prevent pathology. Freud’s work revolved around distinguishing depression from healthy grief and how melancholia and unhealthy grief are similar: “In some people the same influences produce melancholia instead of mourning and we consequently suspect them of a pathological disposition” (Freud, 1914-1916/1957, p. 243). Freud goes on to say that the work of mourning the object or loved one demands “that all libido shall be withdrawn from its attachments to that object” (p. 244). In summary, many experts (Bonanno & Kaltman, 1999; Stroebe, 2001; Stroebe & Schut, 1999; Worden 2002) believe Freud’s work was based on the need to help the bereaved break the bonds with the deceased and move on to other relationships, thoughts, and activities to get beyond grief. Intense grief was seen as pathology to be cured, with the cure based on freeing the ego from its attachment to the lost object. However, Freud himself wrote that his empirical support for this theory was “insufficient” (p. 250).

Taking a different perspective than Freud, John Bowlby stressed the biological processes of attachment in viewing grief (Stroebe & Stroebe, 1992). Bowlby’s work was based on studies of animal behavior, neurophysiology, and information theory, as well as
psychoanalytic theory (Glick, Weiss & Parkes, 1974). Bowlby endeavored to tie early object relations concepts to mourning without the concept of ego identification (Klass, 1987). When applying his efforts to bereavement, Bowlby did acknowledge the importance of the relationship with the deceased, but focused on the early relationships the bereaved had with attachment figures. His concept of “internal working models” developed during early childhood are said to be the basis for relationship patterns in adulthood (Rutter, 1997). Rutter (1997) notes that attachment theorists have become more flexible and believe that attachment style can continue to be developed after the first two years of life. He further states that attachment can also be expanded to more than one primary attachment figure.

Attachment behavior is defined by Bowlby (1980) as “any form of behaviour that results in a person attaining or retaining proximity to some other differentiated and preferred individual” (p. 39). Clegg and Lansdall-Welfare (1995) state that Bowlby “maintains that attachment behaviour is appropriately displayed by people of all ages facing psychological or physical threats” (p. 295).

Bowlby suggested the four stages of mourning as: numbing, yearning and searching, disorganization and despair, and reorganization. Healthy mourning is experienced by persons who had “available, responsive and helpful” (p. 242) attachment figures early in life, and continued to build secure relationships in later years. These current relationships and beliefs about self-help the bereaved reorganize “fortified perhaps by an abiding sense of the lost person’s continuing and benevolent presence” (p. 243). “Disordered” mourning was viewed as: imitation of the deceased, taking on symptoms of the deceased, feeling possessed by the deceased, or seeing another person or
animal as transformed into the deceased. Factors affecting bereavement include: role and identity of the deceased, age and sex of the deceased, circumstances of the loss (long period of caregiving, mutilation of the deceased, how death notice was given, relations between the deceased and bereaved immediately prior to death, and who is deemed responsible for the death), social or psychological factors at work during the time of the loss and following the loss (living arrangements, resources, and cultural beliefs), and the personality of the bereaved, especially capacity for love and ways of handling stress. Disordered mourning is linked to disturbances of personality originating during early development and caregiving. Events during early development cause the organization of the individual personality to be anxious and insecure or based on assertions of self-sufficiency. Bowlby believed traditional psychoanalytic theory did not adequately account for the observed experience of the bereaved. He believed attachment theory would offer a better explanation. Bowlby applied his theory to bereavement-based studies by researchers such as Erna Furman and Colin Murray Parkes.

Erna Furman’s (1974) psychoanalytic studies of children whose parent had died provided case studies of loss. Furman believed children’s bereavement is complex and grief is even more pronounced for children than for adults. She did note, however, that adult mourning was not well enough understood to serve as a good comparison. This bereavement study is complicated by the fact that children are more dependent on others, having less autonomy and control than adults. Furman cautioned against attributing too much importance to developmental factors, finding that the personality of the deceased and the relationship with the surviving child were very influential. Pain, sadness, grief, anger, and guilt existed in different intensities in the study children. The children
displayed capacity to bear lengthy and intense emotional pain. She noted, “The mental representation of a dead parent is never completely decathected. It remains alive in the form of memories and feeling, and indirectly contributes to the child’s identifications and to certain aspects of his personality development” (p. 117).

Furman’s observations about children’s emotions during bereavement following parental death provided evidence of children’s capacities to grieve, and she emphasized an individual, not developmental focus. She also acknowledged the lack of solid theory on adult bereavement and did not attempt comparison to the adult bereavement processes. The possible impacts of limited autonomy and control are addressed in her studies and are relevant in addressing all dependent populations, such as adults with DD.

Parkes (1974) completed three bereavement studies. He applied attachment theory to adults who were bereaved of spouses. Attachment theory was now being carried forward from children to adults, and from the primary attachment relationship to the spousal relationship. Parkes made efforts to try to distinguish typical from atypical grieving. The three studies comprising Parkes’ research were: the Bethlem study, which included 21 bereaved males and females hospitalized for psychiatric treatment with a focus on atypical grief; the London Study, a longitudinal study of 22 widows; and the Harvard Study, which focused on American widows and widowers under age 45 with a focus on atypical grief. Parkes tied his observations of loss of loved ones back to the infant and mother attachment. Behaviors such as alarm, searching, mitigation, anger and guilt, and gaining a new identity were themes expressed by his participants. Strength of attachment, security of attachment, reliance, and involvement served as determinants of the type of grief, typical or atypical. His findings on the experience after bereavement
were similar to Bowlby’s four stages of mourning. He found evidence that supports the notion that the type of attachment, even in a spousal relationship, can affect the bereavement and grief response.

Attachment theory constructs became more formalized when Mary Ainsworth provided empirical research on specific attachment styles using the Strange Situation involving an infant, a mother who leaves the room and a friendly stranger who stays (Noppe, 2000). The attachment styles coined from this research (anxious-avoidant, secure, and anxious resistant) were utilized by John Bowlby in his later work. Secure attachment is defined as the ability to use mother as a secure base (Noppe, 2000) and as having bonds of affection based on “positive mental models of being valued and worthy of other’s concern, support, and affection” (Wayment & Verthailer, 2002, p. 131).

Anxious resistant attachment is defined as high levels of distress at separation followed by inability to be consoled on reunion (Noppe). Anxious avoidant attachment is defined as no distress upon separation followed by resistance at reunion (Noppe). Disorganized attachment, a mixture of insecure styles, was added later by Main (1996). Bartholomew and Horowitz (1999) expanded the categories by using the constructs of internal working models for self, as well as for others. They proposed four attachment styles: secure, preoccupied, fearful, and dismissing. Fearful and dismissing classifications break up the avoidant category. The “preoccupied” classification replaces the anxious category, the “fearful” classification implies avoidance to fear of getting hurt, and the “dismissing” classification implies lack of value of relationship (Bartholomew & Horowitz).

While John Bowlby was working on attachment theory, a more popular movement to address death and dying was led by Elizabeth Kubler-Ross in the 1970s.
Her work on stages of grief and loss brought death and dying to the general public. Kubler-Ross’ work was protesting the treatment of death as a medical event (Corr, Nabe & Corr, 2003). The stages she proposed to apply to dying were anger, bargaining, depression and acceptance (Kubler-Ross, 1969). Kubler-Ross’ work has been applied to bereavement, as well as death and dying as noted by Costello and Kendrick (2000). They point out Kubler-Ross’ chapter on the family’s reactions in her book, *Death and Dying*. Implied in stage models of grief is the notion that grief has to be confronted (work through denial and move on to acceptance) and recovery should follow (Wortman & Silver, 1989). Even Bowlby’s early attachment work, which began in the 60’s, supported existing notions that loss had to be confronted and bonds need to be severed to move on to other relationships (Lindstrom, 2002). Wortman and Silver noted, “Despite its prevalence, available evidence provides little support for the assumption that those who fail to experience distress shortly after loss will have difficulties later” (¶ 12).

Kubler-Ross’ efforts to normalize grief, the stages of grief for the dying or the bereaved, are still viewed by some in the context of the medical model of recovery from grief (Walters, 2000). No research has supported Kubler-Ross’ stage concept. (Corr, Corr & Nabe, 2003). Bonanno (2001) also states, “Whereas the vast majority of bereavement researchers and theorists viewed grief work as the only appropriate means of resolving an interpersonal loss, there was almost no empirical evident for such a supposition.” (p. 719)

Although initially descended from psychodynamic roots, John Bowlby’s later endeavors and the efforts of current attachment theorists embrace the idea that a relationship with the deceased attachment figure changes due to physical loss and can be
reformulated in how the person continues to think of their loved one. Current literature supports the concept of continuing bonds with the deceased, not a severing of attachment. Recent attachment theorists have built on Bowlby’s 1981 work relating to grief and loss. Noppe (2000) posits that work on attachment may help researchers and practitioners explain and predict more complicated grief. She states, “The empirical work on infant and adult patterns of attachment imply that the security of attachment patterns are not uniform and that such differing patterns may explain individual patterns of responding to grief and loss. (p. 520). This view is shared by Stroebe (2002) who notes, “[The] attachment style, internal working model and way of letting go…have enormous implications” (p. 133). Stroebe, Stroebe, Abakoumbin and Schut (1996) discuss the belief proffered by attachment theorists that the loss of attachment figures cannot simply be compensated by social support.

Attachment theory offers a framework from which to view the emotional response to loss of a loved one. Broadening the view of attachment literature to look for relevant literature on loss, Mann and Kretchmar (2006) offer insight. They discuss application of attachment theory in treatment of a toddler, Rachel, placed in foster care who had suffered parental separation, loss of safety and home, in addition to other losses. From the case story of Rachel, the authors shared six principles that were used in work with Rachel from the attachment theory base. The six principles included: (a) “I am here. You are worth it” (p. 33), (b) Behavior is communicating a need, (c) “Miscues” (p. 33) wherein child sensing the adult cannot deal with the real problem will pretend or “miscue” the caregiver that she is fine, (d) the biggest need: “being with” (p. 34) the child in pain, (e) mistakes made by a caregiver are normal and don’t have to be harmful if they can be
acknowledged and subsequent improved efforts made, (f) the helper or caregiver needs to be self-reflective. The concept of behavior as communication, “miscuing”, and the importance of “being with” are consistent with what is seen for adults with DD who have experienced loss and grief. DeSchipper, Stolk, and Schuengel (2005) note that the cues that children with ID provide are often misinterpreted by caregivers as a result of verbal communication challenges, and secure attachments may not always be formed. They state that children with ID have even fewer coping mechanisms than typical children and may need adult caregivers even more so to provide a safe holding environment for their fears and grief. It may be that as adults with DD, secure relationships and coping mechanisms have not increased a great deal, putting them at continued risk of unsupported stress, unregulated emotions, or both. Marvin, Cooper, Hoffman and Powell (2002) discuss their work with Circles of Support interventions, which are based on attachment theory. The intervention focus for parents of young children with attachment disorders is on the parent or caregiver. By changing the caregiver’s behavior, the child’s interactions can change. This may be crucial in understanding how to better support adults with DD who are dependent on caregivers for their needs.

In their work, DeSchipper et al. (2005) explored attachment for children with intellectual disabilities who displayed behavior problems. They note, “First, a history of secure attachment interactions may contribute to well-regulated emotional responses to stressful situations. Children with a secure attachment history may respond better to stressors. Secondly, attachment relationships may be used by a child as a solution for the stressful situation. (p. 3) DeSchipper et al. provide food for thought about how adults with DD have grown up and been nurtured. They tie problems with coping to lack of
security in attachment. It also stands to reason that if secure attachment relationships are not available, there are limited opportunities to rely on others to share stressors, such as grief, in a safe and secure manner.

Recent studies of bereavement have been done through the lens of attachment theory. Balk (1996) researched the existence of ongoing attachments and their effects on bereavement response in 80 college students: 15 males and 65 females. Quantitative methods were used in a longitudinal study, with data collected at six-week intervals. The study looked at degree of attachment, not type of attachment, based on secure or insecure categories. Balk found the majority of the subjects remained attached to the deceased and those with higher attachment experienced more enduring distress (more mood swings, intrusive thoughts, depression, anxiety, obsessive-compulsive behavior, paranoia and psychotic symptoms). Those classified as having “some” attachment displayed less distress, but significantly more of the above-cited symptoms than those with “low” attachment. Those with low attachment showed little of the above-noted symptoms. Years since the bereavement varied among the participants, and only six weeks lapsed between data gathering periods, thus limiting the validity of the study.

Field and Sundin (2001) studied attachment style and its impact on conjugal bereavement in a longitudinal study of 89 bereaved spouses. The theoretical framework was primarily attachment theory, but stress and coping theory was also utilized. Field and Sundin developed three hypotheses. The first was that those rated as anxiously attached appraised themselves as unable to cope with the loss. Second, anxiously attached subjects displayed chronic grief. Third, appraised inability to cope mediated impact of anxious attachment on symptoms and avoidant coping mediated the impact of avoidant
attachment on symptoms. Anxious attachment was associated with inability to cope with loss. The existence of long term adjustment problems and emotional numbing were also associated with loss. Avoidant attachment was not related to bereavement adjustment. Limitations of the study include: lack of pre-loss measures of attachment, a high drop out rate of subjects, and use of a grief scale that had not been validated. Environmental factors are ignored.

Wayment and Vierthaler (2002) studied the question of whether attachment style is associated with physical or affective response to bereavement. Subjects were recruited, with 70 of the 91 participants being female. Attachment theory formed the theoretical framework. The authors found anxious ambivalent attachment style was related to greater grief and depression, and avoidant attachment style was related to greater somatic symptoms. Limitations of the study included generalizability issues as a consequence of a recruited sample and a heavily female element. Existence of pre-bereavement depression may have affected the results, again limiting the validity of the study.

Waskowic and Chartier (2003) researched the questions of whether attachment style is related to a positive or negative grief reaction, and whether attachment style and feelings of a continuing bond with the deceased were related. Through snowball sampling, 77 participants were selected. Insecurely attached participants were found to have greater despair, depression, anger, guilt, death anxiety, social isolation, rumination, and somatization. Securely attached participants had significantly higher scores for interchanges with the deceased and reminiscing about the deceased as shown by the Continuing Bonds Scale (CBS). Limitations of the study include generalizability issues
because it was a primarily female convenience sample. In addition, pre-existing disorders may have affected the results, weakening the validity.

Fraley and Bonanno (2004) studied attachment style and adaptation to loss with 59 bereaved adults. Hypotheses tested encompassed: (a) attachment related anxiety (not attachment related avoidance) is associated with severe grief, (b) both attachment related anxiety and avoidance are associated with maladaptive grief, and (c) highly secure adults will adapt easily to loss while insecure adults will not. Secure and dismissing attachment styles were related to: resilience to depression, anxiety, high grief symptoms over time, and Post-Traumatic Stress Disorder (PTSD). Depression, anxiety, and greater grief symptoms over time, as well as symptoms of PTSD, were found for those rated with preoccupied or fearful attachment. The study results were limited by absence of pre-loss measurement of attachment and only two measurement points. In addition, the majority of participants were women, which limits generalizability.

Attachment theory is strengthened by its ability to acknowledge the impact of the loss of attachment figures. The theory can be beneficial in treatment if it can predict healthy or unhealthy grief reactions based on attachment style of the bereaved. An intense view of one aspect of bereavement is addressed. Attachment theory has just begun to be applied to adults with DD. No literature dealing specifically with attachment theory and bereavement for individuals with DD was located, however two small studies were found that do address attachment issues for individuals with DD. One of these studies focuses on adults and the other on children. Each will be described below.

Clegg and Lansdall-Welfare (1995) provide three case studies of adults with DD. Clegg and Lansdall-Welfare note that bonding is more challenged with the infant who
has a disability. Bonding is at risk if residential care was initiated early in life, as lack of knowledge about attachment impeded emotionally nurturing environments for residents. Attachment theory was used as a basis for intervention with the three individuals and their caregivers. Enmeshment is the identified problem. The histories of the adults included death, loss, and separation from family. Similar to Mann and Kretchmar (2006) and Marvin et al. (2002), work is done initially with the caregivers. Further, work with the client involved creating a safe and secure relationship with a therapist, which was called “building a secure base” (p. 302). Groundwork was laid on finding ways to communicate. Art and music were found to be useful devices. The authors noted, “Being alone with one person and given their undivided attention is such a foreign experience for some individuals that they reject the intensity of the relationship” (p.302). Additionally, as mentioned by Mann and Kretchmar, reflective work and continued dialogue about the attachment issues and intervention were continued with staff. The authors reported decrease in client anger and discomfort, more exploratory behavior for clients, and an expansion of the number of social relationships for each client. The work was to increase the sense of security for the client to carry through in their life course.

De Schipper et al. (2005) provide information about a small study of five children with ID in a childcare setting. The researchers explore whether or not the children display attachment behaviors with paid caregivers. Attachment behavior was measured by means of the Attachment Q-Sort. They did find evidence of varied attachment behaviors among the study children, no differences related to the level of functioning or diagnosis, and evidence of inter-rater reliability for measurement of behaviors. Although a very small sample size limits the study’s generalizability, the researchers are hopeful that children
can form attachment relationships and secure bases with paid caregivers. This study may also have implications for work with adults with DD.

Attachment theory offers one way of viewing loss and bereavement. It provides ways to view both the reaction to loss of a loved one and clues as to why some individuals may react differently to a loss than others based on the presence or absence of a secure base. This is just one explanation for bereavement responses. To offer a broader view of bereavement, a discussion of stress and coping theory is provided next. Stress and coping theory offers yet another lens for viewing and explaining the bereavement experience.

**Bereavement and Stress and Coping Literature Review**

A more recent framework for viewing bereavement comes from the stress and coping literature. Bereavement is viewed as a major stressor, with individuals coping through use of personal and environmental resources. Stress and coping theorists in bereavement focus on cognitive variables, social and environmental supports. Schwarzer (2004) notes that three meta-theoretical assumptions underlie stress and coping theory. The first of these is transaction. Emotions, he believes, occur as the person interacts with the environment and a mutual influence of person or environment or both exists. Second, process is assumed. Emotions and cognitions are constantly changing and evolving in response to the environment. Third, context is tacitly vital. The meaning of transactions is dependent on the context, the time and place of the interactions. Appraisal is another important construct. Primary appraisal is how the situation is perceived, whereas secondary appraisal is the person’s perceived ability to cope with the threat or stressor. Personal resources to cope with stress embrace beliefs such as self-efficacy. Other coping
resources are external, such as social support (Schwarzer). Taylor and Aspinwall (1996) also describe two coping styles, avoidant and confrontive, which they posit act as mediators between personal resources and emotion outcome.

Richard Lazarus, a pioneer in analyses of stress, emotions, and coping defines stress as a type of relationship between the person and her environment that exceeds the person’s resources. He identifies appraisal as assessment of the event or encounter, which can be viewed in either a threatening or an optimistic way. Coping, or how the individual chooses to manage the reaction, is affected by the assessment of the challenging event and the person’s relationship with her environment (Lazarus, 1990). Emotion-focused coping is described as efforts to deal with the feelings created by the stressor, such as sadness and anger at the death of a loved one. Problem-focused coping is defined as the actions required to deal with the effects of the stressor (Taylor & Aspinwall, 1996). Examples of problem-focused coping are planning a funeral, notifying relatives, and sorting belongings after the death of a loved one. These problem-focused coping strategies expand to include daily living tasks such as going on with work, finding a new home, or learning the tasks usually done by the deceased.

Pearlin, Lieberman, Menaghan, and Mullan (1981) state that stress response in Stress and Coping Theory ironically has been linked by Horowitz, Field, and Classen (1982) to early work in the 1890s on hysteria by clinicians such as Freud. The biological stress model was developed by Hans Seyle in 1956 (Seyle, 1983; Wheaton, 1996). Another model of stress, the engineering model, describes stress and coping in terms of force, resistance, and capacity. Since the late 1980s, Stress and coping theorists expanded work on moderating and mediating factors in psychosocial stress (Taylor & Aspinwall,
Baron and Kenny’s (1986) definitions help clarify the role and importance of moderators and mediators.

A moderator is a qualitative (e.g., sex, race, class) or quantitative (e.g., level of reward) variable that affects the direction and/or strength of the relation between and independent or predictor variable and a dependent or criterion variable. (p. 3)

A mediator variable accounts for the relation between the predictor and the criterion. Whereas moderator variables specify when certain effects will hold, mediators speak to how or why such effects occur. (p. 7)

Age, gender or social support can be viewed as moderator variables that affect the strength of bereavement as moderator variables. Mediator variables, such as worldview and coping style, can directly impact the bereavement experience. Pearlin et al. (1981) state, “The process of social stress can be seen as combining three major conceptual domains: the sources of stress, the mediators of stress, and the manifestations of stress” (p. 337). These authors state that social stress is a complex process with many variations.

Taylor and Aspinwall (1996) believe personal, social, and external resources (moderators of the stressor) are mediated by appraisal and coping processes to affect psychosocial outcomes of stress. Personal and social resources may influence the process earlier than the focal event with social support having indirect effects on appraisal and coping. (See Figure 1, Taylor & Aspinwall, 1996, p. 98.) Wheaton (1996) helped focus attention on chronic stressors. Chronic stressors exert influence over time, whereas event stressors represent discrete events. Wheaton stated that stress and coping theory is strongest when accounting for multiple stressors in the life course when life events are viewed in the context of daily annoyances and chronic stressors, whereas impact of
current life stressors can be understood only in the context of a person’s lifelong stress domain.

Stress and coping theoretical concepts were refined by Folkman (1997) for specific application to bereavement. Folkman revised the stress and coping theoretical framework developed in conjunction with Richard Lazarus. Meaning-based coping was added as an option to the emotion outcomes “positive emotion” and “distress”. Positive emotion was added as an outcome of meaning based coping. Positive emotion sustains the coping process and feeds back to event appraisal. (See figure 5 Folkman, 1997, p. 1217). Folkman’s research is further explained in the following section.

Lazarus and Folkman (Folkman, 1997) developed a theoretical model for stress and coping. An event is appraised as a threat, a challenge, or a harm, or is appraised as benign or irrelevant. Coping follows either problem-focused coping or emotion-focused coping with event outcome ensuing to produce either a favorable or unfavorable resolution, or no resolution at all (See Figure 5, Folkman, 1997, p. 1217).

Attempting to address more of the complexity of bereavement, Norris and Murrell (1990) studied life events, stress and social support in the bereaved. They conducted a longitudinal study of 130 adults whose spouse, parent or child had died. Using matched controls, they found that low social support, no new interests, financial problems, and high global stress predicted greater post-bereavement depression. These factors may be important to study in other populations, such as adults with DD following death of a parent.

Wortman, Silver, and Kessler (1993) began studying conjugal bereavement in the 1980s using a longitudinal, national sample of 804 widowed individuals who were
interviewed in 1986, with 616 of the original group re-interviewed in 1989. The researchers also launched a prospective study of older adults to follow those who became bereaved. Coping resources, worldview, and reaction to the loss were studied. The hypothesis was that men and women experience different types and levels of strains associated with the loss of a spouse, and that hypothesis was supported. In the prospective study, social support was found not to be associated with lower depression post-bereavement. Those who had viewed the world as controllable were established as being more greatly affected by the loss. Sample size, national data, and longitudinal design made this a strong study. The findings here are indicative of the complexity of bereavement. Evidence is starting to accumulate that indicates gender and worldview play a role in bereavement response, and, interestingly, social support has not weighed in as a predictive factor.

Focusing still on conjugal bereavement, W. Stroebe and M. Stroebe (1993) completed a two-year longitudinal study of 60 widows and widowers matched with 60 married individuals. The recruited bereaved sample consisted of men and women four to seven months post-loss. The research question asked if adjustment to bereavement was based on SES, individual/personality factors, circumstances of loss, mode of death, quality of marriage and/or social support. Adjustment to bereavement was termed “health” and was measured by low depression scores and low numbers of physical health complaints. The Deficit Model of Loss based on Stress and Coping Theory was used for the theoretical framework. The Deficit Model consists of Loss Orientation (confronting emotions) and Restoration Orientation processes (daily living changes and distractions from grief). Each orientation includes an avenue for positive meaning (re)construction
(positive reappraisal, revised goals, interpreting events as positive, and expressing positive emotion). In addition, each orientation provides an avenue for negative meaning (re)construction (rumination, negative reappraisal, dysphoria, and unproductive goals). The authors found no association between sociodemographics, age, emotional stability, locus of control, or religiosity and health over time. The authors found women were affected more by the loss of a close relationship, while men were affected more by the loss of what they perceived as a less emotionally close relationship. Unexpectedness of death increased immediate vulnerability to bereavement stress, but this was reduced over time. However, unexpected loss and low internal control were associated with high depression scores and greater somatic complaints with little improvement over time. Socioeconomic status (SES) and perceived and received social support offered no buffering effects. Confrontation of grief or “grief work” was explored. Widows did not improve over two years if they confronted grief, whereas widowers did improve. One third of the bereaved sample showed little improvement in depression and somatic symptoms over the two years. The authors discussed the possibility of selection bias affecting their study. In addition, a prospective study would have been ideal to measure the state of mental and physical health of the participants before bereavement. Again, the complexity of bereavement factors is illustrated. Gender, the closeness of the relationship, the expectedness of loss, and individual internal control were noted as factors that interacted to affect response to bereavement after death of a spouse. Whether these factors are at work after loss of parents is an avenue worthy of pursuit.

In 1997, Folkman completed a longitudinal study of gay men caring for partners with AIDS. Her first research question was in regard to the kinds of coping processes that
maintain positive psychological states during extreme stress. Her second question was, “What is the theoretical significance of positive psychological states in the coping process” (p. 1207)? Stress and coping theory provided the framework. Findings indicated positive affect plays a role in bereavement response. Problem-focused coping, positive appraisal, spiritual beliefs and practices, and finding meaning in ordinary events were positively and significantly related to positive affect. From this study, she proposed revision of the original stress and coping model to include meaning-based coping and positive emotion. A limitation of the study was the concern about the generalizability of the model to heterosexual couples. One of the strengths of the study was that it brought attention to bereavement as more than a negative life event or an event that causes pathology. Exploration of personal growth and meaning helps provide a holistic view of bereavement in the complex web of human development and human relationships. Folkman (1997) concluded that a revised model of stress and coping was needed for application to bereavement. She believed the revised model should incorporate meaning-based coping as an emotion outcome. Folkman also believed the concept of positive emotion should be shown as a factor supporting the coping process. Folkman’s work should be expanded with exploration of meaning-based coping extended to other populations and other bereavement situations.

Stroebe and Schut (1999) developed the Dual Process Model (DPM), which frames bereavement as a process of oscillation between Loss Orientation and Restoration Orientation. Loss Orientation is a concept similar to emotion-focused coping and dealing with emotions resulting from the loss. Restoration Orientation is a concept similar to problem-focused coping’s learning of new roles, distraction from emotions, and putting
energy into new activities or relationships. Healthy grief, they posit, is an oscillation between emotion and avoidance of emotion by way of purposeful action. The DPM can accommodate gender differences.

Nolen-Hoeksema and Larson (1999) studied coping with loss in a large longitudinal research project with 455 recruited subjects between the ages of 20 and 86. The theoretical framework was Stress and Coping Theory. Quantitative measures and qualitative questions on ability to make sense of the loss and finding something positive in the loss were included. The overall inquiry explored why some bereaved cope with loss with less distress over time than others who are bereaved. Three research questions included in this study are of particular importance to the stress and coping literature. The study looked at whether type of loss and circumstances of the loss were related to adjustment to the loss. The authors also investigated whether subjects coping styles and global personality traits were significantly related to adjustment to loss. Finally, growth and resilience to loss were dealt with. They found the nature of the relationship had no effects on depression scores for spousal or parental loss. A significant difference was found in ability to make sense of the death and depression scores. Subjects who indicated finding something positive in the loss by six months post-loss had lower distress scores at 6, 13, and 18 months. No one factor of what was perceived as a positive result was any more significant than another. The group least likely to find positive meaning in the loss was the group of bereaved spouses. Those finding positive meaning in the loss were more likely to use reappraisal and active problem solving, and were more generally optimistic than those who did not find positive meaning in the loss. Neither spirituality nor religion were significant indicators of finding positives in the loss, although spirituality helped the
bereaved make sense of the loss. Social support was not related to finding positives in the loss. Ultimately, the authors concluded, “Finding something positive is connected to one’s personal outlook on the world and typical ways of coping with stress” (p. 160). A prospective study would have been ideal to measure the state of mental and physical health of the participants before bereavement. Limitations of this study include generalizability being limited to white females. Large sample size was a study strength. Worldview is emerging as an important factor in bereavement processes, at least with white females.

Moskowitz, Folkman, and Acree (2003) studied positive and negative psychological states over three years of bereavement for men whose partners had died of AIDS. Stress and Coping was the theoretical framework. Findings indicated that predictors of positive and negative psychological states were highly related, but represented different dimensions. Optimism was found to have a protective role predicting lower depression scores. Scores on the Positive States of Mind Measure at one month predicted recovery from depressed mood, whereas the depression measure was only marginally able to predict recovery from depressed mood. The longitudinal nature of the study added strength, although findings are limited to men who are homosexual. However, evidence is building that worldview and states of mind are at least keys in understanding bereavement response.

Hogan and Schmidt (2002) studied 167 bereaved parents in efforts to test their Grief to Personal Growth Theory. Study variables included despair, detachment, intrusion, avoidance, social support, and personal growth. “The final model… depicted grief leading to intrusivity, intrusivity leading to avoidance, avoidance leading to social
support, and social support leading to personal growth” (p. 627). A grief to personal growth direct pathway was also found. Small, predominantly female cross-sectional sample size limits generalizability, but the study offers more evidence that bereavement is a complex process allowing for a variety of emotions and reactions that include positive personal growth.

Stress and coping theory also has some biological support in terms of physiological reactions to grief and links to somatic complaints and mortality. A strength of stress and coping theory is that it is truly one of “person-in-environment” addressing transactions between persons and the environment. Stress and coping theory attempts to explain and predict behavior of a person affected by a stressor through understanding the person’s appraisal, coping resources, and coping style. Current stress and coping studies address circumstance of the loss, personality, worldview, and coping resources in the study of bereavement. Structural equation modeling offers a means of trying to map out the bereavement experience, but individual factors over the lifespan still need to be taken into account. As a theory, stress and coping is strongest when accounting for multiple stressors, such as life events in the context of daily aggravations and chronic stressors, because it gives a more accurate picture of the process of stress (Wheaton, 1996).

Taylor and Aspinwall (1996) describe the value of nested models that encompass genetics, individual factors, coping styles and strategies, as well as daily stress. Taylor and Aspinwall posit that external resources and coping have effects prior to the focal stressor’s effects by affecting exposure to and engagement in previous stress processes. This would help place the current life stressor in context of a person’s lifelong stress domain. Wheaton states stressors may act as mediators, multipliers, and moderators.
They may trigger future distress, may mobilize coping, or may deplete coping. They may affect mental and physical health. Viewing the whole stress domain is imperative, rather than viewing just one event in isolation. Therefore, stress and coping theory has less predictive power when viewing an isolated event, such as bereavement. To be more useful, the Stress and Coping model needs to be multifaceted to accurately reflect the complexity of human transactions in time and context. Stress and coping theory is evolving in terms of explaining general bereavement, but the complexity of human loss is still not well represented by existing theory.

Discussion of Attachment Theory and Stress and Coping Literature Review

Attachment and stress and coping theories have provided some insight into bereavement for the general population. However, a clear picture of bereavement in the general adult population does not yet exist. Attachment theory has highlighted one factor, attachment to the deceased, which has been shown to play a role in predicting some individuals’ grief as typical or atypical. It also addresses the notion that opportunities are needed to share emotions safely and find a connection with others who understand the pain or anger. Stress and coping theory has uncovered a myriad of factors that moderate and mediate the response to the event of bereavement in the context of an individual’s life span. Coping strategies and processes have been suggested but are still being fine tuned for application to diverse populations. Is it not clear if these theoretical frameworks, attachments, factors, coping strategies, and coping processes can be applied to diverse populations, such as adults with DD.
Bereavement after Death of a Parent

Efforts to study bereavement include attempts to narrow the focus to specific types of bereavement, such as death of parents for adults. “The loss of any loved one is painful, but the loss of a parent is particularly significant. They are the givers of our lives, our nurturers, guides, and the constructors of our initial realities” (Angell, Dennis & Dumain, 1998, p. 3). Death of parents has been viewed from developmental (Scharlack & Fredriksen, 1993) and attachment theory (Moss, Rubenstein & Moss, 1996-1997; Shmotkin, 1999) and stress and coping theory (Horowitz et al., 1984) in an effort to explain bereavement responses. Research on parental death for adult children is still emerging. I review existing literature on bereavement following parent death for adult children in the general population next.

Horowitz, et al. (1984) completed a longitudinal study with 72 adults who had experienced death of a parent. A clinical sample (33 female, 2 male) and a non-clinical sample (18 male and 19 female) of parentally bereaved adults comprised the research groups. Stress and coping theory provided the theoretical framework for the study. Intervention was provided to the clinical sample in a treatment group based on stress reduction. Over time, the significant difference between the treatment and the control groups was the decrease in avoidance activities and emotions about the parent’s death. Distress reduction was found to be related to cumulative life stress, lower level occupation, lower social class, lower self-concept developmental level, mother versus father role, and higher self-blame for death. Again, we see a heavily female clinical population. In this sample, those with lower SES and lower self esteem accompanied by
higher stress overall responded to bereavement after death of a parent with more distress, which, in turn, was amenable to interventions for stress reduction.

Scharlach and Fredriksen (1993) studied reactions to parental death for 83 adults one to five years post loss. Developmental life span theories were used as a framework to view death of a parent as a normative life span event in middle age. The research questions focused on how the death relationships and the respondents’ sense of mortality were related. The authors reported that parental death increased feelings of personal maturity and autonomy for the majority of participants. An increase in a sense of mortality was reported for many. Overall, parental death was perceived as a personal growth experience. Scharlach and Fredriksen pointed out parallels between the reactions to parental loss and the tasks of middle adulthood. Tasks of middle adulthood are usually based on Westernized typical development and ignore the experiences of diverse persons with non-Western or atypical developmental paths.

Tyson-Rawson (1996) reported on the College Women and Father Death study completed between 1992 and 1993. The research question asked how the death of the father impacted daughters’ lives during college years. Grounded theory methodology was employed. Tyson-Rawson used women in her study to “allow a sense of continuity with previous research and made overt the gender-specific nature of bereavement models to date” (p. 130-131). With regard to emotional attachment to father after death, attachment themes of welcome presence and intrusive presence were found. Detached themes were ritual respect and emotional cutoff. Participants who described some sort of resolution described it as: “(a) coming to terms with the death in the sense of its having meaning, (b) an increased individual ability to function effectively, and (c) a sense of acceptance of the
loss as apart of their life histories” (p. 140). Participants who expressed greater resolution were those “able to revise or restructure their internal working models to accommodate the fact of the death in a way that ameliorates their distress” (p.143). College educated young adult females offer themes about bereavement after parental death that might reflect themes for other females on the same developmental track.

Kilpatrick (1996) studied 81 adults whose parent had died within the last five years. She applied four categories of attachment: secure, fearful, dismissing, and preoccupied. Kilpatrick developed nine hypotheses concerning attachment style and pattern of grief. Securely attached adults were predicted to move from high initial distress to relatively low distress over time. This hypothesis was supported by the study findings. Dismissing attached adults will stay at low distress. Kilpatrick found the group started out low, but moved even lower on the distress scale. Preoccupied style adults will have high distress and remain at high distress. Again, this was supported by the research results. Kilpatrick also hypothesized that unexpectedness of death will predict higher intensity of grief. She found little difference between the unexpected deaths and briefly expected deaths. This result caused her to conclude that it is more appropriately stated that expectancy of death helps lessen the intensity rather than to state that unexpected deaths cause intensified grief. Higher numbers of previous losses predicting higher intensity of grief was not supported. Greater emotional closeness of adult child to parent was thought to predict higher intensity of grief. Using a closeness in adulthood measure, this hypothesis was supported. Using a closeness during childhood measure, the hypothesis was not supported. The loss of a second parent was hypothesized to predict higher intensity of grief, but this hypothesis was not supported. Young age of the adult
predicting higher intensity of grief was not supported. Single adults were predicted to experience higher intensity of grief, which was not supported. From Kilpatrick’s study, the importance of a secure attachment style and closeness during adulthood were found to be a stronger indicator of intensity of grief. Again, this study offers a focus on the relationship with the parent based on early attachment, but it ignores other factors that might affect the bereavement experience, such as cumulative stress, worldview, and personal outlook. It also focuses on only the distress involved in bereavement, not on personal growth that has been shown to be a component in some bereavement experiences.

Moss, Rubinstein, and Moss (1996-1997) conducted interviews with 43 sons aged 40-65 years who had experienced death of their fathers. Attachment theory and the pivotal effects of parental relationship provided the rationale for exploring parental death. Key themes discovered included: efforts to control grief expression, action-focused responses to grief, focus on cognitive processes in dealing with grief, and the value of privacy for expression of grief. Efforts to control grief included:

1. the assumption that grief is cognitive and not always emotional;
2. the use of experiential metaphors rather than direct emotional expression;
3. restriction of the expression of grief in time and space; and
4. affirmation of the intergenerational legacy of control of grief (p. 264).

The authors discussed the heavy research base of feminine grief that focuses on emotion expression and acceptance, as well as the focus on relationship. Moss et al. encouraged the exploration of theory that can incorporate both gender orientations toward
grief. The importance of Moss et al. is the reminder that in exploring parental loss for any group of individuals, gender may play an integral role in the loss experience.

Shmotkin (1999) studied attachment bonds of adult children with deceased parents in Israel. A bond intensity study was completed with 363 participants and both a bond intensity and bond evaluation were explored with 217 participants. Attachment theory, life course theory, and family systems theories appeared to provide the theoretical framework. Shmotkin hypothesized that for surviving adult children, the bond intensity would be lower with deceased parents than for living parents, that higher bond evaluation would exist for deceased rather than living parents, and that daughters would show greater affective bonds with deceased parents than sons. Bond intensity was found not to be lower for daughters and deceased parents, and daughters tended to report higher bond intensity than sons. Bond evaluation was higher for deceased parents than for living parents. Daughters were found to be motivated by bonds of affection, while sons were motivated by filial obligation. Affective bonds with deceased parents were strong and enduring for adult children, leading the authors to note, “This study suggests that both researchers and practitioners integrate adult children’s bonds with their parents into a broader developmental trajectory that transcends parental death” (p. 480). The findings suggest that death of a parent may be a pivotal factor in adult development.

Evidence is accumulating on the impact of death a parent for adult children. To date, gender (Moss, Rubinstein & Moss, 1996-1997), perceived closeness of adult child to parent relationship (Kilpatrick, 1996), expectedness of death (Kilpatrick, 1996), and attachment (Kilpatrick, 1996; Moss, Rubinstein, & Moss, 1996-1997; Shmotkin, 1999; Tyson-Rawson, 1996) all have been shown as factors affecting bereavement after
parental death for adults. Themes of developmental tasks around acceptance of mortality and the meaning of life (Scharlach & Fredriksen, 1993) have also emerged as factors of interest during bereavement after parental death for adults.

Background On Adults With Developmental Disabilities

The exploration of bereavement and parental death has not even begun to address the questions for adults with DD. Before focusing on bereavement in the population of adults with DD, I will describe the population of interest. A developmental disability is “a severe, permanent, physical or psychological impairment originating before age 22 and causing severe functional disruptions (handicaps) in the person’s life” (Graziano, 2002, p. 421). Adults with DD fit within this category, having IQ’s below 70.

As a result of medical technology and improved living conditions, life spans for people with developmental disabilities (DD) have been lengthening in pace with the life spans of the general population (Ansello, 1992; Graziano, 2002). In 1920, 10 years was the limit of the life expectancy of a person with Down Syndrome, a form of DD with accompanying medical complications (Watchman, 2003). Currently, estimates of life expectancy for someone with Down Syndrome range from 55 to 60 years of age (Lifshitz, 2002; Palley & Van Hollen, 2000; Todd, 2002; Watchman). Persons with DD classifications other than Down Syndrome often have life spans from 70-74 years (Strauss & Eyman in Nochajski, 2000).

How many people does this involve? In the United States, 3.2 to 4.5 million people are regarded as developmentally disabled. Eighty-eight percent of those with DD live either with family or within the community in their own household (Senate Bill 1809). Seltzer and Krauss (2001) report that 60% of persons with disabilities live with
their families. Parents in the U.S. who are 60 or older care for over 450,000 sons and daughters with developmental disabilities in their homes (Senate Bill 1809). Hammel and Nochajski (2000) report there are approximately 526,000 adults with DD over 60. This population number is expected to double by 2030. Until recently, parents outlived their adult children with DD. Now the children outlive the parents (Ansello; Seltzer, Greenburg, Krauss & Hong, 1997). All adults with DD face the inevitable loss of a parent due to the aging process, if they have not already experienced this loss.

Luchterhand and Murphy (1998) list 11 differences that adults with mental retardation (DD) may have when compared to adults without a disability:

1. difficulties in learning or understanding (cognitive difficulties)
2. decreased or altered expression of emotion
3. tendency to respond in a positive manner
4. behavior (rather than words) being indicative of true feelings
5. often family members or professionals treating them differently from others
6. family members or professionals often acting as reporters or interpreters
7. lack of social support
8. sense of connection to others being not obvious
9. history of multiple losses
10. lack of resources
11. uncertain future (p. 16)

If accurate, these factors would influence the bereavement experience for adults with DD.
As individuals with DD face bereavement, the community and their caregivers are ill prepared to assist them (Bennett, 2003). Higgins (1992) notes unsubstantiated assumptions are made that if adults with DD grieve, they go through the same grieving process as the general population. Whether Sharlach and Fredriksen's (1993) suggested parallels about midlife developmental tasks being facilitated by parental death would hold for adults with developmental disabilities has yet to be explored. Graziano (2002) noted, “Compared to those without disabilities, they [youth with disabilities] have higher rates of school dropout, unemployment, poverty, behavior problems such as depression and attempted suicide, physical and psychological abuse by others, and dependence on others (e.g., parents) for their living arrangements” (p. 386). Generally, adults with DD are not afforded opportunities for personal autonomy (Clark, Olympia, Jensen, Heathfield & Jensen, 2004; Heller, Miller, & Factor, 1999) and many lack employment (Bray, 1997; Sowers, McLean, & Owens, 2002). Social networks tend to be sparse, especially if the adult lives with family (Grant, 1993; Krauss & Erickson, 1988). Krauss and Erickson found that “family members played a pivotal and somewhat exclusive role in the lives of their relatives with mental retardation who had not been placed in formal residential settings” (p. 200). Since adults with DD are usually unemployed with little autonomy, Horowitz et al.'s findings may suggest that individuals with DD could be at higher risk for distress after parental bereavement.

Persons with DD often have communication and behavioral differences that make the identification of healthy versus unhealthy grief even more challenging than in persons without a disability. Death of a family member has been documented as a trigger for
symptoms of psychopathology and cause for crisis intervention for individuals with DD. (Bonnell-Pascual, et al., 1999; Dodd, Dowling & Hollins, 2005; Emerson, 1977; Kloeppele & Hollins, 1989; MacHale & Carey, 2002). Grant (1993), in his study of support networks and transitions, found that deaths in the family “were talked of as having profound, long-lasting but not always well understood effects on the person with a mental handicap” (p. 47). Kaufman (1996) blames the overall dehumanization of people with DD for historical oversight in acknowledging grief in this population. Van Dyke (2003) states, “In my experience of counseling people with disabilities who lose their only parent, it is not the finality of the loss, but the aftereffects of poor planning or no planning whatsoever that leave the deepest emotional scars” (p. 38). Gradually, social scientists and providers of care have begun to acknowledge that depth of human feeling exists for those whose cognitive abilities fall below a standard score. Little work has been heretofore completed on adults with developmental disability and the bereavement experience. Throughout the growing body of bereavement literature, no studies of attachment theory or stress and coping theory and bereavement thus far have included individuals with DD. Only a handful of studies exist, most based on cognitive-developmental theory as proposed by Jean Piaget. Developmental studies that explore concept of death for adults with DD will be discussed next.

_Cognitive Understanding of Death for Adults with DD_

A growing body of research exists on exploration of the concept of death for adults with DD. Piaget’s stages of cognitive development are often used as key concepts in the research process for this area. Piaget and Inhelder (1969) discuss the stages of sensori-motor, pre-operational, operational (concrete operations) and formal operations.
The stage of concrete operations is a stage when most children are able to understand the concept of death (Silverman, 2000, p. 48). Speece and Brent (1996) note that children often can understand some components of death before the concrete operational stage. Concrete operations mean the child can use her senses to deal with tangible materials to understand causation. Reasoning is done “step by step” (Piaget & Inhelder, p. 100).

Concept of death includes understanding factors such as irreversibility of death, non-functionality after death, and the inevitability and universality of death for all living creatures (Lipe-Goodson & Goebel, 1983). Lipe-Goodson and Goebel explored relationships between IQ, age, sex, percent of life institutionalized, with age perception of self and others and concept of death for 68 adults with mental retardation (MR). Age was found to be a significant predictor of understanding the concept of death with IQ approaching significance as an indicator. Life experience may then play a greater role than cognitive abilities in understanding the concept of death.

McEvoy (1989) explored understanding of the concept of death with 38 adults with MR. He found adults who were rated higher in communication skills, self-care, and community skills had a better understanding of the irreversibility and non-functionality concepts of death, but few understood universality. He found no significant difference between age, sex, or experience with death, and understanding the concept of death. He did find that adults who said they knew they would die someday had higher scores on understanding the death concept. Methodological problems existed with this study’s open-ended questions, which were acknowledged by the author.

Kuekes (1996) studied 39 parent and adult child with DD dyads in an effort to determine the ability of parents to accurately reflect their adult son or daughter’s
understanding of the concept of death. Kuekes found that parents overestimated the adult child’s understanding of concept of death. Parent death anxiety was not statistically significant in predicting congruence with the adult child’s score on death understanding, although the results approached significance. No relationship was found between place of residence and congruence between parent prediction and adult child actual scoring.

Levelle (1997) studied 18 adults with mental retardation (MR), 17 adults without MR, eight children with MR and 21 children without MR to examine differences in understanding the concept of death. She took a multi-dimensional look at age, intelligence, cognitive development, quality of attachment relationship, experience of death of loved one, religious affiliation, and socialization. She hypothesized that age and diagnosis of MR would be related to understanding the concept of death, which was supported in the findings. She predicted that level of MR and age would affect understanding the concept of death, which was not supported. She hypothesized that age would be related to the understanding of the universality of death, which was supported. She conjectured that more experience with death would be related to greater understanding of death. She found that the number of people known by the participant who had died was associated with two concepts of death issues, universality and appearance. Other death related activities, such as funeral attendance, were not related to death understanding.

Kennedy (2000) explored the concept of death among 108 adults with MR. She examined cognitive developmental factors including verbal comprehension knowledge and Piagetian cognitive level and socialization factors including experience with death and social inference skill (ability to interpret social cues). The most interesting finding
was that experience with death was shown to predict death understanding independent of IQ. Additionally, the more severe rating of MR correlated to the less exposure to death related activities such as funerals and the less understanding of the concept of death.

Speece and Brent, in 1996, cited multiple sources supporting the hypothesis that children’s intelligence has a positive association with children’s understanding of death. They did note several exceptions from the literature, however. Other literature currently available also demonstrates that the concept of death has been explored and evidence is beginning to accrue indicating that understanding of death for adults with cognitive disabilities is not just a phenomenon of IQ, and that it may not be a phenomenon that can be fully understood by means of quantitative data. Lipe-Goodson and Goebel (1983) and Levelle (1997) did find age to be a factor in death understanding. Age brings with it experience, relationships, and a rich volume of interactions that are difficult to sort into measurable variables. McEvoy (1989) found individuals with higher communication skills, self care abilities, and community skills possess higher death understanding.

Bereavement Research Involving Adults With DD

It is time for research to move beyond exploring whether adults with DD can understand the concept of death and turn the focus to the emotional impact of bereavement on this population. In speaking of adults with MR, Yanok and Beifus (1993) noted:

It also mistakenly has been assumed that they are unable to form the emotional bonds and intimate interpersonal relationships that ultimately could culminate in feelings of personal loss and mourning (Deutsch, 1985; McDaniel, 1989). Although such rationalizations may serve to simplify the professional
responsibilities of practitioners, they conversely can exacerbate the levels of anxiety, distress and depression experienced (p. 144).

Emerson (1977) wrote of being called in as a consultant for adults with DD who were displaying emotional disturbances. “Crisis intervention approaches routinely try to find a precipitating stress: by looking for one, I have found that 50% of the time there has been either the death or loss of an individual close to the client preceding the symptoms” (p. 46).

Read (2000) speaks of the loss history of most adults with LD. Few have even a “written history of their past” (p. 230). She lists common losses as

- loss of identity
- loss of ability
- loss of accessibility
- loss of opportunity
- loss of independence (p. 230)

Even as these losses accumulate, few have their losses acknowledged.

Kauffman (1996) argues that adults with DD have been dehumanized by the oversight of their emotions, especially by the lack of acknowledgement of their reactions to loss and bereavement. Kauffman labeled the grief of persons with DD as disenfranchised. Citing case studies of adults, he shared a comment by a woman whose behavior became more violent as the eleventh anniversary of her mother’s death approached. “She said she felt ‘like I made her die by my problems’” (p. 268). Another young man reacted violently when told about a staff member dying. “Before I could finish the statement, he started shouting that he did not do it” (p. 266). “The sense of
being blamed and faulted was a pervasive undercurrent of this client’s emotional life that flooded and determined his experience and meaning of death. In a simple, magical, concrete way he heard the news of death as an accusation” (p. 266). Those adults who were institutionalized, Kauffman noted, often struggle with abandonment issues, as well. Kauffman pointed out the layers of losses that exist for many adults with DD. “In processing current griefs with clients, I have found a remarkable persistence of unresolved, long past grief affects right under the surface” (p. 269). What is worse: to never ask about feelings of loss because it might bring hurt out in the open, or to medicate and program treatment for “behaviors” that may be linked to feelings of loss and grief? Kauffman reported a story of a woman labeled DD who was in a group discussing feelings about the death of a staff member. After hearing many reactions the following occurred:

The young woman sitting next to me jumped up and started waving her arms, pointing at the speaker, and vehemently shouting “How would you feel if you died? How would you feel if you died? How would you feel if you died. How would you feel if you died! How would you feel if you died! How would you feel if you died! How would you feel if you died! How would you feel if you died!

Everyone responded to this woman.

“I’d be sad.”

“I’d be angry. Angry. I’d be angry that I died.”

“I’d be scared.”

The woman then said, “It’s scary. Like a mystery” (p. 270).
Carder (1987) reported about a young man’s reaction to the drowning death of a friend from his institution: “It’s spooky. I dream about it. She was swimming behind me. I was pacing her. I kept looking back and all of a sudden she wasn’t there… Will we go to the funeral? I want to see her again.”(p. 21)

Ghaziuddin (1988) completed a review of charts of 65 British clients with DD who had been referred for treatment due to behavior problems. He focused on life events that may have triggered behavior problems. Four adults had experienced bereavement and three had experienced hospitalization of a parent prior to their treatment referral. Ghaziuddin noted that symptoms are often not viewed from the broader perspective of life events. He noted that the means of expressing distress are much more limited for those with DD.

Singh, Jawed and Wilson (1988) discussed a case report of a developmentally disabled man who became notably more manic six weeks following the death of his father. He made verbal comments about the loss of his father and his affect changed when told of his father’s death. Singh et al., note the importance of acknowledging life stress, especially bereavement on the lives of adults with DD.

McDaniel (1989) described a bereavement group of eight males with DD that ran for 10 weeks. She reported two themes. The first theme was the feeling of being left out of family experiences when someone was very ill, and the second theme was worry over who would look out for them after their parents had died.

McLoughlin (1989) provided a case report of a developmentally disabled woman who first lost her mother and then her father. He reports that following the death of her mother, she began wandering, searching for her mother all over her town. She was then
moved to a group residence, as her father was ill. Her wandering continued for several years before abating. When her father died, she began wandering from her group residence again. McLoughlin argues for more research to be done on ways to decrease the distress of adults with DD facing loss.

Oswin (1991) interviewed individuals with DD and their families. She conducted individual interviews, solicited letters, and completed group sessions in England. She reported the themes, as well as individual stories. At the book’s beginning, she cites one of her 1978 publications in which she described the following evocative scenario:

In the garden of a large mental handicap hospital, a thin, tall, middle-aged woman stood apart from the other women; she was holding a large, brown, knitted doll and looked full of despair. The long legs of the doll were held over the woman’s hips, her hands were clasped behind its back; she looked down onto its soft shapeless face and moved her lips, then lifted it and kissed it. The staff explained that this woman had only been living in the hospital for six months. She had come when both her elderly parents had died within a few months of each other and there was nobody else to look after her. “It’s about time she got over it,” a member of the staff said. “She won’t do anything and she won’t be separated from that old doll. She brought that from home. We don’t mind her having it, of course, but it reminds her of home too much. She should be over all that by now, as she’s got quite a lot of sense” (page102). [pp. 13-14]

Oswin explained how she had stated in 1978 that more should be done to understand how to help bereaved people with DD. In her 1991 work, she states that staff often focuses on the disability. They don’t expect to see, therefore miss recognition of
signs of grief. She speaks of the secondary losses of home and community that isolate the grieving individual even further. For those who already live in a residential placement, she reports that some adults are simply told ‘‘you won’t be visited anymore’’ after a parent dies, and they may connect this with punishment or rejection” (p. 29). Oswin describes the disempowered position of adults with DD in society and the misguided efforts to protect them from reality.

She reported five themes from family input. The themes included concerns about telling the person with DD about a death and widows struggling with their own desire to pretend they hadn’t loss their spouse. Also cited were the fears of the remaining parent about their own mortality, as well as the son or daughter’s fears about losing their last parent; enmeshment; and finally, feelings of loneliness and wanting help.

Oswin then discussed the special needs of those multiply disabled adults who were placed in residential care. She speaks of the loss of the structure and security of the long term-type of care they had received:

…in the way they were helped to eat and drink, their clothes, the lights, smells, and sounds of the house, foods and drinks, cups and spoons, the way of being lifted, held and touched, of being washed, dressed, and talked to. All this suddenly disappears when they are admitted to residential care. (p. 80)

She reports somatic problems that develop after placement such as “digestive disorders, headaches, loss of weight” (pp. 80-81). She cited reports of three adults of middle age who died within a year of placement following parent death. Their deaths were attributed to heart attacks. One case story of a man whose father died included nursing reports of “bedwetting, ‘bad temper’, ‘spitting’, ‘hitting radiators’, ‘swearing’, and ‘attention
seeking’. (p. 116). The records indicated the instruction to staff was to ignore these behaviors.

Oswin also provided information from a group of bereaved adults with DD. The themes they shared included that “’keeping a person company’ and talking to them was helpful.” (p. 133). They also shared:

“We are sad when people die.”

“We are lonely.”

“Friends can help.”

“When people are kind and talk to us, are friends, it helps the loneliness and sadness.” (p. 133)

She also reported the helpfulness of continuing family rituals that were valued.

Oswin’s findings are best summarized by, “The differences between experiences of loss for people without learning difficulties and those with learning difficulties was shown not in the reaction of the latter group but in their vulnerability and in other people’s attitudes towards them. (p. 142)

Hedger and Smith (1993) described a death education group that involved training professionals in which the professionals, in turn, did a death education group with adults with DD. The curriculum included discussion of life cycles of plants, animals, and humans, as well as discussion of feelings. Hedger and Smith reported, “Many can recognize and identify stages in the life cycle and relate this, in some way, to themselves as individuals. It was also found that people with a DD/MR go through stages of mourning as unique individuals.” (p. 35)
In 1995, Sue Read established a counseling/support center for those with learning disabilities experiencing loss or bereavement (Read, 1996). She reports that initially she began counseling specifically those with DD around bereavement with steady referrals, and then came the requests to address counseling to cope with the myriad of losses for this population.

Dell’Aquila (1996) interviewed fourteen individuals with developmental disabilities for a qualitative study of impact of life events on grief experiences. She noted that her participants had few opportunities to process the thoughts and feeling around most life experiences and that this was especially true for bereavement experiences. She found “the social experience of being developmentally disabled does create a disadvantaged state from which to approach grief” (p. 108).

Bonnell-Pascual et al. (1999) completed a study of bereavement in adults with learning disabilities five years following the initial measurement of grief symptoms at two years post-loss. The authors noted that from quantitative data gathered “it was hard to disentangle… the effects of the bereavement itself and the effects of associated life changes” (p. 350). From the qualitative data, however, the authors noted an extended period of mourning, as well as the “continuing sense of loss… demonstrated through things such as tearfulness, crying out for the deceased parent, mood swings and physical symptoms” (p. 350).

Read (2000) provides a qualitative analysis of a bereavement counseling program over twelve months. The program included services to help clients deal with losses of all types. Action research was utilized through the development and use of focus groups with the bereavement counselors. Read noted that “there was a perceived ‘gap’ in the
bereavement counseling service, but the professionals involved did not know how, or in what way, the service needed to be adapted in order to accommodate this [learning disabled] client group” (p. 22).

Read reported the counselors likes and dislikes working with people with LD. The likes included the feelings of success in seeing the client empowered, using concrete interventions (art, stories, remembering), and openness and honesty of the counseling relationship. The dislikes included the lack of clear counseling guidelines and resources, feeling inadequate to help with all the needs, only being allowed to work on one aspect of the client’s life, timing and evaluating actions (were they helpful?), challenges due to complications with confidentiality and assessing if the client really wanted to be there or was being compliant, and how to end. The counselors found work with adults with LD to be similar to all bereavement work by the challenge of evaluation of success, parallels of difficulties ending mirrored work with older adults, and what were termed boundary and informed consent issues said to parallel work with children. Differences between typical clients and clients with LD were noted to be types of interventions and level of language used, attention spans were shorter for the clients with LD, and the counselors became more fatigued from doing more verbal work. A recommendation made by Read is that evaluation forms be developed that are pictorial with simple language. She noted that “working with bereaved people with a learning disability, bereavement counselors often witness profound sadness that they can perceive but may never fully comprehend” (p. 31).

MacHale and Carey (2002) studied 20 bereaved and 20 non-bereaved adults with DD to determine impact of the death of a primary caregiver on subjects’ mental health
status and behavior. The cross-sectional study used support staff to complete measures, finding significantly higher neurotic disorders, organic conditions, irritability, lethargy, and hyperactivity in the bereaved group. Proxy ratings and lack of pre-bereavement ratings limit this study’s generalizability.

Two intervention studies (Read, Papakosta-Harvey & Bower, 2000; Stoddard, Burke & Temple, 2002) were completed that focused on bereavement support group outcomes and outcomes of a workshop on loss. Read et al.’s qualitative study of an eight member loss workshop group uncovered two key themes from interviews: confusion and frustration with understanding the loss, and loss causing them to lose control of important life decisions. Stoddard et al. completed pre- and post-tests prior to a bereavement group. Anxiety scores and understanding of death scores did not change significantly. Depression scores were found to be reduced after treatment. It was found that participants with dual diagnoses had significantly lower depression scores after treatment. Only 21 referred participants were evaluated. It is not clear specifically what was addressed in the groups or how the study links to current bereavement theory.

Gualt (2003) presents a case study about work with a 55-year old man whose father had died six years earlier. The man was not included in the funeral for his father. He had displayed agitation that continued to escalate, especially when death was mentioned. Gualt describes staff creating a life event book with the client. He incorporated photographs of friends and family into the book. A counselor began work with the client that included death education. Eventually, a church service was planned to honor his father. The client attended, supported by staff. “He is now able to go into a
church, say a prayer for his father and light a candle in his memory. This was simply not possible before counseling” (p. 27).

Clements, Focht-New and Faulkner (2004) present two case studies of adults with DD, and one case study of a child. The adult male, James, had anxiety about sleeping after being prescribed a heart medication. He said his grandmother had died in her sleep two years ago. James had little information about his own condition or his grandmother’s death. Medication, group and staff support were provided to James to increase his understanding and coping. Sabrina, a 46-year old woman lost her mother at a young age and was raised by her grandmother. Three years after her grandmother died, Sabrina was having difficulties traced back to her grief over her grandmother’s death. The counselor used a storybook about grief and loss to help normalize Sabrina’s feelings. Her progress was slow but steady, and she requested the book about grief at every session.

In 2004, Read and Papakosta-Harvey replicated work with an earlier grief group comprised of individuals with DD. They employed grounded theory and narrative analysis to analyze the taped sessions. Death of loved ones, death of pets, moves, and divorces were included in the list of losses. Of the now reported ten participants, 7 had experienced multiple losses. Responses to loss included:

- Physical reactions (“it made me kick out”; “a sense of shock”; “I cried”)
- Emotional reactions (“upset”; “angry”; “sad”; “annoyed”; “felt down in the dumps”)
- Cognitive reactions (“why me?”; “you always remember the bad news”; “blaming self and others”; “wanting to be involved and knowing the truth about loved ones’ illness and death”)
• Behavioral reactions (dealing with anger) (p. 204). Participants found supportive staff and family, memories and dreams helpful. One indicated medication helped with anger and group counseling also was reported to be helpful. Another stated she regretted no one offered counseling at the time of loss.

Current research by Dodd, Dowling and Hollins (2005) describes bereavement work with 60 bereaved adults with DD. The interviewers used photographs, art, books, and pictures to supplement verbal communication, while observing body language and affect. “Some people cried or clasped and unclasped their hands. What these research participants were ‘saying’ could be captured through qualitative methodologies, interviews and observation.” (p. 541).

Kauffman (2005), in his Guidebook for Helping Persons with Mental Retardation Mourn, ties his work to Theresa Rando, Ken Doka and John Bowlby. He provides case studies of adults with DD that illustrate “behavioral language of grief” (p. 41). “The grief language of persons with mental retardation discloses intellectual capacities that are no less powerful, complex, subtle, disturbing, deep, and spiritual than found in the more discursive and dialectical grief language of persons without mental retardation” (p. 41). He includes examples of psychological reactions to grief that include anger, aggression, anxiety, compulsive behavior, dependence, and ambivalence. Through case stories of his own research preparatory to writing his book, he describes the loss history, the behavior, and his interventions. He does an excellent job pointing out the role of the environment in supporting or challenging grief work. “The communities in which a person with mental retardation lives are the social environments in which he experiences himself; so grief
support needs to begin with recognition of grief by the community in which the person lives." (p. 8) Kauffman’s book is also written as a guide for counselors in working with adults with DD.

Dowling, Hubert, White and Hollins (2006) report on a study completed with 31 adults with LD. Eleven received an integrated intervention and 20 received a counseling intervention. The integrated intervention was given by day program caregivers and home-based caregivers who had received training. The home-based providers focused on activities related to remembering and honoring the loss. The day-based providers were to focus on the future and not encourage talk of the loss. This intervention was based on Stroebe and Schut’s Dual Process Model. The integrated intervention group faced many challenges with implementation and only one participant improved. That participant had bereavement counselors implementing the program.

On the other hand, Dowling, et al.’s (2006) counseling intervention group received 15 sessions of counseling from bereavement counselors who were given a two-day training on LD. The counselors used a variety of techniques including art, books, and photographs. Quantitative and qualitative data were collected. Improvement was noted for the counseling group on two measures except for one portion: inappropriate speech. Qualitative data reflected positive changes from the perspective of the participants, staff, and families. The bereavement counselors noted surprise at the success of their efforts. They were challenged by the communication issues, but were pleased that they found creative ways around barriers. They felt personal satisfaction that their work was successful. Finally, they noted their own professional and personal growth from the
experience. They noted the richness and depth of the counseling relationships they developed.

It has only been in the recent past that adults with DD have been asked to speak for themselves, providing researchers with limited knowledge about their lived experience. The context of their experience must be explored, including their living situation, their supports, and remaining family, as parental bereavement is often a life altering event for everyone with or without disability (Angell et al., 1998).

Cognitive differences do exist, yet do emotional processes differ? Since the time of Freud, social scientists have struggled to explain and predict the outcome of bereavement for the general population. Attachment theory and stress and coping theory are two frameworks among many that have been applied to the issue of bereavement. Clear understanding of the complex process of bereavement has still not been achieved in the empirical world. Adding developmental disability to the people in either of these existing frameworks creates even greater uncertainty as to outcomes.

Existing Literature on Grief Intervention for Adults with DD

Incorporated into the exploration of the experience of bereavement for adults with DD, bereavement counselors were asked what helped and what hindered the grief process. They were asked what interventions they used to assist bereaved adults with DD. These responses are compared with the research-based literature. In addition, since literature has begun to appear on interventions with adults with DD, a brief summary is provided for comparison.
As described earlier, Kauffman (2005) provides clinical intervention examples, as well as program development guidance based on his work with adult with DD, in his *Guidebook for Helping Persons with Mental Retardation Mourn*.

Read (2005) provides research-based guidance for bereavement work with adult with DD. She states that “creative approaches (incorporating the therapeutic use of life story books, memory books, photographs, drawing, …poetry and reminiscence work) are all recognized ways of helping bereaved people with learning disabilities” (p. 35). She promotes attending funerals, providing decision-making support and open communication with caregivers. Read is clear that adults should be treated as adults. They should not just be allowed to grieve, but encouraged and supported to grieve. This all pre-supposes knowledgeable and open communication by the caregivers. She recommends a model of support based on death education; ongoing participation in life cycle losses and opportunities; and intervention based on assessing, supporting, normalizing grief, educating about death and referring to formal grief counseling when indicated.

Markell (2005) developed a book to guide establishing grief rituals for people with DD. He notes the need for activities that are concrete in nature with clear and simple instruction, yet symbolic in nature. He suggests twenty different ideas, such as using photographs to spark memories, storytelling, sorting and storing possessions of the deceased, and planting a tree or flower. He notes his ideas are not really different from rituals suggested for the non-disabled population, but gives clear ideas how to implement each activity. Case example notes are included. His efforts should help counselors in de-mystifying bereavement interventions for those with DD.
Luchterhand and Murphy’s 1998 book, *Helping Adults with Mental Retardation Grieve a Death Loss*, is designed to guide caregivers and professionals in accompanying adults with DD through bereavement. The book describes 108 rituals and activities designed to help adults with MR. A final chapter is devoted to screening for professional assistance.

Cassin (n.d.) developed a publication from the State of Maine’s Office of Learning and Development. The publication includes articles on grief and loss, as well as suggestions for intervention. Within this publication, Lavin outlines differences between how loss and death affect people with DD and without DD. She notes their lack of inclusion in preparation for loss limits their ability to learn and practice coping skills. Another difference is the protection mindset by caregivers that is linked to lack of learning coping skills. Lavin also states most people with DD don’t receive acknowledgement or support for their losses. Despite impairments, she points out, each person has unique abilities and is capable of coping. Concrete and active interventions are recommended. Recall and transferability of skills may be limited within the DD population. Some adults have an egocentric view of the world, which Lavin likens to a child’s view. She implies that an adult with DD may feel more responsible for deaths or losses than an adult without DD. Also noted is the limited size and strength of support networks for many adults with DD. Verbal communication may not be a strength, so communication by behavior is key. Lavin recommends “role playing, visits to mortuaries, noting deaths in nature related to the change of seasons, caring for animals, and drawing feelings related to death and loss” (p. 54). Lavin offers a listing of recommendations for
caregivers. This handbook provides other chapters and recommendations for interventions that have been seen as helpful to adults with DD in their grieving process.

Van Dyke’s (2003) book provides guidance with language (concrete and to-the-point) to use in counseling, and techniques, such as use of balloons and peanuts. Balloons, as described by one of the participants can be released to demonstrate the soul leaving the earth. Peanuts are used also as concrete examples of a shell of a body and a soul or spirit inside. Van Dyke also provides protocols for a six-session grief group. She incorporates the use of spiritual beliefs in her interventions. She illustrates points with concise and moving case stories.

Down’s Syndrome Scotland provides a downloadable handout about loss, *Coping with Loss*, written by Marsden (2005) and a booklet, *Let’s Talk about Death* by Watchman (n.d.). Both are well done and can be accessed at http://www.ds Scot land.org.uk

The above publications provide a mix of intervention ideas, grief theory, and background on people with DD. The materials are appropriate for practitioners, as well as caregivers or family members.

**Significance of Pursuing Research on Bereavement for Adults with DD**

Exploring bereavement after parental death or death of a loved one for adults with DD is important because a knowledge base about the nature of the bereavement experience for this population is very limited and the need for informed guidance is so great. The assumption that adults with DD understand death concept the same as children of the same developmental level has been put in question by Kennedy (2000), Levelle
Assumptions regarding lack of ability to attach have been challenged by early efforts to document feelings of grief after loss and bereavement (Bonnell-Pascual et al., 1999; Dell’Aquila, 1996; MacHale & Carey, 2002). Dell’Aquila (1996) and Kauffman (1994) argue that continued adherence to these assumptions, in fact, could cause harm in denying expression of human emotion. In addition, it is irresponsible to apply general bereavement theory to persons with DD. Generalizing findings from studies conducted using adults without DD to those using adults with DD assumes that they grieve the same as the general population, with the same risk factors for atypical grief. Such generalization assumes adults with DD need the same grief interventions at the same time as the general population. How responsible is this when their lives are often lived out in different spaces and contexts than the general population with less personal control over their decisions and activities? As Dell’Aquila noted, adults with DD do not have avenues to process feelings about relatively minor emotional experiences. Will bereavement losses be more complicated due to accumulations of long ignored feelings? Will bereavement losses have greater impact on their lives? Will health care professionals continue to treat emotional disturbances that could be bereavement reactions with medication and behavior programs and not address the underlying problem? Intentional practice needs a strong theory base. The theory base is currently nonexistent for adults with DD experiencing bereavement.

The need to document the bereavement experiences of adults with DD and compare them to adults without DD is the course researchers need to pursue. This study proposes to accomplish both the exploration of adult stories of bereavement influenced
by DD through the eyes of bereavement counselors and the comparison of those stories to those related by persons not influenced by this experience. Bereavement counselors serve a wide range of children and adults and are able to provide some comparisons from their practices with different populations. The study was completed by interviewing bereavement counselors experienced in working with adult clients with DD following the death of the client’s parent or loved one. The experiences conveyed are compared to extant bereavement literature based on and derived from the general population to look for commonalities and differences. The best way to begin this search for knowledge was from the path of qualitative research.

Need for Qualitative Approach

Why qualitative research? There are two compelling schools of thought, both supportive of this methodology. The first is that not enough is known about persons with DD and bereavement, and qualitative research provides a base (Devers & Robinson, 2002). The second is that grief that results from bereavement is not an entity that can be objectively measured and explained by quantitative methods (Bryman, 1984).

When we speak of ‘quantitative’ or ‘qualitative’ methodologies, we are, in the final analyses speaking of an interrelated set of assumptions about the social world which are philosophical, ideological, and epistemological. They encompass more than simply data gathering techniques. (p. 87)

It is the premise of this proposal that the phenomenon of grief is not an entity that can be known and described as a static event; neither can it be measured separately from the researcher and the subjects. The researchers join the participants in this search for the reality of loss that can only be known in the “realm of the knower” (Smith, 1983 p. 46).
The complexity of the social worlds of the participants is acknowledged, as Smith noted, and is too complex for laws of causality. Two noted bereavement theorists, Phyllis Silverman and Dennis Klass (1996), discussed the appropriateness of research methods to study grief: “[The empiricist] approach dismisses the subjective experiences of people and minimizes the importance of relationships in the human experience because these are difficult to study in their model” (p. 21). In Continuing Bonds: New Understandings of Grief, Silverman & Klass (1996) state:

Researchers applying qualitative methods do not set out to verify a hypothesis or to prove a preconceived theory. They are instead reporting on what people experience and the way people make meaning out of their experiences. Using this method, it is possible to hear and legitimate the web of relationships in which the bereaved are involved, including that with the deceased. (p. 22)

Strauss & Corbin (1998) echo the argument for use of qualitative methods when the aim of the research “attempts to understand the meaning or nature of experience of persons” (p. 11).

My own model of grief is important as Kirk and Reid (2002) state: “How that problematic or undesirable state is understood by the practitioner is usually relevant to the selection of the intervention and its objectives.” (p. 71) This is true for researchers as well. It is not just the methodology (for instance, a comparison group study versus structured interviews) that is important. What is key is how I view reality and how I can come to “know” a social and emotional phenomenon termed bereavement. I view bereavement as a complex, multi-layered phenomena. There are behaviors that can be observed and noted, but there is another level of experience that only a person living in
that situation can describe and explain. A challenge exists for me to be clear about my
own background, but to bracket my own perceptions as I gather and read the data. I have
already made the point that bereavement for adults with DD is new territory. Coupling
the state of research with my own perspective on reality mandates the use of qualitative
study. The proposed study will utilize qualitative research techniques in general, and
grounded theory specifically. As noted by Devers and Robinson (2002):

Qualitative methodologies presuppose the existence of multiple subjective
realities that are continually being constructed and revised, the importance of
interactional dynamics and the inherent worth and credibility of the participants
(subjects, as well as researchers). They are particularly well-suited to explore
phenomena that have not yet been fully described, that are social and interactional
in nature, and are both complex and multifactorial” (p. 242).

Research, whether quantitative or qualitative, is aimed at “discovery and
explication of theory” (Devers & Robinson, p. 242). Grounded theory, as developed by
Glaser and Strauss (1967/1999), works to derive theory from the data as they are
collected from participants. “Grounded theory research is an inductive method of inquiry
that yields substantive, or middle-range theory following a rigorous analysis of data from
a variety of sources, most commonly, detailed semi-structured open interviews (Glaser &
Strauss, 1967)” (as cited by Devers & Robinson, p. 243). Thematic content is presented
alongside extant literature for comparison. Charmaz (1990) described four phases of
implementing grounded theory: creating and refining the research, data, and the
collection questions; raising terms of concepts; asking more conceptual questions on a
generic level; and making further discoveries and clarifying concepts through writing and
rewriting (p. 1162). The data are examined for concepts, concepts are reviewed looking for repeated themes, and relationships are analyzed between theoretical categories.

The following chapter explains the methodology in detail, including the sampling criteria, data collection techniques, proposed questions, data analytic strategy, and data analysis. This chapter defining the methodology will provide a roadmap to the construction of a grounded theory explanation of bereavement following the death of a parent or loved one for adults with DD from the perspective of their bereavement counselors. The knowledge gained from this study can then lead to an informed, intentional practice with the growing population of adults with DD whose parent or loved one has died.
CHAPTER TWO: METHODOLOGY

To construct a grounded theory explanation of bereavement for adults with DD following the death of a parent or loved one, sampling, data collection, data analytic strategy, and analysis must be determined. In the following section on sampling, the process and criteria for selection are reviewed. At the end of this section, dialogue includes: efforts to limit possible harm to participants, consent issues, confidentiality, and how study information is made available to participants at the project end. The chapter ends with a discussion of how my background and belief system may impact my role as a researcher, particularly with regard to the questions asked, the data collection strategy, and most importantly, the analysis.

Sampling

The first decision to be made was sampling technique and scope.

I requested permission to recruit 20 bereavement counselors who have worked with adults with DD around loss of a parent or loved one. Recruitment was via letters to bereavement counselors at hospices throughout the nation and to bereavement counselors known or identified through hospices. Pursuant to the letter, telephone calls were made to the hospices or counselors to further advise them about the study. After consultation with my dissertation chair, it was decided to include counselors who had had even one client with DD. It was recognized that interviews might provide rich data or could be so scant that little depth is shared. The decision was made to be inclusive in the interviews, allowing participants with any level of experience to share their stories.
Human Subjects Protection

Three key concepts must be considered when evaluating a research proposal with human subjects. The principles of justice, respect, and beneficence from the 1979 Belmont Report provide a platform for evaluating the benefits versus risks of the study. Justice demands that we listen to and honor the often-ignored losses of adults with developmental disabilities. Justice was the first principle to be reviewed. I have a duty to include bereavement counselors who work with adults with DD in bereavement research. Assuming persons with DD experience bereavement the same as the general population and grieve the same way as the general population can potentially do damage. Respect is the next principle. Although the presence of a developmental disability may limit clients’ ability for verbal interaction and dialogue, the counselors have attempted to serve their clients with the goal of providing support easing emotional pain. These counselors are breaking ground in a little discussed arena. This leads us to the third principle: benevolence. The price of silence evoked by continued disregard for the experiences of bereavement for adults with DD and the challenges faced by their counselors is high. It is imperative we pursue understanding of bereavement for this population. Until understanding is gained, harm will continue to be done through lack of understanding of unique processes. In addition, inappropriate responses, such as medicating misunderstood behaviors, may be prevented. The study gives voice to the counselors’ compassion and support for a population many avoid.

Plan For Obtaining Informed Consent

Participants were mailed or emailed a letter describing the study, and a telephone call ensued. Consent forms were mailed or faxed and were returned prior to the interview.
**Procedures To Ensure Confidentiality**

The following procedures were utilized to ensure confidentiality:

- Audiotapes, computer copies, and hard copies of data and consent forms were kept in a locked environment.
- Audiotapes were transcribed by a professional transcriber who signed a confidentiality agreement.
- Initial or assigned letters (Participant A, B, C, and so forth) only will be used in transcriptions.
- Audiotapes and transcription copies will be destroyed at the end of the required 3-year period and prior to year 4.
- No real names or initials are used in final report.
- All participants were emailed or mailed the transcript to approve before use.
- No names are used to report demographic information.
- Interviews are used for analysis of themes, categories, and development of grounded theory around bereavement after parental death for adults with DD. Direct quotations are used to illustrate points.
- If a summary request was made, the summary request, which can be separated from the consent form, will be destroyed after the copy of the report is mailed.

**Feedback To Participants About Results Of The Study**

A summary of the results is to be mailed to participants after the study completion. Verbal presentation of the results to any interested group or organization will be given on request. Several providers who were not study participants have emailed requests for the summary report.
Data Collection

A semi-structured interview format with primarily open-ended questions was used. Open-ended questions were used to elicit the unique story of each participant. The final data were from a semi-structured interviews with bereavement counselors who had worked with adults with DD post-loss.

Project and Interview Protocol

The protocol included:

- Sending letters to hospices/bereavement counselors in the region, then expanding as needed. (Sending a letter by email was added in an amendment.)
- Calling grief counselor or bereavement department of hospices and explaining the study.
- Asking if persons with cognitive disabilities have been served there. If no, thank them for their time.
- Asking if I could send or fax a flier and consent form to counselors serving those clients. Explaining I will mail a hard copy of the consent and need to have it returned before I can set up interview.
- Sending or faxing flier and consent
- Mailing hard copy of consent with SASE
- Answering questions by phone or email.
- Once the consent was returned, calling to set up interview.
- Participants living within 100 miles of researcher
  - Taped in-person or phone interviews determined by participant choice
• Participants living over 100 miles from researcher
  • Taped phone interviews- may be able to arrange in-person interviews in special circumstances
  • Sending copy of transcript to participant for revision or corrections or both.

Recruitment was based on obtaining a convenience sample. Some elements of snowball sampling were evident within the agencies or corporation-linked hospices. Listings of hospices were located on line by searching for the state and “hospice and palliative care organization”. I also searched and found an online guide to counselors in the Seattle, Washington area and sent letters or emails to five who indicated they provided grief counseling. A web search also located a counselor in Texas who provided bereavement counseling as well as counseling to adults with DD. I sent her a recruitment letter. Approximately 350 general recruiting letters or emails were sent. Approximately 125 follow-up phone contacts or voice mails were completed.
  • Letters were sent to hospices in the local area and to a known bereavement counselor in my town. Follow-up phone calls were completed.
  • Letters were sent to hospices in Idaho, Washington, and Oregon. Follow-up calls were made to hospices.
  • Letters were also sent to grief counselors listed in online or telephone directories, as they were located. One in Texas and several in the Seattle, Washington areas were found.
  • Letters were sent to approximately half of California hospices. The remainder received emails with the letter attached. Follow-up calls were initiated.
• When emails returned as undeliverable, letters were sent.

• When the Pacific Northwest did not provide enough participants, the researcher expanded to include New York, Vermont, Arizona, and Florida to provide a broader base sampling.

• Arizona and Florida were selected primarily due to email directories being more available. The telephone contact process began in New York, Arizona, and Florida. Telephone recruiting ended when 20 participants had indicated interest.

After phone contact and explanation of the study, consents were sent to 26 bereavement counselors. Consents were received back from 23 bereavement counselors, all affiliated with a hospice bereavement program. One participant who completed the consent process was eliminated before the interview because she realized her only contact had been with an individual under the age of 18. Toward the final days of the study, one potential participant returned a consent form sent to someone else at her agency. When called, she described limited experience in the past and said she would wait to see if she was really needed for more data input. I had reached data saturation by that point and decided to not include her. Another participant returned her consent over six weeks after it was sent out. I was finalizing the study and felt confident no new data would alter the themes. I left two phone messages offering to include her if she could participate in the interview that week, but she did not respond. The total number of participants interviewed was 19. I then eliminated one participant who related her comments to older adults with Alzheimer’s Disease. During the interview, the participant could not identify any client with DD that fit the criteria for also having a developmental disability. I did
pay her as a participant, but did not use her data. After scrutiny in the selection process, I used data from 18 participants for the analysis. All participants performed bereavement work for a hospice.

Participants

Participants included six from Washington State, four from California, one from Arizona, one from Florida, one from Oregon, and five from New York. (See Table 1) The counselors’ educational background was varied. Half (nine of the participants) had their Masters in Social Work (MSW). There were two with Master of Arts in Marriage and Family Therapy (MFT), four with Master of Arts in Counseling, one with a Masters of Arts in Art Therapy, four with Master of Arts in Divinity, one of whom also had a doctorate in Divinity. One participant had two Master of Arts degrees, one in divinity, and one in counseling. (See Table 2)

The participants worked with a variety of bereavement clients, some for hospice-related deaths only, and some with bereavement around hospice-related deaths and non-hospice deaths. Several bereavement counselors rendered outreach to the community, specifically into group homes. Half of the participants had previous experience interacting and working with persons with DD. One bereavement counselor did not have current bereavement experience at hospice working with adults with DD, but had previous residential work experience with adults with DD and had supported them through a loss. This participant also had experience with three hospice clients with DD who were themselves dying. Although the participants gave rough estimates of the numbers of clients with DD served, these estimates add up to well over 300 adults with DD. As the participants spoke, their experiences and observations were not just based on
experience with one client with DD. Two participants had each served over 100 adults with DD. In addition, eight of the participants had worked with between four and ten adults with DD. (See Tables 3 and 4 for experience information.) Perhaps the data would have been enhanced if I had asked the participants to speak of one particular client and the demographics of that client. However, as the participants spoke of their experiences, most offered insights from working with multiple clients with DD. The participants spoke of trends in general of this client group, as well as unique reactions of clients.

The fact that some participants saw clients who had not been supported by hospice during the death of a loved one is important to recognize. Most of the participants were able to discuss a variety of scenarios of notification and inclusion. Hospice agencies work to include all family members into the death preparation and support services. If hospice-only bereavement clients were seen, only one view of bereavement would be reported. The fact that many bereavement counselors worked with adults with DD around non-hospice deaths provides more realistic data. In addition, several participants mentioned that they do automatic follow-up when a hospice death occurs. This means that family members are contacted for bereavement assessment. Intervention is offered. This is important, as it is evidence that some of the clients with DD being referenced in this study are not necessarily referred due to a severe or pathological grief response. Also, participants mentioned their outreach role with group homes. They may offer bereavement support services to residents of a group home without a specific targeted client identified. Understanding how adults with DD entered the bereavement system provides more evidence that the clients being discussed are not just a group of clients with severe grief reactions.
Only one interview was completed in-person. The other participants elected to be interviewed by telephone or were further than 100 miles from my location necessitating a telephone interview.
<table>
<thead>
<tr>
<th>STATE</th>
<th>Number of Participants</th>
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<tbody>
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<td>1</td>
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<tr>
<td>Washington</td>
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<tr>
<td>New York</td>
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<td>California</td>
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<td>Oregon</td>
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Table 2.

**Participant Educational Background**

<table>
<thead>
<tr>
<th>DEGREE</th>
<th>Number of Participants</th>
</tr>
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<tbody>
<tr>
<td>Masters – Social Work</td>
<td>1</td>
</tr>
<tr>
<td>Masters - Counseling</td>
<td>2</td>
</tr>
<tr>
<td>Masters – Divinity or Religious Studies</td>
<td>3</td>
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<tr>
<td>Masters – Family Therapy</td>
<td>4</td>
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<tr>
<td>Masters – Art Therapy</td>
<td>5</td>
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<tr>
<td>Doctorate - Ministry</td>
<td>6</td>
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</tbody>
</table>

It is noted that one participant held two Master of Arts degrees. One has an MA and a Doctorate in Ministry.
### Table 3.

**Participant Experience Serving Adults with DD**

<table>
<thead>
<tr>
<th>Number of DD Clients served</th>
<th>Number of participants (counselors)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
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* One participant worked with 3 dying hospice clients & multiple adults with DD in a previous job

** One participant described experience only as < 10.
Table 4.

*Years of experience in bereavement counseling*

<table>
<thead>
<tr>
<th>Number of years of experience</th>
<th>Number of participants</th>
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<tbody>
<tr>
<td></td>
<td>1</td>
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<td>1 - 2</td>
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<td>6 - 8</td>
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<td>9 - 10</td>
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<td>12 - 15</td>
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</table>
Semi-structured interview questions:

Demographics:
  Years as grief/bereavement counselor?
  Educational background/licensure?
  Approximate number of individuals with DD served?
  Type of agency/practice?
  County/State?

Client related questions:

1. When you have received a referral for a client with a cognitive disability due to
deat of a parent or loved one what have been reasons for the referrals
  (triggering events or behaviors)?
2. How have your clients with cognitive disabilities found out about the death or
  that the parent/loved one is dying?
3. When did they find out?
4. Have you found that your clients with cognitive disabilities attend the
  funeral/memorial services?
5. How did the clients show their grief?
6. What generally has been helpful for clients in dealing with their losses?
7. What has hindered clients with DD coping with their loss?
8. What interventions have been useful in helping these clients cope with their
  loss?
9. What impact has the death had on the rest of the client’s life?
10. What other types of losses have most of your clients with DD experienced?

11. How are clients with DD different than your other grief counseling clients?

12. How are they the same?

13. What do you think would be most helpful for adults with cognitive disabilities to better prepare them for dealing with death of parents/family members?

14. Loss in general?

15. What has been helpful to you in preparing yourself to work with adults with cognitive disabilities?

16. What would you recommend for other counselors to increase their expertise with this population?

Thank you for your time.
Data Analytic Strategy

My study is a grounded theory methodology. Grounded theory is one way of developing theory in an area where little research exists. In grounded theory, building of the explanation for the phenomena is an integral part of the research process (Strauss & Corbin, 1998). I did not just use an existing theory to explain the experience of bereavement for adults with DD. While data were being gathered, they were compared and analyzed. Explanations of the phenomena being studied were developed through the process of exploring the depth of the emerging concepts in the data and how they were interrelated (Strauss & Corbin, 1998). Bereavement for adults with DD is a field of study with little theoretical grounding, as demonstrated in the literature review. I questioned whether existing theory can adequately explain the phenomena of bereavement for adults with DD. As Glaser and Strauss (1995) point out, “Grounded theory can help forestall the opportunistic use of theories that have dubious fit and working capacity.” (p. 4) I worked to develop substantive theory in the area of bereavement for adults with DD, taking data provided by participating bereavement counselors and looking to see the higher abstraction of their actual words (Glaser & Strauss, 1999). I will now explain how I proceeded to gather and analyze the data collected.

The data were taped interviews of bereavement counselors. In order to be able to analyze the data, the tape-recorded interviews were transcribed in standard text by a professional transcriptionist. After receiving the transcriptions, I utilized Atlas.ti software to assist in managing and coding the data. As Strauss and Corbin (1998) describe, the text was reviewed and analyzed using open coding. Parts of the text were “microanalyzed” (p.57) which allows the words to be viewed in many contexts, “opening up” (p. 102) the
meanings of words, phrases, and sentences. Coding is done for identified processes that help identify connections between topics, actions and how they came to be, assumptions about the participants and consequences of the processes, and actions and assumptions about the actions (Charmaz, 1990). Charmaz’s questions were utilized when coding data: “(1) Of what larger process is this action a part? (2) How did this action (belief, definition, relationship, pattern or structure) evolve? (3) What do these data state or assume about self and about relationships?” (p. 1168). As Charmaz notes, the coding and categorizing of data “help to build an analysis of the data rather than remain at the level of ethnographic description” (p. 1167).

Data analyses are presented in Chapters Three and Four. Chapter Three includes the coding and layers of analysis that led to the conceptual categories under the first theme. Before proceeding, I will define terms.

Raw codes are developed in the first level of coding, grouping obvious concepts and comments together, and naming them. Raw codes are italicized. Conceptual categories evolve after looking deeper into the raw codes and asking what those codes really represent and how those concepts, events or observations fit together. Conceptual categories represent a deeper analysis of the data. Conceptual categories are indicated by capitalizing the first letter of each word, such as Coping Challenges. I am also using two themes that tie the categories together under a broader schema. Each theme will be discussed in a different chapter. Themes are indicated by capitalizing the first letter of the word, and bolding, such as Disconnection.

The raw codes evolved while completing initial analysis of the data. New raw codes were added during subsequent reviews. Toward the last phase of analysis, inter-
related codes were absorbed into larger categories to reduce the number of codes repeatedly until six categories remained. I completed further questioning and analysis, altering the categories and the name of the second theme. The six final codes are grouped into two major themes.

The Researcher And Analysis

I have worked in hospice settings for six years and with people with DD for nineteen years. This background gives me credibility in analyzing this particular data, but adds a responsibility in being accountable for interpretation of the data based on my experience and background. As noted by Strauss and Corbin (1998a), this professional knowledge allows a deeper awareness of issues that are brought out by the participants. On the other hand, how I situate myself with regard to disability has a profound affect on how I see and hear the data. My perspective is resonant with the social model of disability that views the environment and society as disabling. The deficits are not situated in the person. The person would flourish if barriers were removed (Mackelprang & Salsgiver, 1999). Furthermore, in line with DePoy and Gilson (2004), disability is viewed as constructed. Although I am not imposing these views on the participants or on the data, it affects how I filter and interpret what is said, and how I frame and organize the data. I bracket my own views as much as possible. However, I understand my worldview will impact the interpretation and analysis phase of research. The point at which this interpretation becomes most evident is where the codes that emerged from the data and the deeper meanings are explored. Additionally, the counselors who participated report the clients’ experiences from their own filters and perspectives, which have been influenced by their own life experiences and professional education. I experienced a true
interplay with the participants and did note “reciprocal shaping” (Strauss &
Corbin, 1998b, p. 173). The constant challenge was making sure that the codes and
themes really emerged from the data, not from my previous knowledge or other readings.
Great care was exerted to take concepts that emerged and then to reaffirm that the data
were there to support them.

To keep the work grounded in the data, a challenge noted by Strauss and Corbin (1998b), I must first explain how I reached my conclusions about how to code the raw
data. I need verification that my codes are consistent with another researcher's. I must
then explain the basis by which I coded certain statements, such as coping, or loss, or
discomfort. The thought processes that produced these codes into categories for me must
be then made transparent to the reader.

To begin the process, I began to make notes about the data and my questions and
observations at the start of data analysis. Observations were made about the codes as they
were developed. I was able to truly immerse myself in the data by clearing most of my
schedule and blocking quiet times alone with the data. Atlas.ti was a helpful tool in terms
of providing software to make notes about possible codes, making ongoing memos and
code comments, and tracking quotations. The network feature allowed visual
diagramming of the relationship of the codes to each other. I also observed that time
away from the data allowed ideas to “simmer” and rise to the top of consciousness while
I was in the midst of other activities.

After initial reading of the data, I then went back to the text and started open
coding some of the words and phrases, looking at themes of some of the meanings, and
finding similarities. Moving through the text, the next job was to reduce the number of
codes identified and to find themes. Labels were given and categories created. Connally (2003) describes this as an interpretive phase. “Axial coding” (Strauss & Corbin, 1998a p. 126) is a procedure that also was used to help illustrate the dimensions of the categories and how the categories might relate to each other. This process involves looking for subcategories, as well. As Charmaz (1990) states, I would be “raising terms to concepts” (p. 1168). “When treating a term as a conceptual category, the researcher specifies its properties, notes the conditions under which it arises, relates how it changes, describes its consequences, and ultimately, specifies its relationship to other conceptual categories” (p. 1168). Raw codes were numerous. They were reorganized and reduced for the purpose of identifying categories of themes. Originally, a code for protection was developed, as well as a code for protection versus preparation. These codes were merged. Help and hinders were codes that were deleted, because they seemed too vague. A more specific code, “caregiver/staff discomfort” was broadened to “discomfort”. “Family support” was included in the broader category of “connecting”.

Interviews continued to add data until no new categories or properties were emerging, or to the point of saturation. Saturation was close after 12 interviews. After 15, it was clear no further categories were going to emerge. Nineteen interviews were completed.

A colleague was given three interviews to blind code. She was later given a list of my original codes, merging history and rationale for the conceptual categories and themes to verify my analysis. My chairperson also read the codes and to ascertain agreement with whether or not they truly represented the data.
For each category named, it is necessary to question and discuss what the category means, when it is of concern, what are the consequences of it being absent, how it is achieved, and whether it ever was not an issue (Charmaz, 1990). During this phase, constant comparison was performed while continuing to question the data. Constant comparison means the bereavement counselors’ reported experiences about work with adults with DD were compared to each other. With the addition of tracking, how the categories themselves were associated or compared to each other adds another layer of depth to analysis.

The categorical codes are organized and discussed under two broader themes. The first is Disconnection and is discussed in Chapter Three. The second is Growth, which is discussed in Chapter Four. Chapter Five includes the discussion of how the codes, concepts, and themes from the data relate back to the existing literature.
CHAPTER THREE: DISCONNECTION

According to *Webster’s New World Dictionary* (1988), disconnected means “separated, detached…broken up into unrelated parts” (p. 391). **Disconnection** is the state of being detached, apart, not joined to others. The first set of categorical concepts that emerged as part of the grounded theory explanation of bereavement for adults with DD, consisted of: Loss, Coping Challenges, and Grief Response. These are grouped under the theme of **Disconnection**, since the data speak of the obstacles faced by adults with DD during bereavement. The discussion of **Disconnection** will be presented first, followed by descriptions of the conceptual categories, and an account as to how the raw codes defined the categories and led to the overall theme. Fictitious names have been given to the participants who tell the story of **Disconnection**.

To address Charmaz’s (1990) questions, first it should be asked why **Disconnection** is a concern. **Disconnection** is significant because it implies a lack of unity and coherence, a separateness, or even possible segregation. It is important to know from what a person is disconnected. In the case of a person disconnecting from an abusive or violent relationship, the implication is far different than in the instance of separating from a loving family or losing touch with reality. For a whole population to be viewed as disconnected implies large scale powerlessness and despair. While the consequences of being connected are those of feeling supported, unified and a sense of being “together”, the consequences of being disconnected are a sense of insecurity or abandonment, of being scattered, or of not having a grip on reality. **Disconnection** occurs when one physically or cognitively separates the self from others, or one separates
feelings or beliefs from actions. **Disconnection** is not an issue when one has strong social support, a solid grounding in reality, and congruence between feelings, thoughts, and actions. But where these elements are missing, as is often the case with adults with DD, **Disconnection** widens the gap between this population and the rest of society. For the group of clients discussed by the participants in this study, **Disconnection** has many causes and implications. **Disconnection** is a theme that reflects the lack of social status of adults with DD. These individuals have but a peripheral presence among us. Being on the periphery, information often is not delivered directly and participation in life appears almost haphazard. At times, being sent to the sidelines of life by caregivers is deliberate and is cloaked as protection. At other times, not being invited or included in life’s rituals appears to be the result of oversight. Individuals with DD are simply forgotten.

Participating bereavement counselors noted that their clients with DD generally had small social networks and received limited social support. The counselors reported that cognitive challenges created barriers for the clients with DD in understanding the reality of a death that often was further complicated by an insufficiency or absence of information. Participants outlined the frustrations and obstacles many adults with DD face in processing their grief including isolation, lack of information and understanding of death, and lack of knowledge regarding coping skills. If the adults with DD did have methods with which to soothe themselves, those may be actions that would be punished or medicated. The journeys of grief that the participants described were marked by frustrations and obstructions. Little groundwork is currently being done to help guide adults with DD through grief and loss. Many unintended consequences emerge as the result of sometimes well-intended protective reactions. The participants noted that the
feelings of grief were not always understood either by the client or by the caregiver attempting to serve the client. The counselors found their task was to guide their clients in linking how they were feeling and thinking to their behavioral response to bereavement. Ideally, the counselor’s goal is to educate families and caregivers about grief and about what are typical and acceptable responses. The adult client with DD was perceived to be further isolated by a lack of understanding of typical grief responses within themselves. This was seen to be complicated by the lack of understanding by caregivers as to how the adult client with DD should be approached. Many adults with DD are dependent on caregivers for daily needs and decision-making. Often these caregivers were presented as well-intentioned but uninformed. It is necessary to acknowledge that those providing the care and guidance for bereaved adults with DD live in a society that avoids discussion of death and dying and any attendant display of deep feelings. Little is done to educate around grief and loss issues for any of society’s members, disabled or non-disabled. I asked participating bereavement counselors about their work specifically with adults with DD who had experienced death of a parent or loved one. The participants spoke of the primary loss due to the death and the secondary losses that followed. I then asked them to discuss the broader loss history that may have preceded the death and those losses that followed death. These data were grouped into the category of Loss.

Another dimension of bereavement are the coping processes for dealing with change and loss. Over one’s lifespan, events occur and milestones are reached or bypassed. How the general public reacts and responds to these events is shown by literature to be individual and widely varied. The participants articulated clearly that loss history and the way in which people with DD are regarded impacts how bereaved adults
with DD are able to or attempt to cope. It must be noted that the participants in this study were bereavement counselors. They informed me about bereaved adults with DD. They reported consistently that working with adults with DD who had not experienced problems coping was the exception, not the norm. Bereavement counselors generally see the clients who are not coping well with bereavement. Many challenges in coping specifically identifiable to this population came to light and enough data was gathered on Coping Challenges for it to become another conceptual category. Yet another dimension of loss embraces the emotions of the bereaved, as well as the feelings of their caregivers and the professionals assigned to serve them. By including a discussion of emotions within Coping Challenges rather than Loss, a thicker and more substantive description of the emotions of loss is achieved.

The final category in this chapter is Grief Response. This category is about the thoughts and feelings associated with the loss for the adult with DD and how they were communicated to the counselor participants. Behavior was typically the initial vehicle for communicating the reaction to loss. The data in this category illustrate the emotional, cognitive, and behavioral texture of the response to the death loss. The informants paint pictures of how painful loss is and how it was seen to affects mind, body, and spirit of adults with DD. An appreciation for the far-reaching affects of Disconnection is better illustrated by viewing it through the three lenses of loss, coping challenges, and grief response.

Loss will be discussed first, as the death of a loved one is just one event preceded by or followed by a long history of changes, moves, transitions, and lost opportunities.
Loss

Loss has been defined many ways. Generally, it implies something is missing or harmed. *Webster’s New World Dictionary* (1988) definition of loss includes “damage…disadvantage” (p. 799). Damage, in turn, is defined as “injury or harm to a person or thing, resulting in a loss in soundness or value” (p. 348). Loss was the reason the counselors in this study came to know their clients, and primary loss through death was usually the event preceding the bereavement referral. Other losses were noted as the work with the adult with DD unfolded. Loss is a rich category with many dimensions. In this case, it incorporates secondary losses including changes, moves and transitions triggered by the death, and a history of past losses of people, relationships, status, spaces, and opportunities, to name only a few. Casualties of self-esteem and opportunity are fitting examples of the intensely personal damage experienced as losses. The participants had the privilege and the heartbreak of seeing and hearing the clients’ experiences of being devalued and of witnessing the layers of their losses as they journeyed through life. Though I heard it secondhand, the effect was still staggering.

The themes of the narratives link to a broader chronicle about our Western society. *Death/feeling denial society* was a raw code developed from comments about how society avoids talk of death and gives mixed messages about strong emotions. Societal avoidance of uncomfortable topics forms the roots of the category Loss. I finally saw this code of Loss as the macro embodiment of the theme, *Disconnection*. Adults with DD growing up in Western culture suffer the same disadvantage as most of its citizens in this regard. The societal avoidance may affect all citizens of all ages and abilities. It speaks to a risk of *Disconnection* shared by all who live in Western society.
Suppression can start when we are young and continue as we age, until very few wish to speak of death or of deep emotions. We are told to toughen up or to look at the bright side. When we grieve, we are told to hurry and get over it, to move on. One of the participants, Chris, stated, “There seems to be a general societal urge to just get on with it.”

Elizabeth spoke of the tendency of our society to avoid the subjects of death and grief:

I think we can do a lot better in general, just with children as they continue to grow up, talking with them about losses, talking with them about feelings, helping them to understand what feelings come with loss, helping them to understand what to do with those feelings, how do we cope with feelings when we have them. I think we could do a lot better job, you know, but I think that that’s something that most of us struggle with. We just don’t know how to do that. We don’t know how to talk about those things. You know, even people who are clinicians sometimes struggle with how to talk about that. What do we do? How do we tell people how to cope with feelings, and how do we teach them to cope with feelings and, … I just do so much, I just try so hard to do so much of that and try to help people understand how to do that. But I think we definitely could do a better job. Sometimes I think we do a better job at teaching kids math than we do at teaching them how to cope with their feelings.

The impact of this societal belief system will be related throughout the data and serves as a backdrop for making sense of the origins of the disconnections. Another participant, Jessica, discussed how most children are raised with death as a taboo subject:
I think the world needs to get on the bandwagon about educating children. I mean, it’s really funny in this day and age, the hush-hush - don’t let the kids know, and whisked from out of the room, and, you know, just like try to keep secrets from them.

When asked how to better prepare adults with DD for inevitable losses, Chris answered, “How do you prepare this entire society?” When answering the same question, Amy pointed out:

You know, include them in the whole grieving process. And what we recommend for kids, now, if their pet dies, have a little funeral with a box and bury them in the backyard and have a little ritual, teach them about the cycle of life and things like that. The reality is that until you’re there, nobody really listens.

The fear of death and the overwhelming emotions of grief trigger the urge to protect children and those perceived to be vulnerable. When an adult is perceived as vulnerable and unable to make decisions, this is yet another loss. Lost is independence and control over personal choice or destiny that adults without DD are able to experience. Adults with the label of “disability” also lose privilege to information and their participation in events is screened. Adults with DD rarely receive full disclosure about moves, changes, illness, or deaths that directly affect them. Participants often made parallels to adults with DD being as disempowered as children and being given no control or input.

With the stage set for denial and avoidance of death, another phenomena, that of protection, emerged. This code appeared early with links to frequent citations. Some participants even used the term “overprotect”, such as when Marta referred to
“overprotective caregivers”. The word protection can mean safety, kept from harm or attack, planning in anticipation of problems. Protection became a concern when it impeded preparation, inhibited building coping skills, or prevented exploration and social connections. The consequences of not being protected are being at-risk, being taken advantage of, or being harmed, but overprotection can mean deprivation of opportunities for growth, exploration, and maturation. Overprotection was identified when parents and caregivers were not entirely honest; gave limited information about illness, death, or transitions; and prevented adults with DD from fully participating in caregiving or hospital visits to the sick and or dying. Overprotection creates a loss of freedom, growth, information, and understanding. Nicole described how her clients have experienced protection by the limiting of information about the imminent death:

Probably the most common [form of overprotection] would be that the person is involved, at some level, but maybe there are still some things being withheld, “to protect” the person, and they’re not really given the full information that be the most helpful to them. I guess sometimes there’s this tendency to protect and to not, oh, I don’t know if the word is trust, but to not allow for the person to have their range of feelings, but a concern about that and so they’re maybe not given all the information that would be helpful to them.

When asked what hindered adults with DD coping with loss, Elizabeth expressed concerns about the denial of the opportunity to be involved or say goodbye:

Not bringing them to say goodbye. That’s, I think, the most severe thing that can happen is that they’ve, even if they’re living in a boarding care home, they’ve had a relationship with their parent, and not wanting to bring them to the facility or to
wherever it is that this person is dying, so they’re not even telling them. And then, of course, not taking them to a service.

Protection was noted as parallel to work with children who are grieving. Parents and caregivers were perceived as viewing adults with DD as vulnerable and the parents and caregivers were described as struggling with how much to share, educate, and involve them. Chris noted that the protective strategies only complicated the bereavement experience for her clients with DD. “There is this more socially normal avoidance of talking to children and disabled people about death, and that was one of the big factors of why, I think, they had such difficult times.”

Overall, participants presented families and caregivers as being misguided in their efforts to protect the adults with DD from pain. Amy said, “I think sometimes we’re misguided in our wanting to protect people from something that happens in life, just is a normal natural thing to happen.” Limiting information and preventing early preparation or participation in death and dying discussions was described as well intentioned but unhealthy for the adult with DD. I view the overprotection and lack of preparation and coping skills as unintended consequences of well-meaning caregivers.

If I had retained protection as a conceptual category, I would have renamed it Protection/Dependence. I asked myself if protection really was denial of rights. After consideration of all the protection issues inherent to research committees for human subjects protection, and attempting to originally get the voices of adults with DD into my research process (see Appendix F), I became sensitized to the rights issues. I wondered about caregiver and guardian fear and discomfort underlying the protective actions. I had experienced what I believed to be fears of governing bodies putting participants with DD
at risk, as well as the possible discomfort and fears of individual members of these
governing bodies. I knew it had been my role to demonstrate protection in my protocols
and I struggled with the issue of the amount of protection offered. When does protection
really deny participation? I heard the statement by seasoned bereavement counselors that
protection impedes preparation for loss and grief.

Protection and overprotection were often linked with the idea of disenfranchised
grief, and it was also associated with the experience of children. Protection was viewed
as encompassing a later code, delayed notification/limited inclusion. I began to consider
delayed notification/limited inclusion as consequences of protection or overprotection,
again, often a result of the dependence of the adults with DD on guardians or caregivers.
As I continued to interpret the data, protection began to look like yet another of the losses
experienced by adults with DD. Protection and overprotection can embody a denial of
typical opportunity for knowledge and inclusion that most adults believe are their
entitlement. Growing up and being included in adult discussions and decisions is often a
missing milestone if one is labeled DD. Reviewing the comments on protection and on
loss, I could see a direct relationship with coping obstacles or challenges. The data clearly
describe counselor perceptions of the clients’ limitations of coping skills and few layers
of defenses against stress. Was the information about coping challenges another category
of information, or just one more loss in the long list of missed opportunities and missing
relationships? I decided to keep Coping Challenges as a separate category.

Another code, staff/caregiver misperceptions, was linked to comments regarding
lack of specific knowledge about what is best practice in grief work and death education.
The misperceptions were stronger when associated with protection issues. This code was
merged with protection. Later, when the consequences of protection were analyzed further, misperceptions were seen as resonant with the larger category of Loss. Comments alluding to the need for more education were linked to the conceptual category Connecting, which was later broken into Being Honored and Being Together. Overprotection, loss of involvement and loss of inclusion were less of an issue when hospice guidance was in place for the caregivers. The counselors believed they could better serve their clients when the family and other team members had clinical supervision and support. This will be addressed in the sections on Being Honored and Being Together.

Loss also involves history of loss, which is the lifelong accumulation of social injuries, missing developmental events, moves, changes, and separations from friends, roommates, family, and schools. Change is constant was an early raw code. This code reflected that life is a constant series of changes and losses. The code was too vague and could be captured by History of loss and later, just Loss as the conceptual category.

History of loss was a rich code with multiple quotations from the data. The history of loss code involves the realization for an adult with DD that their life was not equal to the lives of others without disability. Few achieve careers, marriages, cars, mortgages and families. “The good life” as seen on TV is rarely their experience. Unfortunately, most live in poverty. If they work, they worry about making too much money and jeopardizing their Supplemental Security Income.

Another major loss that emerges is the lack of regard. Societal ignorance of people with disabilities, especially cognitive disabilities adds to the myths and fears about them. That adults with DD are forgotten, just like children, is often mentioned. Their
presence is not noted. They are described as living almost in the shadows of their families at times of crisis, or are viewed as somehow not the same as the rest of humanity, with feelings and needs overlooked. Data originally included under the raw code *parallels to children* in regard to being forgotten, like children, were merged with Loss. As a result of overprotection, the adult with DD is noted as consciously told only partial information or deliberately kept uninformed. The data bring out another phenomenon of literally being forgotten. “Forgotten” and “invisible” were words frequently mentioned in connection to adults with DD. They were termed “forgotten mourners” or “disenfranchised”, like children. The inference was “being overlooked”. I created a code *forgotten/invisible* that I renamed *disregard*. Eventually, I merged disregard into the larger category of Loss. *Disregard* as a raw code was determined to be different than overprotection. Losses related to disregard have their roots in the historical treatment of people with disabilities. Dave describes how past policies and the present status quo affect bereavement for adults with DD:

The loss of independence, the loss of all of the usual milestones that everyone else reaches in their life, or many people, the loss of their family because they would be “put away”. A lot of these people are still alive today. If you were mentally retarded, you were very often just automatically put in a home and never seen again by your family. So there was the loss of family; there’s a loss, I think, of privacy; a loss of comfort and intimacy, and safety, particularly for the people who were institutionalized. There’s a loss of the milestones – graduating high school. And I think the two biggest things, particularly for developmentally disabled people who understand that they are developmentally disabled and can
compare themselves with people who are not, they know there’s two things
missing from their lives and that’s a job and a marriage. Those are two things that
I think that they miss the most and actually will verbalize that those are the things
they really want out of life, that they wish that they could have. And some
actually pursue it with some difficulty. When I worked, this is over 20 years ago
and these were the actual diagnoses, in their charts from the 1920s, 30s and 40s
was “idiot”, “imbecile”, “moron”. That was an insult. In one of the group homes I
used to work in, they would get angry at each other and call each other low
functioning.

Dave noted that adults with DD have lost dignity and self regard by being labeled.

Kim sums up history of loss by saying:

The universe seems to bring them loss after loss after loss after loss. But I’m not
just talking about, you know, human loss. I’m talking about health loss. I’m
talking about financial loss, security loss, relationship loss. It’s just multiple.

Alecia described the losses and the awareness of difference many adults with DD
share:

Just because they’re retarded doesn’t mean that they’re not aware of what they
don’t have. You know, they don’t have the wife, they don’t have the house, they
don’t have a big wedding, they don’t have children. They see how other people
live and they know that their life is not the same, and that’s a terrible sadness, I
think, for some of them.

Echoing the losses and hurt mentioned above, Jan summed up what adults with
DD have observed:
Well, I think they’re aware of the fact that they’re different and that they don’t get
to have the things that other people have. So there’s a loss of being able to marry,
being able to drive, being able to be independent in the world. I think they’re very
aware of their limitations and the fact that they’re not getting to do the things that
other people do, so they’re sort of lifelong losses.

The participants noted that typical milestones had been bypassed for many young
adults with DD. Marta noted for one young woman, “Part of that loss was, ‘I’m too
disabled to drive. I’ve never been able to drive.’ And, that’s a huge milestone for people
as teenagers, [to] get their driver’s license.”

With respect to being overlooked, Alecia explained how many adults with DD
have relationships that are not acknowledged. When that significant person dies, the
family is not even aware they should include their boyfriend or girlfriend in the rituals:

Many of them do have long term relationships with someone and its an
unrecognized relationship, so they aren’t necessarily included The group home
will call the family and the family takes care of the funeral, but that doesn’t mean
that the family includes his girlfriend from 30 years in the whole thing.

Nicole noted that some adults with DD are given delayed death notifications in an
offhand manner. “I mean this is the whole other end of the continuum. [They] might be
told by a staff member that, you know, ‘Your sister called and your father died last
week.’” Chris brings up that adults with DD are often not kept informed, similar to the
situation with children. She refers to them both as disenfranchised. Hannah was outraged
as she told me about one client whose mother had been on a ventilator. “February, March,
April, May, June, the end of June, so five months, I was the only person that spent the
time exploring his feelings with him."

Elizabeth added, “I would say that people forget to think about them. They can’t
call for themselves [for counseling].”

Amy concurred, also pointing out the fact some adults with DD do not have the
ability or the information necessary to refer themselves for help.

I find that people with disabilities don’t refer themselves. They don’t say to
somebody, they don’t call us up and say, “I want counseling,” or, “I need
counseling.” So, generally, they’re getting referred by the people who they’re
living with, which is the same as with children.

The comparison with children is expanded by Nicole:

Because I think that both populations, their grief is sort of disenfranchised in a
way, and so they don’t get as much of an opportunity as other folks in the
population where people approached them and [said], you know, “How are you
doing?” and “I know this must be hard,” and those kinds of things. People don’t
approach children.

Nicole continued with the suggestion that the bereavement process and life in
general, would be healthier if adults with DD were not only included after the fact.

“[J]ust allowing someone to participate in it rather than having it happen to them would
be a good start.”

Attempts are often made to include adults with DD, but their needs are sometimes
forgotten in terms information processing and full disclosure. At times, they seem like
visitors to a world where no maps are included. This is a loss of regard for their individual needs and humanity. Nicole advised:

Make sure [what] you do is fully inform someone so that they’re making an informed decision. So, if you’re saying to them, “Would you like to go in and see your mom? It looks like she may not live much longer. Would you like to go in and kind of say goodbye to her?” then you should tell them what they’re going to see, if it’s like in a hospital where there’s all kinds of tubes and machinery and stuff, that it might look kind of scary, but it’s fine. That there are different noises that are getting made by the machines, and that’s OK. Just give them that information, “Would you like to go to the funeral?” because [that is] something I do with kids a lot, too. They don’t know what a funeral is. Well [if] the person that you’re talking to doesn’t know what that is, they’ve never been to one before, say, “Have you ever been to one before? Would you like to hear what it’s like?” And then just describing whatever you know of it. It’s going to be in a church, it’s going to be in a funeral home, or it’s going to be in the home. These are the kinds of people that’ll be there, and these are the kinds of things that will happen. There’ll be music, there’ll be people crying, so that they’re really able to say, “Yeah, yeah. It sounds like something that I want to do”, or, “You know, no, I don’t think I’m going to be comfortable with that.”

Even early in hospice service provision, when education of the family is done, it was reported that information was often not provided in a manner or at a level that an adult with DD can understand. Bethany stated:
I think that our staff does it, and I’ve taken this back to our nurses and our social workers, they’re not taking into account that these people aren’t processing everything they’re saying and they’re not hearing it the way [staff is] saying it, and they don’t understand. They look like they do [understand], you know, and they’re presenting like, Yeah, we understand. But, if you’ve worked with people with DD before, you pick up these cues that they’re not quite getting it, and yet they’re given the same information a regular functioning person would be given.

Information, participation in care, and attendance at and participation in planning for a funeral or memorial service are regarded by hospice workers as essential components for the grief process. At times, the adult with DD was not kept informed or even invited to participate in the care and ritual surrounding death. When asked what hinders adults with DD coping with grief, Elizabeth answers, “Not bringing them to say goodbye. That’s, I think, the most severe thing that can happen.”

Most of the participants’ clients with DD attended the funeral or memorial, but Nicole questioned whether this was an informed choice and if they had been truly prepared. “And I think sometimes we make assumptions and we don’t give information that’s necessary for them to actually make a decision.”

It was often described as though the adult with DD was invisible in the grieving family. Little early preparation was reported, which was attributed partly to protection, and partly to the assumption that no one thought of it. Marta described the following scenario:

One client’s family just simply didn’t inform her… just sort of did everything around her. So I can say clearly that that was one family. And then I actually met
with her. They put her in a workshop, a sheltered workshop, and I actually met
her at the sheltered workshop, and I think the referral was actually from the
workshop, as I think about it. It was like Mom never showed up at home and they
put her in a board and care and sent her to the workshop. And, of course, she just
vapor locked.

Pat described a similar situation:

This one particular person was never told. They knew their father was in bed and
the mother had said he was tired and when he passed, he was not there when [the
son] came home, and the mother never said where he [the father] went.

It became clear that the counselors believed that lack of preparation created
obstacles. Preparation for Losses was originally used as a raw code. Early preparation
was viewed by participants as helpful and integral part of the hospice philosophy. The
quotes tied to this code were divided, with lack of early preparation/late notification
quotations recoded to the Loss category. Comments referring to work to prepare for
losses were recoded and merged with the Connecting category, which was later changed
to form Being Honored and Being Together.

To be disregarded means to be overlooked, to not be attended to, or to be not
seen. Visibility means easy to be seen, recognized, discerned. It is difficult for the
feelings of a person with DD to be regarded when no really sees her or perceives what
she is trying to communicate. Loss of visibility as a sensitive, responsive fellow being
was noted by counselors. It was reported that lack of knowledge regarding what to look
for and how to support the bereaved adult with DD, frequently results in grief being
ignored by caregivers. Lynn addressed this issue by saying:
They’re young [group home staff] and there’s usually one or two, the manager
and maybe the assistant manager, who are educated, but usually the help, lovely
as they are, and caring as they are, just really don’t understand.

Professionals, as well as family were commonly described as not being aware of
the need to refer the person with DD for help or guidance. The person with DD was
typically described as unable to make the referral themselves, due to their disability.
Other participants noted that there is a misconception that “those people” are unable to
gain from counseling. Some clients had needs that were anticipated and were referred as
a result of the lack of comfort derived from caregivers in meeting those needs.

Another important dimension with respect to the loss of regard must be addressed.
Neglect in paying attention to or failure in making an effort toward understanding
behavior can marginalize attempts by the adult with DD to communicate deep feelings.
Grief related behaviors were often reported to be puzzling, annoying, or misunderstood
by caregivers. Behavior was often reported as being what was noticed, not the person’s
feelings or humanity. Sometimes, if behavior was non-problematic, the assumption was
made that the client is fine. Jessica noted that group home staff often discouraged follow-
up. “ ‘Oh, they’re all better now,’ and they don’t let you come back.”

Lynn’s observation inferred that most caregivers do not allow the adults with DD
to discuss their losses. “[I ] just find that so many people are uncomfortable with just the
topic, that when they have someone who can, [and] who will really listen to them and not
judge them, it’s very helpful.”

Being overlooked can be associated with discomfort, coping obstacles, as well as
with loss. Loss was a deep vein, a major component, in the counselor’s view of the
experience of bereavement for adults with DD. Being separate and becoming invisible is reflected on by Marta:

In the ideal world for me, is that we just have a culture in which however you function, you’re out there in the world functioning at your level and that we don’t have a category for people and a specialness for people. I think it’s the special container that we put people with disabilities in that enhances much more grief around life challenges.

Difference is sometimes met with avoidance or segregation. When speaking of the history of losses for adults with DD, Pat pointed out the following losses that included their separateness:

Loss of their family at a very early age, and then the loss of the family they had adapted to in the institutional environment, and then being brought out into the community that they were never a part of.

Initially, a code Other Issues was implemented, but it was subsequently merged with Other Losses. It became clear that the issues, such as abuse or lack of resources, fit under the broader code of Other Losses and eventually under the conceptual category, Loss.

Sometimes being different from the accepted standard of normal was met with violence. Marta talked of a woman who, despite having grown up with her family, was rejected by her father and suffered abuse at his hands:

She just started discussing the rage towards her father. It was, in fact, because he, he batt[er]ed her because he was mad at her for being mentally retarded. And, so,
it was Mom [who] finally had to throw him out of the house because he was
abusing her.

Paul also had a client whose adopted father died. This young woman, too, had a
history of being severely abused as a child.

As noted under the discussion of protection, events were described as happening
to the individuals with DD. Decisions were reported as rarely being made with them.
Case managers, job coaches, aides, and residential staff came and went. Roommates or
housemates in residential centers were admitted and discharged. Co-workers or other
trainees/students switched programs or moved. We all have life changes, but for adults
with DD, the social circle was described as very small. A ripple in this limited group
could have major effects when the only people that they know besides family are usually
paid to be with them. Isolation/Limited Social Support was an initial attempt to separate
the absence of social support from the presence of social support. Isolation/limited social
support was partly merged with Loss, and partly with Coping Obstacles, as it fit into the
category of other losses faced by adults with DD.

A small social network often intensifies changes that occur within that network.
Jessica stated that the staff changes and reassignment of case managers has tremendous
effects on the residents. She notes that it “adds to the insecurity”. Many of the other
participants concurred that staff changes were a major source of loss and transition for
adults living in residential settings. Most noted that these losses went unrecognized and
disregarded as potential losses to the residents. Lisa described the loss and how it affects
group home residents:
When a staff member leaves one of our facilities, there’s a loss. They always ask, “Well, I wonder what Jane’s doing now. Remember how she used to work with us and she really liked us, and she took us for ice cream?” That type of a loss. So they mourn a staff member leaving, or they mourn a friend moving away, and they mourn the loss of a pet.

The participants described how adults with DD have experienced years of unacknowledged deaths of other residents and of staff. Chris observed, “…then all their other grief issues that they haven’t touched in their lives come rushing out.”

As adults with DD age, losses were described as cumulative. One, then two parents died. The deaths discussed were preceded by numerous other losses, moves and deaths. Jan touches on the issue of cumulative losses.

And it also was the second parent to die in less than a year and a half, so there was a lot of added concern by the time the second parent died. At the time of my working with at least the three that are uppermost in my mind right now, they all had previous deaths. Like the one boy with both parents, the young woman that lost the grandfather a couple of years before the grandmother, my nephew’s dad died.

Residential staff transitions were not always just due to moves and promotions. A staff member’s illness and death could have immense impact when the resident’s circle of friends is small and each relationship has great significance. Dave described a death loss in a residential setting:

When I worked with the mentally retarded, there were some serious deaths. One of them, as a matter of fact, was [when] one of the staff died. She was a young
woman, I think she was only 23. She died of cancer and this was a group of eight mildly retarded women. This was back in the early 80s when we actually virtually lived in the group home with the population. So this was a staff member who was a virtually almost like family, who virtually lived with them in the group home.

Most of us choose the family members with whom we want to stay in touch. Most of us at least know who our family is. Chris’s comments highlight the loss of family history, as well as the weak ties to families that can exist:

Sometimes the family comes from a long distance and shows up all of a sudden from who knows where. And I’ve seen a situation where it totally surprised everybody that knew this person that there was any family involved because he’d been transferred from just one home to another, and all of that information didn’t come with him.

As the participants told the stories of their clients, it became clear that accurate family histories may not be recorded or may not be available for adults with DD living in group situations. The residents may not be able to verbally describe the deaths, the moves, and the lost friendships. When asked about other losses that her clients with DD had experienced, Amy answers:

If I’m working with somebody who’s been in the group home, very often they don’t know the loss history, because that isn’t something that the group home thought to ask or talk about at the time that the person was moved to the group home. So I don’t always have a good loss history, and very often the person themselves can’t tell me a lot about it.
At one time, the life expectancy for adults with DD limited the occurrence of additional disabilities from the aging process, and disease. However, with advances in medical care and treatment, they suffer loss of health and loss of abilities as a result of accidents, and age. Nicole described physical changes in aging. “Folks are aging and so, losses related to just their own bodies changing and that process. So, there’s just a lot that is going on for them that we can focus on in terms of loss.”

Amy described family changes that threaten security, such as divorce and abandonment:

Then they might tell me about other losses - that their parents divorced, or that their dad or their mother abandoned them or left, and they were moved in with their aunt or uncle … and then they moved into some other place.

Adults with DD discussed were not immune to abuse and violence. Loss of physical safety and fear of being hurt or victimized are described by Marta. “When she just started discussing the rage towards her father, Mom finally had to throw him out of the house because he was abusing her. So often the grief work was over loss of safety, in that case.”

Chris added, “There are things [that] came up like murder, watching father drown, watching somebody beat somebody else, , a friend being shot in the street. You know, lots of losses can exist.”

Adults with DD met with bereavement counselors because each had experienced the death of a parent or loved one. As relational beings, humans cannot escape the experience of loss. The deceased may have been someone who filled any of the several important social roles for the adult with DD, including that of primary attachment figure
and caregiver. The deceased may have been the person who came to visit each week or
the one who took the client to their home for holidays. The clients with DD lost mothers,
fathers, friends, and staff to death. Absence of this loved one can leave their social circle
even smaller. Death losses described by the counselors triggered changes socially,
emotionally, physically and behaviorally. The grief reactions to death losses experienced
by these clients will be told by their bereavement counselors in a later section. The
secondary losses that accompanied the death will be outlined here.

Secondary loss was a large initial raw code. It incorporated moves, staff changes,
shrinking of the social circle, fewer visits, and an array of other changes. Secondary
losses are common following the death of a loved one, however, these losses were
reported as having great impact for adults with DD. Their already small social network
was diminished and, as they were frequently dependent on others for their care, the loss
resulted in the need for a replacement in that role if the deceased was the caregiver or
guardian. Secondary losses fit under the larger conceptual category of Loss. Nicole was
asked how the death of a loved one affected her clients with DD. She answered:

[The death has a] huge impact and it might even be that the residence they move
to means they have to change, that it’s not close geographically, so they have a lot
of other losses connected to it. So, the primary loss is Mom or Dad, but then
there’s all these secondary losses of a home that they’re familiar with, a
neighborhood that they’re familiar with, a place of work, maybe, that they’re
familiar with, or a school that they’re familiar with, friends and all of that. So,
that’s a huge upheaval, so for some people, it’s a huge, huge shift that they have
to adjust to.
The death of a loved one was often discussed as being followed by other losses associated with absence of that person. Hannah described how the death of a mother has consequences of also losing the mother’s friends. “The relationships that the person once had in the home, whether it be the mother’s friends who used to come to visit or other family members, you don’t have that activity now.”

Dave discussed his client’s reaction when her adoptive father died. The remaining parent, the mother, had health problems and deteriorating vision. The mother was having her own difficulties dealing with another child in the home, in addition to the loss of her husband. “She lost the person in the family that she felt closest to and when he was gone, next was Mom. She was pretty close to Mom, but the mom wasn’t as available as, as she could have been.”

Any death can trigger changes that profoundly affect the survivors. Shared activities, holidays, and visits will never be recreated and exist only in memories of the past. Jan described feelings of an adult with DD around the loss of a brother. “[He] talked a little bit about the hole that his brother left in certain things and that he knows he won’t have again that were the special things that he shared with his brother.”

An important aspect of loss that was discussed for adults with DD is that the parent is often the caregiver. When the last parent dies, the caregiving role could be left empty. Jan framed this by saying she believes people have to address basic needs before they can really address grief. Her comments addressed the belief that if the loss of a loved one triggers secondary loss of home and provision of care, the secondary loss has to be addressed first.
I have kind of a different outlook on bereavement in general and I use Maslow’s Hierarchy of Needs a lot. If you don’t have food, clothing, and shelter, you can’t do grief work. So, if you’re scared about where am I going to live and how am I going to eat, immediately your mind turns to survival.

The loss of a parent may trigger a move to another family member’s home but often it means an unplanned move to a residential setting with paid caregivers. Amy describes the effects of a move for one young man:

It meant, for him, moving into a group home situation, when his whole entire life he’d lived with his mother, and that was a huge upheaval and a huge adjustment.

So, that really added to his grief, and his grief reaction.

Theresa discussed a similar client situation. “He had to move out of his mother’s home, his family home that he was used to, into a group home, and that was a huge transition for him.” Even if the parents or loved ones did not provide daily care, they often were described as playing important roles in the lives of the adults with DD. Again, the ripple effect of a death in a small social network, appeared to have great impact. Amy described the effects of this type of loss:

It always has some impact in some way, at least with all the people that I’ve worked with, even people who are in a group home in which a family member dies, very often that family member was somebody who contributed to their life somewhere, took them places, visited them, and even though their living situation didn’t change, where they went or what they did changed, or being able to go home to visit changed. Maybe even their financial situation changed because this may have been the person who provided some financial support for them in some
way that now they don’t have. So, I would say just about everyone that I’ve seen, it changed their situation somehow.

Sharon described a young man who had always been over at his grandmother’s helping her around the house and doing her chores. After her death, the young man lost his role as his grandmother’s helper.

When a parent or family member dies, the death affects the rest of the family, as well. When a caregiving parent dies, often the surviving parent or a sibling inherits the caregiving role to perform, frequently unassisted. It is important to recognize that the surviving parent or sibling could still grieving their own loss, and problems may arise. It is often difficult to add new duties when one is overwhelmed by grief, a time when preexisting obligations may seem too much to bear. Jessica described a father who lost his wife and had to step into the sole caregiver role. As she described his efforts to carry on, she noted some problems “because the father was lost, too.”

At times, the adult with DD was depicted as believing it would be unsafe for the security of their care to express their grief, anger or sadness. The counselor perceived that the adult may believe from the actions of the parent or caregiver that the client would be unable to handle the emotions of grief. Lack of security or safety were viewed as interfering with coping based on the assumption that adults with DD were fearful of sharing their true feelings and moving unimpeded through grief. Nicole described the loss of a secure base that hindered her client’s coping as “feeling like they couldn’t talk about it because it would upset the other person, so they had to keep it to themselves.”

The death of a family member may alter the stability of the family. The adult child with DD may be worried about the tears, sadness and preoccupation of other
surviving family members. The adult with DD may not want to further stress their family members and instead may give cues that she is fine. In other cases, the adult with DD may act out his own feelings and confusion about the family changes. As noted by the participants, loss of safety or an insecure base may be demonstrated when the adult with DD interprets the environment as not being safe and concludes the caregivers will not be able to manage if the adult with DD shows their true emotions.

[They can’t show their emotions] because then their parents cry and they think that they’re making them cry, and so, therefore, it’s not a good thing to talk about what’s sad because it makes them [the parents] cry and it’s their fault. (Jessica)

Sometimes the caregivers may doubt their own abilities to provide a secure, safe setting. Nicole pointed out that “people that are around them [the adult with DD] are concerned about whether or not they’ll be able to help them and contain that [emotion].”

Children, as well as adults with DD who are dependent on caregivers to meet their basic needs, were also noted to keep their feelings from the caregiver if they sensed the caregiver would be overwhelmed or unable to handle their feelings. Nicole added that they were “feeling like they couldn’t talk about it because it would upset the other person, so they had to kind of keep it to themselves.”

Reactions to not having security or safety include losing control, feeling unable to cope, withdrawing, lashing out. Paul described one of his clients who was having difficulties after her father died. “But the mom wasn’t as available as she could have been, not unusual in a family where one parent dies. But, in this case, her needs for that attention were pretty high and she wasn’t getting it.” If the adult with DD believes the caregiver is not capable of managing her grief, the adults with DD may just shut down.
their own emotions. Marta painted a clear picture of her work with a young woman who had determined when it was safe and unsafe to express her deep grief:

The one I’m working with now, we are just holding her grief. [M]any of us are working with her just to hold her grief and let her express it because she is shutting it off like a faucet and then she opens it up when we’re with her and then she shuts it off and, so, we’re just being that container until she can get stopped leaking.

Counselors explained that sometimes, the loss of a parent left the adult with DD with an unsafe or non-nurturing caregiving parent. When dependent on others for daily needs, this could cause fear or unhappiness for the adult with DD, compounded upon the grief of the death. Amy tells about a young woman whose father died. The father had been the primary support and positive influence in the client’s life.

I’m thinking in one particular situation with a disabled adult who lived at home, and her father died, and there was not a good relationship with her mother, and everything got very, very complicated and it ended up being just a really awful situation and her grief just got worse and worse and worse because she was so unhappy with where she was and where she was living, and it didn’t feel like she was being treated very well by her mother. I think that really makes it a lot harder, when you’re in a situation that there just isn’t somebody around that you feel comfortable with or that you feel safe with and you begin to feel not safe in your environment because maybe the person who provided the safety in your environment died, and now [is gone, you] just feel so alone and, and so vulnerable.
In the eyes of the participants, sometimes caring others are present, but they often were too uncomfortable with grief to allow the adult with DD to mourn. It then was viewed as the job of the bereavement counselor to provide that witnessing and holding of the grief.

Comments related to the security of the relationship with a caregiver and the safety of expressing grief were coded as Security/safety. This code was identified early in the interview process. Having ‘security/safety’ provided an avenue was believed to help the client move forward with grief. I eventually split the interview data tied to this raw code to link with larger categories. The passages that referred to loss of security and safety were merged with Loss. Those quotes that referred to the presence or building of ‘security/safety’ were merged with Connecting. Later, the comments about Connecting were moved to the renamed Being Together category. Structure evolved as a raw code from comments about need for structure in the counseling activities and in the home environment. Structure was linked with security/safety, as both were believed to help create a predictable environment. Within the constraints of structure, consequences are understood and trust could be built. In one sense, I saw lack of structure comments needing to be merged with Loss. Comments about the benefits of structure were merged with the Connecting category that was later changed to incorporate the Being Honored category.

When reviewing data related to loss, comments about lack of trust emerged. Trust was initially viewed as a raw code. Trust was mentioned as a necessary part of the counseling process. The counselors believed they had to demonstrate that they would actively listen and witness. The issue of trust was also implied in comments made about
the client not sharing feelings with caregivers for fear they could not handle the pain. I wondered if trust-building was more important with adults with DD, or if they were more trusting than adults without DD. Several counselors mentioned their clients’ willingness to engage in treatment, more so than adults without DD. It became apparent, with deeper questioning, that lack of trust was viewed as leading to lack of safety and was a Loss. Building of trust led to feelings of security and was part of Connecting. In essence, observations related to trust were divided between Loss and Connecting. Comments merged with Connecting were moved into the new category, Being Together.

In summary, the category of loss was formed from raw codes including:

- Death/feeling denial society
- Change is constant
- History of losses
- Isolation/limited social support
- Other issues
- Other losses
- Disregard; parallels to children protection; staff/caregiver misperceptions; lack of early preparation/inclusion; preparation for losses
- Secondary losses
- Security/safety; structure; trust

The raw codes formed the foundation for the categorical concept of loss. The data tells the counselors view of adults with DD growing up in a death and grief avoidant society. Loss of opportunities, financial well-being, careers and dreams often seen as the result for those labeled as cognitively disabled. The cognitive disability is believed to
have created obstacles to being privileged to information, full inclusion in decision-
making, or early preparation for any sort of loss or change. In Western society, cognitive
disability usually translates as dependence on others. If the adult is in the care of well-
meaning but ill-informed others, the result may be perpetuated unintended losses of
securely attached relationships. If the parent or caregiver dies, domino-affect secondary
losses were described as being set in motion. Small social networks were often said to be
dramatically reduced by the loss of a family member, roommate, or staff resulting in
emotional losses, as well as social, recreational, and resource losses. The data up to this
point, paint a picture of problems located outside the individual adult. Loss and change,
as the participants tell us, are inevitable. For adults who are dependent on others, how the
caregivers, parents, guardians, and staff help the adults prepare for loss and change is
viewed as crucial. For the adults with DD discussed so far, the scorecard shows the
participants believe that they see unintended consequences of loss heaped on loss. It is
not surprising that the next conceptual category that emerged was Grief Response.

Grief Response

“How do adults with DD show their grief?” This interview question triggered
responses primarily about behaviors and emotions. *Webster’s New World Dictionary*
(1988) defines grief as “intense emotional suffering…” (p. 593). Response is a reaction.
‘Grief response’ was an initial code that was deleted early in analysis. At first I believed
that showing feelings and behaviors separately better illustrates the bereavement
experience for adults with DD. After many reviews of the data, I realized the participants
were telling me that behavior could not be separated from emotion. *Grief behavior versus
grief language* as a raw code was tied to reports regarding a limited capacity to speak or
an inability to find the right words to express their feelings. Acting out the feelings was
the usual means of expression.

Grief response for the adult with DD is of as much concern as it is a key part of
bereavement for the typical person. Since one of the research questions is about the
bereavement experience, grief response is a salient aspect to explore. The general
bereavement literature provides material for comparison to bereavement of adults with
DD. The general grief literature does note that some people do appear to behave as if
unaffected by grief and do not mourn as others expect (Bonnano & Field, 2001). Nolen-
Hoeksema and Larson (1999) also include lack of apparent emotion as part of the initial
phase of grief. If adults with DD did not show grief symptoms or any change in behavior
after a loss, it would be important to document. The opposite, however, is well illustrated
in the data. Behaviors and feelings were reported to be very much linked with grief and
loss responses and these behaviors were often presented to the counselor as negative. The
work to tie behaviors to feelings and thoughts became viewed as the task of the
counselor. I noted that I often had to ask for behaviors to be described. Behaviors were
depicted by the counselors in a matter-of-fact tone. The feelings, however, were
described passionately. The tenor of the data inferred that the counselors read the
behavior, then translated it to a feeling. They then focused on the feeling. I wrote a memo
about the data early on commenting on the fact the counselors had made observations,
then analyzed and interpreted what was being experienced by the adults with DD. The
counselors had witnessed the primary experience and had filtered it for me with their own
interpretations.
I had developed an early code named *Grief-related feelings* to encompass anger, sadness, loneliness, and guilt. Sadness, loneliness, and anger were initially raw codes. I began to see that they fit into the category of grief-related feelings. The feelings had graphic qualities to them. The feelings usually had strong adjectives, like “extremely sad”, “deep, deep grieving”, “the deep feelings which are usually sadness”, “the deep sadness”, and “loneliness was huge”. The feelings were intense. This triggered a code I developed later that I named *intensity of grief feelings*.

Part of the grief response that I thought early on might be missing from the data was *searching*. However, *searching* was identified in the middle of the interviewing process. Participants began to clearly identify behaviors as searching and I was able to go back to earlier interviews and see that searching had been there, I just had not recognized it. The questions regarding where the loved one was now is clearly linked with the quest to locate the loved one. The reported pursuit to locate the bereaved is resonant with Nolen-Hoeksema and Larson’s (1999) inclusion of searching into the second or middle phase for cognitive reactions of grief stage theories. *Searching* is a grief reaction. It was merged first with *grief response*, and then with *discomfort*. *Searching* ended up in the Grief Response category.

Unsurprisingly, *behavior change* emerged quickly in the data and remained prominent. *Behavior change* as a code was linked with verbal communication challenges, as well as grief behavior versus language and with grief reaction. The change in the behavior was often the referral trigger for non-routine follow up. Reported behavior changes included: crying, outbursts, hyperactivity, restlessness, telling the story over and over, lack of motivation, appearance of not being affected, sobbing, and isolating self. A
few of the participants noted self-referrals for help. These behavior changes will be compared with existing literature in Chapter 5.

The intensity of the grief emotions was noted earlier. *Intensity of grief feelings* was also subsumed under a broader code, *grief-related feelings*. During the data collection, I noted the feelings, but during analysis, I really felt the impact of the depth of those feelings. Later, I merged grief-related feelings into the larger category of Discomfort. As analysis progressed, I merged this code back into Grief Response. The feelings were intense and undesirable for both the client and the caregiver. By merging into one larger feeling-related category, grief emotions were presented as a dimension of the bereavement experience. One of the first raw codes to be identified was *anger*. I noted early in the process that *anger* was mentioned repeatedly. The colleague who checked my coding also recognized anger as a response while performing her blind coding. I wondered whether the anger was due to lack of being included, as well as anger at losing someone the bereaved cared about. In any event, *anger* was clearly related to the loss.

It was stated by all participants that anger was part of the typical human response to loss. Anger was expressed in words and described in actions. Hitting, striking out, were noted in *behavior changes*. I viewed outbursts, striking out, hitting as physical manifestations of anger. For one client of a participant, excessive drinking was noted, which could be a response to the feeling of anger. Adults with DD were described as often lacking words for their anger. Anger seemed to be given substance by the actions of the bereaved. Kubler-Ross (1969) said:
This stage of anger is very difficult to cope with from the point of view of family and staff. The reason for this is the fact that this anger is displaced in all directions and projected onto the environment at times almost at random (p. 50).

The ideas of displaced anger fit with behavioral descriptions of lashing out. These behaviors may have been confusing and upsetting for the caregivers, especially if they sought to find the immediately preceding triggers for the hitting or lashing out. I also wondered about the assumptions that were made about the anger. When history is not known, verbal communication is limited, and only the recent death is identified, anger could be related to other occurrences or memories not immediately connected to the death.

The participants usually noted that behavior had changed after the loss, so the anger was most likely linked to the loss or the events surrounding the loss, such as a trauma response. Later, I wondered if anger really fit under the broader category of feelings, as sadness, loneliness, and a list of other emotions began to emerge. Further into the process, I began to see grief feelings as just one facet of the category of grief response. Chris remarked on anger triggered by the unplanned emergency response initiated by a neighbor not familiar with the hospice protocol:

When the death occurred, the neighbor’s boyfriend called the rescue squad. And, of course, hospice doesn’t do that. So, there was a big mess to that at the same time that it happened. So, he had that memory and that experience to cope with and he was a little angry about that at first.

At one point, I grouped feelings of discomfort for clients, caregivers and professionals as under a raw code named *Discomfort*. As I worked the data, I began to see
that this classification minimized the reactions of the bereaved. The response to loss discussed was intense. It was at this point I decided it was necessary to break out the grief reaction. I struggled with separating feelings from behaviors, but in the case of adults with DD, I realized that in doing so I would not accurately be reporting the data.

Behavior was reported to convey the feelings in a very eloquent way. For most of the clients discussed, behavior could not be separated from emotion. Viewing feelings and behaviors as dimensions of the bereavement experience for adults with DD brought a deeper understanding of the experience. Counselors reported that communicating through behavior is a key piece of the bereavement experience for adults with DD that is more manifest than for adults without DD. If verbal communication is limited, behavior is the natural way to communicate needs. Also, as noted by participants, adults with DD often did not have words to accurately describe the intensity of their feelings, even when they had verbal communication skills. The participants often made comparisons between the expressions of grief in adults with DD and expression of grief in children through behavior due to the limitations of their vocabulary.

Referrals were triggered predominantly by behavior. Behavioral cues were given repeatedly. The data clearly indicated that many adults with DD were viewed as speaking through their behavior. Connecting behavior to the meaning behind it was believed to be a major part of the work for many of the bereavement counselors. The counselors felt they must understand the grief-related behaviors in order to assess and assist their clients. Lisa described how most of her clients display their grief:

Those types of issues are usually acting out, with my particular clientele, it’s mainly behavioral. You know, they’re extremely sad, they’re extremely angry,
those types of issues. Either they’re extremely sad, depressed, or, in their work environment, they’re acting out, they’re exhibiting behaviors that they normally don’t exhibit: anger, slapping another client, acting out… those types of behaviors.

Lynn described behavioral, and physical symptoms that include sleeplessness “[having] outbursts. [and]. this one particular, the 50-year old, was not sleeping. He was having nightmares.” Paul explained the behavior change that initiated the counseling referral for this client:

What her mother was seeing was a lot of acting out, cranky behavior. She said she’d always been a happy child and she was not presenting that way at all. This five-year old grandson that they also adopted lived in the home, and the daughter was being really mean to him. Just her disposition was quite a bit different from what the mother was used to.

Elizabeth spoke of severe to more typical responses:

Crying, acting, having some behavioral challenges that certainly increase. I had one young lady who just threw a huge temper tantrum, rolled on the floor, and was really difficult for her mother to manage her, for probably 30 minutes. And I really feel that was her display of her emotion, knowing that she had come to this location where her father had died. But, that would probably be the most severe to the very typical response, which would be tears. Isolating, just wanting to search for them. “When are they coming back?” They’ll ask questions like that.

Bethany discussed cognitive and emotional responses:
His grief had been demonstrated by some confusion about “why do I feel like this?” He doesn’t understand it, because they don’t understand and it scares them and the emotions are pretty strong.

When asked how her clients with DD showed their grief, Amy responded:

Generally they come to me because there’s a behavior. And some of the behaviors that people get most concerned about are angry, lashing out, you know, they’ll lash out at people. They’ll get angry, and that gets very concerning, or they withdraw and they find that they’re in their rooms a lot, and they don’t seem to want to be talking. Sometimes they’ll lose their appetite. They don’t seem to be eating. These kinds of things are a concern. They seem to lose interest in doing activities. They don’t want to go places. That’s another thing. You know, somebody who might have before enjoyed certain activities and getting out and doing things, now they don’t like to do it anymore, and they turn people down and say, “No, I don’t want to go,” and to a lesser degree, they’re doing lots of crying.

Appearance and affect may not match behavior due to the disability, such as autism. Behaviors could be misinterpreted and misunderstood. Participants did note that the most common reason for a non-routine visit was triggered by behavior change. When asked how her clients showed their grief, Pat answered:

One, not eating, not sleeping, extreme pacing. Their behavior problems come out as anger. You know, they don’t verbalize it, but they may throw stuff or push over [something], do something because they’re not understanding where that parent is.
Jessica explained a range of reactions that she has witnessed as a “change in behavior or it could be as simple as crying. It could be a little like a depression type of a thing that they see. Sometime striking out - maybe not physically, but acting out, striking out.”

Bethany described going out on a bereavement call and finding the bereaved all were adults with DD:

They were very, very animated and kept kind of yelling over and over about what had happened and they were really appalled, I would say, at how he died and what happened and they were just very verbal and very, very upset, to the point of… they had to keep telling their story over and over and over and over.

I remarked earlier about a memo to myself that the participants analyzed the clients and, in fact, did some analysis of the data for me. As part of their professional skills, they interpreted behaviors and coded them as responses to emotions. Some adults with DD were described as verbal and able to express their feelings. Anger, sadness, loneliness, fear, and searching were reported by counselors. Lisa noted, “There’s a sadness that I’ve noticed with a lot of my clients and they keep repeating and talking about that loss over and over and over. They become almost obsessed with that loss.”

Chris described a young man whose thoughts are still focused on the death of someone he took care of:

This one young man that was a caregiver for somebody who died on July 4th last year, well it’s hard for him this month. He speaks as if it was yesterday. He doesn’t seem to have moved at all, you know, in his grief

Kim observed “a lot of anxiety, listlessness and anxiousness.”
Fear of abandonment and worry over who would take care of them now did emerge in the data. Jessica addressed these fears.

And if they realize who the other people are in their lives that they can get support from, that they will always be there to help, they can grieve without being horrified and really scared about what’s going to happen to them.

Lisa added, “She’s afraid now that everyone around her is going to die. A real fear. So that particular client is really afraid that everyone around her that she loves is going to die.”

A person with DD is often reliant on others for his or her care and daily needs. Their stability may be at risk when a caregiver dies. Dave explained:

A developmentally disabled person is dependent. So, because there’s a fear of abandonment in the real sense, because they fear they won’t be cared for. [In addition, there is] fear of other people dying.

Lynn discussed one client who described suicidal ideation:

He was saying he wanted to take his own life. And this was after the death of his mother. He lived in a group home and the referral came from the administrators of the group home. There’s so much deep sadness. You hear one story and you’re like, “Oh, my God. How can it get any worse?” [A] few days later, you hear something worse.

One of the important messages of the data is for others to see that adults with DD are part of humanity. The counselors insisted their clients are the same as everyone in the depth and range of emotions. They bled, they cried, they felt grief, just like everyone else. The participants were passionate that others get this message. Clearly, the implication in
the data imparts that the feelings of persons with DD are just like those of anyone, whether they are typically developing or not. *Same* and *recognition of sameness* were coded frequently in the early interviews. Very quickly these two codes were merged into one, *recognition of sameness*. The sameness was always used in reference to feelings and emotions related to grief. *Recognition of sameness* was used in saying adults with DD shared the spectrum of human emotions. Having human emotions entitles them to be viewed and treated equally with all others. *Webster’s New World Dictionary* (1988) defined “same” as “alike...equal” (p. 1186). Alike was defined as “similar” (p. 34). I thought about people having things in common. One of Webster’s definitions of “common” was “belonging”. (p. 281)

Below are all the comments made about how grief feelings are shared by all people whether they are non-disabled or have a cognitive disability:

The same feelings. They come up at different times, naturally. Some of us are better able to recognize them. (Jessica)

Well, they’re the same as everybody else, I think, in that they feel the loss and grief and pain and sorrow and hurt. (Chris)

I think they experience the same heartache and feelings that anybody else does. (Jan)

I think they’re the same in that their feelings are the same, certainly. They have the same human feelings. (Lynn)
They’re not a different species, you know. (Nicole)

You can be slow, but you don’t have to be dumb, you know. (Chris)

As far as needs and wants and desires and to be treated with respect and consideration, there’s no difference. (Pat)

But, as far as being the same, they feel with their heart, they worry. I think that that’s not so different from anybody else. (Elizabeth)

[Adults with DD are] mostly the same because grief has its own process. (Kim)

They’re the same in that they have feelings, and those feelings are there, and grief is, I think, one of the biggest feelings we ever feel. It’s the most intense of our feelings. I find they have those feelings and those feelings are intense, and that, like with most people, it’s very frightening. It’s very scary to have these very intense emotions. And that they want to find a way to feel better. I mean, that’s a way that it’s similar to all the people that I see, who have had a loss and are grieving, is that they want to feel better, you know, they really do, and they don’t know how to do it. They don’t know what to do to feel better. (Amy)

Because of her verbal ability, she was able to put into words really typical grief feelings. (Paul)
They’re the same in that they’ve suffered the loss. (Lisa)

Pain of grieving is pain of grieving. Don’t exclude them because they might have a younger understanding of things, because they still have the same feeling. (Kim)

I think understanding that we’re all on the continuum, and that this client was a whole lot more like me than not like me. (Paul)

For weeks I had coded a set of comments about grief response as *individualizing*. I believed the data were emphasizing how each person grieves differently, whether disabled or not. As I polished the writing on the final sections, I questioned what the data was really conveying. The more I looked at it, the more I could now see that what I thought was important originally was “individual”. After time, and repeatedly reading the data, I began to see that what was being said was really a description of the individual nature of the grief response for all people, not unique qualities about bereaved individuals with DD. Below are further descriptions of the range of response in clients with DD:

Some of them were upset, some of them had absolutely no apparent response to it. (Jessica)

Some folks are very tearful and some folks are not wanting to talk about [it], others are needing to talk about it a lot, and sort of debrief and share. And then, with the group, when we talk about all the different feelings that are part of the
grief process, they all can relate to the fact that it’s this whole wave effect. That
sometimes you’re angry, sometimes you have happy memories, sometimes you’re
sad, sometimes you might feel guilty, sometimes you might feel responsible,
sometimes you might feel afraid. All that stuff is there, so I think it’s pretty
similar to anyone’s reaction. You’ve got the whole range that’s in there. (Nicole)

I think pretty emotionally, especially at first. Especially in some cases, and not in
others. I’ve seen other people not grieve or have anything to say. That varies, just
like it varies in the general population (Chris)

He hadn’t been able to shed any tears. In two weeks they were going to have a
beautiful memorial for Mom and the whole family was gathering, all of them.
And he figured it out in his mind, he said, “You know,” he says, “that day
everyone is going to be crying.” He says, “That’s the day I’m going to cry.” And
he did, as it happened. (Kim)

They grieve like everyone does, you know, and that’s the one thing that’s hard to
stress, that we all have our unique way of grieving. Some people show it by
tearing, some people show it by anger, some people hold it down. (Pat)

Through anxiety, through restlessness, most grieving people have a problem with
concentration and short term memory and focusing, but this particular person was
exasperated. (Kim)
All of this hurt. (Chris)

The hurt, the deep angst that the cognitively challenged experience is as deep as the non-challenged child and adolescent and adult. It can’t be measured. It’s all the same, as far as the hurt and the deep loss. As far as the similarities, everybody can identify sadness and anger. That is common throughout every group, every population. As low as their IQ is, they can still identify sadness and anger and loneliness. (Hannah)

Some would say that because we are relational beings, loss of a loved one is the most powerful loss experienced. When a person has a small social network and very few loved ones, the impact surely could be greater. This loss is reflected in reports of loneliness. When describing loss for a young man who had lost his mother, Jessica said, “He missed being able to come home and tell her about his day.”

Lynn commented on the impact saying, “I just think loneliness is huge, especially if it’s a parent.” As Dave explained, “I think the impact for mild or moderately disabled people, the impact might be greater because I think the sense of intimacy is greater.”

Jan conveyed how a man described his feelings a year after the death of his brother. “When it was almost a year after his brother’s death and I asked him if he thought of him very often, [he] said, ‘I think of him every day.’”

Finally, Nicole summed up how some hang tightly to memories, and some let go: For the other it might be sort of this real deep sadness and regret that keeps coming up a lot about. *I just really miss my Mom and Dad. I really wish that they were still here with me.* From the other one, it might be more, *Well, that was*
really great growing up and now I know that they're in Heaven, I'll see them after I die. One person might still be saying, I just, I think about it every day.

In summary, behavior change, grief-related behavior and grief response were originally raw codes. Some of the data about behavior was associated with expression of feelings of discomfort. At other times, examples of behavior were used to reflect how grief was experienced by adults with DD and how the adults tried to communicate their desire for support or help. Behavior was depicted as expressive for the clients and illustrations of behaviors painted clear pictures with the data. I believe that underneath the rhetoric about behaviors were two messages. One message was about the disconnect for clients and caregivers between behaviors and thoughts and feelings. This can lead to continued pain and isolation. The other message was that adults with DD are seen as usually reaching out by means of their behavior to ask for help. They are viewed as communicating the need for joining with another to have their feelings heard and their needs met.

The category of Grief Response was developed from the following raw codes:

- Behavior change; Grief-related behavior; Grief behavior versus language
- Anger
- Sadness
- Intensity of grief feelings
- Individualizing
- Loneliness
- Feelings
- Searching
- Same; recognition of sameness
- Discomfort
- Guilt

Loss and the reaction to loss and bereavement have been described so far by the data. How the counselors perceived adults with DD actually dealing with and coping with loss and their stress around the loss will be discussed next. The reaction to loss is coalesced under the category of Coping Challenges.

Coping Challenges

Coping is the way we deal with stress, loss and change. A death loss is a major stressor in anyone’s life. The stress and coping theorists posit that how we cope with death and loss is multifaceted. Coping is managing emotions, not letting the emotions override physical and social functioning. Not coping is losing control of the ability to stop or start feeling states. Coping is of concern because it keeps human systems in balance. Occasional bouts of not coping well can be managed, but loss of control of emotions with no sense of how to regain balance can be frightening. Insomnia, anger, restlessness, lack of appetite can ensue. Balance is lost.

Coping challenges was identified as a raw code and held its own as a categorical code. Almost all participants noted the limited coping skills of the client. Obstacles to coping may be related to a co-occurring disorder, such as schizophrenia or bipolar disorder. Coping obstacles often mentioned were poor defenses and lack of skills in self-calming. Coping challenges also included rules for staff about touching clients, client discomfort with touch, limited family and social support.
Because some participants taught coping skills such as relaxation, deep breathing, and problem solving and reported success for the client, the question arose in my mind as to whether this was another loss as opposed to separate category. On the one hand, coping challenges seemed to exist as results of protection. Protection is viewed as a part of loss. Limited family and social support I view also as losses. Coping obstacles remain tightly connected in my mind to protection and Loss, since adults with DD typically have not been presented with many opportunities to learn coping skills. On the other hand, coping obstacles included the actual cognitive impairment. Impairment of abstract thinking, retention of knowledge, and ability to generalize knowledge are organic problems. These obstacles are inherent in each person. Those labeled as DD have some type of cognitive challenge that alters thinking about and understanding of death. Cognition affects how feelings are perceived and dealt with. Therefore, cognition affects behavior. How and what I think about an event will have an impact on how I react to it. Here there does exist uniqueness that not all bereaved adults will share with adults with DD. Using person-in-environment (Boyle, Hull, Mather, Smith & Harley, 2005) as a perspective from which to view the data, I first considered the data from the background provided about the conditions that affect client coping. Then I moved to the foreground of the actual client experiences as described by the participants.

Assumptions by caregivers that adults with DD were incapable of handling stress or learning coping techniques seemed to be the subtext of the data. These assumptions were based on the fact that the bereaved had DD. Misconceptions about what a person with DD can learn or can control were evident. Involvement in decisions around changes,
discussion of how the changes feel, and dialog about what methods work to make the person feel better about changes often do not occur. Nicole reflected:

What do we need to do to make those changes more comfortable, for both people knowing about it sooner rather than later, and being able to have some input into any of the choices that might be a part of it.

Coping challenges were described as in part organic, in part social, as a consequence of protection.

Opportunities to practice coping are numerous due to multiple losses experienced by the DD population but, opportunities for being guided through coping means the losses must first be recognized and acknowledged. It also requires that the caregiver or family members believe that the individual with DD is capable of learning to handle stress and strong emotions.

Over-concern of others can relay a message that they aren’t capable of coping in some way. They tend to believe what other people convey to them, and I think people indicate to them that, because of their condition, they must not be able to cope. (Jan)

I began to wonder whose problem coping really was. The data clearly told me that caregiver/professional discomfort is as an obstacle for adults with DD. This discomfort is rooted in the Western society’s avoidance of discussion of death and dying. Discomfort can be described as being uneasy, not at peace, restless, distressed, unsure, out of a comfort zone. It is an emotional state based on cognitive appraisal of the situation. It is affected by knowledge and understanding. Discomfort is of concern because to decrease discomfort, avoidance or partial avoidance is often used. The consequences of not having
discomfort (that is to say, having comfort), would be the caregiver or professional feeling at ease about their actions or words. The actions would be based on knowledge of how to involve the adult with DD in learning about the death or forthcoming loss and on being conversant in ways to help the adult cope with the loss.

The participants returned my thinking to the way Western society avoids discussion of deep feelings and death. Little early preparation is done around these issues. It is not uncommon for families, caregivers and even professionals to have some aversion to these topics. Sometimes it is simply that no one has offered any guidance in how to approach the topic for children or adults with DD. Elizabeth described how caregivers often request help with explanations of death or imminent death:

It can happen from a family care provider out in the community who lets us know they’ve experienced a death of one of their consumers living in their homes and so they’re having difficulties knowing how to share information with the other consumers that are in the home. Maybe the patient has a child or an adult who has a developmental disability and they’re looking for information on how to tell him that their mother or their father or their brother is dying.

The reactions of caregivers gave clues to the counselors that the grief response of the adult with DD was of concern and that it was amplified by stress. Jan discussed this added stress stating, “People around them [are] overreacting to their expression of emotion and giving them the impression that it is a crisis that they’re crying or something like that.”
Untrained caregivers at times referred the clients to a counselor, further “pathologizing” the grief response. Listening and a supportive presence could have sufficed in the counselor’s eyes. Amy provides further insight:

They are beginning to exhibit some behaviors after there’s been a death in the family, which concerns staff, which could be lashing out, like angry behavior, or withdrawal, lots of withdrawing into the room. That usually gets staff very concerned. And sometimes, if they feel like they’re crying too much, then they will refer because they feel like there’s too many tears or they’re crying too much.

Elizabeth explains that often she gets calls just to notify the adult with DD of the death, “that the death is going to occur. That’s one of the times that we get called in because they don’t how to break that news.” If caregivers, staff and families could be more open about death, dying, and grief, and give support, professional intervention may not be needed. Amy further discusses this:

It really has to do with the discomfort level of the people they’re living with. You know, everybody has a different idea of how much crying is too much. So, if they have somebody they’re living with [that] says, “You know, this is too much crying. They’re crying everyday,” for example, then they might refer for that reason.

Nicole supported Amy saying:

It might be that they [caregivers] believe that because the person isn’t behaving like they should, maybe they are not crying enough or don’t seem to be upset enough, they think they must not really grieve.
Discomfort can occur when the topic of death arises and the caregiver’s own fears of mortality, own pain and lack of understanding of healthy grief arise.

He was being quite emotional and not... which, you know, is fine, but the people around him, I think, were less comfortable with that than he was. (Jan)

One particular person was never told. They knew their father was in bed and the mother had said he was tired and when he passed, he was not there when he came home and the mother never said where he went. (Pat)

Discomfort could also arise for counselors when they doubt their expertise. Most were raised steeped in Western ethic that labels persons with DD and regards them as “special”, as discussed earlier. The data began to give rise to the belief (or myth, as I see it) that the general service system is not equipped to serve adults with DD. The counselors also may enter into areas of their own fears, such as in working with the disabled, a fear of becoming disabled and dependent, themselves.

As counselors, we’re very transparent. And, children and individuals who have disabilities are really keen. They’ve had to deal with people all their lives who don’t like them, so they really know, I think, really quickly who does and who does not. (Elizabeth)

But do you know what I think it comes down to? The fear of the unknown and if we can just relax and just take every moment as it comes and allow whomever we’re working with, whether it’s a young child or the cognitively disabled, to lead and we follow. (Hannah)
I think it’s also important to know when you can’t do something. Because you
know what? They’re going to know it. (Elizabeth)

If people come to you and you refer out, maybe you need to get a bigger toolbox
(Marta)

Well, one thing that immediately comes up for me when you ask that is to let
themselves get into their own discomfort and see what it’s about and, if there’s
fear there, sort of there but for the grace of God go I kind of thing, or it could be
catching… I think most people have fears about somebody who’s different…to
get in touch with what that is, and allow themselves to address it so that they can
be more present and not be in their own stuff when working with this population.
(Jan)

Bereavement counselors have to be comfortable with issues of death and dying.
Several participants mentioned the need to examine their own feelings about death and
dying before working with any population. This groundwork must be laid before a
bereavement counselor can expect to be effective with any population.

It’s your own journey, it’s your own journey first. (Kim)

The data pointed out to me the need to keep Coping Challenges as a separate
category and merge it into sections of another raw code “caregiver/professional
discomfort”. That code had been merged with discomfort, but I believe it needed to be
once again separate to reflect the effects of caregivers onto the adults with DD. The
broader environment in which individuals with DD live has to be understood before one can truly understand their coping efforts around death of a parent or loved one.

How do adults with DD cope with the discomfort around loss and following major loss? The data offer the following insights:

Just a lot of, you know, trying to soothe themselves, whether it’s by perseverating a physical behavior or verbally. (Hannah)

They’re struggling and using whatever coping mechanisms they have just like anyone else. (Theresa)

And they often perseverate when they can choose words for their feelings, they will perseverate, whether it’s I miss Suzy, I miss Suzy, I miss Suzy, I miss Suzy, I’m so sad, I’m sad, I’m sad, I’m sad. (Hannah)

Poor coping skills, ability to control their anger, control their anxiety, kind of like short fuses, not having quite the same ability to be in control of everything as other [clients] would. I don’t see the people we are talking about as having as thick of skin, the coping skills to keep the emotions under check quite as much as a person with the ability to cope better. So, it’s really, its right there on the surface. If they’re sad, they’re sad. If they’re anxious, they’re anxious. (Kim)

Pat described her work to reconnect family members and the obstacles she encounters:

I had reconnected the family and they were just getting to the point of being really comfortable. He and his wife and the client [were] OK. Then he and his wife
divorce and that had a real impact on the client because she was just starting to connect… she had been institutionalized and starting to connect with me, so that I couldn’t really get [out] of her sight at first. They got divorced and that really threw her whole equilibrium.

The intensity of grief feelings has already been discussed. Grief can overwhelm even the most stable person with many social supports and resources. For someone with DD, fewer resources, and less developed coping skills, grief could be frightening, as Jan explained:

I think most people can be very uncomfortable with very strong feelings. I’m thinking of one developmentally disabled man in particular that just was extremely uncomfortable when strong feelings would arise and would get a little panicky and agitated and, that would usually prompt the caregiver to call for help, or he would call. He actually got the number himself used it, learned to use it at all hours of the day and night.

Jessica brought up her experience with a client with DD in terms of physical touch, such as hugs. Other participants find their clients with DD had welcomed physical connections such as hugs. Individuals cope differently and react differently to physical touch, whether a disability exists or not. For Jessica’s clients:

I think their ability to receive support is much more limited because, for one thing, a significant way that culturally we support people who are grieving is physically, to use touch through hugs and, you know, different kinds of physical contact, and my experience is that a lot of developmentally disabled people don’t go in for that.
I think just an ability to cope, which happens in a lot of people and not just people with cognitive limitations, I think it’s a difficult thing. Some of them, though, if they’re very, very limited, I just go and deal with them at whatever level they’re at as, as best I can. (Jessica)

More comments on coping are included below:

It’s harder for them to process and I think they have fewer controls. It makes it harder. (Lynn)

Gains, not being able to carry those as well, fixations and sort of revisiting and a little more than you see sometimes. Maybe they kind of get stuck and possibly don’t do as much processing on their own, so maybe they sometimes get stuck a little bit. Come for one session, maybe two, off the radar, call again, come back in again. (Sharon)

Being dependent and having limited resources sometimes added to coping obstacles, as Alecia related. “I think the difference for them is that they don’t have as much control over their lives or as many resources or choices as other people do, and that makes it even more scary.” Participants often brought up issues related to coping that they associated with the client’s cognitive limitation. Two issues were developed as raw codes concreteness and egocentrism. Concreteness was identified early in the coding. It was used to explain how many adults with DD understood death and was used to describe
effective interventions. Parallels were made to children’s understanding when

concreteness was used. Concrete thinking emerges repeatedly through the transcripts.

Bethany described a widower who had DD:

He wanted to show me all his wife’s belongings. And it was very important for
him to show me all her crafts and pictures of her and all of that. So, what helped
him were these real tangible things and showing them, you know. Just not talking,
but showing me all this stuff. And so that was very helpful to him. He really was,
I think, showing her tangible things. And, even showing me, he’s saying, “Now
this is where I sleep and this is where I toss and turn.” You know, very black and
white thinking. “This is where I am when I can’t go to sleep because I think of my
wife and…” Very, very concrete.

Nicole described the need to give information in concrete terms. “I think the most
important thing is to give them as much information as possible in very simple concrete
language that they can understand.”

Egocentricism was noted by several participants. Egocentricism refers to seeing
the event only from one’s own perspective, not taking the perspective of others into
consideration. Some adults with DD are viewed as more egocentric in their worldview,
more like young children. The adult may only see the death or loss as related to his or her
own behavior, triggering guilt. Jan explains how some of her clients with DD have been
very focused on their own experience of loss:

…an immaturity, so they’re perhaps still not egocentric child thing, but still the
same feelings. Because, you know, there’s more of an issue of me, me, me…
Well, how, how am I going to get along, how's my life going to be different, and less ability to have empathy.

Alecia also noted increased *egocentrism*: “I think they’re a little more egocentric in their view of things than other people admit they are.” Bethany described how one client finally saw one of the positive benefits of his wife’s death. “When ---- was alive, I couldn’t go on field trips, and now I’m going on field trips.”

Both concrete thinking and *egocentrism* refer to cognitive development. These terms sent me back to Jean Piaget’s literature and the writings of Phyllis Silverman. Silverman (2000) noted that discussions of the child’s understanding of death often oversimplify the factors involved. She notes that even for children, experience in the world and with death will impact each child’s thoughts about death. “Children’s understanding of death is presented in an orderly manner as if children move in a linear way from one level of understanding to another.” (p 49). Silverman asserts that death understanding does not coincide neatly with age/stage categories. Each child’s uniqueness in response to death is echoed by Erna Furman’s work. Silverman notes that “many adults still have difficulty taking the view of others” (p. 59). She cites instances of “magical thinking” (p. 49) concerning death in adults, about which she says, “Observing these thoughts in themselves was embarrassing” (p. 49). It appeared to me that concrete death understanding and egocentrism may be more prevalent in adults with DD, but not necessarily represent how all adults with DD view death and loss. Individual differences seemed very important to take into account. Interestingly, one of the participants also had observed and noted this similarity and offered that perhaps adults with DD just were less
practiced at hiding their egocentricism than adults without DD. For children Silverman (2000) notes:

Children are dealing with the impact of death at the personal, social, and emotional levels; thus their cognitive understanding of death may not be consistent with their level of maturity and may be different from the understanding of children who have not experienced death. (pp. 49-50)

This would seem to carry easily to application with adults with DD. Concreteness and egocentrism were related to both Coping Challenges and to individualizing interventions. Subsequently, the Individualizing Interventions category was changed to Being Honored, that is to say, being validated as unique members of humanity.

In addition to their own limitations with cognition, the disability that caused the cognitive challenge often affected their speech as well. The expression of emotions, therefore, was usually described as communicated via behavior. Even if verbal communication existed on some level, often it appeared hard for the adult with DD to find words to encompass the depth of feelings. Verbal communication challenges was a code used when obstacles with clear speech or limited speech were noted. These challenges were seen as a difference from “typical” bereavement clients. The diversity of the DD population supports the importance of individualizing interventions. Verbal communication challenges also were related to Coping Challenges. They were described as creating challenges for communicating the grief response. The bereavement counselors believed it was good practice to connect the behaviors to thoughts and emotions, especially if words are not available. Verbal communication challenges as a code was
merged with Coping Challenges as a category. When the adult with DD had no words to share pain or anger, it limited the options for coping. Chris summed this up by saying:

I think lack of ability to communicate or the lack of having somebody that really understands [hinders coping]. I find it more challenging to communicate and to explain the grief journey or to figure out what’s normal in terms of what they’re feeling because I’m not sure I can hear what they’re feeling.

Coping may be self-stimulation, rocking, or tantrums if no other means are offered. Isolating was also mentioned in several interviews. Hannah identified behaviors and nonverbal communication that she interprets as distress:

A lot of physical, besides the acting out. A lot of walking, up with their hands, you know, holding their hand tight, and the finger movements. I don’t know if you’ve been witness to that, seeing a lot of finger movements, hand movements combined with the rocking, to sort of self-soothe. Just a lot of trying to soothe themselves, whether it’s by perseverating a physical behavior or verbally.

Co-occurring mental health disorders were mentioned several times by participants. I began coding *co-existing mental health disorders* as a separate raw code. I then merged that code under *other losses*. I later wondered if co-existing disorders were more of a Coping Challenge. A mental health diagnosis concomitant with DD would create more distancing from typical life experiences. It could, on the other hand, exacerbate coping as well. The data on co-existing disorders were generally brought up in association with coping challenges.

An additional challenge that falls into the cognitive arena is the existence of shortened *attention/pain span*. *Attention/pain span* was a code developed mid-way
through the process. The references to shorter attention span and the time span that emotional pain could be tolerated were noted when the participants were asked what was different about bereavement clients with DD than other bereavement clients. Participants said that most adults with DD were more like children than adults in term of attention/pain span. Participants drew parallels to children’s limited coping skills and time span they could hold pain. Lynn described the pain in comparison to children and adults without DD:

A difference is that, like children, I think their pain span, if you will, is shorter.

The time they can tolerate a painful feeling is shorter than an adult without who’s cognitively OK.

Shorter attention/pain spans as a code tied to the codes ‘parallels with children’ and coping challenges. It was also associated with individualizing practice to meet unique needs. Two additional obstacles that complicated coping were attributed to cognitive limitations. Retention and generalization of knowledge limitations and struggles with death understanding were developed to capture the data around challenges in providing ongoing counseling to adults with DD. Differences in cognition due to the disability seemed to be reflected here. The reason for problems in this area appeared organic. The data reflected differences from typical clients, but not all clients, as other clients have difficulty retaining and generalizing. Most of the data best fit under the conceptual category of Coping Challenges as a result of the disability. A few comments linked well with the category Individualizing, but then I later moved it into the Being Honored category.

The struggles to understand the concept of death is clear from the data.
For someone with a lower capacity, a lower IQ, there’s the extra step of having to explain what death is. (Dave)

They exhibited it by being really very traumatized by the actual death event and not understanding what the nurse had told them ahead of time. Because they don’t understand, really, on a real deep level, what’s going on here. (Bethany)

I think they don’t quite understand the loss. I also do bibliotherapy, reading a scenario about loss that’s more geared to my younger population. So reading a story is helpful, but sometimes there are blocks and it takes a long time to get through those blocks. (Lisa)

They just know that the person’s not there, and they don’t like that, you know. So, you have to kind of just take it from where they are. And I always like to find out, if it’s possible, where they are developmentally and what issues they have, just so you kind of know how to approach this, because it’s a very difficult thing, you know… loss. (Jessica)

…because they’re not understanding where that parent is. (Pat)

We weren’t able to discern what was in his mind, what his true understanding of the death was. He just knew that she wasn’t there. She was dead. (Jessica)
Just wanting to search for them, you know. “When are they coming back?”

They’ll ask questions like that. (Elizabeth)

I put children [and], the adults with cognitive limitations almost in the same category. They’re just… they’re a different level, but they still have feelings and they just… you need to find a way for them to express themselves and try to help them understand. Forever isn’t an easy thing to explain. They have to live it sometimes. (Jessica)

The code *struggles with death understanding* addressed the difficulties with cognitive grasp of the finality of death. The struggles were described as due to the cognitive disability. Adults with DD were viewed as needing concepts about the loved one’s death to be explained in concrete terms tied to experiences. The cognitive challenges appeared to create coping obstacles, as the adult with DD struggled to understand where the loved one had gone. There is a great deal of overlap with death understanding struggles and the need for concrete language and images.

As described, the losses connected with overprotection and limited social contact got in the way of coping. Marta explained how she views the consequences of overprotection:

It’s that subpopulation that I think is who’ve not been in day treatment or program or anything that’s given them a broader social network. That’s been damaging. There was the interpersonal development delay, so there was a kind of half a person left, this grief was so deep and profound and constant, there was no
coping. It was just kind of connecting with a social world in which they could slowly enter and start connecting with other people in a less symbiotic method.

I think their ability to have participated in what was happening to their loved one or what did happen to them, or to participate in things like preparing the funeral and things like that, you know, the rituals that accompany grief that we do to console ourselves [was limited]. (Jan)

Caregivers were depicted as often not expecting adults or even children with DD to learn social skills, coping skills, management of emotions, or boundaries. Jan described how this lack of skills has unfair consequences to the adult with DD:

…that because of his disability there was sometimes a reluctance on people’s part to set limits with him and I don’t think that’s appropriate. I think that it is appropriate to set limits and expectations, and part of it was helping him not think that it was a crisis. That it’s like, you know what? What else can you do if it’s two o’clock in the morning?

It would be difficult to cope when one does not understand why the loved one never comes to visit anymore or doesn’t call or take him on outings anymore. Spiritual beliefs are often reported as helpful in making sense of where the deceased is now located. Hannah described how one of her clients uses spiritual images to cope:

She’s always collaging or drawing images of heaven and she, she just believes that her father is in heaven now and he’s safe, so she does a lot of angels, she does a lot of clouds, of sky. So, that’s how she’s able to process.
If religious or spiritual belief systems are not in place, some found it hard to make sense of the death. Even adults without DD face this struggle. Lisa discussed religious beliefs and how they can impact bereavement:

Depending on the level of their religious beliefs, too, some believe that they’ll see them again in heaven, so you’ve got that that you can talk about. But, for those that aren’t religious, it’s gone; just gone.

Jan commented, “Some of our folks go to church and I feel that maybe that’s helpful; that they can know that eventually we’re all going to go to heaven.”

Not being able to view other’s stress and grief, the adult with DD may see the caregiver’s own grief-related behavior as their fault as well. This was inferred in trying to protect the caregiver from having to deal with the adult with DD’s expressions of grief. Guilt was also included in the recitations of emotions that adults with DD experienced following bereavement. These are additional challenges to coping. It appears that adults with DD have not been given opportunities to build on their coping abilities as a consequence of the overprotection and the discomfort of caregivers.

Throughout the data, frequent comparison is made to children. Parallels to children was a code developed from other codes, such as concreteness, egocentric, forgotten/invisible, short attention/pain span. Some referred to the dependence and immature coping. Some referred to cognitive development closer to a child’s cognitive level. I delved deeper into these data and then split the raw codes out again, with some comments around concreteness and egocentrism merging best with Coping Challenges, and others with Individualizing, which was later renamed as Being Honored.
In summary, attempts at coping may or may not be successful. Coping was seen as achieved many different ways, as the literature points out, and different techniques worked for different people. Coping is something that everyone strives to achieve. As relational beings, we experience interpersonal stress, as well as environmental stress. Counselors reported that individual cognitive impairments, such as problems with retention of information, generalizing information, short attention spans, and verbal communication limitations made coping a challenge. Coping was seen as challenged even more by overwhelming cumulative losses including those imposed by overprotection and lack of preparation for death.

The Coping Challenges category was developed from at least portions of the raw codes:

- **Parallels to children, Struggles with death understanding, Egocentrism, concreteness**
- **Verbal communication Challenges**
- **Retention and generalization of knowledge**
- **Co-occurring disorders**
- **Caregiver/professional discomfort**
- **Original coping challenges code**

Most of the participants believed the client’s obstacles to coping were not insurmountable with presence of a caring other augmented by specific guidance and teaching for the adult with DD and their caregivers. This will be further addressed in the following chapter.
Chapter Four addresses the theme of **Growth**. I found it interesting that this chapter pushed me to a new level of understanding of the data and the research process. One of the participants, Lynn, urged me to read Judith Viorst’s *Necessary Losses*. I took the book with me to read when I was volunteering at a children’s bereavement camp in the midst of my data analysis. That first night, by the lake, after the children were in their sleeping bags for the night, I sat in a bunk and read:

> When we think of loss we think of the loss, through death, of people we love. But loss is a far more encompassing theme in our life. For we lose not only through death, but also by leaving and being left, by changing and letting go and moving on. And our losses include not only our separations and departures from those we love, but our conscious and unconscious losses of romantic dreams, impossible expectations, illusions of freedom and power, illusions of safety—and the loss of our own younger self, the self that thought it would always be unwrinkled and invulnerable and immortal…. These losses are a part of life—universal, unavoidable, inexorable. And these losses are necessary because we grow by losing and leaving and letting go. (pp. 15-16)

Yes, I said, as I read this. Yes, loss is supposed to be about growth. The participants told many stories of client growth through loss. Bereaved adults with DD were presented as almost begging for opportunities to process and engage others around their grief. The counselors’ comments illustrated a belief that most adults with DD are just as capable of growth as anyone. I knew the majority of young children whose stories
of loss I had heard during camp would heal and continue to grow. The bereavement camp counselors were conveying their belief in the children’s resilience, as well as providing safety and comfort to them. The concept of possibility lies just at the edges of the holding environment for grief.

Some of the adults with DD were presented as having so many obstacles in their paths that they seem stuck in the pain, and experience, as one participant said, “incredible sadness”. But it would be difficult to miss the participants’ belief that most adults with DD know growth is possible. Most, when they were given a chance to tell their story to the counselor, engaged and communicated sagas of loss. The bereaved adults with DD were presented as continuing to hope that their grief was not insurmountable, not completely devastating. The counselors showed this by telling stories of their readiness to engage in rituals, interventions, and sharing. Bereavement counselors saw that hope existed in the bereaved adults with DD and could be fostered by their interventions.

The story of how this chapter unfolded is definitely about growth. I had to leave old ideas behind. I had to let go of my own paradigm and really let the data speak to me. As I continued to write up the data, I found the data kept trying to redirect me. I felt as though a client was trying to convey that I was not getting what they were saying. It was as if I had ended a session knowing that somehow I had misinterpreted the cues and that my client was frustrated. This experience was different from just seeing new categories in the data. I knew it was something more basic and important that I was missing. I struggled to find a deeper message in the data. I believed a positive theme was emerging and that Chapter Four was to describe the theme Growth. I had coded data that I thought held two categorical codes: Individualize and Connecting. I had already merged another
category, Normalization, with Connecting after being told by a reader that I had not convinced him of the integrity of that concept. I had made many changes in the categories and theme names for this chapter.

At one point, I thought **Affirming Humanity/Hope**, was the theme. Later, after I went back to the research question and reframed my thinking, I believed for a time the term **Joining** better captured the data. Feedback that **Joining** and Connecting were too similar sent me back to analyze the data once again. I momentarily thought of splitting the Connecting category into Enhancing Coping. Yet, Enhancing Coping seemed to fit with the connections that client and counselor made in skill building. I decided to leave the large Connecting category, along with Individualizing.

As I edited the section on individualizing and re-read the quotations, I once again balked at forcing the data into categories that still did not fully capture the message. Late one night, as I worked with words to replace my original categorical code Individualize, I thought of “re-vision” and “re-model”. At last, I realized that I was seeing the experience of the bereavement counselor, not what they were saying about the experience of the adult with DD. When I went back to the data to hear what the participants said about the clients, I was able to focus on a different level. What I was hearing from the data was that growth and healing were viewed as possible if the clients believe that their abilities, feelings, and needs are all heard and honored. Feeling honored and feeling heard are accomplished by the client believing that someone is truly **being with** them, and creating interventions designed to meet their personal needs. The category is best described by **Being Honored**. This phrase captured the listening presence, the witnessing, and the...
willingness to find appropriate interventions that met the needs and abilities of the bereaved adult with DD.

The second modification I needed to make in my interpretation was again to refocus on the counselors’ view of clients in terms of the data about Connecting. I had repeated my original mistake by placing the focus on just the counselor’s experience and not their observations about the adult with DD. Getting lost in the data and seeing interventions had shifted my attention to the worker, not the client. I was back in my own comfort zone of the professional role. Hearing the data through the counselors about the primary targets, the clients, was harder than I had imagined. What the counselors reported was that Being Together is a positive way that adults with DD moved through bereavement. The clients they spoke of as doing well and not needing intervention were individuals who had family or strong social support. The counselors spoke of some clients with DD doing well during group counseling or with the help of bereavement counselors, peers, or staff.

Being Together can be defined as understanding the relationship between behavior and emotion. It can mean being able to control emotions. It can describe being or feeling connected with others who are also grieving. Being Together can imply forging new relationships or re-connecting with family or religion. Two important meanings of being together are to not be alone and not to feel fragmented.

Following the sadness underneath the frustration, the participants all spoke of the strength of their clients with DD. Some spoke of their eagerness to engage. One participant said the clients with DD were like others in that “they just want to feel better.”
The participants were witness to relief, change, and growth. Sometimes the changes were made quickly, sometimes the changes took months or years.

Thanks to Lynn and Judith Viorst, the broader message of the positive categories is better described as **Growth**. Growth can be seen as expansion. *Webster’s New World Dictionary* (1988) defines it as “…formation and development” (p. 597). Growth is the opposite of stagnation and stunted development. Personal growth is how a person moves forward, expanding ideas and incorporating experiences. The consequence of not having personal growth is being stuck in the same mental place. Learning does not continue. Growth is achieved by exploration, by discovery. Viorst (1986) based her writing on psychoanalytic principles. She believes growth comes from moving away from security and the known. I see ties to the attachment theorists with the concepts of letting go and reattaching. Rather than focusing on the letting go as a detriment, consider that the reattaching moves the individual one space further on the game board of life. Growth is positive movement toward a new level. It is not recovery or a definite event. Growth is a process. Admittedly, the data gathered do not address long-term consequences of the process of positive changes. We receive bits and pieces of hope, but there is no denying those small steps toward healing are present in the stories recounted by the participants. When a green shoot pushes through a layer of asphalt, we do not need to see the grown plant to realize the power of growth.

**Growth** seems to be challenged for adults with DD. There are some people who view them still as “perpetual children” (Mackelprang & Salsgiver, 1999) to be protected and shielded. Sometimes, rather than being helped to move forward with all their losses, obstacles discussed in the previous chapter keep them stuck in the same place of pain and
loneliness. The data describe successful experiences of bereavement as journeys through the pain of loss *accompanied* by a caring other who listened and supported. Many adults with DD do not have this support. The participants reported that caregivers often described uneasiness with dealing with the sadness, tears, or other behaviors, as described in the section on discomfort. At this point, a bereavement counselor referral may be completed. The bereavement counselor then accompanied the bereaved on the journey of loss. What the counselors reported as being successful for some of the adults with DD was this positive regard, a willingness from the counselor (or anyone) to work with individual needs. If the adult with DD had a positive bond to the therapist, therapeutic work moved ahead. The work was often focused on linking feelings to thoughts, thoughts to behaviors. The client’s feelings and needs dictated how work proceeded to teach coping skills and involved the bereaved in rituals.

**Growth** was also reflected in the work of counselors and clients jointly to create or repair linkages to other family members or community groups. These connections broadened the base of security for further exploration for the client, and a sense of Being Together.

The theme of **Growth** and the concepts Being Honored and Being Together were the next building blocks in the grounded theory explanation of grief counselors’ perceptions of bereaved adults with DD. The second concept that emerged when the focus was shifted is Being Honored. To be honored is to be treated as worthy. To Be Honored is to be respected, listened to, with feelings, ideas, and needs being taken into consideration. On the other hand, the opposite of Being Honored, being dishonored, is to be ignored, ridiculed, disrespected. Feelings, ideas and needs are ignored. Within therapy,
to be honored is to feel someone is present with you, hearing your experience, fears or hopes. Treatment is predicated on the client’s specific abilities, desires and needs. A “cookie cutter” approach of therapy is contraindicated. If, for instance, the counselor has only one method of therapy, perhaps talk or insight therapy, all clients will receive talk or insight therapy as part of their goals. If the client is not able to participate, that client will not benefit, will not thrive, will not grow.

Being Honored is important because it is how a competent, evidenced-based practitioner should treat a client (Gambrill, 1997). It is important because people have diverse needs and backgrounds. Diversity is common within developmental disabilities, just as it is in all humanity. As reflected in the discussion, Being Honored is something that needs to be practiced with each client.

Clients with DD range in ability and strengths, as do other clients. I found myself being very sensitive to words and labels. I knew my own beliefs about disability were very much at work as I struggled with terms such as difference, what was normal or typical and what really was unique. I grappled with the notion that, in general, people with DD do have a few unique needs that most non-disabled adults do not have. We all have unique needs. The important point is that these needs do not make anyone less than human. One specific area that makes working with most adults with DD different than working with non-disabled adults is the need for concreteness. Participants tended to use more concrete modalities and found it very important to use words that the client could understand. Individualize was the initial category name. It emerged as a category that reflected the openness and creativity. Some of the data that had been coded as Individualize were later moved to coping obstacles. Some data were really just describing
grief response and not making a point of individual difference. These data were moved to the grief response section. The category named Being Honored was fine tuned.

For successful outcomes for the clients, the participants did note some differences between working with adults with DD around grief and typical grief work with non-disabled adults. Some of the differences in the way the participants intervened with adults without disabilities were related to coping obstacles, such as cognitive limitations and lack of coping skills. The counselors described how responding to the unique feelings, thoughts, and needs of adults with DD is a way of honoring their uniqueness and was viewed as a helpful practice for the client.

Despite unique obstacles and long histories of loss, I held out hope that at least the individuals with DD who had been seen by these bereavement counselors made it through grief. I realized I had been holding my breath in fear of hearing the data tell me that the counselors’ believed that cognitive disability was a major impediment to successful journeys through grief. The chapter on Growth was a celebration of the counselors’ hope that their use of diverse methodologies did indeed assist individuals with DD move successfully through bereavement.

Being Honored

A discussion of how the category Being Honored developed follows. As noted above, this category began as Individualize. One of the raw codes that led me to this category was willing to engage in treatment. If an adult with DD has his or her needs noticed and someone was willing to listen, the counselor usually viewed the treatment as successful. The clients were reported to be motivated and hopeful. There were much data to support the notion that the participating counselors saw adults with DD as more open
to treatment. Subsequently, some data emerged that contradicted this code. As I reviewed codes, I believed there was a link with the code *trust*. Some counselors reported that adults with DD built trust with them and engaged them in the counseling process, while others did not. If the client were Being Honored, it would make sense that willingness to engage would increase. Some clients may simply not have been ready for intervention. Some counselors may not yet know how to meet the needs of adults with DD, as well as others. Some data relevant to *willing to engage in treatment* were related to Loss and other data were relevant to Being Honored. Again, the parallel to children emerged in the data regarding willingness to engage.

I found that I really enjoyed working with adults with cognitive and developmental disabilities just the way I enjoyed working with children, partly because there’s an openness about them. I feel like working with people with developmental disabilities is, in a lot of ways, similar to working with children in that, number one, children are often, and people with developmental disabilities, a lot less defended about their emotions, so they’re much more willing to kind of let their emotions come out, which I find very refreshing and a lot easier to work with than adults who are often much more defended about their feelings, or are often quite not as well in touch with their feelings as children and adults with developmental disabilities. (Amy)

When children are grieving, they’re usually very resilient and they’re very open to kind of all that you have to bring to the situation. They’re open to hearing what’s available to them to sort things out. (Nicole)
As I worked on the draft after multiple revisions, I realized that Being Honored made sense in terms of the constant reference of parallels to children. Children, as dependents, often are not honored and respected as persons. They, too, are viewed as dependent and not full participants in decision-making. Commonalities reported between children and adults with DD included the perception that work progressed when the child or adult with DD communicated relief that at last someone took them seriously. Some counselors brought up their clients’ lack of defenses, their openness and readiness to work. How the counselors perceive the clients has impact on the therapeutic process. How the clients perceive the counselor is also vital. Marta described her experience with clients with DD as being less defended.

Whereas my cognitively disabled tend to be more forthright, because they know they are hurting and there’s not that social need to put up a good front, put on a happy face. So that I think we can, as difficult as it is sometimes to get the feelings articulated, which is the same in both cases, the defensiveness is less. Nicole echoed the openness and welcoming of her clients with DD when asked if they wish to be involved in talking about their losses:

Persons with developmental disabilities, too, is that for the most part, they’re going to welcome the opportunity to discuss what’s happening and to sort of feel like this is legitimate, that we can talk about this.

I also find that people with cognitive disabilities are much more open to alternative kinds of therapies, much more open to art and music, for example, and story telling, or sand tray. [W]e have a sand tray at our Hospice and so we do sand
tray work with people, and if I try to encourage my teenagers or adults to do a sand tray, they think I’m nuts. You know, they don’t want to do that. But, my children, you know, up until the age of 12, and the people I work with cognitive disabilities, oh, they’re very happy to do those kinds of things. Very happy to do music and art and sand tray, and I find those kinds of therapy to be very, very helpful for expression. (Amy)

Being open also can mean readily sharing what one is thinking. Bethany talks about her experiences with clients telling her all the unfiltered details:

And they’re also different in that they’re a lot more honest. They’re much more honest about what they’ve seen, how it made them feel. They’re pretty graphic in their descriptions of what happened, whereas, I think a lot of other people just bury it because they know how, and often times DD people, you know, they’re just right out there. Everything’s right out there.

Part of Being Honored is having someone attend to our individual needs. Since many adults with DD have cognitive limitations that may impair attention span, the data revealed that many were perceived as doing better with shorter, structured sessions.

Shorter structured sessions was a raw code connected to comments about the length and format of interventions for adults with DD. Shorter attention and pain span of adults with DD was mentioned by several counselors and is related to Coping Challenges, perhaps due to lack of coping skills. Organic causes and environmental causes could interfere with coping skills. This code also reflected the counselors’ belief in the need for more structure during interventions. Benefits of structure lead to relationship building, ability
to let go and share feelings and lead toward the work to connect feelings, thoughts, and behaviors. One participant noted that she believed the need for structure was a learned trait. She perceived that adults with DD were used to being told what to do, and this way of interacting was in their comfort zone. Regardless, the clients who were viewed as having done well, had communicated by word or behavior to the counselor that shorter sessions work best. The counselors listened and honored the request by shortening the sessions. Amy describes how she determines session length:

My sessions with them are shorter. I usually let them determine how long, you know, they want to be here in my office, and generally I find that a 30- to 40-minute session is about right for them, and I don’t force them to leave early or stay longer. I really let them make the decision about that, and they will tell me I’m done. People with cognitive disabilities like a structured session as opposed to a non-structured one, while adults have a tendency to like a more non-structured session. They’re more likely to come in and just sit down and start talking and they want to talk about what they want to talk about, while children and people with developmental disabilities generally look to me to kind of tell me what to do, kind of thing. I think it’s because both children and adults with cognitive disabilities are used to people telling them what to do.

Some data placed into the code shorter structured sessions are related to Coping Challenges and these comments were merged into that category.

Amy noted a difference in the demands of intensity and energy on her ability to have more than two adults with DD at a time on her caseload. She put energy into
working with her clients and found the best way to honor them was to be careful about her schedule:

I just found that I enjoyed it, but I also found it very tiring. It was exhausting work, so I knew that I couldn’t have… for some reason, this work exhausted me or tired me out more than my work with children so that I couldn’t have lots of people with developmental disabilities on my case load. I had to limit it to one or two at a time

Not creating dependency and teaching about boundaries are done out of respect for the client. Some clients may have never learned social rules. Allowing a client to break them because they do not know any better is detrimental to the client. Honoring means holding everyone to the same expectations and teaching them how to better navigate in social situations. It would be dishonorable to set clients up to attach too strongly in temporary relationships such as client/counselor. Respectful and ethical counseling helps the client grow to develop new bonds with others outside the counseling relationship. Theresa brought up how she had to be extra careful of dependency issues with adults with DD. Marta elaborated:

We don’t reproduce that dependency in the work, you know, because dependency is a natural piece of the therapeutic process in the beginning. You kind of create a service dependency and then you sort of help them individuate.

As the participants thought aloud about these issues, some started to retract what they were saying. They found similarities to other populations in boundary work.

*Boundaries/dependence* was labeled as a raw code. Being more careful about setting and teaching boundaries was emphasized by a few. Participants also mentioned working to
get the adults with DD connected to others and more self-reliant so they would not have to rely only on the counselor. Eventually, the data indicated that these are typical concerns that may be more important to watch for with adults with DD. I thought the data spoke to ties with the original category Normalization, as all counselors must address these two issues. However, Individualize, then Being Honored better fit the data in terms of the boundaries and dependence issues needing more careful attention for a counselor of adults with DD. One participant mentioned the dependence issues were more similar to working with older adults. Background, experience, and social skills are different for each person. Treating each member of the counseling relationship with respect and explaining rules and expectations are part of Being Honored.

One of the messages from the data was that change needed to happen with others, as well as with the adult with DD. These comments were coded as *change environment not the client*. For instance, Paul noted:

> What we’re dealing with for healing is support, not so much knowledge and understand[ing], and so having a support structure in place would probably be the most helpful thing, not so much to prepare the person, but to prepare the surroundings, the environments so the person has the support.

Working on educating others and changing service provision is a part of working with the person in their environment. Universal access, for example, would require that all bereavement clients have access to materials that are pictorial, as well as written, that materials are available on audio and videotapes, and that activities are multi-modal. Different language versions would be available as well. If this were the case, hospices
and agencies would have materials on hand so that they could meet the needs of a wider variety of clients. Staff would be trained to use these materials.

The data push for death education and discussion of intense feelings for all children, disabled or not. The ideas related to change the environment not the client originally seemed to fit well with the Connecting category. After final changes were made in the category names, this material better illustrates Being Honored. The client with DD is not always the one with the problem. The counselors believed that often the best way for them to assist the client was to intervene with the home or larger environment.

Being Honored in therapy equates to having client strengths capitalized. Areas for growth are identified and interventions are utilized that best suit the client’s skills and abilities. Methods of therapy must be individualized. Each person is a unique being with varied strengths, gifts, and abilities, as well as experiences. All persons, even those with DD, have different levels of understanding and a different ways of expressing themselves. The counselors found a variety of methods to help the adults with DD use their own gifts and abilities in the counseling and healing process. Varied modalities were developed as a code after intervention appeared too broad. Counselors spoke of using art, clay, stories, role plays, groups, skill building for relaxation, deep breathing, music, and movement. These activities are also used for children and for adults without DD. Some counselors find talk therapy the most appropriate avenue for clients with whom they work. Appropriateness means what is best suited for that individual client. As varied modalities were explored further, the data were linked with the conceptual category Individualize, then revised to Being Honored. Counselors describe activities beyond talk
therapy that they perceived as helpful to the adults with DD coping with grief. To perform best practice with bereaved adults with DD, counselors worked to have clients feel they were Being Honored. Honoring clients is demonstrated by getting to know the person, their history, how they show their emotions, what makes them happy, sad, stressed. Helping is based on what their needs are, how they process and understand, and how they best work, whether through words or music.

No matter what the obstacle or disability, follow client lead was a code developed for comments about the need to go where the client indicated a need and to meet the needs on the client’s level. The practice of client-centered care is presented as best practice for all clients, disabled or not. The data strongly suggest that for the counselors seeing these particular bereaved adults with DD, the client was capable of leading the therapeutic process. When the counselors used what they perceived to be the modalities best suited to the client, that client’s grief could be experienced in a healthy and successful manner.

Gambrill (1997) encourages such behaviors as involving important others into treatment, developing a relationship of support, being patient and not hurrying clients, a strengths focus, and the need to “tailor your personal style as needed to individual and situational differences” (p. 275). She includes empathy, warmth and genuineness, respect, concreteness, structuring interviews, and attentive listening into the category of interpersonal communication skills (p. 297). Counselors participating in the study echoed these same elements as necessary elements for successful outcomes with adults with DD. Awareness of boundaries, care about transference, counter-transference, and overdependence were reported to carry over to work with adults with DD. Client and
counselor relationships need vigilance with these issues. It is not just work with clients with DD that requires careful, self-reflective practice.

The data followed two parallel paths. On one track, the participants spoke of what they viewed as best practices targeting helping the client. Another track developed with counselor observations and suggestions targeting professional improvement. The parallel paths run through both the Being Honored and Being Together categories. The need for counselors to deal with their own issues and fears about death was identified early in the data. The code counselors need to deal with own mortality/death issues was connected to self-reflective practice that I felt fit under the original category of Normalization. As a bereavement counselor, the professional must address mortality and death issues for herself before they can be of assistance to any client and is not different when working with adults with DD. Addressing these issues is then recognized to be the same for bereavement counselors working with all populations.

Self-reflective practice was used to code comments about the counselor needing to take care of his or her own issues before being able to assist the adult with DD. Self-reflective practice is vital for all counselors and involves being comfortable about issues of one’s own mortality when the counselor works in bereavement. This code was merged originally with the Normalization conceptual category, as it is a component of good counseling practice. As I reworked the concept of Normalization, I came to believe that the core ideas were linked to the need for counselors to connect their beliefs, feelings, and actions so that they were being congruent. Being comfortable with their feelings of death and mortality was first believed to fit best under the category of Connecting. Later this category was changed to Being Honored. Being Honored resonates more closely with
the underlying message of the counselor needing to take care of her own internal business first so she can then focus on the client.

The first thing that comes to mind is to prepare ourselves, to recognize that death is a part of life and that death is going to happen to every one of us, and if we acknowledge that and we learn about it ourselves, and we learn about ourselves and how loss is a part of our lives, and what it is that we do to cope with it, then we’re much more likely to be able to be present for other people in our lives who are going through a loss or a death. (Amy)

I guess the advice would be, make sure, if you know that that’s what you’re going to go into, just make sure you’re personally prepared and not too tired and you’re present and all the things that we do to make sure we’re present to people, you know. (Bethany)

You would incorporate them and mentor them on the way you accept grief and the way you go through grief. Let them be part of it. Let them have a place to talk about their feelings. Don’t negate those feelings. You know, if they have fears and everything, let them have them and talk through. (Kim)

Counselors themselves have to trust that the process they use with any other grieving client is fundamentally the same for a grieving client with DD. Jan described her philosophy of care:
I don’t discount anybody, whether it’s somebody with Alzheimer’s or somebody cognitively disabled. It’s a willingness to recognize the spirit in everybody and be willing to attend to that in the manner that’s fitting for, the person. I don’t think there’s anybody that you can just discount and say they’ve got IQ of 50, what could bother them? So it’s that willingness to me, each being that I meet and just to find out where I can connect with them with the expectation that because I always believe that the spirit is intact. That no matter what happens physically and to the faculties and to the brain or whatever, I don’t believe any of that happens to the spirit. Sprits are whole by definition and irrevocably, or soul or whatever you want to call it. So, I guess I try. It’s that believing -- that and looking for the connection with that. We work around the other stuff.

When asked about interventions, about what helps adults with DD cope with their loss, participants gave answers that reflected general practice principles. The comments were truly telling others to honor the client. Jessica told me what she thinks is most important. “It’s the therapist use of self. I mean when I’m with them, I’m with them.”

Lynn explained how to proceed, which echoes beginning texts in engagement and assessment for helping professionals. “Just having a particular person to be there just for them who’s, you know, non-judgmental and really interested in listening… that seems to be the most important thing.”

Bethany added the concept of presence, which is stressed in death and dying and grief work. Many times nothing can be done to fix the situation but the counselor being with the client who is hurting is therapeutic. “[B]ut it’s more the personal contact, just
understand[ing] that what we bring to them is really our presence, which we bring to anybody.” Hannah pointed out the importance of validating feelings:

I see a lot of one-on-one, if somebody’s grief is so deep that the counselor will take them aside and sit with them or walk with them and just identify those feelings and reassure them that what they’re going through is OK and validate their feelings.

Looking at client strengths and current coping is important in honoring our clients. Gifts/abilities/strengths emerged as a code fairly early in the analytic process. Remarks are made about the client’s intuition, resilience or openness. These comments connect well with the concept of strengths-based, client-centered practice and this code was first merged into the category of Normalization. After further analysis, I came to believe the message of the data is that each individual should be viewed as having gifts and abilities. Counselors and others need to connect with these gifts in order to help the client grieve. Tapping into gifts, abilities, and strengths is how coping is enhanced. This code belonged in the category Being Honored. Dave clearly sees all his clients through the perspective of strengths. The strengths perspective focuses on clients’ gifts and abilities and resources.

[Use] strength based [practice] and try to identify for people the things they do that do seem to work for them and then encourage and support those things. And, so, she responded very well to that.

Jessica outlined her method of identifying coping skills that could be used with anyone and stresses listening as a key criteria in Being Honored:
You know, once I figure out where they’re at, how to bring them around to be able to talk about it and identify feelings and most of all, identify coping skills.…

What do you do when you’re upset? What do you do when you’re sad? What is OK? What is not OK? It’s a matter of listening - listening to them and listen to what they say and how they respond.

Kim, compared her work with adults with DD to her work with other clients:

I don’t prepare myself any differently for this population than any other because every single person is different that comes to me for grief counseling. And, you take that person where they’re at. So they don’t have a high IQ, well that’s just one of the things they don’t have So, I don’t prepare myself any differently because the person gives me the information to make my decisions on how to support them and to help them, as they come to me.

A vital part of honoring clients is the ability to listen. *Listen and explore* was coded as a constant message from the data. Listening and exploring are key components of good counseling practice, no matter who the client is. Participants make it clear that *listening* means interpreting behavior and cues, as well as hearing spoken words. The fact that few adults with DD have ever had a counselor listen to give them undivided attention becomes clear and raises the importance of listening. As a code, I first merged it with Normalization because it reflects good practice, no matter who the client is or what label they possess. Later in the analysis process, I merged *listen and explore* with Connecting. Finally, as the last categories took shape, I saw the natural fit with the data on Being Honored. Listening is the first step. It may be *listening* to behavior and facial expressions or drawings. Pat echoes this by saying, “There’s very simple things that you can do to
help. One [is] listening.” Hannah, too, remarked about the power of listening. “If you just take the time to listen and validate feelings, then the journey becomes less painful internally.” The counselor must honor and believe in the counseling process and the ability of the client to be successful. Hannah added:

You just have to have confidence. You have to believe that if you create that safe holding space, something good will come out of it. You really have to be comfortable with yourself to have a comfort level to work with any population and not feel like, how can I say this? You’re going to do the right thing if you just listen and follow the lead of the person you’re working with. And if you can just let go, then I think the process just unfolds so naturally.

Kim spoke of the need to develop a trusting relationship between the client and the counselor, which, in turn, helps the client feel they are Being Honored, “…finding out that it’s safe for them to trust you, then be able to show their feelings with you.”

If the counselor believes the client should adapt to the counselor’s particular method or usual interventions, the client is not receiving client-centered services. Jan challenged counselors to be flexible and open. “Just be willing to accept them on their own terms. Because [with] some people it’s sort of like, there has to be a willingness to meet people where they are and not with our agenda.”

None of the data in this section are unique to working with adults with DD, or even to grief counseling. What the participants said helped their clients were truly client-centered practice principles. For clients with DD, unfortunately, it is an unusual occurrence to be witnessed, listened to, and regarded with respect. *Witness and hold emotions* was a prevalent code. It is the essence of the work of the counselor with any
Witnessing and holding emotions is a key component of practice. It creates a sense of affirmation and safety for the client. It honors the client’s experience. It is integral to bereavement counseling and is described as particularly vital for adults with DD. Few of this population have ever had their feelings witnessed and held, often due to discomfort or fear on the part of the caregiver. As further analysis unfolded, this code was merged with Connecting. At first, I thought it was a good example of a category initially called Normalization, since witness and holding emotion is part of the generic counseling process. Normalization implies conforming to a standard, which seemed to miss the point. After further analysis, the data clearly belong in the category of Being Honored.

Nicole illustrated how she honors her clients in her work by using language and activities that they can understand:

With children and with persons with developmental disabilities, the more concrete you can be, the more helpful it is, and so a lot of the education that we do with people who are involved with those populations, whether it’s parents or caregivers or whatever it is, to use very concrete language and to take advantage of concrete opportunities. Like, it might not be as important for an adult to actually see the body after the person as died as it is for someone with a developmental disability or for a child, so that it really becomes clear to them. Oh, I see. The person is no longer breathing. Their eyes don’t open anymore. They’re not moving. The heart’s not beating. So, that concreteness, I think, is really helpful to both populations. And I don’t know that I think it’s valuable in general for folks who might hear other folks say that it was helpful to them to actually see the body, but I don’t know if it’s as necessary as it almost is for those populations. So, that’s, I
would say, a difference from sort of the general population, is that I think the concreteness is even more crucial.

Lisa honors her clients by assessing what methodology will work and what interventions will be helpful in their grief journey:

...extremely bright young gal. We do cognitive. She’s able to process cognitively, so we do cognitive therapy. For the most part, my therapy is projective: drawings, art therapy, bibliotherapy where you’re reading about, [for] example, Fall of Freddie the Leaf, by Buscaglia, that type of a book, then talking about the book: How was that like the person that you lost? Tell me about that?

Lisa described her work to respect varied abilities and modes of expression:

The clientele that I work with, I think it’s just being able to express their grief, whether it is through drawing, my more cognitive more high-level clients through talking about it. Repeating the story over and over and over. That has been extremely helpful and just replaying the scenario of the funeral and what happened, so... And then our therapy has been helpful. You know, the drawing, talking about the person that’s died. Tell me about that person.

Amy further described the diversity of her clients with DD and how she adjusts her practice to meet their needs:

I work with people who have cognitive disabilities, who are very verbal, and so we can do a lot of talking about what happened and about the situation, which is a nice release for them to have a safe place to come to talk about it. And I’ve worked with people who have cognitive disabilities who are non-verbal, and, in that case, obviously, we don’t do a lot of talking, so, I have a tendency to use art a
fair amount with people with cognitive disabilities. We do different kinds of art projects that they enjoy and they like. I have a tendency to do kind of music expression. We will listen to music together, we will listen to slow music, sad music, happy music. I encourage them to bring in their own music with them. I use some story telling, both with people with cognitive disabilities who are pre-verbal and who are verbal, we’ll do some story telling. And, all those things, I think, help in terms of expression, in terms of helping them to get out what needs to come out, in terms of their grief so that it doesn’t stay in there and roll around in there

When clients are honored and feel their pain has been witnessed and heard, they may be grateful. *Appreciation* was a limited raw code. Appreciation implies thankfulness and gratitude. To appreciate someone or something means to take notice. Appreciation is important to note because people are appreciative of positive experiences and feelings. They are appreciative of another’s kindness. Clients express gratitude for relief of distress, the letting up of their pressure or pain. They are appreciative of someone to listen to them and acknowledge their feelings. Hannah shared the ending of a story of a man she met whose mother was dying. “When I was concluding our sessions, he was just so incredibly thankful, so candid, saying, ‘Thank you for allowing me to show my feelings with you.’ It broke my heart.” Hannah interpreted this thanks as a confirmation that her listening was helpful to the client.

Nicole went on to describe a recent experimental activity:

[We did] role playing and we had some specific examples. One was a staff member coming and saying to the resident, “I’ve really enjoyed our time together,
but I have kind of some exciting news for me, but also some sad news in that I’ve gotten an opportunity to move to another job and it’s not in this state, and so I won’t be able to see you after I leave here. And we have a couple more weeks together, but then I’ll be gone.” It’s sort of like role playing that out. And then we move to the next level. The second role play was about hearing that your mom just called and she wanted the staff member to tell you that your aunt just died, and so, we did that and actually, some of the members of the group helped out after we did the first role play and demonstrated in taking different roles. And I think that actually really got people involved. That was kind of an exciting. We hadn’t ever done that before. See, what we’ve [done] is ritual and art projects, and we’ve done some movement and poetry, writing like a group poem and things like that.

Lynn believed she honored her client’s need for comfort in the night to help him deal with nightmares since the death. “[I gave him a teddy bear] and told him, you know, when he woke up at night and was sad, to just hug his teddy bear. And, you know, he named the teddy bear? He named it after himself.”

Beth advised that part of honoring the client is staying centered and believing in the process. She described the need for the counselor to stay anchored and let the client experience their feelings fully:

I think with people who are so in the moment, and to understand that all their angst and what they’re experiencing in that moment, [but] you know, an hour later, it may not matter? It’s like, that was last hour’s crisis. Here’s a new one.
And to not get so wound up inside and to just know that they’re going to move on from this at some point, but it could be pretty wild while they’re in it.

Nicole outlined basic suggestions for working respectfully with others who have cognitive limitations. These ideas, in fact, should be standard practice for respectful work with all clients.

Do what you would normally do, but maybe check out are they understanding, because it may be that your language might be too complex, that you need to simplify your language.

Treating each client as an individual, regardless of mental status, is what counseling is about. Jessica describes how she modifies her practice to meet needs of individuals with DD:

I have just taken what I have learned with regular bereavement and figured out ways to apply it to those who are cognitively impaired. But see, I see it as the same. It’s just, it’s my problem to figure out how to get the information across and how to figure out how they can express it to me with whatever abilities they have. [I use] a paper that has all feelings faces on it, so if they can’t identify with words, they can identify faces and then I’ll try to link it to what’s causing that face to be like that.

The core of good counseling is discovering what works for the client and what their life, fears, and hopes are. Marta explains how she accomplishes this. “Finding a place where their language works, where their communication has to work. Making sure you walk into their world.”
Specific interventions that were believed to help clients deal with loss and change tended to be concrete and helpful for visual, tactile, and auditory learners. One participant suggested that if a counselor was struggling, perhaps he or she needs “a bigger toolbox.”

And then I read, *Who Moved My Cheese*, the children’s version, because it’s about change and how scary change can be and what kind of a little mouse are you? (Jessica)

I use balloons because that concreteness, watch it float up as that balloon floats up in the air and they visualize that this was their mother or that is father, or sister, or brother. (Pat)

They can take pictures, images from magazines, create a collage and then put the photograph of the loved one and themselves in it or choose not to use, perhaps, themselves, but of the loved one, and it’s just beautiful. (Hannah)

Since each person has a different loss history to contend with, and different experiences with caregivers, or has never had anyone explore their pain, individual cues must be watched for and followed for the client to be respected and honored. Marta described how she intuited cues from the young woman she once had as a client:

She always wore this necklace of wooden animals and she always touched it, so I started with talking to her about how much I liked her animal [necklace]. She would start talking and then pretty soon we were able to connect an animal with a feeling. And, in that process, she was able to talk about her grief over her mother’s death, but also her rage toward her father and his death. So, we did a lot
of work, but it was using her - what she was comfortable with as a medium of
exchange of communication.

When I began coding, I first used “different” as a code, and then changed it to the
category Individualize. I chose the word Individualize because it is more in keeping with
a belief that we are all unique in some way, despite our commonalities. The quotations
linked to these codes are about possible unique qualities in the working relationship for
counselors dealing with adults with DD. Eventually, I saw these comments as the need to
honor each client’s needs and merged these quotes with Being Honored.

About mid-coding I developed a code forgiveness. I realized later it only had one
quotation tied to it. The participant is speaking of adults with DD generally being open to
intervention and being very forgiving if the counselor made a mistake. This code was
included in the broader category of Being Honored. Amy discussed the concept of
staying in tune with her clients and acknowledging when she has gotten off track:

I mean, I think that in some ways, if you give something a try, you learn, and one
of the things I find with both kids and people with cognitive disabilities is that
they’re very forgiving. So, if you make a mistake, they’re much more willing to
forgive you. And, believe me, I’ve made mistakes, and I have to apologize and I
have to say, I think I’ve said the wrong thing or done the wrong thing or I don’t
think you and I were too comfortable that last session, were we? And I have to
honor that. But, I think the first thing is to just be willing to give it a try. I mean,
people with cognitive disabilities are people, you know, just like all of us, and all
they really want to do is feel better and learn how to do that and it’s just like
making a relationship with anyone. You just kind of start where they’re at, and you take it from there.

Yet another limited code developed early in the coding process was *patience*. It was a code that referred to the need to let the client take her time to work at her own pace during the grief process. I know patience and letting the client set the pace is an element of all client-centered practice, but participants implied extra patience might be necessary. This would be especially pertinent in cases of limited verbal communication or speech difficulties. I believe the data that tend to portray the need for patience are part of the larger category Being Honored.

Being Honored is essential because people with DD so often are put into categories of “those people”, “that population”, and “the mentally retarded”. Their one common deficit, atypical IQ, throws them into a one-size-fits-all grouping that they have had to fight against all their lives. The disability category seems to mute and blur their individual uniqueness. The consequences of not being heard and respected are often felt by these adults every day. Assumptions are made about them based on their IQ score or physical appearance. The participants stress ways to honor the individual.

You know, you have mental retardation? OK. You have CP? OK. We’ll just work around it. So, that’s my whole philosophy. (Marta)

They often have an incredible strength, from my experience with the cognitively disabled, especially in the group home environment, they’re incredibly strong.

(Hannah)
You take that person where they’re at. So they don’t have a high IQ. Well, that’s just one the things they don’t have. I mean, yes, they have a low IQ, but sometimes they have wonderful insight and wonderful abilities to pick up - intuition, wonderful intuition, and I think you can play to that. (Kim)

I just try to take my cues from other people that are more in tune with them, you know? You know, like the staff that works with them. (Chris)

In summary, individualize began as a raw code and then the category named Individualize. Individualize eventually subsumed codes relating to uniqueness or difference. The raw codes that were merged into Being Honored as a conceptual category are separated into two tracks. One focuses on what is perceived to be helpful in practice to clients with DD. The other focuses on what counselors believe they, themselves, need to work on.

The first three codes address the counselor focus:

- Need to address counselor’s own issues of mortality/death
- Self-reflective practice
- Boundaries/dependence

Raw Codes that reflect what type of practice may be helpful to bereaved adults with DD:

- Parallels to children, shorter/structured sessions, willingness to engage in treatment
- Gifts/abilities/strengths
• Witness/hold emotions
• Intervention, varied modalities
• Different
• Forgiveness
• Patience
• Listen and explore
• Follow client lead
• Appreciation

The counselors voiced their perceptions that once a bereaved adult with DD connects with someone who stops long enough to find out what was distressing her, how she best comforted herself, and what and who she wants to have in her life, the adult with DD is finally been honored by being recognized and heard. Taking into account these issues in practice are viewed as helpful to bereaved adults with DD.

Being Together

When asked what they view as helpful to adults with DD to get through grief, most participants answered that family or strong social support is beneficial, in addition to the client having access to someone who listens to them. Clients being heard and respected were viewed as therapeutic and were categorized as Being Honored. It seems possible that social support and family by themselves are not a guarantee of a smooth journey through grief, but if both a social network and supportive listening are available, clients were presented as being more stable. Family and social support, connections to
community, and the more subtle bringing together of behavior, thoughts and feelings compose the category of Being Together. As Amy said:

People who have supportive people in their life, seem to be able to cope a little bit better. That makes a difference. Having somebody, I think, around you or near who you can be with or talk to or can comfort you. I guess that’s the best way to say it. Having people who can comfort you and who you feel comforted by, I think, makes a difference.

This category is well represented by the data. First, what does together really mean? Together means connected, joined, sharing space, making contact, discovering similar emotions as in “He and I really were together on this”. It can imply that a person is doing well, feeling good about herself, as in, “That person really has it together.”

Togetherness is vital for human beings who live interdependently. Feeling disconnected may result in loneliness and despair. Disconnection may also be feelings and behaviors that don’t match, or feeling disjointed. To communicate easily, feelings and actions are expected to be congruent.

This final contextual category is about relationship, skill building, and self-reflection. It is about reconnecting clients’ emotions, thoughts, and behaviors. It reflects the counselors’ sense of success when work is done to connect with clients in a therapeutic relationship, to help clients incorporate coping strategies, and to link clients to family members or community groups like a place of worship. It also encompasses the counselors’ own connections between previous experience with people with DD and bereavement counseling with adults with DD. Again, the parallel pathway of counselor need and client need were evident in the category, Being Together. The experience of
bereavement for adults with DD was presented as being impacted greatly by caregivers, staff, and the attitudes of society. The data begin with the stories of what works in practice. When working individually with the bereaved, the counselor may use stories, videos, or tell the person that others all share those same feelings. The idea that the adult with DD is not alone in their grief is vital. They need to know that others may feel the same way, whether they have a disability or not.

Just kind of map out a little bit of some things that they might expect to feel emotionally and telling them that that’s normalizing (Sharon)

We’re just showing them the grief journey about different emotions that are normal. (Chris)

I think definitely having others around who are sharing it with them and sort of helping normalize it, in a sense, in that they’re not the only one having these feelings, for reassurance that it’s OK to feel the way they do, or talk about it. (Jan)

Counselors reported providing security and safety by offering varied means of expressing emotions, such as sculpting clay, collage, drawing, music, movement, and talking. The counselor’s presence was perceived as comforting to the bereaved. The assumptions were that by letting the client know that grief feelings were normal and not stronger than is the client was able to handle, helped stabilize the client. Hannah explained a variety of ways that this can occur:
You have to believe that if you create that safe holding space, something good will come out of it. It just provided him with a safe environment to be able to go there with his feelings to express himself. [It] made me realize that if you just take the time to listen and validate feelings, then the journey becomes less painful internally. You know, people will sense whether you’re uncomfortable with them and when they feel that you’re safe with them, and if you can provide the safety and the trust, that’s more than 50%. I see a lot of one-on-one, if somebody’s grief is so deep that the counselor will take them aside and sit with them or walk with them and just identify those feelings and reassure them that what they’re going through is OK.

Successful interventions are designed to bring together or connect thoughts and emotions, emotions and behaviors. Helping the adult with DD identify and understand their feelings, as well as the cause of their feelings is presented as requisite. Assisting the client to link behaviors or physical responses and thoughts connected to these emotions is perceived to be another essential component. Finally, problem solving and teaching skills, or helping with connections was thought to solidify client growth. Jessica discussed how problem-solving can be taught:

Identify feelings and, most of all, identify coping skills. What do you do when you’re upset? What do you do when you’re sad? What is OK? What is not OK? And, of course, harming yourself or harming somebody else is never OK.

Everything else is OK. Anger is big one. Anger comes up a lot, so we talk about good coping skills with anger, like punching pillows when you’re mad. It’s not going to hurt anything. But you can’t hit other people and you can cry, you know.
There's lots of things you can do. And then you try to find out from them what makes them feel better. But it’s OK to be sad for a while, but then you need to figure out how do you make yourself feel better. So, if they can identify that, then, then we’re teaching them, you know, teaching them to recognize their coping skills, or teaching them new ones.

Dave discussed how prevention and early education are key:

…explaining the loss, giving as much information as possible. If the loss is expected, I believe the developmentally disabled person should be treated just like any other family member. They should have the opportunity to have as much information as they’re able to take in to prepare them, if there’s an impending death, with the understanding that Johnny is very, very sick and is not going to get better and allowing the developmentally disabled person to be involved in caretaking, if possible. If the death is sudden, then to explain very clearly that someone has died and to explain what death is, if the person’s understanding is not the same as an adult understanding.

Physical touch is mentioned as being helpful for some, and not for others. Dave believes that touch is important:

I think that physical touch is very important, particularly for anyone that’s suffering a loss, but maybe particularly for a developmentally disabled person who is able to tolerate touch. The staff and family know this person more than anyone else. They will know whether the person’s able to tolerate being touched or not when they’re upset. So, if it’s been shown in the past to soothe this person, there’s no reason to not do it in this situation as well.
The modalities are developed to teach about feelings and how they affect our bodies and minds. The participants reported teaching clients about feelings and connecting them to sensations or memories. Jessica spoke of how she proceeded to help her clients with DD.

And then you try to find out from them what makes them feel better, but it’s OK to be sad for a while, but then you need to figure out how do you make yourself feel better. So, if they can identify that, then we’re teaching them, you know, teaching them to recognize their coping skills, or teaching them new ones.

Some clients may be able to process deep thoughts and feelings, but have difficulty with verbal or written expression. One of Paul’s clients has a 12-year old cousin who came up with a creative alternative. “She had a 12-year old cousin and they got into a custom of the client’s telling what she was thinking, feeling and so on and the cousin writing it down for her. And that seemed to be really helpful.”

Teaching about feelings is viewed as key to early education. Teaching awareness of emotions was presented as especially important with feelings of grief. Jan discussed why this is important:

I would say that this population in particularly need[s] reassurance that it’s OK to have the feelings that they’re having In specific, very specific and cognitively appropriate coping skills that, you know, when this happens, you can do this, this, or this, and I’ll have them repeat that back to me, like, OK. Now, if you get really, really sad, what are the three different things that you can do to take care of yourself? And maybe one is that I can call so-and-so, or I can.. sit down quietly and just wait for the feeling to ease by itself, or I can have a good cry. You know,
like that, and they seem really grateful for those specific -- that you would think were obvious, but aren’t so much. That you have to make this connection, that \textit{OK, you do this, this, and this}, and I find they’re wonderful clients in the sense that they’ll by God do it. I’m thinking of one that would panic with the feelings, and I did work with him on some deep breathing and stuff like that, so I guess that would count as something besides talk. Yeah, that was one that, now that I think about it, that was one of the ideas that I gave him that when, if the feelings were strong and felt kind of overwhelming, that went with the be quiet thing and to just take some deep slow breaths and tell himself that he could be calm.

Finding ways to explain that death is irreversible and the person cannot come back challenges many parents, caregivers, and professionals. Use of concrete language, activities, books, and video were seen as helpful to increasing the client’s understanding. The counselors also endeavored to help the clients connect to good memories and feelings to keep a healthy bond to the deceased. Work on continuing bonds to the deceased was seen as therapeutic. Encouraging participation in rituals is usually encouraged, even though not all counselors are sure of the level of understanding.

I don’t think they quite comprehend, depending upon their level, I don’t think they quite comprehend the finality of the funeral, but yes, for the most part, they have been able to attend. (Lisa)

Helping the client recall and talk about good memories and form remembrances is part of bereavement work. \textit{Remembering} was developed as a code to represent data associated with rituals and activities to link the bereaved with a positive memory of the deceased. \textit{Remembering} has rich meaning. Linking with memories, keeping a mental
image and an emotional connection are implied by this term. *Remembering* and rituals are spoken of as positive activities. Nolen and Hoeksema (1999) summarize the final cognitive phase of grief as “realistic memory of deceased, pleasure in remembering, and new meaning in life” (p. 4). The counselors worked to get the adults with DD to link with comforting memories and create a new mental and emotional connection to the deceased. After analysis, the code fit well under the broader conceptual category of *Connecting*. The category was changed to Being Together that carries with it the connotation of continued connection to the deceased.

I asked about funeral participation, so *funeral* was a frequently mentioned raw code. It referred to the participation in memorial rituals. When hospice is involved, there is a strong message given to clients to include all in the memorial/funeral. This code was merged with the category, *Connecting*, then later with *Being Together*, as all the participants believed that participation in the funeral or any remembrance ritual is healing and builds a healthy emotional tie to the memory of the deceased. Jan utilized ritual in her work:

I have been able to devise simple rituals that a person can perform on their own and have seen followed through, like making a little special place with photos and mementos or making a special ornament for the person for a Christmas tree. And so, there are ways in which they can do that, too. I know my nephew did and I know another boy that did, that [they] were able to participate, that were able to speak at the services and, in a way that pretty well… with an eloquence that pretty well floored [everyone].

Hannah incorporated memories and memory-making in her work:
Do you remember your mother's favorite color? And, if they struggle with that, I’ll say, Well, what do you remember your mother wearing? You know, Was it a favorite shirt? What color was the favorite shirt? to get to that point, to get to Oh, OK, so perhaps it was red. She always wore this red shirt. So we’ll work with that. But to keep it simple to have, and if you ask them what their favorite color is, they have a favorite color. So, connecting to colors, shapes. And I think, when you simplify it like that and they’re able to use metaphors and symbols and expression that, in its simplicity, it’s incredibly powerful and it… they feel very comforted by it.

Chris suggested memorial ceremonies be attended or developed:
Participating in some kind of memorial. At Christmas, one house made a memorial garden, others have done Christmas ornaments that have the names of people that weren’t there anymore on them. We have talks about grief and how they remember the person and who the person was. That seems to help.

Alecia uses ritual and activities that revolve around the memories of the deceased.
A lot of rituals are helpful with everyone and making cards that say what you would like to say to somebody, or collages, cutting out pictures of things that they used to do with them, or things that meant a lot to them. I did encourage all of them to get a linking object, a memento of some kind.

When speaking of death and dying, religion and spiritual beliefs usually arise. Spiritual beliefs are referred to as a means of coping or making sense of a death. Spiritual beliefs are key components in the stress and coping literature, especially in regard to efforts to make sense of a death. Concrete beliefs about an afterlife are reflected in the
data with the notion of the loved one now living in heaven mentioned. The struggle to make sense of the meaning of life and death, no matter whether one had a DD or not, is described by one participant. Quotes related to connecting to spiritual beliefs were merged with Connecting, then the new category, Being Together. Comments about lack of spiritual grounding or beliefs were merged with Coping Challenges. Several participants report helping the person connect to spiritual beliefs for explanation of death and perceived increase in comfort.

If they believe there’s heaven and [the deceased is]watching over them, that that’s important. (Lynn)

Her journey, her grieving journey is that knowing he’s safe in heaven. (Hannah)

Well, I think that everybody needs some kind of philosophical foundation, shall we say. Some context in which to hold the suffering of life that we’re all subject to and I don’t think that that is one bit less true for people with cognitive disability. They can have faith and have religious beliefs and so forth, and need the opportunity to be exposed to that kind of thing and talk about that kind of thing. Something that will help them understand. I don’t know if we always understand, but just help them have some context in which to place the ultimately inexplicable. (Jan)

If they have a religious belief system, it’s a good time to pull it in. I always ask and the reason I ask is, it’s a good coping skill. (Jessica)
Grief is a strong emotion that is often frightening in its power. If a person has an experience or emotion that they believe no one else ever had, feelings of isolation is a potential result. If this emotion is grief-related, the intensity of it may cause fear that this emotion is one that cannot be lived with or controlled. With grief, several emotions are often present. The grief-related emotions that the data provide are anger, sadness, guilt, searching and loneliness. The feelings of the adults with DD were communicated in behaviors that were considered to be problematic by some caregivers. Without words to express the pain, hitting and lashing out might be observed, or withdrawal, or not eating. For the bereaved adult, there may be the fear that these strong grief emotions will take over and destroy all previous and existing coping mechanisms. Knowing that others have coped or survived this emotion could be comforting. Explaining that others share the same feelings or experiences is called normalizing. Normalization can be achieved through books, movies, education and talking with others. Not knowing others feel the same way would not be an issue if everyone were well-connected and well-prepared. I believe it would no longer be necessary to normalize feelings of grief for adults with DD or, for that matter non-disabled adults or children, if there were more early preparation and dissemination of information. Education could then be reinforced with open communication throughout the life span.

Not knowing the prevailing circumstances and not being privileged to certain information leads to secrets and non-disclosure. These can threaten safety and trust, as discussed under Loss. Safety and security were presented as less of an issue when the bereaved understood that their feelings were normal and knew how to cope with them, and with whom they could share their emotions.
They’re going to welcome the opportunity to discuss what’s happening and to sort of feel like this is legitimate, that we can talk about this. (Nicole)

I think being able to talk about it, being able to just say whatever they need to say about it, and have somebody with them. And, in some cases, providing information. They need to know things. They don’t necessarily think of the questions to ask, but seem to really take in being provided with some information about, well, when somebody dies. (Jan)

The comments and suggestions for education and training are focused on connecting staff and caregivers with knowledge and helping them make cognitive connections about what they have seen and what others recommend.

Factors that are noted as helping adults with DD get through grief included *Family or social support*. Social support is a major concept in the field of social services. In this study, family or social support is identified as a factor that, if missing, was believed to create more coping challenges. If support was present, it was viewed as providing stronger connections. Comments that showed lack of social or family support were tied to Coping Challenges, whereas comments that spoke of good support or work to reconnect were tied to the category of Connecting, then later, to Being Together.

In addition to working with the client and the family, staff often assumes the family caregiving roles and may themselves need assistance. *Staff needs* was an initial code that was assigned to data that mentioned staff needs for support, as well as education, as discussed in staff/caregiver misperceptions. Staff was seen by at least two participants as having issues and concerns that may interfere with their ability to support
the bereaved adult with DD. In that sense, I saw a connection to safety/security. The caregivers need to be in control of their own grief process so that they can provide a safe container for the bereaved adult with DD. Comments that dealt with existing staff needs fit with coping challenges. I viewed data related to how to meet staff needs as appropriately linked to the category of Connecting, and finally, fitting best in Being Together.

The counselors look beyond themselves and the client to the family or care situation when assessing. All participants note that caregiver guidance designed both for families and paid caregivers is needed. *Education and training* as a code in regard to needs for caregiver support was developed early. *Education and training* could also apply to bereavement staff and other counselors. I heard the participants all indicating the need for guidance in what healthy bereavement is about and ways to navigate the grief journey. The focus on education is to fill the gap left by the perception of societal avoidance of death and dying and the intense feelings of grief and loss. Originally, I decided to merge the concept of *education and training* into Connecting. What education and training comments carry with them was a way to repair gaps and prevent future misperceptions. Knowledge and understanding are presented as means to prevent fear and reduce existing anxiety. Connecting caregivers and professionals with knowledge was seen as a way to assist not just adults with DD through grief, but everyone. When the Connecting category was changed, the information on *education and training* was moved to categories that were more fitting, including Being Honored and Being Together. Comments about training caregivers to recognize and support the grief reaction can be
viewed as Being Honored. If comments were about the act of going out and connecting with others to teach, these can be viewed as Being Together.

Caregivers, teachers, and family members are viewed as capable of being able to help pave the way for more positive grief and loss experiences in the future. Connections take place between the counselor and the caregiving staff. Counselors guide and mentor caregivers about grief processes and how to support the client. Elizabeth also worked with the parent or caregiver to alert them to the work she and the client are doing, as well as what may be triggered emotionally.

There’s the other piece: educate the parent. Even though it seems as if we didn’t do a whole lot, just know that their emotions may surface later, and in one specific situation just not very long ago, I was really glad I had told them. The fact that she said that that evening that young lady had really had a hard time sleeping, she was being very tearful and wanting to be held.

Some of the education is about how structure can be comforting to the client.
Lynn explained:

A lot of it was working with staff to make sure that their structure, their daily structure, was the same, to keep things as normal as possible for them. With their world kind of turned upside down by the loss, the structure of their day helps.

Many participants mentioned the need for more training in residential centers and early training for all children, including in schools, and subject specific training for health care professionals. The counselors believed that if education and support were worked on by all the players, adults with DD would be better supported when life’s inevitable losses occur. Amy described how she views her role as an educator, as well as a counselor:
I also think that early education... I mean, I go into schools all the time and teach about grief and death and loss for the teachers who’ll let me in the classroom. I have just a really nice presentation for all ages, all the way up through, you know, little ones and middle schoolers and high schoolers... to just talk about life and death and the way that they go together and to talk about that when someone dies, there are feelings we’re going to have and that those feelings are normal. And I think that that’s one of the best ways we can prepare all of us for that, is through just the education of life and death and what’s going to come when we experience a loss so that we know it. I do workshops with staff who work with people with cognitive disabilities. I try to help them to know that don’t keep this a secret, you know. If a person has a loved one who’s in the hospital or who’s deteriorating or who’s very ill, or who has cancer, don’t keep it a secret. Don’t feel like you’re protecting that person from it, because we can’t protect people from death, you know. We just can’t. I mean, we can protect them. Certainly we want to protect them from certain things that happen, bad things that can happen to them, and we’re really big on safety and we want people to be safe, but we can’t protect them from death. So the best thing we can do is teach them how to cope with it, and in order to teach them how to cope with it, we have to be able to let them know what’s going on. Give them the information they need so that they can have what they need to cope with it.

Jan spoke to the need for more efforts in education about death:

I am a firm believer, because I work with children a lot also, that a subject should be on the table and I don’t think that either cognitively disabled or children have
near the fear of morbidity as so-called normal people do, and I think that’s even more true when the subject is on the table, which means that when a death occurs, whether it’s something in the news, or you see a dead animal somewhere, or you hear about somebody else having somebody die, that, with both populations, you take that opportunity to talk about it a little bit, so that you just, from the get-go, you’re just… it’s, the subject is just there.

These counselors can be a great community resource for education, as well as for counseling around grief issues. Jan noted, “What I’ve gotten more there is people who work with people with cognitive disabilities calling to ask me for guidance and how to help their folks.”

Jessica addressed the her belief in the need for more training for group home staff:

Group homes ought to have educational pieces and things that they provide to the clients, whether it’s through Arc or, you know, whatever organizations are around there, but I also think the schools need to do it, too, for everybody. I think it’s so that it’s out there more, that people talk about it so that they understand that people just… We know everybody’s going to die. They’re not going to die tomorrow, hopefully, but when they do, you know, this is what is normal.

Healthcare workers, especially, were seen as needing more education around grief and death and dying, as Chris stated, “I think every nurse should and every doctor and every health care provider should have some training in bereavement.”

Dave addressed the issue of protection and honesty in death education:

I would say that we would need to always be honest with them about someone’s illness whenever death, which always does arise in some way in our lives,
whether it’s on TV, in the news, or whether it’s a family member or a neighbor or someone in the community, death is always happening, so there’s really no way to avoid it. So, to use those opportunities to explain death and to talk about it and, as caregivers, helpers, or family members, to be open to talking about it ourselves.

The participants all provided bereavement counseling through a hospice program. Hospice has a philosophy of inclusion and education for family and caregivers. Hospice preparation was coded at first, as it was perceived as a positive factor in adults with DD dealing with bereavement. The team concept of many providers addressing the holistic needs of the family in preparation for loss is believed to be beneficial. Some bereavement departments do community work. A difference was noted when people have had some preparation for loss difference versus no preparation. Loss is never easy. Some say there is no way to prepare. Later in the analysis process, the meaning of hospice preparation was found to be helpful due to the connections made with the counselor between the counselor and the caregiver and the client and others. Hospice preparation was seen as helping to correct overprotection. As a raw code, it was merged with Connecting, then with the new category, Being Together.

Education was a favorite topic and emerged frequently in different forms. Professional education and resources was a code developed to represent the data that spoke of desires for more consultation and materials to guide practice with adults with DD. I believe that this need for more knowledge was a part of the larger raw code education and training. When participants speak of professional education and resources they request clinical supervision, more written guidelines and articles, mentoring, and information. They want to connect more knowledge to their practice so they can better
meet the needs of their clients with DD. The code *professional education and resources* was eventually merged with the larger conceptual category *Connecting*. Later, this was modified to Being Together.

The counselors who try to assist adult with DD on their grief journeys want education, mentoring and support, themselves. When they reach out and work together with others for this guidance, the adult with DD is seen as benefiting. Amy talked of her efforts to connect to others with experience with adults with DD:

I think reading some articles really helped me. I know that when I first started, I kind of started to read some articles about other people who had worked with people with cognitive and developmental disabilities, and that just really helped me to hear about what other people did or saw or sometimes their actual research helped me. But certainly reading articles from other people who were seeing people with cognitive and developmental disabilities and ideas of things that worked. That’s where I got the idea to do certain art things that I do like collages and things like that.

And also the storytelling, I got that idea from an article, too. Lots of times, people with cognitive disabilities love stories, so if you start out by telling stories or reading stories and then ask them to tell a story, that’s a really fun thing and a really good diagnostic tool. So those are my two pieces of advice.

And if possible, I guess finally, if possible to talk to somebody who is currently seeing people with disabilities. I know we do a supervision, all the staff, we do a peer supervision. We have an hour a week that we get together to talk about cases and just recently, one of the newer staff members I’ve got told me that they were
working with somebody who had a developmental disability and this is what was happening, that they were pretty much done after 30 minutes and they didn’t know what to do with the rest of the time and they started asking some questions like kind of telling some of the things that they were struggling with and it just really helped for all of us to sit there and talk about it together and say, *Well, you know, I’ve tried this, or I’ve done this,* And she was very grateful to hear that. Very often I will end the session after 30 or 40 minutes because the person is done, and if a person’s done, they’re done, you know, and it’s OK to be done early. There’s no reason why you have to kind of force somebody to sit there for 50 minutes if they’re done, you know. So just having those kinds of conversations and discussions was really very helpful. So I guess I would give that. I would offer that suggestion also to people who might be willing to do this, but aren’t exactly sure about it or if they’re a little uncomfortable with that is to talk with somebody who is working with people who have cognitive disabilities, because then that just helps increase your comfort level when you hear what other people are doing.

As professionals talk about what they need to do their jobs and how other counselors could better serve adults with DD, “more clinical supervision” was a code that emerged. This code paralleled mentoring for the professionals. I saw this code as being appropriate to merge with Connecting, then to the new category, Being Together. Knowledge and mentoring are aimed at connecting the counselor with the literature, discussing cases with another counselor for feedback. Being Together captures the holistic nature of these activities. Obtaining new ideas for practice and guiding the
counselor in self-reflection are believed to be more appropriate in the Being Honored category.

Throughout the data, various pieces emerged that appeared to be of importance, but then faded. *Anticipating* was one of these early codes; it was thought to indicate caregiver assessment of risk for the bereaved adult with DD. If a behavior change had not been noted after the death or if early intervention was offered to an adult with DD, it was usually based on the expectation that future problems would arise. *Anticipating* had both positive and negative connotations. On the one hand, it fit with protection and loss issues. On the other, it acknowledged coping challenges and was an effort at connecting the client to help. Data on *anticipating* is either linked clearly to Coping Challenges, or it is a positive comment about connecting the person with more education and support. In the latter cases, it fits with Being Together.

The concept of connecting the bereaved with others as being therapeutic is found in various comments throughout the data. *Connection broader than therapist* was used as an early code for remarks about connecting the client to family and others and working to not create dependence on the counselor. This code was merged with the category Connecting, then merged with Being Together.

The loss of a loved one can leave a large hole in the life of the adult with DD who already has a small social circle. Counselors who participated often mention their work to re-involve siblings or other family members in the life of the client. Sometimes broader connections are made to community resources such as places of worship.

[I] kind of get other family members involved... adult brothers and sisters who no longer lived at home, but some of who[m] were still in the area and helped
advocate for her and do all of those things to help get her into a situation that was just healthier and she was happier in. So that had a huge impact on her life.

(Amy)

Try to foster - if it’s not with family because sometimes they’ve lost their family - to foster some sort of relationships in the community in which they live that will always remain constant, whether it’s a church or a synagogue or some sort of social connection outside of the group home or outside of the day treatment program, so that way there are some constant relationships in their life, I think help mitigate change, the pain of change. Some things will always be the same.

(Dave)

…like the young man who lost both of his parents. It was the mother died second and he was very dependent on her. I did see him because I worked with him over a year, and I did see him do a pretty darn good job of shifting that dependency to other people who were fortunately, apparently, available for him to do that, although I think he would do that with whoever presented themselves and was able to consciously do that and accept that he needed that support and he was going to get it from anybody that might be willing to give it. If anything, I think he would incorporate anybody that he possibly could into his support system (Jan)

I bring in the rest of the family, or in this case that I’m working with now. We got her transportation to come to our memorial service to give her a sense of
public safety and now we’re going to be transitioning her. She gets a clear idea that her long-term support is going to be through her church and through a center near her. How are we going to get you hooked up with your church? so we just kind of immediately attend to the, I’m not replacing Mom. This is you can call me and we can talk, and let’s talk about how we’re going to get you a life in your community. Our goal is to get her into activities through her church and perhaps a senior center because she’s in her late 50s, and because of her disability, we believe she would be able to go to a senior center. (Marta)

At times, the work is to connect the grieving adult with DD with others who are grieving. This is viewed as part of the normalization process.

As noted in the discussion of the sample demographics, half the participants had previous experience with persons with DD prior to work as bereavement counselors. Experience = comfort was a raw code assigned to quotes that indicated that participants who previously worked with people with DD were more comfortable with the referrals they received for adults with DD. One person, Marta, reflected on how bereavement work linked to all her other social work jobs. “Grief work is a seam in everything that we experience in life, so it’s all made me prepared to do hospice work.”

This category also applied to the phenomena whereby clients often are referred to bereavement counselors who are known to have previous job or practice experience with adults with DD. This implies that both the caregivers and clients may have felt more comfortable with a known counselor assisting them with bereavement issues. I initially merged this code into the Discomfort category. I then questioned whether it truly belonged in the Connecting category. I finally decided to place this information in the
Being Together category. Experienced counselors speak of their perceived successes in bringing comfort to the clients with DD. Bereavement counselors who made previous connections with adults with DD felt trusted. Bereavement counselors believe they connect better with clients and understand their needs when they have previous experience with the population.

Counselors who worked previously with people with DD, have relatives with DD, or who have done work with children requiring concrete interventions, expressed more comfort. Nicole described her years of experience as a case manager for individual with DD:

Having worked in the field of developmental disabilities for the years that I did was the biggest assistance because it was, you know… I mean, I knew about disabilities and I knew about all the losses that they experience and I’ve been aware of people not being included in information about loved ones that were terminally ill and things like that, so I sort of had all that background. So, when I came to this work and began to get referrals of people who were family members of somebody on hospice who was dying and they were developmentally disabled, it wasn’t unfamiliar. It was totally familiar, so that was, I think, good, good background. And then, just to put the two together, to kind of go, Oh! (Nicole)

I learned from this population that you take the time, you make eye contact. Everything else you block out, but you listen to this person and what they have to say because it’s critical. So, I think that those early experiences that I had
provided me with a comfort level now, to work with this population in the hospice setting. (Hannah)

Having spent my life with a nephew with cognitive disabilities [was] kind of built in preparation because I’ve always been close to him and devoted to him. (Jan)

Bethany believes her background in Special Education made a difference in how she approaches adults with DD in the hospice setting. “I’m kind of lucky because I have a background in Special Education so that made it easier.”

The counselors who developed comfort working with adults with DD brought up the concept of mentoring. Mentor was used as a code for comments about helping other professionals by modeling good practice. Counselors also describe modeling skills for clients, thus mentoring clients in coping skills. I viewed mentoring as connecting clients to information and skills and connecting colleagues to information and skills. Again, parallel data tracks were uncovered for client and professional. For these reasons, I merged this code with the category Connecting. Connections made with colleagues working with persons with DD or with mentors were positive experiences and created better counselors for the adults with DD. I changed this category to Being Together.

Elizabeth suggests:

…to find someone to consult with, someone who has expertise in the field and, even better if they can find someone who has expertise in the field and in developmental disabilities. So, it might take two. It might take talking to somebody who’s familiar with developmental disabilities, because they’re going to know exactly how to approach this individual. And then you need the expertise
of somebody who’s in the bereavement area, so that you know how to approach that specific type of topic. That way, hopefully, you can increase your own competence.

Nicole talked of her mentoring another staff, and Paul said he networks and talks with colleagues. Chris talked of observing other people working with adults with DD and found this helpful. Dave recommends:

Seek out people who have experience with that population and talk to them about it and, if there are other staff who are also in the agency, maybe have other staff people accompany the person who doesn’t have experience. So that way, that person can model for them.

Feedback to the counselor has been that the clients with DD are helped through the counseling process. Once a counselor has a track record of working with adults with DD, generally, more referrals followed.

And it always just seemed that from then on, I kind of got known with some of the agencies that I was willing to see people and that I seemed to do a good job, because they got better and their behaviors got better. (Amy)

We’ve done a lot of different kinds of creative kinds of tasks, but this was really focused on talking about it and usually we do some talking educational piece in the group, and then we do a project related to that, an art project related to that, then get back and everyone shares what they’ve created. But this was actually all talking because we talked and then we did the role plays, which was more talking.
And I was a little concerned about how that would be for them, if it would just be
too much, but it actually worked really well. (Nicole)

It was reported that other counseling professionals can be helped to connect
corcepts and modalities that assist other clients to work with adults with DD. Mentoring,
clinical supervision, and other means of education and training can help counselors see
commonalities. Assisting others to see the commonalities between adults with DD and
typical adults is viewed as having potential to decrease the isolation and lost
opportunities for adults with DD. Hannah described how her supervisor had her put out a
staff voice mail about her work with an adult with DD so that others would see the
possibilities:

…but if it wasn’t for my supervisor who encouraged that, outreach to the other
staff and educating them, because now the nurses are like, Wow, this is good to
know because we often go into homes and we’re like what do we do? We flounder.

You know, who can help this person? So, I’m sure more referrals will come from
it.

In providing their services, most participants brought in the concept of structure.

*Structure* was provided both in counseling sessions and recommended for home routines.
Information sharing was key. Jan believes structure and continuity were helpful for one
of her clients. “He did live in a group home, which was very good, so that he had that, the
continuity of the stability of that.”

With the myriad of changes and transitions in the life of a person with DD, steps
can be taken that appear to lessen the stress. Dave described some methods to decrease
the stress:
That when changes in life happen, to discuss these changes in detail [as to] what they might expect. When these changes happen, to maintain as much of a routine as possible, to keep the same routine. If the routine is the thing that’s changing, to try to maintain as much of the old routine as possible, even if it means keeping some of the same objects. Like if someone is moving from one group home to another, maybe that person can keep their same blankets, or to keep their personal items. I would say, the best way to prepare someone is to discuss change and to always have more than one person who is a constant in the person’s life who can always be a source of comfort and guidance.

Counselors work to help the caregivers connect behaviors to emotions and help the caregivers interpret and respond. Ideally, they wanted more time to follow-through and make better connections in the home and immediate environment. Most of the counselors wish they had more time with clients and wanted more help from the caregivers in implementing and following through on client goals. **Need for reinforcement at home** was a raw code linked to data that spoke to the perceived disconnection between counseling and the home environment. Many caregivers were presented as either not involved in follow-up or uninformed due to rapid staff turnover that challenged continuity of care. It was believed that when reinforcement at home existed, clients did better. I decided to split the data that was connected with this code. Comments about making connections with caregivers to reinforce treatment were merged with Connecting, then later to Being Together. Comments about the lack of reinforcement at home were merged with Coping Challenges. The data from this study that links to Being Together reflect the work to move the adult with DD toward
connections with memories, coping strategies to keep emotions under control, and work to connect or reconnect the adult with DD to family or community.

In summary, without others, people live in isolation. Without connecting feelings, thoughts and actions, balance and harmony are lost. Connection is at the heart of the work of the counselors who participated. They work to have the adults with DD achieve connection with their feelings and with others. From the bereavement counselors’ perspectives, work at connections helps guide the adults with DD more successfully through bereavement. Attention to creating more connections between death information, feeling discussions and awareness, and inclusion of all are believed to be key to improving bereavement for anyone facing death of a loved one.

When clients are helped to experience their emotions fully and learn that they will not be overwhelmed by those feelings, the client appeared to increase coping abilities. Coping was believed to be enhanced by rituals of remembering, clay work, artwork, movement, music, role play, and talking with a caring other. For the adult with DD to have a healthy bereavement and be able to move on, it was seen as necessary for the counselor to connect with the client. A belief existed that the client needed to then be linked with inner and external resources. The counselor and client were reported to benefit from collaboration with other colleagues who have comfort and experience with adults with DD. The counselors see the need for more education and training around death and loss for all, not just for adults with DD. The journey of grief was thought to be less lonely and less confusing if those around the bereaved were open and understanding.
The category Being Together was developed with all or pieces of two tracks of raw codes. One track addressed counselor, caregiver and staff issues. These raw codes were:

- Mentoring
- More clinical supervision
- Staff needs
- Education and Training
- Anticipating
- Experience = comfort
- Structure
- Need for reinforcement at home

The second track addressed issues for bereaved adults with DD. These raw codes were:

- Funerals
- Remembering
- Connection broader than the therapist
- Parallels with children, Security/safety,
- Trust
- Interventions, Varied modalities

The next job is to take the findings discussed in the last two chapters and link them with extant literature.
CHAPTER FIVE:
DISCUSSION AND COMPARISON TO EXTANT LITERATURE

In summary, the data reveal five categories and two major themes. The categories are Loss, Grief Response, Coping Challenges, Being Honored and Being Together. The categories organized themselves into two themes, Disconnection and Growth. The story behind the data describes lives full of loss and change. Many adults with DD have been disconnected from families, roommates, staff, typical developmental opportunities, as well as financial stability and personal choice. The ability of adults with DD to cope with these transitions is challenged by cognitive limitations, as well as protection strategies and disregard by caregivers and society in general. Many also have verbal communication challenges that those without disabilities do not have the patience to construe. They communicate through behavior that is not recognized by many caregivers or providers as being linked with feelings and stress. Their dependence creates barriers that impede them from accessing services directly. Their reliance on others for care puts them at greater risk for major transition if the caregiving parent dies. When the spotlight is placed on death of a parent or loved one, the focal loss must be viewed in terms of this history of disconnection. The emotional response to bereavement parallels that of the general population. The grief response may fall anywhere on the scale from intense to subdued or even unrecognized. The portion of the response that is heightened is the behavioral reaction, which may be exaggerated in instances where verbal communication is limited. The grief response is interpreted by the body as stress. The coping mechanisms, as noted above, are compromised by internal and external factors. The adult with DD may remain stuck in grieving if current coping mechanisms continue to fail.
Bereavement counselors uncovered unresolved loss that preceded bereavement. If caring individuals and strong family or social support are present, or outside intervention is sought, a different response is possible: **Growth**.

When bereavement counselors did routine follow-up after a hospice death, they noted social support and a listening presence usually helped the adult with DD move along in their grief without need of professional intervention. When a listening presence and social support were absent, the counselors noted greater difficulties in moving through grief. If the counselor was able to provide two components in the counseling relationship, relief and change was noted. The first of these components is a respectful listening presence combined with interventions determined by client ability and need. The second comprises efforts by the counselor to work on or with the client’s social network.

Bereaved adults with DD often stay disconnected. What moved the client forward was Being Honored and Being Together. The themes, **Disconnection and Growth** are illustrated in Figures 1 and 2 on the following pages.

The question is, how do these data compare to existing bereavement literature for the general population and for adults with DD? Answering this question requires review of existing literature and comparing the data of the current study with findings from previous studies. Initially, comparisons are made with general grief literature. This is followed by discussion of congruence with the general loss literature. Next, parallels with attachment theory and stress and coping theory literature are reviewed. Finally, the data from the current study are correlated to existing studies on bereavement with adults with DD. Similarities and differences are noted.
**Figure 1. Disconnection Cycle**

- **LOSS**
  - Long history of unrecognized losses

- **COPING CHALLENGES**
  - Cognitive limitations
  - Protection
  - Disregard

- **GRIEF RESPONSE**
  - Primarily behavioral; unrecognized or unsupported
Figure 2. Disconnect Cycle And Potential For Growth

Disconnection Cycle For Adults with Cognitive Disabilities

GROWTH

LOSS
Long history of unrecognized losses precede current death loss

COPING CHALLENGE
Cognitive Limitations Protection Disregard

GRIEF RESPONSE
Primarily behavioral unrecognized or unsupported

BEING TOGETHER

BEING HONORED
General Grief Literature

According to the literature on bereavement, grief response of adults with DD is compared to the description of general grief response as compiled from the literature by Martin and Doka (2000). Grief responses that were common to adults with DD and the general population are noted. In terms of physical reactions, counselors noted the bereaved adults with DD experienced appetite loss and inability to sleep. Emotional responses included: feelings of sadness, anger, guilt, jealousy, anxiety and fear, shame, powerlessness, and in one case, emancipation. Some counselors noted their clients with DD experienced all the same emotions as clients without DD. Changes in cognition due to bereavement are noted to include obsessive thinking, inability to concentrate, apathy, and talking about the circumstances of the loss repeatedly. Spiritual responses to loss included references to heaven and an afterlife. Finally, behavioral changes reported included: crying, anger, searching, seeking reminders of the loss, obsessive activity, isolating or social withdrawal, numbing or shutting down, and one instance of reported increase in substance use. Change in behavior from pre-loss to post-loss was discussed the most, with sadness, anger, and isolation frequently mentioned. Neither physical illness symptoms nor changes in spiritual expressions were mentioned. Visiting the cemetery was often only possible if arranged by caregivers. There were instances when the client’s return to work was thought to be helpful in terms of activity. Absentmindedness and accidents were not mentioned. Admittedly, obsessive thoughts and behavior may have been pre-existing. It is unclear if the symptoms worsened or stayed the same.
Looking at Nolen-Hoeksema and Larson’s (1999) summary of the symptoms of grief in stage theories provides basis for comparison of adults with DD to the general population. The first phase noted by Nolen-Hoeksema includes “psychic numbness, blunting, euphoria, hysteria, appear unaffected” (p. 3). For the second phase, they noted “sadness, yearning, anxiety, fear, anger, irritability, guilt, depression, loneliness, apathy, anguish, relief” (p. 4). Since it was unknown what phase the adults with DD were in, all the feelings are examined. Certainly the sadness, yearning, anxiety, fear, anger, irritability, guilt, depression, loneliness, apathy, and anguish emerged from the data. It was only later, when reviewing the work of the stage theorists, I realized that less painful feelings, such as relief and euphoria, were not present in the narratives about bereaved adults with DD. There are several reasons these may not have been included in the data. One such reason is that they are possibly harder emotions for the adult with DD to describe. Another reason is that those displaying relief or euphoria may not have been referred for treatment. I believe use of a broader category still captures the varied emotions and allows comparison to extant literature.

For phase two, behavioral reactions include all of the former plus “restlessness, accident proneness, psychomotor retardation, withdrawal, support seeking, dependence, avoidance, lack of initiative” (p. 4). There is a strong similarity between the behavioral symptoms in the data and the behavioral symptoms of phase one and two of the stage theories. Accident proneness and sighing were not mentioned. Psychomotor retardation is often already present with adults with DD, so may not be noted as a change in behavior. Support-seeking is a coping mechanism and was initiated by some who were able to request assistance, but many adults with DD do not have the physical capabilities to
connect themselves with others for support without the help of caregivers. This ability to initiate support seeking may be the biggest difference from the literature on grief stages for the general population.

The success of working with remembrance and ritual fits well with the stage theorists’ final phase of grief. Nolen and Hoeksema (1999) summarize the final cognitive phase of grief as “realistic memory of deceased, pleasure in remembering; and new meaning in life” (p. 4). Nolen-Hoeksema and Larson note that emotionally, at this final phase, the bereaved have returned to a “normal range of emotions” (p. 4). Behaviorally, the bereaved have returned to “normal functioning, new or renewed social relationships; new or renewed activities” (p. 4). Physically, a return to previous functioning is noted. The data indicate that much of the work was moving clients toward a healthy state of functioning. Long-term follow up was not always possible. A specific question could have been asked about how the counselor knew the client was dealing well with grief. Such a question would have provided more data on the issue.

Overall, the comparison between the general bereavement literature and the grief response reported by bereavement counselors serving adults with DD is strikingly similar. The difference is that the adults with DD in this study were noted to express their grief more behaviorally than other adult clients. Many times the parallel was drawn with children, as both children and adults with DD have fewer words and language to express grief.

Loss Literature

Looking to the loss literature, definite reflection of loss as outlined by Brown (1980) was seen. The counselors noted histories of loss of self-worth and social roles;
loss of loved ones such as through death or through frequent staff changes; loss of home, neighborhoods, possessions; and developmental losses, such as their own aging, or the aging their parents and the subsequent lose of ability to care for them. Rando’s (1993) category of secondary losses was reflected in reports of moves to group homes; loss of neighborhood, job, or school; loss of mother’s, or loved one’s friends as part of their social circle; and losses of the caregiving rituals and familiarity of their care needs. The history of losses amazed even bereavement counselors who were used to dealing with death and loss. Elizabeth explained:

These individuals have more losses than anyone ever imagined because they are always losing friendships. Friends leave, no one tells them what’s going on.

Where did they go? Often times they are not given an opportunity to say goodbye to people. I think they live a lifetime of losses.

Kim’s statement sums up the point clearly, “…but some of these people, the universe seems to bring them loss after loss after loss after loss.”

Stress and Coping Literature Comparisons

Bereavement as a stressor was discussed by the majority of participants. Grieving was assessed by the caregiver or counselor by means of efficacy of coping mechanisms. Interventions focused many times on enhancing poorly developed coping skills. This information from the data links back to the work of Lazarus (1990). The death of a loved one required the adult with DD to receive help as their personal resources were not adequate to deal with the loss. Further expanding this discussion to Schwarzer (n.d.), as noted earlier, reveals that he believed personal resources to cope with stress include beliefs such as self-efficacy. Other coping resources are external, such as social support
(Schwarzer). Adults with DD may have lower self-esteem due to social stigma (Lund, Carmen & Kranz, 1981) and smaller social support networks (Grant, 1993; Krauss & Erickson, 1988). The coping challenges that existed for the adults with DD may have been further complicated by the low levels of social support for some and by low self esteem. No measures of self esteem, however, were available for the clients discussed in the data.

On the one hand, adults with DD were reported to have survived lives full of transitions and developmental losses. On the other hand, few had had opportunities to learn about death and grief. Over and over counselors shared frustrations with lifelong caregiver efforts to protect the person with DD. The result of protection was that the adults were not given opportunities to learn healthy coping strategies. As noted earlier, Taylor and Aspinwall’s (1996) beliefs are that personal, social, and external resources (moderators of the stressor) are mediated by appraisal and coping processes that then impact the psychosocial outcomes of stress. So, it is no surprise the data described that adults with DD experienced stress with bereavement. They have limited personal, social and external resources being mediated by unknown appraisal (due to protection and limited information and limited cognitive understanding), in addition to limited coping processes. The stress was evidenced by the behaviors and grief responses noted by the participants.

Importance of loss history and effects of cumulative loss emerged from the data. This links back to the work of Wheaton (1996) who emphasized the need to take into account not just one stress event (bereavement), but also the stress event in context of a
history of stressors (lifelong losses). The lifelong losses were key in understanding the reaction to the focal death loss that brought the client into treatment.

Amazingly, the adults coped in their own ways by giving vent to frustration and pain or by withdrawing. These forms of coping, however did not move the person along in terms of healing or growth. Giving listening ears, interventions appropriate to their needs, and information that “normalized” their feelings, healing and growth could occur. Hogan and Schmidt’s (2002) Grief to Personal Growth Theory may have relevance here. “The final model… depicted grief leading to intrusivity, intrusivity leading to avoidance, avoidance leading to social support, and social support leading to personal growth” (p. 627). They also identified a direct pathway from grief to personal growth. When adults with DD withdrew or did not display grief symptoms recognized or expected by the caregiver, they were referred for counseling. Through counseling they received social support with evidence of change and the beginning of healing. Some evidence exists that an indirect pathway to personal growth may exist for adults with DD. It is difficult from my data to discern whether a direct pathway may exist.

In reviewing Silverman and Worden’s (1993) findings related to children’s coping with parental loss, similarities and differences were found. The children all had friends and at least one remaining parent. Most adults with DD have very small social circles and many have lost both parents. The children with the most change to their daily structure had more physical symptoms. The children who had the poorest functioning were those with little peer support, low self-esteem, and high external control. Adults with DD generally fit the above profile due to their social status and dependence. Adults with DD are also dependent on a caregiver, just as children are. It was reported that 35% of the
children appraised their parent’s coping and then, during the bereavement period, acted in a manner they perceived to be helpful to that parent’s coping. The data in my study reflect a similar tendency for some adults with DD. Resiliency was evident in Silverman and Worden’s one-year assessment. Strengths and willingness to engage help and keep connecting despite years of loss shows resilience for adults with DD.

When stress and coping theory is applied to bereavement in adults with DD, it assists in explaining the effects of layers of loss, poor coping skills and little social support.

Attachment Theory Literature Comparison

Attachment bonds were discussed by several counselors. The loss of one of the primary attachment figures and the resulting problems due to few available others in whom they could reinvest emotional energy were referenced. References are made to setting up a safe container, a relationship built on trust. Participants made mention that clients knew they could let go with the therapist and not be totally overwhelmed by feelings. The fear of loss of control was decreased with the counselors’ assistance. The impact of losing a secure base and needing to establish another secure relationship was evident in the data. This link to Bowlby and subsequent attachment theorists is significant.

More specifically, are Bowlby’s (1981) stages of mourning and numbing, yearning, searching, disorganization and despair, and reorganization reflected in the stories? Numbing was not specifically named, but it was evident in the following statements: “She just vapor locked;” “She was very shut down”; “… because she is shutting it off like a faucet.” Other comments about isolating and withdrawing may also
fall into the numbing category. Stories of yearning and searching, disorganization and
despair were documented. References to reorganization emerged after counselors did
work to connect the client’s feelings with behavior and thought processes, to link clients
with others who were mourning, and to renew or establish client contacts with others for
social support and further relationship. There were definite links to attachment theorists’
view of the grief response. Mourning was evidenced by limited verbal communication
from most clients, but was illustrated clearly by the client’s rich behavioral expression.

Were Waskowic and Chartier’s (2003) symptoms of despair, depression, anger,
guilt, social isolation, and rumination uncovered in collected narratives? All of the
emotions noted by Waskowic and Chartier were documented consistently in the
interviews and all symptoms noted. The difference is that the evidence is often behavioral
expression with the interpretation and connection done by the counselor or informed
caregiver.

The concept of continuing bonds (Klass, Silverman & Nickman, 1996) is
reflected in the comments about clients who continued to think of the loved one daily.
The gentleman who needed to show the counselor all his wife’s pictures and possessions
demonstrated continuing bonds. As one respondent said, the clients demonstrate
reminiscing by showing pictures of the deceased. The young woman who always depicts
her father in heaven alludes to continuing bonds with her images. The benefit of ritual
and remembering are reflected in successful art projects and discussions. The data
indicate that continuing bonds are just as healthy for the adults with DD in this study as
they are for the general population.
There was a strong tie from the data to Mann and Kretchmar’s (2006) work on attachment. The importance of behavior as language and miscuing were obvious in the participants’ accounts of how grief was communicated. Behavior has to be interpreted by caregivers and by counselors. It is noted that some clients hid their emotions from caregivers they perceived as not being capable of handling the client’s feelings. This is what Mann and Kretchmar outlined in their observations regarding their intervention with a young child. How clients were helped by Being Honored and Being Together closely parallels the concept of “being with” (p. 34) presented by the Mann and Kretchmar. Additionally, the need for work with the caregiver was identified in their work, as well as in this data concerning adults with DD. For adults with DD, work can be done primarily with the clients, but it is preferable that work be done with the whole unit of caregiver/client or parent/adult child. Several bereavement counselors mentioned the frustration of being limited in the scope of the work they could do with their clients with DD. This supports Marvin, et al.’s (2002) and Clegg and Lansddall-Welfare’s (1995) focus on the counselor becoming a secure base with the ideal being that the caregiver is coached to assume the role of the secure base.

The attachment case study provided by Zelenko and Benham (2002) provides further material for comparison. Successful work involved participation by the caregivers, as well as the child. Establishing structure and routines were key parts of intervention. Bringing familiar toys and possessions to the new home reinforced security. The data on adults with DD echo the needs for caregiver involvement and structure and security. The use of play as a medium and encouragement of many opportunities to discuss the death is similar to recommendations by bereavement counselors in this study.
The use of balloons as a concrete symbol was the same. The encouragement of rituals of remembrance is also viable in studies. Attachment theory helps explain the importance of Being Together and Being Honored for bereaved adults with DD. It can be used to understand the intensity of the loss and the barriers small social networks and low social status may create in forming the new attachment needed for healing. It appears that interventions based on attachment theory can be helpful in addressing the needs of adults with DD following bereavement.

Bereavement and Developmental Disabilities Literature

Reflecting on the literature concerning bereavement and DD, Dell’Aquila’s (1996) work was revisited. She had found evidence that “the social experience of being developmentally disabled does create a disadvantaged state from which to approach grief” (p. 108). The data from the bereavement counselors in my study support Dell’Aquila’s finding. The history of disconnection, the protection and dependence created obstacles that complicated the already compromised coping process.

One of Levelle’s (1997) conclusions was that for the adults in her study, participation in the funeral was not related to understanding the death concept. One bereavement counselor in particular came to the same hypothesis from her observations. Others merely mentioned how difficult death was to explain to a person with cognitive limitations. From the data, it would seem that teaching and hands-on-activities may be required for many adults with DD to understand the concept of the irreversibility of death.

Read’s (2000) list of common losses, including identity, ability, accessibility, opportunity, and independence was supported by these data. Discussions of other losses
with the clients uncovered long histories of damages and missed opportunities. Most participants noted that these losses were unacknowledged by most caregivers and further connected the losses to the concept of disenfranchised grief. Doka (1989) defines disenfranchised grief as “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported” (p. 4). Doka gives three categories of unrecognized grief. They include: lack of acknowledgement of the relationship, the loss itself being overlooked as an important loss, and the mourner being overlooked. He includes adults with cognitive disabilities in the latter category stating that their grief reactions may be unrecognized. It is evident from the data that this is true for many of the adults discussed in this study. In addition, the client losses of friends, residences, and staff were not recognized as important to address. One participant specifically addressed the lack of acknowledgement of romantic relationships and attachments. When a significant other dies, the cognitively disabled partner is often left out of any grief rituals and may not even be given condolences. Disenfranchisement of grief adds to their emotional burdens. Doka states that disenfranchised grief tends “to intensify emotional reactions” (p. 7). Doka’s theories were supported in the data. Kauffman’s case studies and his uncovering of layers upon layers of loss were also noted by the participants. These losses included death losses, as well as the losses as outlined by Read and Doka.

One of the themes uncovered by McDaniel’s (1989) study included the feeling of being left out of family experiences when someone was gravely ill. The second theme was concern over who would look out for them after their parents died. The first theme was reflected clearly in the narratives about “partial inclusion” of adults with DD in
family experiences. Some adults with DD were entirely left out of the family discussions and plans around a relative’s failing health. With hospice assistance, some adults with DD were fully included around the time of death and after. One or two participants related incidents that hinted at client concerns about future caretaking. One male client had a year of treatment to help him connect with others who could meet his needs. A female client reported to her counselor that she was afraid everyone else in her life would die. The need for structure and security after loss was evident in the narratives.

Oswins’ (1991) work provided a good opportunity for comparison of findings. She worked directly with adults with DD, as well as parents and caregivers. This study and Oswin’s both documented misguided efforts of caregivers. Multiple secondary losses, such as moves and care changes, are also clearly evident in both studies. The two studies highlighted the loss of structure and security after the death. Behavior was a common means of displaying grief and included hitting and outbursts. Oswin noted the largest difference between grieving adults with and without DD was the attitude of others toward the bereaved. When consulted, Oswin’s participants with DD asked for treatment and support. The types of interventions they requested are in accord with the support and interventions provided by the bereavement counselors who participated in this study. Additionally, reports on the need to individualize services due to the unique ways people cope with grief align with Hedger and Smith’s (1993) statement that each adult with DD had a different way of grieving.

The participants of this study were reflective of many comments of the participating counselors in Read’s (2000) report. Unique bereavement services to this population addressed shorter attention spans, need for concreteness, use of hands-on
activities, boundary concerns, and openness and honesty of the counseling relationship. Challenges in terms of not being able to impact the wider client environment hindered the counselors’ goals. All but the consent issues were essentially similar. No consent issues were brought up in this study. Strikingly, a comment about “profound sadness” was repeated in this study of bereavement counselors as well.

Read et al.’s (2000) qualitative study of the loss workshop produced two key themes that can be used for comparison. The first was confusion and frustration for adults with DD in understanding the loss. These same feelings were evident in this data. The second was that loss caused them to lose control of important life decisions. In this study, secondary losses and moves were clearly documented and the lack of inclusion in decision-making regarding moves was well supported. The primary difference is that the clients themselves with DD voiced the concerns in their own words in Read et al. Had adults with DD been interviewed for this study, this information may or may not have been conveyed differently.

Gault (2003) presented a case story in which a memory book is used as an intervention. The use of pictures and collage are implemented by several participants in this study. One of the case stories presented by Clements et al. (2004) involved the reading of a book about grief, which was presented as an effective intervention. Bibliotherapy techniques are utilized successfully by study participants with their clients with DD.

Kauffman (2005) presents case studies that include examples of psychological reactions to grief that include anger, aggression, anxiety, compulsive behavior,
dependence, and ambivalence. All these psychological reactions were cited in the data
gathered for this study.

Read and Papakosta-Harvey (2004) reported on the physical, emotional,
cognitive, and behavioral responses of participants to Loss. The physical responses were
reflected in this bereavement study. Shock-like behaviors were noted, such as
withdrawing, questioning, and protesting the death but were not identified as shock. The
emotional reactions were the same. Little information was gained on the cognitive
reactions beyond struggling with understanding death. Behavioral responses were similar.

Dowling et al.’s (2006) study included two different intervention groups. The
group who received counseling with a variety of techniques including art, books, and
photographs had noted improvement except in appropriate speech. The bereavement
counselors in Dowling et al. admit to being initially challenged by the communication
issues, but were pleased that they found creative ways around barriers. This was echoed
by bereavement counselor and client experience in this study. A similar richness and
depth of the counseling relationships were noted by counselors in the Dowling et al.
study and is echoed by several participants in this current study.

Lavin’s (n.d.) information was upheld by the data. She noted lack of inclusion in
preparation for loss limits the ability of adults with DD to learn and practice coping skills.
Another difference she described is the protection mindset by caregivers, which is linked
to lack of learning coping skills. Lavin also states most people with DD do not receive
acknowledgement or support for their losses. She points out that despite impairments
each person has unique abilities and is capable of coping, which was demonstrated by the
clients of the participants in the current study. Concrete and active interventions are
recommended and were supported as successful by the majority of participants. According to Lavin, recall and transferability of skills may be limited as well, which was supported by these data. Some adults with DD have an egocentric view of the world, which Lavin likens to a child’s view. She implies that an adult with DD may feel more responsible for deaths or losses than an adult without DD. This egocentricity was noted by at least three participants. Also noted is the limited size and strength of support networks for many adults with DD, which held true for these data. Verbal communication may not be a strength, so communication by behavior is crucial. Behavior was key in the current study findings. Lavin’s recommendations for role playing, funeral home visits, drawing, and discussing deaths in nature related to the change of seasons were also reported in the data.

Read’s (2005) work outlines recommendations that were reinforced by the participating bereavement counselors in the study. The participating bereavement counselors shared their clients’ stories of grief journeys that were made more comfortable by actions aimed at meeting the client’s individual needs through the common experience and continuum of grief feelings.

To summarize, the data gathered for this study support the findings of the existing studies on bereavement for adults with DD. A minor difference is the weak information on cognitive reactions to death in my data.

Review Of Differences From Existing Data

In comparing the general bereavement literature to my study, I found that the emotions of grief are similar to the general population, but the experience of grief is different. Long histories of disenfranchised grief and unrecognized losses preceded the
focal death loss. Societal disregard of persons with DD contributes to the oversight of their losses. In addition, dependence on a caregiver or guardian often triggered protection behavior. Protection interferes with inclusion and early preparation for losses. Social circles tend to be smaller for adults with DD than for the general population, increasing the impact of the death of a loved one. The preceding factors further complicate coping responses that are naturally challenged by the cognitive disability itself. The grief response, in summary, can be more complex for the adult with DD than for the adult without disability.

Cognitive reactions to grief were less evident in the data than in the general bereavement data or in studies done with the adults with DD as the participants. Use of bereavement counselors as the reporters of the bereavement experience of adults with DD places the data one level away from the target population’s experience. If adults with DD had been interviewed, as was originally planned, more data about their cognitive reactions may have been gathered. Counselors primarily focused on interpreting behaviors and discussing feelings with a more limited discussion of what the clients thought about the loss.

Physical symptoms, such as illness as part of the bereavement experience, were not noted in the data. There are a variety of reasons that could account for this. With limited verbal communication, the client may have had to rely on the caregiver to report symptoms or illnesses. The caregiver may not have realized the importance of mentioning these occurrences. Another possibility is that the adult with DD was ill, but even the caregiver missed the symptoms or manifestation of the illness. In addition, the counselor may not have explored the issue if the client failed to bring it up or missed
appointments. Finally, there was no specific interview question that would have triggered the counselor’s memory to include physical symptoms. A summary of the findings is provided next.

Summary

In summary, these data provided support for the notion that adults with DD have emotional experiences that fall within the typical range of grief experiences for the general population, as summarized by Martin and Doka (2000). Their losses fill every category suggested by Brown (1980), Rando (1993) and Read (2000). The data provided ties to both the attachment and stress and coping literature indicating that for adults with DD in this study, both theories contribute to explanations of the experience of bereavement. Bowlby’s (1980) stages of mourning were supported for the adults with DD discussed in this study. Links were found to the existing literature on bereavement and DD strongly supporting the finding that the emotions of grief are common to all, including the adults with DD in this study. Lavin’s (n.d.) overview of bereavement and adults with DD was substantiated by the data in this study.

The experience of bereavement for adults with DD, however, cannot be explained through the use of two theoretical lenses. The data demonstrate that bereavement is an event that cannot be understood in isolation. Many factors impact the experience of loss. Society and culture, laws and regulations, as well as lack of empowerment, are broad influences on bereavement for adults with DD. Learned behaviors also play a role. Just as there is no one theory of bereavement for the general population, there is no one explanation for the experience of loss for adults with DD.
Adults with DD tend to be disconnected in terms of their status, their power, and access to full information, in addition to participation in life’s events. One of the most mysterious and often painful life events is death. Death of family and friends finds adults with DD in isolation and confusion trying to deal with their losses. Bereavement experienced by these persons is preceded by long histories of loss. An existing support system may not be in place to provide the typical supportive listening and secure relationship to hold the grief. The potentially heightened effects of the broken attachment bonds, the increased risk of coping obstacles, long histories of unrecognized losses, and prevalence of disenfranchised grief typify the bereavement experience for adults with DD discussed in my study.

When adults with DD find their way to bereavement counselors associated with hospices, supportive presence, coping skills lessons, and remembrance rituals appear to be effective from the counselor’s perspective. Joining adults with DD to others, introducing them to new coping skills, and helping them stay connected to the memory of their loved one emerged as positive experiences. When behaviors were linked to thoughts and emotions, personal growth appeared to occur for the bereaved adult with DD. The participants in this study felt any bereavement counselor could successfully aid bereavement if the counselor joined with another for mentoring. Linking past experience with clients or family members with DD provided a zone of comfort for at least half of the participants. The data spoke eloquently to the ability of adults with DD to move away from the lonely ledge of bereavement with simple, individualized attention to their needs. In closing, the words of Silverman (2000) can frame the impacts of disconnection and joining on the bereavement experience of adults with DD:
None of us lives in a vacuum. The attitudes and values of our particular society influence what we believe and how we think; they provide a framework for ordering the things that happen to us, for defining our purpose and place in the world, for relating to ourselves and others, and for making sense of our experiences. (p. 9)

In conclusion, although stress and coping theory did provide insights into understanding bereavement for adults with DD, and the existing literature on this population has been generally upheld, the work has just begun. More stories need to be gathered. Individuals with DD, themselves, need to be asked to tell us first hand about what the experience of bereavement feels like, looks like, and sounds like. We then need to listen and share those stories so that more of us can learn what hinders and what helps adults with DD cope with bereavement.

Limitations Of The Study

There are always limitations to a study. This being a self-funded doctoral dissertation, time and money were factors in the scope of the study. The original study would have included adults with DD, themselves, but the approval process and protection layers created too many delays for a student project. The selection of bereavement counselors as participants moved the data one layer away from the actual experience of the adults with DD who were their clients.

Bereavement counselors may do routine follow-up with all bereaved clients, but most see clients who are having problems with coping. Other adults with DD who never make it to bereavement counselors may have a different experience of bereavement than was addressed by this study.
Additional limitations of the study included the limited sample size. Even though data saturation was believed to have been achieved, a larger sample might have revealed additional themes. Convenience sampling was implemented for ease of access for contacting hospices. Those with email listings available online were prioritized after saturating the Pacific Northwest region. Effort was made to include east coast, as well as more southern and southwest regions for variability. Random sampling of states or hospices to contact would have strengthened the study. Phone interviews could capture only part of the information. In-person interviews would have provided richer data and an opportunity to add nonverbal information. Time and money for travel precluded nationwide in-person interviews.

Limitations may also include the emerging nature of research and limited studies of this population for comparison. Future studies, ideally with adults with DD, themselves, are needed.

**Implications For Policy And Practice**

The grounded theory explanation of bereavement that emerged from this study has urgent implications for practice and policy. The cycle of disconnection described by the participating counselors can be used as a powerful depiction of the need for change. The counselors’ belief in the potential for growth for adults with DD holds promise that professional and community efforts can help move adults with DD through grief and loss towards hope and healing. The data show that participating counselors believed in the therapeutic effects of honoring the individual needs of their clients with DD, and helping them feel togetherness within themselves as well as with others.
One of the first steps for change is the need to educate others about the depth and breadth of loss for this population, including history of losses, secondary losses, protection, and disregard. Interrupting the continual cycling of loss requires attention to the coping challenges of adults with DD, which include cognitive issues, verbal communication issues, and lack of skills, complicated by caregiver and professional discomfort. Improvement must include teaching caregivers, as well as professionals, how to enhance their own knowledge, understanding, and comfort with loss and grief. This must be coupled with training on varied methods to increase coping skills for adults with DD. Work in these areas requires prevention work, in terms of early death education and early involvement, and notification of any anticipated changes. Caregivers, as well as professionals, would benefit from mentoring in ways to honor individual needs and ways to be with clients with DD. It necessitates professionals and families working to connect adults with DD to others for social and emotional support on an ongoing basis. Education is needed for caregivers and professionals to improve understanding the myriad of ways grief response can be communicated, so grief can be made visible and its depth and effects honored and witnessed.

To achieve the goal of breaking the cycle of disconnection, varying levels of change are needed across disciplines in practice as well as policy. This study of the bereavement experience for adults with DD has implications for professionals of varied disciplines, for hospice and palliative care, for grief counseling agencies, and for grief counselors in private or other practices. The study provides lessons to be learned by counselors working with adults with DD. The study also has implications for the field of DD services, as well as for the general community.
It is important to examine how the issues involved in bereavement for adults with DD are situated in professional fields. The bereavement counselors interviewed have various professional degrees and professional ties. The fields of social work, marriage and family therapy, counseling, and ministry or divinity were represented. Each has different professional societies, journals and conferences. Some may have certification and licensure requirements. The common denominator of hospice work was present for all participants. Hospice agencies are part of the larger network of palliative care and hospice care, an interdisciplinary arena that includes health care workers and pastoral care workers. Volunteers from the community receive training to support patients and their families. Hospices may belong to larger palliative care organizations nationally and internationally. Training, journals, and conferences exist that are tailored to end of life issues.

In addition, adults with DD now live in communities, within neighborhoods, and often within group or residential facilities. The adults with DD are served both by generic systems such as schools, employers, recreation, transportation providers, by health care providers, and by specialized systems such as case management for people with DD, specialized residential, school, recreation, residential and employment services.

Both counselor and client are impacted by their state’s rules and regulations, as well as societal values and beliefs about death and dying, grief, and about people with developmental disabilities. A small change in any one of these systems can create ripples of change throughout the overlapping DD and end of life care systems. I am hopeful that positive change in education at any of these levels can positively impact many arenas. For instance, adding to the literature and disseminating information at conferences in the
DD arena can prove effective. Presentation of study findings in the bereavement field can benefit providers who work daily with clients around loss and change, as well as counseling professionals who work with adults with DD dealing with bereavement issues. The messages to be conveyed should be inclusive of the unintended consequences of protection that further complicates coping. Coping requires honest, concrete messages and inclusion in rituals of death of dying. Message must honor the losses, the moves, the life transitions, and death of loved ones for adults with DD. Their losses need to be heard and witnessed. Their feelings about these losses need to be normalized so they do not feel as though they are further diminished or solitary in their grief. When intervention is required, there is no one right way to work with an adult with DD. They are as unique as any other client, particularly since the label of developmentally disabled with a cognitive deficit covers a wide range of abilities. There are some general principles that may be helpful such as: shorter, structured sessions; use of concrete language; and use of experiential activities such as sculpting, drawing, collaging, movement and music exercises. Role play and bibliotherapy may also be useful. Both individual and group treatments have been experienced successfully. Remembering and involvement in ritual has been useful to those with and without DD.

Although references are made about parallels to children, it is children’s disadvantaged and disempowered states that that align them with adults with DD. Some adults with DD may have developmental levels similar to some children, but they are adults first. Their coping challenges have been exacerbated by others treating them as children. There is much to be improved on in how children are treated in terms of grief and loss, which parallels but is outside the scope of this project.
The issue of discomfort can be addressed on multiple levels. In terms of the discomfort with adults with DD, counselors who do general bereavement or counseling work need to examine their own fears and concerns. The solution may be as simple as trying to work with an adult with DD, finding a mentor, reading a suggested book, or just talking with a person with DD. Agencies could engage speakers, most preferably consumers with DD. These adults with DD can best work to demystify the needs and demonstrate the shared humanity. It would help normalize the needs, desires, and feelings of those labeled DD. DD providers could identify consumers to help train hospice and counseling personnel.

For counselors who encounter grief and loss issues, continued education is requisite. Jordan (2000) addresses the problem specifically around issues of bereavement.

Most grief counselors can attribute the models of mourning and recovery that guide their care giving although for many clinicians their working theory has developed almost exclusively out of personal and professional experience with loss, rather than the findings of relevant empirical research. (¶ 6)

The counseling field, in general, needs training updates and specific training in regard to bereavement and adults with DD.

In terms of the caregivers and staff who already work comfortably with adults with DD, the comfort attendant to death and dying and grief is often the challenge. Again, agencies can bring in consultants and trainers to work around the issue of death and dying and how to deal with intense feelings such as grief. Work can be done then to normalize grief feelings and often their intensity. Hospice personnel can be utilized to provide this training.
Part of the real solution, as the participants so adamantly stated, is teaching children at a very young age about the cycle of life and death, using nature as examples. Another piece of this is teaching children about feelings and how to cope with them, especially scary feelings such as anger and grief. Teaching should be done both at home and at school. Use of teaching moments with death of pets and deaths in nature should be used. Children should be told concretely about funerals and rituals and allowed to make decisions to participate. Teaching about feelings and how to cope with them, finding ways to soothe, and finding support can be taught, demonstrated, and modeled in daily life. At home, this presumes a secure base for children to experience their full range of feelings. If all children grew up with this foundation, protection and discomfort likely would decrease for all. Children would grow up to be knowledgeable caregivers, family members, and professionals and would be better prepared to involve and support all humans, including adults with DD. Children with DD would be provided the same education and, it is hoped, the impact of losses would be minimized by increased understanding and support. Dissemination of the study findings is the first place to start in terms of making change.

Dissemination Of Findings

Study participants completed a form requesting a summary report about the study results. All participants requested a summary. In addition, prior to or after their interviews, two participants requested reading suggestions or resources that might guide their practice before the summary was written. Written resources have been emailed to two participants already. Other professionals contacted in the recruiting process asked to
be sent summaries even though they did not participate. Those requests will be honored after the summary is written and ready for dissemination.

Presentations of data will be submitted for consideration at conferences such as The Council of Social Work Educations (CSWE) Annual Program Meeting, Society for Social Work Research, palliative care and death education groups, and National Association of Social Workers (NASW) conferences. I will also submit a proposal for presentations at conferences targeting the needs of adults with DD.

Journal articles will be developed and submitted to publications such as *Journal of Qualitative Social Work*, *Death Studies*, *Omega*, *Journal of Applied Research in Intellectual Disability*, *Journal for the Association of People with Severe Handicaps*, and *Journal of Intellectual & Developmental Disability*. Offers will be made for presentations to local hospices and DD providers. The dissemination of findings will be ongoing and build the base for another study, it is hoped with adults with DD telling the story themselves.
APPENDIX A: Recruitment Letter

Dear Colleagues,

My name is Mary Ann Clute. I am an MSW and doctoral candidate working on a dissertation at Case Western Reserve University. I have experience working with people with disabilities and as a hospice case manager. I am very interested in bereavement in the population of adults with cognitive disabilities (adults with developmental disabilities with IQ's under 70, such as those with Down Syndrome). I am doing a study to find out more about how death of a parent or loved one affects adults with cognitive disabilities. I am looking for study participants. I will be interviewing bereavement counselors with experience working with adults with cognitive disabilities following the death of a parent or loved one.

The interview will take approximately an hour. Each participant will receive $25 that is his/hers to keep or to donate to the agency based on agency policy.

Interviews will be in-person or by phone for those living within 100 miles of Spokane, WA. For those more than 100 miles from Spokane, a phone interview will be arranged. In special circumstances, an in-person interview may be possible for those at a distance. The interviews would be held during “off work” time, such as lunch time or before/after scheduled work hours.

I will be calling hospice bereavement departments and private practitioners who are identified as grief counselors serving adults with cognitive disabilities. If you know you have counselors who would be interested, please pass this information on to them. They may call me directly at 509-359-2377. They may also email me at maryannclute@msn.com.

I will mail a consent form to those interested in participating. Once I received a signed consent, I will contact the counselor for an interview.

I am excited to begin and look forward to talking with you and/or your staff!

Sincerely,

Mary Ann Clute, MSW
Doctoral Candidate
Case Western Reserve University
Dear Colleagues,

I am attaching a flier about a research study I am completing for my dissertation at Case Western Reserve University, in Cleveland, Ohio. I am interviewing bereavement counselors who work with adults with cognitive disabilities (people with developmental disabilities with mental retardation) around death of parents or loved ones.

If you would forward this to your bereavement counselors and/or other community grief counselors in your area, I would be very appreciative!

If you have questions, I can be reached in Spokane, Washington at 509-359-2377 (PST) or maryannclute@msn.com.

Sincerely,

Mary Ann Clute, MSW
Doctoral Candidate
Case Western Reserve University
Dear Colleague,

Enclosed please find the consent form and a SASE for the research study we discussed on the phone. The research project is for my dissertation from Case Western Reserve University and is to explore how adults with cognitive disabilities experience the death of a parent or loved one. I am seeking your observations and impressions from any past or present bereavement clients with cognitive disabilities.

Once I receive your signed consent, I will call to schedule the interview. You may choose an in-person interview or a phone interview if you live within 100 miles of Spokane. If you live more than 100 miles from Spokane, a phone interview will be arranged. In special circumstances, an in-person interview for an at-distance participant may be arranged. The interview will take approximately one hour. You will receive $25 for your time.

If you have any questions, please contact me at 509-359-2377 or email me at maryannclute@msn.com.

Thank you again for considering participation in this research.

Sincerely,

Mary Ann Clute, MSW
Doctoral Candidate
Case Western Reserve University
APPENDIX D: Informed Consent

Bereavement following death of a parent of loved one for adults
With cognitive disabilities

You are being asked to participate in a research study about bereavement for adults with cognitive disabilities (CD) following the death of a parent or loved one. You were selected as a possible participant. You were identified as someone who has provided bereavement counseling for adults with cognitive disabilities in the course of your general practice. Please read this form and ask any questions that you may have before agreeing to be in the research.

Researchers at Case Western Reserve University are conducting this study.

Background Information
The purpose of this research is to explore how adults with cognitive disabilities experience the loss of a parent or loved one. This topic has become more relevant as people with disabilities outlive their parents and other family members. The research information is being sought from bereavement counselors who have worked with adults with CD following parent/loved one death. This study explores what triggers bereavement referrals for this population. It addresses how the adults with CD receive news of the death/imminent death of a parent or loved one and explores participation in funerals and memorial services. The study is aimed at also uncovering what helps and hinders the grief process for adults with CD, and how these adults may be alike or different from other bereavement clients. The research aims to identify other changes in the life of the adult with CD that are secondary to the death of the parent/loved one.

Procedures
If you agree to be a participant in this research, we would ask you to participate in an audiotaped interview in person or by phone. The interview will be by phone if you reside more than 100 miles from the researcher. In special circumstances, an in-person interview may be arranged for at-distance participants. The interview is a one-time session lasting approximately one hour. You will receive a copy of the transcript of the interview to revise and correct.

Risks and Benefits to Being in the Study
This research has no foreseeable risks, except loss of time spent in other valued activities.

The benefits of participation include contribution to the sparse knowledge base about the needs and experience of bereaved adults with CD.

Compensation
You will receive $25 cash after the interview. If a phone interview occurs, the $25 will be mailed to you. Depending on agency policy you may keep or donate your $25 compensation.
Confidentiality
The records of the research will be kept private. In any sort of report we publish, we will not include any information that will make it possible to identify you as a participant. Research records will be kept in a locked file, and access will be limited to the researchers, the University Review Board responsible for protecting human participants, and regulatory agencies.

Voluntary Nature of the Study

Your participation is voluntary. If you choose not to participate, it will not affect your current or future relations with the University or the researcher. There is no penalty or loss of benefits for not participating or for discontinuing your participation. You will receive the $25 if you complete part or all of the interview.

We will provide you with a summary report if you provide your contact information at the bottom of this form.

Contacts and Questions

The researchers conducting this study are: Dr. Jerry Floersch and Mary Ann Clute. You may ask questions you have now. If you have questions later, you may contact Mary Ann Clute by email at maryannclute@msn.com or by phone at (509)359-2377. You may contact Jerry Floersch at jerry.floersch@case.edu or (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, Oh 44106-7230.

You will be given a copy of this form for your records.

Statement of Consent
I have read the above information. I have received answers to the questions I have asked. I consent to participate in this research. I am at least 18 years of age.

Print Name of Participant_____________________________
Signature of Participant_______________________________   Date______
THIS IS A SEPARATE SHEET THAT WILL NOT BE KEPT WITH YOUR SIGNED CONSENT FORM.

AFTER IMMEDIATELY SENDING YOU A COPY OF THE SUMMARY REPORT, I WILL DESTROY YOUR CONTACT INFORMATION (this sheet).

Do you want to receive a summary report of the research?
Yes______  No__________

If yes, send to:

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
APPENDIX E: Transcript Review Cover Letter

Dear ____________

Attached is the transcript from our interview. Please read it through and notify me of any questions, revisions or corrections you wish to make. You may contact me by phone (509-359-2377), email (maryannclute@msn.com) or via mail at 1323 W. Smythe, Spokane, WA 99224.

Please notify me by ________________ or the transcript will be used as is.

Again, thank you for your time and involvement in this project.

Your contribution to this research is greatly appreciated!

Sincerely,

Mary Ann Clute, MSW
Doctoral Candidate
Case Western Reserve University
APPENDIX F: Background on Proposed Original Study with Adults with DD

The data originally sought was the experience of parental bereavement told in the voice of an adult with DD. Originally, adults 25-65 years of age with documented cognitive disabilities were to be recruited from a region in a selected state. The participants were to have had a legal guardian assigned, no community protection orders, no major mental illness. In addition, the participants were to have lived with the parent at least 10 years and were to have experienced the parental death in the last two to five years. Both Case Western Reserve University (CWRU) and the state’s Institutional Review Board (IRB) permitted additional recruitment from local DD providers of residential, employment, advocacy, senior services, and community access services. Community fliers were circulated and meetings set up with DD case managers, residential and day program providers throughout a selected county. The plan was to be implemented in the target county and expand to other counties, as needed. Additional IRB approval was obtained to include flier text in the Arc newsletter, and to include the flier in a parent advocate mailing done by a local Arc. Arc is an advocacy and service agency with a mission of improving quality of life for adults with developmental disabilities.

After four months of recruiting, no participants had been identified. An addendum was requested of the state IRB to expand the research criteria. I requested the inclusion of adults with DD with no assigned legal guardian and an open bereavement time period. I also requested inclusion of those with mental health diagnoses, but assessed as stable, with no psychiatric hospitalizations within the last year, as well as a change of parent to include a caregiver who has lived with the participant for at least five years. Letters of
support from an Arc advocate and a bereavement counselor who works with adults with DD accompanied the request. The addendum was met with requests for further information, as well as concern about the “capacity to consent” for those without guardians. At this point, I presented the situation to my chair and my committee and received permission to revise my study and pursue less direct access to the information sought. Bereavement counselors who have served adults with DD could answer many questions from their counseling experience. The state IRB study was closed and CWRU approved an addendum to interview bereavement counselors nationwide.

I had pursued approval to interview adults with DD themselves because I believe the bereavement literature should include the voices of adults with DD, in addition to adults without DD. I used the Belmont Report (1979) as a rationale. Respect demands that we acknowledge the importance of the loss and allow the speaker to share in the common human experience of grief. This must be done in terms and questions that the participant can understand. Beneficence demands that all have the opportunity to participate in telling their story and have the opportunity for a respectful and perhaps healing experience. Talking about the story of the death or loss has been shown to be healing. Rosenblatt (1995) argued, “Hurting may be part of healing. I think bereaved people may gain enormously from talking with someone who takes their stories seriously and witnesses and acknowledges pain” (p. 144). Again, grief, the expression of emotion around loss, is not an expression of pathology.

Yet, great difficulty was met with the research proposals. There are several reasons the original study may have been received with such caution by reviewers. “Vulnerable adults” being interviewed about a “sensitive topic” triggered the need for
many layers of protocols. Capacity to consent was one area discussed at length. I argued that potential risks were outweighed by the potential indirect benefits.

Dye, Hendy, Hare and Burton (2004) address failure to include people with intellectual disabilities due to concerns regarding capacity to consent:

The research... indicates that low numbers of people with learning disabilities have capacity to consent to participate in research, according to the current concept of consent. It can be argued, therefore, that if capacity cannot be demonstrated, individuals should not participate in research. This view corresponds to the “protection model” and excludes people who lack capacity from participating in research (National Bioethics Advisory Committee (NBAC) 1998). Under this model, exclusion from participating in research in agreement with the underlying principle of protection from harm. The opposite view is the “access model” in which a total ban on participation in research by people who lack capacity is not supported because such a ban may prevent some people from obtaining the potential benefits that participating in research may provide (National Bioethics Advisory Council (NBAC) 1998). (p. 146)

Further, Dye et al. point out that, in essence, despite concerns about capacity to consent, persons with intellectual disabilities do communicate their desire to continue or stop participation by their actions.

Whilst using the current concept of consent would force one to conclude that many people with learning disabilities are unable to consent, a different picture is evident when participant’s behavior is observed. Dye et al. (op cit.) reported that 17 participants, who originally agreed to take part in the research, withdrew from...
the study at some point, effectively withholding their consent. Although it is
unlikely that these participants would have “passed” the capacity test, they were
able to effectively demonstrate their capacity by choosing to opt-out of the study.
This would indicate that the measures to assess capacity to consent are not
tapping into the decision-making processes of people with learning disabilities, or
adequately reflecting their concerns. (p 146)

Adults with DD have historically been subjects of research with others as
informants. It is only recently that some adults with DD have been asked to tell their own
stories (Booth & Booth, 1994). Although protection issues may have been resolved with
time, the continued greater risk may be that persons with intellectual disabilities are being
overprotected. They are thus being prevented from sharing their views and experiences
and are being barred from participation in research and program change. Inclusion of
adults with cognitive disabilities in bereavement research also makes an effort to uncover
resilience in the face of many losses and challenges, an important element in no longer
disenfranchising the grief experience for this population (Attig, 2004).

The original study held many challenges for informed consent. Grisso and
Applebaum (1998) outline the requirements for informed consent. They include:
disclosure of information, voluntariness, and competence. Consent forms were required
for the adult with DD and from the legal guardian. Even if the legal guardian agreed,
consent would be obtained from the adult with DD, as well. Consent was to be reviewed
at each meeting with the risks and benefits discussed. Explanation of consent is vitally
important with persons with DD, who are viewed as vulnerable adults. In a study of
consent to research participation by adults with DD, Arscott, Dagnan and Kroese (1998)
note that participants did not clearly understand some of the costs of participation, such as missing an activity, or using up their personal time. Arscott, et al., found that 42% (17) participants did not understand they could withdraw at any time. These findings help highlight the need for clear discussion around consent to participate. Time commitments, missing other events, and the possibility of experiencing negative emotions are risks. Benefits include the opportunity to talk about the death and, if problems are identified, obtaining a referral for services. The overall goal of greater knowledge and future attention by professionals and caregivers to bereavement for people with DD is a long term commitment, but not a personal benefit for the participant.

In a research study by Cambridge and Forrester-Jones (2003), a photograph of the interviewer was attached to the consent form so that the participant with an intellectual disability could see who was going to be meeting with him to help him decide if he wanted to participate. I included a photograph of myself on the original recruitment flier.

The subsequent paragraphs describe some of the challenges I might have faced in interviewing adults with DD post loss. Booth and Booth (1996) speak of the “‘excluded voice thesis’ …that narrative methods provide access to the perspectives and experience of oppressed groups who lack the power to make their voices heard through traditional modes of academic research” (p. 55). They state, “Those who most need to have their stories heard may be least able to tell them” (p. 59). The difficulty in accomplishing this for individuals with DD poses an extra challenge, as language is “central to most qualitative research because of the emphasis on symbolic understanding and communication” (Biklen & Moseley, 1988, p. 156). Using language as the tool for research with individuals with limited intellectual ability and vocabulary requires
consideration. Challenges documented with persons with DD can be inarticulateness, unresponsiveness, and difficulty with time concepts (Booth & Booth).

Individuals with DD have been socialized to cooperate and be compliant to professionals in their lives. A significant power differential exists. Further, individuals with DD have varying levels of cognitive development that requires the interviewer to put questions in clear understandable terms without cueing the participant to a desired response.

Techniques for initiating the story of loss for an individual with DD pose challenges.

According to many authors, the vulnerability to suggestion of people with LDs results from a number of factors, including their susceptibility to influence by authority figures, acquiescence, problems understanding the language used, lack of knowledge of appropriate words and an inability to concentrate (Gudjonsoon, 1992; Sanders & Young, 1994)” (Milne & Bull, 2001, p. 95).

Yet, there is inherent value in continuing to overcome the obstacles so that the voices of individuals with DD can be heard. Biklen and Mosely (1988) found that in research with adults with DD, understanding for both participant and researcher is improved if during the interview comparisons are not used and if subjects are discussed separately. Milne and Bull (2001) reference Cardone and Dent’s 1996 recommendations to use “non-leading specific” (p.95) questions rather than “free report”. Biklen and Mosely (1988) concur suggesting, “Break requests for information into parts and ask separate questions about each… What were you doing the day before…?” (p. 158). Environment should be comfortable, yet privacy is an issue. Extra time allowance for
rapport building and settings free of distraction are recommended (Milne & Bull; Biklen & Mosley). Biklen and Mosely suggest a “home-like” environment (p. 158). These authors also point out the potential problem of participants becoming preoccupied with a particular issue and needing help to advance the conversation. It was suggested that the interviewer turn the questions back to the participant regarding their options on a particular issue, and this seemed to help the participant move on to other areas.

Acquiescence is a well documented problem (Milne, Clare & Bull, 2002; Sigelman, Budd, Winder, Shoenrock & Martin, 1982; Sigelman, et al., 1980; Sigelman, Winer, Shcoenrock, 1982). Acquiescence is evidenced by finding that “adults with intellectual disabilities were more suggestible on all measures, and less resistant to misleading questions than their counterparts from the general population” (Milne, Clare & Bull, 2002, p. 14). Yet, Papley and Antaki (1996) argued that, “The interview’s logic produces a range of pseudo-acquiescent responses in the face of interviewers’ reformulations, and their pursuit of plausible and acceptable factors” (p. 207). The interview is often perceived as a “test” situation by individuals with DD (Papley & Antaki). From conversation analysis provided by the authors, repeated instances are offered where the interviewer is not skilled in picking up the correct conversational cues from the participant. Their conclusions point to interviewer error rather than acquiescence on the part of the participant. Papley and Antaki supply reminders of the need of the interviewer to respect and carefully listen to the cues of the participants.

Cambridge and Forrester-Jones also noted that a participant’s own photographs were excellent supplements to interviews. March (1992) found use of photographs in research with persons with severe developmental disabilities increased “the number of
spontaneous comments, gestures and signs made by the participants and so could be said to have increased participants’ responsiveness to the interview situation as a whole” (p. 127). Booth and Booth (1994) found use of family photographs to be very beneficial when interviewing adults with learning disabilities.

Finlay and Lyons (2001) summarize recommendations for interviewing participants with mental retardation by: using important events as time markers; not using comparisons, but asking about elements separately; checking meaning of answers; avoiding double negatives in questions; avoiding modified adjectives; and keeping sentence structure simple and language non-technical.

Literature on child interviewing for court testimony provides other valuable techniques that are designed to ultimately solicit the narrative in the child’s words without influencing the information (Sternberg, Lamb, Esplin, Orback & Hershkowitz, 2001).

In addition, the context must be captured, including time, space, and person. Space is a contextual factor explored with older adults experiencing grief (Hockey, Penhale & Sibley, 2001). Specifically, use of both domestic and public space, as well as meanings attributed to space and objects, were explored over time to give a better picture of the “landscape of loss” (p. 739). The bereaved’s relationship to public space was broached by questions about effects of bereavement on the rest of the client’s life. Hockey et al.’s use of the context of space brings an interesting dimension to the study of the loss experienced by those with developmental disabilities. As noted by MacHale and Carey (2002), the death of a parent may cause loss of residence for individuals with DD.
Death of a parent impacts the social network of the individual, perhaps even limiting access to previously frequented public spaces and activities (MacHale & Carey).

Unfortunately for this project, the personal stories of grief, as well as resilience, could not be captured. Given additional time, I believe these issues could be resolved with agreement on reasonable protections for inclusion. Since the project is part of a dissertation with a graduation time frame in mind, a compromise was necessary. With, admittedly, some frustration, the study approved through the state IRB proposal was closed. It is my hope that I can develop a future research project that will capture the direct experiences and voices of bereaved adults with DD.

The original interview questions for adults with DD were:

1. Would you tell me a little about the people you live with?
2. Would you tell me a bit about your family?
3. Sometimes friends and people we like move away or get new jobs and we don’t see them anymore. Would you tell me about people you wish you could still see?
4. If they don’t mention their mom or dad died, then say:
5. I was told that your mom or dad died awhile back. I am sorry about that.
6. Would you be willing to tell me something about your mom or dad?
   a. If yes, continue.
   b. If no, ask: Can I ask you some questions about other things?
      i. If yes, skip to: What kinds of things do you like to do now?
ii. If no, thank participant for his/her time. Give gift card. Notify guardian if not present. Notify home site and case manager, if known.

7. Did you bring a picture of him or her?

8. Talk about the picture(s) Prompt with questions such as:
   a. What kinds of things did you like to do with your mom/dad?
   b. What places did you like to go with your mom/dad?
   c. Is it okay if I ask more questions?
   d. What do you remember most about your mom or dad?
   e. What do you miss most about your mom or dad?
   f. Where were you living when your mom or dad died?
   g. Is it okay if I ask more questions?
   h. What happened after your mom or dad died? Was there a funeral?
   i. If they mention that they missed mom/dad, ask: What/who helped you when you missed your mom/dad?
   j. Is it okay if I ask more questions?
   k. What kind of feelings do you get when you think about your mom/dad today?
   l. Whom can you talk to about your mom/dad now?

9. Okay, now I’d like to ask some questions about now! Is it okay to ask you a few more questions?
   a. What things do you like to do now? Who does those things with you?
b. What places do you go now?

c. Who goes with you?

d. Where has been your favorite place to live

Okay, I think that’s enough questions for today!

10. How was this meeting and all these questions?

11. Is there anything you want to ask me before we wrap up?

12. Can we set up a time I can go over what I wrote up and make sure it’s right?

   I’d also like to ask you how you are doing after all these questions that last visit.
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