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AGENCY STAFF PERCEPTIONS OF END-OF-LIFE CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Dedication

I want to thank Dr. Sarah Gehlert for her mentorship and guidance. Her patience and kindness kept me motivated even when things became challenging. Her dedication to health social work has been a constant inspiration for me and is a reminder of how important this field is and why our work is important.

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I would like to thank my parents Jeff and Mary Sue Moro for always believing in me even when I had doubts. Thank you for listening to my tales of woe and sharing in my victories. I am sorry that my father was unable to witness this adventure come to an end.

Finally, this dissertation is dedicated to Dan, Eloise, and the littlest family member. They put up with me at my worst and kept me laughing. I love you all very much.

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Chapter I

Introduction

Approximately 4.9 million people in the United States have an intellectual or developmental disability (I/DD) (Braddock et al., 2011; Braddock et al., 2015). The life expectancy for people with I/DD has dramatically increased in the last 20 years (Bittles et al., 2002; Emmerich, 2010; Haveman et al., 2010; Margallo-Lana et al., 2007; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000; Perkins & Moran, 2010; Strydom et al., 2010). Adults with I/DD now live long enough to acquire the same chronic and life-limiting health conditions as the general population, such as cardiovascular disease and cancer (Emmerich, 2010; Friedman, Helm, & Woodman, 2012; Haveman et al., 2011; Patja et al., 2000). While specific chromosomal, genetic, and neurodevelopmental conditions linked to I/DD may also impact aging, often the interactions are not well understood (Janicki, Henderson, & Rubin, 2008).

There is evidence to suggest that health care disparities are prominent for adults with I/DD, in particular at the end of life (Havercamp & Scott, 2015; Todd, 2002; Tuffrey-Wijne, 2003). Adults with I/DD face disability specific barriers at the end of life (Friedman et al., 2012; Havercamp & Scott, 2015; Marks, Sisirak, & Hsieh, 2008) including: a lack of accessible medical equipment in health care providers offices and hospitals (Marks et al., 2008); underutilization of palliative care services (Cross, Cameron, Marsh, & Tuffrey-Wijne, 2012; Friedman et al., 2012; Marks et al., 2008; Tuffrey-Wijne, Hogg, & Curfs, 2007); communication difficulties; limited or no health care provider training or experience working with adults with I/DD; residential transitions; and poor pain and symptom management (Bradbury-Jones, Rattray, Jones, & MacGillivray, 2013; Friedman et al., 2012; Hahn & Cadogan, 2011; Ouellette-Kuntz, 2005; Perkins, 2010; Read, 2005; Ryan & McQuillan, 2005; Tuffrey-Wijne & McEnhill, 2008; Webber, Bowers, & Bigby, 2010). As a result, many older adults with I/DD will acquire conditions that go unrecognized, are improperly diagnosed, and are inadequately treated (Haveman et al., 2011; Marks et al., 2008).

Although the majority of children and adults with I/DD in the United States live with a family caregiver (Braddock, 2013), many will transition from their family home into a community agency residence as they age (Bigby, 2010; Botsford, 2000; Post, 2002; Todd, 2002, 2005; Wiese, Stancliffe, Balandin, Howarth, & Dew, 2012b). These transitions are often a result of the illness or death of a family caregiver (Braddock et al., 2011; Haley & Perkins, 2004; Jokinen, Janicki, Hogan, & Force, 2012; Merrick & Morad, 2011; Webber et al., 2010). In the United States, the place of residence and funding for older adult services varies by state (Bigby, 2010; Engquist, Johnson, & Johnson, 2012).

Adults with I/DD and agency staff often have close relationships and may even refer to one another as family (Ryan, Guerin, Dodd, & McEvoy, 2011b; Todd, 2013). However, agency staff are often unprepared for caring for someone who is at the end of life (Ryan et al., 2011b; Todd, 2005, 2013). Although agency staff report both positive and negative experiences in the literature (Kirkendall, Waldrop, & Moone, 2012; Ryan et al., 2011b; Todd, 2005, 2013; Wiese et al., 2012b), there are numerous issues inherent in end-of-life care that make this experience emotionally and physically challenging (Kingsbury, 2010; Ryan, Guerin, Dodd, & McEvoy, 2011a; Todd, 2005; Todd & Read, 2010). In addition, staff often lack the training and resources to provide end-of-life care (Fahey-McCarthy, McCarron, Connaire, & McCallion, 2009; Ryan et al., 2011a; Ryan, McEvoy, Guerin, & Dodd, 2010; Stein, 2008; Tuffrey-Wijne, Bernal, Hubert, Butler, & Hollins, 2010b).

While improvements in end-of-life care for adults with I/DD are needed, the care that these individuals currently receive and the complex experiences of their agency staff caregivers are not well understood (Fahey-McCarthy et al., 2009; Kirkendall et al., 2012; McCallion, McCarron, Fahey-McCarthy, & Connaire, 2012; McCarron, McCallion, Fahey-McCarthy, & Connaire, 2011; Ryan et al., 2011b; Ryan et al., 2010; Stein, 2008; Todd & Read, 2010; Tuffrey-Wijne, Bernal, & Hollins, 2010a; Wiese, Dew, Stancliffe, Howarth, & Balandin, 2012a). This dissertation research will contribute to the literature by exploring where improvements in care are most needed and how to best reduce the inequities in end-of-life care for adults with I/DD and their agency staff caregivers. The long-term goal of this dissertation research is improve the end-of-life care experiences of adults with I/DD and agency staff by better preparing community agencies and health care providers to provide quality end-of-life care to adults with I/DD.

Specific Aims and Research Questions

The purpose of this dissertation research was to explore the experiences of agency staff who provided end-of-life care for adults with I/DD in order to clarify the services currently being provided, identify gaps in services, and to describe implications for social work clinical practice and policy. The Ecological Systems Model (Bronfenbrenner, 1979, 1986) provided the organizing framework for the aims and data analysis of this dissertation research. According to this model, an individual is an open system that interacts with and is influenced by four interrelated environmental systems, i.e., miscrosystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1979, 1986, 2000). This dissertation contributes to the limited scholarship about how end-of-life is currently being conducted by community agencies providing services for adults with I/DD and what needs to be done at the micro-, meso-, and exosystemic systems levels in order to improve care.

The microsystem encompasses interrelations between an individual and his or her interactions within a specific setting, e.g., relationships between an adult with I/DD and community agency staff. The first study aim focused specifically on the microsystem comprised of adults with I/DD and the community agency staff. The mesosystem can be conceptualized as a system of microsystems and is comprised of interrelations among two or more settings in which the individual participates, e.g., relationships amongst individuals with I/DD, community agency staff, and family members. For this dissertation research, the second study aim explored some of the mesosystems adults with I/DD at the end of life and their agency caregivers interact with. Individuals are impacted by exosystems but do not participate directly in them, e.g., adults with I/DD are impacted by community agency rules, and state and federal regulations. The third study aim focused on some of the exosystems that adults with I/DD at the end of life and their agency caregivers are impacted by.

Aim 1. The first aim of this study was to explore agency staff perceptions of their own participation and role in end-of-life care for adults with I/DD from diagnosis until after death. This aim was addressed by answering the following questions:

How did the agency staff describe their experiences working with adults with I/DD at the end of life from diagnosis until after death?

- How did agency staff describe their own participation and role in providing end-of-life care for adults with I/DD?
- How did agency staff describe their relationships with clients?

- What recommendations were offered for microsystemic improvements for end-of-life care delivery for people with I/DD?

Aim 2. The second aim of this study was to explore agency staff perceptions of how care was delivered at the end of life for adults with I/DD from diagnosis until after death, how medical decisions were made, and the roles and participation of family members and health care providers in end-of-life care. This aim was addressed by answering the following questions:

How did the agency staff describe the medical needs and the care received by adults with I/DD at the end of life (from diagnosis until after death)?

- What were the medical needs of adults with I/DD? How did their illness progress? What care did they receive at the end of life? Where was care received?
- Who made medical decisions for adults with I/DD? Were adults with I/DD involved in medical decision making? If so, how were they involved? If not, why were they not involved?
- How did agency staff describe the participation and role of family members? How did agency staff describe their relationships when working with family members?
- How did agency staff describe the participation and role of health care providers in hospitals, hospices, or nursing homes? How did agency staff describe their experiences working with these health care providers?
- What recommendations were offered for mesosystemic improvements for end-of-life care delivery for people with I/DD?

Aim 3. The third aim of this study was to identify and describe agency staff perceptions of exosystemic facilitators and barriers to end-of-life care for adults with I/DD from diagnosis until after death. This aim was addressed by answering the following questions:

> What exosystemic facilitators and barriers were implicitly or explicitly identified by agency staff when describing their experiences with end-of-life care (from diagnosis until after death) for adults with I/DD?

- How did agency staff describe agency programs and policies? Were these programs and policies perceived as facilitators or barriers to end-of-life care?
- How did agency staff describe rules and regulations in hospitals, hospices, and nursing homes? Were these rules and regulations perceived as facilitators or barriers to end-of-life care?
- How did agency staff describe state and federal rules and regulations, including Medicaid and Medicare? Were these rules and regulations perceived as facilitators or barriers to end-of-life care?
- What recommendations were offered for exosystemic improvements for end-of-life care delivery for people with I/DD?

Chapter Overview

Chapter II contains a review of the literature and orients the reader to current research in end-of-life care for adults with I/DD. Chapter III consists of the background of the parent study and a description of the study investigator's (Moro) role in that study. Chapter IV contains a review of the analytic methods used for this dissertation research. Chapter V contains a description of the results of this dissertation research. In Chapter VI, the study data are analyzed. Chapter VII contains a discussion of the dissertation study results and the implications for social work.

Chapter II

Review of Literature

This chapter is divided into three sections. First, some of the often ambiguous terms found in the aging and disability literature are clarified. In the second section, the ecological systems that individuals with I/DD at the end of life interact with are explored. Finally, a brief review and identification of the gaps in the literature are highlighted.

Term Clarification

Intellectual disability. The term *intellectual disability* is now used to describe the same group of individuals previously labeled as *mentally retarded* because the latter term does not communicate dignity or respect (Schalock et al., 2007). The terms *intellectual disability* and *developmental disability* are not synonymous, although they are often used interchangeably. Developmental disability is an umbrella term that includes intellectual disability; however, many individuals with a developmental disability, e.g., cerebral palsy or epilepsy, may have physical impairments with no intellectual component. Developmental disabilities are usually life-long conditions beginning in the developmental period that are due to an impairment in physical, learning, language, or behavior areas (Centers for Disease Control, 2013). The term *intellectual disability*, refers to disabilities that occur before the age of 18 and are characterized by significant limitations in both intellectual functioning (problem solving, learning, reasoning), and adaptive behavior (conceptual, social and practical skills) (American Association of Intellectual and Developmental Disabilities, 2013; Schalock et al., 2007). Intellectual disability is often linked to chromosomal, genetic, and neurodevelopmental conditions, such as the autism spectrum disorders, Down syndrome, and spina bifida (Janicki et al., 2008). In the United

Kingdom, the term *learning disability* is often used instead of the term *intellectual disability* (Heslop & Marriott, 2011; Tuffrey-Wijne et al., 2010a).

An intellectual disability is also one type of *cognitive disability*. However, cognitive disability also encompasses conditions contributing to sub-average intellectual performance and limitations in adaptive behavior that occur throughout the life-span including, autism spectrum disorders, severe and persistent mental illness, brain injury, stroke, and Alzheimer's disease (Braddock, 2013).

End of life. In general, the end-of-life literature lacks conceptual clarity surrounding exactly how to define the *end of life*. According to a 2004 *National Institutes of Health (NIH) State-of-the-Science Conference Statement* (National Institutes of Health, 2004):

> The evidence does not support a precise definition of the interval referred to as end of life or its transitions. End of life is usually defined and limited by the regulatory environment rather than by the scientific data. A regulatory definition is a barrier to improving care and research relating to end of life…There are individuals for whom identification of end of life is relatively clear; however, data support that this is relatively uncommon.

Although there may be no precise definition, in the NIH 2004 conference statement, two primary components of end of life are listed, specifically that an individual has a chronic disease and that the symptoms resulting from this disease require care from others and can lead to death. The care required may be provided by either formal, paid professional caregivers or informal, unpaid caregivers.

For the purposes of this dissertation, the American Association of Intellectual and Developmental Disabilities (AAIDD) definition of *end of life* will be used (American

Association of Intellectual and Developmental Disabilities Board of Directors, 2012). According to the AAIDD:

> End of life refers to a period in which death is soon anticipated in individuals with life-threatening or life-limiting conditions. Individuals are not at the end of life when they are living in a stable condition that requires significant life-sustaining treatment (such as a mechanical ventilator or a feeding tube) and wish to continue receiving such treatment. Individuals may be considered to be at the end of life when: (1) they have a condition that is progressive and irreversible, such as late-stage Alzheimer disease or terminal cancer, or (2) they have a condition or functional impairment whereby improvement or recovery is not expected, and withdrawal of life-sustaining treatment is under consideration.

In the general literature on aging, there is some agreement about what components should be measured or attended to within end-of-life care (Teno, 2005). Specifically, there is substantial agreement that the following are important aspects of end-of-life care: physical comfort; emotional support for the dying person and his or her family; open communication and shared decision making; and access to end-of-life care.

End-of-life care. Often, the terms *palliative care* and *hospice care* are used synonymously with *end-of-life care*, but each of these concepts represent unique phenomena. Although end-of-life and hospice care are both components of palliative care, palliative care refers to a model of patient and family-centered, compassionate care that can also be used to treat people at earlier stages of illness (National Consensus Project for Quality Palliative Care, 2013; National Hospice and Palliative Care Organization, 2013). Some people who receive palliative care will go on to fully recover from their condition. For example, palliative care may be used in conjunction with curative care in order to treat individuals with cancer who eventually go into remission. Palliative care may also be used to treat individuals with chronic illnesses, such as multiple sclerosis, who utilize palliative care services during periods of medical crisis, but who require fewer or no services once the crisis has been alleviated (Gruenewald, Brodkey, Reitman, & Del Bene, 2012).

While hospice care is a type of end-of-life care, not all end-of-life care can be considered hospice. Hospice care refers to a specific model of care for a person in the final stage of a life-limiting illness (Hospice Foundation of America, 2013b; National Hospice and Palliative Care Organization, 2013). For people receiving Medicaid or Medicare benefits, hospice care is only an option after a physician certifies that they have six or fewer months left to live based on a “terminal prognosis” (U.S. Department of Health and Human Services, 2013).

Health care disparities. The term *health care disparities* refers to differences in the presence of disease, health outcomes, quality of health care, and access to services that unequally affect specific groups of people (National Conference of State Legislatures, 2014). Factors contributing to health care disparities include inadequate access to health care, a lack of available care, poor quality care, and economic obstacles. Health care disparities are generally seen in specific racial, ethnic, and socioeconomic groups. In the United States, adults with I/DD experience worse health and more barriers to finding, traveling to and affording health care than adults in the general population regardless of their racial or ethnic background or socioeconomic status (Botsford, 2000; Botsford & King, 2005; Krahn, Hammond, & Turner, 2006; Perkins & Moran, 2010; Prater & Zylstra, 2006).

Presence of disease and health outcomes. Over the past 20 years, the life expectancy for people with I/DD has dramatically increased (Bittles et al., 2002; Emmerich, 2010; Haveman et al., 2010; Margallo-Lana et al., 2007; Patja et al., 2000; Strydom et al., 2010). Adults with I/DD now live long enough to acquire the same chronic and life-limiting conditions as the general population, such as cardiovascular disease, respiratory conditions, and cancer (Emmerich, 2010; Friedman et al., 2012; Haveman et al., 2011; Patja et al., 2000). While many adults with I/DD have the same life expectancy as members of the general population, the severity of I/DD impacts life expectancy (Bittles et al., 2002; Coppus et al., 2008; Patja et al., 2000; Patja, Mölsä, & Iivanainen, 2001; Thomas & Barnes, 2010; Todd, 2007; Tyrer & McGrother, 2009; Wagemans, van Schrojenstein Lantman-de-Valk, Tuffrey-Wijne, Widdershoven, & Curfs, 2010). According to Bittles et al. (2002), the median life expectancy for an adult with mild I/DD is 74 years, 67.6 years for people with moderate I/DD, and 58.6 years for people with severe I/DD.

The higher mortality rates for people with more severe limitations may be attributed to the medically complex co-morbidities associated with their chromosomal, genetic, and neurodevelopmental conditions (Janicki et al., 2008; Reilly, Hastings, Vaughan, & Huws, 2008). For example, people with Williams syndrome have decreased elastin which can contribute to serious heart conditions (Janicki et al., 2008). Limited research suggests that osteoporosis, fractures, constipation (Haveman et al., 2010; Haveman et al., 2011), heart disease, and thyroid disorders (Morin, Mérineau-Côté, Ouellette-Kuntz, Tassé, & Kerr, 2012) are also more prevalent in older adults with I/DD than in the general population.

Certain chromosomal, genetic, and neurodevelopmental conditions linked to I/DD also impact aging, but often the interactions are not well understood (Janicki et al., 2008). For example, little is known about aging with rare genetic disorders, such as Prader-Willi and

Williams syndromes (Dykens, 2013). There has been more research conducted exploring the link between Down syndrome and Alzheimer’s disease than with other chromosomal conditions. Adults with Down syndrome have higher rates of dementia than both their peers with I/DD and people in the general population (Janicki et al., 2008; Strydom et al., 2010). The primary explanation for the interaction between Down syndrome and Alzheimer’s disease is that some of the genes coded on chromosome 21contribute to the early emergence of dementia (Moran, Rafii, Keller, Singh, & Janicki, 2013).

While many adults with Down syndrome will never develop dementia, almost all of them have the brain plaques and tangles associated with Alzheimer’s disease (Emmerich, 2010; Strydom et al., 2010). Adults with Down syndrome who do develop dementia tend to exhibit signs in their mid-50s which is earlier than both their peers with other I/DD syndromes and the general population (McCarron, McCallion, Reilly, & Mulryan, 2014; Strydom et al., 2010). Dementia can be challenging to diagnose in individuals with I/DD due to the variability in cognitive functioning and because there may not be anyone who can attest to their baseline level of functioning (Moran et al., 2013). Clients may not have anyone who can provide a historically accurate account of their baseline functioning because of agency staff turnover, and inconsistent relationships with family members and health care providers.

Quality of health care and access to services. Krahn, Hammond, and Turner (2006) conceptualized health care for people with I/DD as a cascade of disparities because there has been inadequate attention to their health care needs, a lack of focus on health promotion, and limited access to health care services. Many older adults with I/DD will acquire preventable conditions that go unrecognized, are not diagnosed properly, are not diagnosed in a timely manner, or are inadequately treated (Haveman et al., 2011; Marks et al., 2008). Adults with I/DD may also receive a lack of information, and face transportation barriers and a lack of accessible medical equipment in health care providers offices and hospitals (Marks et al., 2008). There is evidence to suggest that palliative care and hospice services are underutilized by people with I/DD (Cross et al., 2012; Friedman et al., 2012; Marks et al., 2008; Tuffrey-Wijne et al., 2007). While members of the general population may face barriers to care, such as lack of insurance coverage, or misconceptions about hospice care, adults with I/DD face additional disability specific barriers at the end of life (Friedman et al., 2012; Havercamp & Scott, 2015; Marks et al., 2008). Two of the primary barriers to quality end-of-life care are communication difficulties and limited or no health care provider training or experience working with adults with I/DD (Bradbury-Jones et al., 2013; Friedman et al., 2012; Hahn & Cadogan, 2011; Ouellette-Kuntz, 2005; Read, 2005; Ryan & McQuillan, 2005; Tuffrey-Wijne & McEnhill, 2008; Webber et al., 2010).

Ecological Systems Involved in End-of-Life Care for Adults with I/DD

In this section, the literature on the systems that individuals interacts with and are affected by are explored in order to better understand what the end of life currently looks like for adults with I/DD and their agency staff caregivers. According to the Ecological Systems Model (Bronfenbrenner, 1979, 1986), an individual is an open system that interacts with and is influenced by other environmental systems. There are four specific interrelated systems (miscrosystem, mesosystem, exosystem, and macrosystem) with the microsystem as the smallest unit and the macrosystem as the largest (Bronfenbrenner, 1979, 1986, 2000). The microsystem encompasses interrelations experienced between the individual within a given setting, e.g., an adult with I/DD and agency staff. The mesosystem can be conceptualized as a system of microsystems and is comprised of interrelations among two or more settings in which the individual participates, e.g., an adult with I/DD and the community service agency, agency staff, and family members.

Individuals are impacted by exosystems, but do not participate directly in them. Examples of exosystems for adults with I/DD include state laws, the judicial system, and health insurance. The macrosystem refers to the broad culture in which the other systems are situated, for example, cultural views about death. Adults with I/DD at the end of life often interact directly and indirectly with multiple environmental systems including community agencies, hospitals, nursing homes, hospices, and state departments. The literatures on the systemic interactions at the miscrosystem, mesosystem, and exosystem levels, and the systemic facilitators to end-of-life care for adults with I/DD are reviewed below. The macrosystem level literature is beyond the scope of this dissertation.

Microsystems. Aging adults with I/DD are often cared for by family members or community agency staff. Their primary microsystems include family members and agency staff. Adults with I/DD may also have important relationships with extended family members and peers. As an adult with I/DD ages, his or her microsystems will likely change as a result of transitions and illness. For example, when an adult is ill health care providers become a more important part of his or her microsystem. The complexity and change inherent in all of the individual’s microsystems are beyond the scope of this review, thus this section will focus on the literature about prevalent microsystems that directly impact the care of adults with I/DD at the end of life including: residential transitions from family to agency care; clients and agency staff;

clients and family members; clients and health care providers; and clients and palliative care professionals.

Residential transitions from family to agency care. In accordance with the Omnibus Budget Reconciliation Act, adults with I/DD in the United States who do not need nursing care must reside in community settings (Hsieh, Heller, & Freels, 2009). Approximately 71.5% of all of the children and adults in the United States with I/DD live with a family caregiver (Braddock, 2013). Twenty-five percent of these family caregivers are over the age of 60. As of 2011, there were 613,184 children and adults with I/DD in the U.S. living in out-of-home, non-family residential settings. Seventy-seven percent of these individuals were living in settings with six or fewer people including, supported living, ICFs/ID, host or foster homes, and apartments. The place of residence for older adults with I/DD varies by state (Bigby, 2010; Engquist et al., 2012). In Illinois, there are approximately 29,809 children and adults with I/DD living in non-family residential settings including ICF/DDs, CILAs, group homes and apartments, and supported living arrangements and 32,732 individuals living with family caregivers who are over the age of 60 (Braddock et al., 2014).

CILA is the acronym for community integrated living arrangement. In the state of Illinois, a CILA is a supervised community residence home for eight or fewer adults over age 18 with I/DD and/or a mental illness. CILA residents must work towards the goals of self-sufficiency and economic independence by developing an individual integrated services plan (Social Security Administration, 2007). Based on the individual’s needs, CILA programs should provide residents with the following supports: locating and obtaining education, vocational training, or employment; obtaining necessary medical and rehabilitation services; developing independent living skills; developing money management skills; meeting transportation needs; and locating and participating in social activities. These residences are often run by community agencies serving adults with I/DD.

ICF/DD or ICF/IIDs are Intermediate Care Facilities for Individuals with Intellectual Disabilities. According to the Centers for Medicare & Medicaid Services (2015), federal regulations at 42 CFR 435.1009, an ICF/IID is defined as:

> an institution (or distinct part of an institution) that: (a) Is primarily for the diagnosis, treatment, or rehabilitation for individuals with intellectual disabilities; and (b) Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration for health or rehabilitative services to help individuals function at their greatest ability. …The primary purpose of the ICF/IID is to furnish health and rehabilitative services to persons with intellectual disabilities or persons with related conditions.

While ICF/IID is the official term used by the Centers for Medicare & Medicaid Services (2015), ICF/DD is used in this dissertation because this is the term given by the study participants.

Adults with I/DD are often concerned about their housing placements (Innes, McCabe, & Watchman, 2012; Shaw, Cartwright, & Craig, 2011), yet most families do not have concrete placement plans established (Bibby, 2012; Heller & Caldwell, 2006; Shaw et al., 2011). Many adults with I/DD transition from their family home into a group home, residential facility, or nursing home as they age (Bigby, 2010; Botsford, 2000; Post, 2002; Todd, 2002, 2005; Wiese et al., 2012b). Often, these transitions are precipitated by the illness or death of a family caregiver (Braddock et al., 2011; Haley & Perkins, 2004; Jokinen et al., 2012; Merrick & Morad, 2011;

Webber et al., 2010).

Adults with I/DD and their families may incorrectly assume that they will receive life-long care after moving into a community agency residence (Bigby, Bowers, & Webber, 2011). However, community agencies that provide housing for adults with I/DD often have limited nursing support (Botsford, 2004). When someone requires intensive nursing care they may transition from their residence into an ICF/DD or nursing home (Jokinen et al., 2012). These transitions are more likely to occur after a hospitalization (Webber et al., 2010). In their study exploring the deaths of adults with I/DD, Kerins, Price, Broadhurst, and Gaynor (2010) found that adults with I/DD were admitted to nursing homes at an earlier age and remained in them longer than members of the general population. People with Down syndrome tend to experience more relocations and are more likely to die in nursing homes than other adults with I/DD (Patti, Amble, & Flory, 2010).

Clients and agency staff. As adults with I/DD age and their social networks become smaller, agency staff may assume personal and friendship roles previously occupied by family members (McCallion et al., 2012; McCarron et al., 2011). Relationships between adults with I/DD and agency staff often last many years (Todd, 2005) and staff may think of the clients as family (Ryan et al., 2011b; Todd, 2013). While each staff member brings personal and professional experiences, many are unprepared and may have never contemplated providing end-of-life care until they are confronted with the impending death of a client (Ryan et al., 2011b; Todd, 2005, 2013). For some, the death of an adult with I/DD is a shock (Todd, 2013). Agency staff are exposed to a variety of losses ranging from the sudden death of a client to caring for someone throughout an extended illness (Todd, 2013; Wiese et al., 2012b).

Agency staff report both positive and negative experiences caring for adults with I/DD at the end of life. Caring for clients at the end of life is viewed by some as an important part of their caregiver role (Kirkendall et al., 2012; Todd, 2005, 2013; Wiese et al., 2012b). Some staff reflect positively on the care that they provided and feel privileged that they were present when the client died; others feel incompetent because they were not able to provide the care they wanted to (Ryan et al., 2011b).

There are several issues inherent in end-of-life care that can negatively impact staff, including the emotional stress of caring for someone who is dying, being uncomfortable discussing death, or feeling conflicted about telling adults with I/DD about their illness severity (Kingsbury, 2010; Ryan et al., 2011a; Todd, 2005; Todd & Read, 2010). Staff may have limited knowledge of what caring for a dying person looks like and are unprepared for the sometimes unpleasant and challenging experience (Todd, 2013). Staff generally prefer to keep adults with I/DD in their homes at the end of life and may have strong reactions when they are unable to provide end-of-life care to the clients (Bekkema, de Veer, Wagemans, Hertogh, & Francke, 2015; Bigby et al., 2011; Todd, 2013). Staff may feel guilty when clients are transitioned out of the agency because they were not present when the client died (Ryan et al., 2011b).

Agency staff cite a lack of training and resources as barriers to providing end-of-life care (Fahey-McCarthy et al., 2009; Ryan et al., 2011a; Ryan et al., 2010; Stein, 2008; Tuffrey-Wijne et al., 2010b). For example, staff may find it difficult to discuss clients’ illnesses with them because they do not understand the diagnosis themselves (Tuffrey-Wijne et al., 2013) or staff do not know how to discuss death with clients (Wiese, Stancliffe, Dew, Balandin, & Howarth, 2014). Not being trained in areas such as pain and symptom management can make staff anxious about providing care (McCarron et al., 2011). The lack of training can have a direct impact client transitions because staff are more apt to transfer someone if they believe they cannot provide the necessary care (Bekkema et al., 2015; McCarron, McCallion, Fahey-McCarthy, & Connaire, 2010).

Agency staff report that they more often look within their own agencies for guidance with end-of-life care than to seek out help from palliative care professionals (Ryan et al., 2011a; Ryan et al., 2010). Despite the stress of working with a dying client, agency staff are rarely given the opportunity to discuss and process their end-of-life experiences (Blackman & Todd, 2005; Ryan et al., 2011b; Todd, 2013).

Clients and family members. Family members play an important role in end-of-life care for adults with I/DD even when there has been limited prior contact (Tuffrey-Wijne et al., 2010b). In the United States, legal decisions for adults with I/DD are generally made by a surrogate who is either a family member or a court appointed state guardian (Kohn, Blumenthal, & Campbell, 2012). When a parent caregiver dies, siblings or extended family members may become the guardian (Bigby et al., 2011). Who should be involved in decision making may be unclear when family members are guardians, but have not been involved with the individual in years (Kingsbury, 2010).

End-of-life care planning for adults with I/DD is often precipitated by an urgent health crisis, such as a cancer diagnosis or cardiac arrest, which can make health care decision making and planning stressful for the individual and their family (Haley & Perkins, 2004; Kingsbury, 2010). End-of-life decisions are particularly difficult for family members who generally are focused on mitigating suffering (Wagemans et al., 2013). There is evidence to suggest that adults with I/DD want to be informed and participate when they have life-limiting medical conditions (Kingsbury, 2010; Ryan et al., 2011a; Tuffrey-Wijne, 2012; Tuffrey-Wijne et al., 2010a; Tuffrey-Wijne & McEnhill, 2008). However, these individuals are often excluded from making health care decisions for themselves (Bekkema, de Veer, Wagemans, Hertogh, & Francke, 2014b; Ryan et al., 2011a; Savage, Ast, Bess, Castrogiovanni, & Conway, 2010; Tuffrey-Wijne et al., 2010b; Wagemans et al., 2010). Some family members make health care decisions for adults with I/DD without eliciting their preferences (Levy & van Stone, 2010) or decide that, in order to protect the individuals from distress, they should not be fully informed about their condition (Bekkema, de Veer, Hertogh, & Francke, 2014a; Savage et al., 2010; Tuffrey-Wijne, 2012; Tuffrey-Wijne et al., 2010a; Tuffrey-Wijne et al., 2010b; Tuffrey-Wijne et al., 2013). However, for some adults with I/DD not being given the information and support they need to understand their diagnosis creates additional stress (Tuffrey-Wijne et al., 2010a).

Clients and health care providers. Health care providers generally have no training or experience working with individuals with I/DD (Cartlidge & Read, 2010; Krahn & Drum, 2007; Marks et al., 2008; Perkins & Moran, 2010; Ryan et al., 2010; Stein, 2008; Tuffrey-Wijne et al., 2010a; Webber et al., 2010). Health care providers' lack of experience can impact their communication with adults with I/DD and their attitudes about how to involve individuals in their health care. Communication encompasses an individual's ability to articulate their symptoms and treatment preferences, and a health care provider's ability to understand the person with I/DD. Many adults with I/DD have communication limitations, such as speech impairments, or difficulty articulating verbally (Ryan & McQuillan, 2005; Stein, 2008; Tuffrey-Wijne & McEnhill, 2008; Ward, Nichols, & Freedman, 2010).

Several scholars have reported incidences of poor communication between adults with I/DD and health care providers (Bradbury-Jones et al., 2013; Gates, 2011; Tuffrey-Wijne et al., 2010b; Webber et al., 2010). A lack of communication can negatively impact care by contributing to incorrect diagnoses, poor pain and symptom assessment, over or under treatment, and negative rapport with patients (Friedman et al., 2012; Perkins & Moran, 2010; Todd, 2005; Tuffrey-Wijne, 2003; Tuffrey-Wijne, Bernal, Jones, Butler, & Hollins, 2006; Tuffrey-Wijne et al., 2007). Some adults with I/DD who are able to verbally communicate cannot clearly articulate their pain to a health care provider (Findlay, Williams, & Scior, 2014). Misdiagnosis can also occur as a result of *diagnostic overshadowing* (Hospice Foundation of America, 2013a; Robinson, Dauenhauer, Bishop, & Baxter, 2012; Tyrer & McGrother, 2009) which refers to incorrectly attributing symptoms to a trait associated with the individual's I/DD and not his or her underlying medical condition (Hospice Foundation of America, 2013a; Kim, Hoyek, & Chau, 2011; Moran et al., 2013).

Some providers believe that adults with I/DD cannot comprehend medical information or participate in health care decision making (Johnson, 2010; Kingsbury, 2010; Tuffrey-Wijne et al., 2006; Ward et al., 2010; Webber et al., 2010). There is evidence to suggest that adults with I/DD often receive incomplete information about their illness and treatment options when compared to members of the general population (Friedman et al., 2012; Tuffrey-Wijne et al., 2010a). However, in their recent study Tuffrey-Wijne et al. (2013) found that health care providers felt that individuals with I/DD should be told about their diagnosis and prognosis provided that full disclosure was right for the individual. These health care providers noted that the person's comprehension impacted whether or not they disclosed the information.

Clients and palliative care professionals. Professionals in palliative care, including hospice caregivers, generally have limited or no experience working with adults with I/DD (Cartlidge & Read, 2010; Cross et al., 2012; Kirkendall et al., 2012; McCarron et al., 2010; Ryan et al., 2010; Todd & Read, 2010; Tuffrey-Wijne, Whelton, Curfs, & Hollins, 2008). A lack of training makes it difficult for palliative care professionals to ascertain patients' understanding of their condition, in particular if the individual has communication limitations (Ryan et al., 2011a).

Mesosystems. The mesosystem can be conceptualized as a system of microsystems, or the interrelations among two or more settings in which the individual participates. For example, one mesosystem is the relationship between clients, their families, and agency staff. Another example is the relationships between clients, agency staff, and health care providers. The literature often focuses on one microsystem and less on the interactions between multiple microsystems. The literature exploring the following mesosystems is reviewed below: clients, agency staff, and family members; clients, agency staff, family members, and health care providers; clients, agency staff, and palliative care providers; clients, agency staff, and surviving peers; and clients, agency staff, and community agencies.

Clients, agency staff, and family members. Some clients are close to their family and others are not (Ryan et al., 2011b; Todd, 2013). The relationships between agency staff and clients' families can become strained when the client is at the end of life (Ryan et al., 2011b). For example, staff may feel left out, or find it problematic when families who have not had an ongoing relationship suddenly reappear when the client is at the end of life (Ryan et al., 2011b; Todd, 2013). While some families want staff involved in planning funerals, other families decide exclude staff entirely from mourning rituals after a client dies. When clients are not actively involved with their family members, staff plan funerals for clients (Todd, 2013).

Clients, agency staff, family members, and health care providers. Some health care provider attitudes and communication styles hinder rapport with both adults with I/DD and their caregivers (Backer, Chapman, & Mitchell, 2009; Gates, 2011; Webber et al., 2010). Adults with disabilities have reported negative experiences with health care providers including, feeling misunderstood and unsupported, not being given enough time to understand and ask questions about their medical condition, and providers talking to their parents or agency staff about their condition instead of directly to them (Gates, 2011). Wilkinson, Dreyfus, Bowen, and Bokhour (2013) found that while women with I/DD and their physicians generally reported positive relationships, at times both were dissatisfied with the clinical encounter. Both participants were frustrated by how long general medical appointments took. Women with I/DD felt rushed while their physicians regretted being unable to spend as much time as necessary. Physicians in this study said that they primarily communicated with the support person who attended the appointment. The women in this study wanted the physician to talk directly to them and not their support person.

Family members and agency staff have also reported issues including health care providers being indifferent or appearing uncomfortable working with adults with I/DD, and providers ignoring information supplied by caregivers (Webber et al., 2010). In contrast, Wagemans et al. (2013) found that some families rely on health care providers for guidance and support with end-of-life decision making.

Several scholars discussed the potential for collusion between health care providers and caregivers of adults with I/DD (Cartlidge & Read, 2010; Ryan et al., 2011a; Tuffrey-Wijne et al., 2010a). Sometimes family members collude with health care providers to conceal the seriousness of the client's illness, or they impose restrictions about what illness related information can be shared with the clients (Ryan et al., 2011a; Tuffrey-Wijne et al., 2010a). These attitudes differ from that of agency staff who generally believe that adults with I/DD have a right to know about their life-limiting illness (Ryan et al., 2011a; Savage et al., 2010; Todd, 2005; Tuffrey-Wijne, 2012; Tuffrey-Wijne et al., 2010a; Tuffrey-Wijne et al., 2013).

Clients, agency staff, and palliative care providers. Staff have reported that they are better suited than palliative care professionals to provide end-of-life care (Ryan et al., 2011b). When palliative care is involved there may be confusion from both agency staff and palliative care professionals about their specific roles (Cross et al., 2012; Kirkendall et al., 2012; Todd & Read, 2010). In one study, both groups of caregivers were unclear about what their role was, what services the other provided, and how the services were run (Cross et al., 2012). Additionally, both groups have reported a lack of partnership, communication, and information sharing with one another (Kirkendall et al., 2012). In a recent study, McLaughlin, Barr, McIlfatrick, and McConkey (2014) also found that, despite the fundamental importance of working together, a partnership between palliative care and intellectual disability services was rare. However, the experience was positive when these two groups engaged in a partnership.

Clients, agency staff, and surviving peers. When a client is at the end of life everyone in the agency home is affected. During the final stages of an illness, agency staff spend an inordinate amount of time caring for the dying person and other clients' needs may be minimized (Blackman & Todd, 2005). Before and after the death, agency staff must cope with their own grief while simultaneously caring for grieving clients (MacHale, McEvoy, & Tierney, 2009;

McEvoy, Guerin, Dodd, & Hillery, 2010).

Clients, agency staff, and community agencies. Limited resources are often cited as barriers to providing end-of-life care services for people with I/DD in community agencies (Botsford, 2004). Limited resources include a lack of on-site nursing support, inadequate access to palliative care services, and few resources to devote to end-of-life care (Botsford, 2004; Ryan & McQuillan, 2005; Stein, 2008). For example, an agency may not be able to afford to adequately train staff or hire additional staff when a client is at the end of life (Botsford, 2004; Todd, 2005; Tuffrey-Wijne et al., 2006). Even when a client is in a hospital, agency resources are taxed if the agency has to pay overtime or hire additional personnel to be with the individual in the hospital (Webber et al., 2010).

Exosystems. Individuals do not participate directly in exosystems, yet they are impacted by them. Adults with I/DD are impacted by multiple exosystems including: the judicial system; Medicare and Medicaid; and the United States federal government.

The judicial system. The meaning of the terms capacity and competence are often misunderstood (Kingsbury, 2010; Levy & van Stone, 2010). The term *decision-making capacity* refers to an adult's ability to understand and make decisions. Capacity is presumed in all adults unless there is evidence to the contrary. There is no standardized assessment used with adults with I/DD to determine capacity (Kingsbury, 2010). An adult's capacity to participate in decision making is impacted by cognitive ability and affective state and can change for reasons including having an illness.

In the United States, *competency* is a legal term and adults over the age of 18 are considered legally competent to make medical decisions for themselves (Johnson, 2010). This issue is complex for adults with I/DD. Currently, there is no accepted definition of a never-competent individual and the courts rely on the opinions of physicians to determine whether an individual with I/DD can consent to medical treatment (Levy & van Stone, 2010). The court may be asked to make a determination about whether the individual is currently and/or previously competent to make medical decisions. For adults deemed not competent, but who previously were considered so, their express wishes for medical decisions must be considered. However, if the individual is considered never-competent guardians do not have to obtain the individual's input.

There are several other cases in which the judicial system may be involved. For example, if an adult with I/DD's competence is questioned despite being his or her own guardian (Levy & van Stone, 2010). When a guardian dies and no surrogate decision maker has been identified a judge may appoint a state guardian to make some or all decisions on behalf of the individual (Kohn et al., 2012). Court-appointed guardians often do not receive training in the choices and procedures for making end-of-life decisions and may not fully understand them (Botsford & King, 2010).

Medicare and Medicaid. In the United States, most adults with I/DD receive Medicare or Medicaid funding (Braddock et al., 2011). While there are some services, e.g., inpatient and outpatient care, screening tests, and nursing services, that are mandated by the federal government, states differ in what additional services are covered (Braddock et al., 2011). The regulatory provisions for end-of-life care also vary by state (Botsford & King, 2010; Friedman et al., 2012).

The states determine funding for The Medicaid Home and Community Based Services

(HCBS) Waiver, ICF/DDs, targeted case management, and personal care, clinic and rehabilitative services (Braddock et al., 2011; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). The HCBS Waiver program is the primary funding source for providing long-term supports and services for people with I/DD (Rizzolo et al., 2013). This program reimburses the states for providing community-based programs including, habilitation training, respite care, employment, transportation, and behavior management.

The United States federal government. The Older Americans Act 1987 amendments enabled funding for aging services for adults with I/DD (Bigby, 2010). Agencies devoted to aging and those working with people with I/DD were encouraged to work together to develop appropriate services. Despite a recognized need for collaboration between the aged-care and disability sectors, little progress has been made over the last 20 years. In a recent literature review, Bigby (2010) found limited progress in developing and implementing support services for aging adults with I/DD in the United States where aged-care and disability care sectors are overseen by separate governmental agencies with little collaboration between the two.

Facilitators to Promote Quality End-of-life Care

In this section, the literature on facilitators that promote quality end-of-life care for adults with I/DD is presented. These facilitators span several systems, thus are not presented using the ecosystems framework.

Involve clients in health care decision making. Several scholars have advocated for the inclusion of adults with I/DD who have the capacity to participate in their own health care and end-of-life decision making (Blackman & Todd, 2005; Bradbury-Jones et al., 2013; Kingsbury, 2010; Kingsbury, 2012; Levy & van Stone, 2010; McCallion et al., 2012; Savage et al., 2010).

The current guardianship model of decision making for adults with I/DD has been criticized by scholars who caution that this system should only be applied in cases in which an individual lacks the capacity and should not be used as a result of faulty assumptions about ones functional ability or as a routine part of permanency planning (Kohn et al., 2012). When an adult with I/DD is his or her own guardian, but is no longer be able to make decisions, a health care agent can be appointed instead of having the individual declared incompetent and appointing a guardian (Levy & van Stone, 2010). This option is rarely utilized for adults with I/DD.

A supported decision-making model is one alternative to the current guardianship model (Kohn et al., 2012). With a supported decision-making approach, adults with I/DD are the decision-makers but they articulate their preferences and receive support from trusted others to help them understand the decisions to be made. In addition to their cognitive abilities, how much an adult with I/DD comprehends is also impacted by factors including their life experience and how much they are helped to understand their diagnosis (Tuffrey-Wijne et al., 2010a). Even when an adult with I/DD is considered legally incompetent, he or she may have the capacity to participate in end-of-life care planning and health care decision making. In a recent literature review, Kohn and Blumenthal (2014) found insufficient research to determine whether or not the supported decision-making model is beneficial for adults with I/DD.

Create advance care plans with clients. Adults with I/DD rarely have any formal future plans in place (Bibby, 2012; Heller & Caldwell, 2006). Several scholars have advocated for advance care planning with adults with I/DD before a health crisis arises (Bekkema et al., 2014a; Bibby, 2012; Heller & Caldwell, 2006; Kingsbury, 2010; Levy & van Stone, 2010). Advance directives are one component of an advance care plan and may be general or include detailed choices about future medical treatments (Levy & van Stone, 2010). An advance care plan should include: who will make decisions for the individual if they cannot; what the individual wants if they become ill; and what living well means to them (Kingsbury, 2010). Future planning should also include desired living arrangements, financial planning, and legal safeguards (Heller & Caldwell, 2006). This plan should be revisited and include information about an individual's diagnosis, prognosis, and goals for treatment if one's condition changes (Bekkema et al., 2014a; Kingsbury, 2010). If adults with I/DD are unable to articulate what they want at the end of life, others who know and love them should work together without making assumptions about what they should want. Having discussions before a crisis decreases the stress on the agency staff and the client (Kingsbury, 2010). Future planning can also help individuals and families avoid legal obstacles when a crisis arises (Levy & van Stone, 2010).

Improve interactions with health care providers. In a study conducted by Webber, Bowers and Bigby (2010), agency staff reported having positive interactions with health care providers in hospitals with distinct policies and systems in place to provide quality care for adults with I/DD. Staff at these hospitals adapted communication styles in order to work with nonverbal individuals, took the time to understand the unique needs of adults with I/DD, and provided post-discharge support. Agency staff in this study made the following recommendations for improving care for adults with I/DD: have family or agency staff present when meeting with health care providers; agency staff and health care providers should work together; agency staff should provide health care providers with information about how the individual with I/DD communicates, including their triggers and responses to stress, ways to calm them, what they need assistance with, and information about medications; agency staff need to advocate for adults with I/DD in order to avoid premature discharge and transitions to nursing homes.

Gates (2011), conducted focus groups with adults with I/DD in order to determine what supports they needed from health care providers. The study participants made the following recommendations: provide easy-to-read information with symbols and pictures; do not use acronyms and abbreviations; if needed, an advocate should be present; health care providers need training in working with people with disabilities; and health care providers need to value and not talk down to people with disabilities.

In Tuffrey-Wijne's (2012) study on breaking bad news to people with I/DD and life-limiting conditions, participants reported that they coped better with bad news if they understood what was happening. Breaking bad news should include all of the appropriate caregivers including agency staff, family, and health care providers and should take into account the individual's capacity and understanding. Information needs to be broken down into singular chunks and delivered gradually in a slow, ongoing process that builds on an individual's knowledge and understanding.

Provide additional end-of-life training for agency staff. Although there is a need for additional training and support for staff who provide end-of-life care for adults with I/DD, little is known about what the training should look like (Bekkema et al., 2015; Dunkley & Sales, 2014; Ryan et al., 2011b). Several expert driven resources provide practical guidelines for including adults with I/DD in health care and advance care planning decisions (Aging with Dignity, 2011; Blackman & Todd, 2005; Botsford & Force, 2004; California Department of Developmental Services, 2007; King, Janicki, Kissinger, Lash, & Last Passages Advisory

Council, 2004; Kingsbury, 2009; NYSARC; Savage et al., 2010; Sunderland People First). However, the efficacy and applicability of these resources have not been empirically tested.

Three studies have been conducted to empirically test training programs for agency staff working with adults with I/DD and life-limiting conditions (Cross et al., 2012; Fahey-McCarthy et al., 2009; Hahn & Cadogan, 2011). The first was an intervention study designed for agency staff working with adults with I/DD and advanced dementia (Fahey-McCarthy et al., 2009). This intervention was designed and implemented by a multidisciplinary team consisting of I/DD and palliative care professionals and consisted of 20 sessions over 6-8 weeks and a student workbook. According to the formal feedback from the study participants, the educational intervention was valuable and addressed staffs' concerns.

The second study consisted of a palliative care curriculum and educational program for staff providing services to adults with I/DD in long-term care (Hahn & Cadogan, 2011). This program consisted of nine modules including topic-specific modules, handouts, exercises, clinical practice guidelines, references, and a resource list of supplemental materials. A live eight-hour train-the-trainer session was held for staff working in developmental centers. Study participants reported an increase in their preparedness to and confidence in providing palliative care.

The third study aimed to increase access to palliative care services for people with I/DD (Cross et al., 2012). Two different training programs were conducted. One training program with professionals in I/DD and another for palliative care professionals. This training lasted two full days. In addition to the training, professionals from I/DD and palliative care were linked with one another in order to provide the other with support. The agency staff reported benefitting from the training, but there was less agreement about the benefits for palliative care professionals. The linking between professionals was not successful.

Gaps in the Literature

The last decade has ushered in an increase in the literature exploring end-of-life care for adults with I/DD, however, much remains unknown (Perkins & Friedman, 2012; Todd, Bernal, & Forrester-Jones, 2013). While there is a good foundation of information, in particular regarding the microsystems, such as the relationship between a client and his or her agency staff, what is less prevalent in the literature is how the microsystems interact at the mesosystemic level. For example, the complexity of the agency staffs' role and how their interactions with clients, family members, other clients, and health care providers impact their ability to provide end-of-life care is not well understood. In addition, there is limited research exploring the impact that exosystems, for example, how the individual state funding and state specific regulations impact end-of-life care for adults with I/DD.

Finally, the literature is generally well-rounded in identifying the pertinent issues that need to be addressed when providing end-of-life care for adults with I/DD, but there is less research addressing what needs to be done. For example, there is evidence to support a need for additional training for agency staff; however, the proposed content of the training is less clear. Of the three studies reviewed above that empirically tested training programs for agency staff working with adults with I/DD and life-limiting conditions (Cross et al., 2012; Fahey-McCarthy et al., 2009; Hahn & Cadogan, 2011), none addressed how agencies would fund this additional training. The same can be said of health care and palliative care provider training; while there is a clear need, there is less empirical research to support any specific training models.

Chapter III

Background of the Parent Study

Overview and Aims

The *End-of-life Care for People with Intellectual and Developmental Disabilities* study was conducted through the University of Illinois at Chicago College of Nursing from April 2010 through June 2012. This study was part of a P30 center grant (#P30 NR010680) funded by the National Institute of Nursing Research. The team members for this project were Dr. Teresa Savage, PhD, RN (Principal Investigator), Teresa Moro, AM, LSW (Project Director), and Jacquelyn Boyden, MS, MPH, RN (Research Assistant). The purpose of this study was twofold. First, this was a feasibility study conducted to see if it was possible to recruit, consent, and include adults with I/DD in focus groups and individual interviews about end-of-life (Savage, Moro, Boyden, Brown, & Kavanaugh, 2015). The second purpose of this study was to explore the patient-centered and family-focused dimensions of care and the desired dimensions of a respectful death for people with I/DD by describing the perspectives of adults with I/DD, family members, and agency staff on: 1) advance care planning; 2) desired death experience; and 3) perceived facilitators and barriers to the desired respectful death.

Research Design and Methods

Design. This study used an exploratory, descriptive methodology involving focus groups and individual interviews. The design and implementation of the focus groups were informed by the guidelines developed by Krueger and Casey (2009).

Study setting. Participants were recruited from four community agencies providing services to adults with I/DD. All of these agencies were located in a metropolitan area in Illinois.

Information about the four participating agencies is listed below in Table 3.1. The agencies were selected because members of the research team had professional contacts with agency administrators.

Table 3.1

Study Setting Information

Agency	Clients	Services for Adults with I/DD
A	Serves about 7,000 children and adults with a range of disabilities	CILA homes Day Programs Home-Based Services
B	Serves about 3,000 children and adults with developmental disabilities	CILA homes Day Programs Home-Based Services ICF/DD
C	Serves about 600 children and adults with developmental disabilities	CILA homes Day Programs Home-Based Services ICF/DD
D	Serves about 600 children and adults with developmental disabilities	CILA homes Day Programs Home-Based Services ICF/DD

Sample. In total, 20 adults with I/DD, 19 family members, and 22 agency staff participated in this study. Nine focus groups and 34 individual interviews were conducted with the participants. A list of all four agencies (A-D), the type of interview (focus group or individual), and what participants groups (family, agency staff, client) were interviewed at each site is listed in Table 3.2. As will be described below, only the agency staff data were used for this dissertation research.

Table 3.2

Interviews Conducted at Sites

Agency	Type of Interview	Staff	Family	Clients
A	Focus group	3	0	3
	Individual	7	0	5
B	Focus group	0	1	0
	Individual	3	5	0
C	Focus group	0	1	0
	Individual	1	1	0
D	Focus group	0	1	0
	Individual	3	4	5

The inclusion criteria for agency staff were: 1) 18 years of age or older; 2) English speaking; 3) provided care to an adult with I/DD (at least 18 years old) who died; and 4) the death occurred a minimum of three months prior.

Only the agency staff data were used because the staff discussed multiple experiences with providing end-of-life care whereas the family members and clients generally referred to only one case. The research design, time constraints, and specific focus of the parent study did not allow for data to be collected from agency staff, clients, and families about a specific death. In addition, the majority of the agency staff participants were from agency A whereas most of the family participants were from agencies B and C, thus presenting a difficulty when attempting to present a cohesive picture of end of life.

Data collection measures. Semi-structured interview guides addressed: 1) end-of-life care experiences; 2) desire for advance care planning; 3) desired end-of-life care; and 4) facilitators and barriers to desired end-of-life care and advance care planning. Descriptive demographic information was also collected.

Procedure. The focus groups were both digitally audio recorded and transcribed using

Communication Access Realtime Translation. By using this transcription method, each speaker was clearly identified and speech was instantaneously translated into text during the focus groups. The individual interviews were digitally audio recorded and transcribed verbatim. All of the transcripts were checked by a team member for accuracy. An in-depth report of the recruitment procedures with adults with I/DD is described elsewhere (Savage et al., 2015). All of the study materials and consents were approved by the Institutional Review Board at the University of Illinois at Chicago.

Data management and analysis. Preliminary analysis of transcripts began immediately after the first focus group was conducted. Analysis involved indentifying themes and was guided by Krueger and Casey (2009) and Miles and Huberman (1994). Throughout the coding process, the codes were clarified and expanded as relevant. All of the interview data were double coded and discrepancies were resolved until intercoder reliability reached 100%.

Role of study investigator (Moro) in parent study.

As project director, Ms. Moro was involved in every aspect of the parent study including: assisting in writing and preparing the P-30 grant; preparing initial applications and subsequent continuing review materials for the internal review boards; preparing National Institute of Health reports in compliance with grant funding; and manuscript writing and submission. Ms. Moro worked closely with Dr. Savage to give presentations about the study and to recruit the community agencies. Ms. Moro recruited study participants and coordinated focus groups and individual interviews. Ms. Moro attended all of the focus groups and conducted a majority of the individual interviews. The codebooks were created by Ms. Moro and edited by Dr. Savage and Ms. Boyden. Ms. Moro collaborated with team members on data coding, data analysis, and writing manuscripts for publication. A list of the manuscript, conference papers, and posters from the parent study are included in Appendix A. An additional manuscript exploring the parent study aims has been submitted and is in the process of being edited for publication. The published and submitted manuscripts were not included in this dissertation because they are copyrighted material.

As will be described in Chapter IV, this dissertation research addressed questions not presented in the parent study and positioned these questions within a systems framework in order to present a more in-depth look at the agency staff data than the parent study aims necessitated.

Chapter IV

Analytic Methods

Grounded theory analytic methods were used to conduct a secondary analysis of agency staff perceptions about their experiences of caring for adults with I/DD at the end of life (Charmaz, 2011; Charmaz & Bryant, 2010; Corbin & Strauss, 2008). This dissertation research used data collected from the parent study (see Chapter III) in order to analyze unexplored portions of the data and to answer questions not previously addressed. All of the data coding for this dissertation research was conducted by the study investigator (Moro).

While many researchers use grounded theory with the aim of constructing a middle-range theory, these methods have been used successfully for secondary data analysis when the parent study was not created using grounded theory with the goal of theory construction (Andrews, Higgins, Andrews, & Lalor, 2012; Corbin & Strauss, 2008). These methods are well established and add rigor to the data analysis by providing structured guidelines for exploring qualitative interview data (Charmaz, 2011; Charmaz & Bryant, 2010; Corbin & Strauss, 2008).

Research Design and Methods

Design. Grounded theory is a coding-based, inductive analysis in which the phenomenon of interest is understood based primarily on the study data and not on preconceptions or predetermined theory (Gibbs, 2010c). The analytic methods employed with grounded theory allow researchers to interact with the data in order to discover categories (Patton, 2002), and to locate the study participants’ experience within the larger social context (Corbin & Strauss, 2008). This inductive approach is useful when there is not a lot known about the phenomenon of interest. Grounded theory was selected for this study because of the limited empirical research exploring the experiences of agency staff who work with adults with I/DD at the end of life (Fahey-McCarthy et al., 2009; Kirkendall et al., 2012; McCallion et al., 2012; McCarron et al., 2011; Ryan et al., 2011b; Ryan et al., 2010; Stein, 2008; Todd & Read, 2010; Tuffrey-Wijne et al., 2010a; Wiese et al., 2012a). These methods were also chosen because one of the core elements of grounded theory is to discover social processes, in this case, the experience of caring for adults with I/DD at the end of life. Coding in grounded theory is an ongoing and active process in which codes are created by the researcher as she defines and scrutinizes what is seen in the data (Charmaz, 2006).

Study setting and sample. All of the agency staff data from the parent study were analyzed. In total, three focus groups and 14 individual interviews were conducted with 22 agency staff from all four of the participating agencies. All of the agency staff participants reported working full-time and held a variety of roles within their agencies including: social workers, counselors, art and music therapists, social service professionals, program managers, and agency administrators. The agency staff demographic data is listed in table 4.1.

Table 4.1

Demographic Data

Agency Staff Participants	n=22
Mean age in years (range)	43.67 (23-58)
Gender	
Female	19
Male	3
Race	
African-American/Black	4
Asian	1
Hispanic/Latino	1
White	15
Other	1
Mean years caring for people with I/DD (range)	19.38 (1-41)

Participants within each focus group were from the same hierarchical level within the agency, meaning that supervisors were not in the same group as staff who worked for them. The focus groups included 13 staff from Agency A. Eight of the staff from Agency A participated in focus groups only and seven participated in focus groups and individual interviews. Individual interviews were conducted with seven additional staff from Agency A, three from Agency B, one from Agency C, and three from Agency D.

Data management and analysis. The coding was conducted in two phases (Charmaz, 2006; Corbin & Strauss, 2008; Gibbs, 2010a). Phase one consisted of open or initial coding in which all of the interview text was reviewed, coded, and preliminary categories were developed (Birks & Mills, 2011). Focus group and individual interview data were each analyzed individually. When two agency staff participated in the same individual interview the interview was analyzed as one narrative. Sentence-by-sentence coding and memo construction were done concurrently by the study investigator (Moro). Each sentence of the interview transcript was coded using gerunds which are nouns formed from a verb by adding *-ing* (Charmaz, 2011). Using gerunds allowed the study investigator (Moro) to focus on what study participants were describing in order to avoid simply paraphrasing what they said. Only the answers to the questions asked, and not the questions themselves, were coded. Below is an example of a participant quote and the sentence-by-sentence codes assigned.

Participant quote: “She survived longer than the physician had ever thought she would.”

Code assigned: “Client surviving longer than MD thought”

In some cases one sentence of text yielded multiple codes, below is an example.

Participant quote: “It’s…We are a family. I know it’s unprofessional but we do operate as a family here. So….”

Code assigned: “Knowing it's unprofessional, but we operate as a family” and “agency being a family”

In cases in which several sentences or sentence fragments were expressing one idea, they were coded together in order to maintain clarity. Below is an example of several sentences or sentence fragments that were coded together.

Participant A: “There's some stuff in like our on-the-job training that we have to read like this pamphlet on it. Which I haven't done yet, but –

Participant B: About death?

Participant C: Yeah.

Participant B: Probably something –

Participant C: Yeah, like talking about death and grieving and mourning with clients.

Participant B: Probably something new.

Code Assigned: “Staff receiving on-the-job training/ pamphlet talking about death, grieving and mourning with clients”

In total, there were 4103 sentence-by-sentence codes.

Memos were constructed concurrently with the codes in order to move the analysis forward by writing down questions, observations, and possible categories (Corbin & Strauss, 2008). Unlike the sentence-by-sentence codes which were as close to the data as possible, the memos included the study investigator’s (Moro) reflexive thoughts and interpretations, hypotheses, and preliminary analysis of the data.

Category construction began as soon as the sentence-by-sentence coding and memos were completed for the first focus group transcript. Once each transcript was completed, the memo notes and sentence-by-sentence codes were evaluated using the process of constant comparison in order to construct preliminary categories (Corbin & Strauss, 2008). Constant comparison refers to the ongoing process of grouping conceptually similar sentence-by-sentence codes together (Gibbs, 2010b). New categories were created if the sentence-by-sentence codes did not fit within an existing category.

All of the data management, sentence-by-sentence coding, and category construction was organized using ATLAS.ti v7 (Friese, 2013). This software allowed the study investigator (Moro) to organize and analyze the focus group and individual interview data directly in the program. For example, the categorization was done in ATLAS.ti v7 (Friese, 2013) by grouping the sentence-by-sentence codes into code families. Code families were a way to organize codes into categories without changing the initial codes. Thus, codes such as “client saying all my friends are gone and I’m still here” and “everybody dealing with death differently” were placed into the “Grief and Bereavement” category, but the original sentence-by-sentence codes remained unchanged. All of the memos were constructed and maintained in Microsoft Word.

The second phase of coding began after the sentence-by-sentence coding and memo construction were complete. This phase, called intermediate coding, was done by exploring the relationships between the categories and making connections between them (Birks & Mills, 2011; Gibbs, 2010a). In order to engage in intermediate coding, all of the focus group and interview codes were critically reviewed to determine whether the sentence-by-sentence codes were appropriately located in the preliminary categories or if they needed to be moved, or new categories created, in order to more accurately reflect the meaning. As will be described in detail below, once this phase was complete there were a total of 12 final categories.

Chapter V

Results

A total of 12 final categories were identified from the data. The final categories were: agency resources, client experience, planning and placement, client understanding/involvement, working with family/guardian, staff experience/role, external professional caregivers, systemic issues, grief and bereavement, recommendations, general background, and no code. Each category is briefly presented below. Below the term *client* is used to refer to the individuals with I/DD who are described by the agency staff. This term was selected because it reflects a trend towards calling service users in community agencies clients.

The first category was *agency resources* which referred to comments about agency services for clients who were aging and/or at the end of life. The second category was *client experience* and referred to comments about the clients' experiences of aging, decline, illness, and/or death. The next category was called *planning and placement* which referred to comments about placement and client future planning when clients were declining or at the end of life. The fourth category was *client understanding/involvement* and referred to comments about clients' understanding of illness and death and their involvement in medical and end-of-life decision making. The next category was *working with family/guardian* and referred to comments about the role of the family/guardian in end-of-life care, their relationships with the family member with I/DD, and their relationship with agency staff. The sixth category was *staff experience/role* and referred to comments about staffs' role and their professional experiences of caring for clients as they age and/or were at the end of life. Next, was the category *external professional caregivers* which referred to comments about the care received from non-agency and non-family caregivers when clients were ill or at the end of life. The eighth category was *systemic issues* and referred to comments about state and federal agencies, programs and regulations, and liability and financial issues that impacted client care. The next category was *grief and bereavement* and referred to comments about how clients, staff, and families reacted to death. The tenth category was *recommendations* and referred to comments about what end-of-life care should or should not be and the resources, training, and supports needed to provide care. The eleventh category was *general background* and referred to comments about general information that is not related to aging or end-of-life for people with I/DD. The final category was *no code* which was used to code the questions asked by the interviewer as well as interruptions, or requests for question clarification. The data coded as *no code* were not presented in the following analysis because they were not participant responses.

The results of this dissertation research are split into two chapters. In this chapter, each category is explored for each focus group and the individual interviews. At the end of each category a section with the investigator's (Moro) brief reflexive comments and impressions about the data is presented. The investigator's comments also include any relevant information from the memos. Since focus groups facilitate the formation a unique group synergy (Kruger & Casey, 2009) data from each focus group are presented individually even though all of the focus groups were conducted at Agency A. Below, the focus groups are labeled as FG1 (focus group #1), FG2 (focus group #2), and FG3 (focus group #3). For the individual interviews, Agency A interviews are presented together and are labeled with an IA. The individual interview data from agencies B, C and D are presented together and labeled with an IB-D below. These groups were created because the agency staffs' experiences of providing end-of-life care was impacted by whether or not the agency had an ICF/DD. ICF/DDs are for clients who need 24-hour residential care, including those who need more extensive nursing support. Agencies B, C, and D had ICF/DDs and Agency A did not.

In Chapter VII, all of these data are analyzed in the aggregate in order to address the study aims and briefly discuss the main points from this dissertation research data. Since the next chapter presents a synopsis of the data none is provided in this chapter.

Agency Resources

FG1 agency resources. Agency A offered day programs for clients that lived in agency homes, in family homes, and in the community. There was no medical staff at this agency. This agency did not have any formal policy for providing end-of-life care services. While the staff had discussed forming an end-of-life policy, it was difficult to come up with one.

The agency offered an employee assistance program for staff training. Some staff did not recall having any end-of-life training in years, if at all, but said if they had this training it was limited to only some staff members. The direct service provider training manual may have had a small section on end of life, but the training was basic and outdated. Other staff recalled the agency bringing end-of-life trainers in, but not regularly. Some staff were uncertain whether or not end-of-life training was offered at the agency.

FG2 agency resources. Agency A provided services to clients residing in their own apartments and agency housing. This agency did not have a formal policy for providing end-of-life care, but the staff had discussed creating a policy. When making decisions about clients at the end of life staff talked to people who were “higher up” in the agency administration. Staff reported that they did not get training on end of life or grief and loss. Direct service providers received on-the-job training on end of life and had some training based on the Kübler-Ross stages of grief.

FG3 agency resources. There was no formal policy for providing end-of-life care at Agency A. Some staff said that they did not have end-of-life training, but it may have been added. When they started at the agency some staff received training on the Kübler-Ross stages of grief, but the training was not in-depth and only a small section was on death. Staff received on-the-job training in areas including death and medications. The agency had an art group for clients.

IA agency resources. Agency A had a day program, CILAs, and other residences. This agency did not have any ICF/DDs which were for people needing a high level of medical care. There was one nurse for the entire agency consisting of about 200 residents. Some clients lived in the community with roommates. Some clients in the day program did not live in agency residences and others lived in agency residences, but did not attend the day program. Clients could continue in the day program as long as they were able to tolerate the program and move around the agency. Residential care was the most intense level of service at this agency and each residence had a unit staff person and house manager. The agency had a wellness program for clients that included dance, music, and art therapy.

Some staff said that end of life was not addressed at the agency. Other staff reported that there were open discussions regarding end-of-life issues. According to one staff member, the "permanent focus" at the agency was on the people who were going to continue receiving services.

The agency promoted family and community involvement, education and understanding, and a holistic approach to working with clients. Staff did not know if there was any bereavement follow-up with families. There was no formal policy at the agency for providing end-of-life care, but there was a protocol for handling client emergencies. The agency also did not have a policy about appropriate and inappropriate touch when working with dying clients. The agency did have a value statement about respecting clients, and the program handbook outlined what happened when clients choose not to participate in agency programs. Some staff were uncertain whether or not there was an official end-of-life care program or policy at the agency.

According to staff, there was no formal, regular agency training on end of life. However, seminars, workshops, continuing education, and guest speakers were all offered for staff training. Some staff read an article on grief and bereavement for people with I/DD when they were first hired. Other staff recalled briefly reviewing Kübler-Ross' stages of grief during training. The direct service providers had a class on grieving and received a pamphlet about the grieving process. The managers conducted on-the-job bereavement training with staff. Staff also received training on client behaviors, abuse and neglect, and appropriate touch. Some staff were uncertain whether or not there was end of life training offered at the agency.

IB-D agency resources. Agencies B, C, and D all had CILAs and ICF/DDs and were able to provide end-of-life care for clients. One staff member did not think that their agency had end-of-life services, but other staff members from the same agency reported that they did. None of the staff described a formal policy for providing end-of-life care. However, staff at all three agencies described other agency protocols. One agency had a dementia screening, fall risk protocol, and it was "sort of" a policy that the nurses discussed advance directives, do not resuscitate orders, and end of life with families. Another agency had a chain of command for who was contacted when a client died. The third agency had regulations about what constituted appropriate and inappropriate touch.

All of the ICF/DDs provided 24-hour nursing care and each agency provided different levels of nursing care based on the clients’ needs. One agency also employed allied health care professionals including a dietician, occupational therapist, physical therapist, speech-language pathologist, a licensed clinical professional counselor, and a social worker. Another agency had a medical staff including nurses and a physician. The third agency had homes with part-time nursing for clients that needed more care than individuals in the CILAs and less than those in the ICF/DDs.

All three agencies had day programs. As long as the clients were safe, physically capable, and wanted to participate they could continue in the day programs. Staff at one agency noted that clients could not attend the day program if they required skilled nursing or additional staff support. One agency had a leisurely paced program tailored towards older clients who retired from their day or employment program. Some clients lived in the community and attended the day program. Other clients lived in agency residences and worked in the community. Community clients at the end of life often stopped coming to the day program. At one agency, staff provided resources but were not as involved with the clients living in the community as they were with clients in agency residences. The nurses at this agency were not involved with community clients at all.

Staff in all three agencies received some training on end of life, although the amount of training varied. Two of the agencies used the GRACE Project manual for training staff. The manual consisted of modules for working with older adults with I/DD. At one agency, staff were given salary incentives for receiving training and could choose to take classes on hospice and aging. Staff were trained on agency policies end-of-life training was required for staff working with geriatric clients. The qualified intellectual disabilities professionals were not required to take end-of-life training. One staff member said that the agency training was “great” but limited. At another agency, the staff were not trained in end of life, but speakers came to the agency to talk about grief and loss. The grieving process was discussed during direct service provider and professionalism training. At the third agency, staff reported getting a news paper article on grieving during their initial staff training. Training at this agency differed between the day program and the residential staff and only some staff at this agency were sent for training.

Investigator comments on agency resources. Agencies with more nursing staff and ICF/DDs were better positioned to care for adults with I/DD at the end of life. More research is needed to identify whether the presence of a nursing staff and an ICF/DD substantially limits the number of clients who are transitioned out of their homes when they are critically ill. Since none of the caregivers who participated in this research worked in ICF/DDs many clients were cared for in CILAs by residential agency staff. End-of-life care is emotionally and physically challenging, yet this care is being provided by staff who have limited or no training. Agency staff are generally trained to promote and support clients living active lives, thus, providing end-of-life care represents a very different focus.

I found it disconcerting that some of the staff who provided end-of-life care did not know whether or not their agency had end-of-life training or protocols. In addition, when training was available the staff described it as limited and outdated. For example, some of the staff said that their training was based on the stage model of Kübler-Ross. The scholarship on end-of-life has not subscribed to a stages model of grief for over a decade. As the community of adults with I/DD live longer, there is a critical need for CILA/residential staff to receive more training and supports for providing end-of-life care. Ideally, end-of-life training should be a regular component of the state mandated direct service provider training, but more work is needed in order to convince the state of the importance of this type of training. There is also a need to inform staff about what the end-of-life care provisions are within the agency.

None of the agencies had a formal policy for providing end-of-life care services. Based on observing in the interviews, staff seemed to want an end-of-life protocol, but formulating one proved challenging and did not seem to be an agency priority. Further research should focus on what a protocol might look like and explore the pros and cons of having a formal end-of-life care policy. Would it be more efficient to have a protocol if death is so common, or is handling each case individually more effective?

Client Experience

FG1 client experience. Although their needs at the end of life were the same as the general population, clients were vulnerable because of their disability. Staff described one client with “terminal cancer” and another with a short illness. Staff said it was “painful” for clients to learn that they won’t be around anymore and their responses to their own illnesses varied. For example, one client with terminal cancer “went on like she didn't think anything was wrong with her.” Another client in hospice wanted to talk about his feelings:

> But what was interesting, um, he actually – because of the time I came, I guess, he vocalized that, um, he – like going to bed at night was the hardest, and he actually asked that I come at night whenever I could….I mean he's got so many feelings and thoughts

> going on, and, you know, and we're only even tapping into a fraction of those….but again it's not like, you know - if somebody, like if somebody just walked in, he would just say I'm fine, you know, or whatever.

Some clients wanted to come to the day program when they were at the end of life.

FG2 client experience. Some client’s at Agency A were declining and/ or showing signs of dementia. While some clients had illnesses, such as colon cancer, and lived longer than expected, a majority of clients died suddenly and unexpectedly. One client died after being pushed down the stairs by another client. Another client died unexpectedly from a heart attack while he was in the room with his roommate. One staff member posited why clients’ often died suddenly:

> The people that have been in my programs that have actually died are almost always like really sudden, like you just – it just – yesterday they were fine and today they are dead. And some of it’s because – the reason why they are cognitively challenged might be because of birth issues with brain, you know, functioning from the very beginning.

The way clients reacted to having a life limiting condition was impacted by the individuals themselves and how information about their condition was presented to them. Staff said some clients were “frightened.” Other clients wanted to continue as if nothing had changed, to “live it up”, or “to fight.” Sometimes clients did well in the hospital and other times they had difficulty. Some clients did not want to engage in end-of-life conversations. Clients often lived together for a long time and when someone was ill their peers asked about them. Peers also asked about clients who had been transitioned to a nursing home or hospital.

FG3 client experience. The clients were aging and a lot of them were ill with conditions including gallbladder problems and cancer. One client died young and another lasted two to three years with cancer. Clients' responses to their illnesses varied. For example, one client swore at staff when she went to the emergency room, whereas another client was pleased with the care he was getting. One client grabbed herself in pain and prayed more often. Another client wanted to listen to the radio 24 hours a day. One client was granted a wish from the Make-A-Wish Foundation.

The clients interacted well at home and would ask about sick peers even if they were not close, or if the client was in the hospital. They wanted to know if the client was okay and when he or she would be back. One client reacted negatively and would engage in "bad behaviors", such as going outside at 2:00 or 3:00 in the morning, when someone close to him left the agency. Staff were unsure how this client would cope if his sister died since she had been ill. Clients would also ask staff to tell them if they were ever leaving. In addition to the death of a peer, clients also experienced the death of family members.

IA client experience. Many clients were aging and declining or were already medically fragile. Clients had a variety of illnesses including cancer, chronic obstructive pulmonary disease, seizures, hearing impairments, cardiac problems, breathing issues, and mobility limitations requiring the use of a wheelchair. According to staff, some studies linked Down syndrome to Alzheimer's disease. Some clients lived longer than expected after receiving life-limiting diagnoses and others died suddenly. Some clients sustained injuries after falling. One client was assaulted and murdered in the community. According to staff, clients were at risk of being conned and scammed by people in the community.

Clients responded to having a life-limiting illness in a variety of ways. For example, one client with chronic obstructive pulmonary disease liked living in a nursing home where he could continue to smoke. Other clients “acted out” in hospitals and rehabilitation centers. One client in hospice appreciated when staff visited him at night. One client wanted to retire and go to a senior center and their families supported this decision. Another client wanted to move back to where he was originally from.

Clients experienced a number of losses including the death of peers and family members. Some clients were able to be with loved ones when they died. When clients were ill or transitioned out of the agency their peers visited them in hospices, hospitals, and nursing homes. It was difficult for peers to visit when clients were moved to facilities that were far from the agency.

IB-D client experience. Clients were aging and some were deteriorating or already medically fragile. Clients had a number of life-limiting illnesses including liver disease, organ failure, dementia, degenerative ataxia, breast cancer, and Alzheimer’s disease. Clients also had Down syndrome, seizures, falls, bed sores, functional decline, and reduced mobility requiring assistive devices. Some clients died suddenly, others had conditions that deteriorated slowly, and others lived longer than their physicians’ predicted. One client died from an infection that occurred a few days after he fell and broke his nose. Some clients deteriorated physically with no cognitive changes while others were physically healthy despite cognitive decline. According to staff, individuals with Down syndrome aged faster than the general population. One staff member said that adults with Down syndrome had an approximately 85% chance of having Alzheimer’s disease. Clients with Alzheimer’s disease and dementia hung on for a long time because they were physically healthy. Staff reported that while every client was different, similar things happened when clients with dementia or Alzheimer's disease began deteriorating, for example clients would forget how to get dressed, brush their teeth, walk, eat and drink, and use the bathroom,

Clients had a variety of responses after being diagnosed with life-limiting illnesses. Some clients experienced pain and fatigue whereas others did not exhibit any signs of being ill. Some clients wanted to go on outings and continue in the day program and others did not. One client with liver disease quit smoking and tapered down his soda pop intake. Another client with Alzheimer's disease refused to come to the day program and lived with elderly parents who were unable to bring him. One client who loved boating was very happy when the staff took him on a trip and he died the next day. According to staff at one agency, all of the clients had a "good death" except for one. Some clients who transitioned out of the agency wanted their peers to come and visit them.

Sometimes clients were like family to one another. Clients' responses when a peer was at the end of life were variable as two staff members described below:

> Participant A: Some - some [clients] get sad. Some also act inappropriately. We have one client that, when someone passes, they want their room and their stuff. … And then you have some people that just, I know they're back there. They're in the room. It's okay. And no more, no more talk about it. Just let me know when they've died kind of thing.
>
> Participant B: And then you've got another one that wants to sit in the room the whole time and hold their hand. She'll just hold the person's hand. Maybe scope out the room and whatever but- but she's very- we've got a professional mourner and our professional supporter. You know?

One client did not want to admit that his best friend was dying. After clients were transitioned out of the agency their peers either called or visited them. According to one staff member, sometimes clients were not informed as their peer's condition deteriorated, so it appeared that all of a sudden their peer went from sick to dead and the clients were not involved in the end of life piece.

Investigator comments on client experience. Staff worked with medically fragile clients with conditions including: cancer; dementia and Alzheimer's disease; functional decline; chronic obstructive pulmonary disease; organ failure; seizures; hearing impairments; and mobility limitations requiring the use of assistive devices. Some clients deteriorated physically with no cognitive changes while others were physically healthy despite cognitive decline. Working with people with these conditions can present many emotional and physical challenges for caregivers. For example, as staff reported, clients with dementia or Alzheimer's disease might forget how to get dressed or use the bathroom. This finding reiterates the need for additional training and supports for agency caregivers.

Many clients died suddenly and unexpectedly. Some clients died tragically due to accidents such as: being pushed down the stairs by another client; falling; and being assaulted and murdered in the community. While it is unclear whether these tragic accidents occur more commonly in adults with I/DD, these findings speak to a need for staff to be well supported by their agencies in order to cope with the tragic and sudden loss of the adults they care for.

Clients' responses to having an end-stage-illness seemed very individualized much like within the general population. The staff descriptions indicated that many clients not only responded appropriately to their circumstances, but had greater insight and depth than staff assumed they were capable of. This finding presents a welcome addition to some of the academic literature that too often focuses on difficult behaviors of adults with I/DD. These data are an important reminder to not automatically pathologize adults with I/DD when they are responding to an incredibly challenging situation.

Planning and Placement

FG1 planning and placement. Staff reported that each case was handled on an individual basis. According to one staff member:

> Because everything is really individual here. Everybody's circumstances are so different. It's really hard to say or give a statement that this is what we do when this happens, because it depends on what the individual needs are and what the resources of the program are as well.

In some cases, the *Fives Wishes* document was used in order to see what clients wanted at the end of life. In other cases, there was never a consensus about how to handle end of life. Some clients were transitioned into a hospice or nursing home care when their medical needs increased or if they needed hospice services. Some clients' transitions were sudden and/or they were transitioned to facilities far away from the agency. One staff member described the following scenario:

> I know in years I've been here, that happens a lot, when somebody's having medical issues, and then all of a sudden, okay, there's somebody that's been living with you in an eight person CILA for 18 years and now they're out, let alone the individual that is now, you know, pulled out of their circumstance.

Staff made sure the clients went to a "good facility" and in one case staff physically helped a client move their belongings out of their community apartment into a nursing home. Some families wanted clients to live in the families' houses at the end of life.

FG2 planning and placement. End-of-life planning for clients was done informally on a case-by-case basis. Some clients had a formal plan in place. One client had a plan his parents had made, but the plan got lost and staff helped to create a new one:

> His parents had made plans but in the process of leaving the – what do you call it, approved home, a nursing home or whatever you call it – you know, the plans got lost. So we took-up and we started something else for him, with a cousin also who was involved.

Staff worked with clients and families to determine what was best for clients at the end of life. In one case, staff "elected to keep him [the client] there, you know, for awhile until he really deteriorated to the point where he was beyond our care." Other clients went in and out of the hospital, or transitioned to a hospice or nursing home. Usually staff did not care for clients at the very end of life and staff had limited experience with hospice. Several clients died after they were transitioned out of the agency, often in the hospital.

FG3 planning and placement. The staff were not involved in developing advance directives for clients, but one client did have one. Clients were transitioned out of the agency when they were beyond the staffs' ability to care for them. As one staff member noted:

> We're only trained to a certain extent. We can't even give the medication. When they get their medication, it is them pushing – it's hand over hand training. Because we're not even allowed. I mean – no. We can't. It's so much that we only can do. Once they're beyond our care, they have to be moved out.

The staff did not know of any client who received hospice care at this agency. In one case, the family thought the client should be in a nursing home. Another client died a year after going to a nursing home.

IA planning and placement. Families rarely had an end-of-life care plan in place for the clients. Staff reported that end-of-life care was complicated and handled on an individual basis. Care plans were "reactive" meaning that there was no plan in place until a client had medical issues or received a life-limiting diagnosis. One staff member thought the *Five Wishes* document had been used with clients. Staff discussed clients during their regular meetings when the clients showed signs of physical decline. Agency nurses, the client's physician, case managers, agency administrators, house managers, and residential staff were all involved with the client and family in end-of-life planning. Family and/or guardians were responsible for making decisions and filling out paperwork, such as advance directive or power of attorney forms. According to one staff member, making plans ahead of time was both positive and negative because of changes that occurred between when the plan was made and when it was enacted. For example, the plan may have been to place the client in a particular facility, but the family had since moved away.

Staff preferred to keep clients in their current living arrangements. Although some clients were transitioned out of the agency for hospice care, clients were able to receive these services while living in the CILAs. According to staff, transitioning clients out of the agency was a medical decision because staff were unable to provide clients with 24-hour nursing or medical care. Staff were unsure if the agency would ever provide care to clients with medical needs.

Whether clients were transitioned to an ICF/DD or nursing home depended on what services they needed. For example, many of the CILAs were not accessible so clients had to be transitioned out of the agency if they required the use of a wheelchair. Some clients were transitioned from a hospital to a nursing home or rehabilitation facility for treatment. In some cases, these clients returned to the agency and in others they were remained in the other facility permanently. The staff worked with nursing homes and rehabilitation facilities to make sure clients were appropriately placed. Families also had input into where clients were transitioned to and some chose to move the clients into facilities closer to them. Moving clients nearer to families sometimes meant moving them far away from the agency. Some clients were transitioned in and out of the agency multiple times. Staff reported that some clients had died in their homes while others had died in nursing homes and hospitals.

IB-D planning and placement. Staff at all three agencies convened meetings with families and/or guardians when clients had changes in behavior or functioning. End-of-life care planning was handled differently at each agency. At one agency, end-of-life planning was done on an individual basis and staff tried to proactively plan when clients exhibited signs of functional decline. When clients’ conditions were progressing staff discussed do-not-resuscitate, do-not-transfer, and do-not-intubate options with families and/or guardians. Staff at the second agency had attempted to discuss pre-arranging funerals when clients first began services, but had discontinued this practice. According to one staff member, they needed to have a conversation before addressing funerals and another afterward; however staff did not have enough time to do this. Thus, end of life was now addressed when clients were at the end of life or showed signs of dementia.

At the third agency, advance care planning was discussed when clients first began services in order to proactively plan for their future. Clients and families were given resources and information, but were not required to complete any paperwork. According to one staff member, some families and/or guardians were not ready to discuss advance care plans as illustrated below:

> Some of them, they don’t want to think. I mean it’s kind of it’s too soon or I’m not prepared yet. It’s heartbreaking why we’re talking about it. It’s a very sensitive topic. Cause, I know when [speaker name] came and discussed this in one of our [agency] meetings, it’s really…one of my parents when I used to be doing the staffing had them sign, complete those. You put tears in your eyes. They cried. I go no I don’t want to talk about it. Not right now. So kind of they’re not ready yet.

At this agency, the nurses were more comfortable discussing advance care planning than were the qualified intellectual disabilities professionals. The nurses gave families and clients information about living wills, advance directives, medical power of attorney, do not resuscitate orders, and finances and trusts. This information was further discussed and plans were reevaluated as a routine part of the annual individual service plan meeting. Some clients at this agency had future plans and funeral arrangements and others did not.

Clients were only accepted into CILA homes if there was a crisis in the family home, for example when caregivers were aging or at the end of life. According to one staff member, moving into an agency as an adult was difficult for some clients:

> Mostly people coming in now are either at the age of 22 and transitioning into that adult kind of time. That’s the ideal situation for us to be able to bring them in when they’re 22. We’ve had other individuals that have come in when they’re 40, 45 and living at home with no demands and all of a sudden coming to a setting where there’s different expectations, that’s a challenge. That can be a challenge, for sure. It makes it much more

> difficult to get them to adapt kind of to this type of a setting.

As clients aged and their mobility required assistive devices some clients had to move to CILAs without stairs. Moving a client from one CILA to another was difficult because it often meant displacing another client. According to staff, some families viewed transitioning clients from one CILA to another or from a CILA to a higher level of care negatively. According to staff at one agency, verbal clients did not have anyone to talk to at the ICF/DD since most of the clients were non-verbal. The staff had never worked with a client who entered the agency at the end of life, but thought it would be difficult to get funding for that. Some clients went to nursing homes for rehabilitation and returned to the agency after being hospitalized. Some clients moved multiple times before they were at the end of life.

According to one staff member, clients and families assumed they were coming to the agency for the rest of the client's life, but this did not always happen. Staff at all three agencies reported that the preference was to keep clients in their agency homes when they were at the end of life. According to one staff member:

> We think of it as their home and any person would rather be at their home when they're dying rather than in a strange hospital or nursing home. So we try to make it as comfortable for them, bringing in hospice to help us out with things we can't do for them, trying to let them die comfortably in their own home.

Clients were only transitioned out of their home in order to accommodate their aging or medical needs. Moving a client from their CILA to an ICF/DD within the same agency was dependent upon availability. At some agencies, a client had to die before there was an opening for another client in the ICF/DD. Sometimes the process of transitioning a client from their CILA to an

ICF/DD was easy and other times it was more difficult. One staff member described the process of moving clients from one level of care to another:

> I mean, our first preference is to allow someone to age in place and to remain in their primary residence. There are realities though of the financial aspect of that so if their end-of-life care is going to require twenty-four hour nursing, for instance, we are not financially able to offer that in the CILA. The funding is just not there so, as I mentioned, we do have the ICF/DD program with twenty-four hour nursing and if we had a spot available, then that might be an option we offer people. Obviously, the other option which has happened is to move to nursing home but that is not anywhere near our preference or we don't jump to that by any means. Those are sort of last resorts.

At one agency, all of the clients had been cared for with agency nurses providing "hospice-like" care. Depending on the family's' wishes, some clients were brought back from the hospital in order to die at this agency. The staff did not know if this agency would be able to provide all of the clients with end-of-life care indefinitely, or if some clients would eventually have to go to nursing homes. At the other two agencies, hospice care was brought in so clients could stay in their home. However, some clients at these agencies also transitioned to nursing homes or hospitals. Moving to a nursing home was a big change for clients and sometimes families wanted to move the client closer to them. Staff assisted in locating nursing homes for clients. Some clients died at home while living in agency housing and others died in hospitals.

Investigator comments on planning and placement. Most clients did not have any advance care plans until there was a crisis. Although most member of the general population also do not have advance care plan, the ramifications for adults with I/DD may be direr. Future research should explore the effectiveness of the clinical guidelines for advanced care planning with adults with I/DD. Further research is also needed to identify the effect that the timing of these conversations has on clients and families. These conversations are important and we are doing a disservice to clients and families by not having them earlier. However, the question is when, how, who should be involved, and how to prepare and compensate staff.

Staff at all of the agencies reported a preference for keeping clients in their agency homes. However, clients in Agencies B-D more often remained in their homes than those in Agency A. Some clients who were not at the end of life, but acquired mobility limitations requiring a wheelchair also had to be transitioned out of their home because of a lack of accessible CILAs. As will be explored below under *systemic issues*, having inaccessible CILAs and being unable to get funding to make necessary modification seems to be one change that will become increasingly important. Unfortunately, this change requires the state to provide additional funding which seems unlikely.

Transitions are difficult on both clients and staff, yet the current system makes transitions almost inevitable. Why are there so many obstacles to keeping clients in their homes if this is the goal of both the state and the agency staff? The question becomes whether or not community service agencies are equipped to care for clients at the end of life, and what are the best care alternatives if they do not provide care? While staff may want to care for clients in their home, an agency may not want to assume the liability of providing this type of care. I believe it would be beneficial for agencies to determine whether or not this is a service they can and should provide and then be transparent about the limits of agency care. In the event that agencies are not able to provide this care, an appropriate protocol for transitions should be in place.

Client Understanding/Involvement

FG1 client understanding/involvement. Staff described working with clients who had "moderate" and "severe to profound" functional abilities. Clients were generally aware that they were ill, although in some cases it was challenging for staff to determine whether or not clients were aware. Staff described one case in which the client understood his illness even though his family believed that he did not. Staff described another client who could not speak or voice an opinion. Often clients were told about their condition by the agency staff in the day or residential program. In some cases, family asked staff to tell clients about their diagnoses. Staff said that other clients knew something was different after a client died even if they could not verbalize their feelings.

FG2 client understanding/involvement. Some clients had "no idea" what is going on when they were diagnosed with a life limiting condition and they did not understand the consequences being ill. Other clients communicated and had an understanding of their condition. Some clients were able to verbalize that they were going to die. In one case, staff felt that the client lived longer because:

> He knew the information, he knew it was hospice he was going to go on, and he lived, continued to live like he wanted to live, and even probably did some things that he wanted to do that prolonged, I think, his wanting to live more.

Sometimes staff were uncertain how much the client understood. For example, even though some clients were non-verbal:

> They might be communicating in a different manner or way that we don't comprehend or understand but they're still communicating something to how they feel, either through

> whatever, you know, mouthed out behavior or doing certain things, withdraw or whatever. But sometimes I think individuals who are profound, severe, do communicate, it's just that we don't know – we can't comprehend what they're trying to communicate in the small term, the short term, maybe long term.

The staff talked to the clients about what their physicians told them.

Some families did not want anyone to tell the client about his or her diagnosis. Families wanted to protect them or believed that the client could not tolerate knowing that they were dying. It was difficult for staff when families did not want them to tell the clients about their illness. In one case, the agency CEO became involved:

> The CEO talked to the family and said we have to tell this individual.…he was explained the severity of what was going on with him medically. Again, the family didn't want to do that, they really did not want that. And it was a hard, fought-out – so we had to get to the CEO to actually talk to the family.

The staff had a philosophy that "people with the right support knowing someone's level of comprehension and communication that they have the right to know what's going on with them medically." The staff reported cases in which families also did not want clients to be told about the death of a sibling, parent, or other family members.

A client's ability to participate in end-of-life decision making depended on his or her level of functioning. Some clients were unable to tell staff "I want this" at the end of life. Other clients with "mild" functional impairments were capable of understanding and participating in decision making. Some clients participated in their own end-of-life decision making. In some cases, staff assessed clients' capacity to consent to medical procedures. Staff described one client who was his own guardian, but who was incapable of making medical decisions for himself. Staff looked into pursuing guardianship for this client. According to staff, there was a “knowledge gap” about death for people with I/DD, for example, a client not understanding what cremation was.

FG3 client understanding/involvement. Some clients understood the concept of death and knew that they were at the end of life while other clients did not. Staff worked with some clients who had “severe intellectual disability.” According to staff, clients were “fact based” when discussing end of life and said things like, “I’m going to die…. What we going to have for dinner?” At end of life, clients understood that people were doing special things for them or that something was different even if they did not comprehend their diagnosis or the intellectual concept of death. A staff member described one client’s understanding of her cancer:

> Mentally she didn't know what was happening to her. But she knew she kept going to the doctor every day, getting chemo and getting the blood transfusions. And she would – she knew that something was going on with her body. Because I guess when she got pain, she would yell, “ow,” and she would grab herself. She prayed more. She had all the special prayers she would pray. She started praying more. But her behavior didn't change. She was the same – she used to go and kick her peer's door and tell her get up. So that didn't change at all.

According to staff, clients may have comprehended more than staff were aware of. Sometimes people, including family members, imposed limits on what the clients understood and there was a disconnect between what others thought clients could do and what they were actually capable of. Sometimes staff knew that the clients were capable of more than their families gave them credit for. For example, some families believed that clients did not know what they wanted for themselves at the end of life, but staff said that clients often knew what they wanted and could probably answer questions such as what music to play at their funeral. According to one staff member:

> There’s one client that sticks out in my mind and he was a male, and I would say late 30s. Pretty severe intellectual disability. Developmentally he was okay. But didn't really quite understand everything that was going on. And the complication of planning and like hearing the family wanting certain things. And believing that the client could only understand a certain set of ideas and beliefs. And-- but with work with the client we saw so much more.

Some clients became aggravated with family members who imposed limits on them and staff had to show family members what the client was able to do. Staff gave clients choices at the end of life. In one case, the client had trouble speaking, so staff and family had a system of interpreting what he wanted for his advance directive. Other clients were never told about their illnesses.

Surviving peers understood what it meant when a client died. Clients also knew when a staff member was ill and one client asked if the staff member would disappear. Some clients who were not ill also talked about their own death saying phrases like, “I know I’m going to heaven.”

IA client understanding/involvement. Staff described working with some clients who had “mild” to “moderate” functional abilities and other client who ranged from being “high-functioning and verbal” to “low cognitive level and nonverbal.” Some clients had a family or state appointed guardian and others were their own guardians. Staff reported that clients understood death in their own way and that they knew more than they could explain or communicate.

Sometimes people assumed that clients who were ill did not understand what was going on, however, staff reported that clients often knew their condition was serious before they were diagnosed. According to staff, some families understated the severity of the client's illness because they thought that clients were unable to cope with knowing that they were at the end of life. Staff advocated for giving clients direct information about their medical condition and asked clients questions about future planning during annual reviews. One staff member reported that the agency promoted person-centered planning. To the best of their abilities, staff told clients about their diagnosis and prognosis even though that was difficult. Staff reported that some clients understood their diagnosis and treatment and others did not. Also, depending on their level of understanding, some clients could answer questions and others were unable to make decisions about end of life. Staff were not sure that clients always made informed decisions or completely understood end-of-life planning. They had used the Aid to Capacity Evaluation with clients in the past.

In order to protect clients, some families downplayed the severity of a loved one's illness or did not tell the client at all. One family did not tell the client about a parent's illness because they did not want the client to become anxious or depressed. As the following case illustrates, clients knew their loved one was sick even if they were not told:

> There are definitely family members who do not want to tell the person…there was a situation not too long ago somebody who…understands at a very high level and his mother had just recently been diagnosed with a brain tumor. And the family's initial reaction was to not tell him. And in the meantime, she was having severe seizures and

> being hospitalized….I mean, like he already knows something's wrong….And so we very strongly advocated for him. They did come around-- you know, they took a little time to kind of digest the information themselves, and you know, work on her care. But then did tell him. So he was able to see her, he was able to be with family, you know, when she died.

Clients were upset when they were not told their loved one was sick because they did not get a chance to talk to them or say good-bye. Staff advocated for telling clients and encouraged families to be straightforward. One staff member recounted the story of a family who did not tell the client about her grandfather's death:

> This young woman had lived with her grandparents for years and years. And then they kept telling her her grandfather was asleep, and you know, that she couldn't see him or he was sick. They even, you know, would change a little bit what was said to her…and we kept saying, you know, it's not good. It's not healthy for her, you know, and if something -- and we really had to appeal to her grandma directly after awhile and just say, you know, if you get sick or some -- like, she's going to fear, you know like, what's happening. And she knows she's not seeing him present in her life anymore, you know.

Staff reported having difficulty with not telling clients about a loved one's illness when families decided this was best. Some families eventually told the clients about the illness.

IB-D client understanding/involvement. Staff described working with clients with "mild" and "profound" or "severe" functional abilities. Some clients understood their illness and others did not understand their diagnosis or why they were tired and in pain. Staff said that sometimes clients' lack of understanding was beneficial because they did not know they were dying or show signs of being ill. In other cases, a lack of understanding was a barrier to end-of-life care. Some clients were challenging to understand due to their limited communication abilities. According to one staff member, individuals with Down syndrome had had flatter, wider tongues which contributed to speech limitations. One staff member recounted a case in which a client's care was impacted because he was unable to articulate his pain:

> Maybe he would have been able to say I'm not feeling well before he was in his bed knocking on Heaven's door. I mean the next day after the fall he was up. He was completely normal [client's name] and then it was the next morning, I mean I'm sure he was feeling all kinds of different things I would think with an infection, he might have been able to tell someone.

In one agency, nurses initiated conversations about the end of life. In another agency, nurses, physicians, and family explained diagnoses to clients. Some families did not know how to explain the diagnosis because they wanted to protect the client.

Some clients were involved in making their own decisions, but others could not articulate their preferences. The staff and family determined whether clients should be involved in decision making. While staff listened to what clients wanted at the end of life there were many different opinions about what was best for them. Some clients were their own guardians, but most had a family or state appointed guardian. Planning was done by their family if the client was non-verbal. Parents were generally their children's' guardian. According to one staff member, as guardians aged, staff made sure that they were still capable of making decisions on the client's behalf. Some parents appointed co-guardians or transferred guardianship to aunts, uncles, cousins, and siblings. Other families rushed to find someone when the client's guardian died.

Staff had to intervene if clients were their own guardian, but could not make their own decisions.

While some clients understood that a peer was ill or had died others did not. Clients thought more about the present than what they wanted for their funeral. Some clients knew the purpose of a memorial service, but other clients only knew that refreshments would be served and not why they were attending. While some family said that clients' did not understand that a peer had died staff said that the clients did understand.

Investigator comments on client understanding/involvement. According to staff, a client's ability to participate in end-of-life decision making depended on their level of functioning, meaning that people with more "severe" impairments were less likely to be able to participate. Staff also noted that understanding is challenging to measure, in particular in adults with communication difficulties. I am uneasy with the idea that people with a label of "severe" functional abilities are all categorically unable to participate in end-of-life decision making. These labels can be inaccurate, or fail to take into account communication difficulties or life experience. Future research must examine the accuracy of these labels, how they are implemented, and what they mean in terms of decision making. I have no doubt that there are some people who will not be able to make end-of-life decisions, but given the historical marginalization of adults with I/DD it is important that we make multiple attempts at inclusion before determining that the individual is incapable of participation.

Agency staff described numerous cases in which families underestimated clients' abilities or protected them by not discussing their illnesses. Agency staff, conversely, generally believed that clients were capable and had a right to know about their medical conditions. My immediate inclination is to agree and empathasize with staff who think of families as overly protective. My experience both as an agency staff member in a day program and as a medical social worker likely influence my bias towards believing that staff were correct about families being overly protective. I need to be mindful of my potential bias and remember that these are only agency staff impressions of family member's motivations.

Working With Family/Guardian

FG1 working with family/guardian. Some families were actively involved in clients' care and others were not. In some cases, the family became involved when the client was at the end of life after having no or a limited relationship previously. Sometimes staff were more actively involved in clients' lives than their families were. Staff reported that some families did not honor the client's wishes while others provided clients with support.

Families didn't know what to do and looked to staff for answers when clients were at the end of life. Staff discussed end of life and supported the family. Staff and the client's families and/or guardians often worked well together, however sometimes the relationship was adversarial. For example, one staff member described working with state guardians:

> We can fight and say that, you know, you can go home with a clear conscious at the end of the day and say I fought it, but if there's a state guardian in place, they're not going to listen to anything. They're going to do what the state has deemed them to do.

Another staff member described a "battle" with one family:

> And I mean at the end of the day, the family, the guardian won that battle and for those of us who are caregivers at that time, we felt it was a battle, because we were truly in that person's life and they were there for holidays and it was a really tough time.

FG2 working with family/guardian. The staff worked with the families and provided services based on the client’s and family’s wishes. A lot of clients’ families were not involved in their end-of-life care. Other clients had families and/or guardians that were involved. The staff had this to say about the role of state guardians:

> If it’s [state guardian] – then they really are responsible for making all the arrangements, and it’s not like – they usually say what would you like? They just take over, and there’s some Potters field somewhere, and that’s it.

In some instances, there was conflict between what the family wanted and what the staff felt was best for the client. For example, what one client wanted for her funeral “became a big argument with her family, because what she wanted her family thought she was overspending and overdoing.” In this case, staff articulated that what the client wanted for her funeral should be her decision.

FG3 working with family/guardian. According to staff, some families were “good” because they did not interfere and let staff do what they thought was best. Other families were hard for staff to deal with as illustrated in the following staff member quote:

> If you're in a setting where there's like family members around, and people that have been very emotionally involved in that person's life and care for a very long time, it can get at times pretty ugly, depending on how well they're listening to the person.

Some families did not engage with clients the way that staff did and they did not know what the clients wanted at the end of life. One staff member also reported issues when working with unrelated guardians:

> I've just seen a lot of very strong decisions made. I think death brings like for different people – I saw a lot of guardians that weren't related that really were probably

> overstepping boundaries is what I'm trying to say. And I think death tends to do that to people. Want to control. Because they're out of control. So that does happen. A lot. Yeah. And I think probably even more so with this population. Because of the – you know, high concern for care and high concern for them getting everything that they possibly can and want.

IA working with family/guardian. Some families maintained regular contact with the clients. Other families only became involved when clients were at the end of life. Sometimes clients and/or family members did not want contact and in some cases they never reconnected. Staff reported that it was difficult to work with families who had no previous involvement with clients and then suddenly became involved at the end of life because they were often out of touch with the clients' wishes. One staff member explained the difficulty inherent in working with these families:

> The hard thing that still comes into play is sometimes where there is, you know, family members that are making decisions, and have been very absent from somebody's life and is not, you know, um, really honoring their friends and their relationships. And, you know, just because they really haven't had contact-- I mean, it's not usually family members who have a lot of contact, it's usually those that have been very absent and now suddenly are back in this person's life. So, um, so I think those are the things we struggle with most.

State guardians had huge caseloads, so depending on the guardian, some visited clients while others never communicated with staff or showed up to meetings. According to one staff member, state guardians were more likely to be involved with high-profile cases, for example if something happened to the client at the nursing home. If the case was not high profile the case was not going to be looked at and guardian's response was, "they're eating, they're living, nothing medically, okay, next." Some families and/or guardians were not receptive to staff and wanted something done a particular way even if it contradicted how the staff preferred to do it. Sometimes staff felt devalued when family members moved or buried clients far away.

Staff supported family members at the end of life and many families were grateful for the care the client received. One staff member described the story of a family that appreciated the staff support:

> His family later said that they were so… taken by his residential staff and my involvement. And we also had other clients visit him, and you know-- but they really saw how much, you know, that brought not only to him, but really how the family felt. Because they realize that, you know, that all their places that they placed him over the years-- and you know, it really became apparent to them-- how good his care was, and how, you know, much of a life he really had. And, you know, and it was really, you know, a lot of healing and closure for them.

Some staff continued to work with clients' families after clients had transitioned out of the agency. For example, one staff member assisted a client's sister in making sure the client received appropriate services in her nursing home and another staff member drove a client's mother to visit him. Working with families also presented challenges for staff. Some families did not recognize the progress clients made and others complained about the client's care. According to staff, sometimes they only received negative feedback and felt that families did not appreciate the work that they did.

IB-D working with family/guardian. Staff at one agency said there was a lot of participation from families. Another agency had a family association and website, but did not provide formal counseling services for families. The third agency used to have a social service person work with families when clients were at the end of life, but they did not anymore. Some families relied on staff support since they had been present in each other's lives for many years. These families thought of staff as part of their family and considered the agency a second home. Families and staff communicated with one another when they noticed signs of functional decline, for example, a client exhibiting signs of dementia or forgetting to take medication.

Some families were actively involved in the clients' lives and participated in their end-of-life care. Other families were not present during the end of life or after the client died. According to one staff member, some families wanted to say good-bye even when they had not been in contact. According to another staff member, family members who willingly took over guardianship were sometimes more invested than parents:

> I feel at least in my experience that whenever an aunt, or an uncle, or a cousin willingly takes over guardianship they happen to be more invested or involved in the person's life. Whereas some parents where they just kind of I guess maybe in their mind they were dumped with the responsibility of being a guardian, they're not necessarily as involved.

Staff asked that families participate whenever clients went to the hospital. When families were out-of-town or unavailable staff would go to the hospital until the family arrived. Two staff members described a case in which the family did not come to the hospital until the client was in cardiac arrest despite their attempts at contacting the family several times over two days. This client died in the hospital and the family immediately ceased all communication with staff. One staff member described what she wanted to say to the family after they ceased contact:

> One resident that passed where we kind of got shut out, it was- and I'm being selfish….But I just want them to understand that we take care of them. We help them get dressed. We help them bathe. We are there for them whenever they needed anything and we would like to be there at that time….or at least say goodbye. We do care. And people that have this kind of job aren't here- we choose to be here. It's not an easy job….But saying that to families is hard.…But we've been lucky where most of our families have made us a part of their family too.

Staff asked families who they wanted to be present with the clients when they were at the end of life. Sometimes family members and staff took shifts staying at the client's bed side. At one agency, the nurses and qualified intellectual disabilities professionals were closely involved with families when clients were at the end of life. Another agency had a family association and families supported each other when a client was at the end of life.

Sometimes relationships with family and/or guardians were awkward and staff had trouble respecting the family's decisions. For example, some families disagree with staff about a client's diagnosis of dementia. Staff perceived some families as not caring and were frustrated when they did not show up to annual meetings or had no contact with the client for decades. One staff member described a guardian who had no contact with the client, but came to the agency after he died and said, "I don't need his possessions. I just want to know if there is money left in the bank."

Some families chose to maintain contact with staff and clients at the agencies after a client died and others did not. According to one staff member, at her agency families chose to remain connected after a client died:

> When people come to [agency] and you become part of the family association, that's a network of friends that you don't lose just because you don't have a child here anymore. I think their heart is still with [agency] and they want to be a part of that ongoing network which is really nice. I know families that have continued to stay in contact with some of the key staff members that might have cared for their child when they were dying.

Investigator comments on working with family/guardian. I am interested in further exploring the dynamic between families and clients and why some families and clients maintain close, active relationships and others choose to have limited or no communication. While I don't dispute that there are some clients and families for whom having no relationship is perhaps the best option, there may be other families that lose contact for reasons that should be addressed.

I found it disheartening that while staff discussed some positive experiences with families, they more often cited negative interactions. In conducting the individual interviews and observing the focus groups, it appeared that the staff had an "us" vs. "them" relationship with families. I also found this to be the case when I worked with individuals with I/DD. Although some families may be difficult to work with, I think it is important to facilitate the relationships between family, clients, and staff when appropriate. Improving relationships between family and staff may help make end-of-life care less stressful for everyone involved.

More research is needed to explore these complex relationships before clients become ill because it is likely that the communication breakdown occurs years or decades prior. Further research may indicate that the relationships between clients, family, and staff differ based on the agency. For example, some agencies may focus more on family involvement than others. I also found the staff experiences with state appointed guardians to be unsettling and believe that this is also an area that requires further exploration, in particular with regards to guardians making medical and end-of-life decisions.

I am intrigued by the notion that the residential agency staff actually live with the clients and are intimately involved in their day-to-day lives, yet have no legal input when clients are ill or at the end of life. While I don’t necessarily think that staff should have any legal input, I do empathasize with staff who are watching families make decisions they believe are antithetical to what the client wants. This issue is complex and brings up a number of questions including, what qualifies as “knowing” the client well enough to productively offer input? Does knowing the client mean anything when the staff has no legal standing? Should staff have an expanded role in end-of-life decision making? If so, which staff should be involved? How would these staff be involved? Would agencies want to shoulder the responsibility of staff being involved in decision making?

Staff Experience/Role

FG1 staff experience/role. The staff had worked at the agency in the day, community, and residential programs for many years and often in multiple, different positions including direct care, case management, and program management and administration. The focus group participants had experienced the death of a client, but other agency staff members had not. According to staff, there was a lot of fear surrounding talking about death and dying and other staff members thought that was taboo. Others looked to staff for answers, but staff had to look for them too. Some staff educated others in talking about death or shared what they learned after attending grief and loss training.

Staff operated as a family for clients. One staff member said, “I know it’s unprofessional but we do operate as a family here.” According to another staff member:

> You know, if you have family, your family might be there to support your need when you have – and when the doctor has determined you won't be around long and you need a certain level of care and I think what we find here with our participants sometimes is that there's no family to look out for the individual and so we are that family, and so we have to work to make sure that all their needs are met and is this a good facility for them to go to to convalesce or to get treatment while they're making their transitions. So I guess if you think about what would be different for people with disabilities as opposed to folks who don't have, that's one of the things that I see, that as an agency, we become the family in making decisions that a family would most likely make.

The program director, manager, case manager, advocates, direct care staff and other staff in both the day and residential programs supported clients at the end of life. Staff said that their role when clients were at the end of life was to support, advocate, help, and make sure clients’ needs were met. Staff also helped some clients with moving and visited clients who transitioned out of the agency. Staff described working with clients at the end of life as “overwhelming”, “frustrating”, and “horrible.” Staff also said that they had to make difficult decisions, emotions were high and that they did not have a lot of time to process information. Staff discussed the importance of having one-on-one moments with dying clients, but said they don’t always get to have those. Staff also said that sometimes things went smoothly and they felt fortunate to have supported the client at the end of life. In addition to caring for the dying client, staff supported other clients and staff members. Staff took clients to visit their peers at the end of life.

FG2 staff experience/role. The staff had worked at the agency for a number of years in a variety of capacities including respite work, direct care, management, case management, administration, day program, and mental health. Some staff worked in several different positions, such as direct care and then management.

Staff reported that seeing clients decline was difficult. When speaking about a case in which a client stayed in their agency home with hospice care, a staff member remarked that they "spent so much time on how to care for someone dying than actually people who are living." At the end of life, staff focused on client's enjoyment and made sure they were comfortable. Staff advocated for and supported clients in their homes and workshops. The direct care staff made sure that everything was taken care of and clients' needs were met. Staff counseled clients at the end of life and helped "adjust red tape" that came with the program and working with new physicians. Staff were also responsible for telling peers when a client was at the end-of-life. Staff were nervous when caring for clients with medical needs because they did not have medical support in agency homes. Although staff were "stretched very thin", they were good at working with clients even without end-of-life training. Staff learned a lot on the job and one staff member took a religious course that included end of life on her own.

In addition to caring for clients, the staff cared about them and said that they were the client's family. Staff tried to make the best decisions possible for clients by talking to one another and consulting with agency administrators when they did not know what to do. Staff did not have medical power of attorney and were not involved in medical decision making for clients. They were not sure if there were any scenarios in which staff could make decisions for clients. As illustrated below, while staff were not involved in decision making they were frequently responsible for making final arrangements even when the client had a guardian:

> I know we make like the formal – or the funeral arrangements for them. We make sure that all of our clients have…some type of funeral arrangements. And a lot of times – the families are not – don't want to have anything to do with it…or even with the body – They just want it handled…afterwards or anything like that. So it's kind of like you're up in the air with what you even do – like I had one over at [residence], we made the arrangements for his cremation and everything else.

When clients were in-patient staff helped them communicate with hospital staff. After clients transitioned out of the agency, staff visited them and brought their peers.

FG3 staff experience/role. Some staff had worked at the agency less than one year and others had been there for many years. While some staff had not experienced any client deaths at this agency, other staff had experienced a number and one death was recent. One staff member sought outside training. Some staff were told explicitly not to become too close to clients, but others were not. The staff reported that sometimes there is "no feeling" from the agency after a client dies. For example, one staff member found out a client died and immediately had to take a medication exam.

Staff were advocates for clients, made them comfortable, and alerted the appropriate people if something was wrong. Some staff talked to the clients about death. Staff took clients to physician appointments and the hospital when needed. Staff were limited when caring for clients at the end of life because they were unable to give medications and had no legal authority to decide if clients could stay in the agency or had to be transitioned out to a nursing home. When clients transitioned out of the agency the staff visited them.

Staff cared about the clients and said they were like family. Clients also referred their peers and the staff as their family. Staff spent more time with clients than at home so when clients were at the end of life it was like losing a family member. Staff knew the “little things” about clients, for example, how they liked their coffee or how something might affect them. When clients were at the end of life staff worried more than the clients did.

IA staff experience/role. According to staff, they had limited experience caring for clients at the end of life. There were other staff at the agency who had no experience providing end-of-life care. One staff member attributed the lack of experience to high staff turnover. Staff in residential care worked with more clients at the end of life than staff in other areas. When clients were at the end of life the residential department was in control and the agency administration took a supportive role. Some staff sought outside training opportunities, or read books on end of life and shared the information with colleagues.

Staff knew how to provide end-of-life care and how to handle emergencies. When they were uncertain about what to do they consulted with the agency’s risk committee. At the end of life, multiple staff members were involved with the clients’ care including the agency nurse, residential staff, day program staff, the director of residential services, and managers. Staff in the residential and day programs communicated well with one another.

Staff provided clients at the end of life with love, warmth, and compassion. Staff knew the clients well and went “out of their way” for them. They did everything they could for clients including: talking to them about the end of life; providing support and counseling; monitoring how they were doing; looking out for their interests; and keeping them active by engaging them in educational activities and scrapbooking. Staff wanted to help clients make decisions but they did not know if they had any legal standing. Staff sometimes made funeral and burial arrangements for clients. In one case, a client's brother asked staff to handle the final arrangements. Staff explained burial or cremation options and helped clients find the least expensive option.

Even when they were far away, staff visited clients in nursing homes and hospitals after they were transitioned out of the agency. When clients were inpatients in hospitals staff visited them so they had someone familiar around. Staff were also protective of clients in nursing homes. While caring for clients at the end of life, staff also provided support to their peers. Staff explained to peers what was happening and made sure that peers were able to visit clients in their agency residences. Staff also took their peers to visit clients after they had been transitioned out of the agency. Clients received counseling in the day program if needed.

Staff described clients as their family. Some clients had been at the agency for a long time and did not have any family other than the agency staff. Staff had a hard time when they realized clients were at the end of life. Everybody dealt with caring for clients in their own ways and staff were able to care for the clients and let their "emotions go" afterwards. Some staff found providing hospice services rewarding. Staff had a support system at the agency and could talk to house managers, directors, and supervisors. Other people were brought in if necessary. Staff talked to one another about how caring for clients at the end of life affected them. According to one staff member, staff knew that they were not alone because:

> Enough people have had experience with situations that, you know, there's somebody nearby or another residence, or a manager-- you know, somebody who's dealt with it so that some of that initial, like you're all alone and there's so much to figure out and there's

> so much happening-- and you know, getting other clients through it too, or like what's going to happen. You know, are we going to be able to provide support for somebody here. So a lot of the discussion is really open.

IB-D staff experience/role. Only a few staff described how long they had been at the agency and what their position was. Two staff members said they had worked in the agency for decades, some worked in CILAs and one staff member was an administrator. One staff member said that the qualified intellectual disabilities professionals did not have a lot of personal experience with aging because they were mostly young and just out of college. These professionals were case managers and were responsible for facilitating team meetings, getting consent forms signed, taking clients to the physician, and maintaining the client's clinical chart. Staff experience caring for adults at the end of life was variable. At one agency, staff reported seeing many people with Down's syndrome and dementia in the last five years. However, staff also described colleagues with no personal or professional experiences with end of life. According to two staff members, a colleague who had never experienced death wanted to be involved whereas some older staff were "almost cold" after seeing so many people at the end of life. Although each case was different, staff said that sometimes the end of life was "hectic."

When caring for adults at the end of life, staff had multiple roles including: coordinating care with agency health care providers; recognizing medical illness; providing physical and emotional care; making funeral arrangements; and providing care to other clients. Staff coordinated with agency health professionals, such as nurses and dieticians. Staff alerted the nurses when they noticed clients showing signs of illness including bed sores, trouble breathing, and seizures. Agency nurses were receptive to staff and proficient at caring for clients. In cases of emergency, staff brought the medical chart and accompanied clients to the hospital because clients could not always tell healthcare providers what was wrong.

End-of-life care required a team approach and staff were committed to providing the best possible care. Staff provided any services the clients needed and physically cared for the client by assisting with toileting and giving medications. Staff also kept clients safe, made them as comfortable as possible, and advocated for them. Staff knew the clients' well and were aware of their quirks, habits, how to make them smile, and their likes and dislikes. At two agencies, the direct service professionals worked closely with the clients. At the third agency, the direct service professionals were by the client's side, but did not provide any actual care at the end of life. At this agency, care was provided by agency nurses and a physician and the agency administrators provided additional support to the clients and their families. When clients in this agency could not attend the day program staff provided music and sensory treatment in their home. At one agency, when clients did not have any final arrangements in place, the director of the residential program made the arrangements.

Staff were close to the clients. Staff from two agencies referred to clients as being part of their family, or being like family. According to one staff member:

> We consider them our family. Yes we have a job to do, but you're with them every day, caring for them. They become close to you just as, you know, family members. You see them more than you do your own family members so it's a great loss and you want to be there just as you would if your sister or your mother or your father. It was very important for us to be there.

In some cases, staff and peers assumed the role of the family that was absent from the client's life. Staff remained involved with clients for years after they transitioned out of the agencies. Staff called or visited clients in hospitals, nursing homes, hospices, and rehabilitation facilities. Staff also took peers to visit the client at the end of life. Staff supported other clients by having house meetings and discussing the client at the end of life.

At one agency, the administration was sensitive to staffs' experiences. At another agency, staff were told by the administration that they were at the agency to do a job and not to be the client's friends or family. One staff member had difficulty saying this is my job and this is not my family member. One staff member described why the staff wanted to be present despite the supervisor telling her to go home:

> We spend days there….I can't say that they [agency administrators] really support us doing it but they don't not support us either. I mean, with the first person that died, we were there literally for three days, spent the night on the couch, took shifts sitting with her, sat in the room with her, whatever. And her sister was there too, so we all kind of took shifts. And our supervisor was telling us to go home and we said no. It's what we needed to do for her and for us. So, I mean, of course they supported it because, I mean, they'd be cruel and heartless if they didn't. But on the same note, they, you know, trying to tell us to go home.

Staff at this agency helped and supported one another by keeping everyone updated about the client's condition and telling other staff when to come and say their goodbyes. Staff were also not allowed to touch the clients which was hard because they wanted to give the clients hugs and comfort them.

Investigator comments on staff experience/role. Although the literature discussed high staff turnover in social service agencies, most of the staff who participated in this study had worked at their agency for many years. The staff described having multiple and complex roles caring for both clients at the end of life and their peers, as well as providing support to families. I was not surprised when the staff referred to the clients as family due to the intimate care provided and because the staff had often cared for the clients for many years. However, this brought up a number of questions about whether or not viewing clients as family is beneficial for the clients or the staff, and who exactly was “like family.” Was everyone at the agency “like family” or just a few of the residential staff? Does the intimate nature of these relationships blur the lines between the personal and the professional? What are the pros and cons for the clients, their families, and the agency staff? How does the dynamic between clients and agency staff impact the staffs’ perceptions of families? I am interested in further exploring the literature on how hospice caregivers are prepared to see if their training would be applicable for residential agency staff. I am wondering how individuals specifically trained to do end-of-life care are able to maintain a professional relationship with clients or if there is also sometimes a blur between the personal and professional. While all agency staff would benefit from end-of-life training, this may not be a realistic goal given agency and funding constraints.

Throughout the process of analyzing the data I was continually struck by the idea of whether or not end-of-life care should be provided by agency staff. While I am not questioning staffs’ motivations or competence, I am thinking more in terms of putting direct care agency staff in a position of doing hospice work without any training or additional compensation. Is it fair to expect direct care staff to provide this type of care and cope with their own existential issues while expecting them to also care for other clients? While some staff welcomed the opportunity to provide end-of-life care, others were overwhelmed and found the process to be difficult and frustrating. Staff clearly need more support and training than they are currently receiving from their agencies. However, the question becomes how are agencies supposed to afford providing extra supports, such as counseling, or time off to grieve, or extra training?

This section also presented an interesting point that while staff have limited or no input in making end-of-life decisions, they are often expected to make funeral and burial arrangements even when the clients have family guardians. I was previously unaware of this phenomenon and I am not sure if this is reflective of a majority of agencies. I am interested in why final arrangements became the responsibility of the staff and what this implied about the importance of adults with I/DD. I am curious as to why families would not view this as their obligation.

External Professional Caregivers

FG1 external professional caregivers. Although it was often staff who told the client about his or her illness, staff reported working with one doctor that "really, had a lot of compassion and understanding of persons with disabilities, so it was different. Um…he was able to explain to the individual what was going on with him and his medical condition." Staff described a medical team that supported the client attending the day program even though the client had a do not resuscitate order.

One staff member said that nursing home settings depended, but they could be "a dark, lonely place."

FG2 external professional caregivers. Staff worked with clients' physicians and were instrumental in supporting clients, as described in the following case:

> And I remember one of ours at [hospital] was deaf, mute, and blind, and he was going

> through all that stuff. And it was really difficult for the hospital, but with us there we could communicate with him, and he did very well. Because he had no idea what was going on and how do you explain to this person what was going on.

In another case, the physician told the staff the client needed a guardian and asked the staff for their permission to operate on the client. The staff could not give permission so the hospital made a decision on the client's behalf. According to staff, clients' experienced both misdiagnosis and delayed diagnosis. Staff were not always told the cause of death after client died even when an autopsy was performed. In some cases staff were informed but the cause of death was unprofessional sounding, for example, "bad brain."

The staff reported positive experiences working with hospice providers and called them "wonderful" and said that they "cared for [the client] tremendously." Hospice caregivers helped the agency staff and coordinated the clients' care well. The *Five Wishes* booklets were for sale from the hospice. Staff had a different experience working with nursing homes. Staff called the communication with nursing homes "poor" and "difficult." One staff member said the following about nursing homes, "I think that some institutions greatly diminish how much you can care about a person with an intellectual disability and they dismiss the relationships that they have built along the way." According to another staff member, "sometimes we don't even know they're really, really ill until we get the call that says they're gone. And that's just poor communication with some of the nursing homes that I've worked with."

FG3 external professional caregivers. The staff only discussed three external caregivers or facilities. First, staff said that there was a volunteer that worked with a client and made the client's day. Second, staff noted that the *Five Wishes* document was used by one hospice agency.

Third, one staff member said that she was “not saying they [nursing home] didn't do a good job.”

IA external professional caregivers. Staff described interactions with health care providers in hospitals, hospices, and nursing homes. Staff took clients to physician appointments and worked with healthcare providers when clients were in the hospital. The following case is one example of agency staff and healthcare providers successfully working together:

> We had a guy at [hospital] who was blind, deaf and mute.…we tried to have someone there 16 hours a day….And then when they had to do x-rays or anything, we would be there with him, and he would do fine if we were there. If we weren't there, then he would be acting out.…We couldn't do it 24 hours a day…so that-- at night they would more or less strap him down because he would be pulling everything out. You know….The staff there had no idea how to deal with someone like that where they had no way of communicating. So you know, we would take it upon us to try to explain to them-- you know, like they would get all whacked out when he would touch their head or their face. And we're going like, that's okay. Then he knows if he's touched you before, then he's okay because you have been here before. But they would get freaked out by that. It's like he's not going to hit you, he’s not going to hurt you. He's just seeing who's here. And they were receptive to that. And, you know, it just all depends on how you present things and-- you know, most of the time they're very willing to listen to the staff.

Sometimes clients’ experiences with healthcare providers were not positive. Staff reported that care was impacted by healthcare providers’ perceptions of people with I/DD. The level of client functioning also impacted care and some clients were unable to articulate where their pain was. Staff reported incidences of clients being improperly medicated, over-medicated, and acquiring preventable conditions because of poor medical care. One staff member reported that a physician automatically assumed that a client with Down syndrome was regressing due to Alzheimer's disease. One staff member reported witnessing the following exchanges between clients and healthcare providers:

> I've seen things in hospital settings, from my own personal experience, where they [healthcare providers] necessarily won't talk to the person [client] directly or they'll talk about them like they're not in the room, because they don't think they can understand what's happening, or maybe even react appropriately.

Staff reported that healthcare providers also used different language when talking to clients.

Staff also worked with providers in hospices, ICF/DDs, nursing homes, and rehabilitation facilities if clients were transitioned out of the agency. Staff had positive experiences with hospice and said that people with I/DD were treated equally by the providers. Staff were uncertain if hospice had specific people who worked with clients with I/DD. Staff did not describe their experiences with ICF/DDs, but noted that some were run by agencies providing care to people with I/DD and others were independently run. According to staff, some of the agency run ICF/DDs were excellent.

After client's transitioned to a nursing home or rehabilitation facility, staff worked with medical, social work, and nursing providers in order to help them understand and become familiar with the clients. Staff was unaware of any nursing homes that specialized in caring for adults with I/DD. Some nursing home staff were receptive to agency staffs' input, but others did not understand why agency staff remained involved with clients. According to staff, nursing homes and rehabilitation facilities were for-profit businesses and were concerned with filling their beds, thus the quality of care clients received in nursing homes was dependent on the facility. Some nursing homes treated clients well and others did not. According to staff, some providers in nursing homes were mean and were not concerned about clients getting quality care. These staff members assumed they did not have to care for clients as well as they would for people without I/DD. Once in the nursing home, clients could rarely keep their own primary care physician and they were cared for by the nursing home's physician who might have 200 patients.

Nursing home staff did not always treat clients' families well. However, clients who had family or agency staff involved with their care were more likely to be treated well by nursing home staff than clients who did not have these supports. The more active and vocal the family and/or guardian was the more receptive the nursing home staff was, in particular if the family and/or guardian indicated they would call the office of state guardian or the Department of Public Health. Staff also reported having poor communication with nursing homes because several times they were not told that a client had died until a week later. Staff reported feeling "sad" and "disappointed" when they were not informed that a client had died. According to one staff member, "it's almost like they [clients] didn't count enough" for the hospital or nursing home staff to tell agency staff that the client had died.

In addition to providing medical care, sometimes primary care physicians were instrumental in determining where clients resided and if they could attend the day program. Physicians had input into whether clients could be cared for at the agency with hospice or if they needed to be transitioned out of the agency. Physicians also determined whether or not clients at the end of life were medically able to return to the agency after receiving care elsewhere. In one case, the physician determined that an 80 year-old client should stay in her agency home with staff during the day and retire from the day program because of the stairs. According to one staff member, the physician's input was critical, provided s/he used the appropriate wording:

> If a person is at home, and needs assistance at home, then-- and the physician has the information written up correctly to a point that we [agency staff] can argue with the State saying, no, then we will get the funding, without any question….But again, the hardest thing is to get the doctor to write in a language that-- in this case scenario, that the reason why this person is okay at home but not okay at a other day program facilities.

With the assistance of the physician, staff were able to obtain at-home funding from the state so that the 80 year-old client could stay at home during the day.

IB-D external professional caregivers. At one agency, staff had good relationships with the clients' physicians. Psychiatrists also saw clients at this agency but they did not do much direct treatment. Since the psychiatrists were minimally compensated for their services, they relied on staff for information about the clients. This agency also had volunteers who helped staff and clients. Another agency had a physician who regularly came to the agency to read labs and sign paperwork. According to one staff member, staff at the third agency had difficulty locating physicians and dentists who were willing to work with adults with I/DD. In addition to providing medical care, sometimes physicians influenced whether clients at the end of life could attend the day program and where these clients resided. Staff at two agencies discussed working with hospices and one staff member described working with nursing homes. According to this staff member, there were a few nursing homes that were able to work with adults with I/DD, but clients with Alzheimer's disease and Down syndrome were difficult for nursing home staff.

Clients went to hospitals close to their respective agencies. Some of the hospitals were good and others were not. Staff helped healthcare providers in hospitals communicate with clients and encouraged providers to talk directly to them. According to staff at one agency, healthcare providers had antiquated ideas about people with disabilities and sometimes appeared to be nervous around them. As one staff member from this agency explained, these assumptions affected the client's care:

> The doctors and nurses often themselves get very nervous and … scared that something is going to happen to them. They often look at me with this look of fear like are they going to hurt me? Are they going to hit me? A lot of times they're just trying to tell the doctor something and yes, it can be scary because they might not be pronouncing words or they're pointing their finger at them but they're trying to tell them something is wrong and instead the doctor keeps his distance and oh, okay, I'll go order a test instead of trying to become their friend and gaining their trust they just assume that this person has problems and I'm going to get hurt.

Staff members from this agency also stated that the quality of health care depended on the individual provider:

> Participant A: It just depends on the day, the shift, the bed. Some people [healthcare providers] are just excellent and you just want to take them back with you and then some it's a nightmare.
>
> Participant B: And sometimes and it's happened more than once where we are trying to say no, something is still not right, something is not right….And they won't necessarily listen to us and I'm thinking of the situation with [client] where they release her and we bring her home and we're calling 911 again because she's having this seizure.

One staff member also described two cases in which the clients' care was impacted because they had I/DD:

> She [client A] is very stubborn, strong willed person and she would tell you exactly what she wanted to tell you. I think it was easier to say goodbye, have a good day than try and talk to her and keep her in the bed and not trying to run out the door. We've done all we can. We're going to wash our hands of this now. The only other hospital thing is with [client B]….He broke his nose but the x-ray didn't show that something up here had flapped open causing an infection. When he was brought to the hospital and he coded in the ambulance, the hospital told us they did a CT, that it's mandatory if you fall and hit your head that they do a CT and we fought with them. I was sitting two days ago in the emergency room with you and you didn't do it. And it was a battle. Maybe that could have helped him and he would have still been here.

According to one staff member at another agency, poor medical care contributed to client's decline.

Staff at two of the agencies worked well with hospice providers and reported having positive experiences saying that they were "great," "phenomenal," "wonderful," and a "fabulous support." Sometimes the staff and the hospice caregivers learned from each other since the hospice providers had no prior experience with adults with I/DD and staff had limited experience working with people at the end of life. The hospices sent providers from nursing, clergy, and social work. At one agency, hospice providers taught classes for the staff. When clients were in hospice the staff provided clients with a lot of activities and interactions with others as opposed to lying in bed. At another agency, the hospice sent volunteers to entertain and talk to the other clients when their peer was at the end of life. This hospice also gave staff a book that outlined what may happen to the clients at the very end, for example they might have visions or no longer need to eat. The staff reported one negative experience with a certified nursing assistant who came at the wrong time and was insensitive to the clients. The staff called the hospice and they no longer sent this nursing assistant to care for the client. Staff at the third agency did not discuss working with hospice, but said that a speaker from a local hospital talked to the staff about grief and loss.

Investigator comments on external professional caregivers. Staff interacted with health care providers in hospitals, hospices, and nursing homes. Too often these interactions were described as being negative. There is a clear need for improved communication between clients and health care providers, and between health care providers and agency staff and/or family caregivers. Improved communication is critical because physicians impact both medical care and are instrumental in determining where clients reside and what services they are eligible for. There is also a need for improved access to medical, dental, and psychiatric healthcare providers. This section reifies the need for research to determine how to best educate health care providers and how to make this training attractive and accessible to busy providers who often do not see many clients with disabilities. Ideally, better communication and training will improve some of the inconsistent treatment that clients receive.

Staff also reported predominately negative interactions with nursing home staff. Since some clients are moved to nursing homes for both rehabilitation and end-of-life care future research must begin to explore client experiences in these facilities and find out where improvements are needed. Surprisingly, staff did not mention experiences with ICF/DDs, however future research on end-of-life care should include ICF/DD staff.

I am excited that staff reported positive experiences working with hospice providers because my two areas of interest are end-of-life and disability. I was not surprised to find that agency staff seemed to respond well to palliative care providers. The palliative care literature and disability literature share a similar ideology and focus regarding how one should approach working with individuals. In 2014, I was a member of an expert panel of scholars from several different disciplines specializing in the areas of disability and end of life. During this panel we discussed end-of-life care for adults with I/DD and all participants were eager for further exploration and collaboration.

Systemic Issues

FG1 systemic issues. Many social service agencies had issues with state funding. Funding impacted both the formation of an agency policy and the agency's ability to provide care to clients at the end of life. According to one staff member:

> There was a team that worked quite diligently on a grief and loss policy for the agency, and at the time a couple of things that came up then was just like if certain requirements were put in place by the agency, then how would we fund those requirements? So there were a lot of things that like [other participant] brought up that we – we would have things that we would love to do, but how do we make that happen? Because you know we can't just pull money out of our hat to do it.

State funding also prevented at least one client from receiving in-home hospice care. One staff member recounted the story:

> Funding becomes a big end-of-life issue. We could not sign on for hospice for that

> person, so that they could stay within the home that they had known all this time because they were already funded this way. If they needed that kind of care, then they needed to go into a nursing home. It was like we were stuck between a rock and a hard place of trying to help them to stay with the family and the house that they knew, and yet the state was saying, no, you can't have this. We can't fund this, and yet the program didn't have medical staff in there that could take care of the issues that needed to be taken care of. So I think that – I'm sure we're not the only agency that's had that issue when it's come to what they call double-dipping (laughter) in the state's little till of trying to help out clients.

In addition to state funding issues, staff described legal concerns they had when working with a client at the end of life who had a do not resuscitate order and wanted to attend the day program. The staff in the day program was concerned about what they should do if the client choked.

FG2 systemic issues. According to staff, the agency had limited resources and training was, "just a question of resources." Aging clients put a strain on the program and caring for them was challenging. When the client did not have family involved and risky decisions needed to be made staff talked with legal counsel. According one staff member:

> I guess legally we're afraid of being sued…And having our reputation tarnished… Because you just – you can't always forecast who is going to sue you and you don't want to make decisions based on that. But a lot of times we do think we'd better throw this past someone else who is higher up than we are, to like [administrator], to make the final decision. So I think if it were something where we were the primary and there wasn't

> family and we were maybe making some decisions that we thought were risky we'd throw in like a vice president.

The staff reported circumstances that necessitated working with other state or federal organizations. The death of some clients required a death investigation that cast suspicion on the agency and involved police and possibly the FBI. For example, when a client under 21 years-old was rushed to the hospital and died the police were called. One staff member described another case in which one client caused the death of another:

> But also, there's one case, I just remember now, that of actually another client causing a death of a client, pushed down the stairs. And the individual had head injuries that led to a person's death….Because you did have police, [state agency], and the alphabet, you know? KGB, FBI, you know, everything that came out. And that really I mean, as [other participant] said, they were under scrutiny up the yahoo. I mean it was, I mean very much scrutiny on everything and why do you have this client here, you knew the client was violent, or dah, dah, dah? Who was watching this client? How exactly did they fall down? And what did you do next? And I mean it was constant. And that's very, very draining already, and you're going through the grieving process….I think for six months, until things got down to normal, you know?

In another case, a client died in the room with his roommate. As described by two staff members, while they did not have a lot of issues with the police in this case, the process was challenging:

> Participant A: But the first thing that you're right, goes to your mind, you know, you have to fill this out, and did you do everything okay….And it takes them four months to decide if you're guilty or not…Yeah, that's awful.

Participant B: The [police] tape stays up forever.

Issues surrounding decision making for clients who were their own guardians, but who were unable to make decisions for themselves also necessitated working with the state legal system. In one case, the staff looked into guardianship for a client and said the following of the process:

> Participant A: It – I didn't realize it was so hard. It's been years, $9,000, it's like –
>
> Participant B: And that's to get the [Office of State Guardian] to take the person over, is that what you're saying?
>
> Participant A: They don't touch it.
>
> Participant C: Right, because the person needs to go through court and declare them incompetent and stuff. And when you call the [Office of State Guardian], you have to hire a lawyer….To get the estimate from the lawyer, 300 hours of $30 an hour, (group laughter) which was $9,000….So we're investigating now a different firm of lawyers (group laughter) to see if we can get them any cheaper.

According to staff, becoming a clients' medical power of attorney would have been cheaper than getting them a guardian. Staff were also hesitant to have a client declared incompetent because that meant taking away the client's right to be his own guardian and it was hard to get rid of a guardian.

FG3 systemic issues. Staff were uncertain how they could get the legal authority to help clients. Staff also said that death investigations made the client's death more complicated.

IA systemic issues. Funding was identified as a barrier to client care and agency service offerings. For example, the state would not pay for any additional staff training and the agency had closed two homes that provided nursing care because they were too expensive to keep open. Staff also reported that as a result of funding cuts that the agency would probably not care for clients with medical needs in the future. The staff noted that end-of-life care also presented liability challenges for the agency. For example, when one client with a do not resuscitate order attended the day program staff feared what would happen if the client choked.

CILAs were overseen by the Department of Human Services. The agency was required to comply with the state regulations. For example, all clients were required to be out of their home during the day and each person had to have an individual service plan addressing four service goals. Staff reported that the goals were in the areas of money management, community, medication, and possibly hygiene. Clients had to work on these goals as long as they remained in the CILA, even at the end of life. The staff did not know if agencies were penalized if clients at the end of life could not work on these goals.

Clients who received funding from the Department of Human Services had their care coordinated by a case manager called a PAS agent or ISA. The case manager visited the client quarterly, looked at their service plan, and worked with agency staff. Staff was unsure if these case managers had power of attorney. The case manager had to approve any changes in the clients' residence and whether the clients could remain at home during the day. The case managers could require that the agency keep clients instead of transitioning them out, although this was not likely to happen at the end of life. When clients funded through the Department of Human Services died the staff were required to call the Office of the Inspector General even if the death was not suspicious. The Office of the Inspector General conducted an administrative review to assess for egregious neglect that could have contributed to the client's death. The police were also involved after the death but their presence was minimal.

The state had adopted a person-centered, best practice focus to caring for adults with I/DD. According to the staff, the state funding did not always match this person-centered ideology and getting additional funding for clients requiring specialized or one-on-one services was difficult. For example, many of the agency homes were not wheelchair accessible and the staff found it challenging to obtain funding to alter the homes. In one case, the agency was awarded a grant from the Department of Human Services to construct a wheelchair ramp in the front entrance of the CILA, however they did not receive additional funding to alter the stairs inside the home. Thus, the CILA was still not accessible. In addition, clients could not remain in a CILA if they required IV medication regardless of whether the medication was for pain management, hydration, or a medical illness. Staff could administer client medications through a port or stent, but reported being uncomfortable doing so.

According to staff, most clients' received either Medicaid or Medicare and were socioeconomically disadvantaged. Clients lack of financial resources and their reliance on Medicaid and Medicare limited their choice of health care providers and where they could be placed if they were transitioned out of the agency. One staff member discussed the state funding and individualized care:

> There just isn't a lot of flexibility right now the way that things are funded and the service models and really good end-of-life individualized care or individualized care in any sense is more expensive. So unless someone has resources, they're probably going to end up in a place that's supporting more people than just one. Ideally it would be someone with their close friends and family or people who have cared for them and really

> love and support them but that’s not efficient so if they can’t afford something like that they’re going to have to go, you know poverty plays a big role, and they’d have to go to an ICF/DD which may support 147 people.

Another staff member described the impact having private insurance and/or family money had on the quality of nursing homes clients were placed in:

> There are some nursing facilities that-- again, I don't want to paint them all being horrible or nothing like that. But there's some facilities that would-- do have an interest and do have a-- a desire to provide good services, good active services for their patients and participants. But again, in most cases that's going to be the individuals who have money, the families can afford to put them in that particular facilities. Most of the individuals who are in our population who are getting older, who need these services, don't have the family involved and don't have the family money. And they strictly rely on the Medicare insurance. And of course people are younger, Medicaid, you know, even worse.

Clients’ funding changed when they left the agency and went to a rehabilitation facility or nursing home. Agencies were no longer paid to care for the client once they were transitioned. Thus, when staff worked with family members or staff at other, the agency was paying for the staff member’s time, but receiving no compensation from the state. According to one staff member, the Department of Human Services preferred to keep clients in their homes as opposed to state run facilities, but once transitioned to a nursing home the state was no longer invested in the clients’ placement:

> [Department of Human Services] really-- they really don't want to see people move that much. Even for the better sometimes….So the State really wants people to stay where

> they're at. They like to keep people where they're at so they know where people are at, and that they also know that there's stability in their lives. …They can't send anyone back to a State operated facility, unless it is extremely, extreme-- I can only think of maybe one or two cases that I know of that they actually-- a person went to an agency and was sent back to the State Op. facilities. …So they-- the nursing home I don't think-- I think they-- they wash their hands of it once the doctor says this person needs to go to rehab, nursing-- nursing skilled facility.

IB-D systemic issues. Staff at all three agencies discussed the impact limited state funding had on client care. According to staff, funding for social service agencies continued to be cut. There was a difference between making sure clients received necessary services and the agency getting reimbursed for them. Agencies received the same amount of state funding for each client regardless of age even though senior services were more intensive. At one agency, there was no social service liaison to work with clients at the end of life because of limited funding. This agency could also not afford to take over the responsibility from families of making final arrangements for clients. According to a staff member from another agency, they were working off a large deficit. This staff member also noted that paying for staff to attend client funerals during their work hours was challenging. Staff training was also affected by funding because the state did not mandate or pay for end-of-life specific training. The state mandated training for qualified intellectual disabilities professionals, middle management, and direct service professionals.

Agency funding impacted whether clients could stay in their home, or needed to be transferred to another facility. Agencies could not afford to provide 24-hour nursing care to clients in CILAs. Agencies could also not afford to hire additional staff or pay staff overtime to stay with clients in their CILA home if they could not attend the day program. According to one staff member, the agency also worked with the guardians to try and fund the client staying in his or her home. When clients were sick the agency had to pay staff overtime to stay with clients in their home.

The Department of Human Services and the Department of Public Health were the state agencies responsible for licensing and regulating agency residences for adults with I/DD. Staff listed several CILA and ICF/DD regulations without specifying which program they were from. These regulations included providing clients and families with information about advance directives, staff not being allowed to run an IV or do injections, and making sure clients adhered to their specific dietary requirements. Client that lived in CILAs and ICF/DDs received state funding, but their funding changed when they transitioned from one to the other. CILA funding was hard to obtain, desirable, and important to families. Once a client transitioned out of the CILA there was a difficult reapplication process if the client wanted to move back. The ICF/DDs provided more medical care than CILAs. One agency applied to the Department of Human Services for home-based supports for a client living in the community whose parents were unable to provide the level of support he needed. According to staff, the state wanted to know when the agencies had openings in either their CILAs or ICF/DDs and how the agency planned to fill them. The state did not want agencies to build any additional homes.

CILAs and agency day programs were licensed and funded by the Department of Human Services. The CILA regulations dated back to the 1980s. The Department of Human Services mandated that clients who resided in CILA homes had to be out of the home for 6 hours a day and had to work on specific goals including money management and health. According one staff member, staff had to be creative in designing goals that adhered to the state regulations and improved clients' quality of life. Sometimes clients had to work on these goals until the day they started hospice care. However, the state had become more flexible about modifying or waiving the program requirements when clients were in hospice.

ICF/DDs were licensed and funded by the Department of Public Health. The Department of Public Health surveyed the agencies annually. According to one staff member, when the agency began providing hospice services in their ICF/DD there was a dilemma between the goals of hospice and the Department of Public Health. When clients did not want to participate in their formalized program, the Department of Public Health wanted staff to readjust the program instead of ending active treatment. This staff member did not know if this conflict still occurred. As illustrated below, another staff member described an issue with the regulations that occurred when clients needed psychotropic medication:

> If you're on a psychotropic, you have to have a behavior program. Well, when you get to sort of the later stages of dementia and Alzheimer's, that's a challenge because they may still need the medication to help with the agitation but there's no behavioral program that's necessarily going to help.

While some had private insurance, most clients received Medicare or Medicaid funding. Clients were eligible to receive home health and hospice funded by Medicare and Medicaid. However, one staff member said that getting home health funding for clients on Medicaid was difficult. CILA clients receiving Medicaid were eligible to receive a waiver if they met emergency criteria. One staff member reported that there were a number of changes to Medicaid, for example dental services were no longer covered. Since the Department of Public Health mandated that clients saw a dentist twice a year the staff member was uncertain how these visits would be funded. Another staff member noted that psychiatrists could not spend much time with clients because they paid minimally to work them.

Sometimes client deaths required a formal death investigation. For example, a death investigation with the involvement of the police and coroner was mandatory when the client had a state appointed guardian. When clients in the ICF/DD at one agency died, staff informed the Department of Public Health, but the agency had never been investigated. Another agency conducted a formal death review in order to evaluate what happened and verify that everything that needed to be done medically had been done.

Investigator comments on systemic issues. Staff at all of the agencies discussed the impact limited state funding had on client care. When working on this category I found myself empathizing with the staffs' frustration with trying to provide care and being met with financial barriers. I was particularly struck by the need to move clients to other homes because their CILA was not accessible. None of the CILAs I worked in were accessible either. Clearly this will increasingly become an issue since this population is aging. While this is an area that will ultimately require policy change, I do not have clear ideas about how to convince the state of the importance of caring well for the dying when the agency focus is on living fully. Ethically, I could make the argument that caring for the dying is part of caring for the living, but where should the funds come from?

The ICF/DD regulations from the Department of Public Health and CILAs regulations from Department of Human Services posed some challenge to caring for adults at the end of life, but staff said that the state was becoming more accommodating, so more research is needed to determine whether or not these are areas that requires further improvement. Medicare and Medicaid funding issues for adults with I/DD were generally the same as the issues experienced by members of the general population who also obtained these services.

Grief and Bereavement

FG1 grief and bereavement. Aside from a comment about struggling with death as a culture, staff described the responses of other clients' and not their own reactions when discussing the death of a client. According to staff, surviving clients needed to have the opportunity to acknowledge and talk about their loss. The agency provided therapists to work with peers after a client died. One staff member turned her own training into a grief and loss group which ran for a few cycles. After one client died staff and surviving peers received aftercare from the hospice:

> Hospice actually provided eight weeks of aftercare therapy for the staff and clients that lived in that home where they came in weekly to say how are you, what's going – but you wouldn't get that for anyone else, and it would be nice to have something like that for everyone in this world where everybody might need a little extra something, um, to deal with grief and loss that can't reach out on their own and think about it.

Despite the importance of mourning after a client died, in several instances the surviving clients intentionally not invited to participate in the family's memorial service. In one case, a staff member had to convince the family to let peers attend the service:

> I was just amazed a couple of years ago when someone passed suddenly, and their relatives had no intention of us being involved in the services. They were like, no, we –

> why would you want to come? And I'm like, we need closure. The people that have been his family that he's lived with, that he goes to the day program with, they all need closure. And we were able to talk them into it, but I felt bad this we even had to work on talking someone into having a service for other people to honor that person and to kind of have the closure.

Other families included peers and staff in memorial services. Staff described communication with these families as “wonderful.” If possible, staff took peers to attend clients’ memorial services. The agency also held memorial services and created memory projects for clients who died.

FG2 grief and bereavement. According to staff, some people believed that adults with I/DD could not “handle” death, but staff reported that clients were able to cope with loss. Staff noted that as a society we were “terrible” at thinking about death for people with I/DD. Clients experienced the deaths of family members, other clients, and staff. Peers talked about clients after they died:

> It was really great to see how they handled it [death of client] and just so they could talk about it, you know? [Client] always tells me about [deceased client], you know, the one that couldn’t see, hear, or anything. And, yeah, [deceased client] is up there, looking at us down here in the van laughing at us because [staff] has got that country music on, you know? So, and they do that, and then we can talk about it and joke about it.

Sometimes there was a funeral for a client and sometimes there was not. When there was a funeral, staff took busses of clients to the funeral home. One family did not think anyone would attend the client’s funeral and they were overwhelmed because so many people came. Staff had problems with some funeral homes because “they tend to think someone with a disability is like Potter’s Field and that’s it.” Staff put together memory books and when there was no funeral a memorial service might be held at the agency. One staff member described the importance of the memorial service:

> And so in some of those instances where we just got the call the person is gone, there’s no funeral, there’s like nothing, we sometimes had memorial services by us so that the clients that they befriended and us who have served them for many, many years and came to love them were able to have some closure when the system didn’t allow us any closure.

In one case, a client was cremated and his family did not want the ashes, so a staff member took them home.

When a client died, staff worked with other clients by telling them about the death and helping them cope with the loss. Staff had difficulty with supporting surviving clients while they were themselves grieving. Coping with their own grief was additionally difficult if the staff had to make the funeral arrangements. Staff remembered the experience and feelings they had when clients died. As two staff members recounted:

> Participant A: I don’t know if you remember [client name], over at [agency home]?
>
> Participant B: Yeah, I remember going with you to see if the body was….dead.
>
> Participant A: Yeah. And I was like, oh, my. I mean to this day I still feel the whole experience, and he was like cold and I just found him in his bed. That was my first ever experience, and it was – I don’t want to – well, I guess it was kind of traumatic. But I still every time I remember it. Until now I couldn’t even remember his name, but I saw the

> face and, you know, everything. And I just experienced – so it was – it was an experience, you know, so. And I, basically something I think that will stay with me the rest of my life because every time it comes up, I remember the experience and the feelings.

Staff mourning was complicated by external factors that impacted their ability to grieve. For example, when one client caused the death of another, it took months for everything to "return to normal." One staff member described the experience of having the authorities involved after another client died:

> You don't even get to grieve properly because…you're scared and you're trying to grieve, all at once. And you know you didn't do anything wrong but that doesn't mean the authorities won't know that, you know?...And it just gets all complicated. So that's happened to me twice, and it was very unpleasant, to say the least.

Sometimes staff were able to talk and joke about clients who had died.

FG3 grief and bereavement. Staff reported that clients were upset after their peer died. Clients would self talk about death and discuss the loss with one another. According to staff, it was important to clients to attend the client's funeral. As one staff member articulated, clients also appreciated being included in the mourning rituals:

> Because they [clients] were talking a lot about – like I think a couple clients got to make small speeches. And they talked about it for weeks afterwards. Like how it meant so much to them and they got to talk about their friend, and everybody heard.

There was one family that did not want clients to attend the funeral of a peer. Staff provided grief counseling and did legacy work using art with clients after their peer died. One staff member tried to lead a grief support group, but it was not taken to.

The death of a client was always shocking and hard on staff even if they knew the client was ill. Staffs' grief was the same whether the death was anticipated or sudden. One staff member lamented not being present when a client died:

> She was still – I wished I could have been there to see her when….When her last – yeah, I wish I could have been there to see her just shutting her eyes. I wish I could have seen – you know been around her then.

Another staff member recalled her experience after a client died:

> When I first found out she was passing, I had came from the clinic with her….I'm like wait a minute, I'm trying to – tears rolling down my eyes for her….My mind – I just was on her. My heart was broke.

IA grief and bereavement. According to staff, they told clients when a loved one died and all of the clients reacted to the loss. When a client at the agency died, many of the other clients were their good friends. Sometimes clients talked to staff about their feelings and how much they missed the person who had died. Clients also expressed their grief by telling stories and laughing, drawing pictures, and writing about the person. Some clients became obsessive about thoughts of death and wanted to be with the deceased. Sometimes staff had difficulty ascertaining how much the clients emotionally processed their loss. The agency provided a lot of support and opportunities for clients to express themselves after a peer died.

Attending a peer's funeral was important to clients and staff made sure they were able to do so. Some families welcomed people from the agency and asked clients to say a few words at the funeral. Staff helped clients prepare if they were speaking at the funeral. According to one staff member, sometimes families were surprised by the support they received:

> We always make sure that as many people as is appropriate go to the funeral or the memorial services or whatever and give support to the families. Oftentimes the families are shocked by how much we get involved and how much we involve other clients in the whole process. And they're like, wow, so many people are here, we didn't expect this. But we think it's important for the living as well as for the deceased and the deceased's family. I think they need to know that their loved one was cared for outside of them.

Staff also collected client mementos and brought them to the family or to the other clients in their residence. Families were encouraged to stay in contact with the agency after the client died. Some families did not invite staff or clients to attend funerals. When people from the agency were not invited to the funeral, the staff organized memorial services.

Staff likened the death of a client to that of a family member. In one case, a staff member took home a client’s ashes because the family did not want them. When a client died staff wanted to be asked how they felt and to express their grief for the person. However, sometimes the circumstances surrounding the client’s death made grieving difficult. For example, when staff were not told about a client’s death until after the funeral, or when one client was murdered. Staff had a difficult time and were angry after the client was murdered. In this case, staff received support from other staff and the managers and directors within the agency. One staff member used art to process the death of a client.

IB-D grief and bereavement. Clients often lived together for many years and were like family to one another. According to staff, clients responded to the death of peers in a variety of ways. When staff talked to clients about the death of a peer, some talked about being sad and how much they cared about the person. Other clients did not say very much. According to one staff member, clients were honest and might say the following about the person who died, “she’s a mean person” or “she steal money.” One staff member recalled providing support to a client who asked her why younger people died before him and another that said that he, “don’t have nobody.” One agency had a counseling department offering a grief and loss support group and individual therapy for clients. Clients at this agency also talked to staff, qualified intellectual disabilities professionals, friends, and family members. Outside counselors or religious officials were also brought to the agency depending on the clients’ preferences. Another agency recently started having a staff member provide grief support for clients. If needed, outside support was brought in to this agency to conduct a grief and loss support group.

Staff also had a hard time after a client died and supported both surviving clients and other staff members. At one agency, staff were able to talk to someone at the agency or were given a support phone number to call after a client died. Staff at this agency also created memorial boards with pictures and mementos of clients who died. At another agency, staff were called immediately when a client died so that they did not find out the next day at work. Staff at this agency were debriefed and told that they had done everything possible. Staff covered each others’ shifts so they could attend client funerals.

Staff and clients were generally welcome to attend clients’ funerals. One staff member described attending a client’s funeral:

> At the funeral home, we will bring their most loved things with. We’ll bring pictures of them and their friends if that’s what they really cared about. We brought one of the illuminated Christmas gnomes….a yard decoration. She [the client] loved it. It was her

> friend. She’d carry it around. And he [the gnome] was there and when the brother-in-law asked, “Why is this gnome here?” And we told him and he was like, “I didn’t know that.”

One agency had a space where they could hold funerals. Having this space meant that clients and staff could more easily attend the funeral. At the other two agencies, staff supported clients and took them to peers’ funerals. Sometimes clients and staff were asked to actively participate in the service. According to one staff member, two clients participated as pall bearers at their best friend’s funeral. One staff member expressed concern about how clients’ presented themselves at funerals because they were not dressed in proper funeral attire. Staff at two of the agencies described holding memorial services where staff and clients could celebrate the life of the person who died.

Sometimes no funeral arrangements were made because families did not view this as their responsibility or did not want to incur the costs. According to one staff member, this decision was upsetting for clients and staff:

> Sometimes families choose not to have services, like they won’t have an actual funeral…. A lot of our staff and the surviving clients do want to celebrate the life of that person so that’s where there may be a difference because the families are like we’re not going to fork over the money for a funeral and it’s hard for our clients and our staff to say goodbye.

In other cases, the final arrangements made did not reflect what the client wanted, for example staff at one agency knew that a client wanted a burial but the family decided on cremation. Staff at another agency described one family that ceased all communication with the staff after a client died suddenly. Some families paid for the burial expenses, but were never physically present before or after the client died. Other families only made a connection with the client after he or she was dead.

Investigator comments on grief and bereavement. I was surprised that some families prefer that clients and staff not be present at funerals. I was surprised because of the lengthy history that peers and staff often have with clients. My guess is that not being allowed to participate in family funerals may be linked to several factors, one of which may be the contentious relationships between some families and staff. The findings in this section also illustrated that people with I/DD are generally able to cope with death that there is a clear need for greater agency support for staff coping with the death of a client.

Recommendations

FG1 recommendations. One staff member lamented the lack of an agency end-of-life care policy saying:

> I was disappointed to hear that at the end it [agency policy] never happened because I think that that's an excellent opportunity to talk with the people that we serve about that and help them to be aware of that issue.

Staff also expressed concern that a more formal policy could create additional red-tape and create more paperwork for staff. Despite not having a policy, the staff stressed the importance of having regular, open dialogues about death that should occur over time and before a client is at the end of life. As one staff member suggested:

> I think that having an open dialogue with an individual, extending that also to their family/guardian is wonderful. I think that it is a way to find out what the person wants. Indirectly it's a way to just address the issue, talk about the issue, learn about, you know,

> what someone may not understand. Um…And you know, hopefully this is this not something that's done in crisis. It's done over time and it's something that can open up that dialogue. So I think that right there, when I think of what to ask, I'm probably missing a lot of things, but just simply would you want to have a funeral? Would you want to be buried? You know, who would you want to have there? Maybe that's a little too much. Um…Is there someone that you want to speak? You know, little things like that, just actually planning or not planning, you know, a service. You know, maybe someone would say I want to be cremated or someone maybe wants to find out what cremation is because it happened to their grandpa and they didn't know.

According to staff, these open dialogues could help clients both manage their fear and become a part of their own end-of-life process. While staff were not certain at what age to begin these dialogues, they stressed the importance of creating plans before the client was at the end of life. Staff advocated for having clients participate in their own end of life process by talking to them about what they wanted and allowing them to make choices if they wanted to. Staff noted the importance of also working with clients' families in order to educate them about what may happen. Staff suggested having a person whose main area of expertise is to help find resources and to help mediate that relationship between the "blood family" and the "caregiver family."

According to staff, they needed training in both working with clients at the end of life and in working with their surviving peers. In terms of end-of-life training, staff recommended the following: having annual training; reminding staff that it is all about the clients even if they disagree; not bringing in staffs' personal views; helping staff be a part of the process when clients are at the end of life. For working with surviving clients, the staff reported that the following would be helpful: having a general understanding of grief, loss and death; learning to support surviving peers and other staff members; understanding that clients come first. Staff also said it was important to have supports in place for the surviving clients. The staff wanted more, up-to-date resources. The staff identified the following resources that would be helpful: books geared towards adults with I/DD and not children; activity books about loss and coping; a list of agencies or professionals that could help support end-of-life issues; a list of information for staff and families about hospitals, hospices, and nursing homes agency the agency has worked with; and having end of life for people with I/DD being an area of specialization.

FG2 recommendations. Staff recommended creating a formal agency policy for providing end-of-life care services and having an end-of-life or crisis team comprised of a physician, therapist, psychiatrist, psychologist, and nurse. This team would also include a large, core group of staff members. When a client was at the end of life, staff who were not as involved with their care would be on the team because the staff caring directly for the client would be more upset. All of the house managers would be qualified to be on this team and each would be responsible for one additional house. This team would also include staff with expertise in end of life. According to one staff member, this team would

> hopefully encourage that with the person's – hopefully with a therapist, with doctors, the whole team approach, and having the person feel that they have an opportunity to do whatever they – as much as they can do, to either have a finality to it or to fight.

Additional recommendations for agency changes included: having an agency run facility between a nursing home and a CILA where clients would have community based medical and hospice care; looking into insurance and future planning for funerals; conducting medically and legally acceptable client assessments to ascertain their ability to make medical decisions; and making it less taboo to discuss death in the agency; and supporting staff and helping them feel comfortable caring for clients at the end of life. Staff said that dignity was of paramount importance and they needed to figure out what dignity meant to each client and how to make the end of life as dignified as possible.

Staff said that clients should not be sheltered from illness and death and should be involved in making decisions for themselves. As one staff member reported:

> It seems like our philosophy is that people with the right support knowing someone's level of comprehension and communication that they have the right to know what's going on with them medically, and that it's – I've heard stories about even if a parent dies don't tell the person with the disability….And that is not our way, at all. We think people have – can tolerate and have the right to grieve and know about loss, and we want to help them deal with it.

According to staff, clients should have the same opportunities for end-of-life involvement, such as planning their own funeral, as members of the general population. Staff recommended supporting and encouraging client preferences at the end of life. In order to involve clients in decision making, staff suggested educating clients about their options and empowering them to feel their decisions will be respected. Staff suggested using the *Five Wishes* document or developing a curriculum using pictures in order to present the concepts. One staff member said that the *Five Wishes* document may not be the right thing to use. Staff also recommended educating client's families and/or guardians:

> I think it's also important for families, guardians, to be educated, as well, to diagnosis

> and to individuals having the right to know about their own bodies and know about their future, and know about their options, know about their future and what they can do.

Staff recommended letting families know ahead of time that they would not hide anything about a client's diagnosis from them.

Staff suggested other staff receive training in the following areas: facing one's own mortality and the idea of death; dignity; person centered planning; agency philosophy; navigating choices at the end of life; doing what's best for the client regardless of personal opinions; working with families who don't want to tell clients about diagnoses. According to staff, training should include how people grieve and grief counseling in order to support the surviving clients. Staff said it would be helpful to have hospice or other experts conduct their training.

FG3 recommendations. According to staff, end-of-life care should be about the clients' wishes, letting them say everything they need to, and making sure they are comfortable. Staff said that it would be best for clients to remain in their agency homes at the end of life and they recommended bringing in hospice care. As illustrated below, staff also noted why they should not have hospice come in to the agency homes:

> Participant A: I don't think we would want that on our hand, because even if hospice come in, we have to be a-- we have to be, you know, certified to be a hospice person.
>
> Participant B: Right.
>
> Participant A: If we-- something go wrong, then they would be saying, oh, what did you do? Because something could happen in a split second.
>
> Participant C: Right.
>
> Participant B: That could be the reason.

> Participant A: With hospice you're supposed to have your eye on that person at all time. Because if you stepped out to take care to cook an egg or have a sandwich and that person has been deceased for 15 minutes and you're in hospice care, you have to answer to that.

When clients were in-patient at the hospital staff wanted to be allowed to do their shift there so clients were around familiar faces. Staff said that the clients should be offered the ability to celebrate the time they had left and suggested events such as putting up a Christmas tree in August or celebrating client's birthdays early. Staff described the need for a grief support group for clients that would use pictures and art to help them understand the end of life and encourage them to talk about the deceased.

Some staff said that clients should be told about death, but others questioned whether they should be informed that they were dying. Staff agreed that they should not promote any religious agenda with clients, nor should they constantly remind them about death. Staff could, however, help clients verbalize that they were dying. Staff said that clients should be given choices and included in making decisions for themselves. They suggested including clients in end-of-life decision making by using the *Five Wishes* document, asking them what they would want, and incorporating questions about death into client meetings. One staff member was uncertain if the *Five Wishes* document was used with people with I/DD. Staff also mentioned forming support teams consisting of any staff with client contact. While these teams would discuss death with the client and family, experts would also be brought in to the agency because they might pick up on issues that the others missed. Staff also suggested that family members should talk to clients about what will happen after their death.

Staff were unaware of any good resources and said that they should receive training from someone with experience in end of life. One staff member was not sure if there should be specific resources for people with I/DD since death was the same for everybody. Staff suggested that children's books or material with understandable concepts and watching and discussing a documentary about a client at the end of life would both be helpful resources.

IA recommendations. According to staff, agencies needed more funding in order to provide quality end-of-life care. Currently, the agency was unable to afford staff overtime or one-on-one care for clients. With increased funding the agency could also hire a more educated staff and provide more mental health counseling and creative art therapies. The agency could also provide client and family counseling for a low cost. One staff member advocated for the federal government taking over human services because it could mandate better educating staff as well as providing better medical and mental health coverage. One staff member said no additional resources were needed.

Staff advocated for having more open discussions about end of life and giving clients' truthful information about their diagnosis. One staff member explained the importance of person-centered planning:

> So person-centered is really respecting the preferences and choices and knowing about those before someone isn't able to make them, or it's kind of shaky. So I think that's a really good thing and if we can incorporate that into sort of all aspects of someone which includes the way they want to die or conditions when they wouldn't want to continue living.

Staff recommended involving clients to the best of their ability by giving them choices about end of life and post-death planning. Staff noted that clients would need help and that things would need to be explained a little bit differently. According to one staff member, some advance care planning forms were too “lawyer sounding,” so the *Five Wishes* document, or a modified version, could be used. Another staff member also suggested using a *My Health Passport* document. Some staff suggested discussing end-of-life planning when clients first entered the agency, but others said that the conversation could scare clients and they might become obsessive about death. Other staff suggested discussing end of life before the clients were ill because care was more complicated at the end of life. However, some staff suggested waiting until someone received a life-limiting diagnosis before discussing end of life.

According to staff, clients at the end of life should receive the same care as members of the general population. They suggested taking a holistic approach and incorporating the following into end-of-life care: supporting clients; making sure clients are comfortable; treating clients with compassion and respect; providing a positive environment; keeping clients’ interests and wishes in mind; allowing clients to grieve and talk about death; using appropriate therapies including movement, art, and music; and allowing clients to die in a dignified manner. One staff member described her perceptions of a “good death”:

> I think a good death is to be surrounded by those that love you to the best extent possible. And to be-- have your pain managed as perfectly as possible…to explore what your life was all about, so you feel like you had purpose on this earth.…And even people who have intellectual disabilities or maybe have extreme physical disabilities, they touched people in their lives, and they need to know that. And they need to feel like their lives had purpose so that when they-- when they die, it was all worth something.

Staff said that clients should be allowed to stay in their homes and receive services while being surrounded by close friends and family.

Staff wanted tools that they could use when explaining end of life to clients. For example, staff said that there were a few children's books that were helpful because they had visual images and conceptual information. In addition to caring for clients at the end of life, staff also cared for their peers before and after the client died. Staff offered the following suggestions for caring for peers after a client died: talking about death and encouraging questions; conducting therapy in the clients' homes instead of the day program; helping clients process their emotions by making things for their peer; maintaining contact by visiting the cemetery; and helping clients dress appropriately for their peer's funeral. Staff also suggested having a list of nursing homes that specialized in working with people with I/DD and information about places where client without any future plans or money could have a funeral and be buried.

Staff also wanted resources to help them open up discussions about end of life with other staff in order to discuss how they were affected by the death of a client and to help other staff be more comfortable talking about death. According to one staff member, staff without compassion or respect presented a barrier to end-of-life care. Staff said it was important that staff in both residential care and the day program were informed when clients' were at the end of life.

Staff wanted more formal and ongoing training on end of life, grief support, and bereavement. Staff recommended having outside speakers, such as a client or family member, come in and talk to the staff. The training should also include learning about the different types of loss, gaining comfort using “dying terminology”, and being open to fielding “odd” questions from clients. One staff member suggested making Kübler-Ross' stage model part of their training. Another staff member wanted more training on knowing when their oxygen was low when caring for clients on oxygen.

Staff said that when clients transitioned out of the agency they should coordinate their services and that healthcare providers in other organizations needed additional training in working with adults with I/DD. Staff identified not being involved in the client's care and decision making as barriers to end-of-life care. It was particularly important for staff to be involved when the clients' families were not. According to staff, physicians and nurses needed education in being compassionate and caring. Healthcare providers also needed to learn how to tailoring their care to the clients' needs and determine when clients were in pain. They also needed to understand that clients knew what was happening. Providers in hospices and nursing homes also needed to tailor their services to people with I/DD and to treat clients like human beings. According to one staff member, nursing homes needed to do better background checks on their staff.

IB-D recommendations. According to staff, quality end-of-life care should include respecting, advocating for, talking to, and comforting clients. Clients needed to feel safe and secure and know that they were not alone. Clients should be surrounded by family, staff, hospice caregivers, peers, or other favorite people who are compassionate and want to be part of the process. Although, some staff members said it might be strange for the client if their previously uninvolved family members were around 24-hours a day. One staff member suggested maintaining the same habits and conversations that they had with clients before they became ill. According to staff, clients wanted to be in their homes and not a hospital or nursing home.

Staff made several recommendations for improving care for clients at the end of life.

Their suggestions for agency changes included: having an agency end-of-life protocol; bringing clients in to the agency in their 20s; having an agency hospital; verifying that all necessary tests were run before clients left the hospital; and keeping appropriate attire at the agency for clients attending funerals. Staff said it was important for all of the staff working with the client to meet as a team and discuss client care. Staff also discussed preparing clients before their peer died by bringing in someone to discuss death with them. Staff recommended having a support group for clients immediately after a peer died in order to discuss their death instead of each client discussing his or her own previous losses in a general support group. Staff said that supervisors should understand when they needed to step away or cry. Staff recommended structuring the end of life conversation and having a social service person as a liaison between staff, families, peers, and hospice care providers. The liaison would prepare the family for the end of life and provide updates on the client's condition to staff and peers.

Staff suggested bringing in an expert or having hospice staff train them on end of life and grief. Training should also include teaching staff to be nonjudgmental and have compassion and respect for families and their decisions. Staff should not assume that families agree with them about what is best for the client at the end of life. Staff should also be sensitive when talking to family members about aging because the guardians were aging too. Encouraging families to remain connected to the agency after the client dies may aid in their healing.

Staff also recommended changing the state regulations when clients were at the end of life. They proposed modifying the clients' service goals and creating a new individual service plan instead of adjusting the existing one. One staff member explained why a new individual service plan was important:

> The ISP usually is developed when the person is in good health and I don't think, as the person's health declines, we might change things but never – I don't think we ever look at starting all over. Okay, this is the same person but in a very different situation now and what would their ISP look like if they were just entering the agency with the needs that they currently have? So I think that, you know, we would be able to change the way we work with the person by maybe stating something about when a person goes into a hospice care situation, that a whole new ISP be designed to meet their current needs and the needs of that person in the near future.

Investigator comments on recommendations. While several staff suggestions were more long-term, such as changing the state regulations, staff also offered several ways to improve end-of-life care that could be implemented more quickly and with little or no funding. For example, staff suggested having more discussions with one another about end of life in order to make the subject less taboo. After looking at both the data describing what end-of-life care currently looks like and the staff recommendations, I think the most immediate impact I can have on end-of-life care for adults with I/DD is to design a staff training that incorporates these dissertation data with the research and clinical literature. However, a lot more ground work needs to be done in order to design a training that is beneficial for staff, clients, and families while also being short, low cost, and not disruptive to the daily operations of the agency. This training must incorporate end of life, grief support, and bereavement.

General Background

FG1 general background. Staff described their personal experiences with death and discussions about death with their own family members.

FG2 general background. The staff discussed previous work experience, similarities between discussing sexuality and end of life with clients, and death in general. One staff member worked with another agency for years and experienced the death of clients at that agency. This other agency had therapists for clients and met with parents after the client died. The staff said that often the elderly die without dignity.

FG3 general background. Some of the staff members had personal experiences with end of life and others did not. One staff member described being ill, in the hospital, and not wanting to think about death. Two staff members had previous professional experiences at other agencies in which clients died and/or received hospice.

IA general background. Staff reported that the agency previously had a pediatric program. Staff described resources at other agencies, including ICF/DDs and more nurses. Staff made a few general comments about clients and never heard of the “futility argument.” One staff member discussed previous professional experiences working in hospice care. Another staff member described caring for a client at a different agency who received hospice care. One staff member experienced a number of deaths in her family and had a family member with I/DD. Another staff member described the poor care his family member received in a nursing home. One staff member had a life-limiting illness and had not completed an advance care plan.

IB-D general background. Staff discussed aging family members and medical care their family received. Staff also described programs at other agencies and a brief history of the care of adults with I/DD. In the 1980’s, clients were warehoused in institutions and nursing homes all day. Day programs flourished as clients were moved out of nursing homes. Previously, agencies had to transition clients into nursing homes in order to allow them to die with dignity. According to one staff member, most families currently kept their children with I/DD at home with in-home services.

Investigator comments on general background. I thought that the staff describing the similarities between sexuality and end of life discussions with clients was interesting because it speaks to how taboo intimate discussions are with adults with I/DD. However, I think the discomfort with discussing death is also cultural and reflects the discomfort many people in the U.S. have with talking about illness and death.

Chapter VI

Data Analysis

The purpose of this dissertation research was to explore the experiences of agency staff who provided end-of-life care for adults with I/DD in order to clarify the services currently being provided, identify gaps in services, and to describe implications for social work clinical practice and policy. For the following sections, the coded data were compared in the aggregate in order to address the study aims. While the aims addressed recommendations within specific systems, the participants reported recommendations more generally. Thus, the agency staff recommendations for improving end-of-life care are presented in their own section. This chapter concludes with an overview of the main study findings.

Aim 1

The first aim of this study was to explore agency staff perceptions of their own participation and role in end-of-life care for adults with I/DD from diagnosis until after death. This aim was addressed by answering the following questions:

> How did the agency staff describe their experiences working with adults with I/DD at the end of life from diagnosis until after death?
>
> - How did agency staff describe their own participation and role in providing end-of-life care for adults with I/DD?
> - How did agency staff describe their relationships with clients?
> - What recommendations were offered for microsystemic improvements for end-of-life care delivery for people with I/DD?

Agency staff participation and role. This section utilized data from the following categories in Chapter V: *planning and placement; client understanding/involvement*; *staff experience/role*; *external professional caregivers; grief and bereavement;* and *general background*. Agency staff had a range of personal and professional experiences working with adults with I/DD at the end of life. Staff working in agency residences generally had more experience providing end-of-life care than staff in other agency programs. Staff participated in multiple roles when clients were at the end of life. They were caregivers and advocates for both the dying clients and their surviving peers. Staff supported and counseled surviving peers by discussing death with them and taking them to visit ill clients. Staff also worked with families and/or guardians when clients were at the end of life.

Staff provided emotional support and physical care to clients at the end of life. Staff treated clients with love, warmth, and compassion, and made sure that they were comfortable and that their needs were met. Staff told clients about their diagnoses and prognosis and counseled them about death. Staff helped clients with activities such as toileting, going to physician appointments, and taking medications. Some clients were unable to articulate their pain and staff helped health care providers communicate with clients. Staff advocated for clients and helped them adjust programmatic and medical obstacles to care.

Staff worked with families and/or guardians when clients needed to be transitioned to another home. Staff continued to be involved with clients who had transitioned out of the agency residences into hospitals, nursing homes, hospices, and rehabilitation facilities. Staff were frequently responsible for making final arrangements, including funeral and burial or cremation plans, even when the client had a guardian. After death, staff organized memorial services and created memory boards for clients who had died. Staff brought pictures and treasured objects to clients' funerals. Staff took surviving peers to clients' funerals.

Relationship between clients and agency staff. This section utilized data from the *staff experience/role* and *grief and bereavement* categories in Chapter V. Staff and clients had often worked together for a long time. Staff cared about the clients and knew them well. The clients were like family to staff. Some clients did not have any family other than agency clients and staff. Staff found it difficult to observe clients declining. Sometimes everything went smoothly when a client was at the end of life. At other times, the end-of-life experience was hectic and staff were frustrated and overwhelmed. In these cases, emotions were high and there was not enough time to process information.

Staff dealt with caring for a client at the end of life in their own individual ways. Some staff members wanted to care for clients at the end of life, found the experience rewarding, and reported being fortunate that they were able to provide care. Others were jaded after experiencing many client deaths. Some staff had difficulty internalizing that the individual was a client and not a family member. Staff supported one another, but the agency support for staff was variable. At some agencies staff were informed immediately when a client died or they were given a support phone number. However, staff also reported being told they were there to do a job and that they should not to get too close to the clients. Staff were reminded that they were not the client's friend or family member. Staff wanted to be asked about how they felt.

Experiencing the death of a client was like losing a family member. In one case, a staff member took a client's ashes when the family did not want them. Staff supported each other and covered each others' shifts in order to attend a client's funeral. Staff reported having difficulty experiencing their own grief while supporting the surviving clients and other staff. Their experience was even more difficult when they had to make the funeral arrangements for a client. Mourning was further complicated when the authorities were involved.

Aim 2

The second aim of this study was to explore agency staff perceptions of how care was delivered at the end of life for adults with I/DD from diagnosis until after death, how medical decisions were made, and the roles and participation of family members and health care providers in end-of-life care. This aim was addressed by answering the following questions:

How did the agency staff describe the medical needs and the care received by adults with I/DD at the end of life (from diagnosis until after death)?

- What were the medical needs of adults with I/DD? How did their illness progress? What care did they receive at the end of life? Where was care received?
- Who made medical decisions for adults with I/DD? Were adults with I/DD involved in medical decision making? If so, how were they involved? If not, why were they not involved?
- How did agency staff describe the participation and role of family members? How did agency staff describe their relationships when working with family members?
- How did agency staff describe the participation and role of health care providers in hospitals, hospices, or nursing homes? How did agency staff describe their experiences working with these health care providers?
- What recommendations were offered for mesosystemic improvements for end-of-life care delivery for people with I/DD?

Medical needs and illness progression. This section utilized data from the *client* *experience* and *planning and placement* categories in Chapter V. In general, staff did not discuss clients' specific medical needs or illness progressions. Staff talked more in generalities about the types of illnesses and where clients received care. Staff worked with clients with a variety of aging related conditions including: dementia; Alzheimer's disease; hearing impairments; and mobility limitations requiring assistive devices. Some clients with dementia and Alzheimer's disease were physically healthy despite their cognitive impairments. Other clients had degenerative, life-limiting conditions including: cancer; heart disease; chronic obstructive pulmonary disease; and organ diseases. Some clients lived longer than expected and others died suddenly and unexpectedly as a result of medical illnesses, falls, and murder.

While agency staff preferred to keep clients in their agency home, their ability to provide necessary medical care and meet accessibility needs of clients at the end of life varied by agency. Staff at Agency A generally did not care for clients at the very end of life because the clients were transitioned once their medical needs were beyond the staffs' ability to provide necessary care. Agency staff were unable to provide 24-hour nursing care and some of the CILAs were not wheelchair accessible. Agencies B, C, and D managed CILA and ICF/DD facilities and cared for clients at the very end of life in both. In two of these agencies, hospice care had been brought in to the CILAs as needed. In the third agency, agency nursing staff provided hospice care. Some clients lived in their families' houses at the end of life. Often clients transitioned multiple times before they were at the end of life, e.g., they went from the agency to the hospital and then to a rehabilitation facility and eventually back to their agency home.

Medical decision making. This section utilized data from the following categories in Chapter V: *client experience; planning and placement; client understanding/involvement; staff* *experience/role; external professional caregivers;* and *systemic issues*. The staff did not specifically discuss medical decision making, but spoke more generally about making decisions when clients were at the end of life. Staff wanted to help clients with decision making but they did not have any legal authority. End-of-life planning was handled somewhat differently at each agency and none of the agencies had a formal policy or protocol for providing end-of-life care.

At Agency A, each case was handled on an individual basis and most clients did not have advance care plans. Generally, end-of-life care was not discussed until a client became ill or received a life-limiting diagnosis. Families or guardians were responsible for making decisions and filling out paperwork. Staff were not involved in creating advanced care plans for the clients. End-of-life planning was also variable between Agencies B, C, and D. Similar to Agency A, at two of these agencies plans were developed when clients exhibited signs of functional decline or were at the end of life. At one agency, end-of-life planning, including do-not-resuscitate and do-not-intubate orders, was discussed. At the other agency, staff had previously tried to discuss pre-arranging funerals when clients first began services, but they had discontinued this practice. At the third agency, advance care planning was discussed when clients first began services at the agency. Agency nurses provided families and clients with resources and information about living wills, advance directives, medical power of attorney, do-not-resuscitate orders, and finances. Clients and families were not required to fill out any paperwork, but information and any resulting plans were reevaluated annually as a part of the client's individual service plan meetings.

Agency staff focused more on describing clients' understanding of death and others' misconceptions about their abilities than on clients' actual participation in making decisions.

Staff and family determined whether clients should be involved in decision making. A client's ability to participate in decision making was dependent on his or her functioning. Staff worked with clients' with a range of functional abilities including clients with "mild", "moderate" and "severe and/or profound" I/DD. Some clients actively participated in decision making and others were not capable of participating. Some clients were aware they were ill and at the end of life. Other clients did not understand that they were ill. At times, staff were uncertain whether or not clients understood their illness. While some clients were their own guardian, most had a family member or state appointed guardian. In some cases, physicians determined that a client who was his or her own guardian was incapable of making decisions. Staff looked into obtaining guardianship for one client in this situation. According to staff, the client would have to be declared legally incompetent and the process was very expensive. Being declared incompetent meant taking away the client's right to be his own guardian and it was hard to get rid of a guardian once obtained.

Sometimes other people, including family members, believed that clients were incapable of understanding their diagnoses or of knowing what they wanted at the end of life. Staff knew that some of these clients were aware of their illness, knew what they wanted, and were capable of telling others. Sometimes family members also requested that a client not be told about his or her illness or not be informed about the severity of the illness. Staff advocated for giving clients direct information and encouraged families to be straightforward. Client reactions to having a life-limiting illness were impacted by how information was presented to them.

Family member participation and role. This section utilized data from the *working with family/guardian* and *grief and bereavement* categories in Chapter V. According to staff, some families were actively involved in clients’ lives while others never communicated. Some families only became involved when the client was at the end of life. Although state guardians had huge caseloads, some were invested in the clients while others were not. Families who were involved worked with staff when clients showed signs of functional decline and took turns being at a client’s bedside when he or she was at the end of life. Some families made final arrangements and others did not view planning a funeral as part of their responsibility or did not want to cover the expenses. In some cases, staff continued to be involved with families after clients transitioned out of the agency or died.

Relationship between family and agency staff. This section utilized data from the *working with family/guardian* and *grief and bereavement* categories in Chapter V. Staff had often worked closely with clients’ families for many years. In some cases, agency staff were even more actively involved in the clients’ lives than their families were. Sometimes interactions between agency staff and clients’ families were positive. In these cases, families did not interfere with the staff. Staff supported family members and the families were grateful for the care their loved one received. Families relied on agency staff and treated them as a part of their family. One agency had a family association and the staff reported that the families in this association also supported each other when clients were at the end of life.

At other times the interactions between family and staff were negative. Staff described interactions with families as adversarial and reported having conflict. Some families were not receptive to the staff and did not appreciate them. Staff perceived families as being uncaring and were frustrated that they were not in contact with the client and did not attend annual meetings. Staff reported that these families did not know or respect the clients’ wishes for the end of life.

Agency staff had trouble respecting the decisions these families made on behalf of the clients.

After death, some relationships between staff and families continued to be positive and others were negative. Generally, staff and clients were welcome to attend client funerals. Sometimes clients and staff actively participated in funerals and families were overwhelmed by the support they received. Other families did not view planning a funeral as part of their responsibility, or the family paid for final arrangements but did not attend the funeral. Some families did not want clients or staff to attend the family funeral or memorial. Staff had to convince families to allow them to attend. Both clients and staff wanted to celebrate the client's life and were upset when families did not have a service. Sometimes the arrangements made by families did not reflect what the client wanted. After a client died some families continued to be involved with the agency and others ceased having communication with agency staff.

Experience with health care providers. This section utilized data from the *external professional caregivers* category in Chapter V. Staff worked with health care providers in hospitals, nursing homes, ICF/DDs, and hospices. Staff interacted with physicians, nurses, social workers, and dentists. Staff had difficulty locating physicians and dentists willing to work with adults with I/DD. The quality of the care that clients' received from health care providers was dependent on the individual provider. Staff described one physician as compassionate and understanding. At one agency a speaker from a local hospital came and talked to staff. Interactions with other providers were negative. Staff described incidences of clients receiving poor medical care including: clients being misdiagnosed or receiving delayed diagnoses; clients being improperly medicated or over-medicated; and clients acquiring preventable conditions as a result of poor care. According to staff, medical care was impacted by health care providers' antiquated perceptions of people with I/DD. For example, some providers made assumptions about a client’s ability to understand information and talked to staff about the client as if he or she was not present. Providers also made assumptions about a client’s illness being directly related to his or her disability. Health care providers were nervous around clients and ordered tests or discharged them because it was easier than trying to work with them. Sometimes health care providers did not tell staff when a client died.

In addition to providing medical care, physicians influenced whether or not clients at the end of life could continue to attend the agency’s day program. Physicians also impacted whether or not ill clients could remain in their agency residence and receive additional services, or if these clients had to be transitioned out of the agency.

Agency staffs’ experiences with caregivers in nursing homes and the quality of care clients received was dependent on the facility. Some nursing home caregivers were receptive to agency staff and treated clients well. Staff also reported having poor or difficult communication with caregivers in nursing homes. Sometimes nursing home caregivers did not tell staff when a client died. According to staff, nursing homes were for-profit businesses and were more concerned with filling their beds than providing quality care for people with I/DD. Some nursing home caregivers did not understand why agency staff remained involved in the client’s care and did not treat clients or their families well. Clients were treated better when family and staff were actively involved with the client’s care. Clients in nursing homes did not get to keep their own primary care physicians and nursing homes had one physician for hundreds of patients.

According to agency staff, some agency run ICF/DDs were excellent. Staff also had positive experiences working with hospice caregivers and they learned from one another.

Hospice caregivers helped agency staff coordinate the client’s care. Some hospice caregivers taught classes and gave agency staff helpful resources, such as the *Five Wishes* document and a book outlining what happens at the very end of life. Hospice volunteers came to the agency to talk peers when a client was at the end of life.

Aim 3

The third aim of this study was to identify and describe agency staff perceptions of exosystemic facilitators and barriers to end-of-life care for adults with I/DD from diagnosis until after death. This aim was addressed by answering the following questions:

> What exosystemic facilitators and barriers were implicitly or explicitly identified by agency staff when describing their experiences with end-of-life care (from diagnosis until after death) for an adult with I/DD?
>
> - How did agency staff describe agency programs and policies? Were these programs and policies perceived as facilitators or barriers to end-of-life care?
> - How did agency staff describe rules and regulations in hospitals, hospices, and nursing homes? Were these rules and regulations perceived as facilitators or barriers to end-of-life care?
> - How did agency staff describe state and federal rules and regulations, including Medicaid and Medicare? Were these rules and regulations perceived as facilitators or barriers to end-of-life care?
> - What recommendations were offered for exosystemic improvements for end-of-life care delivery for people with I/DD?

Agency programs and policies. This section utilized data from the following categories in Chapter V: *Agency resources; staff experience/role*; *systemic issues;* and *recommendations.* None of the agencies had formal policies or universal protocols for working with clients at the end of life. Some agency staff recommended having a formal agency policy and more discussions about end of life and death. Other staff expressed concern that a formal policy could create additional red-tape and paperwork. While staff did not discuss any specific agency rules or regulations pertaining to end of life, they did discuss the type of services the agency offered and the training staff received before providing end-of-life care. Staff also discussed liability concerns that arose at their agencies such as: obtaining guardianship for clients; staff not having the legal authority to help clients; staff being uncomfortable providing medical care; and caring for a client with a do-not-resuscitate order.

All of the agencies offered day programs and residential living arrangements, including CILAs, for adults with I/DD. For purposes of providing end-of-life care, the primary difference between Agency A and Agencies B, C, and D was the presence of medical staff and agency run ICF/DDs. Agency A did not have an ICF/DD and only had one nurse for about 200 residents. The other three agencies had ICF/DDs and were able to provide clients with multiple levels of medical care based on their needs. Of these three agencies, each offered one or more of the following allied health services: nursing; occupational therapy; physical therapy; speech-language pathology; social work; licensed clinical professional counseling; and dietary counseling. One agency had a physician on staff.

All of the agencies offered staff training, but the degree to which training encompassed aging and end-of-life issues varied. At one agency, training on aging and end-of-life was either non-existent, only offered to certain agency staff, or was limited, outdated, and based on the stages model developed by Kübler-Ross. Two other agencies used the GRACE project protocol to train their staff on issues surrounding aging with I/DD. One agency required end-of-life training for staff working with geriatric clients, however, their qualified intellectual disabilities professionals were not required to take end-of-life training. Other staff received limited training on grieving. Some staff received training on end-of-life care independent of their agency training and shared the information with other agency staff.

Hospital, hospice, and nursing home rules and regulations. As described above in *Aim 2: Experience with health care providers*, the agency staff focused on their experience with health care providers and the care clients received, but they did not discuss any hospital, hospice, or nursing home rules or regulations.

State and federal rules and regulations. This section utilized data from the following categories in Chapter V: *planning and placement; systemic issues;* and *recommendations*. A lack of state funding was a frequently cited barrier to providing agency services for aging clients and individuals at the end of life. While the state had adopted a person-centered philosophy towards working with people with I/DD, state funding did not reflect this focus. At least one agency was working off of a large deficit and another closed two homes that offered nursing care because these homes were too expensive to maintain. State funding for the agencies was limited and continued to be cut. Limited funding impacted agency staff because the state would not pay for additional end-of-life training. Staff discussed a need for more state funding in order to pay them to provide one-on-one care when clients were at the end of life and to subsidize mental health counseling for clients and families.

Agencies received the same amount of funding regardless of the client’s age; however older clients put a strain on the agency programs because the senior services were more intensive. Obtaining additional funding to make agency homes accessible, or provide specialized or one-on-one services for clients, was difficult. When clients living in CILAs were ill the agencies had to pay overtime to have staff members stay with the client in their home. The agencies could not afford to provide 24-hours nursing care or hire additional staff to work with clients who lived in CILAs but were unable to leave their home during the day.

Client residential and day services were funded and regulated by two state agencies. Specifically, the Department of Public Health oversaw ICF/DDs and the Department of Human Services oversaw CILAs and day programs. CILA funding was desirable and hard to obtain. If clients were transitioned out of their CILA, returning to the CILA in the future was challenging. One of the CILA regulations was that clients must be out of their home for six hours a day. Clients living in CILAs had to work on four service goals including money management. The Department of Human Services had recently become more flexible about modifying or waiving the CILA requirements when clients were at the end of life. Staff also recommended that the state create new individual service plans when clients were at the end of life.

The care of clients in CILAs was coordinated by a case manager also called a PAS agent or ISA. According to staff, the state Department of Human Services preferred to keep clients in their agency homes. However, clients could not reside in CILAs if they needed IV-medication for any reason. The case managers had to approve any changes in the clients' residence and whether or not clients could stay in their home during the day. These case managers could require that the agency continue to care for clients instead of transitioning them out.

Being able to move a client with changing medical needs from a CILA in to an ICF/DD within the same agency was dependent upon the agency having an open bed in their ICF/DD. If no bed was available the client potentially had to be transitioned out of the agency into another ICF/DD, hospital, or nursing home depending on their needs. Sometimes these transitions were sudden and clients were moved far away from their agency home. When agencies had an opening in either their CILA or ICF/DD the state wanted to know how the agency planned to fill the vacancy. The state did not want agencies to build any additional residences. The agency was not paid when a client went to a rehabilitation facility or nursing home.

Sometimes there was an investigation when clients died in agency residences. Depending on the type of death, the police and possibly FBI were involved. When clients in CILA residences died, staff were required to call the state Department of Human Services and Office of the Inspector General and an administrative review was conducted. When clients died in ICF/DDs the staff informed the state Department of Public Health. A death investigation was mandatory when the deceased client had a state appointed guardian. According to staff, death investigations were challenging for staff and cast suspicion upon the agency.

Most clients were socioeconomically disadvantaged and received Medicaid or Medicaid funding. This funding covered home health and hospice care for clients. However, staff reported having difficulty obtaining home health services for clients with Medicaid funding. Medicaid and Medicare funding limited the clients' choices of health care providers and where they could be placed if they were transitioned out of their agency home. According to agency staff, better services were more expensive. One staff member discussed recent changes to Medicaid that dictated that dental services for clients were no longer covered. This staff member was uncertain how the state Department of Public Health mandated bi-annual dental visits would be funded for clients if Medicaid would not cover these visits.

Agency Staff Recommendations

This section utilized data from the *recommendations* section of Chapter V. Staff made multiple recommendations for improving the ways in which end-of-life care was currently being delivered for adults with I/DD. Staff offered suggestions in the following areas: 1) client participation in decision making; 2) providing quality end-of-life care to clients; 3) providing support to peers when a client is ill or dies; 4) necessary agency resources and staff training; 5) support that staff wanted from their agencies; and 6) training recommendations for health care providers.

First, staff advocated for including clients in their own end-of-life process. According to staff, ill clients had a right to know about what is going on with them medically. Staff recommended having end-of-life discussions with clients over time. Staff differed on the timing of these conversations. Some staff recommended discussing end-of-life planning when the client first entered the agency and others recommended waiting until a client received a life-limiting diagnosis. Some were unsure when exactly to have these conversations. Staff said that they should educate and empower clients about their options and include clients by asking them what they wanted for their own end-of-life and post-death. Staff suggested that pictures or documents such as the *Five Wishes* or *My Health Passport* might be helpful. Staff reported that they should engage in person-centered planning and support and encourage clients’ preferences at the end of life. Staff should also tell families that they will talk to clients’ about their diagnoses and should encourage families to remain connected to the agency even after the client died.

Next, staff offered several suggestions for providing quality end-of-life care for dying clients. End-of-life care should be holistic and focus on the clients’ wishes and interests. Care should be provided in the clients’ homes with additional services as needed. Clients should not be moved to a nursing home or hospital. Clients should be surrounded by loved ones, including family, friends, and staff who want to be a part of the process. Staff also recommended the following when providing quality end-of-life care to clients: treat clients with compassion and respect; make sure clients are comfortable and their pain is well managed; talk to clients and allow them to grieve; support clients and let them know they are safe and not alone; make sure the end of life is as dignified as possible; let the clients know they have purpose and touched peoples’ lives; maintain the same conversations and habits as before they were ill; and celebrate their time left, e.g., celebrate Christmas in August, or have an early birthday party.

Third, Staff suggested working with surviving clients on their understanding of grief, loss, and death by using pictures and art. Staff recommended having a grief support group immediately after a peer died so that clients could discuss their collective loss. Staff also suggested conducting therapy with clients in their home and not during their day program. Staff reported that taking clients to the cemetery after a peers died could be beneficial.

Fourth, staff discussed the resources and training they needed in order to care for clients at the end of life. Staff recommended creating a designated agency team to work with clients at the end of life and their families. An agency social service person or other staff member could be a liaison between staff, families, peers, and hospice care providers. The staff also said they needed up-to-date resources including: books or documentaries about loss and coping that were for adults with I/DD and not for children; a list of other agencies, professionals, hospitals, hospices, and nursing homes; information about low cost funeral and burial options; and information about other supports for families and surviving clients.

Staff needed training in caring for clients at the end-of-life, their families, and surviving clients. Staff said that this training should be formal and ongoing and cover the following issues: end of life, grief support, and bereavement; types of loss; facing mortality; dignity and person-centered planning; using dying terminology; Kübler-Ross stages; having compassion and respect for clients; answering client questions; navigating end-of-life choices; mediating relationships with clients' families; caring for clients on oxygen; helping clients without promoting personal or religious agendas; being nonjudgmental and having compassion and respect for families; understanding that guardians are aging; feeling comfortable caring for dying clients; and counseling surviving clients. Staff training should be conducted by hospice caregivers or other experts with end-of-life experience. End-of-life care for people with I/DD should be an area of specialization.

Fifth, staff wanted supervisors to understand that sometimes they needed to step away or cry when clients were at the end of life. Staff at Agency A suggested having an agency run facility where clients received medical and hospice care. Staff at another agency suggested having an agency hospital. Other suggestions for agency changes included: bringing in experts; looking into insurance and future planning for funerals; verifying that all necessary tests are performed while clients are at the hospital; bringing clients into the agency in their 20s; and keeping appropriate attire at the agency for clients attending funerals.

Finally, staff made suggestions for health care providers in hospitals, hospices and nursing homes (see the *external professional caregivers* and *recommendation* categories in Chapter V). According to agency staff, health care providers needed training in working with people with I/DD. This training should include: treating clients as human beings; being compassionate and caring; tailoring services to the clients' needs; determining clients' pain; and not making assumptions about what clients do or do not understand.

Main Study Findings

While the above section addressed the specific study aims, below is a brief overview of the three main findings from this dissertation research that span across all of the study aims. In the next chapter the importance of these study findings and implications for further research are explored.

Main finding #1. The first main finding from this dissertation research is: *Staff have complicated relationships with clients and their families and they perform multiple, complex roles with limited end-of-life training and support.* Clients were like family to the agency staff. Some clients had no family other than agency staff and clients. Staff found it challenging to observe the clients declining and to remember that the client was not a friend or family member. Some families were actively involved in clients' lives while others never communicated. Often, staff had worked closely with clients' families for many years. Sometimes working with a family was a positive experience. However, relationships between staff and families were also described as adversarial.

Agency staff worked in a multiple complex roles including caregiver, advocate, liaison, mediator, and care planner when caring for adults with I/DD at the end of life. Staff provided emotional support and physical care to clients at the end of life while simultaneously caring for their peers. Staff acted as a client advocate with both health care professionals and family members by encouraging them to be straightforward with clients about their diagnoses and prognoses. Staff also advocated for including clients in making decisions about their own end-of-life care. Staff were frustrated and had trouble respecting a family’s decisions when the family did not know or follow the client’s end-of-life wishes. Staff advocated for giving clients direct information and encouraged families to be straightforward. Staff also advocated for including clients in their own end-of-life process and said that clients had a right to be informed and to participate in decision making. Staff acted as a liaison between health care providers and clients by facilitating communication between the two. Finally, in their care planner role, staff worked with families when clients needed to be transitioned to another home. Staff were often responsible for making final arrangements, including funeral and burial or cremation plans because families were not involved, or did not feel obligated to plan and pay for a funeral.

While none of the agencies had formal policies or universal protocols for providing end-of-life care some staff recommended forming such a policy. Other staff were concerned that a formal policy would create more paperwork. All of the agencies offered staff training, but staff generally described end-of-life training as either non-existent, only offered to certain agency staff, or limited and outdated. Two agencies used the GRACE project protocol to train their staff on aging issues. Some staff independently sought out training in end-of-life care and shared the information with other agency staff. Staff wanted more training and said they needed additional resources in order to provide quality end-of-life care to adults with I/DD. Staff reported that end-of-life care for people with I/DD should be an area of specialization.

Some staff reported being fortunate and found caring for adults with I/DD at the end of life rewarding. Other staff were uncomfortable providing medical care and reported that the end-of-life experience was frustrating and overwhelming. Staff reported having difficulty experiencing their own grief while simultaneously supporting the surviving clients and other staff. Their experience was even more difficult when staff had to make funeral arrangements or the authorities were involved. Staff supported one another while caring for clients at the end of life, but the support they received from their agency was variable. Staff wanted to be asked about how they felt and for supervisors to understand that sometimes they needed to step away or cry when clients were at the end of life. Some staff were debriefed and informed immediately when a client died. Other staff were given a support phone number. According to other staff, agency administrators told them to remember that they were not the client's friend or family member, they were there to do a job, and that they should not to get too close to the clients.

Main finding #2. The next main finding from this dissertation research is that: *Decisions are often made for clients by others who underestimate their functional abilities and may not know them well*. Many clients did not have any advance care plans. While some clients were their own guardian, most had a family member or state appointed guardian. Families or guardians were generally responsible for making decisions. At times, physicians were also involved in making decisions, such as determining whether or not clients at the end of life could attend the agency's day program and remain in the agency residence or if they had to be transitioned out. Physicians also determined when clients who were their own guardians were incapable of making decisions.

Although sometimes agency staff were more actively involved than a client's family, staff were not involved in creating advanced care plans for the clients. Staff wanted to help clients with decision making but they did not have any legal authority. Staff looked into obtaining guardianship for a client who was his own guardian but could not make decisions for himself. According to staff, the client would have to be legally declared incompetent. This process was very expensive and meant taking away the client's right to be his own guardian. Staff reported that getting rid of a guardian was more challenging than obtaining one.

Staff and family determined whether clients should be involved in decision making depending upon their functional abilities. While some clients actively participated in decision making at the end of life other clients did not. Some clients were not capable of participating, but other clients were not given the opportunity to participate. Some people, including family members and health care providers, believed that clients were incapable of understanding their diagnoses or of knowing what they wanted at the end of life. In some cases, family members did not want a client not be told about his or her illness or how sick he or she was. In three of the four agencies, end-of-life was not discussed until a client became ill or received a life-limiting diagnosis. Staff knew that clients were often aware of their illnesses and were capable of making decisions for themselves. Staff recommended having end-of-life discussions with clients over time. Some staff recommended discussing end-of-life planning when the client first entered the agency and others recommended waiting until a client received a life-limiting diagnosis. Staff reported that client reactions to having a life-limiting illness were impacted by how information was presented to them.

Main finding #3. The third main finding from this dissertation research is: *Agency staff want to provide end-of-life care for adults with I/DD in their agency home, yet they are currently met with more systemic barriers than facilitators to providing care*. Agency staff preferred to keep clients in their agency home at the end of life. The Department of Human Services also preferred to keep clients in their agency homes. However, agency staffs' ability to provide necessary medical care and meet the accessibility needs of clients at the end of life varied by agency. As a client's health deteriorated the client and agency staff increasingly interfaced with health care providers in hospitals, nursing homes, ICF/DDs, and palliative care. Agency staff also interfaced with a number of agencies that impacted caring for clients at the end of life. Specifically, the Department of Human Services oversaw CILAs and agency day programs and the Department of Public Health regulated care and funded clients living in ICF/DDs. The care of clients in CILAs was coordinated by a case manager who had to approve changes in the clients' residence including allowing clients to stay in their home during the day. Staff discussed facilitators and barriers at multiple systemic levels including the agency, health care providers, and the state.

The quality of the care that clients' received from health care providers was dependent on the individual provider. The staff described incidences of clients being misdiagnosed or receiving delayed diagnoses, being improperly medicated or over-medicated, and acquiring preventable conditions as a result of poor medical care. Care at the end of life was facilitated by health care providers being compassionate and understanding. Staff described multiple barriers to providing quality end-of-life care including: difficulty locating providers willing to work with adults with I/DD; health care providers being nervous around clients; health care providers making assumptions about clients' ability to understand their diagnosis or participate in decision making; and providers' assumptions about illness being directly related to disability

Agency staffs' experiences with caregivers in nursing homes and the quality of care clients received was also dependent on the facility. Client care was facilitated when nursing home caregivers were receptive to agency staff and treated the clients well. Family and agency staff involvement with the client also facilitated quality end-of-life care. Staff described barriers to care including: treating clients and their families poorly; caregivers in nursing homes not understanding why agency staff remained involved in the client's care; and poor communication between agency staff and caregivers in nursing homes. Clients in nursing homes were unable keep their own primary care physicians and nursing homes had one physician for hundreds of patients. Health care providers in both hospitals and nursing homes did not always inform staff when a client died.

Staff reported having predominately positive experiences working with hospice caregivers. Client care at the end-of-life was facilitated by staff and hospice caregivers learning from one another. Hospice caregivers helped agency staff coordinate the client's care, taught classes, and provided helpful resources. Hospice caregivers also talked peers when a client was at the end of life.

The presence of medical staff and an agency ICF/DD impacted staffs' ability to care for clients at the end of life. Agency A did not have an ICF/DD and only had one nurse for about 200 residents. Thus, staff at Agency A often did not provide care for clients at the very end of life because they were transitioned once their medical needs were beyond the staffs' ability to provide necessary care. The other three agencies had ICF/DDs and provided multiple levels of medical care based on clients' needs.

A lack of state funding was identified as a constant barrier to providing end-of-life services for adults with I/DD. State funding was limited and agency funding continued to be cut. One agency had closed two homes with nursing care because these homes were too expensive. Agencies received the same amount of state funding regardless of the client's age even though senior services were more costly. Staff had difficulty obtaining additional funding to make agency homes more accessible, or provide specialized services. The state would also not pay for any additional staff training, including courses on end-of-life.

Obtaining CILA funding was challenging and if clients were transitioned out of their CILA home returning was difficult. Being able to move a client between a CILA and ICF/DD within the same agency was dependent upon availability. When agencies had an opening in either their homes the state wanted the agency to fill the vacancy. Thus, if there was no open bed the client might be transitioned out of the agency into another ICF/DD, hospital, or nursing home. Sometimes these transitions were sudden and clients were moved far from the agency. When clients were moved to ICF/DDs, even within the same agency, their care was now regulated and funded by the Department of Public Health. Many clients transitioned multiple times before they were at the end of life. Agencies were not compensated when a client went to a rehabilitation facility or nursing home.

Most clients received Medicaid or Medicaid funding which posed several barriers to care for clients at the end of life. Specifically, clients had limited choices of health care providers and limited choices of where they could be placed if they were transitioned out of their agency home. Staff reported having difficulty obtaining home health for clients with Medicaid funding.

The Department of Human Services oversaw CILAs and day programs. At the end of life, some CILA regulations were barriers to care. For example, some clients had to keep working on their goals, such as money management, even when they were at the end of life. The Department of Human Services had recently become more flexible about the CILA requirements. Clients in CILAs had to leave their residence for six hours a day. This regulation impacted client care because the agencies could not afford to provide 24-hours care to clients in CILAs who were unable to leave their home. There were also state requirements for reporting a death when the client was in a CILA or ICF/DD. Sometimes the police and possibly FBI investigated after a client died. A death investigation was mandatory for clients with a state appointed guardian. Death investigations were challenging for the agency and staff.

Chapter VII

Discussion

The purpose of this dissertation research was to explore the experiences of agency staff who provided end-of-life care for adults with I/DD in order to clarify the services currently being provided, identify gaps in services, and to describe implications for social work clinical practice and policy. While there has been an increase in the literature describing the experiences of adults with I/DD and their agency staff caregivers at the end of life, much remains unknown (Perkins & Friedman, 2012; Todd et al., 2013). There is a good foundation of information, in particular at the microsystemic level; however, how all of these various microsystems interact at the mesosystemic level is less prevalent in the literature. There is also limited research exploring the impact that exosystems, such as state funding and regulations, have on end-of-life care for adults with I/DD. This dissertation research contributes to the literature by further identifying critical issues at the micro-, meso-, and exosystemic levels and by describing agency staff suggestions for facilitators to end-of-life care. First, this chapter contains a description of the strengths and limitations. Next, the main findings from this dissertation research are reviewed. Third, staff recommendations for improving end-of-life care are presented. This chapter concludes with a discussion of research implications and the role of social work. In order to highlight the contribution to the scholarship, this section will situate these dissertation findings with the current literature.

Study Strengths and Limitations

The study investigator (Moro) recognizes that this study had several limitations. First, the secondary analysis of qualitative data poses the risk for intensifying or exaggerating any bias effect that might have been apparent in the design of the original study (Thorne, 1994). In addition, the sample size in this study is small and the participants were not selected randomly, thus the results are not generalizable. Along similar lines, the literature and these data indicate that in the United States end-of-life care provision for adults with I/DD differs by agency and by state. Thus, the sample used in this dissertation research may not be indicative of the end-of-life care provided by other community agencies. However, as will be explored in the Chapter VII, many of the findings in this dissertation research confirm the observations from both the national and international clinical and empirical literature.

The greatest conceptual limitation of this dissertation research is that by only including the agency staff perspective, the voices of other important microsytems, e.g., clients, family members, and health care providers, are lost. Thus, the picture of what end-of-life care looks like for adults with I/DD remains somewhat incomplete. This is particularly problematic when reviewing the data about the agency staff relationships with clients and families because at times the data do not present families in a favorable light and may influence the reader to make inferences about families without knowing anything about them. While these dissertation findings are important because they illustrate the impact that relationships with families have on agency staff, they do not offer any meaningful insight as to how to address, and ultimately facilitate, more positive relationships between families, clients, and agency staff. Additionally, the small sample presented in this study may not reflect other agency staff experiences with families. As will be discussed in more detail in the *implications for future research* section below; further research should include multiple perspectives, including those of the clients and their families.

This dissertation research also had numerous strengths. Specifically, data management and analysis were ongoing and guided by established grounded theory analytic methods. The interviews used for this study were transcribed in real time by a CART professional and any errors were corrected. In addition, the transcripts were compared to the digital recordings to assure accuracy. The methodological design of this study also had many features which minimized subjective interpretations and maximized the rigor of the study. Triangulation was used to further analyze external factors, such as state CILA regulations and Medicare provisions, which impacted end-of-life care. Credibility and dependability of the study procedures and outcomes were also enhanced by the study investigator (Moro) maintaining an audit trail which outlined and documented of all procedural and interpretative decisions made throughout data collection and analysis (Sandelowski & Barroso, 2003). In this dissertation research, the memos served as an audit trail in which the study investigator (Moro) documented her thought processes and ongoing interpretations of the data. Relevant memo data were presented in the *investigator comments* sections in Chapter V.

Main Finding #1

The first main finding from this dissertation research is that staff have complicated relationships with clients and their families and they perform multiple, complex roles with limited end-of-life training and support.

Agency staff relationships with clients and families. Similar to the findings of several other scholars, agency staff in this dissertation study had close relationships with clients (McCallion et al., 2012; McCarron et al., 2011; Ryan et al., 2011b; Todd, 2005, 2013) and described the relationships between clients and their families as variable (Ryan et al., 2011b;

Todd, 2013). Staff referred to clients as being like family (Ryan et al., 2011b; Todd, 2013) and often the two had worked together for many years (McCallion et al., 2012; McCarron et al., 2011; Todd, 2005). Some families were actively involved in clients' lives while others never communicated (Ryan et al., 2011b; Todd, 2013). Staff in this dissertation study had often worked closely with clients' families for many years.

Similar to the findings of Ryan, Guerin, Dodd, and McEvoy (2011b), the relationships between staff and clients' families could become strained when the client was at the end of life. While working with families was sometimes a positive experience for the staff they also described the relationships as adversarial. Staff were frustrated and had trouble respecting a family's decisions when the family did not know or follow the client's end-of-life wishes. Other scholars have also found that staff found it problematic when families who have no ongoing relationships suddenly reappear when the client is at the end of life (Ryan et al., 2011b; Todd, 2013).

Agency staff reported working in a multiple complex roles including caregiver, advocate, liaison, mediator, and care planner. Staff provided emotional support and physical care to clients at the end of life while simultaneously caring for their peers. Similar findings were echoed in a study by Wiese, Stancliffe, Dew, Balandin, and Howarth (2014) where they found that agency staff assisted people with I/DD to understand the end-of-life and its component parts. Several scholars have also discussed the affect that the death has on both staff and the surviving peers (Blackman & Todd, 2005; MacHale et al., 2009; McEvoy et al., 2010). For example, staff often spend an inordinate amount of time caring for the dying person and other clients' needs may be minimized (Blackman & Todd, 2005). Similar to finding by (Todd, 2013), staff in this dissertation study were often responsible for making final arrangements, including funeral and burial or cremation plans.

Staff also acted as a client advocate with both health care professionals and family members by encouraging them to be straightforward with clients about their diagnoses and prognoses. Staff acted as a liaison between health care providers and clients by facilitating communication between the two. Staff also advocated for including clients in making decisions about their own end-of-life care. Advocacy has been previously identified as an important component of the agency staff role (Brolan et al., 2012). Several scholars have also found that agency staff generally believe that adults with I/DD have a right to know about their life-limiting illness (Brolan et al., 2012; Ryan et al., 2011a; Savage et al., 2010; Todd, 2005; Tuffrey-Wijne, 2012; Tuffrey-Wijne et al., 2010a; Tuffrey-Wijne et al., 2013).

Staff experience providing end-of-life care. Some staff reported being fortunate and found caring for adults with I/DD at the end of life rewarding. Several scholars have also reported that caring for clients at the end of life was viewed as an important part of staffs' caregiver role (Kirkendall et al., 2012; Todd, 2005, 2013; Wiese et al., 2012b) and that some staff felt privileged to be present when a client died (Ryan et al., 2011b).

In both the literature and this dissertation research, other staff describe the experience as frustrating, or overwhelming (Kingsbury, 2010; Ryan et al., 2011a; Ryan et al., 2011b; Todd, 2005; Todd & Read, 2010). Staff in this dissertation study were also uncomfortable providing medical care and reported that the end-of-life experience was hectic. McCarron, McCallion, Fahey-McCarthy, and Connaire (2011) also found that not being trained in pain and symptom management made staff anxious about providing care. Similar to previous findings (MacHale et al., 2009; McEvoy et al., 2010), staff in this dissertation study reported having difficulty experiencing their own grief while simultaneously supporting the surviving clients and other staff. The end-of-life experience was even more difficult for staff when they had to make funeral arrangements or the authorities were involved.

Limited training and support. Several scholars have cited a lack of training and resources as barriers to providing end-of-life care (Fahey-McCarthy et al., 2009; Ryan et al., 2011a; Ryan et al., 2010; Stein, 2008; Tuffrey-Wijne et al., 2010b). In this dissertation research, all of the agencies offered staff training, but the degree to which aging and end-of-life were included was variable. Staff generally described end-of-life training as either non-existent, only offered to certain agency staff, or limited and outdated. Staff wanted more training and said they needed additional resources in order to provide quality end-of-life care to adults with I/DD. Staff reported that end-of-life care for people with I/DD should be an area of specialization.

Staff in this dissertation study reported receiving variable support from their agency. For example, some staff were given a support phone number and others were told that they had a job to do and that they should not to get too close to the clients. Several scholars have posited that agency staff are rarely given the opportunity to discuss and process their end-of-life experiences (Blackman & Todd, 2005; Ryan et al., 2011b; Todd, 2013).

Main Finding #2

The next main finding from this dissertation research is that decisions are often made for clients by others who underestimate their functional abilities and may not know them well.

The guardianship model. According to the staff, most of the clients did not have any advance care plans. Clients generally had a family member or state appointed guardian who were responsible for making decisions. According to the literature, there is a guardianship model of decision making in the United States (Kohn et al., 2012). Thus, legal decisions for adults with I/DD are generally made by a surrogate who is either a family member or a court appointed state guardian. In addition, most families do not have concrete placement plans established (Bibby, 2012; Heller & Caldwell, 2006; Shaw et al., 2011) and family members play an important role in end-of-life care even when there has been limited prior contact (Tuffrey-Wijne et al., 2010b).

Staff in this dissertation study reported looking into obtaining guardianship for a client who was his own guardian but could not make decisions for himself. According to staff, the client would have to be legally declared incompetent and the process was very expensive. Being declared incompetent meant taking away the client’s right to be his own guardian. Staff reported that getting rid of a guardian was more challenging than obtaining one. The guardianship model has been criticized by scholars who caution that this system should not be used as a result of faulty assumptions about ones functional ability or as a routine part of permanency planning (Kohn et al., 2012). One option when an adult with I/DD is his or her own guardian, but is no longer be able to make decisions, is to appoint a health care agent instead of having the individual declared incompetent and appointing a guardian (Levy & van Stone, 2010). However, this option is rarely utilized for adults with I/DD. Although sometimes agency staff were more actively involved than a client’s family, staff were not involved in creating advanced care plans. Staff wanted to help clients with decision making but had no legal authority.

Health care provider role in decision making. According to staff, physicians were involved in making decisions for client that reached beyond providing medical care. They determined whether or not clients at the end of life could attend the agency’s day program, and whether clients could remain in the agency or if they had to be transitioned out when they required additional services. Physicians also determined when a client who was his or her own guardian was incapable of making decisions. According to Levy and van Stone (2010), there is no accepted definition of a never-competent individual and the courts rely on the opinions of physicians to determine whether an individual with I/DD can consent to medical treatment.

Client participation in decision making. While some clients actively participated in decision making at the end of life other clients were not given the opportunity to participate despite staff perceptions that the individual was capable of being involved. There is evidence in the literature to suggest that adults with I/DD want to be informed and participate when they have life-limiting medical conditions (Kingsbury, 2010; Ryan et al., 2011a; Tuffrey-Wijne, 2012; Tuffrey-Wijne et al., 2010a; Tuffrey-Wijne & McEnhill, 2008). Staff in this dissertation research reported that client reactions to having a life-limiting illness were impacted by how information was presented to them. Tuffrey-Wijne, Bernal, and Hollins (2010a) additionally found that not being given the information and support they need to understand their diagnosis creates additional stress.

Why clients are not involved in decision making. According to staff, some people, including family members and health care providers, believed that clients were incapable of understanding their diagnoses or of knowing what they wanted at the end of life. In some cases, family members did not want a client not be told about his or her illness or how sick he or she was. There is evidence to strongly suggest that adults with I/DD are excluded from making health care decisions for themselves (Bekkema et al., 2014b; Ryan et al., 2011a; Savage et al., 2010; Tuffrey-Wijne et al., 2010b; Wagemans et al., 2010). In addition, it is not uncommon for family members to make health care decisions for adults with I/DD without eliciting their preferences (Levy & van Stone, 2010) or to decide that, in order to protect the individuals from distress, they should not be fully informed about their condition (Bekkema et al., 2014a; Savage et al., 2010; Tuffrey-Wijne, 2012; Tuffrey-Wijne et al., 2010a; Tuffrey-Wijne et al., 2010b; Tuffrey-Wijne et al., 2013). While not explicitly discussed by the staff in this dissertation study, collusion between health care providers and family caregivers has been described in literature (Ryan et al., 2011a; Tuffrey-Wijne et al., 2010a). Staff in this dissertation study had trouble respecting a family's decisions when the family did not know or follow the client's end-of-life wishes.

In three of the four agencies, end-of-life was not discussed until a client became ill or received a life-limiting diagnosis. Staff advocated for giving clients direct information including them in their own end-of-life process. According to the literature, agency staff generally believe that adults with I/DD have a right to know about their life-limiting illness (Ryan et al., 2011a; Savage et al., 2010; Todd, 2005; Tuffrey-Wijne, 2012; Tuffrey-Wijne et al., 2010a; Tuffrey-Wijne et al., 2013). Staff recommended having end-of-life discussions with clients over time and some recommended discussing end-of-life planning before a client received a life-limiting diagnosis. Similar sentiments were echoed in the clinical literature where scholars and disability advocacy groups have offered resources that caregivers can use to discuss aging and end of life with adults with I/DD (California Department of Developmental Services, 2007; Donaghy, Bernal, Tuffrey-Wijne, & Hollins, 2002; Kingsbury, 2009; NYSARC; Sunderland People First).

Main Finding #3

The third main finding from this dissertation research is that agency staff want to provide end-of-life care for adults with I/DD in their agency home, yet they are currently met with more systemic barriers than facilitators to providing care.

Health care provider barriers. The quality of the care that clients' received from health care providers was dependent on the individual provider. The staff described incidences of clients being misdiagnosed or receiving delayed diagnoses, being improperly medicated or over-medicated, and acquiring preventable conditions as a result of poor medical care. Several other scholars have discussed older adults with I/DD acquiring preventable conditions that go unrecognized, are not diagnosed properly, or are inadequately treated (Haveman et al., 2011; Marks et al., 2008).

According to staff, care at the end of life was facilitated by health care providers being compassionate and understanding. Other scholars have identified the following facilitators to the client and health care provider interaction: adapting communication styles in order to work with nonverbal individuals; taking the time to understand the unique needs of adults with I/DD; providing post-discharge support; having a family or agency staff present (Webber et al., 2010); providing easy-to-read information with symbols and pictures; not using acronyms and abbreviations; not talking down to people with disabilities (Gates, 2011); including all of the appropriate caregivers including agency staff, family; and breaking down information into singular chunks and delivering it gradually in a slow, ongoing process (Tuffrey-Wijne, 2012)

Staff described multiple barriers to providing quality end-of-life care including: difficulty locating providers willing to work with adults with I/DD; health care providers being nervous around clients; health care providers making assumptions about clients' ability to understand their diagnosis or participate in decision making; and providers making assumptions about illness being directly related to disability. Two of the primary barriers to quality end-of-life care identified in the literature are communication difficulties and limited or no health care provider training or experience working with adults with I/DD (Bradbury-Jones et al., 2013; Friedman et al., 2012; Hahn & Cadogan, 2011; Ouellette-Kuntz, 2005; Read, 2005; Ryan & McQuillan, 2005; Tuffrey-Wijne & McEnhill, 2008; Webber et al., 2010). There is also evidence to suggest that some providers believe that adults with I/DD cannot comprehend medical information or participate in health care decision making (Johnson, 2010; Kingsbury, 2010; Tuffrey-Wijne et al., 2006; Ward et al., 2010; Webber et al., 2010). Adults with I/DD often receive incomplete information about their illness and treatment options when compared to members of the general population (Friedman et al., 2012; Tuffrey-Wijne et al., 2010a). In contrast, in a recent study health care providers reported that individuals with I/DD should be told about their diagnosis and prognosis provided that full disclosure was right for the individual (Tuffrey-Wijne et al., 2013).

Nursing home barriers. Agency staffs' experiences with caregivers in nursing homes and the quality of care clients received was also dependent on the facility. Bigby (2010), also found that often adults with I/DD are not as well cared for in residential aged care facilities as they are in disability focused agencies. In nursing homes, client care was facilitated when nursing home caregivers were receptive to agency staff and when family and/or agency staff were involved in the care. Staff described the following barriers to care in nursing homes: treating clients and their families poorly; caregivers in nursing homes not understanding why agency staff remained involved in the client's care; and poor communication between agency staff and caregivers in nursing homes.

Palliative care facilitating end-of-life care. Staff reported having predominately positive experiences working with hospice caregivers. Client care at the end-of-life was facilitated by staff and hospice caregivers learning from one another. Hospice caregivers helped agency staff coordinate the client's care, taught classes, and provided helpful resources. Hospice caregivers also talked peers when a client was at the end of life. The literature exploring the role of palliative care in working with adults with I/DD at the end of life presents a slightly different picture. According to Ryan, Guerin, Dodd, and McEvoy (2011b), agency staff reported that they were better suited than palliative care professionals to provide end-of-life care. Other studies have found that there is confusion from both agency staff and palliative care professionals about their specific roles when they are both providing care (Cross et al., 2012; Kirkendall et al., 2012; Todd & Read, 2010). In a recent study, McLaughlin, Barr, McIlfatrick, and McConkey (2014) also found that, despite the fundamental importance of working together, a partnership between palliative care and intellectual disability services was rare. However, the experience was positive when these two groups engaged in a partnership. There is also evidence to suggest that palliative care and hospice services are underutilized by people with I/DD (Cross et al., 2012; Friedman et al., 2012; Marks et al., 2008; Tuffrey-Wijne et al., 2007).

Medicaid and Medicare. Consistent with the research, according to agency staff, most clients were socioeconomically disadvantaged and received Medicaid or Medicaid funding (Braddock et al., 2011). Medicaid and Medicare funding posed several barriers to care for clients at the end of life. Specifically, clients had limited choices of health care providers and limited choices of where they could be placed if they were transitioned out of the agency. These findings are consistent with the literature on Medicare and Medicaid funding because some services are mandated by the federal government, but the regulatory provisions for end-of-life care vary by state (Botsford & King, 2010; Braddock et al., 2011; Friedman et al., 2012; Rizzolo et al., 2013).

Limited agency resources and funding. A lack of funding and resources were identified in both the literature and this dissertation study as a constant barrier to providing end-of-life services for adults with I/DD (Botsford, 2004). Limited resources may include a lack of on-site nursing support, inadequate access to palliative care services, and few resources to devote to end-of-life care (Botsford, 2004; Ryan & McQuillan, 2005; Stein, 2008). When a client is in a hospital, agency resources are taxed if the agency has to pay overtime or hire additional personnel to be with the individual in the hospital (Webber et al., 2010). According to the staff in this dissertation study, agency funding was limited and continued to be cut. The state provided the same amount of funding regardless of the client's age even though senior services were more costly. Additionally, staff had trouble obtaining additional funding to make agency homes more accessible, or provide specialized services. One agency had closed two homes that offered nursing care due to the expense. The state would not pay for any additional staff training. This finding was consistent with that of other scholars who have reported that agencies may not be able to afford to adequately train staff or hire additional staff as needed to provide end-of-life care (Botsford, 2004; Todd, 2005; Tuffrey-Wijne et al., 2006).

According to the staff participating in this dissertation research, the presences of medical staff and an agency ICF/DDs impacted their ability to care for clients at the end of life. Agency A did not have an ICF/DD and only had one nurse. Thus, the staff at Agency A often did not provide care for clients at the very end of life. The other three agencies had ICF/DDs and offered multiple levels of medical care. These findings are consistent with those of other scholars who have reported that community agencies that provide housing for adults with I/DD often have limited nursing support (Botsford, 2004). Additionally, when someone requires intensive nursing care they may transition from their residence into an ICF/DD or nursing home (Jokinen et al., 2012).

Service delivery barriers in Illinois. There was no research identified specifically exploring the impact of state agencies in Illinois on end-of-life care for adults with I/DD. According to agency staff, in Illinois the Department of Human Services also preferred to keep clients in their agency homes. However, agency staffs' ability to provide necessary medical care and meet the accessibility needs of clients at the end of life varied by agency. As a client's health deteriorated he or she increasingly interfaced with a number of state agencies that impacted care. Specifically, the Department of Human Services oversaw CILAs and agency day programs and the Department of Public Health regulated care for clients living in ICF/DDs. The care of clients in CILAs was coordinated by a case manager who had to approve any changes in the clients' residence including allowing clients to stay in their home during the day. Staff discussed facilitators and barriers at multiple systemic levels including the agency, health care providers, and the state.

Obtaining CILA funding was challenging and if clients were transitioned out of their home returning was difficult. Being able to move a client between a CILA and ICF/DD within the same agency was dependent upon availability. The state wanted the agencies to fill vacancies quickly and if there was no open bed a client might be transitioned out of the agency into another ICF/DD, hospital, or nursing home. Once transitioned into ICF/DDs a client's care was regulated and funded by the Department of Public Health.

Some CILA regulations were barriers to providing end-of-life care. For example, clients had to leave their CILA residence for six hours a day, thus, the agencies could not afford to provide care to clients who were unable to leave their home. There were also state requirements for reporting a death when the client was in a CILA or ICF/DD. Sometimes the police and possibly FBI investigated after a client died. A death investigation was mandatory when the client had a state appointed guardian. Death investigations were challenging and cast suspicion upon the agency and staff.

Staff Recommendations

Staff offered suggestions in the following areas: client participation in decision making; providing quality end-of-life care to clients; providing support to peers when a client is ill or dies; necessary agency resources and staff training and support needs; and training recommendations for health care providers.

Client participation in decision making. Several scholars have advocated for the inclusion of adults with I/DD who have the capacity to participate in their own health care and end-of-life decision making (Blackman & Todd, 2005; Bradbury-Jones et al., 2013; Kingsbury, 2010; Kingsbury, 2012; Levy & van Stone, 2010; McCallion et al., 2012; Savage et al., 2010). Staff in this dissertation research also advocated for including clients in their own end-of-life process. Staff recommended having end-of-life discussions with clients over time, but differed on the timing of these conversations. Some staff recommended discussing end-of-life planning when the client first entered the agency and others recommended waiting until a client received a life-limiting diagnosis. Some were unsure when exactly to have these conversations.

Several scholars have also advocated for advance care planning with adults with I/DD before a health crisis arises (Bekkema et al., 2014a; Bibby, 2012; Heller & Caldwell, 2006;

Kingsbury, 2010; Levy & van Stone, 2010). According to Kingsbury (2010), it may be easier to broach the subject of end of life by starting a conversation with individuals and families about decision making during the mandated annual planning meetings and then gradually work end-of-life care into the conversation. In addition, having discussions before a crisis can decrease the stress on the agency staff and the client. Staff in this dissertation research suggested using pictures or documents such as the *Five Wishes* or *My Health Passport*. Staff reported that they should engage in person-centered planning and support clients' preferences at the end of life. Staff should also inform families that they will talk to clients' about their diagnoses.

Providing quality end-of-life care. According to staff, end-of-life care should be holistic and focus on the clients' wishes and interests. Care should be provided in the clients' homes with additional services as needed and they should not be moved to a nursing home or hospital. This finding is consistent with the literature because staff caregivers generally prefer to keep adults with I/DD in their homes (Bekkema et al., 2015; Bigby et al., 2011; Todd, 2013). Staff also recommended the following components of end-of-life care: treat clients with compassion and respect; make sure pain is well managed; allow clients to grieve; let clients know they are not alone; maintain dignity; let the clients know they have purpose and touched peoples' lives; celebrate birthdays and holidays early. In the general literature on aging, there is substantial agreement that the following are important aspects of end-of-life care: physical comfort; emotional support for the dying person and his or her family; open communication and shared decision making; and access to end-of-life care (Teno, 2005).

Providing support to peers. According to the literature, agency staff spend an inordinate amount of time caring for the dying person and other clients' needs may be minimized

(Blackman & Todd, 2005). Staff in this dissertation research provided several concrete suggestions for working with surviving clients. For example, they suggested having a grief support group immediately after a peer died so that clients could discuss their collective loss. Staff also suggested using art and conducting therapy with clients in their home and not during their day program. Staff recommended taking clients to the cemetery to visit after a peer died.

Agency resources and staff training and support needs. Staff in this dissertation research wanted more training and needed more resources. Although there is a need for additional training and support for staff who provide end-of-life care for adults with I/DD, according to the literature, less is known about what the training should look like (Bekkema et al., 2015; Dunkley & Sales, 2014; Ryan et al., 2011b). Staff recommended creating a designated agency team to work with clients at the end of life and their families. An agency social service person or other staff member could be a liaison between staff, families, peers, and hospice care providers. The staff also said they needed up-to-date resources and training on caring for clients at the end-of-life, as well as their families and surviving clients. Staff said that this training should be formal and ongoing and cover the following issues: end of life, grief support, and bereavement; types of loss; facing mortality; dignity and person-centered planning; using dying terminology; having compassion and respect for clients; answering client questions; navigating end-of-life choices; mediating relationships with clients’ families; helping clients without promoting personal or religious agendas; being nonjudgmental and having compassion and respect for families; understanding that guardians are aging; feeling comfortable caring for dying clients; and counseling surviving clients.

Other studies have reported that staff may find it difficult to discuss clients’ illnesses with them because they do not understand the diagnosis themselves (Tuffrey-Wijne et al., 2013) or staff do not know how to discuss death with clients (Wiese et al., 2014). Staff generally want training in pain and symptom management (Fahey-McCarthy et al., 2009; McCarron et al., 2011). The curriculum designed by Hahn and Cadogan (2011) for agency staff providing end-of-life care for adults with I/DD contained nine training modules. These modules provided the staff with training in the following content areas: a developmental approach to palliative care, including sections on exploring values and choices and being treated as a whole person; case-based scenarios including developing a care plan; spiritual and cultural context, including sections on the importance of spirituality in terminal illness and cultural background and experiences influence spirituality; assessment and management of pain and distress; symptom management and assessment; principles of hospice care; care at the time of death, including recognizing signs and symptoms of imminent death; levels of intellectual disability: facilitating grief and bereavement, including a section on supporting families and staff in grief and bereavement.

Training recommendations for health care providers. There is evidence to suggest that health care providers generally have no training or experience working with individuals with I/DD (Cartlidge & Read, 2010; Krahn & Drum, 2007; Marks et al., 2008; Perkins & Moran, 2010; Ryan et al., 2010; Stein, 2008; Tuffrey-Wijne et al., 2010a; Webber et al., 2010). Staff participants in this dissertation research suggested that health care providers needed to receive training in working with people with I/DD. According to staff, health care provider training should include: treating clients as human beings; being compassionate and caring; tailoring services to the clients’ needs; determining clients’ pain; and not making assumptions about client understanding.

Critical exploration of staff recommendations. In this section, the study investigator (Moro) explores the staff recommendations in order to address feasibility and projected impact these recommendations will have. The staff recommendations for practical short and long-term changes that will better support clients, families, and agency staff are presented in the *implications for future research* section.

Client participation in decision making**.** Facilitating client participation in health-care and end-of-life decision making is an important component of empowering adults with I/DD who have been historically marginalized. There is evidence to suggest that clients are capable and want to participate (Kingsbury, 2010; Ryan et al., 2011a; Tuffrey-Wijne, 2012; Tuffrey-Wijne et al., 2010a; Tuffrey-Wijne & McEnhill, 2008), thus they should be encouraged to do so. I believe that inclusion in decision making is an important step in promoting person-centered planning. While the staff participants differed on when to have end-of-life discussions, I agree with the staff and scholarship that advocate for having these conversations before someone is ill because once a life-limiting diagnosis has been made people generally have a more difficult time making decisions since they are simultaneously coping with assimilating very distressful information. I also agree that it is important for staff to talk openly with families about the importance of discussing illness and end of life with clients. I believe that this will help to foster a collaborative atmosphere that may mitigate some of the frustration staff feel towards families when clients are at the end of life.

Providing quality end-of-life care**.** Some of the staff suggestions for providing quality care are more feasible than others. For example, for staff who are willing to provide care the following general guidelines are reasonable: providing holistic care, treating clients with compassion and respect; allowing clients to grieve; letting clients know they are not alone; and maintaining dignity. However, the staffs' ability to keep clients in their home and making sure pain is well managed are more difficult. Pain management is a critical component of end-of-life care and should not be left to staff alone. Although agency staff provide invaluable input about the clients, others, e.g., palliative care professionals, with pain management training must be involved because they have the resources and background to properly identify and appropriately treat the client.

While I tend to agree with staff that end-of-life care should be provided in the clients' homes with additional services as needed, I recognize that this may not be feasible in all agencies. Since most of the clients receive Medicare or Medicaid, they should all be eligible for in-home hospice care at the end of life; however, issues such as a lack of accessible housing or nursing staff make transitions more likely. In addition, some agencies may not want to assume the liability or have the resources to provide end-of-life care.

Providing support to peers. I have difficulty assessing the feasibility and impact of the staff suggestions for working with surviving clients because I have no reference for what services clients want or the cost of these services for the agency. Having a grief support group immediately after a peer dies so that clients can discuss their collective loss sounds like a useful idea because it allows clients to discuss a collective loss. However, I assume either the agency will have to pay a staff member or outside person to run such a group.

Agency resources and staff training and support needs. On the surface, agency staff recommendations for additional training, resources, and support needs seem straightforward.

Ideally, staff should receive end-of-life training and support if they are expected to care for adults who are dying. However, providing quality training on grief support and bereavement, facing mortality, dignity and person-centered planning, having compassion and respect for clients, mediating relationships with clients' families, feeling comfortable caring for dying clients, and counseling surviving clients are complex issues that often require multiple training sessions. This point is illustrated by the curriculum designed by Fahey-McCarthy, McCarron, Connaire, and McCallion (2009) for agency staff working with adults with I/DD and advanced dementia. Their training consisted of 20 sessions over 6-8 weeks which is a large time commitment from both the agency and staff.

The issue of staff training is additionally complex because it is probably not cost effective or feasible to train all staff to care for someone at the end of life even though all staff will likely be impacted when a client dies. However, it is critical to provide up-to-date training for residential staff because they will likely be involved in caring for adults with I/DD who are aging or at the end of life. I believe that this training is also important for day program staff, but the training could be less involved and may only involve providing basic resources, such as providing contemporary articles. My specific ideas for staff training will be explored below.

Staff also recommended creating a designated agency team to work with clients at the end of life and their families. This sounds like an excellent idea that is less of a time and resource commitment than training a large number of staff, yet may have a far-reaching impact for clients and families. As will be discussed in the *implications for future research* section, this suggestion may provide an entry point into helping agencies in the short-term.

Training recommendations for health care providers. I agree that health care providers need additional training and the staff suggestions for: treating clients as human beings; being compassionate and caring; tailoring services to the clients' needs; determining clients' pain; and not making assumptions about client understanding, are reasonable. However, assimilating this training into a professional curriculum is difficult because many of the health fields, such as medicine and nursing, must adhere to strict course requirements as a component of accreditation.

Implications for Future Research.

This dissertation study supports earlier findings that there are numerous end-of-life issues at each systemic level that can affect end-of-life care for both clients and agency staff and that there are areas where improvements are needed.

Microsystemic Implications

There is a need to better understand family dynamics and how they impact long-term relationships with clients living in community agencies. Further research should explore why some families maintain contact and others do not. Ideally, this research would be longitudinal and include interviews with clients and families and begin when they enter agency care in order to determine if there are factors, such as access to transportation or caregiver age, that impact the relationship and frequency with which clients and family communicate. In cases in which the family or client has chosen to have no contact it may be important to revisit guardianship and the role of family in advance care planning.

Mesosystemic Implications

These dissertation data also illustrate a need to improve interactions between agency staff and the family members because this relationship will likely have a direct impact on the client, in particular at the end of life. These relationships warrant more attention even before a client receives a life-limiting diagnosis. When appropriate, a greater effort should be made to facilitate communication with clients and families prior to such a crisis. In order to explore the relationships between clients, families, and staff, future research must include these multiple perspectives. Since no studies were identified that specifically focused on the relationship between family and staff, this is an area for exploratory research. Thus, a collective case study would be an appropriate method to employ in order to interview clients, their family members, and the agency staff directly responsible for the client's care. The focus of this research should be on the relationships before a crisis arises and should also explore other factors, such as how long clients reside in agency homes that may impact the relationship between families and staff.

Another critical area for future research is how to improve the relationships and interactions between health care providers, clients, family, and agency staff. While there is research exploring the inherent problems that are occurring between health care providers and clients (Bradbury-Jones et al., 2013; Friedman et al., 2012; Gates, 2011; Perkins & Moran, 2010; Todd, 2005; Tuffrey-Wijne, 2003; Tuffrey-Wijne et al., 2010b; Tuffrey-Wijne et al., 2006; Tuffrey-Wijne et al., 2007; Webber et al., 2010), there is less information available on how to improve this communication. However, providing adequate health care to adults with I/DD is not only a moral imperative, but a legal one. According to the Americans with Disabilities Act (ADA), adults with mobility (U.S. Department of Justice Civil Rights Division Disability Rights Section, 2010) and communication (U.S. Department of Justice Civil Rights Division Disability Rights Section, 2014) disabilities have a right to accessible health care. In addition, under Title V, Section 5307 of the Patient Protection and Affordable Care Act authorized funding for the, "development, evaluation, and dissemination of research, demonstration projects, and model curricula for cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities training for use in health professions schools…"(2010).

One way of beginning the daunting task of working with health care providers is to start by exploring the relationship between palliative care and agency staff. These dissertation data are promising because staff who worked with palliative care found the experience rewarding. However, there is still a need for increased communication between disability and palliative care professionals (Cross et al., 2012; Kirkendall et al., 2012; McCallion et al., 2012; Ryan et al., 2011b) and a better understanding of how these two groups of professionals work together. Research exploring the working relationships between these two groups is relatively new (Hahn & Cadogan, 2011), thus exploratory research, such as using focus groups, to interview these two groups will be beneficial.

Exosystemic Implications

There is research to support that there are several exosystems that have a large impact on the end-of-life care for adults with I/DD. While many of the issues discussed, such as communication limitations and health care provider bias, are relatively consistent across the United States, Europe, and Australia, there are also regional differences in the United States that impact adults with I/DD at the end of life. State laws and regulations, and Medicaid and Medicare program funding have a direct impact on the care agencies are able to provide. This study offered a limited glimpse into staffs' perceptions of the impact that the state of Illinois programs and policies have on an agency's ability to provide end-of-life care for adults with I/DD. However, much more work is needed in order to explore the impact that federal and state policies have on end-of-life care and to determine if a successful program at one agency can be well executed at another agency in another region. One area that needs immediate attention is the lack of accessible housing since increasing numbers of clients will acquire mobility limitations.

Another critical area moving forward, is for aging and end-of-life training to be added to the state mandated training curriculum. Future research must address funding for the training and propose how agencies afford the staff time for the training because it may not be feasible to train all staff to care for someone at the end of life, however all staff who work with the client will be impacted since the relationships between client and staff are often very close. Thus, all staff should be offered elective training and have access to the resource manual described above. Ideally, all direct care staff should receive paid training on end-of-life and support if they are expected to care for adults who are dying. However, the training could be less involved for staff who do not directly provide end-of-life care, e.g., less involved for administrators than for residential staff. It is important to note, that the idea of staff training may be impacted by staff turnover. While this was not an issue with the staff in this dissertation research, frequent staff turnover is an issue that has been cited in the literature (Hewitt & Larson, 2007; U.S. Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation, 2006). Thus, staff turnover should be taken into consideration when designing staff training and when making subsequent recommendations for who should be included in the training.

Implications of Staff Recommendations

As described above in the *critical exploration of staff recommendations* section above, some of the staff recommendations presented in this dissertation research were more feasible than others. In this section, some of the short-term recommendations that may have an immediate impact are reviewed followed by a discussion of what additional staff training should look like.

First, while an agency wide official policy or empirical research exploring the efficacy of specific interventions will take time, families or community agencies can receive some guidance on including clients in decision making by employing one of a number of free or low-cost guides or workbooks (Aging with Dignity, 2011; Blackman & Todd, 2005; Botsford & Force, 2004; California Department of Developmental Services, 2007; King et al., 2004; Kingsbury, 2009; NYSARC; Savage et al., 2010; Sunderland People First) many of which are available online. These workbooks provide a framework for initiating difficult conversations as well as formulating advance and end-of-life care plans with adults with I/DD. Ideally, future research will empirically explore the impact of these workbooks and determine whether they can be successfully used and how they affect end-of-life care for clients, families, and staff. As will be discussed below, one or more of these workbooks should be a component of staff training.

Second, staff recommended creating a designated agency team to work with clients at the end of life and their families. An agency social service person or interested staff member could be a liaison between staff, families, peers, and hospice care providers. While setting up such a team may require more of a coordinated effort than creating a resource guide, this is another suggestion that agencies can implement without outside intervention. A first step would be to hold a meeting of all staff interested in or familiar with end-of-life care. In the long-term, having such a group may also help solve the dilemma of which staff should receive end-of-life training given the scarcity of staff time and the financial cost of training.

Third, agencies should determine whether or not end-of-life care is a service that they will provide and then be upfront and transparent with clients and their families about the limits of agency care. Ultimately, research should seek to further identify and remove the barriers to providing end-of-life services in agency homes for agencies that want to provide this service. While this dissertation research offers some insight, such as highlighting the financial barriers to making agency homes accessible, more work needs to be done in order to determine what policy changes are the most critical and how best to address them. In the short-term, although an agency protocol will take time and resources to develop, it may also make it easier for staff to discuss this difficult topic with families. In addition, a protocol including parameters for when someone will be transferred out and how transitions will be handled will allow clients, families, and agency staff to be better prepared if this eventuality comes to pass.

Finally, the staff wanted more up-to-date and ongoing end-of-life resources and training. While providing quality training on end of life is costly and extensive training may not be necessary for all agency staff members, compiling a local resource guide is a low-cost way to begin. A local resource guide should be available to all agency staff. While a resource guide will not replace a well-designed intervention, it will give staff and families a starting point when a crisis arises. This resource guide should include current articles and books, some of which can be located in the reference section of this dissertation.

In order to compile a list of local resources, agency staff will want to contact other community service agencies to determine whether or not any of them already have connections with local palliative care agencies, hospitals, ICF/DDs, and nursing homes who have proven successful working with adults with I/DD. A resource guide should also include any relevant agency policies, or guidelines for caring for clients who are declining or at the end-of-life. This list should also include pertinent state, CILA, and ICF/DD regulations because there may be a large gap between when staff receive this information and when they care for someone who is ill. Ideally, this resource guide will involve regular upkeep to make sure the information, such as web links and contact information are current.

As detailed in Chapter II, there have been several studies that looked at staff training; however, more research is needed to determine critical training content and whether these existing training modules can be utilized across agencies. Based on the staff suggestions in this dissertation research, agency staff training should include topics such as: providing holistic care, treating clients with compassion and respect; allowing clients to grieve; letting clients know they are not alone; caring for surviving peers and families; and maintaining dignity. As noted above, the clinical resources available for end-of-life planning have not been empirically tested. Thus, future research on staff training should also include looking at the efficacy of these clinical workbooks.

The outcomes of staff training research should also look beyond staff perceptions of subject mastery or confidence and take into account the impact the training has on clients and families at the end of life. Other important outcomes may include whether or not the training helped staff to be able to emotionally care for themselves, or to determine what supports staff still need in terms of on-going training and support when providing the care. Thus, issues such as boundaries between agency staff and clients, caregiver burden, and compassion fatigue should also be included in the training.

Role of Social Work

Social workers interact with adults with I/DD in a variety of settings including community agencies, hospitals, nursing homes, and palliative care. Social workers are involved in the care of adults with I/DD in assessment, intervention, and advocacy roles (Robinson et al., 2012). Social workers may be involved in coordinating care across and navigating through systems in order to secure service such as housing, health, transportation, education, and day programs for older adults with I/DD. Social workers are trained to empathetically discuss sensitive issues such as end of life, and are well positioned to facilitate communication between clients, families, and agency staff. Social work is also critical in facilitating and mediating multidisciplinary discussions when adults with I/DD are at the end of life. This may include meeting with social workers who represent the various organizations such as the community agency, hospital, nursing home, and palliative care. Social worker may be instrumental in streamlining the process for referring adults with I/DD to palliative care (Kirkendall et al., 2012). Fostering a successful partnership between community agencies and palliative care can have far reaching benefits for adults with I/DD at the end of life including: improved pain and symptom management; involving the individual in their end-of-life care; and allowing the individual to remain in their home at the end of life. Social workers are well positioned to facilitate end-of-life care for adults with I/DD (Robinson et al., 2012). Training in a systems framework allows social workers to view the individual within the context of their lives and sets the groundwork for successfully engaging in work with adults with I/DD.

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Appendix A

Parent Study Publications

Savage, T. A., Moro, T., Boyden, J., Brown, A., & Kavanaugh, K. (2014). Implementation challenges and successful strategies conducting end-of-life research with adults with intellectual and developmental disabilities. *Applied Nursing Research, 28,* 202-205.

Parent Study Conference Papers

Moro, T., Gehlert, S., Savage, T. A. (2013, November). Caregiver role and health care delivery for adults with intellectual and developmental disabilities at the end of life. Paper presented at the American Public Health Association (APHA) Annual Meeting and Exposition, Boston, Massachusetts.

Moro, T., Savage, T. A., Boyden, J., Brown, A., & Kavanaugh, K. (2013, January). The role of professional caregivers in end-of-life care for people with intellectual and developmental disabilities (I/DD). Paper presented at the Society for Social Work and Research Annual Conference, San Diego, California.

Moro, T., Savage, T. A., Boyden, J., Brown, A., & Kavanaugh, K. (2012, October). Health disparities in the end-of-life care of people with intellectual and developmental disabilities (I/DD). Paper presented at the American Public Health Association (APHA) Annual Meeting and Exposition, San Francisco, California.

Savage, T. A., **Moro, T.**, Boyden, J., & Brown, A. (2012, July). Understanding end-of-life care for people with intellectual and developmental disabilities. Paper presented at the International Association for the Scientific Study of Intellectual Disabilities (IASSID) World Congress, Halifax, Nova Scotia.

Savage, T. A., **Moro, T.**, Boyden, J., & Brown, A. (2012, July). End-of-life care for people with intellectual and developmental disabilities. Paper presented at the American Association on Intellectual and Developmental Disabilities (AAIDD) 136th Annual Meeting, Charlotte, North Carolina.

Moro, T., Savage, T. A., Boyden, J., Brown, A., & Kavanaugh, K. (2012, May). Understanding end-of-life care for people with intellectual and developmental disabilities. Paper presented at the Eighth International Congress of Qualitative Inquiry (ICQI). Champaign, Illinois

Moro, T., Savage, T. A., Boyden, J., & Brown, A. (2012, March). Exploring end-of-life care for people with intellectual and developmental disabilities. Paper presented at the 28th Annual Pacific Rim International Conference on Disability and Diversity, Honolulu, Hawaii.

Parent Study Conference Poster Presentations

Savage, T. A., **Moro, T.**, Boyden, J., Brown, A., & Kavanaugh, K. (2012, May). Advanced care planning for people with intellectual and developmental disabilities. Poster presented at the International Society of Advance Care Planning and End of Life (ACPEL) Care Conference, Chicago, Illinois.

Moro, T., Savage, T. A., Boyden, J., & Brown, A. A. (2012, February). End-of-life care for adults with intellectual and developmental disabilities. Poster presented at the 2012 Minority Health in the Midwest Conference, Chicago, Illinois.