INCREASING END OF LIFE CARE ACCESS FOR INDIVIDUALS WITH
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

A Project

Presented to the faculty of the Division of Social Work
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MASTER OF SOCIAL WORK

by
Karen E. Pekarcik

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Approved by:

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Dale Russell, Ed.D., LCSW

Division of Social Work
Abstract

of

INCREASING END OF LIFE CARE ACCESS FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

by

Karen E. Pekarcik

This descriptive study identified and prioritized resources desired by professionals for inclusion in a toolkit to support access to palliative and end of life care for individuals with intellectual and developmental disabilities (IDD). A non-random sample of 28 medical, palliative care, hospice and case management professionals across four rural northern California counties completed a survey identifying priorities for information to assist in their efforts to identify needs and refer individuals with IDD to palliative and end of life hospice care.
Results of the study indicate that the highest priority of information identified by the respondents is information supporting assessment and communication with individuals with intellectual and developmental disabilities. Additionally, the need for information regarding sharing diagnosis, discussing treatment and end of life processes was indicated as pertinent for supporting this population. Implications of the study indicate a need for a social justice and ethics framework to guide social workers to initiate early discussion and promotion of palliative and end of life care, and facilitate person centered planning for individuals with IDD as a means to increase access to services for which they are historically denied.

_____________________, Committee Chair
Jude M. Antonyappan, Ph.D.

_____________________
Date
DEDICATION

This project is lovingly dedicated to Mollie Rogers. She is one of the wonders in my world. It is also humbly and gratefully dedicated to Rachel Curtis, a social worker who generously held my fears until I could believe that the destiny of a baby diagnosed with Down syndrome could be a long, well lived life. It has been, and with patience, love and faith will continue to be for many years to come.
ACKNOWLEDGEMENTS

The experience of being a member of the Master in Social Work Rural Cohort has been an adventure. It would not have been possible without the creativity, flexibility and support of Calaveras County Behavioral Health Services, the Calaveras County Board of Supervisors and California State University, Sacramento.

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Focusing on the end of life issues of individuals with IDD could not have been accomplished without the encouragement of Dr. Robin Kennedy, Mark Robinson, MSW,
at UC Davis Medical School, and Dr. Dian Baker, CSU Sacramento’s Graduate Program in Nursing; each of whom encouraged this project. There were moments when the information felt like a glimpse of the future. Their belief in the value of the project sustained me when I wanted to stop. Perhaps the project will make a positive change for the future of individuals with intellectual or developmental disabilities, their families and caregivers facing end of life.

I am also grateful for the enthusiastic response of leadership and staff at Amador-Calaveras Hospice, Partners in Care, Mark Twain St. Joseph’s Hospital, Marshall Medical Center, Snowline Hospice, Sonora Hospice, Sonora Hospital, and Valley Mountain Regional Center-San Andreas. Thank you all for your interest in palliative and end of life care for individuals with intellectual and developmental disabilities, your encouragement and participation in this project. Most of all, thank you for doing the work that you do.

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Of course, the questions leading to this project might not have been asked if it was not for Mollie Rogers. Fate definitely smiled, and Destiny continues to laugh as they see how she makes her way. She is an inspiring daughter.

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Chapter 1

INTRODUCTION

Individuals with intellectual and developmental disability (IDD) are identified in research as being extremely unlikely to receive referrals for hospice care following diagnosis with a life ending illness (Stein, 2008; Tuffrey-Wijne, Hogg & Curfs, 2007a). This study surveys medical and social work palliative and end of life care team members to determine their priorities for contents of a toolkit to support their ability to work with, refer and provide end of life care to individuals with IDD. Individuals responding to the survey work in hospital or medical settings, Regional Centers for case management to individuals with IDD, hospice or palliative care organizations, care facilities or advocacy organizations. Fifteen potential content options are presented for respondents to consider. Survey content for prioritization ranges from inclusion of checklists or assessment to address communication styles, anxiety and fears among individuals with IDD, to conversation starters for discussion to learn how a person with IDD considers their own dying experience. Legal, capacity and competency topics are listed, as are categories for spiritual needs of individuals with IDD, “how to” formats for including end of life planning in individual case plans, and categories addressing caregiver supports, housing, financial, and bereavement issues. Survey respondents are also offered an open-ended question to elicit their own perspectives, issues, concerns or priorities they may wish to share on the subject of end of life for individuals with IDD.

Individuals with IDD are a minority population represented by roughly 3% of the population of the United States (Lightfoot, 2009). The population of individuals living
with significant limitations to intellectual ability substantially limiting major areas of life functioning that originates before age 18 years is expected to increase from approximately 650,000 to over one million people during the next twenty years (Lightfoot, 2009). The proportion of individuals with IDD as compared to the general population is small. It is also a population that has only recently begun to reach older ages where they face illnesses common among the elderly, and known to result in long periods of dying. Very few of the medical and social service professionals providing palliative and end of life care have had an opportunity to experience palliative care and end of life with individuals with IDD (Stein, 2008; Tuffrey-Wijne et al., 2007a).

Research indicates that medical providers working with a patient with IDD have a tendency to attribute observed behaviors and symptoms to the disability rather than to the illness (Tuffrey-Wijne et al., 2007a). This results in missed opportunities to identify and treat illness at early stages and can result in delayed treatment, which can result in significant quality of life issues. The lack of communication and understanding of idiosyncratic patterns of distress and alternative methods of communication may also result in missed opportunities to explain diagnosis and prognosis or offer a range of treatment and comfort care options for consideration. Lack of communication can also result in exclusion of individuals with IDD from decision making regarding their health care risking compromising quality of life (Gehlert & Moro, 2011; Tuffrey-Wijne et al., 2007a).

Results of this study may indicate priorities for topics to include in a toolkit supporting professional response to the needs of individuals with IDD at end of life.
Priorities may be indicated either universally or by practice area that would assist professionals in medical care, palliative and end of life care to ensure individuals with IDD have access to palliative and end of life care supported by ethical, legal, and professional standards.

**Background**

Advances in medical sciences and social supports have resulted in an unprecedented increase in life expectancy for the 1-3% of individuals with IDD (Stein, 2008). An example of recent changes to life span among the population of individuals with IDD would be the six fold increase in life expectancy since the 1940’s and doubling of life expectancy between the 1980’s and 1990’s for individuals with Down syndrome; the most common genetic cause of IDD. Approximately 50% of individuals with Down syndrome are now expected to live to age 60, and increasingly beyond age 70. This results in an increase in the number of individuals with IDD who experience a prolonged period of dying and end of life issues related to dementia, heart disease, pneumonia, seizure disorders, and cancer (Stein, 2008; Tuffrey-Wijne et al., 2007a).

Stein (2008) indicates that the numbers of individuals with IDD who have access to palliative and hospice care is extremely low. One important result of so few members of the minority IDD culture accessing services to improve quality of life and relieve suffering is a related lack of palliative and hospice professionals with experience regarding the unique end of life needs of individuals with IDD (Stein, et al., 2010; Tuffrey-Wijne, et al., 2007a). Literature reviewed indicates the need for care teams to understand the necessary considerations related to the nature of an individual’s intellectual
disability, and the associated adaptive, communication and mobility challenges that influence end of life assessment and decisions regarding care (Stein, 2008; Stein, et al., 2010; Tuffrey-Wijne, et al., 2007a). While some aspects of guided decision making in medical and palliative care are similar to the approaches in care for cognitive impairments such as dementia and Parkinson’s disease, individuals with IDD are at risk for assumptions that they are not ever capable of providing meaningful input toward their care.

Many individuals are never told of their diagnosis, let alone asked about their treatment or care concerns (Tuffrey-Wijne, et al., 2007a). Despite their right to know diagnosis and prognosis, individuals with disabilities face increased paternalistic and coercive management of their needs as health care staff, administrators and families work diligently to protect them; often assuming these individuals do not have the capacity to make or express their own care desires. Palliative care teams can be integral to ensuring attitudes and biases regarding intellectual disability, as well as environmental and care barriers are considered openly and with the patient.

Physicians’ attitudes regarding disability and assumptions of poor quality of life are shown to influence the provision of life saving care for individuals with IDD (Stein et al., 2010). Recent studies also indicate that when conversations do not occur with patients, or assumptions of their best interests are made, the rights of patients with IDD to refuse life sustaining treatments and the associated risks of medical care are ignored. For many people with IDD, treatments considered life sustaining—such as intubations and tube feeding, are a way of life. The perspective of the patient with IDD to continue this
care can be quite different than that of a patient without IDD for whom these treatments are perceived as a new, often temporary, emergency event (Tuffrey-Wijne, et al., 2007a).

Differences in cognitive capacity and communication ability among individuals with IDD do not automatically equate to inability to express joy, fear, pain, and quality of life wishes (Stein, 2008; Stein, et al., 2010). Tuffrey-Wijne, Hogg and Curfs (2007a) note that people with dementia and low cognitive functioning express pain through atypical behaviors rather than verbally, and risk having pain under-treated. Individuals with IDD are often regarded as having a high pain tolerance, although no studies have indicated that higher pain tolerance exists in this population (Tuffrey-Wijne, et al., 2007a). The challenge for palliative and hospice care teams becomes one of finding appropriate communication facilitation and assessment methods, and ensuring issues of pain and preferences for care are discussed with the patient and caregivers who are familiar with the patient’s communication styles and cues, personal strengths, fears and life preferences (Stein, et al., 2010).

Consent, power, autonomy and best interest questions drive end of life decisions. Ensuring the inclusion of individuals with IDD in decision making is critical. Palliative care teams can change the historic exclusion from medical care individuals with IDD have experienced by enlisting the patient and the patient’s “team” of family members, advocates, disability care providers and case managers to include early palliative and end of life planning in the patient’s documented “person-centered” plan addressing the daily living and care needs, as well as where, how and when a patient prefers to receive care (Kingsbury, 2011; Stein, et al., 2010; Tuffrey-Wijne, et al., 2007a). Including a life story
or values assessment to distinguish between disability and illness can guide surrogates in understanding which issues require their decisions and which of the patient’s desires can be honored in accordance with the patient’s wishes (Stein, et al., 2010; Tuffrey-Wijne et al., 2007a).

**Problem Statement**

This study specifically targets medical, palliative and end of life care team members in rural communities to determine which content areas addressing end of life issues would be most helpful in a toolkit to support end of life care referrals and services for individuals with IDD. Individuals with IDD may have communication and comprehension challenges resulting in limited ability to verbally discuss, determine and advocate for their own needs and desires. Development of a toolkit for use by medical and care team members to ensure care team member assumptions, values and beliefs do not inhibit access to necessary and available resources is required. Referral and facilitation of access to end of life needs is generally in the control of care team professionals—most often physicians and medical staff (Tuffrey-Wijne et al., 2007a). A toolkit to use with individuals with IDD may assist care team members in moving the control back to the patient.

**Theoretical Framework**

The interdisciplinary relationships and systems supporting palliative and end of life care are complex and inter-connected. This study presents the issues of providing comprehensive, person-centered care to individuals with IDD from an ecosystems perspective, which considers what happens for the individual with IDD as encounters
across relationships, professional practice and medical care occur (McNow & Rhodes, 2010).

While the purpose of this study is to identify supports for professionals that are ultimately responsive to the specific needs of an individual with IDD as a person-in-environment, that environment changes and becomes more complex as palliative team members become engaged at the microsystem level with the individual with IDD and individual family members. The system comprises meso-system level interactions as the palliative care team engages with other caregivers and partner agency representatives supporting the individual with IDD. These can be disability case management agencies, community care licensing, social security systems, legal competency reviews, medical insurance providers, housing authorities and more. Within the hospital or hospice hierarchies, the palliative care team microsystems are further influenced by the culture of the hierarchy and institutional conglomerate relationships. At the macro-level, palliative and end of life care for individuals with IDD is influenced by the hospital, hospice and disability services systems, as well as the accompanying legislation, rights, restrictions and stigmas that are components of health and disability experience in the United States. The combined system structure supports Bronfenbrenner’s ecological systems theory which occurs at the micro-, meso-, exo- and macro-system levels (Higgins, 2011).

The theoretical framework for this study includes consideration of Rogers’ humanistic person-centered approach which theorizes that people are trustworthy, have the potential for understanding themselves and can resolve their own problems. The approach encourages a non-directive engagement in which professionals focus on
reflecting and clarifying client’s verbal and nonverbal communications with the intent to help clients gain insight into their own feelings and move forward in a constructive manner when provided the conditions for fostering growth and deciding their own path toward psychological and emotional wellbeing (Corey, 2009).

The person-centered approach can seem counter-intuitive or counterproductive to some members of the care team, in particular those who represent a medical care perspective of taking action to ensure health, often in an emergency or crisis situation. Within palliative and end of life care, it is important for care team members to recognize their professional orientation and consider how it relates to the individual with IDD in the context of their illness and life. Care team members may serve as representatives of the views and perspectives within their specialty or professional orientation. They present professional standards and perspectives, and have the opportunity to balance team and solo work to broaden team members’ understanding of the many contexts and components of support for the individual with IDD facing end of life (Higgins, 2011).

Many team members may present a level of authority that is incongruent with palliative and end of life ethical standards which seek to ensure the approach and decisions for care are based on the expertise of the individual receiving care with regard to his or her own life (Foster & Turner, 2007; Higgins, 2011; Johnson, 2011; National Association of Social Workers [NASW], 2004; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a).

Application of feminist theory is also a component of this study. It is critical to address the inherent oppression that is present within the context of quality of life judgments, and paternalism occurring when medical professionals or others withhold
diagnosis, prognosis or treatment for individuals with IDD. Framing the patient’s experience with end of life in the context of disability and the cultural aspects associated with that experience in families, communities and Western societies is required to ensure social and system change that values the experience and desires of the individual with IDD (Corey, 2009).

Feminist theory would also apply toward transforming palliative and end of life care planning from a disease model to a model where all contextual variables are considered, and the story of end of life is changed from one of dying, to one of living and coping (Corey, 2009). When palliative care teams seek a more narrative approach to palliative planning by asking for the individual with IDD and the family’s narrative describing empowerment, valuing of diversity, equality and balancing independence and interdependence, the process moves from a medical model to an approach fitting within a feminist framework (Corey, 2009).

**Purpose of the Study**

This study seeks to remediate assumptions and barriers influencing referrals and care for individuals with IDD, by asking professionals in the field to prioritize contents of a toolkit to be developed supporting their ability to meet the needs, rights and individualized preferences for increased access to care in accordance with ethical, practice and professional standards.

The study also asks individual participants to verify that they are serving in a rural area, identify their professional role, length of time in that role, the numbers of individuals with IDD that they have served in the past year, and if any of those
individuals were able to access end of life care in a home hospice setting. This information could provide an indication of the scope of need and access in rural communities. Response to the survey’s listed toolkit content options could also indicate differences in priority among professional classifications. For instance, information supporting medical providers ability to initiate communication and reading individual cues may have a higher priority than it would for caregivers of individuals with disabilities who have day-to-day experience with the individual and are more attuned to the cues and behaviors used by individuals with IDD to display distress (Csikai & Chaitin, 2006; Foster & Turner, 2007; Johnson, 2011; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a). This would help with organizing the toolkit and with training or presentations to specific professional groups.

The simple act of contemplating the categories of information to be prioritized and completing the survey may stimulate individual respondents to become more intentional as they seek information and provide support for individualized and appropriate end of life care for people with IDD.

**Definition of Terms**

Key terms to understand for this study include individuals with intellectual and developmental disabilities, palliative and end of life care. Additional terms of importance are defined in the literature review as they relate to the issues of palliative and end of life care for individuals with IDD.

**Individuals with intellectual and developmental disabilities (IDD):** is the current accepted reference to people historically referred to as mentally retarded, mentally
handicapped, mentally challenged, developmentally delayed or cognitively impaired (American Association on Intellectual and Developmental Disabilities [AAIDD], 2011). Common diagnosis among this population include Down syndrome, cerebral palsy, fetal alcohol syndrome, Fragile X syndrome, Autism, and other acquired, congenital and genetic diagnosis. For the purposes of this study, the definition of IDD adopted by the American Association on Intellectual and Developmental Disability [AAIDD] (2011) is used. AAIDD (2011) identifies an individual with IDD as having a disability occurring before age 18 years, with the disability resulting in characteristics of significant intellectual functioning and adaptive behavior limitations. Individuals with IDD face limitations impacting everyday social and practical skills, including challenges and limitations to conceptual skills such as language, time and self-direction; social skills limits which would impact interpersonal skills, following rules and avoiding victimization, and limits to practical skills used in daily living. Practical skills limits would affect daily living to support personal health care, ability to effectively manage personal schedules and routines (AAIDD, 2011). Individuals with IDD may have limits in some or all categories, with varying levels of impact across the categories. With the disability originating before age 18, individuals who are now living to experience end of life needs in their 50’s, 60’s or beyond, have lived with their IDD for the majority of their life. This is an important distinction between the individual with IDD and an individual of typical development who has lived the majority of life without an IDD, but acquires a change to developmental capacity following injury, illness or onset of dementia. For a
person with IDD, the disabilities they experience may be a part of who they have always been, and may not likely be the foremost concern of their end of life experience.

Palliative care: as used in this study identifies a specific approach to medical and end of life care to end suffering, and increase quality of life. Palliative care is best provided throughout the continuum of a person’s illness, from beginning diagnosis, medical treatment and pain management, to end of life biopsychosocial and spiritual supports to improve comfort and quality of life during the dying and bereavement periods. The World Health Organization [WHO] (Mulkerin, 2011; World Health Organization, 2011) defines palliative care as an approach to improve a patient and the patient’s family’s quality of life as the patient faces life threatening illness. Palliative care is intended to offer relief from pain and other distressing symptoms. The approach considers dying as a natural part of life, and affirms life through the dying process. Palliative care is not intended to either hasten or postpone death. Care teams serve as a support system for dying patients and their families by integrating psychological and spiritual supports throughout the course of the illness and through bereavement. The intent is to enhance the patient’s quality of life, as early as possible during the illness, and in conjunction with other therapies. Early and comprehensive palliative care has been shown to positively influence the course of illness (Mulkerin, 2011; WHO, 2011). Palliative care does not need to begin at the end of a medical intervention and beginning of end of life treatment. While it often begins as medical interventions related to direct medical treatment in hospitals, palliative care is a comprehensive relief of suffering and symptoms through a collaborative approach involving social workers, physician visits,
physical/occupational therapists, specialty or skilled nurses and health aides, pain medication management, inpatient or respite care and spiritual counseling (Csikai & Chaitin, 2006). These multidisciplinary teams include representatives from multiple fields of study, and have a shared interest in coordinating to maximize the opportunity for the patient’s comfort and desires to be met (Csikai & Chaitin, 2006).

Mulkerin (2011) lists several potential goals for palliative care, including restorative or cure-focused care such as following a serious injury. Return to baseline can be a goal for an individual with past history of injury or illness. Improving survival for individuals with a history of serious or life threatening illness can receive a range of medical and life prolonging therapies in combination with psycho-social and spiritual supports. For individuals with changes to their physical or mental capacity, therapeutic interventions may help improve function is likely a goal. Patients facing painful or distressing side effects of their illness, treatment or medication would benefit from a team goal for relieving symptoms or eventually for allowing a natural death (Mulkerin, 2011). Palliative care changes the professional-patient conversation from one of winning or losing a battle with illness to a conversation that seeks the patient’s identification of how their own life is defined, what gives their life meaning, and which states of life may be worse than death to them so that care is respectful of these (Mulkerin, 2011).

End of life care: is used in this study to refer to the final stage of a person’s life threatening illness through which curative care is no longer an option, where the person and/or their family recognize that life does not go on forever, and plans for death begin to be made (Volunteers of America, Inc. [VAI], 2000). End of life care is not initiated as a
consequence of a medical or health event. At best, it is a process to seek and meet the patient’s own vision of a good death which includes support for and from his or her family, through meaningful plans and services (VAI, 2000). End of life care includes palliative care, and may include hospice care to provide a focused and multi-disciplinary approach to supporting the patient and family through dying, burial and bereavement.

The focus of hospice care, whether in the home or in a care facility, is to provide supports and services to ensure an individual’s potential to maintain a level of control and independence over care and living, to continue living as a unique person in the context of relationships with family and others, and to reach out toward hopes and expectations with the deepest meaning for the patient so that the end of life will be met with a sense of completion (Csikai & Chaitin, 2006). End of life occurring on these terms would be considered a “good death.”

End of life is significantly influenced by the objective and subjective strengths and burdens of the patient’s illness and life. In the case of an individual with IDD, this includes challenges to cognitive and communication capacity to understand treatment, prognosis and communication of end of life desires. End of life is also influenced by the cultural, spiritual and religious beliefs influencing the lives of the patient, family, caregivers and care team members. Nevertheless, it is the influences, values and beliefs of the patient that matter during end of life. Professional ethics statements recognize this and consistently reinforce the requirement for end of life planning to be autonomous, with decisions to accept or refuse care based on what is important to the patient (Csikai & Chaitin, 2006; Johnson, 2011; Levy & van Stone, 2011; NASW, 2004).
Assumptions

It is assumed that professionals in medical, social work and care giving capacities across rural counties in California have at least a basic understanding of how individuals with disabilities might differ from the average patient they support. While personal and professional bias has been shown to influence care for individuals with IDD (Stein et al., 2010), respondents will consider a broad and hypothetical request that encourages reflection and ranking of choices. A professional capacity to thoughtfully and intentionally provide input to the survey items that will assist in compiling a meaningful and useful tool for use by peer care team members is assumed.

Justifications

Research indicates that individuals with IDD have complex needs which are assumed to interfere with their capacity and competency to determine and describe their end of life desires, wishes and needs (Tuffrey-Wijne et al., 2007). The result is that a significant number of the increasing population of individuals with IDD who are living longer than ever before, are often not told of their diagnosis, prognosis, treatment options or referred for palliative or end of life care that could improve quality and potentially lengthen the time of life they have left (Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a).

Social workers working with palliative and end of life care teams are expected to adhere to “consultation etiquette” as well as to advance issues of social justice, including the right for individuals with IDD to self-determination and access to necessary resources for end of life care (Mulkerin, 2011; NASW 2004). The required collaboration with
individuals, institutions and families, requires the ability to navigate and discuss different assessments, points of view and technical challenges. The domains of palliative and end of life care are as broad as the professional, patient and family experiences and systems that must be navigated (Mulkerin, 2011). A tool that bridges the range of domains in palliative social work, promotes truthful communication and focuses toward the unique issues experienced in relation to IDD, will support the social worker to help the individual with IDD achieve a person-centered, inclusive and comprehensive approach that respects their desires and needs (Kingsbury, 2011; Mulkerin, 2011).

**Limitations**

The study is limited in that it does not survey the preferences for end of issues from the perspectives of individual with IDD, family member, or the perspectives of paid residential caregivers, but from the perspectives of the professionals working with the end of life and palliative care team services for this population. A survey of individuals with IDD and their family members would have been valuable in adding to this knowledge. In promoting a person-centered planning effort for palliative and end of life care, it makes sense to model the effort at the development and testing stage for toolkit contents to ensure that the information does not conflict or undermine the rights or desires for autonomy and self-determination for the individual with IDD.

Finally, the survey does not focus on any specific cultural, spiritual, religious or life orientation beyond IDD. It is a simple survey of the needs of rural care team members with regard to the population of individuals with IDD that they are likely to meet. More specific needs assessment could be completed to increase understanding of
other cultural, religious or life orientations for individuals with IDD in future studies.

The data is collected from a non-random sample and holds limited collateral validity.
Chapter 2

LITERATURE REVIEW

The purpose of this research is to identify whether or not a toolkit addressing aspects of palliative and end of life care for individuals with intellectual and developmental disabilities (IDD) is needed as a tool for use among professionals and caregivers. The study further seeks to identify which types of information would be useful to professionals and caregivers supporting end of life needs for individuals with IDD. While a few tools have recently been developed to support specific components of end of life care, empirical studies of comprehensive tools to address the array of issues impacting access to palliative and end of life care for individuals with IDD were not apparent.

Current scholarship regarding palliative and end of life care for individuals with IDD is dispersed across practice orientations such as nursing, medical care, social work, and intellectual disability supports, services and intervention. Literature for this review is as comprehensive as are the disciplines and components that are elements of palliative and end of life care. The following thematic literature review addresses research important for consideration in the development of a toolkit for the professionals, caregivers and family members who are integral partners in the palliative and end of life experiences of individuals with IDD.

Because it is important to understand the relationship between the unique characteristics, history and issues impacting the population of individuals with IDD as they experience end of life care, literature reviewed includes related themes of current
IDD terminology, demographics, history and legislation related to IDD, and the impact of changes to life expectancy among individuals with IDD with regard to dying in place. Review of landmark legislation and legal decisions affecting individuals with IDD rights to access services such as palliative and end of life care as well as review of related professional ethics and standards of care is also included. Capacity for decision making and professional/caregiver bias regarding quality of life are issues reviewed, as are the difficulties that communication differences and challenges among the population of individuals with IDD present in assuring an individualized, comprehensive and person-centered approach to end of life. These themes are important for understanding the difficulty in assessing the relevance and effectiveness of existing tools used by care teams, and for assuring appropriate resources use by those providing palliative and end of life care to individuals with IDD. Tools that facilitate communication, support professional staff to provide person-centered care and facilitate collaboration among the care team, family members and the individual with IDD are shown to increase care team support and quality of end of life care whether at home or in a formal care setting (Tuffrey-Wijne, Hoggs & Curfs, 2007a).

The meaning of terms associated with disability has changed multiple times over the past few decades. According to the American Association of Intellectual Disabilities (AAIDD, 2011, para. 1) website, IDD is defined as disability occurring or originating before age 18 years, with the disability resulting in characteristics of significant intellectual functioning and adaptive behavior limitations. These limitations impact many everyday social and practical skills. AAIDD (2011, para. 4) lists examples of areas of
limited functioning including limits to conceptual skills such as language, time concepts and self-direction; social skills limits impacting interpersonal skills, following rules and avoiding victimization; and limits to practical skills used in daily living to support personal health care, ability to manage personal schedules or routines.

Previously acceptable terms used in the United States for IDD included mental retardation, cognitive delay, developmental delay and developmental disability. The current acceptable term used in the United States is intellectual and developmental disability (AAIDD, 2011; Lightfoot, 2009), however, the American Psychiatric Association’s [APA] current edition of the Diagnostic and Statistical Manual (DSM IV TR) continues to use the term mental retardation as a diagnostic label for individuals with cognitive issues (American Psychiatric Association [APA], 2000).

Based on the articles found for this study, the most recent literature from Australia and the United Kingdom employ the term learning disability when referring to IDD. For the purpose of this literature review key words searches included historic terms for IDD such as mental retardation, mental disability, developmental disability and learning disability. To capture literature for this review, secondary terms including aging, illness, palliative, end of life, death, dying, spirituality and grief were also added. Knowing research regarding palliative and end of life care is frequently focused on issues in professional practice, or is targeted toward care for a specific diagnosis such as cancer or dementia, the search included review of nursing, medical and social work journals using care team keywords palliative and end of life.
Demographics

The population of individuals with IDD has only recently begun to live long enough to experience end of life issues common among older adults in the general population (Lightfoot, 2009; Stein, 2008; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a). Advances in medical sciences and social supports have resulted in an unprecedented increase in life expectancy for the 1-3% of individuals with IDD (Lightfoot, 2009; Stein, 2008; Stein & Kerwin, 2010). Lightfoot (2009) cites statistics indicating that the population of individuals with IDD over age 60 in the United States was approximately 650,000, and was estimated to increase to 1.2 million by 2030. An example of recent changes to life span among this population would be the six fold increase in life expectancy since the 1940’s and doubling of life expectancy between the 1980’s and 1990’s for individuals with Down syndrome, the most common genetic cause of IDD. Approximately 50% of individuals with Down syndrome now live toward age 60, and increasingly beyond age 70 (Palley & Van Hollen, 2000; Patti, Amble & Flory, 2010; Stein, 2008). The result is an increase in the number of individuals with IDD who experience a prolonged period of dying and end of life issues related to dementia, heart disease, pneumonia, seizure disorders, and cancer (Foster & Turner, 2007; Lightfoot, 2009; Tood, 2004; Tuffrey-Wijne et al., 2007a).

For individuals with IDD, who are living and dying longer than ever before, and for most of the professionals, caregivers and families that serve them, ensuring they have access to palliative and end of life care is a relatively new concept. Tuffrey-Wijne, McEnhill, Curfs & Hollins (2007b) identified evidence indicating that service providers
supporting care of individuals with IDD often lack the training, skills and experience necessary to provide the comprehensive, person-focused services to ensure individuals with IDD receive palliative care. Research also indicates that access to end of life care is limited for the population of persons with IDD in part because physicians’ attitudes regarding disability and assumptions of poor quality of life are shown to influence the provision of life saving care for individuals with IDD (Stein, 2008; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a). Stein (2008) indicates that the low numbers of individuals with IDD who have access to palliative and hospice care is a significant issue. One important result of so few members of an already minority IDD population accessing services to improve quality of life and relieve suffering is a related lack of palliative and hospice professionals with exposure and training regarding the unique end of life needs of individuals with IDD (Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a).

**History**

Modern palliative and end of life care is built on a medical model foundation to provide hospice care for cancer patients facing end of life (Tuffrey-Wijne et al., 2007a). The hospice movement began in the 1960’s to support patients in achieving a “good death” through facilitation of shared decisions for end of life care among the dying, their family and caregivers. Half a century later, the dying phase of life remains a time of mystery for most individuals in western society; few are involved and aware of the process and experience of dying. For over 80% of the general population, dying occurs in a hospital or care facility with medical providers recommending treatment and management of the patient’s symptomatic needs (Helm & Friedman, 2010). Western
societies have grown to rely on medical care providers, health care administrators, insurance companies, case managers, and others with component responsibilities for management of death. Many of the professionals managing end of life with patients and families are faced with the professional and ethical responsibilities to also consider addressing the dying person’s right to dignity, compassionate and competent care while balancing institutional and regulatory requirements (Helm & Friedman, 2010).

Definitions of palliative and end of life care have been adopted by organizations and associations involved in promoting ethical and accessible approaches to care. End of life has been defined by the National Institutes of Health [NIH] (as cited by Levy & van Stone, 2011) as a period including both persistent and/or fluctuating chronic disease(s), symptoms or functional impairments; and symptoms or impairments resulting from irreversible disease requiring formal and informal care by paid and unpaid caregivers. The World Health Organization’s (WHO, 2011) definition of palliative care which is posted on their website is cited by Tuffrey-Wijne et al. (2007a) in the most significant literature review found on the subject of end of life for individuals with IDD. WHO’s definition has not changed since originating in 2002. It begins with the explanation that palliative care is defined as “an approach that improves the quality of life of patient and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological, and spiritual.” Included in the WHO definition is the intent that palliative care, “provides relief from pain and other distressing symptoms”, and that palliative care is “applicable
early in the course of the illness…and includes those investigations needed to better understand and manage disturbing clinical symptoms” (WHO, 2011).

The National Association of Social Workers (NASW, 2004) defines end of life care as “multidimensional assessments and interventions provided to assist individuals and their families as they approach end of life.” Palliative care is identified as the earlier “identification and comprehensive assessment and treatment of pain and other physical, psychosocial, and spiritual problems,” to relieve suffering and improve quality of life for patients and family members. Eleven practice standards social work and palliative care are also established to guide social workers in ensuring care addresses the ethics and values of the social work profession, as well as bioethics, knowledge of theoretical and biopsychosocial factors in providing care, assessments, intervention and treatment planning, social worker attitudes and self-awareness, empowerment and advocacy, promotion of interdisciplinary teamwork and cultural competence. NASW standards also address the social worker’s responsibility for continuing education to remain familiar with professional standards and state requirements, as well as demonstration of leadership through education, training, supervision and leadership to promote expertise supporting the established standards of practice (NASW, 2004).

Despite ethical standards and positions on the issue, literature indicates that individuals with IDD are unlikely to receive palliative and end of life care for many reasons, including limited capacity for decision making, and perceptions of futility of care by medical providers (Levy & van Stone, 2011; Stein, 2008; Tuffrey-Wijne et al., 2007a). The language in adopted palliative and end of life care definitions and standards becomes
important point of reference for moving toward assurance that individuals with IDD receive a thorough biopsychosocial and spiritual assessment of needs rather than presumptive care. Including terms such as impeccable, comprehensive and multidimensional, and specifying assessments addressing physical, psychological and spiritual needs of individuals leaves no room for exclusion of individuals with IDD from a quality process of identifying and relieving the individual’s end of life suffering (NASW, 2004). End of life needs of individuals with IDD are likely to include added concerns such as cognitive and communication capacity to understand treatment, the dying process and communicate end-of-life issues. The potential exists for the presence of life-long medical complexity and often life-sustaining medical treatments that can confuse end of life decisions for individuals with IDD, and present greater challenge for care teams to seek to learn and/or accept the individual’s self-determination for treatment and end of life goals. Adding the context of the realities of an individual’s life circumstances and experience with IDD, as well as their wishes and desires can challenge a palliative or hospice care team to engage in more complex and comprehensive assessments of their own values, beliefs and expectations than they may generally experience in palliative and end of life care. Levy and van Stone (2011) share the example of the 1996 California case in which a 36 year old woman with Down syndrome was initially denied a heart and lung transplant due to her physician’s assumption that she would not be able to meet the requirements for managing her health and care, and the transplant would be a waste. Once the physician finally spoke with her, and understood her abilities, desires and resources better, he changed his mind resulting in her receipt of the heart-lung transplant (Levy &
van Stone, 2011). Without adherence to established ethical and professional standards, including individualized assessment and direct communication through physician-patient conversations, the risk is a failure to provide for the real physical, medical, psychosocial and spiritual end of life needs of individuals with IDD, their family and caregivers.

Legal Decisions

Landmark legal decisions regarding end of life cases provide a foundation for end of life ethical review that is relevant to the population of individuals with IDD. The 1976 Karen Ann Quinlan case sought to define when death actually occurs in order to decide whether or not to remove life support. *Cruzan v. Harmon*, 1990, provided a precedent for assessing individuals’ consent to receive or cease mechanical life support. Cases have served to initiate discussions which have evolved into ongoing conversations among peer professionals and ethical review boards to help determine operational consensus as to what constitutes death, and when and how life sustaining interventions should be used (Csikai & Chaitin, 2006).

Another important and ongoing legal and ethical review concerns the issue of assisted suicide for individuals with disabilities. The potential problems of clinical depression, unmanaged pain, feelings of hopelessness and helplessness are issues experienced by individuals with and without IDD, and require intervention regardless of the presence of IDD. Werth (2005) notes that the discussion of medical care “futility” and decisions to withhold and/or withdraw life sustaining treatment for individuals with IDD may be a more relevant and important conversation for individuals with IDD than the issue of assisted suicide. Werth’s (2005) concern for individuals with IDD is that others
are presuming that individuals with IDD lack capacity to make qualitative decisions and are making the decisions regarding withhold or withdrawal of treatment for them.

Smith and Hardt (2011) also discuss concerns with making the issue of futility a key for medical treatment decisions. The risk of making decisions based on a professional perception of medical futility is the potential for “giving up too soon” and decisions based on inexperience with or inaccurate understanding of IDD, and personal bias. Smith and Hardt (2005) are equally concerned about making decisions based on vitalism—the motive of protecting life, particularly the lives of vulnerable individuals such as those with IDD. Decisions based on vitalism risk that the decision maker’s desire to “save” the individual has the potential for prolonging or increasing suffering and may result in a burden of care that is disproportionate to the benefit received by the dying person. Smith and Hardt (2005) assert that the best approach to determining care is to ensure honest engagement and discussions among a wide range of individuals involved in care, individuals who are different from typical like-minded care team and patient populations, and discussions that include the individuals with IDD themselves. Without seeking the final say of the individual with IDD, whether due to a presumption of the individual’s poor quality of life or an assumed protective stance, the values of others regarding quality of life are exerted onto that person, resulting in decision of whether they live or die (Werth, 2005; Stein & Kerwin, 2010).

Research in the late 1990’s indicated that individuals with IDD faced pressure to terminate expensive treatment or denial of health care or equipment considered too expensive by insurers (Werth, 2005; United States Senate, 2006). Given the ongoing
difficulties of the United States economy, discrepancies in health insurance and care, and challenges for individuals with IDD to accessing comprehensive medical care, there is no reason to believe that pressure to terminate life support or denial of specific health care interventions does not remain an issue. Physicians and insurers generally make and enforce end of life decisions based on futility. Werth’s (2005) analysis of futility policies, decision tree tools and treatment ending decisions concludes that these are imperfect and often biased. A patient’s race, age, or immobility have all been shown to result in greater determination of futility by physicians, and result in fewer conversations with patients about quality of life issues, resulting in what Alpers and Lo (1995), as referenced by Werth (2005) refer to as “inconsistent, arbitrary and unfair decisions.” Ableism may play a role in physicians’ decisions to limit access to care based on futility (Werth, 2005; Nevel, 2010). Werth (2005) further asserts that decisions based on futility and ableism are a “…form of prejudice, and the result of this discrimination is death.” For individuals with IDD who lack access to informed and skilled case management and integrated support of a comprehensive palliative and end of life team focused on person-centered planning, financial and operational efficiency focused values and biases risk a limited opportunity to experience a good death (Kingsbury, 2011).

One study resulted in some physicians and palliative care staff identifying difficulty around non-verbal individuals with IDD (Tuffrey-Wijne et al., 2007b). Respondents to the study identified limited to no training regarding IDD. A majority of the respondents had no relationship or concept of the disability case management teams supporting people with IDD through individual program plans addressing daily living and
program services. The study cites examples of how professionals with adequate core and adaptive skills were limited by the disconnection between services that could have provided critical knowledge and collaborated to ensure comprehensive and meaningful services to ensure early access to palliative care (Tuffrey-Wijne et al., 2007b).

It is alternatively important to consider that physician and caregiver caution with regard to end of life care, and the ethics influencing current end of life practice are directly influenced by the complex and oppressive history of paternalism, institutional abuse, inadequate care, and devaluing of the lives of individuals with IDD. Fortunately for these individuals, recent disability rights advocacy, legislation and case law offer reference points for individualized planning as to what types of services an individual with IDD might access, and where they may be able to access them (Stein & Kerwin, 2010).

**History and Legislation**

Prior to the mid-nineteenth century, care for individuals with IDD was informal and disorganized. During the 1850’s, the effort to address the needs of the deserving poor in the United States led to the establishment of specialized institutions for the “blind, deaf, and dumb.” Eradication of ignorance was the primary objective in these institutions. Institutionalization became a prevailing approach to care for individuals with IDD. Care was initially provided through organized, scientific charity groups in communities, and before large governmentally managed institutions assumed the role (Lightfoot, 2009; Katz, 1996).

Schools for mentally retarded children were developed across 34 states between 1865 and 1876 established for the purpose of both protecting the children, and protecting
society from them. Justified as a cost effective step toward rehabilitation and education, the education and care component quickly degraded into routine institutionalization of individuals from birth to death. Institutional care provided minimal custodial care, and limited access to health care, education, or social activities, with no opportunity for individual choice or decision making. Institutionalization became a means for the economic and social management of individuals with IDD and for keeping them away from general society (Bazelon, 2009; Katz, 1996; Lightfoot, 2009; Palley & Van Hollen, 2000).

Institutional standards to elevate the needs and care of individuals with IDD were slow to occur. It was not until well after the 1960’s Civil Rights Movement in the United States that individuals with disabilities began to achieve meaningful benefit for social justice and change. An example of the disregard for individual health, care and dignity occurred from 1956 through 1971, as healthy children with IDD living in New York’s Willowbrook State School for Children with Mental Retardation were given injections of live hepatitis virus. The children served as an experimental control group as medical staff observed the effects of the untreated illness, and tested experimental vaccines. Parents were not well informed of the intentional infection and lack of treatment. Parents who received virtually no supports for the care of their children, and who were desperate for placement of their children into a care setting, were often told that openings in the experimental wing at Willowbrook were their child’s only available option (Botsford & King, 2011; EMHR, 2011; Helm & Friedman, 2011; Stein & Kerwin, 2010). While standards for research and care have advanced, it is still common for individuals with IDD
to not be told of their diagnosis or prognosis, and for families to be told that the individual is limited to referral to a nursing home, based on the professional assumptions of knowing how an illness will progress and biases of professional and insurance driven systems (Tuffrey-Wijne et al., 2007a; Tuffrey-Wijne & McEnhill, 2008). Referrals and recommendations for treatment may or may not have arisen from a meaningful and thorough analysis of their needs, desires and a continuum of available resources and individual accommodations (Tuffrey-Wijne et al., 2007a).

In 1978, the Developmental Disabilities Assistance and Bill of Rights Act formalized the provision of case management services to individuals with IDD, noting that the needs of qualifying individuals included “special interdisciplinary or generic care, treatment or other services” that are “individually planned and coordinated.” This definition of qualifying care is very close to the defining characteristics of quality palliative and end of life care. The 1981 passage of the Medicaid Home and Community Based Waiver provided authorization for individuals with IDD to receive state Medicaid funded home and community based services that would have been provided through institutional care in the past. The purpose of the Medicaid funding was to provide individuals with IDD the services necessary to live in community based settings (Lightfoot, 2009). The waiver set a foundation for supporting individuals with IDD the opportunity to “age in place” in family homes or community residential settings rather than risk being sent to institutions where they would remain until death.

The American’s with Disabilities Act [ADA], adopted in 1990, established a Federal mandate to remove barriers to individuals with disabilities access to community
settings and services. Access includes structural, procedural and operational barriers limiting the ability of individuals with disabilities to participate in and contribute to society (ADA, 2011; Helm & Friedman, 2011; Stein & Kerwin, 2010). Passage of ADA enabled people with disabilities to work and more fully participate in society than ever before.

Goode and Maloof (2011), address the challenges and cultural considerations regarding end of life, paying attention to cultural issues, including locus-of-control. In Western culture, internal locus-of-control—the individuals decision making based on their internal desires driving personal decisions is valued over the belief in other cultures that individuals have little control over events in their life (Goode & Maloof, 2011). The 1991 passage of the Patient Self-Determination Act [PSDA] was built on values supporting patient autonomy, informed consent, truth telling by health professionals to openly provide information to people who are ill, and reinforcement of the individual person’s control over their dying process. Goode and Maloof (2011) identify challenges with these values when addressing the needs of an individual with IDD. Asking a dying patient their preferences or desires regarding end of life, is an attempt to respect autonomy, however, the person’s health literacy may be low, and informed consent may be challenging due to low literacy and communication challenges (Goode & Maloof, 2011). Truth telling, generally accepted with regard to medical issues has been generally accepted in North American culture. However, Goode and Maloof (2011) note that historic abuses of minorities and negative public sentiment toward groups of individuals has been connected to a distrust of advance care directives and concern that medical
documentation may lead to a legalized form of neglect or be used to deny care. They also recognize that health care is “culture bound,” with its own set of values, beliefs, language, communication styles roles, relationships and behaviors, putting providers at risk of having conflicting values and practices regarding truth telling to patients with IDD and their surrogates who may have difficulty navigating the medical system (Goode & Maloof, 2011).

Reinforcing the intent of the ADA, the 1999 United States Supreme Court decision in Olmstead v. L.C. and E.W. has implications for individuals with IDD to be able to participate in end of life care, and to “die in place.” The Supreme Court’s Olmstead decision held that the unnecessary segregation of individuals with developmental disabilities in institutions was a violation of their right to live and receive necessary services in the community. Several states presented amicus briefs arguing that the decision to move individuals with IDD from state institutions to community care and service would be unaffordable. The court disagreed, identifying a requirement for states to provide community care in the most integrated and appropriate setting. Through the court’s decision in Olmstead, the Supreme Court determined that the historic, unnecessary and common practice of institutionalizing individuals with disabilities was a violation of the ADA. Olmstead also determined that budget limitations and the indefinite withholding of services due to waiting lists were unacceptable; placing the burden on the state to ensure services are provided as determined necessary, and in a timely fashion. It also determined that government and care providers’ practice of routine placement of
individuals with IDD in nursing homes, psychiatric or other facilities to receive care was unreasonable (Bazelon, 2011; Parish & Lutwick, 2005).

The Bazelon Center for Mental Health Law (2009) cites examples of services in the community supported by Olmstead as including: illness self-management, medication management, multi-systemic therapy, access to natural networks to which people belong and depend, and social support that formal institutions within communities can provide. Lawsuits and advocacy have resulted in the increased availability of community-based, long term residential care so that individuals with IDD may have a greater chance to age in place (Parish & Lutwick, 2005), however, research indicates that it is common practice for physicians to discharge individuals with IDD facing end of life to nursing and long-term care homes (Stein, 2008). This creates an extremely limited ability to complete the final stages of aging in place by being able to die in place, if that is what the individual desires. While specific rights of individuals with IDD to die in place are not specifically addressed in any of the literature reviewed for this study, literature indicates that physicians and care team members in the United States may presume that individuals with IDD and life ending illness are to be sent to nursing homes or long term care facilities (Tuffrey-Wijne et al., 2007a; Stein & Kerwin, 2010). They may also feel unsupported in their efforts to ensure quality care in the home setting (Reddall, 2009). These examples of professional presumption result in a missed opportunity to determine what the person with IDD desires. Without comprehensive tools to support physician’s and care team’s careful consideration of the individual’s needs and desires, the risks for ethical, ADA and Olmstead violations may be a concern.
Dying in Place

Caring for individuals with IDD in the home or small residential care setting requires sensitivity and an individualized assessment of needs and resources in order to ensure individualized care, privacy and preservation of dignity. The changes to health and behavior associated with aging are often a reason for parents to agree to more specialized care settings for their family member with IDD, particularly as the parents themselves face issues of aging and have difficulty remaining in a caregiver role for an aging child with IDD (Shaw, Cartwright & Craig, 2011). Parents reported preferences for housing for their child with IDD and health concerns to be among individuals with less significant IDD needs, however, they often felt obliged to keep their child with them when these preferences could not be met. Nevertheless, placement in settings that could not support accommodation for the inclusion and the needs of the person with IDD was seen as favorable over placement in a medical model of care or an environment that was not “homelike” (Shaw, et al., 2011).

Tuffrey-Wijne (2009) addresses the presumption that home is the best option for an individual with IDD facing terminal illness. Tuffrey-Wijne’s (2009) research has led to the realization that definitions of “home” may be different among the individual with IDD, care teams and family members. Resources and realities of care may challenge caregiver’s ability to meet a stated desire for dying at home. Factors related to illness, individual factors such as social class, education level, and patient preference, and environmental factors including social support, availability of outside home health care influence the preferred place of care for dying individuals. Tuffrey-Wijne identified three
necessary factors to assist individuals with IDD and their care teams to make a meaningful choice of where the person will be cared for during the dying phase of life. First, at least two real, available, high quality options must be presented in a manner the individual with IDD can understand. Second, care teams must have a fair understanding of the prognosis for the individual with IDD, availability of services, and likely mode of death. Tuffrey-Wijne (2009) noted that most disability staff in the research project lacked understanding needed to assist people with IDD to make real choices. Third, the preferences of the person with IDD must be skillfully and sensitively sought and reviewed. The person with IDD must be supported to navigate abstract, uncertain or difficult concepts to comprehend. Care teams and care giving staff must have the ability to address sensitive issues and to present an emotional capacity to listen and support the individual with IDD as they make their choice (Tuffrey-Wijne, 2009).

A study of placement, relocation and end of life issues by Patti, Amble and Flory (2010) identified changes in routine, social environment, and relocations in living with declines in mental status, negative changes in health, and increased mortality. For individuals with Down syndrome, increased relocations and medical changes have a strong relationship with losses in adaptive functioning and cognitive health consistent with dementia. Dementia affects nearly 50% of individuals with Down syndrome as they advance beyond age 40 (Patti et al., 2010; Nevel, 2010). Individuals with Down syndrome have been identified as demonstrating health, functional and behavior changes following death of a parent and changes to their home placement. They are also at higher risk of being moved from a group home setting to nursing home care after age 50 (Patti et
al., 2010). Deterioration related to dementia is associated with changes in social environment and disruptions to routines, adding another dimension to the importance of retaining small care setting placement and prevention of institutionalization for individuals with IDD as they progress through end of life stages and issues (Janicki, 2011; Patti et al., 2010).

A toolkit that supports staff competencies with regard to care of individuals with IDD and dementia could support longer retention of the individual in their familiar care setting. Janicki (2011) identifies the difference between “retaining” and “non-retaining” placements as having staff who “wanted to continue to provide services” to the person with IDD and dementia, and having staff who felt they could provide the individual with a safe, appropriate level of care in the setting. Non-retainers lacked a philosophy of care, and maintained concerns over safety as the individual with IDD deteriorated beyond staff’s comfort with the health changes. Settings with specialized staff trained to understand care for issues associated with dementia, including depression, pain, behavior, ambulation, nutrition and hydration, were more likely to demonstrate a higher quality of life for the individual with IDD and dementia (Janicki, 2011).

**Ethical Considerations**

Concerns regarding dementia and capacity for decision making are often foremost in care team decision making. Lifelong issues of capacity, competency, parity, and quality of life are common in the lives of individuals with IDD (Johnson, 2011). In palliative and end of life decision making, they are critical. Csikai and Chaitin (2006) identify autonomy, nonmaleficence, beneficence, and justice as the moral principles
guiding the care team’s decision and problem solving role in providing palliative and end of life care. They note that within the Western philosophy of medicine, the principle of autonomy, issues of self-determination and informed consent requires an ability to seek and understand knowledge to develop an increased understanding of self which aids an individual’s ability to define what is right and good. Csikai and Chaitin (2006) also state that self-determination with regard to palliative care has evolved into a right to accept or refuse care which must be respected even when care team members disagree with the individual’s decision. Determination of quality of life is most often a result of presumptions regarding issues of capacity. Physicians may not consider the cognitive capacity of the individual with IDD as effectively informing quality of life. Families and caregivers may presume their relationship with the individual with IDD provides enough information of capacity to presume quality of life as well. Nevertheless, only by seeking to understand the life experience as viewed by the individual with IDD can family, caregivers and care teams gain an understanding of quality of life, and assure autonomy and self-determination (Csikai & Chaitin, 2006; Johnson, 2011). Johnson (2011) advises that the values of the individual with IDD are the only values that truly matter in providing them with care, and they have the legal right to accept or refuse care based on what is important to them, whether they are determined legally competent or not.

Kingsbury (2011) acknowledges that many professionals confuse capacity with competency. Care teams, family members and caregivers can quite often improve the capacity for a person with IDD to understanding and communicating through use of specialized tools or simplified language. Competency on the other hand is a legal term
and process that is not easily directly remediated with the individual with IDD, and may require appointment of another party who can understand that a decision must be made, can understand the benefits or consequences of a decision, has the ability to communicate the rationale for a decision as well as the decision itself, and can make the decision in the context of the values and goals of the individual with IDD (Kingsbury, 2011). An appointed conservator or guardian has a responsibility to make decisions with input and in relation to the desires and values of the person with IDD. Unfortunately, as Kingsbury (2011) notes, a common assumption that cognitive impairment is the same as a lack of competency or decision making ability impacts care decisions.

Decision makers often seek and defer to presumed expertise, such as in the common practice of asking a physician the question, “What would you do if this were your family member?” This type of question only elicits a response based on the physician’s experience and values, and may have limited relevance to the desires of an individual with IDD who is not consulted for input into their own care. Without asking the individual with IDD the same question and neglecting to provide medical descriptions of care and consequences, in whatever capacity they are able to understand and respond, caregivers neglect to elicit what is important to the individual with IDD who is experiencing end of life. This is contrary to professional and practice standards (Csikai & Chaitin, 2006; Johnson, 2011; NASW, 2004).

The principle of non-maleficence is the requirement to avoid inflicting harm on another person, either through treatment or through the avoidance of treatment. The medical profession’s intention for beneficence is inherent in the Hippocratic Oath which
serves as a promise to provide care that does the most good for a person. The palliative and end of life care non-maleficence counter to this requires a more intentional review when treating individuals with IDD in order to avoid interventions that are unnecessary, or will not have a qualitative or curative outcome for the treated individual (Csikai & Chaitin, 2006; Johnson, 2011). A dilemma inherent in the principle of non-maleficence is the rule of double effect. Double effect occurs when one presumed necessary action may have a risk of a harmful result—such as increasing pain medication to end suffering, knowing a patient’s risk may be respiratory depression or death (Csikai & Chaitin, 2006).

Csikai and Chaitin (2006) cite examples of injury to patients occurring as a result of an injustice, such as a provider permitting or risking death, under or un-medicated treatment, unnecessary sedation, or unexplained beginning or withdrawal of treatment. Difficulties individuals with IDD experience with cognition and communication place them at high risk of treatment decisions by others that are influenced by professional judgment regarding treatment options, laws, and standards of due care in medicine, or personal or provider bias. These professionalized justifications for the risks of treatment must be weighed against the unique potential for benefit or harm and a lack of self-determination for a person with IDD. Foster and Turner (2007) provide a case study example of disagreement between medical staff and family to keep a patient alive until the patient’s parents could arrive should the patient experience cardiac arrest. The medical staff expressed their decisions of treatment that would be in the patient and family’s best interest, despite having heard from the family the patient of their desire and reasons for no
cardiac compressions. Facilitating conversations among care team members was required to re-focus on the patient’s desire and best interest.

An example of the influence wielded by medical professionals was provided as recently as 2006, with regard to United States Senate review of issues related to assisted suicide. Diane Coleman, president of Not Dead Yet—a disability rights organization promoting self-determination with regard to medical treatment, and a person with a physical disability requiring respiratory and mobility support reported that “A number of…friends have been pressured by hospital employees to sign do-not-resuscitate orders and other advance directives to forego treatment, coupled with negative statements about how bad it would be if they became more disabled.” (Kingsbury, 2006; US Senate, 2006).

Studies indicate clinic directors may assume ventilator use represents a low quality of life, resulting in their limited support for continued use. Physicians attitudes about disability and related types of existence influence whether or not they encourage life-sustaining treatment and other therapeutic interventions—even when these interventions represent necessary everyday care for an individual with IDD (Stein & Kerwin, 2010). Levy and van Stone (2011) also note that physicians’ values are quite often the decision driver in assessing dual effect issues. The challenge for palliative care teams serving individuals with IDD is to have the conversation using the means of communication most effective for the individual with IDD, and engage in the multidimensional assessment of non-maleficence and dual effect based on the quality of life perceptions and desires of the individual with IDD.
An individual who has spent a lifetime with life sustaining respiratory support, or an individual reliant on G-tube feeding due to swallowing issues will require consideration of their feelings as well as an intentional conversation regarding the risks of having these life sustaining and enhancing interventions removed (Csikai & Chaitin, 2006; Johnson, 2011).

**Capacity and Competency**

Care decisions by people with IDD are often considered as controversial and become complicated by the values and biases of the many professional, caregiver and family participants in palliative and end of life care decisions. The confusion may lie in a lack of distinction between capacity and competency, and an inauthentic approach to self-determination and person centered planning.

Multiple sources distinguish between capacity to share decisions and desires and competency to make informed decisions (Csikai & Chaitin, 2006; Foster & Turner, 2007; Johnson, 2011; Kingsbury, 2011; Smith & Hardt, 2011). Legal competency to make decisions for one’s own welfare is assumed for individuals over the age of 18 years. This does not mean that the individual may not need additional help due to IDD or other issues. Smith and Hardt (2011) divide individuals with disabilities into two groups – those who have been able to make their preferences for care and life decisions known to others, and those who have not been able to do so due to either personal intellectual or communication challenges, or due to the limits of their circumstances. Foster and Turner (2007) explain how important it is to recognize the potential for fluctuations in capacity over time and across subjects. While some individuals with IDD may be able to make
decisions about their activities of daily living, they may not have the capacity to make complex decisions for medical care. Alternatively, they may have the inability to meet their daily care needs, yet have the capacity to communicate their desire to continue or end complex care that keeps them alive, or causes pain or discomfort.

Adults with IDD have the right to decide to receive or end medical treatment unless they are under a legal conservatorship. They have the right to state where they wish to live, work, who they will associate with, and how they will use their resources. If they have challenges to their capacity to express their wishes, they may enlist the assistance of a surrogate for decisions in these areas. In most cases, the surrogate is a parent. However, as individuals with IDD are living longer, they may be outliving parents, leaving other family members such as working adult siblings caring for their own families with the difficult task of assuming or declining the role of surrogate (Parish & Lutwick, 2005). This creates an increased reliance on case managers, paid caregivers or others serving as surrogates, many of whom have limited history or experience with the person with IDD, may not read their cues or have familiarity or skill with the person’s mode of communication.

Regardless of who assumes a surrogate role, the surrogate’s responsibility remains to seek to identify as early as possible the expressed interests of the individual with IDD. Many adults with IDD are supported by governmental organizations established to provide case management for the needs of individuals with IDD, or by advocacy organizations filling a policy advocacy role. The result for an individual with IDD is that there are potentially many people associated with the palliative and end of life team who
have or perceive themselves as having a responsibility for speaking for the individual with
IDD (Foster & Turner, 2007; Smith & Hardt, 2011).

Ensuring the individual with IDD has the opportunity to understand all aspects of
care to the best of their capacity is the responsibility of the care team; caution is advised to
avoid making assumptions about capacity (Csikai & Chaitin, 2006; Johnson, 2011).
Individuals with IDD may have capacity to understand but have had limited opportunity to
gain the background knowledge or exposure to support decisions. It is up to the care team
to provide an opportunity or understanding and consent. For instance, due to limited
exposure to academic or functional learning, a patient with IDD may have no knowledge
of how bodily organs or systems work. Taking extra time to share basic background of
the purpose and functioning of the lung, the options and potential outcomes for treatment
can elicit an informed response of the patient’s desire for treatment (Csikai & Chaitin,
2006; Johnson, 2011). Recent studies also indicate that when conversations do not occur
with patients, or assumptions of their best interests are made, the rights of patients with
IDD in the United States to refuse life sustaining treatments and the associated risks of
medical care are ignored. For many people with IDD, treatments considered life
sustaining—such as intubations and tube feeding, are routine care. The perspective of the
patient with IDD to continue this care can be quite different than that of a patient without
IDD for whom these treatments are perceived as a temporary emergency event (Tuffrey-
Wijne et al., 2007a).

professionals as they addressed disability noting “recurrent, ‘distressing encounters’ with
physicians and other health professionals.” Individuals with disabilities, however, indicated they were glad to be alive and often rated quality of life as good to excellent. Physician and caregiver attitudes were often more negative than general public attitudes regarding disability, and underestimated quality of life (Stein & Kerwin, 2010; Werth, 2005).

**Communication**

Literature reviewed indicates the need for care teams to understand the necessary considerations related to the nature of an individual’s intellectual disability, and the associated adaptive, communication and mobility challenges that influence assessment or decisions regarding care (Stein, 2008; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a). While some aspects of guided decision making in medical and palliative care are similar to the approaches in care for cognitive impairments such as dementia and Parkinson’s disease, individuals with IDD are at risk for assumptions that they are incapable of ever providing meaningful input toward their care. Many individuals are never told of their diagnosis, let alone asked about their treatment or care concerns (Tuffrey-Wijne et al., 2007a). Despite their right to know diagnosis and prognosis, individuals with disabilities face increased paternalistic and coercive management of their care as health care staff, administrators and families work diligently to protect them, assuming they are incapable of making informed decisions (Tuffrey-Wijne et al., 2007a). Palliative care social workers can be integral to ensuring attitudes and biases regarding intellectual disability, as well as environmental and care barriers are considered openly and with the patient.
Differences in cognitive capacity and communication ability do not automatically equate to inability to express joy, fear, pain, and quality of life wishes (Stein, 2008, Stein & Kerwin, 2010). Tuffrey-Wijne et al. (2007a) note that people with dementia and low cognitive functioning express pain through atypical behaviors rather than verbally and risk having pain under-treated. Individuals with IDD are often regarded as having a high pain tolerance, although no studies have indicated that higher pain tolerance exists in this population (Tuffrey-Wijne et al., 2007a).

Among studies of palliative care and health care professionals, Tuffrey-Wijne et al. (2007b) identified communication factors as a major obstacle with regard to developing and providing biopsychosocial-spiritual support and medical care for individuals with IDD. Communication difficulties were identified as barriers to professional confidence in adequate diagnosis, managing care conversations, informing patients about diagnosis. Communication barriers also resulted in care team concerns over the amount of time required to attempt meaningful communication with non-verbal individuals with IDD (Tuffrey-Wijne et al., 2007b; Tuffrey-Wijne, 2009). When medical care providers experience difficulty or choose not to explain a diagnosis or prognosis, disability staff are faced with the responsibility. This results in many individuals with IDD never being told of their diagnosis (Tuffrey-Wijne et al., 2007a).

The foundation of palliative care is the relief of pain and symptoms related to illness (Reddall, 2009). For individuals with IDD who have limited or no verbal language, their manner of expressing both pleasure and pain can easily be confused with symptoms commonly related to illness and pain (DisDAT, 2008; Reddall, 2009; van der
Putten & Vlaskamp, 2011). Crying out, squealing, facial grimacing and other behaviors can be signs of pain and signs of pleasure. Communicating pain and distress is highly individual and requires attention to individual behavioral cues to avoid misinterpretation of pain as challenging behavior, or behavior as pain (Tuffrey-Wijne et al., 2007). For instance, not moving or jumping around, and crying out or silence may all be indicators of pain or pleasure. A common myth regarding individuals with IDD is that they have a high pain tolerance. Caregivers and medical providers may mistake lack of verbal indicators of pain as a high pain tolerance. For individuals with IDD, neurological and cognitive impairments may result in non-verbal expressions of pain through changes in activity, sleep behavior, maladaptive behaviors, body movements and facial expression, particularly as people age (Tuffrey-Wijne et al., 2007; van der Putten & Vlaskamp, 2011).

Communication challenges may also inhibit intentional seeking of psychosocial and spiritual desires from individuals with IDD, which has the potential to increase individual distress. In the extensive literature review completed by Tuffrey-Wijne et al., (2007) no research was identified to address the preferences, views and experiences of end of life care for individuals with IDD. Nor was information regarding spirituality found with regard to people with IDD experiencing palliative care (Tuffrey-Wijne et al., 2007).

Sormanti and Ballan (2011), identify “layered loss” resulting from the many transitions people with IDD face over time, and “silent loss,” occurring over their lifetime. Layered loss results from the disrupted relationships of family members, educational and health aides, interpersonal problems with family, peers and caregivers, and secondary impairments resulting from health and functioning challenges. Silent loss is a result of
loss of identity, ability, accessibility, opportunity and independence. Silent losses are a particular concern with regard to palliative and end of life care as they are the result of major life-altering loss, such as death of a parent or caregiver, and are often accompanied by life altering decisions made by others, for which the person is unable to make choices or take actions on his or her own behalf (Sormanti & Ballan, 2011).

The study by Sormanti and Ballan (2011) also challenges the assumption that children and adults with IDD cannot comprehend the concept of death and its impact, and that individuals with IDD do not have the capacity to form relational bonds that result in a feeling of loss or grief. While indications of grief among people with IDD are often observed as behavior or mental health changes, over two-thirds of individuals with IDD indicated understanding of the universality of death, and one quarter indicated that they had fully developed cognitive awareness of death (Sormanti & Ballan, 2011). While individuals with IDD may not have the vocabulary or verbal ability to share grief, they are dependent upon others to recognize and support their experience with anticipatory and active grieving.

Communication cues and signals of alterations to wellbeing or conditions are often quickly read and interpreted by family members, close friends with IDD, and caregivers, making them integral partners in bridging the communication concerns of care team members who may have limited experience with individuals with IDD. Marlow and Martin (2008) identify research indicating the desire of family members to surround the person with love, monitor their welfare and ensure the dying person’s comfort; acts that may also be a response to the intensified desire for meaningful relationships, common
among individuals with IDD experiencing a terminal illness. Marlow and Martin (2008) also note that research is limited with regard to how individuals with IDD conceptualize death, an issue that is compounded by their historical exclusion from the experience of dying, making it critical for communication regarding the experience of death and dying to be presented based on knowledge of that person. It is also important to recognize the unique experience of grieving among friends with IDD, and caregivers. Marlow & Martin’s (2008) review of research notes the surprise of families as they felt enriched by the involvement of friends with IDD in their loved one’s death.

Caregivers of individuals with IDD are often assumed to have a professionalized approach to the individual’s death, leaving them unsupported and unrecognized for their loss of role and relationship with the individual with IDD (Marlow & Martin, 2008; Stein, 2008; Tood, 2004). Staff in care settings can sometimes feel that they have become “family” to the person with IDD, and are often faced with making decisions regarding care, despite a lack of understanding of hospice, palliative and end of life care and needs (Stein, 2008). Many residential care settings have policies on what staff should do in the event of a death, but do not have policies addressing support during the dying phase of life (Tood, 2004). Communication between palliative or end of life care teams and residential care providers is necessary to ensure a comprehensive and shared understanding of needs and desires of the individual with IDD.

Tools for Care Teams

The challenge for palliative and hospice care teams becomes one of finding appropriate, individualized assessment methods, and ensuring issues of pain and
preferences of care are discussed with the patient and caregivers or guardians who are familiar with the patient’s communication styles, cues, personal strengths, fears and life preferences (Stein & Kerwin, 2010).

Finding comprehensive tools to support care teams serving individuals with IDD provided limited results. Tools identified for this study include a “capacity and decision-making flow chart” used by professionals to determine the capacity of an individual with IDD to comprehend, retain and balance the risks and benefits of new information as they make decisions. The flow chart developed by Foster, Whalley, Burnley, Pendle and Rossendale Primary Care Trust (as displayed in Foster & Turner, 2007, Figure 1) provides the professional with a process that can be documented to show professionals have presumed capacity, and progressed through the conversation in a manner that supports documenting the discussion and decisions of the individual and/or team. Foster and Turner (2007) acknowledge the difficulty in assuring individuals with IDD are provided an opportunity to receive complex medical and end of life care information in a manner they can understand. They support the flow-chart with simple examples of key communication components—manner (spoken, gestures, signs, symbols, photographs), level (complex sentences versus one or two key words, abstract concepts, detailed explanations vs. short simple sentences), and pace (what to say/content, time for processing, number of sessions versus all at once, and length of sessions). When an individual with IDD does not demonstrate capacity for decisions, Foster and Turner (2007) provide a table outlining four steps professionals can follow to prepare when faced with making decisions in the best interest of the individual with IDD. The four steps are
to identify the decision-making team members, to clearly state the proposed treatment and other options, to consider the issues in preparation for the discussion, and finally, to hold a meeting of the key stakeholders to discuss the proposal. The process outlined by Foster and Turner (2007) meets the requirements of the United Kingdom’s Mental Capacity Act of 2005, and requires an intentional and methodical approach by care team facilitators.

Another tool useful to care providers is the Disability Distress Assessment Tool or DisDAT (Cooper, 2009; DisDAT, 2008; Regnard et al., 2007). Developed and implemented in the United Kingdom over the past decade, DisDAT was developed by palliative care team members following their realization that the needs of patients with IDD were not being met. DisDAT is free to use and available without restriction via the internet (DisDAT, 2008). DisDAT is not a pain measurement tool. Instead, DisDAT provides a framework for identifying and documenting individual signature distress cues for people with mild to severe communication difficulties. Through caregiver observation of changes to an individual’s behavior, posture and expression, an individual’s behavior becomes an alternative, non-verbal method of communication that caregivers can train themselves to understand.

Regnard et al.’s (2007) study indicated that DisDAT is effective in providing caregivers with a means to document evidence and to check and trust their intuitive observations of distress among persons with IDD. DisDAT assists caregivers in identifying distress cues beyond indications of physical pain. Caregivers with long and short relationships with persons with IDD were effective at identifying cues indicating contentment and distress. Caregivers were able to quickly identify the unique ways an
individual would communicate distress. Alterations in tone, pitch and duration of vocalizations were indicators of that person’s distress (Cooper, 2009; Regnard et al., 2007).

Although Regnard et al. (2007) note that caregivers were not always clear as to the reason for the distress, DisDAT supported their ability to learn a wider “non-verbal vocabulary of distress” and respond to early and mid-stage distress cues, allowing quick intervention once the source of distress is identified. Understanding the context of distress is helpful to caregivers as they make clinical decisions. DisDAT provides a mechanism for caregivers to avoid assumptions regarding distress by learning that distress in medical and a care setting is not always due to pain. Avoiding an assumption that changes in behavior among individuals with IDD are an indication of pain allows caregivers to explore more fully and avoid treating behaviors and non-verbal communication with medication or sedation. Cooper (2009) considers the use of DisDAT in conjunction with a pain assessment as optimal for confidently identifying distress due to pain. Understanding and reading the individual’s non-verbal language of distress also allows caregivers to monitor and adjust therapeutic interventions as needed (Cooper, 2009; Regnard et al., 2007).

DisDAT is not a scoring tool, but rather documents the observations and intuitive interpretations of behavior and cues that caregivers make, connecting them to the context in which the behavior occurs. DisDAT information is useful as a baseline assessment and as a tool for care teams to consider as interventions occur. DisDAT asks raters to identify identical measures for an individual in both a contented and distressed state across the
categories of facial signs, skin appearance, vocal sounds, speech, habits and mannerisms, body posture and body observation. The context of distress and actions that can alleviate distress are documented, as are measures of communication levels. A clinical decision distress checklist is also provided to help assess possible reasons for distress (Cooper, 2009; DisDAT, 2008; Regnard et al., 2007).

Another resource model to support end of life care needs of individuals with IDD is the internet based Last Passages manual (Volunteers of America [VAI], 2000). The online manual was developed in response to an increasingly aging population of individuals with IDD, and provides a range of information, vignettes, resources and sample documents and policies to assist individuals and care providers as they discuss and plan for end of life. Much of the information included in Last Passages is generalized to address common issues related to end of life, dying, and bereavement. The website does offer summary information and links to resources addressing advance care planning, special needs trusts and organ donation that are unique to individuals with IDD (VAI, 2000).

Kingsbury’s (2009) published guide, “People Planning Ahead” is a model tool to elicit healthcare and end of life wishes for individuals with IDD. The guide is a collection of simple explanations and instructions, with open-ended, workbook style forms. Kingsbury (2009) notes that the guide is built around thinking skills and tools developed by the Learning Community for Person Centered Practices to elicit a person-centered baseline of healthcare and end of life plans. The workbook format is also available on a compact disc, to support future reflections and revisions, and provide a format for
gathering and documenting the changing needs, desires or wishes of the person with IDD. The plan that is developed using the workbook can be integrated into or supplement existing medical or biopsychosocial case management plans so that everyone involved with the individual with IDD is operating from the same information.

Kingsbury’s (2009) commitment to person centered planning is evident throughout the workbook. Questions are reflective, and avoid medical process or terminology. The guide includes “A Statement of Common Principles on Life Sustaining Care” developed by the Center on Human Policy, Law and Disability Studies [CHPLDS] (2005). The Statement acknowledges the fundamental human, civil and constitutional rights of all people, including individuals with IDD, to life-sustaining care and treatment that are not sacrificed because of cognitive, psychiatric, emotional, developmental, intellectual, sensory or physical disability. The Statement acknowledges disability as a natural part of the human condition which has historically resulted in prejudice, discrimination and justification for depriving people of their fundamental rights, including access to life-sustaining care and treatment. The Statement reinforces entitlement of the person with IDD to exercise rights to life-sustaining care, treatment, self-determination and autonomy, with life sustaining treatment to be provided unless the clear and convincing evidence of the desire of the individual with IDD is provided or death is genuinely imminent and care or treatment is objectively futile and would prolong the dying process. The statement ends with the requirement that when doubt exists as to whether or not to provide life sustaining care, a presumption must always be made in favor of providing care and treatment (CHPLDS, 2005; Kingsbury, 2009).
Kingsbury’s (2009) guide is structured to have conversations over time to identify information of importance to the person with IDD, such as their favorite things, things they do not like, what a great or difficult day or weekend would look like, positive rituals, how the person communicates, health and safety concerns, where the person lives and dies, rituals for comfort, end of life wishes and final arrangements. It is structured to provide a process to address common concerns that arise with critical, chronic or terminal illness as well as progressive disability, and holds person-centered desires and needs as equally important to medical care concerns (Kingsbury, 2009).

**Person-Centered Planning**

Kingsbury (2011) recognizes the multiple issues influencing end of life planning for individuals with IDD. Consent, power, autonomy and best interest questions drive the effort toward end of life decisions (Kingsbury, 2011). Ensuring the inclusion of individuals with IDD in that effort is critical. Palliative care social workers have an opportunity to avoid the historic exclusion to medical care faced by individuals with IDD. Through enlistment of the patient and the patient’s “team” of family members, advocates, disability care providers and case managers, early palliative and end of life planning can become a component of the patient’s documented “person-centered” plan. Kingsbury (2011) indicates that planning for end of life issues is almost never done as a component of the disability case management standard of person centered care. Given that disability service systems require case planning for every other aspect of life for a person with IDD it makes sense that planning for end of life can begin well before it is imminent.
One reason end of life care planning at the case management level is not occurring may be the general societal discomfort with conversations around death and dying. Knowing that Americans in general are unlikely to engage in advance care planning or to develop Advance Care Directives for themselves, it is reasonable to assume it may be even more difficult to engage in this with an individual with IDD and multiple team members, including family and caregivers (Kingsbury, 2011). Person-centered planning for all other aspects of the life of an individual with IDD has become a routine process through Individual Service Plans (ISPs), Individual Learning Plans (ILPs), Making Action Plans (MAPs), Essential Lifestyle Plans (ELPs) and other structures. Kingsbury (2011) notes that despite the forms and structure of the planning, person-centered planning only occurs when the individual with IDD has a “real voice” in the process. The plan developed from truly listening to the person’s voice, desires and wishes, is not a systems and service delivery plan; it is a plan which moves from medical diagnosis, treatment goals and prognosis, to addressing “what it means to live with the diagnosis” (Kingsbury, 2011). A person-centered plan uses people-first language, rather than focusing on diagnosis. It uses everyday language, understood by the individual and caregivers, and images that are meaningful in the context of the individual’s life experience. It also includes an intentional search for and is structured around the individual’s strengths and gifts, as opposed to the individual’s strengths and needs. The person’s strengths and needs are considered in the context of their community, friends, family, and relationships that are important to them. Finally the voice of the person with IDD is strengthened in the plan as it includes the voice of those who know and love the person. This helps to keep
the plan focused on the defined desires and changes that are wished for by that person, not the desires and wishes of service and care providers operating within structured systems (Kingsbury, 2011).

Person-centered plans address the preferences and desires of the individual with IDD regarding issues of daily living impacted by end of life, where, how and when a patient prefers to receive care, from whom, and under which conditions. Including a life story or values assessment to distinguish between disability and illness can guide surrogates in understanding which how they can make decisions with due respect for the patient’s expressed desires and which issues truly require the surrogate’s decision making. This is especially important when a critical or terminal diagnosis is made, as medical interventions and traditional care systems are likely to mobilize and increase from this point forward (Kingsbury, 2011; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a).

Dying with Dignity

A common element of typical end of life discussions is the concept of “dying with dignity.” These conversations often address a person’s threshold for the level of burden and assistance they will require as end of life and terminal illness care advances. These are issues including being able to use the bathroom unassisted, requiring caregivers to move, bathe, feed, and assist with other activities of daily living. For the individual with IDD, these activities identified by many without disabilities as burdens to be avoided, may have been the activities of their daily existence. As Coleman stated during US Senate (2006) testimony regarding assisted suicide’s implications for individuals with disabilities, the concerns about dignity expressed among the “newly disabled” who face requiring use
of technology to live, or reliance on others to meet their intimate care needs, are not consistent with the realities of many individuals with disabilities. Coleman insists that dignity should be addressed throughout life, and across all aspects of a person’s experience, not just as a component of dying (US Senate, 2006). While reliance on technology may be an extraordinary change in the typical person’s new end of life disability experience resulting in new advance care planning and quality of life considerations, reliance on technology is an ordinary experience for many individuals with IDD and other life-long disabilities. A person-centered conversation regarding the desires of individuals with IDD regarding technology is necessary to avoid quality of life assumptions.

Kingsbury (2011) advises ensuring the person-centered plan focuses on the experience of living, as well as wishes for how dying will be experienced. The question “What does living well mean for this person?” lessens the risk of quality of life assumptions and supports the entire team—which includes the person with IDD and individuals who know and love that person, to elicit individualized, contextual responses and meaningful plans. Starting the palliative and end of life planning conversation as one of “living well” can also develop reflective thinking and increase readiness for future detailed end of life conversations with individual with IDD, family and friends (Kingsbury, 2011).

Early person-centered planning is essential from a systems perspective as well. Kingsbury (2011) notes concerns regarding presumptions that a person with IDD dying at home rather than in a medical setting has been a victim of a lack of medical care. These
presumptions have led to investigations that could have been avoided with person-centered planning.

Understanding the range of needs for individuals with IDD also increases the potential for implementing more comprehensive tools that ensure care teams are aware of and acting on the wishes and desires of individuals with IDD and achievement of a “good death.” Tuffrey-Wijne’s (2009) Veronica Project identified critical elements of a good death for people with IDD as having care occur in familiar or safe surroundings while maintaining close bonds with family, friends and caregivers; being free from pain and anxiety; and providing the closest caregivers with extensive support from program managers and/or outside professionals to ensure they know what is happening, what to expect, can see that the person with IDD is treated with respect, and the caregivers and family have recognition and support for their grief.

Conclusion

Literature specific to end of life care for individuals with IDD is dispersed across the range of topics and practices that make up palliative and end of life care. Individuals with IDD facing end of life issues as elderly citizens are an increasingly aging population thanks to advances in medical and social care (Lightfoot, 2009; Stein, 2008; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a). This has resulted in their increased experience with the complex and long periods of dying resulting from illnesses such as chronic heart disease, diabetes, dementia, cancer and other diseases (Foster & Turner, 2007; Lightfoot, 2009; Tood, 2004; Tuffrey-Wijne et al., 2007a).
Individuals with IDD are also a population with whom most end of life care professionals have had little or no opportunity to work. This lack of exposure results in multiple challenges as limited training and practical experience, personal bias, and value judgments regarding quality of life impact the rights and resources accessible to the individual with IDD (Stein, 2008; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a). It is not uncommon for individuals with IDD to be sent directly to nursing homes to die, and not be informed of their diagnosis or prognosis (Tuffrey-Wijne et al., 2007a; Tuffrey-Wijne & McEnhill, 2008). While many medical staff, case management teams, and families believe they are making decisions in the best interest of the patient, unless they consult with the individuals with IDD and each other, they risk violating that individuals rights and neglecting to ensure consideration and response to the unique needs and desires of the person with IDD and to ensure dignity in dying (Helm & Friedman, 2010).

Physicians and professionals working with individuals with IDD have a range of legislation and professional standards for ethical practice to draw from to ensure protecting the dignity, self-determination and access to person-centered care (ADA, 2011; Stein & Kerwin, 2010). At the same time, professionals have limited exposure to individuals with IDD, and have very few practical tools to ensure that biopsychosocial and spiritual needs at end of life for the person with IDD are met sought and met.

Individuals with IDD have a greater potential for capacity or competency to make decisions for how they wish to live their lives than most care team and family members may realize (Csikai & Chaitin, 2006; Foster & Turner, 2007; Johnson, 2011; Kingsbury, 2011; Smith & Hardt, 2011). Even when they are non-verbal, they most frequently have
some means for communicating their needs, joys, and distress. It is up to the professionals, family and caregivers to seek to support capacity and communication in order to ensure that the historic oppression and lack of access to services is mitigated during end of life (Stein, 2008; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a). Toolkits that are broad and targeted to bridge the differences in professional, family and patient values, cultural perspectives, and personal experience are necessary to help avoid conflict, misunderstanding, and facilitate communication or with the individual with IDD regarding their own wishes, desires, fears or instructions for end of life, whether at home or in a more formal care setting. Increasing the range and availability of tools specific to the end of life needs of individuals with IDD can help bridge communication across disciplines, enhance case management and promote a shared understanding of the need to respond to the varying dimensions of life for the person with IDD (Kingsbury, 2009). Increasing the availability of quality, relevance and efficacy of tools specific to the issues of living and dying with IDD would be a step toward securing the best comprehensive, multi-disciplinary and quality care that is expected with palliative or end of life care.
Chapter 3

METHODOLOGY

Introduction

The purpose of this descriptive study is to identify whether or not a need exists for information and resources to support increased access to end of life and palliative care for individuals with intellectual disabilities, and prioritize the type of resources that would be desired. Individuals with intellectual and developmental disabilities (IDD) are living longer than ever before in history, and are unlikely to be referred to palliative and end of life care (Stein, 2008; Tuffrey-Wijne, Hogg & Curfs, 2007a). Knowing this, a survey targeted to professionals working in hospital, palliative/hospice care and case management roles in four rural California counties was developed to elicit their perspectives regarding specific information to support communication, referrals and end of life service provision needs for individuals with IDD.

Study Design

This is a quantitative, descriptive study of professional priorities for development of a palliative care and end of life toolkit to support services to individuals with IDD (Leedy & Ormrod, 2010). A paper survey format (Appendix C) was used to gather data from participants. The study examines professional roles and experience in relation to ranking priorities of topics for inclusion in a toolkit. Priority of toolkit content is done through an exploratory analysis of data received from a purposive, targeted and non-random sampling among a population of professionals providing direct service medical, social work, and case management for end of life issues (Leedy & Ormrod, 2010).
This is a non-random, purposive study of fifty professionals in California’s Amador, Calaveras, El Dorado and Tuolumne Counties invited to participate in the study. Participants were expected to draw on their personal experience and professional expertise to advise which of the items presented for ranking would be most helpful in their efforts to increase access to palliative and end of life care for individuals with IDD.

**Study Sample**

Fully completed surveys from the seven participating organizations resulted in a sample size of 28 participants [N=28]. All participants chosen for inclusion in this study worked in a palliative or end of life care capacity as either medical, social work, case management or spiritual care providers. Permission to participate in the study was sought and granted by the directors and program managers of Valley Mountain Regional Center, Amador Calaveras Hospice, Snowline Hospice, Partners in Care, Marshall Medical Center, Mark Twain St. Joseph’s Hospital and Sonora Regional Medical Center. Contact with Sonora Hospice and Sutter Amador Hospital did not result in a response to the invitation to participate in the study, thus no surveys were provided to these two organizations.

Non-probability sampling methods were used for this study. The researcher explained the need to reach individuals with specific roles and experience in palliative and end of life care. Organizational leaders recruited these participants and prompted their completion and return of the surveys (Leedy & Ormrod, 2010). Participating lead agency staff agreed to assist with distribution and collection of the consent forms, ensure
security of the surveys and distribution of gift cards provided as appreciation for considering completion of the study. Once consent was obtained through a signed consent form, survey participants were given the survey form which was then deposited into the secured survey box upon completion. The survey consents and secured surveys were then retrieved by the researcher.

The researcher was the only person to retrieve the secured surveys, review and collate the research data. The researcher was not working in any of the agencies from which participants were recruited, was not employed in a hospital or disabilities services environment, and was not employed to work directly with adults with disabilities. The researcher was not a member of any associated agencies or groups affiliated with or potentially benefiting from the study, nor did the researcher receive any monetary or other gifts in relation to this research project, eliminating any actual or perceived conflict of interest.

**Study Questions**

The study survey (Appendix C) was an assessment of professional perspectives and priorities for development of a toolkit to support access to palliative and end of life care for adults with IDD. The survey began with checklists of descriptive questions to determine employment/job roles, rural versus non-rural services, and length of service with current employment. Service and employment role data was collected to identify the amount of exposure participants had to individuals with intellectual disability requiring palliative end of life care. The purpose of this data was to identify significant differences in professional perspectives, type of care provided, or length of professional
experience influencing priorities in ranking of toolkit contents.

The descriptive questions in the survey were followed by an opportunity to rank the usefulness of potential toolkit contents to determine which types of resources are considered most important for increasing access to palliative and end of life care for individuals with IDD. Finally, an open ended question provided an opportunity for participants to volunteer any information they felt should be considered in relation to this study.

Seven checklist format questions were asked as a means to identify professional characteristics including if the participant identified as working in a rural community, the professional category that best fit their work in relation to individuals with IDD, the type of organization in which they worked, the length of time working in this capacity, the number of adults with IDD they worked directly with during the past year, whether any of these individuals received end of life care, and if they did, was the care received in the residence the individual with IDD considered as their home.

An ordinal scale of measurement was developed to support participants’ prioritization of fifteen topics to be included in a toolkit for palliative and end of life professionals working with individuals with IDD (Leedy & Ormrod, 2010). The first set of seven priorities to be ranked consisted of topics to support acute care, initial diagnosis, or emerging end of life issues. Participants were requested to identify the importance of each topic from most to least important. Topics to be ranked included: A need for communication checklists and assessments to determine communication styles and cues of individuals with IDD; conversation starters to determine how an individual with IDD
considers death; self-determination definitions, guides and sample questions; conservatorship information guidance and legal rights; guidance for discussing diagnosis, treatment and prognosis of an individual with IDD; information for peers, friends and housemates of individuals with IDD; and brief descriptions or vignettes of self-determination of individuals with IDD accessing end of life care.

The second set of eight priorities to be ranked included resources and information which might be most helpful to support care teams, family and caregivers of individuals with IDD. Participants were requested to rank the following eight topics from most to least important: legal information regarding state and federal laws supporting access to services by individuals with IDD; information on what to expect at end of life resulting from life threatening illness; palliative and hospice care services, resources and insurance coverage information; caregiver resources for support of individuals with IDD at end of life; financial considerations for individuals with IDD; housing and home based services, resources and rights for individuals with IDD at end of life; “how to…” formats and sample language for including end of life issues in Individual Program Plans and/or Treatment Plans; information to engage consideration and support for the spiritual needs of individuals with IDD, their family, caregivers and friends.

The survey ended with an open-ended question encouraging participants to submit any information, opinion or perspective considered meaningful for the purpose of the study, asking, “What do you think should be considered with regard to supporting individuals with IDD, or developing a toolkit or handbook for increasing access to palliative and end of life care for individuals with intellectual disabilities?”
Leedy and Ormrod (2010) warn that bias is a risk in a non-random sampling such as was presented in this study. This study specifically seeks information from individuals participating on palliative and end of life care teams expected to be somewhat homogeneous in their review of issues in palliative and end-of life care. This could result in a level of bias influencing the study. The descriptive data questions were included in the study to identify any correlations or trends with regard to ranking and prioritization of toolkit topics or content of open-ended question response. By identifying professional roles and service experiences through the descriptive data questions, the study outcomes should be weighted and reviewed in a manner that results in a toolkit assumed to generalize outcomes as attributable and meaningful to all team members.

Protection of Human Subjects

A Request for Review by the Sacramento State Committee for the Protection of Human Subjects was submitted, resulting in review and approval of this study as a no-risk research project. The committee approval number assigned to this study is 11-12-018 (Appendix A). The study was approved as no-risk since the information requested was expected to be familiar to survey participants as it related directly to their work in medical, hospice, palliative care or case management. No physical procedures risking harm were involved in this study. The only activity requested of subjects was completion of the needs assessment survey. There was no risk of harm from the use of equipment, instruments or drugs/pharmaceuticals as none were included in this study.

Given that the participants in this study were reviewing needs assessment questions related to their work in medical, palliative end of life care and/or with
individuals with intellectual disability, there was no risk of harm with regard to their participation in the study. The questions were not qualitatively different from the problem solving and critical thinking questions they would process through the course of their work, therefore this study was considered no-risk.

Prior to participation in the study participants were provided informed consent information (Appendix B) in writing informing them of the voluntary nature of the study, and ending with a statement reading, “Your signature below indicates that you have read and understood this consent form and agree to participate in this survey.” Survey participants checked an “I agree” or an “I do not agree” response indicating they read and consented to the survey, or they did not. Informed consent forms (Appendix B) were signed and dated before surveys were provided for completion.

The paper survey completed by subjects in this study did not ask any personally identifiable information. Survey forms were maintained separately from the consent forms. Completed surveys were placed into a secured box and maintained in a secure location at the agency until surveys were retrieved by the researcher. Survey documents were read and data was collated only by the researcher. During data analysis, surveys and consent forms were maintained separate from each other, and all collected information was kept in a secure locked cabinet in the home of the researcher. Upon approval of this thesis all of the survey and study materials will be destroyed.

**Data Collection and Instrumentation Tools**

The researcher made initial contact with the chosen organizations through telephone calls to the organizational directors and medical social workers. The
researcher explained the study’s purpose and structure, and presented the researcher’s background and contact information. Organizational directors were invited to receive the surveys and incentives, and to encourage staff to participate in the study. All but two organizations responded enthusiastically and agreed to encourage staff participation in the study. Following distribution of surveys, consent forms and incentives to the designated lead agency staff, a timeframe of two weeks was set for the researcher to retrieve the completed consent and questionnaire forms.

Collected data was reviewed, collated and analyzed by the researcher using SPSS system software, facilitating the researcher’s ability to discover differences, similarities and relationships among the variables, including determining frequencies, mean, standard deviation and significant correlations across data fields. Once all data was entered into SPSS, cross tabulations using a Chi-Square test were run for nominal and ordinal data. Triangulation in this study was difficult to achieve, as the source of data is specific to the responses of the small population of California rural palliative and end of life care team members participating in the study (Leedy & Ormrod, 2010).

Questionnaires were distributed and returned in November 2011. The intent of the study, protocols for maintaining the integrity, confidentiality and security of the questionnaire data and procedures for distribution, security and contact information for the researcher was shared with each agency director agreeing to allow staff to participate in the study.

The design of the survey questionnaire was developed by the researcher to elicit response to items identified in existing scholarship and research as being a barrier or
deficiency in ensuring access to palliative or end of life care by individuals with IDD. The survey included open-ended, ranking and checklist categories in order to maximize the information needed in a way that minimized participant time and effort while still providing useful information drawing on their professional expertise and practice wisdom.

**Study Limitations**

This study seeks only to survey palliative and end of life care team professionals with regard to prioritized needs for information that would be useful to support them in providing care to individuals with IDD. The survey is also limited to accessing a small, non-random, purposive sample of care team professionals serving four counties in rural northern California. Future studies may expand sampling to include providers in suburban and metropolitan areas. In addition, studies may be enhanced by identifying the priorities of parents, residential caregivers and others involved in supporting individuals with IDD, as well as the personal priorities and perspectives of individuals with IDD facing end of life. Due to the non-random sample selected purposively for this study, the findings have limited external validity and hence cannot be generalized to the population.
Chapter 4

RESULTS

Introduction

This chapter reports the results of a descriptive study to determine priorities for information to be included in a toolkit for professionals providing end of life care through hospital, hospice, palliative care or regional center services in a rural California setting. Table 4.1 presents the descriptive data detailing respondents’ professional roles. Table 4.2 details the type of agency affiliation through which respondents provide care. Table 4.3 represents simple descriptive data detailing respondents experience providing end of life care for individuals with IDD over the past year. Table 4.4 provides descriptive and correlation detail between the professional role and years of service for respondents.

With regard to the survey hypothesis that professionals providing end of life care for individuals with IDD would identify the most useful information for inclusion in a toolkit to support increased access to care, Tables 4.5 and 4.6 present a ranking of respondents choice of information to be included in professional toolkits.

Fifty surveys were sent to three hospitals, two hospice agencies, one community-based palliative care agency and one regional center case management office. The return rate was 38 surveys, with ten incomplete for use in the study. This resulted in a survey sample of 28 useable surveys [N=28], or 56% of potential respondents for this study.

Respondent data identified information supporting their ability to communicate regarding palliative and end of life care with an individual with IDD as the highest priority for inclusion in a toolkit. This study result is consistent with the available
scholarship leading to this study, indicating that experience and ability to communicate with the population of individuals with IDD facing end of life issues is not common among end of life professionals (Stein, 2008; Tuffrey-Wijne, Hogg & Curfs, 2007a). This limited experience communicating with and caring for individuals with IDD during end of life would indicate a need for communication and assessment tools.

Participants

The sample of survey participants for this study was comprised of 28 professionals working across four rural northern California counties in hospitals, hospice and regional center agency services. Participants responding to the survey routinely work with general populations providing palliative and end of life care or directly with individuals with IDD through case management or daily support services. The professional background of respondents was represented by medical, social work, clergy, case management, support providers and caregivers for individuals with IDD.

Table 4.1

<table>
<thead>
<tr>
<th>Professional Role of Respondent</th>
<th>Frequency (n=28)</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Professional</td>
<td>10</td>
<td>35.7</td>
<td>35.7</td>
<td>35.7</td>
</tr>
<tr>
<td>Social Worker</td>
<td>5</td>
<td>17.9</td>
<td>17.9</td>
<td>53.6</td>
</tr>
<tr>
<td>Clergy</td>
<td>3</td>
<td>10.7</td>
<td>10.7</td>
<td>64.3</td>
</tr>
<tr>
<td>Case Manager</td>
<td>7</td>
<td>25.0</td>
<td>25.0</td>
<td>89.3</td>
</tr>
<tr>
<td>Caregiver</td>
<td>1</td>
<td>3.6</td>
<td>3.6</td>
<td>92.9</td>
</tr>
<tr>
<td>Support Provider</td>
<td>2</td>
<td>7.1</td>
<td>7.1</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>
Medical professionals, including physicians, nurses, medical students, residents or interns made up 35.7% of the survey response. When considering the choice of surveyed agencies and the range of medically oriented professional roles of team members involved in palliative care, the weight of medical professional response to the survey appears reasonable. Case managers working in regional center or day programs for individuals with IDD represented one fourth of survey responses, followed by social workers in palliative or end of life care either through hospitals or hospice organizations, and clergy (including chaplains, pastors or other spiritual support persons). No respondents identified themselves as a parent of an individual with IDD.

Table 4.2

Agency Affiliation

<table>
<thead>
<tr>
<th>Respondent Agency Affiliation</th>
<th>Frequency (N=28)</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unidentified</td>
<td>1</td>
<td>3.6</td>
<td>3.6</td>
<td>3.6</td>
</tr>
<tr>
<td>Hospital, Medical Research Institution or Medical School</td>
<td>12</td>
<td>42.9</td>
<td>42.9</td>
<td>46.4</td>
</tr>
<tr>
<td>Regional Center for Individuals with IDD</td>
<td>5</td>
<td>17.9</td>
<td>17.9</td>
<td>64.3</td>
</tr>
<tr>
<td>Hospice or Palliative Care Organization</td>
<td>9</td>
<td>32.1</td>
<td>32.1</td>
<td>96.4</td>
</tr>
<tr>
<td>Advocacy or Resource Organization</td>
<td>1</td>
<td>3.6</td>
<td>3.6</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

The highest number of responses, 42.9%, came from professionals in hospital settings, followed by respondents working in hospice and palliative care settings which
were represented by 32.1% of responses. A limited number of individuals responding were from regional centers or advocacy organizations.

Results of descriptive data analysis indicate that the majority of respondents have worked in their professional role for over ten years; a long enough period to have had reasonable opportunity to work with an individual with IDD referred for end of life needs.

Table 4.3
Length of Employment and Professional Role Cross-Tabulation

<table>
<thead>
<tr>
<th>Length of Employment</th>
<th>Professional Role</th>
<th>Medical Profession</th>
<th>Social Worker</th>
<th>Clergy</th>
<th>Case Manager</th>
<th>Caregiver</th>
<th>Support Provider</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one year</td>
<td>Respondents</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>% within Professional Role</td>
<td></td>
<td>10.0%</td>
<td>.0%</td>
<td>33.3%</td>
<td>.0%</td>
<td>.0%</td>
<td>.0%</td>
<td>7.1%</td>
</tr>
<tr>
<td>Less than five years</td>
<td>Respondents</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>% within Professional Role</td>
<td></td>
<td>20.0%</td>
<td>.0%</td>
<td>.0%</td>
<td>28.6%</td>
<td>100.0%</td>
<td>.0%</td>
<td>17.9%</td>
</tr>
<tr>
<td>Less than ten years</td>
<td>Respondents</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>% within Professional Role</td>
<td></td>
<td>20.0%</td>
<td>40.0%</td>
<td>33.3%</td>
<td>42.9%</td>
<td>.0%</td>
<td>.0%</td>
<td>28.6%</td>
</tr>
<tr>
<td>Over ten years</td>
<td>Respondents</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>% within Professional Role</td>
<td></td>
<td>50.0%</td>
<td>60.0%</td>
<td>33.3%</td>
<td>28.6%</td>
<td>.0%</td>
<td>100.0%</td>
<td>46.4%</td>
</tr>
</tbody>
</table>
Table 4.4 details the 17% of respondents who have indicated participation in end of life care for individuals with IDD during the past year. Interestingly, this sub-group of respondents indicated that end of life care was received through hospice and hospitals, and most commonly in the place the individual with IDD considered as their home. No case management or care providers indicated participation in end of life care for an individual with IDD over the past year, which has implications on the make-up of end of life care teams and the roles of individuals involved in decision-making with individuals with IDD.

Table 4.4

<table>
<thead>
<tr>
<th>Professional Role</th>
<th>Total Respondents</th>
<th>% within Professional Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Profession</td>
<td>10</td>
<td>100%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>5</td>
<td>100%</td>
</tr>
<tr>
<td>Clergy</td>
<td>3</td>
<td>100%</td>
</tr>
<tr>
<td>Case Manager</td>
<td>7</td>
<td>100%</td>
</tr>
<tr>
<td>Caregiver</td>
<td>1</td>
<td>100%</td>
</tr>
<tr>
<td>Support Provider</td>
<td>2</td>
<td>100%</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>100%</td>
</tr>
</tbody>
</table>

Respondent Experiences Participating in End of Life Care for Individuals with IDD

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Professional Role</th>
<th>Agency Affiliation</th>
<th>Care for Individual with IDD in Past Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Palliative, Hospice, or Home Services</td>
</tr>
<tr>
<td>Medical Professional</td>
<td>Hospital</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Social Worker</td>
<td>Hospital</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Chaplain</td>
<td>Hospital</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Medical Professional</td>
<td>Hospice</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Professional Caregiver</td>
<td>Hospice/Palliative Care</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Respondents also indicated that, of the limited numbers of individuals with IDD facing end of life with whom they have worked in the past year, 80% received end of life care through hospice, home and/or community palliative care services in the setting they consider their home.

While the sample represented in Table 4.4 is not statistically significant, it does imply that individuals with IDD served in the rural areas included in this study are being referred to hospice care and receiving care in their homes. This is in contrast to literature on the subject indicating that individuals with IDD are generally not referred for hospice care (Stein, 2008). End of life service delivery for individuals with IDD may deserve further review to determine if there is a difference between rural and metropolitan rates of referrals of individuals with IDD to home-based end of life care.

Limited availability of nursing home space in rural communities may also influence referral rates to home based services and is worthy of further study. California Healthcare Foundation’s [CHF] 2012 report, “Final Chapter: Californian’s attitudes and experiences with death and dying,” presents survey data indicating that 70% of respondents in the general population preferred to die at home. The CHF study does not provide the preferences of specific populations such as the small population of individuals with IDD.

This desire of the general population to die at home also does not match additional CHF survey data showing that while home deaths for the general population have grown 146% since 1989 to 32%, hospital deaths still occur for 42% of deaths in
California. Only 39% of California deaths to Medicare beneficiaries in 2010 received hospice services (California Healthcare Foundation, 2012). Considering the fact that individuals with IDD most often receive medical care through government supported coverage such as Medicare, even the very small number of referrals of individuals with IDD to home and hospice care represented in this project are notable.

The CHF report also indicates that the average number of days patients spent in hospitals during the past six months of their lives has grown over the past six years. For rural California hospitals like those represented by respondents in this project, the cost of hospitalization for acute care of individuals facing end of life is growing. Decision making based on cost control is an incentive for medical providers to make discharge decisions quickly, placing pressure on medical care staff and social workers to respond far quicker than the rate in which intentional person-centered planning might occur for an individual with IDD. Professional bias regarding individuals with IDD capacity and quality of life may override the ethical responsibility for person-centered communication, assessment and planning time for individuals with IDD when cost pressures are significant.

**Toolkit Priorities Data**

Topics to be prioritized for inclusion in a toolkit for professional palliative and end of life care teams supporting individuals with IDD were presented across two sets of options. Questions in Set A, as detailed in Table 4.5, offered priority choices of information professionals might identify as helpful during acute care, for introduction to the patient early in diagnosis, or as end of life issues are beginning to be impact
individuals with IDD, their families and their peers. Set B, as detailed in Table 4.6, listed items care team members might use to educate individuals with IDD, their families and caregivers regarding resources and rights related to end of life for individuals with IDD.

Each priority option could be scored only once, ranking each option from most important, scoring one point, to least important for inclusion in the prioritization, scoring seven or eight points, depending upon the set the option was in. Three surveys were eliminated from the sample as the prioritization ranking identified multiple items as most important.

Table 4.5
Priority Ranking of Toolkit Options - Set A

<table>
<thead>
<tr>
<th>Seven Priority Options</th>
<th>N=28</th>
<th>Minimum Points for Most Important</th>
<th>Maximum Points for Least Important</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.1: Communication checklists and assessments to determine individuals’ with IDD communication styles and cues for anxiety, sadness, pain, fear, discomfort, frustration, loneliness, etc.</td>
<td>28</td>
<td>1</td>
<td>7</td>
<td>2.29</td>
<td>1.487</td>
</tr>
<tr>
<td>A.2: Conversation starters to determine how an individual with IDD considers death, how they want to be remembered, and what they want to happen after they die.</td>
<td>28</td>
<td>1</td>
<td>7</td>
<td>3.39</td>
<td>1.750</td>
</tr>
</tbody>
</table>
### Seven Priority Options

<table>
<thead>
<tr>
<th>Seven Priority Options</th>
<th>N=28</th>
<th>Minimum Points for Most Important</th>
<th>Maximum Points for Least Important</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.3: Self-determination definitions, guides, sample questions, information and resources.</td>
<td></td>
<td>2</td>
<td>7</td>
<td>4.57</td>
<td>1.451</td>
</tr>
<tr>
<td>A.4: Conservatorship information, guidance, legal rights and resource information.</td>
<td></td>
<td>1</td>
<td>7</td>
<td>4.96</td>
<td>2.045</td>
</tr>
<tr>
<td>A.5: Guidance for discussing diagnosis, treatment, prognosis and end of life with an individuals with IDD to elicit hopes, desires, wishes, fears.</td>
<td></td>
<td>1</td>
<td>7</td>
<td>2.61</td>
<td>1.707</td>
</tr>
<tr>
<td>A.6: Information for peers, friends and housemates of individuals with intellectual disability.</td>
<td></td>
<td>1</td>
<td>7</td>
<td>4.82</td>
<td>1.701</td>
</tr>
<tr>
<td>A.7: Brief descriptions or vignettes of self-determination of individuals with IDD accessing palliative or end of life care.</td>
<td></td>
<td>2</td>
<td>7</td>
<td>5.36</td>
<td>1.521</td>
</tr>
</tbody>
</table>

As shown in Table 4.5, medical, hospice, and end-of-life professionals responding to this study identified communication assessments and checklists as the highest priority for inclusion in a toolkit used by palliative and end of life team members. This is closely followed by inclusion of guidance for discussing diagnosis, treatment, prognosis and end of life with individuals with IDD to elicit their hopes, desires, wishes and fears.
Conversation starters to elicit how individuals with IDD view death and dying, as well as their wishes for after they die were next in priority.

The lowest priority among the first set of options was inclusion of brief descriptions and end of life care vignettes of self-determination of individuals with IDD. Considering the weight of medical professionals responding, information for supportive services would not seem likely to rise to a high priority for inclusion in a toolkit.

Table 4.6
Priority Ranking of Toolkit Options - Set B

<table>
<thead>
<tr>
<th>Eight Priority Options</th>
<th>N=28</th>
<th>Minimum Points for Most Important</th>
<th>Maximum Points for Least Important</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>B.1: Legal information regarding state and Federal regulations and laws supporting access to services for individuals with IDD.</td>
<td>28</td>
<td>1</td>
<td>8</td>
<td>5.75</td>
<td>2.367</td>
</tr>
<tr>
<td>B.2: Information on what to expect at end of life resulting from life threatening, long term illness.</td>
<td>28</td>
<td>1</td>
<td>8</td>
<td>3.71</td>
<td>2.447</td>
</tr>
<tr>
<td>B.3: Palliative care, hospice services, resources and insurance coverage information.</td>
<td>28</td>
<td>1</td>
<td>8</td>
<td>3.71</td>
<td>2.088</td>
</tr>
<tr>
<td>B.4: Caregiver resources addressing supporting end of life for individuals with IDD, and self-care.</td>
<td>28</td>
<td>1</td>
<td>7</td>
<td>3.25</td>
<td>1.669</td>
</tr>
</tbody>
</table>
Of the items in Table 6, the highest ranked item for inclusion in a toolkit for professionals was providing caregiver resources addressing support of end of life for individuals with IDD. The mean for priority of information in both Table 4.5 and Table 4.6 also indicates agreement on the part of professionals responding to this study as to the importance of access to information facilitating communication to assess what the individual with IDD might be feeling, such as pain, anxiety, fear, or discomfort.

Among the lowest ranked toolkit options were information to engage and support the spiritual needs of individuals with IDD, their family, caregivers and friends, and

<table>
<thead>
<tr>
<th>Eight Priority Options</th>
<th>N=28</th>
<th>Minimum Points for Most Important</th>
<th>Maximum Points for Least Important</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>B.5: Financial considerations for individuals with IDD requiring access to palliative and end of life care.</td>
<td>28</td>
<td>1</td>
<td>8</td>
<td>5.86</td>
<td>2.068</td>
</tr>
<tr>
<td>B.6: Housing and home-based services, resources and rights during end of life for individuals with IDD.</td>
<td>28</td>
<td>1</td>
<td>7</td>
<td>4.04</td>
<td>1.598</td>
</tr>
<tr>
<td>B.7: “How to…” formats and sample language for including end of life issues in Individual Program Plans and/or Treatment Plans.</td>
<td>28</td>
<td>1</td>
<td>8</td>
<td>4.71</td>
<td>2.492</td>
</tr>
<tr>
<td>B.8: Information to engage and support the spiritual needs of individuals with IDD, their family, caregivers and friends.</td>
<td>28</td>
<td>2</td>
<td>8</td>
<td>4.96</td>
<td>2.202</td>
</tr>
</tbody>
</table>
providing legal information regarding state and Federal regulations and laws supporting access to services for individuals with IDD. The lowest ranked priority for Table 4.6 was the inclusion of legal information regarding state and Federal regulations and laws supporting access to services for individuals with IDD.

Standard deviation rates indicate strong respondent agreement regarding ranking for the majority of items, particularly with regard to the high prioritization of communication tools to assess needs and explain what individuals with IDD should expect at end of life. This makes sense as all respondents participating in the survey have a need to ensure effective communication with the individual with IDD requiring palliative and end of life care. Respondents’ high ranking of communication enhancement tools may also be related to the majority of respondents working in acute hospital and hospice settings where communication may have an element of urgency. Communication is a consistent challenge among the population of individuals with IDD, making it a priority regardless of the end of life care team member’s role. Communication assessments and checklists support a care team’s diagnostic and intervention responsibilities. They also support team member ability to check for discomfort, pain and capacity and support the biopsychosocial and spiritual desires of an individual with IDD facing end of life (Stein, 2008; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a).

Professionals who have quick access to tools supporting communication using the modality needed by individual patients with IDD may benefit from decreased ethical and legal dilemmas, coercive care or missing information critical to treatment, comfort and
life quality. They may also benefit as tools assist in the likelihood of delivery of care that addresses what is important to the patient (Csikai & Chaitin, 2006; Johnson, 2011; Levy & Van Stone, 2011; NASW, 2004; Tuffrey-Wijne et al., 2007a).

Respondents’ ranking of toolkit options also resulted in no significant outliers; indicating agreement among respondents as to the prioritization of the fifteen toolkit options presented. Prioritization is likely weighted by the numbers of respondents to this study who represent medical provider roles or provide palliative and end of life care in a hospital setting. It also correlates with research findings indicating that physicians and medical staff generally have little exposure and experience with the population of individuals with IDD reaching end of life care needs. It is most likely that ranking indicates respondents’ desire to maximize assessments through the use of effective tools when personal experience is unavailable. The prioritization of communication tools could also support providers to avoid the risk of bringing biases or assumptions into the care relationship which could add difficulty to communication with individuals with IDD who may already experience communication barriers. (Stein, 2008; Tuffrey-Wijne et al., 2007a).

Given the relationship of spirituality to end of life, it is notable that prioritization of information to support engaging individuals with IDD, and their caregivers in conversations regarding spiritual needs was fairly low, with a mean of 4.96. Assessment of spiritual needs may have a low ranking simply due to the low representation of respondents with spiritual responsibilities in the study, and the assumption by other team
members that a spiritual conversation falls within the role of the chaplain or clergy member on the end of life team.

Another notable outcome of prioritization is the low ranking of housing and capacity focused information. The issue of having legal information regarding capacity or housing rights during end of life included in a toolkit was ranked as lowest over all other resources. However, during informal contacts with agencies to begin the survey distribution, the researcher experienced casual conversations indicating concerns about an underlying concern for risk management and avoidance of litigation often impact medical and end of life care team members and service delivery. As an example, Kingsbury (2011) notes that an issue exists in end of life care practice where individual wishes to end treatment or die at home have been honored, only to have the resulting deaths investigated for wrong-doing. Certainly, methods for increased communication and assessment of the end of life needs of individuals with IDD would help mitigate litigation concerns. Reviewing the concerns of care team members regarding risk management or litigation and identifying effective resources for planning with the individual with IDD, families, caregivers and service partner concerns could be very important.

Qualitative comments were also elicited from participants in the survey. Nearly half of the respondents provided comments expanding on or supporting development of toolkits to address the needs of individuals with IDD during end of life. Communication in relationship with the individual with IDD, end of life and support teams, and with the individual’s family/caregivers was the primary theme in respondent comments.
Case managers and chaplains responding indicated a need for toolkit materials to support communication with caregivers and family, while medical providers identified assessment tools and communication resources as most important. Comments affirming a need for communication tools were consistent with research identifying communication challenges and provider bias as a barrier for access to end of life care by individuals with IDD (Stein, 2008, Tuffrey-Wijne et al., 2007a). Respondents shared concerns regarding end of life team member bias, authority and decision making responsibilities—each issues with strong relationships to care team communications with each other and the individual with IDD. Comments included:

“Medical professionals should not assume a diminished quality of life because of an intellectual disability. I have been so angered by that assumption when dealing with the medical community.”

“[Include] Safe ways to discuss end of life w/the [sic] people we support and families. Forms that medical professionals will accept – current forms. One more thing; pain management is not any less important because of an intellectual disability!”

“…too many professionals were confusing to the patients…Guidelines for either transitioning to new support teams or how a palliative care team can resource previous long term support team [sic] and make use of long established trusted relationships.”

Capacity and competency were also an issue addressed in respondents written comments such as:
“Determine the patient’s/individual’s cognitive level of understanding. Provide information specific to understanding.”

“How to include the individuals in consumer’s life and being clear who is the final decision maker. The biggest issue is making the end of life decision for consumers who cannot make the decision him/herself due to ID or physical deterioration.”

Comments also indicated an assumption of shared knowledge, accessible to team members. One respondent’s low ranking for inclusion of information about what to expect at end of life resulting from life threatening, long term illness was explained as, “…I assume a medical professional working with end of life care would already know this information.” Other responses indicated a desire to strengthen understanding and promote collaboration by ensuring that a comprehensive toolkit is made available to other agencies or services involved with the individual with IDD before end of life issues occur.

Results of this study are consistent with much of the literature reviewed for the project. Respondents clearly prioritized resources addressing communication barriers, and concerns regarding capacity, which likely lead to missed review and response of individual needs and desires, and result in less than responsive, individualized care. The risk of assumption and bias is a referral to institutionalized settings which, if outcomes are supported beyond this study, may be less of an issue in a rural setting. This study also supports increasing understanding of ethical approaches to person-centered planning and
self-determination, as well as intentional efforts to understand the spiritual needs of an individual with IDD requiring end of life care.

Development of a toolkit that approaches end of life as a narrative process based on self-determination changes the end of life experience from a medical and disease model addressing symptoms leading to death to a contextual model based on a quality of life story which the individual with IDD wishes to experience (Corey, 2009). Values of empowerment and social justice are strong antidotes for the historic exclusion of individuals with IDD from their own medical care. Communication enhancements at every level of the palliative and end of life care journey would assist the person with IDD facing end of life in creating their own end of life narrative (Corey, 2009).

Increased attention is needed to prepare and support palliative and end of life care team practices for an expected increase in patients with IDD. At the micro level, the relationship and communication practices between individual care givers and patients with IDD must be strengthened. Facilitating and allowing repeated opportunities for effective communication is critical in every aspect of palliative and end of life care. Gullone’s (1996) study of research related to fears in people with disabilities indicates that individuals with IDD experience a more intense fear response than non-disabled peers. Fear response among individuals with IDD tends to occur across a wider variety of areas, and generally is strongest in relation to areas of the unknown, such as medical care and death.

Research also indicates that individuals with IDD appear to have an adaptive response to fear which may be related to the adaptive issues of their disability (Gullone,
1996). These are important points to consider with regard to how care team members perceive capacity and interact with individuals with IDD and communication challenges. Maturity and developmental levels may result in behaviors which are out of sync with the patient’s age and the disease progression normally seen by palliative and end of life care teams (Gullone, 1996). This increases the need for care team members to be supported to seek understanding of the experience of an individual with IDD, and ensure early and frequent efforts occur with the patient to discuss and normalize medical care, fears, and death.

A toolkit appears to be warranted to support professional team member abilities to refer individuals with IDD to meaningful and appropriate end of life care. The increased intentional communication that could result with individuals with IDD may also support minimizing their exclusion from participation in their own medical care, a historic issue among the disabled in the United States.

The study results have a particular relevance to social workers who may be engaged with individuals with IDD through any of the systems represented—medical, hospice/palliative care or case management. Hepworth et al. (2010), summarizes the “cardinal values of social work,” inherent in the NASW code of ethics as access to resources, the inherent dignity and worth of a person, integrity in social work to behave in a trustworthy manner, and competence to practice within the scope of the profession and enhance and develop professional expertise. The social worker involved in end of life care will benefit from tools for meaningful communication across multiple systems
and specializations, and ensure the focus remains on expressed desires and needs of the individual with IDD.
Chapter 5

CONCLUSION

Major Conclusions

The results of this study indicate a toolkit is warranted to address key topics supporting end of life care team members serving individuals with IDD, ultimately increasing referrals to palliative and end of life care in non-institutional settings. While survey participants represent a range of expertise and professional practice, they also provide a snapshot of how narrow the group’s experience with individuals with IDD is, as few indicated recent experience participating in end of life care with this population.

Survey respondents prioritized communication assessments and checklists as most important for inclusion in a toolkit. Given that the majority of respondents were employed in a rural medical capacity or in a setting where they may face limited time to deal with issues other than acute or emergent medical care, prioritizing tools to support accurate communication and assessment with patients seems appropriate. Facilitating communication with individuals with IDD can be assumed to increase accurate and meaningful assessment information for diagnosis, treatment, pain management and response to biopsychosocial, cultural and spiritual needs.

Increased communication is also critical for individuals with IDD who are often presumed to have a high capacity for pain, or are assumed to have a low quality of life, limited capacity for participation in treatment, limited spiritual needs, and limited comprehension of the concept of death (Redall, 2009; Sormanti et al., 2011; Tuffrey-Wijne et al., 2007a; van der Putten & Vlaskamp, 2011).
Study participants also prioritized inclusion of conversation starters, and guidance for eliciting and discussing how an individual with IDD considers death, how the person wants to be remembered, and what they want to happen after they die. This is an important communication task to begin early in the diagnosis and treatment process, if not before. An individual with IDD may benefit from repeated conversations and supported reflection of personal experience with death and loss. Engaging reflection over time could allow time for the person with IDD to consider, change, refine and express their desires within the context of their treatment, environment and personal experience.

Asking questions in a setting such as a hospital, where an individual with IDD may be anxious, fearful or agitated, as well as in pain, could result in responses that would be very different if the questions were asked of the individual at home or among people who can support the person’s capacity to communicate their true feelings (Tuffrey-Wijne et al., 2007a).

The study indicates that development of a comprehensive toolkit would be useful if it included resources applicable across professional specialties. Anecdotal responses indicate some level of meta-knowledge among professional peers as they were aware that they could seek information likely held by others on the team. Participants indicated an expectation that others would be expected to present components of knowledge and experience that would be beneficial to the palliative and end of life team when needed.

Providing tools to increase inclusion of the individual with IDD, their family, caregivers and multidisciplinary teams in planning and care also are indicated as a need among professional care teams. This corresponds with research indicating a need to
increase team member responsibility to ensure person centered planning and care so that the individual with IDD facing end of life is afforded the opportunity to live the end of their life and die in a manner which affords them a standard defined by themselves as respecting their dignity (CHP, 2005; Kingsbury, 2009; Kingsbury, 2011).

**Recommendations**

To be able to develop meaningful interventions for end of life care for individuals with IDD, a constant sensitivity to the concept of “person in environment,” is important. Individuals with IDD, and the professionals, caregivers, friends and family members with whom they interact are all influenced by personal values and culture, professional ethics. In addition, they are likely to face issues influenced by medical, disability, family and end of life system limits, legislation, boundaries and expectations. Each combination of these environmental systems and influences can have significant impacts on the experience of end of life care for an individual with IDD.

Applying an ecosystems perspective to end of life care for individuals with IDD provides a context for understanding that the culture, systems and history of medical and hospice care, and the discrimination, victimization and social action history of disability are intertwined with the life experience of an individual with IDD. Engaging care teams in a spirit of advocacy based on the patient’s wishes and self-determination may increase care teams’ ability to respond with care adaptations, and checking for goodness of fit to ensure the services and supports provided are a match for the individual’s expressed desires and needs (Higgins, 2011; Johnson & Rhodes, 2010).
The attention afforded to eliciting their desires and needs is grounded in Rogers’ humanistic person-centered approach which theorizes that people are trustworthy and have the potential for understanding themselves and resolving their own problems. Holding the individual in high regard, and taking a non-directive stance to engage, reflect and clarify the viewpoints and feelings of individuals with IDD with regard to their quality of life and decisions for care provides a constructive path for the individual with IDD and the care team (Corey, 2009). Too often, perspectives and decisions about care for individuals with IDD are based on the expertise of individuals providing or managing the care. This results in limited opportunities for patient driven decisions (Foster & Turner, 2007; Higgins, 2011; Johnson, 2011; Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a).

Strengthening meso-level approaches for multidisciplinary and interagency relationships should also be considered to enhance intentional person centered planning practice and result in greater palliative and hospice referrals, fewer deaths occurring in hospitals, higher quality and possibly less costly end of life experience for individuals with IDD than occurs now. During outreach to engage organizations in survey participation, agency leaders considering participation in this study voiced a strong interest in development of a shared regional convening, training and planning event to enhance and improve skills and knowledge with regard to individuals with IDD facing end of life.

Given western society’s aversion to open and frank conversations of death, and concern over current societal conversations of health care rationing, professionals,
families and individuals with IDD themselves may be suspicious of or sensitive to end of life planning (Botsford & King, 2011). These concerns make it necessary to connect evidence of an intentional, authentic and consistent conversation across the palliative and end of life care team with the expressed desires and wishes of the individual with IDD, and the significant members of that person’s life. Development of system level practices to inform intentional planning and engagement of policy makers, support systems, communities and individuals with IDD and their families around the unique end of life needs of this population are recommended. These efforts could include development of provisions to support additional case management time allocations, development of resources for facilitated communication and assessment, and information to promote understanding of consent, capacity and competence so that team members and family are comfortable pursuing and understanding of the desires and needs of patients with IDD.

A more intentional investment of time, effort and resources at the point of diagnosis or very early in treatment may be perceived as unnecessary, untimely or costly. It is important that palliative and end of life care teams identify a cost:benefit perspective and identify the cost-savings achieved through “upstream” early planning and interventions more likely to result in the perception and experience of a “good death,” rather than face later costly medical intervention and risks of due process. The generations of individuals with IDD who are beginning to require palliative and end of life services have been the beneficiaries of strong civil rights entitlement legislation, services and due process which changed their experience with schools, community and residential services. It could be safe to assume that the same families and advocacy
groups that challenged hierarchies and authority in those settings will be willing to extend that advocacy to end of life care. Commitment to communication, person centered planning and reasonable provision of individualized care will be necessary for all members of end of life care teams.

At the macro-level, hospital, hospice and case management systems must begin to prepare for the increase in population of individuals with IDD who will require end of life care. Adapting medical and social work education to introduce future care team professionals to effective and ethics driven person-centered planning for the emerging patient population of individuals with IDD is recommended.

Development of staff level training specifically focused on meeting the varied and unique medical, legal, social, cognitive, cultural and spiritual needs at end of life for individuals with IDD and their families can improve individual professional practice. For instance, end of life care team staff who have had limited interaction with individuals with IDD may benefit from training to understand and approach the concept of repeated medical intervention and reliance on medical technology as a component of everyday life for many individuals with IDD. Improving care team behaviors and system culture with regard to implementation of person centered planning is possibly the cornerstone for improving responsive care for individuals with IDD facing end of life. Developing forms, software systems and scheduling interval meetings to review an end of life case with an individual with IDD is not enough to ensure person-centered planning. Unless questions are asked in a manner in which the unique communication and experience of an individual with IDD is allowed to be entered into the conversation, person centered
planning is not likely to occur. This results in the potential for the end of life planning process to serve as a deficit, medical risk management process rather than truly eliciting the desires, wishes, concerns, needs and fears of the individual with IDD during the final experiences of life.

It may also be necessary to ensure end of life care team staff understand the necessity for early and/or technologically supported communication assistance. Just as systems have adapted to support the needs of linguistically, visually or Deaf and hard of hearing populations, efforts to communicate with individuals with IDD must be demonstrated. This can require technology, policy and practice changes on a system-wide level to ensure compliance with individual rights to receive appropriate information and care. Brain research and available technology now make clear that an assumption of a person’s inability to communicate is not acceptable. The weight of responsibility to ensure reasonable attempts to seek to identify and employ an effective mode for eliciting communication and consider the resulting information resides with the care team. Systems, policies and technology may need adaptation to ensure communication efforts occur early rather than in the acute care moments of end of life.

Unless these elements are employed among end of life care teams, the end of life process becomes one of consultation with or audit of the needs of the person with IDD and all care team stakeholders rather than actually developing a relationship of trust and value that prioritizes eliciting the desires of the individual with IDD, and asking team partners to engage in identifying means for support of those desires.
What could be more critical than being able to state and have honored the way one chooses to live through the dying phase of life? Because of limited cognition, communication, and ability to effectively advocate using their own stories and voices, individuals with IDD must frequently depend on others to seek their desires and be their voice for critical matters. Care providers, palliative and end of life care team members can strengthen end of life care practices by actively seeking, facilitating, sharing and honoring end of life desires expressed by individuals with IDD. True person centered end of life planning, recommended to begin at the point of diagnosis or even before illness, can normalize the end of life experience for an individual with IDD. Person centered planning is a practice tool that first respects the needs and desires of the individual with IDD with regard to how they wish to live, and second, supports care teams in assurance that care decisions and actions are the desires of the individual, not risk management actions of compliance or to avoid litigation.

It becomes important for anyone working with an individual with IDD to ask reflective questions, and develop a capacity for eliciting, understanding and seeking to implement the response provided by the individual with IDD. The starting question can be introduced at any point in the life of an individual with IDD. Asking “What do you need to live well now?” or, “Who/what is important to you now?” and possibly, “How do you want to be remembered after you die?” might elicit the individual’s desires. Care teams can begin to introduce families and caregivers early to the concept of a life quality review from the perspective of the person with IDD, by asking them, “What does this person need to live well?” Asking this question during the dying phase of the life for an
individual with IDD can help a family or caregiving team focus on quality of life rather than fear of dying.

Individuals with IDD face a lifetime of medical interventions and relationships with multiple care and case management team members. They risk losing family and peers to death just as the general population does. Throughout their lives they experience limits to their ability to act on their own behalf, address their fears, or fully experience their desires—including spirituality and grieving—without the support of others. Case managers outside of the end of life arena may begin to thoughtfully approach individuals with IDD at any time with quality of life reflective questions, and especially at young adulthood or whenever an individual can relate even a basic response. If asking these questions early were to occur, individuals with IDD facing end of life diagnosis could come to their life threatening diagnosis having been respectfully supported to consider and share their desires and wishes. They may also be more accepting of facilitation for any communication challenges they may have and be able to offer their perspectives early, before critical care is needed. This could reduce distress experienced among the entire team and the family, and especially with the individual with IDD.

It is also critical to address behaviors at individual, agency, collaborative team, and system levels with regard to determining an individual patient’s capacity as well as competency. Competency decisions are a serious aspect of medical care delivery, and are often weighted by medical staff determinations. Individuals with IDD interact with multiple agencies, caregivers, and family members over their lifetime. This range of people, processes and systems involved can impact how effectively an individual’s
capacity to express their desire and will regarding their own experience is reviewed, determined, and expressed at each new milestone and life event, including throughout end of life.

A significant issue of person centered planning is determining whether the individual’s capacity to express their own desires can be increased with supports or whether others are needed to facilitate this capacity. The determination that a person with IDD does not have reasonable capacity to inform and decide medical care does not eliminate the end of life care team’s continuing requirement to identify the individual’s capacity for addressing many other related aspects of their lives.

Care team members, agency collaborations and systems would benefit from a review of policies, procedures and routines to ensure that capacity is frequently and routinely reviewed across events, opportunities and milestones, regardless of conservatorship or established issues of competency. Competency concerns and determinations do not relieve conservators, care teams, or physicians of the responsibility to seek and honor the preferences to accept or refuse care expressed by a patient with IDD. Sometimes simple behavioral responses to aspects of care and daily life are indications of a person’s capacity to “voice” their desires on the subject. Teams can identify allies who can elicit and attest to the individual’s capacity to inform certain aspects of their life. Where needed, the care team can identify appropriate surrogates for difficult decision making. Team members, including the individual with IDD and their family, can outline and share how the individual with IDD communicates, and provide examples of how and when the individual makes decisions. They can also ensure
communication is supported to allow the person with IDD to participate and make all
decisions they are capable of making.

Policy review and changes are also required. Without legislative and system level
policies and procedures supporting legally reasonable and available services, individuals
with IDD risk continued limited care team referral to home palliative and hospice
services (Tuffrey-Wijne et al., 2007a). They also risk an uninformed and unnecessary
referral to nursing home care which has the potential for being determined as
unwarranted institutionalization, whether hospice services are provided in that setting or
not. Failure to seek the desires of the individual because of a presumption of lack of
capacity, regardless of competency is an ethical failure. It may also possibly be a legal
concern under the Olmstead Act (Bazelon, 2011; Parish & Lutwick, 2005) which
addresses unnecessary institutionalization of individuals with IDD.

This study asked whether individuals with IDD received care in the setting they
considered as their home. That question may need to be refined in practice to determine
the setting an individual with IDD considers their home. The response of the care team
may be that home is where the individual resided before group or residential care
placement. The individual may consider their home the residence in which they live.
This distinction has serious ramifications for end of life home based care. Macro-level
review of state and local community care licensing regulating residential group homes is
needed to ensure that individuals with IDD may be assured of the opportunity to die in
the place they consider home, with palliative and hospice services to support comfort and
quality of life even if that home is a licensed residential placement rather than the home in which their parents or family resides.

At the meso level, group home providers, case management and end of life care teams must be supported to begin to develop policies and procedures for how discharge decisions are reviewed and made, and to review the individual communication modalities and procedures available to support end of life desires for each individual in their care. Research is also recommended to review the impact of home hospice, end of life care on other individuals with IDD in the residential care home. Identifying strategies for supporting peers and friends with IDD, as well as group home staff/caregivers as they experience end of life for others in their residential care home setting would be needed.

A thoughtful review of options, including analysis of community care licensing, group home policies and medical/end of life care agency risk management must be in sync with the person centered planning question, “What does the person need to live well?” The systems and professionals supporting individuals with IDD must prepare for an increasingly possible and reasonable response that individuals with IDD wish to live in the place they consider home and among the people most important to them until they die. Medical, case management or care team members cannot assume that home to be a return to the home of a family member, or diversion to a nursing home based on medical interventions. To honor the right of an individual with IDD to self-determination, teams can review the question, “What does this person need to live well?” within the context of the place they consider home. Unless the desires of the individual with IDD are effectively considered, it is not reasonable or ethical to assume care for individuals with
IDD is best received in a hospital or nursing home, or that a nursing home or return to a family member’s home is a least restrictive environment for dying. The individual with IDD may desire to return to the place they consider home, increasingly a licensed residential care, group home or other supported living setting. This is of critical importance where individuals with IDD do not have family members available and must rely on paid caregivers as surrogates and informers to their care needs. Their dependence on paid caregivers who understand their communication, behavioral cues and capacity to express their needs requires time for thoughtful and ethical review by the care team. A review of reasonable accommodations is also recommended before dying in place in residential care settings such as group homes is dismissed or disqualified.

At the individual level, care team members can begin advocating for review of agency practices, policies and standards to ensure a structure exists supporting the unique self-determination perspectives of individuals with IDD facing end of life. They can also be a voice for empowerment and participatory decision making when it appears that opportunities for case, agency, or policy and legislative implementation of person centered planning is a concern.

This study did not seek to identify toolkit or resource priorities from individuals with IDD, their families or caregivers. However, increased research with individuals with IDD facing end of life is recommended. Further research to learn the perspectives, needs, fears and priorities of this population would improve the ability for all on a palliative or end of life care team to prepare, advocate for and ensure access to quality of life enhancements.
Further research is also recommended regarding tools used to assist with assessment, planning and communication regarding end of life. General research across the spectrum of IDD, or focused interventions that work with specific diagnosis such as autism, Down syndrome or other populations would be helpful as these populations grow.

Current research indicates an increasing awareness of the deficits and access challenges for individuals with IDD to access home hospice care (Stein & Kerwin, 2010; Tuffrey-Wijne et al., 2007a). Continued research and development of effective tools supporting professional care team and case management efforts is also recommended. In addition, research could expand to determine if issues of bias or access are the same for other aging populations challenged by stigma and disruptions to their communication skills, including individuals with mental illness. Research could expand on how these populations experience quality of life assumptions and barriers to referral for end of life care. This research could also distinguish if the existing and emerging tools to support self-determination through person centered planning and communication facilitation for individuals with IDD are transferable across populations.

At a system level, it would be beneficial to increase research regarding effective methods for bridging health care systems and reforms with the need to increase referrals to the care individuals with IDD have explicit rights to access should they so desire. Providing research-based methods for assessment, referral and service provision that address ethics, values and practical concerns within a scope of practice as well as address perceived risk management issues are needed.
Promotion of prevention and early intervention for individuals with IDD facing life threatening illness would also be beneficial. Information regarding prevention and early intervention for issues such as diabetes, cancer, and other life threatening issues is generalized to the broad population. Knowing the population of individuals with IDD is growing dramatically, development of effective targeted early disease prevention and intervention strategies for use among the population of individuals with IDD is critical. This information needs to be differentiated to target individuals with IDD, their families, caregivers or the professionals and systems who support them. Where families and caregivers have general control over the time and resources of an individual with IDD, the individual’s access to nutritious food, exercise, and preventive interventions may be challenged as they enter specialized programs such as adult special education and daily skills centers. A review of the value of “dignity of risk,” which supports individuals with IDD to make unhealthy choices and have opportunity to make mistakes may be needed to support systems and programs serving individuals with IDD in reviewing staff modeling of healthful choices. This could occur through a thoughtful review of providing access to harmful foods, sugared drinks and tobacco from on-site vending machines in order to avoid exacerbating diabetes, obesity and pulmonary disease. While individuals with IDD have a right to make unhealthful choices and mistakes, program providers have a responsibility to engage in ethical review and establish practices that consider their population’s capacity for weighing risk. Consideration should be given to the agency’s role and responsibility with regard to failure to provide sufficient supports and assist in minimizing the ramifications of unhealthful choices.
Implications for Social Work

Study participants prioritized information to be included in a toolkit for end of life team communication with individuals with IDD, assessment of their needs and desires, and effectively addressing care, treatment and other end of life issues. Study participants also prioritized shared resources and knowledge across services and practices. Social workers may be in a unique position to facilitate improved multidisciplinary team functioning as improved efforts toward self-determination through person centered planning, and facilitated communication increase. Csikay and Chaitin (2006) indicate that conversations about end of life can be emotionally challenging. They point out the potential in multidisciplinary and family team meetings for conflicting feelings about the appropriateness or timeliness of discussions to arise. These are also opportunities for attitude differences to occur, particularly among professionals and families as quality of life for individuals with IDD is misjudged or assumptions for care preferences or refusal are made (Csikay & Chaitin, 2006). Social workers can serve as the role models for empathic listening, reflective questioning, and facilitation of self-determination review.

Social workers may also be uniquely trained and positioned to be neutral facilitators and educators within the team. They can support team members, including the individual with IDD and family, to address beliefs, assumptions, fears, hopes and wishes. As liaisons to the team, individual and family, the social worker may have the opportunity to bridge understanding of team members’ roles and to facilitate education to address treatment, systems and resources (Csikay & Chaitin, 2006).
Social workers may also be able to temper the reactive response of medical providers as they face increasing health care reform and financial pressures. Through relationship building across the care team and with case managers supporting individuals with IDD, social workers may be the primary advocates for establishing person centered planning early and consistently throughout the individuals’ end of life relationship. If strong person centered plans are developed and serve as the reference point for the care team, risk management and utilization reviews may be more effective.

Social workers have an ethical responsibility to ensure with relationships and awareness of the unique pressures faced in hospital settings may find it helpful to the team to promote comprehensive person centered planning as early as possible in the diagnosis of life ending illness. Social workers may feel increasing pressure to honor the risk management and cost containment pressures faced in medical care, and to ensure ethical palliative and end of life care practice.

Social workers may help inform the process early by advocating for the extra time for person centered planning as an “upstream” investment in care planning that could result in fewer hospitalizations during the final end of life phase if team members are confident that the person centered planning is thorough, intentional and authentically represents the views of the individual with IDD and their significant family and caregiving team. Educating individuals with IDD and their families early about the benefits of early palliative care and hospice with regard to quality and length of life can build a stronger advocacy voice among the patient and family. That strong voice can
support anxious or ambivalent medical teams to slow down and consider the issues more fully.

Social workers can serve as a liaison between hospitals, nursing homes, hospice and the caregivers or family in places individuals with IDD consider home. Each of these entities has financial, system, and practical influences that weigh in determining a good fit for supporting the individual with IDD’s ability to be cared for and die in place. They may also need to join the advocacy efforts to secure Medicare payments for end of life planning for medical care providers. Social workers have a responsibility for engaging in relationships and supporting access and development of necessary and appropriate services at the individual, organizational and societal levels.

In order to ensure social workers are supported in advocacy and end of life service for individuals with IDD, social work education may need to expand to address palliative care issues for individuals with IDD. In addition, social work education explicitly addressing IDD as a population with a unique history of oppression and ongoing exposure to stigma and negative bias within systems could be offered.

These are values that require social work action. Social workers must do more than simply advocate for access to end of life services for all. Targeted advocacy needs to occur to operationalize focused attention on obtaining and securing support for the individual’s expressed desires.

Social workers must promote the inherent dignity and worth of the person with IDD at the beginning of treatment and care decisions. By behaving in a trustworthy manner with the individual with IDD, their family and caregivers, the agencies and
partners working with the person, and the systems providing the services social workers can be the facilitators of trustworthy teams. Earning trust begins with seeking to understand, serving as a vessel to hold the individual’s fears, hopes and desires, and mirroring the concerns of individuals with IDD and their caregivers to the end-of-life systems and teams they are engaged with.

Finally, social workers must have boundaries and awareness to operate within the scope of the social work profession. They must be able to navigate risk management priorities, systems limitations, financial pressures on treatment or capacity decisions that do not seek to communicate with or consider the hopes and choices of the individual with IDD at end of life. Social workers have a history of standing for social justice. This should be the foundation for supporting the rights of individuals with IDD to experience self-determination during illness, end of life, and death.
TO: Karen Pekarcik Date: November 24, 2011

FROM: Committee for the Protection of Human Subjects

RE: YOUR RECENT HUMAN SUBJECTS APPLICATION

We are writing on behalf of the Committee for the Protection of Human Subjects from the Division of Social Work. Your proposed study, “A needs assessment to determine the need and contents for a toolkit to increase access to end-of-life and palliative care by individuals with intellectual disabilities,   

__X__ approved as __________EXEMPT   __X__ NO RISK   __ MINIMAL RISK.

Your human subjects approval number is: 11-12-018. Please use this number in all official correspondence and written materials relative to your study. Your approval expires one year from this date. Approval carries with it that you will inform the Committee promptly should an adverse reaction occur, and that you will make no modification in the protocol without prior approval of the Committee.

The committee wishes you the best in your research.

Professors: Jude Antonyappan, Teiahsha Bankhead, Maria Dinis, Serge Lee, Kisun Nam, Francis Yuen.

Cc: Dr. Jude Antonyappan
APPENDIX B

Consent to Participate

Consent to Participate in Research

A needs assessment to determine the need and contents for a toolkit to increase access to end-of-life and palliative care by individuals with intellectual and developmental disabilities (IDD).

You are being asked to participate in research which will be conducted by Karen Pekarcik, a Masters in Social Work student at California State University, Sacramento.

Life spans of individuals with intellectual and developmental disabilities (IDD) are longer than ever before in history. Examples include people with Down syndrome, autism, cerebral palsy and other diagnosis with associated mild to profound impaired social functioning and decreased ability to comprehend new or complex information or learn new skills. Many of these individuals are now living beyond age fifty, and increasingly into their seventies. The result is that many are facing long term and difficult end-of-life health issues such as cancer, dementia, pneumonia, seizures, heart failure, cardiac and pulmonary disease. Studies indicate that individuals with IDD are often not told of their diagnosis or prognosis, and are not likely to be referred to or receive palliative and end-of-life hospice care. Also, many medical and hospice personnel have never had experience with the end-of-life issues of individuals with IDD.

The purpose of this needs assessment survey is to determine whether or not a need exists for a toolkit or handbook to support palliative care or end-of-life issues for individuals with intellectual disabilities, and to determine the types of information and resources that would be desired by professionals and caregivers to support their effort to ensure individuals with intellectual disabilities have the right to self-determination and access to end-of-life care that meets their medical, psychological, social and spiritual needs and wishes.

You will be asked to complete one needs assessment survey to provide summary employment and service data followed by ranking information regarding end-of-life care for individuals with IDD. The questionnaire is expected to take less than ten minutes of your time. All of the items in the survey request response about your experience and opinion of resources, however, you do not have to answer any question if you do not want to.

This study may present a very minimal risk of discomfort as memories of palliative care and end-of-life cases are recalled. You may also benefit from additional insight into factors that affect your experience working with palliative care and end-of-life issues or experience working with individuals with IDD, or, you may not personally
benefit from participating in this research. It is hoped that the results of this study will be beneficial for medical care, palliative care and end-of-life programs as they provide care to meet the needs of individuals with IDD.

To preserve the confidentiality of the information, you will not be asked any information that would personally identify you, such as your name, address, and social security number or specific details about your employment or caregiving experience. All responses on the questionnaires will be anonymous. Only aggregated data and group results for the project will be reported.

You will receive an incentive valued at approximately $5 for considering participation in this study. Declining to participate will have no effect on any aspect of your work, benefits or your work environment.

This study will be conducted using a paper check-off list and ranking survey format. Completed surveys will be deposited into a secured box in a secure location at the participant’s place of work. The box will be retrieved by the researcher, who will be the only person reviewing and collating the research data.

If you have any questions about this research, you may contact either Karen Pekarcik at XXX-XXX-XXXX, e-mail address XXXXXX@saclink.csus.edu, or Jude M. Antonyappan, PhD., California State University, Sacramento, Division of Social Work, 916-278-7171, email address judea@saclink.csus.edu.

Your participation in this research is entirely voluntary. You may decide not to participate in this study without any consequences. Your signature below indicates that you have read and understood this consent form and agree to participate in the research.

My signature below indicates that I consent to be interviewed, that I have been given a copy of this consent form, and that I read and understood it.

☐ I agree
☐ I do not agree

__________________________________________________________
Signature of Participant                                      Date
APPENDIX C
Project Survey

A needs assessment to determine the need and contents for a toolkit to increase access to end-of-life and palliative care by individuals with intellectual and developmental disabilities.

Life spans of individuals with intellectual and developmental disabilities (IDD) are longer than ever before in history. Many are now living beyond age fifty, and increasingly into their seventies. The result is that many are facing long term and difficult end-of-life health issues such as cancer, dementia, pneumonia, seizures, congestive heart failure, cardiac and pulmonary disease. Studies indicate that individuals with IDD are often not told of their diagnosis or prognosis, and are not likely to be referred to or receive palliative and end-of-life hospice care. Also, many medical and hospice personnel have never had experience with end-of-life issues of individuals with IDD.

This needs assessment survey is seeking to identify information and resources that would support professionals in their effort to ensure individuals with IDD have the right to self-determination and access to end-of-life care that meets their medical, psychological, social and spiritual needs and wishes as much as is possible. Thank you in advance for your participation in this study.

The first seven questions are asked to gain a sense of your background and how you work with individuals with IDD regarding palliative and end-of-life care. Please choose the answer that best fits your role in relation to individuals with intellectual disabilities (IDD):

1. Choose one type of community that best describes where the individuals with IDD you serve live.
   - Metropolitan
   - Suburban
   - Rural

2. Choose one category that best fits your role in relation to individuals with IDD.
   - Medical Professional (Physician, Nurse, Medical Student/Resident/Intern)
   - Social Worker
   - Chaplain, Pastor, or other Spiritual Support
   - Case Manager
   - Caregiver
   - Support Provider (Advocate, Peer Partner or Resource and Referral)
   - Parent of an individual with IDD

3. Choose one category below that best describes the organization you work in to provide care.
   - Hospital, Medical Research Institution, Medical School
   - Regional Center for Developmentally Disabled
   - Hospice or Palliative Care Organization
   - Advocacy or Resource Organization
   - Care Facility/Licensed Residential Care Home/Home Caregiver
   - Parent of an individual with IDD providing care in my own home
4. Length of time you have been working in this capacity:
- [ ] Less than one year
- [ ] Over one year but less than five years
- [ ] Over five years but less than ten years
- [ ] Over ten years

5. Please identify the number of adults (over age 18 years old) with IDD you have directly worked with or had case management responsibility for during the past year:
- [ ] 0 - No individuals with IDD
- [ ] 1-2 individuals with IDD
- [ ] 3-5 individuals with IDD
- [ ] 5-10 individuals with IDD
- [ ] 10-20 individuals with IDD
- [ ] Greater than 20 individuals with IDD

6. Have any of the individuals with disabilities with whom you have worked in the past year received palliative end-of-life care through hospice, home and/or community palliative care services?
- [ ] Yes
- [ ] No

7. Did any of these individuals receive palliative end-of-life care provided in the residence they considered their home?
For instance: If an adult with IDD had to move from one location to another to receive care (residential care home to nursing home; residential care home to parents’ home), they may not have been receiving care in the place they considered home.
- [ ] Yes
- [ ] No
Which of the following items would be helpful in a tool-kit or handbook designed to increase your ability to support individuals with IDD to access hospice and/or home based palliative and end-of-life care?

| Rank the importance of each service below in order of importance (scaled, one option only for 1-7) | 1 is most important and 7 is least important |
|---|---|---|---|---|---|
| Choose one item below as Most Important 1 | Choose one different item below as 2 | Choose one different item below as 3 | Choose one different item below as 4 | Choose one different item below as 5 | Choose one different item below as 6 |
| A.1 Communication checklists and assessments to determine individuals with IDD communication styles and cues for anxiety, sadness, pain, fear, discomfort, frustration, loneliness, etc. | ○ | ○ | ○ | ○ | ○ | ○ |
| A.2 Conversation starters to determine how an individual with IDD considers death, how they want to be remembered, and what they want to happen after they die. | ○ | ○ | ○ | ○ | ○ | ○ |
| A.3 Self-determination definitions, guides, sample questions, information and resources. | ○ | ○ | ○ | ○ | ○ | ○ |
| A.4 Conservatorship information, guidance, legal rights and resource information. | ○ | ○ | ○ | ○ | ○ | ○ |
| A.5 Guidance for discussing diagnosis, treatment, prognosis and end-of-life with an individual with IDD to elicit hopes, desires, wishes, fears. | ○ | ○ | ○ | ○ | ○ | ○ |
| A.6 Information for peers, friends and housemates of individuals with intellectual disability. | ○ | ○ | ○ | ○ | ○ | ○ |
| A.7 Brief descriptions or vignettes of self-determination of individuals with IDD accessing palliative or end-of-life care. | ○ | ○ | ○ | ○ | ○ | ○ |
Rank the importance of each service below in order of importance (scaled, one option only for 1-8)

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<th>Service</th>
<th>1</th>
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<td>B.1 Legal information regarding state and Federal regulations and laws supporting access to services for individuals with IDD.</td>
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<td>B.2 Information on what to expect and end-of-life resulting from life threatening, long-term illness.</td>
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<td>B.3 Palliative care and hospice services, resources and insurance coverage information.</td>
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<td>B.4 Caregiver resources addressing supporting end-of-life for individuals with IDD, and self-care.</td>
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<td>B.5 Financial considerations for individuals with IDD requiring access to palliative and end-of-life care.</td>
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<td>B.6 Housing and home-based services, resources, and rights during end of life for individuals with IDD.</td>
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<td>B.7 “How to…” formats and sample language for including end-of-life issues in Individual Program Plans and/or Treatment Plans.</td>
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<td>B.8 Information to engage and support the spiritual needs of Individuals with IDD, their family, caregivers and friends.</td>
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What do you think should be considered with regard to supporting individuals with IDD, or developing a tool-kit or handbook for increasing access to palliative and end-of-life care for individuals with intellectual disabilities?

*Please provide your response on the back of this form.*

Thank you.
REFERENCES


