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Ethical Implications: End of Life Planning for Individuals with Intellectual Disabilities

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Ethical Implications: End of Life Planning for Individuals with Intellectual Disabilities

Submitted by Kylie Otte

May 2013

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social work research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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Abstract

Individuals with Intellectual Disabilities need to engage in end of life planning, however it is essential to determine how their support networks fit into the process. As individuals with Intellectual Disabilities require support to live their daily lives, they too need support when making decisions surrounding medical treatments and end of life planning. The purpose of this study was to identify ethical implications for social workers, when working with Individuals with Intellectual Disabilities when engaging in end of life planning. Seven respondents participated in this study consisting of qualitative interviews. Each of the interviewees responded to similar question lists, written to elicit professional and personal opinions regarding end of life planning for individuals with intellectual disabilities. Respondents were identified through previous professional contacts of this researcher, and through professional contacts of faculty from the University of St. Thomas. The themes identified by this study were the importance of the care team relationship, individual client needs, communication, and discrimination in access to medical care. Each of the findings relate to implications for social work practice.

Key Words: Intellectual Disabilities, Advocacy, Communication, Care Team, Discrimination, Support, Direct Support Caregivers

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Advancements in medical treatment options are allowing for people to live longer, increasing the necessity of individuals and their families to engage in end of life (EOL) discussions (Kingsbury, 2005; Mackelprang and Mackelprang, 2005). EOL planning includes advanced directives, living wills and do-not-resuscitate /do-not- intubate orders. Each of these options are informed choices to either continue or discontinue lifesaving treatment which may be in the form of nutrition, hydration or medical treatment of any kind (Turnbull III, 2005; Wagemans *et al.*, 2010).

Precise statistics regarding the number of individuals living with Intellectual Disabilities are difficult to find. Sources such as the Association on Intellectual and Developmental Disabilities (AAIDD) and Arc of the US, speculate roughly 1.5 to 2.5 percent of the general population of the United States live with an Intellectual Disability (ID) (Bethesda Institute, 2012). Intellectual Disabilities (IDs) are defined as a persistent physical or medical condition which occurs before the age of 22 with the likelihood of continuing for the remainder of the individual's life (ARC, 2011). IDs inhibit the level of independent functioning or cognitive development in three of the following areas: receptive and expressive language, mobility, self-direction, self-preservation and economic self-sufficiency. Most individuals with IDs live their lives within a broad support network. These individuals may receive services ranging from supported living environments, supported working environments or a combination of the two (ARC, 2011). Lives of individuals living with IDs are usually influenced strongly by the care of others. Most individuals are dependent on help from caregivers to live their daily lives (W van Thiel *et al.*, 1997). These caregivers, in addition to social workers and legal representatives make up the interdisciplinary teams (IDT), involved in the individuals

with IDs lives. Individuals with IDs are at risk of being discriminated against throughout all arenas of treatment due to their limited cognitive abilities and at times impaired social functioning. Individuals with IDs are referred to as vulnerable adults due to the increased likelihood of the individual being taken advantage of. Individuals with IDs are also discriminated against due to their status as disabled, and until the late 1980's and early 1990's, did not have the rights which they currently hold. It is due to the infancy of the disability rights movement that continued discussions surrounding the rights of individuals with IDs continue today.

Due to the intricacies of care for individuals living with IDs, EOL planning is very complex and can be controversial for caregivers, families and physicians. Decisions regarding whether to treat or not treat people at EOL stages must be clearly communicated and documented by those who support them (W van Thiel *et al.*, 1997). Without all members of an individual's IDT in agreement, the ability to ensure someone's wishes will be carried out is minimized. Turnbull (2005) highlights the necessity of IDTs caring for people with IDs to move beyond solely the rights afforded to them as human beings. He proposes IDTs ground their decisions and actions in the trust held by the individuals with IDs and the compassion in their relationship with them.

Social workers are likely to encounter clients living with IDs throughout all avenues of practice. Therefore, the necessity of understanding how disabilities affect daily life scenarios and the individual's decision making ability is essential for those working with them. When engaging in EOL planning, many factors are to be considered, including who should be involved, how much of those involved opinions should be considered and what medical information is pertinent to the clients' decision making.

The research presented here will provide previous literature to examine how EOL planning for individuals with IDs and their non-disabled counterparts has been done in the past. The aim of this research project is to identify ethical implications for social workers to preserve client autonomy while upholding the rights of clients to self-determination.

Disability History in Minnesota

In the 1960s, it became clear to society that institutions, such as state hospitals, in Minnesota and throughout the United States were not meeting the basic needs of their clients with disabilities. (Minnesota Council on Developmental Disabilities, www.mnddc.org) These individuals with IDs were predominantly living in “back wards” which refer to the back portions of state hospitals, where the people housed were in custodial care. Those individuals were not expected to recover and were not provided treatment (Learning from History, 2007). Due to numerous abuses which took place in these institutions, laws began to change. After legislation mandated the inclusion of children with disabilities into public schools passed in 1975, the populations at institutions began to decline. This legislation allowed for some parents to bring their children home and send them to school. During this time, the presence of smaller community based care facilities, such as group homes, began to appear. By the 1990’s, four states and Washington D.C. had closed all of their institutions, and many states had drastically reduced the number of their institutions. Those who could not live in their homes of origin began to live in more community based supported living environments, which ultimately lead to the systems in place today (Minnesota Council on Developmental Disabilities, www.mnddc.org).

Inspiration for the Study

This research project is inspired by my own professional experience working to support an individual through the end of life process in a residential adult foster care setting. The individual who inspired this research was a remarkable person. Mary was born in 1941 with an intellectual disability that limited her communication ability. Mary was deaf, nonverbal, and had limited knowledge of American Sign Language. At three weeks of age, Mary was given up by her biological parents. From this point on she lived her life based on the support of others, none of whom were related to her. Throughout the course of Mary's life, she lived in varying locations from the initial family foster care setting at three weeks of age to varying state run hospitals. Mary moved into her first group home in the late 1980s. In 1996, Mary moved to a new group home residential provider, in the Twin Cities, this would ultimately be her last new provider. While living with this adult foster care provider, Mary lived in various homes. However, in October 2010, she moved into her last home and remained with the same peers until her death in August 2012.

During Mary's life, she had different types of supportive employment. At one point she worked as a housekeeper in a hotel. The training she received on this job was evident throughout the remainder of her life as she would consistently clean and cared for her own belongings. Even cleaning and completing her own laundry into the last few months of her life. As her health began to decline, Mary attempted to maintain her independence, often her direct support staff would continuously offer her more and more assistance, hoping she would allow their help. Mary's days were filled with crocheting, watching cartoons, and various outings. Her favorite outing would be to get her nails

done and then go get fast food. As Mary's health began to decline, she began to refuse outings, and instead of crocheting she would bead necklaces. As time progressed her naps began to fill her days. As her direct support staff noticed changes in her ability to complete these activities and tasks, they noticed her symptoms increasing and trips to the hospital visits were also increasing. Toward the end of her life, Mary's days were primarily filled with beading and napping in her favorite chair by a large window in the living room of her home, surrounded by her peers and direct support staff.

I encountered Mary in my professional role as the group home supervisor. I entered her life shortly after she had been diagnosed with a life threatening illness. Over the course of the following two and a half years, I was part of her caretaking team, coordinating and ensuring the necessary steps were taken for her to access the most comprehensive care possible. Shortly after I began to work with Mary, her health declined and she was diagnosed with a life threatening illness which was closely monitored by her physicians and her care giving team. It was at this time discussions surrounding what her care team began to discuss what would be her end of life process. It was decided by her care team the best thing for Mary would be to remain in her own home, for as long as possible. Surrounded by those who know her well, had already developed a way to communicate with her, and provide her with the most comfort. While I was working to support Mary I had many questions regarding the EOL process for individuals with disabilities. Thus, the inspiration for this study began.

Mary's care team was comprised of her case manager, legal guardian, case manager from her adult day service provider, her direct support providers and I. Mary's case manager had been with her for over twenty years, and some of her direct support

providers had worked with her for ten plus years. Information regarding Mary's daily care was passed on from her direct support providers, to me and to the other members of her care team. Everyone, with the exception of Mary's direct support providers, had input into the decision making process for Mary. These decisions were based on the observations and physician recommendations for her care. Decisions for Mary's care were the responsibility of her legal representative. These decisions were often made in consultation with her care team; each of the care team meetings occurred with Mary in attendance. As Mary's illness progressed the decisions of whether to pursue or not pursue a test or type of medical treatment was based on how much discomfort it would cause Mary and if the results would impact her prognosis. As Mary's health continued to decline, the decision to forgo invasive tests and begin hospice services was made by her guardian. Although Mary was not able to verbally communicate her thoughts and feelings surrounding these decisions, she was a part of each meeting, and observations regarding her willingness or refusal of tests were communicated directly with each member of her team. Mary's compliance with the majority of medical tests, illustrates the level of trust she had for health care providers. Her willingness to seek assistance as she knew how, even in new or different environments, by utilizing picture scales, or her clip art picture book, indicated her desire to communicate to her direct support providers.

Mary lived in various institutions in Minnesota until her move to an adult foster care setting. Her legal representative was a county case manager; her "family-of-choice" became the individuals who worked to support her and her peers. Due to my active involvement in her life and death, I was able to gain an understanding of the limitations of care and choices in the death process for individuals living with IDs. Mary's time with

hospice was initiated in early August 2012; she had been receiving hospice care for a few short weeks when she developed an infection. Because of her hospice status, Mary was unable to receive antibiotics for the infection. A few days later on August 25th, Mary passed away in her own home surrounded by those who loved and supported her for numerous years.

Following her death, there were differing opinions of how and where to lay Mary to rest. She was cremated and a small service was held for her. Because of my strong relationship to Mary, it was suggested by a colleague that I should speak at her service. I wrote a eulogy remembering how Mary had touched so many lives in her time at the group home. On the day of her funeral, we were unsure how many would be in attendance. As I stood there waiting for it to begin, the cars kept arriving; approximately 25 professionals and peers were in attendance. The attendees included her legal representative and case manager from the county who had been involved in her care for many years. Her care coordinator from her health care provider and direct support caregivers from her foster care provider, each of whom had a special place in their hearts for Mary also attended. Through her life and death, she inspired this me and this study.

Literature Review

There is one certainty in life that does not discriminate on ability level, race, cognition, or sex. This certainty is as each of us will live each of us will die. Social workers must promote the quality of life and respectful treatment during end of life stages for all people. They can do so by working to ensure dignified treatment of those who are engaging in the dying process (Luptak, 2004). To do so, it is necessary to ascertain

patients' abilities to make decisions and choices about how to die and what types of pain management they want to control or limit their suffering.

Through the creation of the Patient Self Determination Act (PSDA) in 1990, Americans were granted the legal standing to make important decisions regarding their EOL care. They are able to decide what type of care, which medical treatments they would like to receive, and indicate the location of medical treatment they desire throughout their dying process. The PSDA provides rights to all citizens including individuals with disabilities. These rights include the right to life and the ability to decide how they would like to die. This can mean equal opportunities to medical treatment or the decision to not treat their illness at all. The PSDA places the decision-making responsibilities on the individual first and then the family. This requires individuals, regardless of their status as being disabled, to be consulted regarding their EOL plan (Mackleprang and Mackleprang, 2005). Additionally, PSDA mandated that facilities receiving federal Medicare dollars ask patients upon admission for information on any existing end of life plans. Through this mandate, information regarding Advanced Directives (AD's), Living Wills (LW), and who would take the role of a health care proxy or surrogate, sometimes referred to as a durable power of attorney are required to be documented upon admission to a facility. Documentation of these preferences are to ensure the facility's compliance with the patient's wishes should they become incapacitated (Becker *et al.*, 2007; Fagerlin *et al.* 2002; Galambos, 1998; Luptak, 2004 and Mahon, 2011).

ADs are statements providing treatment preferences determined by the patient prior to their incapacitation. Information provided by ADs will include how the patient

wants medical decisions to be made and who should make the decisions for them when they are no longer able to. ADs are meant to ensure the patients' rights to die as they wish, one of the most significant forms of self-determination. (Fagerlin *et al*, 2002, Luptak, 2004).

Luptak (2004) indicates the initial push of examining how the dying process should be done began formally in the 1970's. This time period also marked the beginning of the palliative care and hospice movement, in the U.S. This movement was not as widely publicized until the passage of the PSDA in 1990. Becker and colleagues (2007) and Stein (2004) highlight the creation of PSDA to the increased popularity of palliative care in recent decades. Palliative care is often referred to as comfort care (the most common form known is hospice). This approach includes many factors such as holistic, physical, psychosocial, and spiritual health throughout the dying process. Mahon (2011) highlights that ADs were created to assure patients would be given the option to participate in their end of life planning while determining someone to make choices for them if and when they become incapacitated by their illness. The name given to this role is often a durable power of attorney; surrogate, or health care proxy. People in this role are legally able and required to make medical decisions on behalf of the patient if and when the patient becomes incapacitated (Fagerlin *et al*. 2002; Mahon, 2011).

Living wills (LW) are another form of planning which assists families and physicians to make decisions after patients become incapacitated. LWs often refer to very specific scenarios which have previously been discussed with the patient. LWs provide specific treatment preferences in relation to the medical scenario. LWs are often

checklists which provide a guide to patient's treatment preferences while being in full compliance of the law (Mahon, 2011). For example, a LW may specify the number of days in which a patient would like to receive life support before ending medical interventions.

In order for living wills to be successful, people in the role of surrogacy, legal representatives and proxies must be willing to comply with the patient's wishes. Individuals creating wills must express stable preferences which do not waiver over time, and surrogates must be able to understand the preferences of the patient prior to their incapacitation (Fagerlin, *et al.*, 2002).

The role of a surrogate or proxy is not one people should take on lightly. Individuals whom assume this role in the life of a dying patient are charged with very difficult and emotional decisions to make. The process of the Family Covenant as described by Doukas and Hardwig (2003) provides support for those in this role by proposing the necessity of value-based planning conversations. The Family Covenant model proposes the necessity of EOL planning to include individuals whom the patient values such as biological or intentional family. The purpose of these meetings is for everyone involved to engage in value based and specific planning conversations regarding how the patient would like to be cared for in time of illness and incapacitation.

Benefits of EOL Planning

"Having a dignified death" was highly valued by patients and surrogates in studies by Hawkins and colleagues (2005), and Klinkenberg and colleagues (2004). These studies propose the primary focus of advanced planning is to prepare, people for becoming incapacitated and death. The main goal of patient preparation in these studies

is to ensure their understanding, and the inevitability of the changes in their physical and mental state. Patients are then able to share their wishes with their families and loved ones. These studies also found the majority of ADs in the United States indicate the patients' preference to forgo medical treatments rather than prolonging life with medical interventions.

Gallo and colleagues (2003) examined the perceptions of physicians regarding their own EOL planning. Their study found the majority of physicians' ADs limit the treatments which they want to receive and express their desire to receive "aggressive" pain management which can hasten death.

For EOL planning to work, people must engage in the planning (Fagerlin *et al.* 2002, Hawkins, *et al.* 2005, Klinkenberg, *et al.* 2004). Fagerlin and colleagues (2002) in addition to Klinkenberg and colleagues (2004) report respondents in their studies believed ADs are only for elderly and sick people. Healthy individuals are likely to procrastinate or not to participate in the AD process at all. Without ADs, family members are left to interpret what they believe individuals would want. As Klinkenberg and colleagues (2004) and Hawkins and colleagues (2005) found, patient preferences regarding treatment choices depend on many different characteristics. They go on to highlight what is important to some is not to others. The phrases "no extraordinary means" or "no heroic measures" are often understood differently by those in the role of patient and those in the role of the surrogate (Mahon, 2011).

People may have difficulty predicting how they want to live and die once they become ill (Fagerlin *et al.*, 2002). Luptak (2004) proposes EOL interventions should emphasize the advanced care planning process. Similarly, according to Seymour and

colleagues (2003) ADs are often a guide for families of the patient's wishes, which can lessen the burden of families and surrogates when making EOL decisions.

The Family Covenant model proposed by Doukas and Hardwig (2003), allows for disagreements over choices regarding moral issues to turn into meaningful and effective conversations. In these conversations members of the covenant are able to express their beliefs and feelings to the patient. Ultimately, the decision is that of the patient, and when expressed, is valued and honored by members of the covenant.

In the Family Covenant model, the role of the physician is the facilitator; their own beliefs are tested as they are forced to inform patients and families of their willingness to comply with the wishes of the patient. The role of the physician after the covenant is to ensure the wishes of the patient are carried out. If disagreements occur after the incapacitation of patients, the physician is able to make decisions or recommendations that align with previous statements of the patient. If they are unable to mediate a decision, they will often refer the process to an ethics committee to ensure the patients' rights are upheld. The written documentation of the covenant in these times allows for the patient's wishes to be understood and carried out by the ethics committee (Doukas and Hardwig, 2003).

Engaging in the EOL and AD planning process can be difficult for patients. Entering into these processes facilitates and requires individuals to examine their desire to communicate and control their care. Patients must also decide whom to trust and who would be their surrogate (Seymour *et al.*, 2003). Fagerlin and colleagues (2002) identify the psychological benefits for patients and their families who have completed EOL

planning. EOL planning provides clear information to families and surrogates regarding treatment preferences that can aid in the surrogate decision making processes.

Benefits of Advanced Directives for Individuals with Intellectual Disabilities

Individuals living with or without disabilities in America are, in general, not prepared to address EOL concerns. Kingsbury (2005) proposes principles to follow when working with individuals with IDs while preparing for EOL. She proposes respect for the autonomy of the individual, forming plans that will do no harm to individuals and allowing EOL plans to encompass what is best for the client. The necessity of justice is an overarching principle to consider when engaging in EOL planning for individuals with IDs (Kingsbury 2005). Similarly, Turnbull (2005) proposes the necessity of justice, indicating despite the disabilities people live with, they still have the right to all available health care options throughout all stages of their lives.

Limitations of Advanced Directives

As previously highlighted, it can be difficult to engage people in EOL planning. Additionally, there are other limitations that can occur once the process of planning has ended. Fagerlin and colleagues (2002) found people hold misconceptions about what will happen when they begin to experience pain or become disabled by their health care condition. They found in a time period of two years, one third of their respondents preferences had changed. These respondents assumed their new beliefs were in line with what they had previously documented. These findings create difficulties for those engaging in the EOL planning process. Without documenting changes, patients may not experience the dying process as they would like. To ensure patients' EOL wishes are

honored, it is essential for patients and their families to have continuing discussions regarding EOL plans to ensure the documentation changes as their preferences do.

Limitations of health care benefits can impact the choices of some patients. Stein (2004) found insurance coverage might shape choices patients make regarding their care. Financial constraints of patients can guide what type of care is chosen. Community based care, such as receiving care in the patients home, may not be covered by insurance plans. Caregiver burnout can also attribute to individuals EOL plans being modified after incapacitation, due to the limitations of what family members are able to sustain. In these cases, individuals may transition into more formal settings in their last stages of life such as hospitals or skilled nursing facilities (Becker *et al.*, 2007). A study by Becker and colleagues (2007) highlighted the issue of individuals wishing to use Medicare benefits for types of palliative and hospice care. These individuals may not be able to enter into these systems as quickly as they would like due to the necessity of being within their last six months of life. Additionally, physicians may have difficulties diagnosing patients as dying which can slow the progression into palliative type services (Stein, 2004).

Surrogate Decision Makers

Advanced Directives can reduce the emotional burden while improving comfort and understanding between patients and surrogates. Fagerline and colleagues (2002) found in their study that most of their respondents with ADs were less concerned with providing specific detailed instructions in their AD. They were, however, more likely to focus more attention and detail into determining the appropriate surrogate and thus placed their trust in the decisions of their surrogate.

Klinkenberg and colleagues (2004) found relatives in the role of surrogacy tend to underestimate the preferences of older patients to forgo aggressive medical treatment at EOL. This can lead to more invasive treatments being pursued than desired by the patient. Surrogates may not be able to accurately predict the wishes of an incapacitated patient. They often make choices in congruence with their own preferences, rather than following the patient's wishes (Fagerlin *et al.*, 2002; Klinkenberg *et al.*, 2004; Seymour *et al.*, 2003).

The role of surrogate is most frequently designated to one person. In a study by Hawkins and colleagues (2005), the majority of patient respondents expressed their desire for those in the role of surrogacy to work in cooperation with physicians to make the necessary choices surrounding EOL care. Conversely, surrogate respondents expressed a desire to include multiple members of the biological and intentional family working in consultation with the physician to ensure the choices being made were the right ones. Patients expressed interest in the ability of their surrogates to override treatment preferences in the AD's as they would be able to consider all of the information, benefits and risks at the time. The expressed wishes of patients in these studies highlight the importance of oral communication in EOL planning to ensure patients are able to express their wishes to their surrogate prior to incapacitation (Fagerlin *et al.* 2002; Hawkins *et al.* 2005).

As a response to these concerns, the Family Covenant model presented by Doukas and Hardwig (2003) would allow for participants to communicate their vested interests in the treatment of the patient while simultaneously gaining the same understanding of the others included in the process. Doukas and Hardwig (2003) and Klinkenberg and

colleagues (2004) identify the necessity of relatives and physicians to act in the best interest of the patient. Families and the physician must engage in specific conversations regarding pain management to ensure the understanding of focusing on what is best for the patient regardless of the family dynamics involved.

EOL Planning with People with Intellectual Disabilities

Caregivers, physicians and families support individuals with IDs throughout transitions in all stages of life. All involved must act on what is important to and for the individual with ID during the dying process (Kingsbury 2005 and Turnbull, 2005). Kingsbury (2005) highlights the importance of support for individuals and their caretakers during EOL planning, ensuring their ability to effectively communicate their wishes. She also indicates that the wishes of individuals with IDs should be communicated throughout one's life, prior to stages of advanced disability or illness, when total incapacitation can occur. Turnbull (2005) proposes the necessity of special care and scrutiny in EOL planning for people with IDs, noting specifically that the more limited abilities a person has, the more caution and scrutiny is required.

According to the Mental Capacity Act, adults with IDs are assumed to have the capacity to make their own decisions even if they should require support from families, caregivers or physicians to do so. Quality of life cannot be guessed or assumed. Caregivers, legal representatives, physicians, advocates and other members of individuals with IDs lives, must not base decisions regarding EOL solely on the level of cognitive ability or function of the individual patient (Medley, 2006).

Intellectual Disabilities commonly affect not only cognitive functioning but other motor skills as well. Individuals living with these types of disabilities may have

difficulty communicating in ways which society views as “normal.” Kingsbury (2005) indicates communication can be received through numerous ways. Individuals with IDs who are unable to speak or form words cannot be considered as not communicating or not having an opinion of the situation. Rather, individuals with IDs and limited verbal skills often communicate through their intentional behaviors or intentional lack of behaviors. Caregivers or family members who support them can interpret these behaviors as consent or assent. More specifically in studies conducted by W van Theil *et al.* (1997) and Wagemans *et al.* (2010) in the Netherlands, when patients’ families were not consulted, physicians and nurses were relied on to interpret the behaviors of patients with IDs. In these studies, the nurses interpreted the continual independent removal of feeding tubes by the patient as an indication they did not want to continue to live with artificial means, and engaged EOL medical treatments. In both of these studies, the physicians and health care providers commonly made determinations of patients “asking to die” based on continual behaviors experienced or repeated conversations regarding heaven.

If individuals with IDs are not able to express their wants or needs in a verbal way, those who support them must be the foundation of the EOL plan. EOL planning then becomes the care teams’ responsibility to initiate and continue the conversations with others who are important in the life of the individual with ID. Individuals with IDs should be included in all conversations regarding their EOL plans regardless of their ability to understand or comprehend the seriousness or importance of this task (Kingsbury, 2005; Turnbull, 2005).

EOL planning should provide a balance of health and safety for the patient with IDs. Patients with IDs, family members, caregivers and members of their intentional communities should be provided the opportunity to share input to assure the wishes of the patients are at the heart of the decision making process and carried through the entire dying process (Kingsbury, 2005; Turnbull, 2005).

Communication among stakeholders in the lives of the patients with IDs is essential. Through these conversations, decisions made by surrogates can be scrutinized for the protection of the patient with IDs. This scrutiny ensures the lack of conflict of interest regarding economic factors, caregiver difficulty supporting an individual with ID, or other psychological concerns which could affect EOL planning process. Most importantly, the stakeholder communication can ensure that these individuals are receiving all possible care for persistent medical conditions rather than being forced into EOL planning solely due to the patients' diagnosis of an ID (Turnbull, 2005).

Role of the Physician

The role of the physician in EOL planning is important to understand as it can shape the decision patients make. Physician treatment preferences are “highly correlated” to those of their patients, and patient willingness to forgo or stop treatment is linked to the physician's attitude of such choices (Gallo *et al.*, 2003). To take advice from physicians is something we often do without hesitation, as Kane, Bershadsky and Bershadsky (2006) note; individuals rely on advice of people they expect to have knowledge of the circumstances.

However, provider anxiety can be a driving force when ADs are not followed. If physicians are concerned patients' choices may violate their professional ethics, they may

not act in accordance with the AD. Patients must understand the viewpoints of their treating physician regarding EOL plans. Physicians may also be concerned family members could seek litigation against them for the accusation of wrong doing which would further violate the patient's right to autonomy and self-determination (Seymour *et al.*, 2003). Fagerlin and colleagues (2002) propose AD planning must take place with family members and physicians in consultation to ensure they are followed when the patient has been incapacitated.

In a study by Gallo and colleagues (2003) regarding attributes held by physicians for AD planning, found 30 percent of respondents who completed their ADs were confident others knew their wishes. Physicians in this study were also more likely to use AD planning to refuse or limit life sustaining treatments. These physicians also documented their desire for pain management, knowing it may hasten death. The same physicians rated their mental health higher than physicians who had not yet completed their ADs.

Physician's Actions with Patients with IDs

Two studies examined practices in the Netherlands to examine what factors physicians considered before taking EOL action for their patients with IDs (W van Theil *et al.*, 1997; Wagemans *et al.*, 2010). Both of these studies were conducted by reviewing previous medical records and conducting interviews with physicians directly involved in patient care. These studies found physicians were likely to overrule the legal representative's decisions regarding EOL actions for clients with IDs, if they disagreed with the decisions provided by the legal representative. These studies also found some physicians, legal representatives and families felt individuals with IDs should be spared

the information regarding their terminal illness and engaged in EOL conversations without the individual's knowledge or input. Specifically, the support networks felt the individuals could not handle the news, or it would give them more undue stress (W van Thiel *et al.*, 1997; Wagemans *et al.*, 2010).

W van Thiel and colleagues (1997) found physicians who took into consideration non-verbal non-autonomous requests and communication from patients asking to die would honor such requests. Out of a possible 67 cases studied, in 50 cases family members or representatives were consulted. Nurses were consulted in all 67 cases, but only in two cases were patients consulted when making decisions to engage in EOL action. In all 67 cases, deaths were reported as natural, and no post-mortem examinations occurred to verify these reports. When questioning the physicians in this study, it was found that the most common reason for engaging in EOL action was to reduce pain or suffering of the individual. Wagemans and colleagues (2010) found some physicians made medical decisions to proceed with EOL treatments solely due to the diminished nature of capacity held by the patient with IDs, not due to a persistent medical condition. Turnbull (2005) likens this to disability discrimination, highlighting that people should not be exploited in life or death.

Patient Beliefs about ADs

Seymour and colleagues (2003) found EOL planning occurring during times of high stress, such as a sudden change in the state of health, often caused anxiety and fear to the patient and their family. They also found ADs allowed for stress to be reduced for the patient and their families during the dying process. ADs allow for families and patients to face illnesses and cope with what it means in terms of the patients' life.

Luptak (2004) found patients often have concerns regarding where to die, who to see, how to distribute their belongings, on top of not fully understanding their illness. Seymour and colleagues (2003) found familial patient relationships are given priority over the physician patient relationship when making EOL decisions. Dying is difficult to predict; it often involves rapid changes which first may be realized by family or care giving members of the patients' life. These rapid changes can include cognitive impairment leading to the inability of the patient to weigh in on decision making. Hawkins and colleagues (2005) agree patients are often mentally and/or physically incapacitated near the end of their lives.

Ethical Considerations for End of Life Planning with Patients with ID

In recent years in the United States, the topic of EOL planning for individuals living with ID has received a growing amount of attention. Kingsbury (2005) highlighted the essential theme of Self-Determination for anyone engaging in EOL planning. Kingsbury (2005) proposed EOL planning should be an ongoing process that should encompass all individuals who support the person living with ID. If legal representatives, for example, make decisions without communicating to caregivers, there can be anger and sadness surrounding the individual in their last days.

Medley (2006), proposes the necessity of care teams to provide skilled and sensitive communication when working with individuals with IDs especially surrounding EOL planning due to the complexity of these decisions. EOL planning for individuals with IDs is a complicated and intricate process. Practitioners base their decisions in varying guiding principles as they assist individuals, families, communities and surrogates of individuals living with IDs in planning for EOL care.

Turnbull (2005) highlights the existence of intentional communities, if an individual with ID no longer has involved family, or never did, often times the decisions are left to those who hold sole legal custody of the person. Sometimes the person involved may know the individual very well; other times, they may be a paid case manager or professional legal representative who may not know the individual at all.

Conversations with members of the intentional community are essential. Turnbull (2005) highlights just because an individual with ID may live in a group home, they choose to do so; they get along with their peers, and have formed bonds with them. The caregivers supporting these individuals are intentional members of their communities. Information shared between these groups of people is not something to look beyond when forming EOL plans. Turnbull (2005) proposes the necessity of including caregivers in conversations regarding EOL planning. Conversations with those who support the individual bring clarity to the desires and needs of the individual with ID, and ultimately confirm their needs are being addressed through the EOL plan.

As individual's EOL plans are implemented, comfort and dignity are essential themes to their experience. Creating EOL plans and having discussions as the individuals with IDs progress in their illnesses, ensures everyone involved will have the information they need to support the individual. Consistency, comforting items, completing daily rituals, photographs and stories of the past provide a person-centered approach to the death process (Kingsbury 2005 and Turnbull 2005). Just as Faye Wetherow stated, "When you ask people their dreams you are walking on sacred ground," (Kingsbury, 2005, p. 10). As you ask individuals to participate in their EOL plan, we are walking on

the most precious ground, helping someone to transition from life to death with dignity and in a manner which they choose (Turnbull, 2005).

Conceptual Framework

There are numerous theories that have been developed regarding the lives of individuals with disabilities. Disability principles focus on the rights of individuals with IDs to accessible and appropriate health care. Disability irrelevance, or the concept disability or not, the options must remain the same for all people seeking treatment. Reasonable accommodations, support networks such as legal representation, surrogate decision making, protection and advocacy may not be fully accessible from the individual with ID alone. It is necessary that the people participating in the care teams support the individual however much or little they wish throughout their lives and self-determination with an EOL plan (Kingsbury 2005, Mackelprang and Mackelprang 2005, Turnbull 2005).

Developmental Life Course

Individuals' decision-making capabilities are formed throughout life experiences, both environmental and individual (Yoshioka and Noguchi, 2009). Individuals living with IDs are shaped not only by their own personal wants and needs, but also the beliefs and lessons learned through the lives of their families, caregivers and peers. The DLC principles take into account environmental and social supports of people, similar to other theories popular in social work. What differentiates the DLC principles is the inclusion of experiences drawn from the "birth cohort" (Yoshioka and Noguchi, p. 874). Birth Cohort refers to people who were born or considered to be in the same generational range, for example the baby boomers, generation Xer's. The main focus of the DLC is to

examine specific physical and social tasks individuals have undergone, focusing on the influence of these tasks in cooperation with the individual's behavior and ability to participate in their environment. For individuals with IDs, many of the tasks they complete physically and socially are grounded in the participation of others who support them. Therefore the individuals with IDs and those who support them are able to socialize and participate together, forming bonds which may align with the same or differing birth cohorts. These relationships and experiences are essential to how decisions are made in support of and for individuals with IDs. This focus, similar to human behavior in the social environment, focuses more attention on the impact of the individual's specific development and the ability to transition between life events (Yoshioka and Noguchi, 2009).

The DLC principles are essential to the process of planning for EOL for individuals with IDs. Often times the social support networks and communities which they live in influence the thoughts and beliefs of those with IDs. So much of their time is spent relying on experiences and knowledge of others some from their birth cohort, and other times from members of differing cohorts. An individual with IDs ability to complete physical and social tasks relies on their support network of peers, caregivers and families to ensure not only their safety but their sense of mastery as well. The DLC framework lends support to examining the experiences and lives of individuals with IDs from the thoughts, feelings and experiences of those who are involved in their daily lives. Caregivers are often some of the most present members in the lives of individuals with IDs. Thus these individuals often want to relate to their caregivers through similar life experiences.

Human Capacity Model

The Human Capacity Model is made up of portions of human development as individuals acquire capacities in the areas of public/medical health, psychology and education. Each of these areas is linked to deficits experienced by individuals with IDs. The ability of individuals to function in their lives depends on their medical, psychological and educational development. Individuals with IDs have deficits in their functioning level in some or all of these areas; therefore, the HCM provides rationale for supportive living environments and life styles lived by individuals with IDs. The HCM is grounded in each of the areas essential to the support of individuals with IDs: medical, psychological and educational. The grounding of this model in all three areas has allowed for the current level of legislation and policies currently in place to provide protection and services specifically to disabled individuals. It is due to these groundings that individuals living with IDs receive the type of care needed to live their lives (Turnbull and Stowe, 2001).

The medical grounding of the HCM has provided the basis for Medicare benefits available for individuals with or without IDs. The HCM additionally acts as a driving force for the individuals living with IDs to have autonomy over their medical choices. The purpose of this model's approach to Medicare is to ensure services are available to support people as they live or engage in the dying process to be supported medically (Turnbull and Stowe, 2001). Through this framework, the necessity of treatment of individuals with IDs is sought. These treatment options should be fully exhausted for individuals living with IDs (Turnbull, 2005).

The psychological aspects of this model allow for the supportive environments individuals with IDs live within. This model identifies that behaviors are shaped from learned consequences associated with actions because of the possibility of individuals with IDS to not comprehend how these behaviors affect other members of the community; they require the protection of supported living environments. In the early stages of disability, history this concept was the idea behind institutionalization, and eventually during the 1980's, the idea behind the deinstitutionalization (Turnbull and Stowe, 2001). The psychological support aspect of this model provides the opportunity for individuals with IDs to draw on support not only from their families but also their care giving teams to assist them when planning and participating in the EOL process.

The educational aspects of this model support the nondiscriminatory evaluation of students, initially developed due to people's diagnosis of mental retardation. Through transitions, this model discusses the need for individuals learning and living environments to support individuals with IDs in achieving their most successful and independent lives of which they are capable (Turnbull III and Stowe, 2001). The use of this model applies to the EOL planning by ensuring individuals with ID are able to receive the education needed to make informed health care choices during their lives and deaths. The educational aspects of this model have allowed for individualized plans regarding treatment, living environments and recreational supports of the individuals with IDs.

Methods

As a practitioner, I work with individuals with IDs in supported living environments. My client base varies from those who have very involved families to

those who have no family and are a ward of the state of Minnesota. The work I do is concentrated on supporting these individuals to live their daily lives in the least restrictive setting, working to maintain and in whatever areas possible improve their independence. It is my work with Mary and other individuals that has driven me to study how EOL planning has been conducted in the past, how it is conducted now and what safeguards are available to the people I serve. The research question for this study is what are ethical implications for social workers surrounding EOL planning for individuals with IDs?

Design and Sample

Individuals who chose to participate made up this descriptive case study. The purpose of this type of case study was to understand how the subjects were able to work together to support an individual through the transition from life to death. The goal of research was to uncover the processes which currently exist and identify possible implications for future practice of social workers to assist in supporting those with IDs at EOL (Berg and Lune, 2012). The choice of respondents involved in Mary's life, allows for an examination of her care from the beginning of her medical decline to the end of her life.

The research conducted for this study used qualitative interviews with voluntary respondents. Participants were chosen based on their experience either working Mary or with other individuals with IDs in addition to advocates for individuals with IDs. Four of those asked to participate in this study worked in collaboration with this researcher supporting Mary during her transition from life to death in the summer of 2012. Others interviewed have been chosen because of the dedication to the advocacy with individuals with IDs within Minnesota.

The respondents of the study come from the following backgrounds: case managers, social workers, legal representatives, physicians, disability advocates, policy advocates and members from advocacy groups here in Minnesota. Some of the professionals who participated in this study were previously known to this researcher and made up a purposive or judgment sample due to their expertise in their area of practice (Berg and Lune, 2012). For the purpose of this study, those chosen are affiliated with various organizations in Minnesota.

Protection for Human Subjects

A research proposal was submitted for review by the Institutional Review Board (IRB) of the University of St. Thomas to ensure protection of human subjects. Participation in this study was completely voluntary. Individuals were contacted via telephone and/or email to assess their willingness to participate in the study. As the majority of the respondents were previously known, to this researcher their contact information was attained through previous professional correspondence. In the first attempt to contact the respondents, the proposed study was discussed in detail; it was also made clear that their participation was entirely voluntary. Individuals who chose to participate were also provided with an informed consent form indicating to them that their participation was completely voluntary, and they could terminate their participation at any time (Appendix B). Signed consent forms have been kept by this researcher in a lock box in her home office which is inaccessible by others.

Data Collection

A set of interview questions was developed based on the review of literature on the topic of EOL planning; these questions were used in each interview with respondents.

Content of questions was aimed to elicit specific opinions, professional and personal of respondents regarding EOL planning specific to individuals with IDs. Each of the questions was open ended, designed to invite conversation with the respondents; each of them was written in a non-threatening manner. The interviewees had the ability to decline to answer any of the questions, without penalty (Appendix A for the full list of possible questions). These questions were reviewed by professional members of the disability field, prior to their submission to the IRB. These questions were reviewed to ensure their effectiveness in the interview, and to limit the possible distress by respondents as they revisited experiences of participating in this research. Participants were also provided with information as to where they could attain free counseling services if the interviews elicited distress. All of the questions used were reviewed to ensure credibility and ethical practices when working with human subjects by the IRB.

The qualitative interviews were conducted in settings chosen by respondents, such as the professional's office or coffee shops. These interviews were audio taped for transcription purposes. Transcriptions of these interviews were completed by this researcher. All interviewees were then de-identified and from this point forward were referred to and identified by letters of the alphabet. All copies of these transcripts were kept with the consent forms in a lock box in this writer's home office which is inaccessible by others. Transcriptions were then reviewed by this researcher and coded to identify themes present in responses by participants. This researcher also employed a coding partner to assist with ensuring the validity of themes identified. This partner is a member of the University of St. Thomas, St. Catherine University Master's program student body. The work of the coding partner was to identify consistent themes

throughout the transcriptions and ensure validity in results found previously by this researcher.

Data Analysis

To analyze the data from the interviews, this researcher engaged in open coding. Berg and Lune (2012) proposes that the central purpose of open coding is to inquire widely to ensure that all possible codes have been identified prior to forming any conclusions about the data. A code was identified as a pattern identified in the data in this study, the transcription. This researcher participated in open coding by reviewing the transcript line by line to identify possible codes. Inductive coding was utilized by this researcher and partner to identify themes within these transcripts. According to Berg and Lune (2012), a theme is formed by three or more appearances of a code within the data; the themes allow for the data to be analyzed in a more general tone. For the purpose of this research, themes were identified with the appearance of five or more codes present throughout the transcriptions. Further, each theme is made up of at least two other sub-themes present in the research.

Strengths and Limitations

Limitations of this research include the small sample size. Seven individuals participated in this study; three advocates and four respondents who worked directly in supporting Mary in her end of life. The sample size in this study was limited due to the time sensitive nature of this study, the duration of this study was not to exceed nine months, and needed to run concurrently with the academic calendar. The results of this research are cannot be widely generalized due to the small sample size (Berg and Lune, 2012). Another limitation is the use of a judgment sample for the research design.

Professionals chosen as respondents were previously known to this researcher and therefore made up the judgment sample. This researcher's choice of a judgment sample, could cause for the loss of valuable opinions regarding how this process should occur for other individuals with IDs. This sample may only provide themes specific to the case of Mary, or, due to the varied backgrounds of the disability advocates, cohesive themes may be difficult to identify.

An additional strength of this study is the presence of differing opinions provided by the respondents. The respondents in this study held a wide array of beliefs and viewpoints regarding EOL planning for individuals with IDs, regardless of their status as disability advocates or as professionals involved in Mary's care. However there is a possible limitation, due to the previous relationship between this researcher and respondents involved in Mary's care, they may not have felt as though they could have been critical of other members of the care team, including this researcher. They also may have been hesitant to share direct personal opinions as they may have perceived they would be contrary to that of this researcher.

The research presented here aims to provide a case study of one individual with an ID who engaged in an EOL plan. The purpose of this study was to provide an overview of ethical considerations for social workers, as well as to assist individuals with IDs, their families and care giving teams through the difficult process of EOL planning.

Findings

The findings presented here are the results of seven transcribed interviews conducted with various professionals throughout Minnesota. Four of the respondents were directly involved in the care of Mary. Three of the respondents are disability

advocates currently working in Minnesota. The respondents will be referred to as letters of the alphabet. Respondent A was a case manager who had worked with Mary for numerous years. Respondent B was a health care coordinator for Mary within a large health care system here in Minnesota. Mary was a part of her caseload for four years prior to her death. Respondent C was a registered nurse with whom daily follow up regarding Mary's health status was required and who consulted with Mary's various physicians. Respondent C had known Mary for two years. Lastly, respondent D was a physician of Mary's who had worked closely to monitor her care for the last three years of her life.

The disability advocates are referred to by latter letters of the alphabet.

Respondent X is a disability advocate who has worked for differing adult foster care providers for upwards of 20 years. He continues to have a presence in the field of disability advocacy here in the Twin Cities through various disability organizations.

Respondent Y is a disability advocate who currently works to investigate and advocate for individuals throughout Minnesota who may not be receiving the appropriate level of care to meet their needs. She has worked in the disability field for a number of years and indicated her driving force is to help people who cannot help themselves, while being able to impact public policy. Respondent Z is a disability advocate who currently works with an educational institution in Minnesota, working to advance research and inclusion of individuals living with disabilities. He began his career in direct support and has since worked in the field to advocate for change for individuals with disabilities.

Several themes were identified in the interviews conducted with the respondents.

The themes identified in this study are: the importance of the care team relationship,

individual client needs, communication, and discrimination in access to medical care. Under each of these themes, sub-themes have been identified to support the overall validity of the theme.

The Importance of the Care Team Relationship

As many responsibilities are required by the care team relationships, several smaller sub themes were identified to highlight each of the areas emphasized by the respondents. The sub-themes of this section identified are: Communication within the Care Team, Care Team's duty to Advocate, The Role of Guardians, The Role of the Physician in the EOL Process, Care Team's role as Educator, The Importance of Direct Support Caregivers, Role of the Caregiver in the EOL Planning Process and Risks of Caregiver Involvement in the EOL process.

Relationships are central to human interaction. Individuals with IDs rely on their relationships with their care teams. The care team is often made up of family, professional caregivers, social workers, case managers, physicians, and friends. The job of this care team is to assist individuals with IDs to live with most independence as possible. The care team is made up of various professionals, each having their own tasks and responsibilities. The goal of allowing individuals with IDs to live with the most independence as possible necessitates a wide array of individualized duties to be carried out by each member of care team. Care teams are made up of each of the above-mentioned people, and their role is to assist the individual. Thus, they must get to know the individual well. They must be able to provide support in the choices which are best for and most benefit the individual. Through their contact, and type of support provided, their role is to assist in advocating for the individual.

These caregivers can provide information to paid guardians regarding the individual's wishes. Respondent Z proposed the following, when discussing the need for members of the care teams to be competent and committed to supporting individuals with IDs, in their everyday life, specifically related to EOL planning,

"...but who cares about them and who will all want to help, and obviously competent people, to have a circle of support and that circle of support, if it were me, I would want my family, I don't know why, I would want to have people who were advocates, and people who had their act together and[take] things seriously,"

Communication within the Care Team

Communication is essential when providing daily support to people living with IDs. The interviewees identified the positivity of the communication received from all involved in the case of Mary. From the protocols developed in collaboration from her physicians and nurse at her group home, to the communication regarding her health status, communication was strong and consistent. Each of the interviewees identified the need for communication from all of those involved in care to ensure everyone was up to date on the information and able to advocate in their respective agencies to meet Mary's needs. Respondent C highlighted the communication between Mary's care team when stating,

"there was really good communication between staff her care providers, between her case managers whether that being you or me as a case manager, her guardians, I think the communication was great and there was a dedication to Mary's health and happiness all around."

In the case of Mary, everyone involved was up to date on her medical status, as changes in her health status were being observed they were being communicated to each member of her team. Through communication, all information is shared and those who have decision making power do so based on all of the facts. Respondent A spoke to this process regarding Mary's care,

“Well I think the big thing with her was her inability to communicate, um so we had to rely on the staff observations and interactions that was um really important, they were, they were her family network.”

The communication in this case was highlighted as a positive, even though Mary's ability to communicate was limited. Respondent A also went on to highlight the necessity including the individual if they are able to take part in the planning and decision making process.

“If a person is able to communicate their needs or their desires and if they are able to understand [the process] then yes, I believe they should be able to have some input, but I think it just depends on what level they are at.”

In the case of Mary, she was present for each of her team meetings. Therefore all members of her team were able to interact with her, and as her health status began to decline, it was seen by each of the members of the care team individually. Respondent D indicated,

“Communication with the person who is dying as best you can, communication amongst the providers and collaboration, staff, whoever has any contact with her, knowing her wishes, I mean as best you can, just keeping lines of communication open I think is the biggest[thing].”

In the case of Mary, communication with the physician was constant, through consultation with the nursing staff at her home and direct support caregivers. The physician provided detailed protocols which allowed for staff to make determinations about her medical status more objectively. Respondent D highlighted the necessity of communication with the team,

“It is, that is why I have called legal guardians, or family members across the country to discuss the details, talk to staff, I think you have to talk to, um, if the person is not mentally competent you have to talk to their guardian and determine, because I mean just being honest about it, there is a risk of under treating, so open communication again is key.”

Respondent D elaborated on the necessity of taking an individualized approach to team communication, regardless of who is present in the daily lives of individuals with IDs, the legal representatives must always be included in discussions. She indicated she has even went as far as personally calling legal representatives to get their input and ensure they know what is going on with the individuals they support.

Care Team’s duty to Advocate

Care teams are responsible for managing and ensuring consistency of care, advocacy on behalf of the individual, ensuring legal representatives, receive all information necessary to make informed decisions. If they believe individuals with IDs are not receiving appropriate health care they also must report any concerns to the appropriate authorities. The most prevalent of these ideas was the ideal that those involved in care teams for individuals with disabilities advocate for the individuals with

IDs to ensure they are receiving the most appropriate and necessary treatment.

Respondent A elaborated on this point further,

“I think the biggest thing was the consistency of care and the staff love of her was so obvious and their willingness to provide everything in her care to keep her in her home setting. I mean that was just the biggest thing and also I think too, the fact that the doctor and the clinic were pretty on board with things, so you didn’t have to bring her out all the time, so she didn’t have to be hospitalized all the time.”

Respondent referred to the impact of the caregivers for Mary. The roles her daily support caregivers assumed to ensure she was being well cared for, such as communicating on her behalf to physicians, community members or other team members highlighted their dedication to Mary. Additionally, these support caregivers took on the task of observing her behaviors and interpreting them as best they could to find deviations in her routine, or other indicators which may help medical professionals gain a sense of understanding regarding how she was feeling. Respondent A also referred to the collaboration between caregivers and the physician as a positive aspect of Mary’s care. Respondent A also highlighted her team’s ability to work together to provide individualized care to Mary, indicating specifically their ability to take into account her ability level, throughout all aspects of her care. This was illustrated by the adaptive ways in which they facilitated medical appointments or procedures in which Mary would need assistance, as well as the modifications made to her clip art picture book to help explain things to her in a way which she could understand.

Due to the limitations of individuals with IDs, like Mary, who are unable to advocate for themselves, Respondent A focused on the need for advocacy, “*you need people to advocate for you, because they may not be able to advocate for themselves.*” Additionally, Respondent B reiterated the need for advocacy stating “*everyone involved had a voice, you know except Mary, but again I think people knew her well enough to advocate for her.*” Although Mary had deficits in her ability to communicate, the relationships formed with her caregivers and support team allowed for them to advocate on her behalf while providing support to her in ways which she accepted and appeared to be comfortable with.

Role of Guardians

Guardianship is a position which requires either unpaid people previously known to the person with an ID, or paid professional guardians who assume the decision making role for people with disabilities. Paid guardians can be solely professional guardians, where their job is to provide guardianship services to individuals who are unable to make safe decisions for themselves. Paid guardians can also be county case managers; these individuals often serve dual roles, not only providing case management services, but also acting as legal representatives. Still other individuals with disabilities may have guardians who are family members or close family friends. These guardians take over decision making responsibilities as specified by the court system. All guardianship decisions, whether individuals with IDs can make decisions on their own or if they are in need of a guardian, are made by the court system. Guardianship may cover all decision making capabilities, or be specified to areas of risk for the individual, such as medical care, or financial decision making. Each guardian is acting on behalf of the judicial

system in the state, and in effect, any decisions made by guardians can be overruled by the court system. In Minnesota, this decision making power has recently been challenged by the judicial system; some risks have been identified with the use of professional guardians who are unknown to the individual before they take decision making power, Respondent Y provided support for this concern specifically referring to EOL decisions for people under guardianship,

“And the judge in that case said that really, only a judge should make that decision [regarding EOL planning]. A guardian can weigh in on it, but in other words they were proposing for the court to do the kind of process that DHS does, because there is no process, some guardians just sign off on it [EOL plans], some will talk to their clients, some won’t. So he felt there weren’t enough safe guards, and that the dignity of life, when someone is under guardianship, that guardians can have lots of powers of when they are alive, but they shouldn’t have the power to decide when the person dies.”

Regardless of whether guardians are paid or unpaid, each guardian must submit paperwork to the judicial system indicating the status of the individual with whom they oversee guardianship issues. Delinquent paperwork can result in the guardianship being taken from one person and given to another if the court system believes the best interests of the person with ID are not being met.

Role of the Physician in the EOL Process

Each of the respondents held beliefs surrounding the role of the physician in EOL planning for individuals with IDs. These roles include the necessity of getting to know the individual, understanding their functioning capabilities and assess changes in this

level based on their normal functioning capacity. The role of the physician was also identified as providing information to the individual, their family, guardian, and care team. Respondent X believes the physicians

“role is to listen find out what the person wants make sure they have all of the information they need, or either do what they want us to do or tell them honestly why we can’t.”

Physicians should provide reasoning and rationale as to why or why not their patients’ wishes can or cannot be followed, regardless of the persons functioning ability.

Respondent Z replied with the following when asked about the role of the physician, stating it is to provide, *“Information, lot of information, lots and lots.”* All respondents believed the ultimate role of the physician was to provide information, and ensure the patients understood to the best of their ability what is going on with their health.

Role of Care Team as Educator

An additional duty identified by respondents for the care team is to educate those involved. Not only do the individual themselves need education, but also those who make decisions on their behalf, whether it be family members or professional guardians. It does not matter what role in the care team professionals take, it is essential they provide education based on their background and knowledge base to ensure everyone has a clear picture of the situation and the possible options. The role of informing and educating those involved in the care of the individual was highlighted throughout the interviews.

The deficits which IDs brings to the individual’s functioning are what bring the support team to the person. These deficits are the areas in which individuals with IDs

often require support; it requires a strong dedicated team to provide care and to make decisions which positively affect the individual. Respondent B indicated in the case of Mary, *“I am sure the guardian had a lot of input with this as well, so I guess it is similar in that everyone involved had a voice, you know except Mary, but again I think people knew her well enough to advocate for her.”* Respondent B highlighted that even though Mary, the individual in this case did not have the ability to verbally communicate, her support team consulted together and worked with her to provide care for her. Some of Mary’s caregivers had worked with her for numerous years; one in particular had worked with her for ten plus years. Other caregivers, who were not as seasoned, were trained and learned about Mary, her preferences and routine from more experienced caregivers, in addition to Mary herself. Although Mary had limited communication abilities, she had a way of providing information regarding what she wanted, liked or did not like. Throughout the course of her life, due to the limitations in her communication abilities, Mary developed adaptive behaviors and gestures in which she was able to indicate to those who knew her well how she was feeling and when she felt comfortable. She also utilized her clip art picture book to communicate with her caregivers.

Mary’s limitations are further highlighted by Respondent C

“Her limitations as far as communicating and advocating for herself, and having no, close friends or family to advocate for her, I think it made it that much more important us as caregivers and team members stepped up to the plate.”

Further, individualized planning is a theme touched on by all respondents, specifically Respondent A indicated,

“In Mary’s case you know her making blankets [her preferred activity] and things like that, is what is important to her that’s what she liked to do. Towards the end, she didn’t care if she went out as much, so I guess it’s that to make sure people are understanding, the staff anyhow of what her needs and wishes are.”

It is necessary for care teams and support caregivers who know the individual and understand what is important to them to advocate for the preferences and the decisions that are important to the individuals with IDs.

The majority of people involved in caring for people with ID are paid professionals. Often individuals with IDs lack peer relationships and friendships; the majority of their social interaction is with caregivers or other members of their care giving team. The interviewees highlighted the necessity of the care team to keep their values and beliefs regarding choices made by decision makers, or the individual with ID separate. Respondent A discussed the differing values of individuals and caregivers,

“I think for the staff to understand the process and the steps of dying, we all have different values. [The staff need] to keep that separate and we need to keep to, like in this instance, we need to keep Mary’s needs at the top. Even though we all have different values and different beliefs, you have to think about who it is you are there for and what is best for her.”

The beliefs held by care team members should not interfere with what the wishes and beliefs of those who they are working to support. All interviewees identified that caregiver inclusion in the EOL process should be determined by the family and the client or the legal decision makers.

Conversely, in Mary's case, her care team assumed very involved roles due to the absence of her family. Those interviewed noted several benefits of the caregiver inclusion in this case. Respondent B stated, *"And everyone seemed to know what that was, even though she really couldn't verbalize that herself, people knew what was best."* The respondent highlighted that despite the communication limitations Mary had, her connections to her care giving team allowed them to get to know her. Through building these relationships, Mary trusted the decisions made on her behalf.

Importance of Direct Support Caregivers

People living with ID receive support from a variety of sources. These sources can include family, paid or unpaid caregivers, guardians, case managers, mental health practitioners, and physicians. Daily life for these individuals involves more contact and in many cases more reliance on others. Caregivers who assist individuals with IDs with daily life are referred to as direct support caregivers. Each of these groups of people is essential to help communicate and provide a continuum of care for people with IDs. Generally direct support caregivers are not included in the decision making processes for individuals with IDs. In the case of Mary, no direct support caregivers had decision making abilities, however, each of them was able to discuss opinions or beliefs about her care with his or her individual supervisor. Many of these concerns or observations regarding quality of life or care were then discussed by the decision making team, and in some cases, impacted the decisions made.

When respondents were asked if caregivers should be included in the decision making process for individuals with IDs, Respondent Y provided the following suggestion,

“There is a whole lot more to communication than words, and so from there obviously there are legal or medical decision makers. But I really think it has to be to the largest extent we can do it, the people who have been around that person, surrounded them, supported them, sometimes it is just really good staff, in conjunction with the family.”

Respondent Z, provided the following rationale regarding caregiver inclusion in the EOL planning process, *Caregivers again that is a sacred bond, it is the day to day, no matter what, that is important,*” when discussing the level of trust individuals with IDs place in their caregivers, pointing to his belief, caregivers should be included in the EOL planning process. To many individuals with limited peer relationships, caregivers often become regarded as members of their family. In the case of Mary, her care team became her family.

Role of the Caregiver in the EOL Planning Process

Respondents highlighted an important role clarification for the inclusion of caregivers in the EOL process. They believe caregivers should be included in the process with respect to how well they know the individual. However to limit their ability to make decisions, highlighting decisions should be made by the family or legal representative regarding the EOL process. Respondent Y stated,

“So when you are talking about a caregiver their input should be limited to their knowledge about the client, and contributing advice and observations but I don’t think they should have the legal ability to do it at all.”

Further,

“Then I think, you know, there is a difference between participating in decision making and the legal decision making. So yes I believe they have a role, but we have to be sure that it isn’t someone who has a conflict of interest.”

This approach would include those who the individual feels is important, and allow those put in the decision making position to decide what is best for the individual.

Caregiver inclusion in the EOL planning process was discussed with respondents, Respondent B stated,

“I do think they should be included and have input, because there with her all the time, with the person and know the level of comfort or discomfort, pain, also their disruption of their quality of life.”

Just as in the case of Mary, this respondent highlighted the relationship between the individuals and care teams, those who support the individual on a personal daily basis understand their perception of quality of life better than other more distant members of the team.

“She did have so much support, and people knew her so well. I mean I don’t, I never got the idea that anybody didn’t, wasn’t very attached to this woman, and they were very committed, so in this case it was very much a positive.”

Respondent B also discussed the level of interconnectedness and the relationship between Mary and her care team as further evidence in their role in the planning and decision making process on behalf of Mary.

Risks of Direct Support Caregiver Involvement in the EOL process

Respondent Z identified the following risk of caregiver inclusion *“Someone inappropriately information sharing, telling the person,”* following with his

recommendation of making the boundaries of the caregiver and decision making person known to limit this risk. Respondent X highlighted the risk of caregivers' beliefs and perceptions of how the death and dying process should go could cloud their judgment. He identified the necessity of the focus being on the individual, *"But I think the most important thing to remember is that this is about them, it is not about you, that is what I think is crucial."* Respondents highlighted how the importance of including who the individual feels is important. Respondent Z went on to say, *"you need to really look at who people are close to and who people care."* Respondent Z is indicating it is important to provide an individualized approach to EOL planning, highlighting the importance of including people who the individual with ID feels are important.

Attention should be paid to ensure the caregivers in the situation are making decisions and acting in the best interest of the individual. Respondents commented on the understanding that not all caregivers are good, and not all decisions made by some on behalf of individuals are in their best interest. *"Yeah if there is any concern by the client or any person who deals with the caregiver that should be looked at, and they should be involved,"* Respondent D further identifies this risk as *"why I say it needs to be on an individual basis."* Additional respondents highlight similar themes of ensuring those making decisions are doing so in the best interest of the individual. Specifically, Respondent B stated

"Because of the more limited understanding [of the individual], I guess that points to the need for really strong advocacy, like Mary received. Yeah it seems like [the level of care individuals with IDs receive] could be less, which is kind of disturbing, quite disturbing."

As professionals it is our job to ensure we are advocating ensuring individuals with IDs are receiving the same level of care, as people without disabilities receive.

Role of Hospice in the EOL Process

Hospice providers were discussed by each of the respondents regarding a type of provider who would be skilled when working with this population. Their role is providing a person-centered approach to the death and dying process and ensuring comfort at the last stage of life. Respondent X highlighted the role of hospice as an additional support to caregivers. Regarding the new different role caregivers are assuming with the initiation of hospice

“As opposed to their role [caregivers’ role] has always been to keep people safe and healthy and now their role is to help people die, so that is a big transition for people. And then to have the right people working there so they can deal with that.”

Respondent X also highlighted the skills of the hospice team to assure, the individuals’ needs are first and foremost.

“I think professional hospice people are really comfortable with that, they are so focused on the person, and we are really good at it. Most of us are really good at it most of the time, until we get into a subject like this, and then sometimes it is really hard to keep focused on them.”

Hospice providers offer a support during EOL not only to the patients, but also as a resource for direct support and care team members to ensure the best possible care is available for individuals as they engage in the dying process.

Individualized Client Considerations

Each of the respondents discussed the necessity of modifying EOL planning to each individual. They each highlighted that, first and foremost, the process is for the individual and for no one else. Ideally, the individual should always be consulted and included when making plans regarding his or her future, his or her health, and his or her life regardless of their ability level. However, this is often not practical. At times, the information regarding an individual's health status or prognosis may overwhelm the individual, increasing symptoms or decreasing their quality of life. As in the case of Mary, she was unable to directly communicate her wishes; the information she shared non-verbally and non-traditionally was used by her care giving team to make decisions on her behalf. In other cases, loved ones of individuals with IDs may feel they cannot handle the prognosis, or they will not comply with the treatment which they need; therefore, these options may not be sought out for them. As each individual is different, it brings the ethical considerations of EOL planning, and from this, the question remains how do we ensure the rights and participation of individuals with IDs in all aspects of their end of life planning?

As each of the respondents indicated, individualized considerations are necessary when engaging in the EOL planning process. However, they provided mixed responses of when and how to draw the line regarding what information should be shared with individuals with IDs. Each respondent believed ability level of the individual is an important factor to consider when determining the need for, type and frequency of support from the care team. When asked who should be included in EOL planning for people with IDs, Respondent Y replied "*The person themselves, first and foremost.*" Respondent X replied similarly,

“Well first and foremost he person themselves as much as they can. I think very often even people with you know, very severe cognitive disabilities can help you with the planning.”

Individuals with ID should not be eliminated from the planning simply because they are living with disabilities.

Inclusion of the individual in the discussion regarding their medical care, in addition to inclusion into society on a daily level was also discussed by each of the advocates as a characteristic of necessity for those living with ID. It is also important for professionals to understand that even with a disability; these individuals have the same right to self-determination as people without disabilities. Even if their abilities to communicate is not traditional, their actions, movements, facial expressions and the noises expressed, indicate preferences, and likes or dislikes, and should be taken seriously by those supporting them. Respondent Y stated, *“We believe people with disabilities deserve to have the same rights to decide to withhold or the same rights to say I want all measures done to keep me alive.”* The question remains, how can we as professionals provide these rights?

Respondent D discussed the necessity of an individualized approach regarding when and what type of information sharing should occur for individuals with IDs.

Regarding prognosis and treatment,

“It’s hard, because um traditionally we say if you have a prognosis of 6 months or less, hospice should be involved. I think it depends on the person again, I have

a patient who, has low IQ and she has lung cancer, but there is a decision made that we are not telling her that she has lung cancer”... it would just make it very difficult for her because of her anxiety, that is why I say it needs to be on an individual basis, all of the providers are all in tuned, we are all following the same thing and we are not being as aggressive with her, but we are involving decision makers to determine do we want to know how it is progressing for prognostic purposes.”

The question of when to initiate the planning discussion sparked a few differing responses; however, the central point was it depends on the individual. Regardless of disability or ability level in different areas, each respondent highlighted it is essential to include the individual in the process. If they are capable, this should be started at a young age; if they are unable at a young age, it should be discussed with them when a condition presents itself; indicating death is near for them. Respondent Z highlighted the necessity of normalizing death, as part of the life process, by including individuals in the death process of others in their lives as it happens, *“make sure when other people die, like family members or roommates they are made aware and are involved.”* Regardless of the individual’s ability level, his or her inclusion when they have a prognosis of a terminal illness is necessary. *“I mean for sure when um anybody has any kind of diagnosis, in anyway at any time of life that is life threatening, then right away, right away, with no question.”* Individuals with IDs have the right to take part in discussions or know about their illness when it could possibly end their lives.

Discrimination in Access to Medical Care and EOL Planning

Intellectual disabilities bring a lot of challenges and concerns to daily functioning, as presented here previously. By definition, part of the individuals intellectual functioning or cognitive functioning is impaired. Due to this impairment, at times they are not able to understand as much as their non-disabled counterparts. Each of the respondents, regardless of their backgrounds as advocates or disability professionals, highlighted the risk of less medical treatment being sought after, understood and provided for individuals with disabilities. More specifically, individuals with IDs are more likely to have physicians make decisions to rule out medical treatments due to their status of being disabled, and in some cases, the diagnosis of a disability can completely eliminate someone's ability to receive a particular treatment.

Differing reasoning and rationale was provided by each advocate; however, the consistent theme presented was the risk is there. Respondent X discussed this risk further stating, *"I think it is still pretty rampant that you get physicians who don't see any reason in spending a lot of treatment resources on someone with DD's I just think that happens all of the time."* Respondent Y discussed communication deficits of some individuals with ID which can limit their ability to participate in their own medical care in a traditional way.

"If you don't present the information to them in the way they are used to hearing it, then they don't understand what you are saying, and they don't question, they just say what are you saying, what are you saying, well we don't have that here, instead of asking you know."

Respondent Y referred to the importance of individualized attention provided to each person with an ID from their providers. This respondent referred to how individuals communicate, and how the provider communicates with them as well. To support individuals with IDs caregivers need to use specific words, phrases, or ways of asking the questions to ensure they are understood. And ways in which we can be sure these individuals can respond, rather than making assumptions regarding care.

Currently, there are no legal requirements stating individuals with disabilities must receive the same preventative medical care, such as screenings, or annual exams, which are part of routine health care for people without disabilities. Respondent Y speaks to this when she states,

“And there were no laws or rules around people with disabilities getting the same annual routine tests we recommend for everybody, mammograms, which is changing now; I mean the science available at the time, annual exams, prostate exams, etc. And again by the time somebody really figures out what is going on they have a disease that is terminal because no one did it. No one was in charge of doing that and therefore it was when we asked providers about that they say, it is not required, but it would be the right thing to do, or couldn’t you at least call the case manager and say at least we think they need X.”

Individuals with disabilities may not be provided with the information or knowledge of tests or treatments; therefore, it is the responsibility of those working to support them to advocate and ensure that the same access to health care is being received as for those without disabilities. The risks of limited care being provided do not fall completely on

physicians. Respondent Y referenced a care facility, which did not seek consultation from a qualified health professional, charted a person through the dying process, rather than seeking additional information or treatment on the individual's behalf.

“We had another very sad one where a person said well you need to observe him, he is not feeling well and did a perfect charting, but because the person doing the charting was a non-clinical, non-medical professional, she perfectly charted the dying process. We could see every step where if we could have intervened here we might have saved him and turned the course of the case.”

The facility responsible for the health care management of this individual with ID did not seek consultation or assistance from medical professionals, and due to their negligence, this individual died. Caregivers, regardless of their decision making abilities, need to be required and provided with appropriate resources to ensure the health and well-being of those they work to support.

The risk of individuals with IDs receiving substandard, or in some cases, no medical treatment for preventable or treatable illnesses is present. Due to this, the need for advocacy is great, not only by the individuals with IDs who are able, but is also essential from members of their care teams. Some respondents provide the ideal of a “checks and balances” system to ensure those in need receive the care. Others point to advocacy; however, the consistent theme is the necessity of those in positions of power to understand and pursue the care needed do so.

If someone is not receiving the level of care which is needed it then becomes the responsibility of caretakers, advocates, case managers, families and the individual themselves is to report the maltreatment to the authorities. Respondent Y alluded to other cases in which *“We have seen people who have needed lifesaving surgeries and the doctor wouldn’t do it because they were disabled.”* If unchallenged these perceptions can lead to providers making treatment decisions solely based on disabilities, *“[We looked at] his records and they said he was dying of mental retardation. We said that is not a terminal illness.”* When referencing individuals with disabilities, Respondent Z stated

“People are less likely to question someone and something, so that is a huge huge huge huge [problem], people want to make people happy, and aren’t always aware and don’t know something is available.”

People with disabilities need to have strong advocacy to ensure their rights are being protected and equal access to medical care is being provided. Respondents in this study also indicated the need for training for support people so they are able to protect themselves, and uphold the rights of the individuals with ID. Respondent Y specifically pointed to this.

“Otherwise they [direct support caregivers] can be held accountable for neglecting or abusing the rights of the person who is there. You know, I would think that to protect their own legal liability whether the corporation or the individual staff member, too often we see abuse and neglect blamed upon the individual caregiver, when the corporate facility never trained them, never told them what to do.”

Direct support caregivers need training to know what they can and cannot do when supporting individuals with ID, and with whom they can and cannot share information with.

Respondent Z discussed the difficult task of support people when caring for individuals with ID as they age, get sick and eventually die, stating,

“Or and a sense of if a person lives with ID, one when a person with ID reaches end of life, there should either be a ton of support and training for direct support people. Because their roles are going to get a whole lot more complicated, and a whole new sphere of providing additional support.”

This respondent highlighted the necessity of training to prepare support staff not only to help the individual as they become more incapacitated, but also to prepare the support staff for what will happen. This respondent specifically highlighted the need for training and support, as these situations will become difficult for all those involved.

The respondents in this study come from differing educational backgrounds however each of them identified similar themes in regards to the EOL process for individuals with ID. Each of the themes presented here highlight the necessity of inclusion for individuals with IDs. Each respondent also highlighted the necessity of communicating with and on behalf of the individuals with IDs who are unable to do so independently. The necessity of providing individualized approaches to EOL planning was essential to ensuring their rights were being upheld, and self-determination respected.

Discussion

Individuals with intellectual disabilities are classified as vulnerable adults due to their limited cognitive abilities, and these individuals are more likely to be mistreated by others. Minnesota Statute 626.557, reporting maltreatment of vulnerable adults, provides legislative mandates to professionals in regards to the protection of individuals with IDs. The purpose of this Statute is to provide legal protection for these individuals and to ensure concerns regarding their treatment be reported and investigated. Individuals with IDs status as vulnerable adults, places them at a higher risk of maltreatment throughout their lives and deaths (<https://www.revisor.leg.state.mn.us/statutes/?id=626.557>).

Respondents in this study identified themes surrounding the likelihood of maltreatment for individuals with IDs, specifically regarding EOL planning. Each had their own beliefs regarding what should be required to be reported. They also held differing beliefs about which aspects of the system they believe work, and potential risks regarding EOL planning. However each respondent believes it is necessary in EOL planning for people with IDs to be individualized and person centered. Each respondent also noted the presence of risks of treatment, of limited treatment, and risks of who to include are present in the daily lives of individuals with IDs. Due to all of these factors individuals with IDs require those involved in their lives advocate to ensure they receive the best and most comprehensive care.

Ethics and Social Justice

“The greatest human freedom is to live and die, according to one's own desires and beliefs. From advance directives to physician-assisted dying, death with dignity is a

movement to provide options for the dying to control their own end-of-life care,” (Death with Dignity National Center, 2012). EOL planning can be a difficult and personal process. For individuals living with ID it may be the most important process of their lives, it could be one decision making process which they have the ability to make choices, without being influenced by those supporting them. All too often, individuals with IDs are left out decision making process or not provided with information to make informed decisions based on other people’s perceptions of what they can or cannot handle. Their ability to participate in EOL planning is an opportunity to ensure their personal wishes are carried out as they age and ultimately, die. Without professionals working to advocate and inform people of their rights, many more people will die without their knowledge of their rights and the choices.

Self-Determination

The ethics of EOL care and planning are present regardless of the professional association or framework you ascribe to. The ethical concerns and considerations for those with IDs are the responsibility of all involved. It is the responsibility of the care team to ensure the rights of the individuals are being upheld and appropriate advocacy is being carried out. The National Association of Social Workers is concerned with the ethical practices of social workers throughout all avenues of practice. Just as much scrutiny should be exercised as social workers they assist in individuals with IDs in EOL planning; the guiding principle of self-determination supersedes the charge to do no harm (King 2005, Kingsbury 2005, Mackelprang and Mackelprang 2005). Self-determination, as defined by the NASW Code of Ethics (2008), proposes social workers assist clients in

their ability to identify and clarify their goals. Self-determination for individuals with IDs will not fully exist until the conversation can be held at a wider capacity. It is essential to ensure every person and provider knows and understands what disabilities are. Further, this understanding must encompass the benefits of proper support for individuals with IDs. This can be attained, through educating professionals and caregivers, to increase their understanding and how to modify their practice to better serve individuals with IDs. As Seymour and colleagues (2003), as well as Fagerlin and colleagues (2002), highlight, EOL planning provides the opportunity for the patient to have choices and autonomy, and ultimately provide the right for their self-determination.

As individuals with IDs by definition have limitations in their cognition, it then becomes the ethical responsibility of the providers, caregivers, case managers and other important members of their lives to act in their best interest. This is a difficult task to handle; however, the research presented here highlights the importance of including all people who support the individual in any aspects of their lives and the individual in the decision making process. Luptak (2004) notes, EOL planning requires competent people to make choices regarding medical treatments, or a competent proxy, if the patient is incapacitated, as is often the case with individuals with ID. Additionally, many respondents discussed the necessity of talking about the process on an ongoing basis to gain an understanding of the wishes of the individual. A study by Mahon (2011) supports this approach, indicating respect for the individual is the main rationale in the EOL planning process. Without this approach, valuable information regarding quality of life, or personal preferences, may be missed which could result in the individual not being heard and their wishes not being carried out.

Each person has the right to determine what care to receive and what care to refuse; each person has the right to self-determination. Individuals with IDs have the identical rights as their non-disabled peers. The interviewees highlighted the necessity of an individualized approach to EOL planning, as was done in the case of Mary. The respondents believed in order to best provide care for these individuals, their cognitive ability level should be fully understood. Each of the respondents also voiced their beliefs of including the person in the EOL planning regardless of their ability level. Luptak (2004) indicates that the role of social workers is to promote quality of care, and respectful treatment during the EOL planning process while working to assure the dignity of the person. Social Workers must advocate to ensure the ability of individuals with IDs to participate in his or her own decision making process is upheld.

The most important person involved in the EOL planning process is the person who is dying, or making decisions surrounding his or her end of life plan. Each respondent indicated the needs of the individual as most important. Caregiver knowledge of these needs was highlighted in the case of Mary due to her limited communication abilities. Mahon (2011) believes through engaging in EOL planning decisions, patients can provide preferences regarding their wishes. Without caregivers who understand the patient and have relationships from which they will be able to elicit these preferences, in the case of individuals with ID, valuable information could be lost. Further, each respondent in this study indicated the importance of the relationship between the caregiver and the individual. Respondents indicated the necessity of caregivers and care teams providing information regarding the preferences, normal functioning level, values and beliefs of the individuals with IDs when engaging in EOL planning.

Advocacy

Without direct advocacy for individuals with IDs, lack of information, lack of treatment options, and lack of education will continue. It is the job of social workers, physicians, nurses, care coordinators and direct support caregivers to work to uphold the rights of individuals living with IDs. As professionals, we must work together to challenge how things are being done. It is our responsibility to stand up for and with individuals who are currently not receiving the most accurate or appropriate medical care. As social workers we may have to challenge other professionals when we do not agree with their course of treatment. Without the strong advocacy work from those supporting individuals with IDs, no forward motion will occur. Until our system does a better job educating and providing resources to these individuals in reference to preventative care models which mandate screenings, or insurance benefits which allow for more time spent with physicians to gain an understanding of a prognosis, we will still be failing these individuals. It is our job as social workers to advocate and make these changes.

All too often we work to support individuals with IDs to live a life in the least restrictive setting, or to help them become compliant. If we do not change the system and if we do not provide better care, why should we expect these individuals time and time again to change for us? Physicians and health care staff should be required to learn about people with disabilities and how their ability to function independently is affected, rather than the system constantly encouraging these individuals to be more “normal.” The system needs to become unified, we need to develop requirements of care, and individuals with IDs need to receive the same level of care no matter which doctor or

hospital they go to. The responsibility of comparative care is not that of the individual; it is that of the system, and as social workers, it is our responsibility to advocate for the necessary changes.

Discrimination in Access to Medical Care and EOL Planning

Discrimination and unequal access to medical care and EOL planning are barriers faced daily by individuals who live with ID. Each of the respondents in this study eluded to the possibility of under or over treatment of individuals with IDs. Specific case examples from each of their individual working environments were described, and most often the common theme was medical treatment not being provided to individuals with IDs based on presumptions of his or her care team. As identified in studies by W van Theil *et al.* (1997) and Wagemans *et al.* (2010) in the Netherlands, patient's families were consulted, but the actual patient was often not. Without the individuals with IDs families input, the decisions made by medical providers often ended treatment and hastened death. The stark findings here indicate it should be the duty of the social workers involved to ensure all avenues desired by the patients are pursued.

Without social workers advocating patients with ID could die prematurely or develop a more significant diagnosis due to lack of preventative care. To prevent further maltreatments, disability focused training should be required for social workers, physicians, nurses and other medical professionals. This training would assist professionals in their ability to not only become comfortable, but competent in providing services to members of the community who are disabled. Just as cultural competency is a mandate in the NASW Code of Ethics, the necessity to become competent in the field of

IDs is crucial in the support of people throughout their lifespans. This topic has not yet been heavily researched; therefore it is an additional recommendation further research in the area is conducted by social workers specifically to measure the level of competency of professionals working with individuals diagnosed with ID.

It is necessary in the pursuit of social justice, for social workers to work in cooperation with other providers, individuals with IDs and medical professionals to advocate on a larger level. Together we must advocate to pass legislation which ensures proper preventative care is required. This legislation would require the same standard of preventative care for all. Placing the responsibility of ensuring this care is provided on organizations or people who provide care to individuals with IDs. The responsibility assumed in providing care is to ensure adherence to the standards, and despite the difficulties. Legislation in regards to disability rights is still very much in its infancy, proving there is much more work to be done. As social workers, we must continue to challenge the system and status quo, to ensure these individuals are not continuing to live within a system, set up to protect them from things which they do not need protection. We must work together to ensure the rights of these individuals are upheld, and if systems currently in place are hindering them, we must change the system in its entirety.

Individual Client Needs

Individualized client needs were discussed by each of the respondents. This researcher agrees with Kingsbury (2005); a person centered approach would be the most fitting to ensure individualized client considerations, needs and preferences are being addressed by those involved in the care team. It is essential to use the person centered

approach to ensure individuals with ID, are able to ask questions and indicate they are unsure of what the process is, or what is going on around them. It is a recommendation of this writer that a person centered focus and the strengths based perspective is used in work with individuals with ID when discussing and engaging in EOL planning. As indicated by respondents, individuals even with very limited cognitive abilities are still able to provide information regarding their wishes and should be consulted in all stages of EOL planning. The use of the strengths based perspective when engaging in this type of work will allow for individuals to see his or her role, and the important aspects of their skills present throughout the process (Kingsbury 2005; Turnbull 2005).

Importance of the Care Team Relationship

Many aspects of the importance of the care team relationship were indicated by the findings. Consistently, respondents indicated the necessity of care team individuals to get to know the individual with ID, to understand what normal behavior is for them, and to understand their normal functioning level. I propose the Family Covenant model (Doukas and Hardwig, 2003) be modified for individuals with IDs. The modifications I recommended would be similar to the approach taken by Mary's team. It would require each member of the care team to have open dialogue with the individual to ensure all members of the care team are on the same page and working within the same parameters. Additionally, through the use of this model, there would be a built in "checks and balances" system of having other professionals who are able to, and called to report any maltreatment of the individuals with ID, in regards to treatments offered or not offered (Doukas and Hardwig 2003).

The main purpose of the Family Covenant model, by Doukas and Hardwig (2003), is to allow for a respectful arena for each of the involved parties to voice their opinions, for the patient to express their values and beliefs, and for everyone to be on the same page of how to handle the EOL process. The use of this process would serve as an anticipatory, to allow the individual to know all the risk and expected benefits of treatment options. The ability of these discussions to occur surrounded by members of the care team the individuals trust, and in an atmosphere which they feel comfortable would be an additional benefit. The ultimate decision would fall on the guardian or the individual themselves with ID, if they are their own guardian, but the decisions made would be done by knowing all of the facts available at the time of the consultation. The case example of Mary provided aspects of this model for review by respondents in this study. Each of the invested parties had his or her own voice and expressed their beliefs and concerns regarding care. Ultimately, her guardian made the final decisions, but these decisions were made upon all of the findings and facts provided by all individuals involved in her care team.

By utilizing a modification of the Family Covenant model, social workers would be able to work in a team, to assist other members with the EOL planning process, while ensuring other needs are met. Additionally, identification of individuals struggling with the anticipated grief and loss, or the individual themselves could be served by clinical social workers involvement in their covenant. In a modified approach to this model, individuals could speak freely regarding health status, and as continued concerns or issues present, prior to decisions being made. This would also allow for the team to

present as a united front. All decisions would be made in conjunction with the individual with an ID.

For a modification of the Doukas and Hardwig's (2003) Family Covenant model to work with individuals who have ID, it is essential to get the entire team on board. There are difficulties and limitations to modifying this model. Some of these difficulties would be to consider how billing and scheduling of all care giving team members would occur. The amount of time participating and implementing this model would also be a difficulty to consider, due to the large caseloads of professionals and social workers. Implementing this model would be difficult and expensive. However, the moral and ethical benefits for each individual would outweigh the fiscal disadvantages. The direct consultation and communication as recommended by this model would allow for all possible disagreements or differing opinions to be voiced at the same time. Thus allowing each person involved to have an opportunity to be heard.

Modifications of this the Family Covenant model by Doukas and Hardwig (2003) would allow for a person centered, team inclusive approach to EOL planning. This approach would allow for the individuals, most important to the person with an ID, to be present, and have full access to information. This model would take into account family of choice participants at the discretion of the individual. If they wanted direct support caregivers included, this environment would allow for their inclusion. At times, some of the most important people in our lives are not blood related, and therefore, the right of the individual to choose who to include would be an additional modification suggested to this model for individuals with IDs. Legal decision making power would still fall upon the

guardian; however, with the assistance of the covenant model, these decisions would be made with group input. Modifying this approach would also allow for a larger support network to be accessible by the individual themselves.

Mahon (2011) and Seymour and colleagues (2003), similarly identify the necessity of surrogates, families and physicians to understand and respect the individual's choices while protecting the patients' autonomy. Although no specific adaptations of the Family Covenant model (Doukas and Hardwig, 2003) have been made, its use could address some ethical considerations for individuals with IDs. For example, if physicians include opinions of loved ones and caregivers in medical recommendations for individuals with IDs, it is hypothesized that the care provided would then be more comprehensive and more in line with the wishes of the individual with an ID. Additionally, through the inclusion of these members of the individual's life, as disagreements regarding treatment choices arise, there would be an opportunity to ensure the rights of the individual with a disability are not being violated.

Communication

Communication was present in each aspect of respondent's beliefs and values surrounding EOL planning for individuals with IDs regardless of their background. Each of the respondents regarded the need for open communication and advocacy for the individuals with ID during EOL planning. Some respondents even touched on the necessity of using communication to ensure individuals with IDs are receiving the same level of medical care as their non-disabled counterparts. This is similar to the view that Seymour and colleagues (2003) presented when discussing the necessity of ongoing

discussions to review plans and ensure each member of the care team has an understanding of the current situation. These care giving teams are a good way to bring all experts together to ensure all information is shared and utilized to make informed decisions. This study highlights the important of the care giving team each doing their respective roles, and having clear communication throughout the process of EOL planning.

The necessity of open communication between the individual, their care team and physicians is rooted in a successful EOL planning process. In the case of Mary, each respondent believed the communication was a successful aspect of her EOL plan. The role taken by this researcher in the care of Mary was to facilitate meetings and continuously keep communication lines open. This, at times, was difficult due to Mary's limited communication abilities. However, the ease and frequency with which I was able to discuss changes in her health status with each member of the team was unlike any other case I have experienced. As her condition worsened, it was the open lines of communication that allowed for members of her team to not only prepare themselves for her death, but to support her as the time came near.

Every member of her care team, from direct support caregivers, her nurses, physicians, case managers and so on, was aware she was not doing well. Each person had the opportunity to do what was needed of him or her to ensure her last few days were comfortable and each need of hers met. Without the planning and continued communication taking place, her transition from life to death would not have gone as well as it did. What was done in the case of Mary is very similar to the modifications of

the Family Covenant model I am proposing. Without the input and information received at all levels of care, needs of Mary's may have gone unmet, and her death process could have been filled with anxiety and fear. Therefore the modifications proposed here would allow for other individuals with IDs to receive the same level of comprehensive care and thus have full participation in their EOL planning process.

Implications for Social Work Practice

Individuals with IDs often rely on the support of others to live their daily lives. These support individuals often require training for each of the people they assist. Depending on the type of services provided, the amount, type and level of trainings required differ. Training was not identified as a theme in this study due to the limited number of times it appeared in the transcriptions. However, each of the respondents who participated in this study indicated an additional level of training should be required for practitioners and caregivers regarding disabilities and EOL planning. Without specialized training regarding IDs, practitioners and caregivers will not be as effective when working with the individuals and their teams.

Training should be a requirement of all people who work to support individuals with IDs. Whether they are direct support staff, case managers, care coordinators, registered nurses, or physicians, at each level of care, individuals with IDs are encountered in practice. Unless professionals are able to modify their practice to ensure individuals with IDs understand what is going on, or are able to communicate with the people who support these individuals, vital information regarding care will be lost. It is a necessity for all involved in the care of these individuals to work to understand the

disabilities, specifically to each person served, to ensure appropriate steps are being taken and care received. Until training regarding disabilities becomes a requirement across disciplines providing care, individuals with IDs will not receive the same level of care as those without disabilities.

Social workers, physicians, registered nurses, and direct support caregivers each have annual training requirements based on their discipline. Educational opportunities surrounding IDs should be available and a percentage of continuing education requirements should include disability education. Curriculums emphasizing how the disability affects the individual, ways to modify practice, and information on differing types of supports available to individuals with IDs should be required. These educational opportunities will not only allow for practitioners to gain a better understanding of the disability as a whole, but will also allow for them to have more insight into the daily lives of their clientele. With these educational opportunities, individuals with IDs may be more comfortable in seeking assistance from providers due to the general sense of knowledge they possess.

Social workers must advocate for changes to individual organization on a community level, and on the macro level to require training in the field of disability education for all professionals. Without specific training, the ability of practitioners to act ethically is severely limited. Social workers must too receive specialized training in regard to disabled individuals in order to continuously advocate for changes on their behalf. Through consultation with disability advocates, and members of the disabled

population, a more detailed curriculum should be developed and implemented in trainings to differing professions.

Recommendations

Caregivers may be family members, paid or unpaid support people who assist individuals in their daily lives. Despite their roles in providing support and assistance in the daily lives of people with ID, their roles in EOL planning is to provide information, rather than make decisions. Caregivers who get to know the individual, often times better than others, are an important link in assuring the best interest of the individual is upheld. Additionally, they will be the most likely to attest to the wishes, needs, beliefs and quality of life issues as they are important to the individual. However, it is important to specify the type of caregiver; if caregivers are transient, or working for their own wishes, or companies' issues rather than those of the individual, this poses a risk. To ensure this, the necessity of reporting concerns to the appropriate state agencies is once again indicated. The use of the Family Covenant model would allow for the assurance that those involved in decision making and care are invested and working in cooperation for the best interest of the individual with ID. Through the use of this framework, the risks could be decreased, and the best interest in the EOL process of the individual will be served by those involved.

Policy Recommendations

Legislation should be enacted to ensure the same measure of access to healthcare offered to people without disabilities are offered to those with IDs. Preventative

screening, tests, and educational information should be provided to patients regardless of their status as having a disability. It is the responsibility of social workers and legislators to ensure further neglect does not occur by increasing the access to these services for individuals with IDs. Physicians, social workers, and caregivers should be held to the same standard of ensuring all types of medical care are accessible to every person with IDs.

Recommendations for Social Workers

The need for advocacy is great within the field of social work. The need for advocacy for individuals with IDs is constant. We, as social workers, must continue to strive to support these individuals while ensuring their rights are being upheld. It is our responsibility as social workers to collaborate and work to challenge the system in place today. As social workers we need to advocate not only for the lives of each individual client, but also for their participation in processes or decisions that affect them.

Strengths and Limitations

A strength of this research was the ability to obtain four respondents involved directly in Mary's care for the last few years of her life. Those respondents were case managers, care coordinators, a residential registered nurse, and Mary's physician. Through the diverse backgrounds and cooperation during the care of Mary, these individuals were able to speak to the process as it went for Mary, and to share to their opinions and beliefs as to what they would recommended for other individuals with IDs.

An additional strength of this research was the ability to obtain three disability advocates from varying backgrounds. One respondent works for a large organization doing direct advocacy work, on the micro, mezzo and macro level. Another respondent works to advocate and further educate people on disability issues and inclusion in Minnesota. The last respondent has worked as a direct care staff since his early twenties, and now currently sits on a major disability advocacy board in Minnesota. Through the varied backgrounds of these respondents, a wide array of experiences and personal beliefs were elicited. Additionally, each of these respondents provided this researcher with information on current issues in the disability population.

The major limitation of this study is the sample size. Due to the time sensitive nature of this study, this researcher only had seven respondents willing to do interviews. The small response number is directly related to the time sensitivity, due to this researcher's inability to recruit for members, based on the necessity of the study's timeline.

Further Research

It is essential to continue to study the process of EOL planning for adults with ID's to ensure that the rights and freedoms afforded to all people are being upheld. With further research it will be possible for social workers and legislators to create the safeguards necessary to ensure the wishes are truly that of the dying individual, rather than some other stakeholder.

It is also recommended further research be conducted using the modifications to the Family Covenant model suggested here. It would be beneficial to research these modifications comparing individuals with families to those without and to see the strengths and limitations of having non legal decision makers included in the process.

It is the belief of this researcher that further research would benefit this area of study. Due to the time sensitive nature of this study, the pool of respondents was small. Conducting this study again with a larger amount of time to solicit respondents in addition to being able to reach a wider array of respondents would allow for differing opinions and the possibility of more validity to the themes identified to occur. It is also recommended a study similar to this be conducted by directly interviewing individuals who have ID. Without their input and knowledge, critical aspects of implications are missed. Additionally, as the research presented eluded to, it is important to include them in their own EOL plan while providing them with a voice to assist others in similar situations in the future.

Conclusion

Individualized, ethical, well informed, inclusive conversations with individuals with IDs and their care giving teams regarding EOL planning should occur throughout one's lifespan. Without social workers, and other professionals working in consultation to ensure the best wishes of the individual are being sought and met throughout the EOL process, individuals will face discrimination, and possibly live or die in ways which are against their wishes.

Just as this researcher has pushed for individuals to be included in their EOL planning processes, it is also a recommendation that these individuals also be consulted for their beliefs and thoughts regarding the process to the ability level they are able. As much as we believe we can make informed decisions around how we as professionals believe things should go, without the personal input from individuals with ID, we will be missing a large amount of information. Finally, this researcher believes consultations with individuals with IDs should be conducted with the individuals themselves to ascertain why they chose particular EOL plans and how they felt the experience was, if they felt they were receiving all necessary information and if they felt they had a voice in the planning. Not until the voice of individuals with ID is heard on the matter, can we truly say we are taking all aspects into account.

References

- Allen, E., V. (1988). Planning for incapacity: Two perspectives on safeguards. reservations about advance directives. *Health and Social Work, 13*(1), 72-74.
- Retrieved from
<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=19104&site=ehost-live>
- Allen, R. S., DeLaine, S. R., Chaplin, W. F., Marson, D. C., Bourgeois, M. S., Dijkstra, K., and Burgio, L. D. (2003). Advance care planning in nursing homes: Correlates of capacity and possession of advance directives. *The Gerontologist, 43*(3), 309-317. Retrieved from
<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=73562&site=ehost-live>
- Becker, G., Sarhatlic, R., Olschewski, M., Xander, C., Momm, F., and Blum, H. E. (2007). End-of-life care in hospital: Current practice and potentials for improvement. *Journal of Pain and Symptom Management, 33*(6), 711-719.
doi:10.1016/j.jpainsymman.2006.09.030
- Berg, B., Lune, H. (2012) *Qualitative Research Methods for the Social Sciences*. Boston, MA. Pearson 8th edition.
- Bethesda Institute. *How prevalent are how prevalent are intellectual and developmental disabilities intellectual and developmental disabilities developmental disabilities in the united states?.* (2012). Retrieved from
<http://bethesda.institute.org/document.doc?id=413>

- Black, K. (2010). Promoting advance care planning through the national healthcare decisions day initiative. *Journal of Social Work in End-of-Life and Palliative Care*, 6(1-2), 11-26. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=80638&site=ehost-live>
- Bomba, P. A., Morrissey, M. b., and Leven, D. C. (2011). Key role of social work in effective communication and conflict resolution process: Medical orders for life-sustaining treatment (MOLST) program in New York and shared medical decision making at the end of life. *Journal of Social Work in End-of-Life and Palliative Care*, 7(1), 56-82. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=82337&site=ehost-live>
- Brennan, M. T., Del Signore, E., Deloge, J., Dillon McDonald, D., Drenga, J. M. L., Joslin, N., . . . Wilson, D. (2003). Communicating end-of-life preferences. *Western Journal of Nursing Research*, 25(6), 652-675. Retrieved from <http://search.proquest.com/docview/57042232?accountid=14756>
- Brotherson, M. J. (1988). Transition into adulthood: Parental planning for sons and daughters with disabilities. *Education and Training in Mental Retardation*, 23(3), 165-74.
- Cochran, D. L. (1999). Advance elder care decision making: A model of family planning. *Journal of Gerontological Social Work*, 32(2), 53-64. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=69475&site=ehost-live>

- Coleman, N., M. (1988). Planning for incapacity: Two perspectives on safeguards. advance directives preserve autonomy despite incapacity. *Health and Social Work, 13*(1), 71-72. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=18677&site=ehost-live>
- de Haan, K., and Huibers, A. K. (1997). Retrospective study of doctors' 'end of life decisions' in caring for mentally handicapped people in institutions in the netherlands. *British Medical Journal, 315*(7100), 88-91.
- Death with Dignity National Center. (2012). Death with Dignity National Center. Retrieved from <http://www.deathwithdignity.org/advocates>.
- Ditto, P. H., Hawkins, N. A., and Pizarro, D. A. (2005). Imagining the end of life: On the psychology of advance medical decision making. *Motivation and Emotion, 29*(4), 481-496. doi: 10.1007/s11031-006-9017-x
- Doukas, D. J., and Hardwig, J. (2003). Using the Family Covenant in planning end-of-life care: Obligations and promises of patients, families, and physicians. *Journal of the American Geriatrics Society, 51*(8), 1155-1158. doi:10.1046/j.1532-5415.2003.51383.x
- Dybwad, G. (1968). Who are the mentally retarded? *Children, 15*(2), 43-48. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=0403.134&site=ehost-live>
- Fagerlin, A., Ditto, P. H., Hawkins, N. A., Schneider, C. E., and Smucker, W. D. (2002). The use of advance directives in end-of-life decision making: Problems and

possibilities. *American Behavioral Scientist*, 46(2), 268-283. doi:

10.1177/0002764202046002007

Ford, D. E., Gallo, J. J., Klag, M. J., Meoni, L. A., Straton, J. B., Sulmasy, D. P., and Wang, N. (2003). Life-sustaining treatments: What do physicians want and do they express their wishes to others? *Journal of the American Geriatrics Society*, 51(7), 961-969. Retrieved from <http://search.proquest.com/docview/57038721?accountid=14756>

Galambos, C. M. (1998). Preserving end-of-life autonomy: The patient self-determination act and the uniform health care decisions act. *Health and Social Work*, 23(4), 275-281. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=65750&site=ehost-live>

Galambos, C. M. (1998). Preserving end-of-life autonomy: The patient self-determination act and the uniform health care decisions act. *Health and Social Work*, 23(4), 275-281. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=65750&site=ehost-live>

Gallo, J. J., Straton, J. B., Klag, M. J., Meoni, L. A., Sulmasy, D. P., Wang, N., and Ford, D. E. (2003). Life-sustaining treatments: What do physicians want and do they express their wishes to others? *Journal of the American Geriatrics Society*, 51(7), 961-969. doi:10.1046/j.1365-2389.2003.51309.x

Hawkins, N. A., Ditto, P. H., Danks, J. H., and Smucker, W. D. (2005). Micromanaging death: Process preferences, values, and goals in end-of-life medical decision-

making. *The Gerontologist*, 45(1), 107-117. Retrieved from

<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=76070&site=ehost-live>

Huibers, A. K., van Thiel, G. J., de Haan, K., and van Delden, J. J. Retrospective study of doctors' "end of life decisions" in caring for mentally handicapped people in institutions in the netherlands. *UK PubMed Central*,

Kane, R. L., Bershadsky, B., and Bershadsky, J. (2006). Who recommends long-term care matters. *The Gerontologist*, 46(4), 474-482. Retrieved from

<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=54751&site=ehost-live>

Kessler, D. P., and McClellan, M. B. (2004). Advance directives and medical treatment at the end of life. *Journal of Health Economics*, 23(1), 111-127. Retrieved from

<http://search.proquest.com/docview/57141396?accountid=14756>

King, A. (2005). What should we do for everyone? response to "what should we do for jay?". *Journal of Religion, Disability and Health*, 9(2), 27-31.

Kingsbury, L. A. (2005). Person-centered planning and communication of end-of-life wishes with people who have developmental disabilities. *Journal of Religion, Disability and Health*, 9(2), 81-90.

Lacey, D. (2005). Nursing home social worker skills and end-of-life planning. *Social Work in Health Care*, 40(4), 19-40. Retrieved from

<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=52309&site=ehost-live>

- Luptak, M. (2004). Social work and end-of-life care for older people: A historical perspective. *Health and Social Work, 29*(1), 7-15. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=74132&site=ehost-live>
- Mackelprang, R. W., and Mackelprang, R. D. (2005). Historical and contemporary issues in end-of-life decisions: Implications for social work. *Social Work, 50*(4), 315-24.
- Mahon, M. M. (2011). An advance directive in two questions. *Journal of Pain and Symptom Management, 41*(4), 801-807. doi: 10.1016/j.jpainsymman.2011.01.002
- McDonald, D. D., Moran, A. B., Del Signore, E., Deloge, J., Joslin, N., Petow, W. A., . . . Brennan, M. T. (2003). Communicating end-of-life preferences. *Western Journal of Nursing Research, 25*(6), 652-666. doi:10.1177/0193945903254062
- Medley, S., Saunders, J., and McEnhill, L. (2006). Providing end-of-life care for people with learning disabilities. *Nursing Times, 102*(15), 21-22.
- Mizrahi, T. (1992). The direction of patients' rights in the 1990s: Proceed with caution. *Health and Social Work, 17*(4), 246-252. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=26800&site=ehost-live>
- National Alliance of Mental Illness. *Learning from history: deinstitutionalization of people with mental illness as precursor to longterm care reform*. (2007, August). Retrieved from http://www.nami.org/Template.cfm?Section=About_the_Issue&Template=/ContentManagement/ContentDisplay.cfm&ContentID=137545

- National Association of Social Workers. (2008). *Code of ethics of the National Association of Social Workers*. Washington, DC. NASW Press.
- O'Grady Reilly, K., and Conliffe, C. (2002). Facilitating future planning for ageing adults with intellectual disabilities using a planning tool that incorporates quality of life domains. *Journal of Gerontological Social Work*, 37(3), 105-119. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=72585&site=ehost-live>
- Pasman, H. R. W., Hanssen-de Wolf, J. E., Hesselink, B. A. M., van der Heide, A., van der Wal, G., and Onwuteaka-Philipsen, B. D. (2009). Policy statements and practice guidelines for medical end-of-life decisions in dutch health care institutions: Developments in the past decade. *Health Policy*, 92(1), 79-88. doi: 10.1016/j.healthpol.2009.02.008
- Pockett, R., Walker, E., and Dave, K. (2010). "Last orders": Dying in a hospital setting. *Australian Social Work*, 63(3), 250-265. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=81261&site=ehost-live>
- Pockett, R., Walker, E., and Dave, K. (2010). "Last orders": Dying in a hospital setting. *Australian Social Work*, 63(3), 250-265. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=81261&site=ehost-live>
- Pugh, G. (2005). The challenges of living and dying well: Response to "what should we do for jay?". *Journal of Religion, Disability and Health*, 9(2), 33-35. Retrieved from <http://search.proquest.com/docview/57120238?accountid=14756>

- Reporting of Maltreatment of Vulnerable Adults, Minn.Stat 626.557 (2012). Retrieved from <https://www.revisor.leg.state.mn.us/statutes/?id=626.557>
- Schick Tanz, S., Fisher, M. J., and Cook, S. E. (2009). Interpreting advance directives: Ethical considerations of the interplay between personal and cultural identity introduction. *Health Care Analysis*, 17(2), 158-171. doi: 10.1007/s10728-009-0118-z
- Scoccia, D. (2010). Physician-assisted suicide, disability, and paternalism. *Social Theory and Practice*, 36(3), 479-498.
- Service, K. P. (2002). Considerations in care for individuals with intellectual disability with advanced dementia. *Journal of Gerontological Social Work*, 38(1), 213-224. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=swhandAN=72712&site=ehost-live>
- Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S. H., and Clark, D. (2004). Planning for the end of life: The views of older people about advance care statements. *Social Science and Medicine* (1982), 59(1), 57.
- Stein, G. L. (2004). Improving our care at life's end: Making a difference. *Health and Social Work*, 29(1), 77-79. Retrieved from <http://search.proquest.com/docview/57139991?accountid=14756>
- Tack, S. (2009). Legal aspects of end-of-life decision policies in health care institutions. *Histoire Et Liberté*, 28(4), 725-738.
- The influence of cultural diversity on end-of-life care and decisions. (2002). *American Behavioral Scientist*, 46(2), 204-219. doi:10.1177/000276402236673

- The Minnesota Governor's Council on Developmental Disabilities. *Milestones in disability history since the americans with disabilities act*. (n.d.). Retrieved from http://www.mnddc.org/news/newsitems/ada_20th_anniversary_timeline.htm
- Turnbull, H. R., III. (2005). What should we do for jay? the edges of life and cognitive disability. *Journal of Religion, Disability and Health*, 9(2), 1-25.
- van Thiel, G. J., van Delden, J. J., de Haan, K., and Huibers, A. K. (1997). Retrospective study of doctors' "end of life decisions" in caring for mentally handicapped people in institutions in the netherlands. *BMJ (Clinical Research Ed.)*, 315(7100), 88-91.
- Wagemans, A., van Schrojenstein Lantman-de-Valk, H., Tuffrey-Wijne, I., Widdershoven, G., and Curfs, L. (2010). End-of-life decisions: An important theme in the care for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 54(6), 516-524. doi: 10.1111/j.1365-2788.2010.01276.x
- Wagemans, A., van Schrojenstein Lantman-de-Valk, H., Tuffrey-Wijne, I., Widdershoven, G., and Curfs, L. (2010). End-of-life decisions: An important theme in the care for people with intellectual disabilities. *Journal of Intellectual Disability Research : JIDR*, 54(6), 516-524. doi:10.1111/j.1365-2788.2010.01276.x
- Yoshioka, M. R., and Noguchi, E. (2009). The developmental life course perspective: A conceptual and organizing framework for human behavior and the social environment. *Journal of Human Behavior in the Social Environment*, 19(7), 873-884. doi:10.1080/10911350902988118

Appendix A

Interview Questions for those involved in Mary's Care:

1. What do you believe is the role of social workers in the EOL process for individuals with IDs?
2. What do you believe went well in Mary's care?
3. What role did you play in the care of Mary?
4. What would you change if you were able to about Mary's care?
5. Do you think with more knowledge regarding the ability to stop and start Hospice to allow Mary to take antibiotics?
6. What information do you think was most beneficial in the decision making process for Mary?
7. Specifically what were the similarities and differences between the process for Mary versus individuals with families or strong support networks
8. What do you believe makes the dying process and death experience successful, what do you believe it should look like overall?
9. Who do you believe should be involved in EOL planning for individuals with IDs?
10. When do you think EOL planning should be discussed for individuals with IDs?
11. What challenges do you think the ID brings to the EOL planning process? Do you think the supportive living environment is helpful or a hindrance of the EOL process?
12. Do you think the medical provisions provided by Medicare affect the choices made by individuals with IDs regarding their EOL care?

13. What do you believe is the most important environmental consideration for individuals with IDs when engaging in EOL planning?
14. Should caregivers be included in the discussion? What would be the benefits and risks of their inclusion? Do you think differing ages of caregivers and individuals with IDs should be considered in their input?
15. Should physicians be able to overrule the decisions of family members or caregivers in the EOL planning process with individuals with IDs?
16. What is the role of the physician when creating an EOL plan specific to individuals with IDs?
17. What if caregivers do not agree with the EOL plan for the individual? Should they get a say? How should this look?
18. Do you believe that individuals with ID, even when healthy should engage in EOL planning? Why or why not?
19. Do you believe there is a risk for individuals with ID of receiving more limited treatment than their non-disabled counterparts? Why or why not?
20. Do you believe safeguards should exist for individuals with IDs who have family members involved in care, or who are their own legal representatives to ensure their full understanding of what is going to occur?
 - a. What should they be? How should it be done? Who should monitor this?
21. Do you believe practitioners working with individuals with IDs should receive additional training as part of their education or continuing education opportunities to assist in their ability to modify the practices to the individual? Why or why not?

22. Should people working to support individuals with IDs be expected to participate in training regarding the EOL process as it applies to those they serve? Should they be included in the discussions with the individual?

Appendix B

Interview questions for Disability Advocates:

1. What motivates you to working with and advocating for individuals with IDs?
What brought you into this field?
2. Do you have any personal experience with EOL planning for an individual with an ID?
3. What do you believe makes the dying process and death experience successful, what do you believe it should look like overall?
4. Who do you believe should be involved in EOL planning for individuals with IDs?
5. When do you think EOL planning should be discussed for individuals with IDs?
6. What challenges do you think the ID brings to the EOL planning process? Do you think the supportive living environment is helpful or a hindrance of the EOL process?
7. Do you think the medical provisions provided by Medicare affect the choices made by individuals with IDs regarding their EOL care?
8. What do you believe is the most important environmental consideration for individuals with IDs when engaging in EOL planning?
9. Should caregivers be included in the discussion? What would be the benefits and risks of their inclusion? Do you think differing ages of caregivers and individuals with IDs should be considered in their input?
10. Should physicians be able to overrule the decisions of family members or caregivers in the EOL planning process with individuals with IDs?

11. What is the role of the physician when creating an EOL plan specific to individuals with IDs?
12. What if caregivers do not agree with the EOL plan for the individual? Should they get a say? How should this look?
13. Do you believe that individuals with ID, even when healthy should engage in EOL planning? Why or why not?
14. Do you believe there is a risk for individuals with ID of receiving more limited treatment than their non-disabled counterparts? Why or why not?
15. Do you believe safeguards should exist for individuals with IDs who have family members involved in care, or who are their own legal representatives to ensure their full understanding of what is going to occur?
 - a. What should they be? How should it be done? Who should monitor this?
16. Do you believe practitioners working with individuals with IDs should receive additional training as part of their education or continuing education opportunities to assist in their ability to modify the practices to the individual? Why or why not?
17. Should people working to support individuals with IDs be expected to participate in training regarding the EOL process as it applies to those they serve? Should they be included in the discussions with the individual?

Appendix C

Dear _____,

My name is Kylie Otte, I am a graduate student at the University of St. Thomas, St. Catharine University in the Masters of Social Work program. I am conducting a study about end of life care planning for individuals with intellectual disabilities. I invite you to participate in this research. You were selected as a possible participant because you are a professional involved in caring for individuals with intellectual disabilities and have experience regarding end of life care or you are an advocate for disability rights.

The purpose of this study is to examine how end of life care planning occurs for adults with intellectual disabilities and the ethical implications surrounding this process.

Procedures:

If you agree to be in this study, I will ask you to do the following things: consent to your participation in this study by filling out this form, participating in this interview which will be recorded and answer questions posed by this researcher. The interview will be approximately one hour in duration. I will transcribe the recorded interview to be reviewed by a peer to ensure its reliability. This information will also be used in a presentation to open to the public in May 2012, in addition to a brief presentation research reviewed to formulate the interview questions.

Confidentiality:

The records of this study will be kept confidential. Each form containing information regarding the respondents will be kept in a secure lock box in my own personal home office. These items including recordings, transcriptions, consent forms and data will be locked in this box. I am the only person who will have access to this lockbox. Findings from the interview will be de-identified and presented to the public in May 2013, as part of the Graduate Research Presentation.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with University of St. Thomas/St. Catherine University, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used for this study.

Please feel free to contact me with any questions you would like to consider prior to your decision to participate in this study. If you have questions later, you may contact me at (651)307-5244. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

Thank you for your time,

Kylie Otte, *LSW*

Appendix D

Consent Form

CONSENT FORM

Please read this form and ask any questions you may have before agreeing to participate in the study.

Please keep a copy of this form for your records.

Project Name	Ethical Implications of End of Life Planning for Individuals with Intellectual Disabilities	IRB Tracking Number	405971-1
General Information Statement about the study:			
This study hopes to examine how end of life planning for individuals with intellectual disabilities should be conducted. The questions asked in this study will draw on personal professional experiences working to assist an individual through the end of life process, or personal opinions from disability advocates of how they perceive the process should occur.			
You are invited to participate in this research. You were selected as a possible participant for this study because:			
I am conducting a study about end of life care planning for individuals with intellectual disabilities. I invite you to participate in this research. You were selected as a possible participant because you are a professional involved in caring for individuals with intellectual disabilities and may have experience regarding end of life care. Please read this form and ask any questions you may have before agreeing to be in the study			
Study is being conducted by:		Kylie Otte, LSW	
Research Advisor (if applicable):		Katharine Hill	
Department Affiliation:		Social Work	
Background Information			
The purpose of the study is:			
The purpose of this study is to examine how end of life care planning occurs for adults with intellectual disabilities and the ethical implications surrounding this process.			

<p>Procedures</p> <p>If you agree to be in the study, you will be asked to do the following: <i>State specifically what the subjects will be doing, including if they will be performing any tasks. Include any information about assignment to study groups, length of time for participation, frequency of procedures, audio taping, etc.</i></p>
<p>If you agree to be in this study, I will ask you to do the following things: consent to your participation in this study by filling out this form, participating in this interview which will be recorded and answer questions posed by this researcher. The interview will be approximately one hour in duration, the interview will be audiorecorded. This researcher will then transcribe the recorded interview to be reviewed by a peer to ensure its reliability. This information will also be used in a presentation to open to the public in May 2013, in addition to a brief presentation of the literature reviewed to formulate the questions which you will be asked.</p>
<p>Risks and Benefits of being in the study</p>
<p>The risks involved for participating in the study are:</p>
<p>There are no known risks.</p>
<p>The direct benefits you will receive from participating in the study are:</p>
<p>To share your opinion regarding how individuals with intellectual disabilities should be cared for during their end of life planning process.</p>
<p>Compensation</p> <p>Details of compensation (if and when disbursement will occur and conditions of compensation) include:</p> <p><i>Note:</i> In the event that this research activity results in an injury, treatment will be available, including first aid, emergency treatment and follow-up care as needed. Payment for any such treatment must be provided by you or your third party payer if any (such as health insurance, Medicare, etc.).</p>
<p>Not Applicable.</p>
<p>Confidentiality</p> <p>The records of this study will be kept confidential. In any sort of report published, information will not be provided that will make it possible to identify you in any way.</p>

The types of records, who will have access to records and when they will be destroyed as a result of this study include:	
The records of this study will be kept confidential. Research records will be kept in a locked file in my home office; a research partner will review de-identified transcriptions of our interview, and will not know who you are. I will delete any identifying information from the transcript. Findings from the interview will be de-identified and presented to the public in May 2013, as part of the Graduate Research Presentation	
Voluntary Nature of the Study	
Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with any cooperating agencies or institutions or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until the date\time specified in the study. You are also free to skip any questions that may be asked unless there is an exception(s) to this rule listed below with its rationale for the exception(s).	
Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with University of St. Thomas/St. Catherine University, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used for this study.	
Should you decide to withdraw, data collected about you	will NOT be used in the study
Contacts and Questions	
You may contact any of the resources listed below with questions or concerns about the study.	
Researcher name	Kylie Otte
Researcher email	kaotte@stthomas.edu
Researcher phone	651-962-XXXX
Research Advisor name	Katharine Hill
Research Advisor email	kmhill1@stthomas.edu
Research Advisor phone	651-962-XXXX
UST IRB Office	651.962.5341
Statement of Consent	
I have read the above information. My questions have been answered to my satisfaction and I am at least 18 years old. I consent to participate in the study. By checking the electronic signature box, I am stating that I understand what is being asked of me and I give my full consent to participate in the study.	

Signature of Study Participant <input type="checkbox"/> <i>Electronic signature</i>		Date	
Print Name of Study Participant			
Signature of Parent or Guardian (if applicable) <input type="checkbox"/> <i>Electronic Signature</i>		Date	
Print Name of Parent or Guardian (if applicable)			
Signature of Researcher <input type="checkbox"/> <i>Electronic signature*</i>		Date	
Print Name of Researcher			

*Electronic signatures certify that::

The signatory agrees that he or she is aware of the polities on research involving participants of the University of St. Thomas and will safeguard the rights, dignity and privacy of all participants.

- The information provided in this form is true and accurate.
- The principal investigator will seek and obtain prior approval from the UST IRB office for any substantive modification in the proposal, including but not limited to changes in cooperating investigators/agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study which may affect the risks and benefits to participation will be reported in writing to the UST IRB office and to the subjects.
- The research will not be initiated and subjects cannot be recruited until final approval is granted.