Abstract

This Master of Social Work practicum report addresses the area of British Columbia adult guardianship and planning statutes and the interpretation and operationalization of these statutes at various practicum locations (Northern Health Authority, British Columbia Centre for Elder Advocacy and Support, and Nidus Personal Planning Resource Centre and Registry) with respect to persons with dementia. The purpose of this practicum was to develop insight into the effectiveness of the adult guardianship and planning statutes in empowering persons with dementia by protecting their rights, promoting their self-determination, and preventing abuse, neglect, and/or self-neglect. The student integrates theory and practice throughout this practicum to explore this topic and, finally, proposes recommendations for social work policy and practice.
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Dedication

To my grandmother and her fierce advocates (my mother and godmother) for teaching me that care, imagination, and hopefulness are the characteristics that enable people to persevere through structural challenges to create social support networks that facilitate empowerment and autonomy for those they love.
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CHAPTER ONE: Introduction

My passion and interest in rights protection and promotion of the self-determination of older adults, persons with disabilities and subsequently persons with dementia (PWDs) is a result of my personal and professional experiences. Social work is a profession committed to social justice, in which social workers promote the self-determination of vulnerable populations by addressing public attitudes and structural barriers causing discrimination and exclusion of these populations from full participation in society (Canadian Association of Social Workers (CASW), 2005; Mullaly, 2010). Despite social workers’ responsibility to promote self-determination, they also have a responsibility to protect vulnerable populations (CASW, 2005). Consequently, as I searched for a meaningful area of study related to my passion and interests, and reflected on the purpose of social work, I was drawn to the topic of adult guardianship and planning statutes (i.e., Adult Guardianship Act (1996), Health Care (Consent) and Care Facility (Admission) Act (1996), Power of Attorney Act (1996), Representation Agreement Act (1996), Patients Property Act (1996), and Public Guardian and Trustee Act (1996)) in British Columbia (BC) specifically applied to the population of PWDs. From here forward, BC adult guardianship and planning statutes will also be referred to as adult guardianship legislation.

This topic directly relates to my interest in rights protection and promotion of self-determination of PWDs, as the adult guardianship reform is characterized by a grassroots, participatory research initiative started by persons with disabilities, caregivers, and their “allies” (Bishop, 1994, p.126) who are persons with privilege working towards ending oppression with those experiencing oppression (Boyce, Tremblay, McColl, Bickenbach, Crichton, Andrews, Gerein, & D’Aubin, 2001; Nidus Personal Planning Resource Centre and Registry (Nidus), 2016d). These groups (the reformers) sought to change adult guardianship law to create
legislation that recognized the human rights of persons with disabilities, older adults, and PWDs and better respected their self-determination and need for protection (Boyce et al., 2001; Nidus, 2016d). In addition, the Representation Agreement Act (1996), which resulted from this reform, is internationally recognized for its paradigm shift and ability to balance the self-determination and safety for persons who need assisted decision-making or may need it in the future (Gordon, 2012; Nidus, 2016d). Prior to the reform, personal planning legislation was based on ethics of justice beliefs such as liberal autonomy; however, the Representation Agreement Act’s (1996) use of an ethics of care epistemology (in which relative-autonomy, rather than liberal autonomy, is the basis for determining capacity) enables the successful balance between self-determination and protection (Gordon, 2012; Nidus, 2016d). Consequently, the adult guardianship reform and resulting legislation deconstructed barriers impeding PWDs’ self-determination and rights to participate in society.

I focused my efforts during my Master of Social Work (MSW) coursework on developing an understanding of the literature in this area. As a result, I decided to enter the practice field to develop an understanding of the application of adult guardianship legislation in practice environments and its effectiveness in protecting the human rights and self-determination of PWDs. Consequently, I decided to complete a MSW practicum and report for my degree. My committee consisted of Professor Dawn Hemingway (academic supervisor), Melinda Allison (practicum supervisor), and Professor Nancy Jokinen (additional social work faculty member).

I was fortunate to receive a practicum placement at Northern Health Authority (Northern Health) with opportunities to spend time with several Northern Health departments (i.e., a palliative care team, a residential care and convalescent care team, and a risk and compliance team), British Columbia Centre for Elder Advocacy and Support (BCCEAS), and Nidus. Since
adult guardianship and incapacity planning is an area of practice in which law and medicine intersect (Hall, 2012), spending time at these organizations provided me with a more thorough understanding of the health care and legal perspectives and their contributions in this field.

The primary learning goal of my practicum was to develop insight into the effectiveness of adult guardianship legislation in empowering PWDs by protecting their rights, promoting their self-determination, and preventing abuse, neglect and self-neglect. Under this primary learning goal, there were sub-themes used to measure progress throughout my practicum: interpretation and operationalization of legislation in practice; determining gaps in legislative and non-legislative processes; legislation and empowerment of PWDs; and assisted and/or substitute decision-making in relation to abuse, neglect, and self-neglect of PWDs. Further detail about my learning goals can be found in the learning contract located in the Appendix of this report.

I used an eclectic theoretical perspective throughout my practicum, emphasizing an ethics of care approach (Botes, 2000a; Noddings, 2013; Rachels & Rachels, 2015), but also blending aspects of an ethics of justice approach (Rachels & Rachels, 2015). I selected a theoretical perspective with an emphasis on ethics of care because the adult guardianship reformers advocated for a new legislated personal planning tool (i.e., representation agreements) founded on an alternative paradigm (i.e., ethics of care) (Gordon, 2012). While adult guardianship still mainly assumes an ethics of justice stance, a personal planning tool (i.e., representation agreements) founded on ethics of care was developed by reformers to provide an alternative legal tool to adult guardianship (Gordon, 2012). Additionally, Holland (2010), a researcher and specialist in adult guardianship social work practice, stated she also adopts this approach in the field. Finally, as self-determination for PWDs is the principle cautiously being advocated for throughout this report and a principle listed in the CASW Code of Ethics (2005), using only an
ethics of care approach would seem inadequate because the focus of ethics of care is on care rather than principles (Noddings, 2013). Consequently, to accommodate the principle of self-determination and respect the epistemology (i.e., ethics of care) of the persons involved in the adult guardianship reform, it is necessary to integrate aspects of ethics of justice within an ethics of care framework. By integrating ethics of justice within an ethics of care framework, this logical error (ethics of care’s rejection of principles other than care) can be corrected (Noddings, 2013). Additionally, through the use of an integrated approach, with an emphasis on ethics of care, self-determination for PWDs can be achieved.

As the adult guardianship reform and resulting legislation was created by the thoughts and actions of minority groups affected by this legislation and their allies, and since I identify as privileged in the areas of age and ability, which causes a divide between these groups and myself, I believed it was important to adopt Freire’s (2010) educational framework. I chose to use Freire’s educational framework so I would be aware of individual and systematic power dynamics that often cause the domestication of beings existing within environments defined by the status quo (i.e., dominant-subordinate power dynamics).

It was a privilege to receive this practicum opportunity and all the mentoring provided by those in the field. I learned a great deal during this process and it developed my ability to connect theory and practice in the area of adult guardianship and incapacity planning. As a result of this practicum, I have better insight into the challenges associated with connecting theory and practice. Furthermore, I have also gained ideas for potential improvements to the adult guardianship legislation and non-legislative processes that could potentially better protect the rights and self-determination of PWDs.
What follows is a practicum report composed of a description of my social position and theoretical orientation, a literature review, description of my practicum experiences, and recommendations for social work policy and practice.
CHAPTER TWO: Positioning Myself

I engage in reflexivity and provide transparency to the reader by illustrating how my experiences, social identities, assumptions, and worldviews informed my theoretical orientation, practicum experiences, and report findings (Berger, 2015; Creswell, 2009; Guba, 1981; Patton, 2015).

I identify as an Asian-Canadian, young-adult, able-bodied, heterosexual, middle-class woman. Since social identities influence the way social workers interact with their clients and affect the way clients experience social workers within the workplace (Mullaly, 2010), remaining aware of my social identities and acknowledging privileges was essential when working with clients during my practicum.

The population of interest for my practicum was PWDs, and generally this population is located within the older adult population (Cunningham, McGuinness, Herron, & Passmore, 2015); therefore, the social identities of age and ability differed between my clients and myself. Since privileged identities are often unconscious to those who possess them, this can cause marginalization of groups in society such as PWDs (Mullaly, 2010). Consequently, I was especially careful about examining my beliefs and assumptions associated with age and ability when working with PWDs.

My interest in rights protection and promotion of self-determination of older adults, persons with disabilities, and subsequently PWDs, is largely due to my personal and professional experiences. Throughout my youth, my adoptive maternal grandmother with disabilities and her caregivers lived with my immediate family. Although it was in my grandmother’s nature to be independent, her autonomy was also enhanced through the efforts of her social support network. My grandmother became a member of many community organizations such as Planned Lifetime
Advocacy Network and the Heart and Stroke Foundation, as well as attended recreational day programs within the community, which further developed her social support network and wellbeing. Oftentimes I would accompany my grandmother to these activities and this is when I became aware that many older adults were living with dementia. During my teen years and throughout my undergraduate education, I volunteered at residential care facilities and this further exposed me to PWDs. Additionally, most of my employment during my undergraduate education was assisting persons with disabilities to achieve their independence goals. Through these experiences, I was able to see families who endlessly advocated for the rights of their family members with disabilities to be self-determining and able to fully participate in society. I am currently employed at a residential care facility in the recreation therapy department and my experiences with residents in this workplace continue to introduce me to the unique needs for rights protection and self-determination promotion of PWDs.

As I reflect on these experiences, continuous connections with older adults and PWDs throughout my life likely lead to my interest in working with PWDs. I recognize that throughout these experiences I was exposed to situations in which persons requiring domain-specific assisted decision-making (i.e., supported decision making in a specific decision-making area such as financial affairs, legal affairs, health care, and/or personal care) were accessing social support networks to facilitate autonomy, wellbeing, and the ability to participate in society. Upon reflection, many of my experiences appear to have been the product of an ethics of care approach in which ideas of relative autonomy were being applied. Consequently, I believe these experiences contributed to my adoption of an eclectic approach with an emphasis on ethics of care for my practicum.
My specific interest in adult guardianship and planning statutes was initiated when I attended an Aging and Quality of Life (for adults with intellectual and/or developmental disabilities) Conference held in Prince George, BC in 2012. During the discussion, D. Hemingway (personal communication, September 12, 2013) raised the idea of representation agreements and how these personal planning documents could empower adults with intellectual and/or developmental disabilities by maintaining their self-determination even if they were considered incapable of creating other personal planning documents.

Since entering the University of Northern British Columbia MSW program, my area of focus has been on adult guardianship and planning statutes as they relate to PWDs. Based on my research regarding this topic, I primarily advocate for an ethics of care approach because I believe this approach facilitates a holistic perception of PWDs and places their personhood at the centre of all decision-making. From an ethics of care approach, a moral life is defined “as a network of relationships with specific people, and it sees ‘living well’ as caring for those people, attending to their needs, and maintaining their trust” (Rachels & Rachels, 2015, p.154). Ethics of care is defined by values such as involvement, relationships, contextualism, and holism (Botes, 2000a; Rachels & Rachels, 2015); thus, persons are perceived within their social environments, rather than as isolated individuals. Within the literature, ethics of care approaches adopt the notion of relative-autonomy, which is the idea that persons are interconnected and decision-making is a social process rather than an individual one (Botes, 2000a; Gordon, 2012; Hall, 2012; Noddings, 2013; Rachels & Rachels 2015). Consequently, it is through social support networks that persons, who may be perceived as incapable in certain domains (e.g., financial affairs, legal affairs, health care, or personal care decision making) under the law, can maintain self-determination in other domains (Gordon, 2012; Nidus, 2012g). Despite labels of domain-
specific incapability (i.e., an adult’s mental inability to make informed decisions in a certain decision making area) under the law, through a relative-autonomy perspective PWDs are perceived as capable, as decision-making is considered to be interdependent for all persons (Gordon, 2012; Zakreski, 2014).

I have chosen a predominantly ethics of care stance because I believe this perspective empowers populations such as PWDs who frequently experience paternalism in society. This is the ethic selected by minority groups involved in the adult guardianship reform, who interface with adult guardianship and planning statutes and, therefore, have an intimate and practical understanding of their needs in regards to these statutes. I assume this position because I want to align with PWDs’ beliefs in what is right for them in regards to this subject matter. This ethic also aligns with my belief that PWDs have the right to be the experts in their lives, regardless of their level of ability judged by the law. In addition, this ethic is also congruent with my belief that PWDs make decisions interdependently, because they are situated within social support networks.

However, my privileged experience with social support networks influences my belief in ethics of care. I have continuously observed caring social support networks, both personally and professionally, that assist in the independence of vulnerable persons. These experiences have resulted in my belief that people have caring, trustworthy social support networks able to assist them with formal decision-making in the case that their domain-specific capabilities become questionable under the law. This is not the case for all persons I came into contact with throughout my practicum, especially those experiencing abuse, neglect, and/or self-neglect, as their social conditions were often the cause of dysfunction and disempowerment in their lives.
Hence, PWDs experiencing abuse, neglect, and/or self-neglect often have social support networks that cause further marginalization rather than empowerment.

As adult guardianship social workers often intervene when PWDs are being abused, neglected, and/or self-neglected and their domain-specific capabilities are in question, the need for protection must be balanced with the value of autonomy (Holland, 2006, 2010). In the context of abuse, neglect, and/or self-neglect of PWDs with questionable domain-specific capabilities, the cause of dysfunction is often within their social support networks, which results in the disempowerment of the PWDs. While I still believe an ethics of care approach should not be abandoned immediately when addressing cases of abuse, neglect, and/or self-neglect and domain-specific incapability, I do recognize that using aspects of ethics of justice is aligned with the CASW Code of Ethics (2005) and may be appropriate in some situations.

I believe an ethics of care approach can often be effective in situations involving PWDs with questionable domain-specific capabilities in a context of abuse, neglect, and/or self-neglect because it allows social workers to perceive the PWDs and their social support networks holistically, recognizing different angles of the story and thus developing greater understanding of the PWDs’ context. Consequently, if benefits are being provided to the PWDs by their social support networks and the PWDs have a desire to stay connected to persons in their social support networks who were involved in abuse and/or neglect of the PWDs, solutions can be determined that help to keep their social support networks intact. These solutions entail retaining the functional components of the social support networks, but providing supports to prevent against further abuse and/or neglect. Throughout my practicum, I observed social workers adopt what appeared to be an ethics of care approach when addressing adult guardianship cases. They would raise awareness within interprofessional teams about benefits provided to PWDs by their social
support networks and reasons to be wary of taking action that may cause relationship breakdown of the PWDs’ social support networks. Of course, in situations defined by imminent danger and consequently, minimal time for assessment, it may be most appropriate to initially assume an ethics of justice approach in which more paternalistic actions are taken to prevent harm. However, throughout my practicum, I did not encounter any situations in which a social worker judged a situation necessary of assuming a solely ethics of justice approach.

Ethics of justice is the predominant worldview used in Western society today, especially within law (Mullaly, 2010; Rachels & Rachels, 2015). From an ethics of justice perspective, a moral life is defined by an individual’s ability to be rational and impartial (Botes, 2000a; Rachels & Rachels, 2015). Generally, ethics of justice is defined by values such as equality, rationality, positivism, and reductionism (Botes, 2000a, 2000b; Rachels & Rachels, 2015). As stated previously, this perspective may be more effective in cases in which PWDs are deemed incapable and require immediate protection. In these situations, the focus needs to be shifted from receptivity to problem solving (Noddings, 2013). While ethics of care and ethics of justice are founded on different epistemological beliefs, singularly aligning with one stance and ignoring the usefulness of the interconnection between the two within the field of adult guardianship and incapacity planning may lead to fewer options for addressing the diverse needs of PWDs. Ethics of care is based on ideas of “feeling with” (Noddings, 2013, p.30), receptivity, and relative-autonomy. While an ethics of care approach is often useful, in certain situations (e.g., emergency situations), it may be useful to shift a social worker’s attention away from ethics of care and use aspects of ethics of justice such as rational thought and problem solving (Noddings, 2013). While ethics of care does not ascribe to ethics of justice’s belief in universal principles, ethics of care can include the use of rational problem solving, which is the
foundational process used for the application of an ethics of justice approach (Noddings, 2013). Additionally, as stated previously, using an ethics of care approach within the context of adult guardianship and incapacity planning often results in self-determination for PWDs, which is an ethics of justice outcome. The connection between the two is especially notable in practice, as flexibility and creativity in blending epistemologies often results in the best process and outcome for PWDs when working in this field.

Social work practice in BC is guided by the CASW *Code of Ethics* (2005), the British Columbia College of Social Workers (BCCSW) *Code of Ethics and Standards of Practice* (2009), and the law. The CASW *Code of Ethics* (2005) and the BCCSW *Code of Ethics and Standards of Practice* (2009) reference self-determination and protection of vulnerable populations as values (Holland, 2010). The values-based approach assumed in both the CASW *Code of Ethics* (2005) and the BCCSW *Code of Ethics and Standards of Practice* (2009) reflects an ethics of justice approach, due to the codes allegiance with the belief in principles. Consequently, in order to balance the CASW and BCCSW values, respect the epistemology assumed by those involved in the adult guardianship reform, and find ways to prevent blind adherence to paternalism for vulnerable populations in society, I believe assuming an eclectic worldview is necessary. Holland (2006, 2010), a social worker specializing in this field, advocates for the use of an eclectic approach emphasizing ethics of care, but also employing ethics of justice to address the complex situations that can arise within the field of adult guardianship and incapacity planning (Holland, 2006, 2010). An eclectic approach is practical, balanced, and utilized by professionals in the field (Holland, 2006, 2010); therefore, I chose to adopt this approach for my practicum.
CHAPTER THREE: Literature Review

This literature review will examine concepts associated with BC adult guardianship legislation applied to PWDs and connect this topic with social work practice. The purpose of this literature review is to critically analyze adult guardianship legislation. To accomplish this, I will explore the following topics: dementia, adult guardianship and incapacity planning terms, social support networks, public attitudes and societal structures, and history of the adult guardianship reform. I will then analyze the adult guardianship and planning statutes’ legal tools and their subsequent definitions of capacity by arranging the legal tools and capacity definitions along an ethics of justice and ethics of care continuum. I will then discuss this topic in relation to social work practice. Throughout this literature review, I will also provide practicum reflections to illustrate connections between theory and practice.

Dementia

The older adult population in BC is a rapidly growing demographic, due to the baby-boomer generation entering older adulthood (i.e., 65 years and older) (Duffy & Healy, 2011; Statistics Canada, 2007). Consequently, the rate of PWDs is also growing, as the “prevalence of dementia at age 75 is estimated to be 10 percent of the population doubling every five years” (Ray, Bernard, & Phillips, 2009, p.55). Age is a primary risk factor for the onset of progressive dementias (American Psychiatric Association, 2013; Cunningham et al., 2015) and therefore, the rates of dementia will also increase with growth in the older adult demographic (Cunningham et al., 2015). The health care system appears to already be experiencing the effects of this shift. During my practicum, it was apparent in observations as well as the conversations I had with health care professionals that many older adults with dementia were waiting in hospital wards and hospice facilities for residential care placements. Although PWDs were waiting in hospice
facilities they were not deemed palliative, rather hospice facilities occasionally allowed PWDs to stay until residential care beds were available.

Based on the predominant perspective regarding dementia (i.e., bio-medical), dementia is often defined as a group of symptoms (e.g., memory loss, impaired reasoning, communication change, etc.) caused by various diseases and conditions that affect the brain (American Psychiatric Association, 2013; O’Connor & Purves, 2009; Ray et al., 2009). While there are several different causes of dementia, this report will focus on progressive dementias such as Alzheimer’s disease, because these are the most common form affecting the older adult population (Cunningham et al., 2015). Due to the disease’s trajectory of cognitive decline and increased functional dependency (Cunningham et al., 2015), all PWDs will require support and assistance with formal decision-making (financial affairs, legal affairs, health care, personal care) at some point in the disease process; thus, PWDs are often reliant on their social support networks or the Public Guardian and Trustee of British Columbia (PGT) to assist with formal decision-making (O’Connor & Purves, 2009; PGT, 2015). Throughout my practicum, most notably in residential care, the need for social support networks to assist PWDs with formal decision-making was apparent. Social workers were often trying to determine if substitute and/or assisted decision-makers existed within the PWDs’ social support networks because situations in which substitute and/or assisted decision-makers were necessary would arise during the PWDs’ time in residential care.

**Adult Guardianship and Incapacity Planning Terms**

Throughout this report, I will refer to appointed decision-makers for PWDs as either assisted decision-makers or substitute decision-makers. The former refers to decision-making occurring through a predominately ethics of care approach (i.e., representatives), while the latter
refers to decision-making that occurs through a predominately ethics of justice approach (i.e., committees, enduring power of attorneys, temporary substitute decision-makers) (Gordon, 2012). Additionally, organizational processes for determining who assists with formal decision-making in cases of domain-specific incapability of PWDs will be referred to as “personal planning” (Taylor, 2015), the “default system” (Taylor, 2015), or advance care planning (ACP) (BC Ministry of Health, 2013). Personal planning refers to the process of determining one’s wishes and appointing formal decision-makers (i.e., representatives, enduring power of attorneys) (Taylor, 2015). The default system refers to the use of formal decision-makers (i.e., statutory property guardians, committees, temporary substitute decision-makers) chosen on behalf of the domain-specific incapable PWDs through legislation or applications to the Court (Taylor, 2015).

ACP is an umbrella term used in the health care system that includes the process of personal planning and the default system, excluding committees and statutory property guardians. ACP is defined in *My voice expressing my wishes for future health care treatment advance care planning guide (My Voice)* (BC Ministry of Health, 2013), a tool endorsed by the BC Ministry of Health and used for education on this subject by Northern Health employees. Consequently, I chose to use the term ACP to maintain consistency with the language used within health care settings. For the most part, health care professionals used *My Voice* (2013) as the basis of information when educating or discussing ACP with the public or fellow health care professionals and workers. However, health care professionals sometimes provided additional personal planning information (e.g., information about Wills and Estates, the PGT, committees, Medical Orders for Scope of Treatment (MOST) forms, etc.) to their patients/residents during presentations or when conversing about ACP to better meet the needs of their patients/residents.
Social Support Networks

Although PWDs often become reliant on their social support networks (e.g., family, friends, community members, health care professionals, etc.) to assist with formal decision-making, this assistance may be paternalistic rather than collaborative (Ray et al., 2009). The outcome is usually removal of self-determination from PWDs because overprotective social support networks act in the perceived best interests of PWDs (Dwyer, 2005; Ray et al., 2009). Throughout my practicum, there appeared to be some misunderstanding of the role of social support networks in their assistance with formal decision-making for PWDs. The idea of relative autonomy in which PWDs are supported by assisted decision-makers was sometimes missed. Occasionally, members of PWDs’ social support networks wanted to create personal planning documents for PWDs rather than inform PWDs of their choices. While my observations occurred within a limited time period in specific environments, these observations lead me to believe this confusion may be caused from a lack of education on the subject and possibly the influence of public attitudes and societal structures, which lead to paternalistic beliefs towards PWDs.

Public Attitudes and Societal Structures

Public attitudes about older adults, persons with disabilities, and subsequently PWDs alongside societal structures often influence the roles and decision-making choices assumed by social support networks of PWDs (Gill, 2000; Goralewicz, 2015; Gordon, 2012; Ray et al., 2009). Structural and anti-oppressive theorists argue discriminative public attitudes based on ageist and ableist beliefs about people with disabilities, older adults, and PWDs, which result in these groups being perceived and treated as though they are homogenous, frail, dependent, and unproductive, are caused by the dominant culture’s ideologies associated with normalcy that are upheld by institutions (Dalrymple & Burke, 2006; Gill, 2000; Gordon, 2012; Mullaly, 2010; Ray
et al., 2009). These ideologies of normalcy cause groups who are considered normal to receive privileges and groups who are considered abnormal to experience oppression in society (Dalrymple & Burke, 2006). Consequently, these discriminative beliefs may influence the social support networks and may result in misguided decision-making and overshadow the voices of PWDs (Dwyer, 2005).

Societal structures, such as many of the adult guardianship and planning statutes (e.g., Patients Property Act (1996), Adult Guardianship Act (1996)) in BC are founded on ethics of justice values. These values reinforce the use of a liberal autonomy definition, which can be defined as “an individual’s ability to engage in the process of rational (and therefore autonomous) thought, explained as the ability to exercise one’s will to reflect upon, and choose between desires, and to adopt those chosen as one’s own” (Hall, 2012, p.6). Defining autonomy through a liberal autonomy lens often results in use of a paternalistic best interest perspective applied to PWDs with domain-specific incapability (Hall, 2012; Nidus, 2012d). Due to the statutes’ epistemological foundation on ethics of justice beliefs that ascribe to notions of liberal autonomy, the wishes of incapable PWDs are, for the most part, considered secondary to those of their formal decision-makers (Hall, 2012; Rachels & Rachels, 2015).

Liberal autonomy asserts that individuals who are capable of rational thought (i.e., capable adults in all domains under the law) make decisions independently and must assume the consequences of their decisions, as long as their decisions are free from inequity such as undue influence and/or unconscionability (Hall, 2012). In law,

The inequitable doctrines of undue influence and unconscionability are explanations of theories for how the interaction between individual characteristics, social context and
relationship context may work to impair a person’s ability to consent truly or freely to a particular decision made in that context. (Hall, 2009, p.124)

The inequitable doctrine of undue influence refers to unfair transactions in which consent is gained by the stronger party’s influence over the weaker party (O’Connor, Hall, & Donnelly, 2009). Another inequitable doctrine, unconscionability, refers to exploitation of the weaker party by the stronger party (O’Connor, et al., 2009). The epistemological perspectives embedded in these statutes further remove power from populations often questioned about their capability (e.g., older adults, persons with disabilities, PWDs) by reinforcing the belief that autonomy is a right held by those with capability (which is often judged solely on intellectual functioning) (Boyce et al., 2001; Gordon, 2012; Hall, 2012).

In addition to many of the adult guardianship and planning statutes, the medical system’s stance on dementia care often reinforces dependency of PWDs, which contributes to societal structures that pose challenges for self-determination in various aspects of PWDs’ lives (O’Connor & Purves, 2009; Ray et al., 2009). The typical approach for providing dementia care, especially within a health care context, is founded on a bio-medical approach emphasizing deficits and often negating the importance of personhood (O’Connor & Purves, 2009; Ray et al., 2009). Consequently, this approach may overlook the desires of older adults and PWDs if health care systems emphasize the physical rather than all of the needs of the persons (Dwyer, 2005; O’Connor & Purves, 2009; Ray et al., 2009). A biomedical approach may also further silence the voices of older adults and PWDs (Dwyer, 2005; O’Connor & Purves, 2009; Ray et al., 2009).

Additionally, physicians often drastically underestimate the quality of life of older adult patients or patients with disabilities when compared to the patients’ perception of their quality of life (Gill, 2000; Somerville, 2000). This skewed perception of older adults and persons with...
disabilities’ quality of life furthers the need for self-determination protection for PWDs, as professionals’ perceptions of these populations do not accurately reflect the populations’ lived realities. While I was expecting to see the literature reflected in my practicum, I was pleasantly surprised when I entered residential care to observe, for the most part, dementia care being provided with an emphasis on quality of life of PWDs despite the constraints of the health care system (e.g., resource shortages, high caseloads). I observed many health care professionals taking a genuine interest in the residents’ individual values, personalities, and preferred activities. Additionally, resident and family council meetings appeared to be an outlet that facilitated the self-determination of PWDs and their social support networks, because it provided a space for their voices to be heard within the residential care facility. While self-determination and personhood of PWDs within this residential care facility seemed to be promoted, it appeared that convalescent care and community care tended to be health care areas in which health care professionals and social support networks were less risk tolerant of vulnerable persons’ self-determination. These risk adverse perspectives appeared to be caused from the belief that independent living, rather than living in care, is associated with greater risk for PWDs. In response to these concerns, oftentimes social workers acted as educators for fellow health care professionals and the public in these situations. They often discussed vulnerable, capable adults’ right to choose to live at risk.

Due to public attitudes and societal structures that generally take away self-determination for PWDs (Boyce et al., 2001; Gordon, 2012; Hall, 2012; O’Connor & Purves, 2009; Ray et al., 2009), finding ways to protect the rights, self-determination, and dignity of PWDs throughout the trajectory of the disease is essential (Ray et al., 2009). The adult guardianship reform aspired to do just that, through the creation of modernized legislation (Boyce et al., 2001). Present day
community organizations (e.g., Nidus, PGT) and the government (BC Ministry of Health) encourage British Columbians to be proactive and engage in personal planning so their wishes will be known and respected should they eventually need assistance with formal decision-making (BC Ministry of Health, 2013; PGT, 2014b; Taylor, 2015).

**Adult Guardianship Reform**

The adult guardianship reform stemmed from public discontent regarding the existing adult guardianship legislation (i.e., Patients Property Act and Power of Attorney Act) (Boyce et al., 2001). Prior to the reform, the adult guardianship legislation was based on “a Victorian philosophy of benign paternalistic intervention” (Gordon, Clements, Cunningham, McLellan, & Romanko, 2015, p.4). The main concerns of the public associated with adult guardianship were the ability of the Patient Property Act to transfer decision-making “power to another individual without the consent of the vulnerable person” (Boyce et al., 2001, p.109) and the Power of Attorney Act’s inability to accommodate the lived experience of fluctuating capacity for many vulnerable populations (Boyce et al., 2001; McClean, 2002). While there were concerns about the infringement of rights and self-determination of adults interfacing with these laws, there were also concerns about inadequate safeguards to protect vulnerable populations from abuse, neglect, and/or self-neglect (Boyce et al., 2001).

This reform began in the 1980s when community groups (e.g., BC Association for Community Living, Alzheimer’s Society, etc.), citizens (e.g., persons with disabilities, caregivers, etc.), and Government of BC came together to review this legislation and conceptualize an epistemology that would better support the protection and self-determination of populations interfacing with these laws (Boyce et al., 2001; McClean, 2002; Nidus, 2016d; Representation Agreement Resource Centre, 2005). Although I could not find any direct
criticisms of the reform, I did find differences of opinion between the proponents of the reform. For instance, originally the reformers’ goal was to develop a single piece of legislation for personal planning and incapacity (Gordon et al., 2015). However, this idea developed into several separate pieces of adult guardianship and incapacity planning legislation (what is now the Adult Guardianship Act (1996), Health Care (Consent) and Care Facility Admission Act (1996), Public Guardian and Trustee Act (1996), and Representation Agreement Act (1996)) (Gordon et al., 2015). Originally, these were to be passed as a “comprehensive and integrated package” (Gordon et al., 2015, p.3). However, prior to the enactment of the legislation, the Bar society raised some concerns, which lead to the government of BC commissioning a report to examine the legislation (McLellan, 2014). This resulted in a number of modifications including the retention of enduring power of attorneys within the Power of Attorney Act (1996) and limiting the financial and legal powers available with representation agreements (McClean, 2002; McLellan, 2014). This illustrates how the original intent of the reform was modified, due to differences in opinion between the reformers (i.e., persons with disabilities, PWDs, and their allies) and the legal profession.

Following this reconsideration, the Government of BC passed the adult guardianship and planning statutes in 1993 and retained enduring power of attorneys under the Power of Attorney Act (1996) (Boyce et al., 2001; BC Association of Community Response Networks, n.d; McClean, 2002; Nidus, 2016d). However, the statutes “did not come into force until 2000, and even then were not proclaimed in full” (McClean, 2002, p.4). Current day, sections of the statutes still have not come into force (BC Association of Community Response Networks, n.d.; Gordon et al., 2015).
The adult guardianship reform was unique because it was a bottom-up (driven by people with disabilities and their allies), participatory research initiative resulting in the current adult guardianship and planning statutes (Boyce et al., 2001; Nidus, 2016d). Populations affected by adult guardianship and substitute decision-making took a leadership role by providing direction to the working groups pushing for legislative change and its eventual implementation within the community (Boyce et al., 2001; Nidus, 2016d). It was the lived experiences and stories of those affected by this legislation that provided insight about policy processes that could better meet their needs (Boyce et al., 2001). In other words, the adult guardianship reform was the product of grassroots civic participation driven by the desire of adults affected by adult guardianship, adults in need of substitute decision-making, and their allies to find ways to modernize these laws so they could better protect the human rights of these populations and allow for civic participation, self-determination, and protection from abuse, neglect, and/or self-neglect (Boyce et al., 2001).

As a result of the adult guardianship reform, BC is now internationally recognized for its Representation Agreement Act (1996) (Gordon, 2012; Nidus, 2016d). This act is recognized for successfully addressing the criteria stated in “Article 12 Equal recognition before the law” (United Nations, 2006, p.10) of the Ad Hoc Committee report for the United Nations’ International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (J. Taylor, personal communication, July 4, 2016). Consequently, this act is internationally recognized for its ability to balance self-determination and safety for persons requiring assisted decision-making (Gordon, 2012; Nidus 2016d). Additionally, this act is acknowledged for its adoption of an ethics of care perspective in which the value of relative autonomy is supported (Gordon, 2012; Nidus, 2016d). The value of relative autonomy results in
all persons being perceived as capable since human existence is perceived as relational and
decision-making is perceived as a social, interdependent process (Gordon, 2012; Nidus, 2016d).

This reform epitomizes the social work values of social justice and self-determination
because it illustrates the strength and power of persons affected by adult guardianship and
substitute decision-making and their allies’ ability to address systematic barriers and create
societal structures that are more humanizing and supportive of diversity.

As stated previously, community groups and the Government of BC are promoting the idea
of personal planning for self-determination preservation (BC Ministry of Health, 2013; PGT,
2014b; Taylor, 2015). While I, too, believe personal planning can promote self-determination, I
also believe each of the default and personal planning options can be situated on a philosophical
continuum based on their level of protection for autonomy. At one end of the continuum is ethics
of justice (the least protective of PWDs’ autonomy); at the other end of the continuum is ethics
of care (the most protective of PWDs’ autonomy). Based on this concept, I argue personal
planning options on the ethics of care side of the continuum are more reflective of the values of
the adult guardianship reform (Gordon, 2012).

**Substitute Decision-Making and Assisted Decision-Making Options**

The substitute decision-making and assisted decision-making options within the current
adult guardianship and planning statutes can be divided into default decision-making approaches
(committees, statutory property guardians, and temporary substitute decision-makers) and
personal planning approaches (enduring power of attorney documents, advanced directives, and
representation agreements) (Taylor, 2015). Default decision-making approaches in BC are
reactive legal approaches used under some circumstances (Taylor, 2015). Default decision-
making approaches may be used if incapable PWDs have not engaged in personal planning
(Taylor, 2015), have engaged in personal planning but are being abused and/or neglected by appointed decision-makers, or have not engaged in personal planning and are experiencing abuse, neglect, and/or self-neglect (Adult Guardianship Act, 1996; BC Ministry of Health & PGT, 2016). Personal planning options are proactive legal tools that organize what is to be done if the person creating the document eventually needs assistance with formal decision-making (BC Ministry of Health, 2013; PGT, 2014b; Taylor, 2015). Personal planning options enable the creators of the documents to preserve their self-determination by creating a plan to be used if they need assistance with formal decision making in the future (BC Ministry of Health, 2013; PGT, 2014b; Taylor, 2015).

The substitute decision-making and assisted decision-making options available within the adult guardianship and planning statutes can be situated on a philosophical continuum from an ethics of justice approach to an ethics of care approach. As stated previously, an ethics of justice approach can be defined by ideas of rationality, individualism, and impartiality (Rachels & Rachels, 2015). The rational human being is considered to make decisions independently and thus, adults judged as lacking rationality are considered to need protection (Rachels & Rachels, 2015). The best interest perspective entrenched in the law, in which incapable persons are considered to need paternalistic protection, is founded on this belief (Hall, 2012; Nidus, 2012d). In contrast, an ethics of care approach can be defined by ideas of relationships, collectivism, and context (Botes, 2000a, 2000b; Rachels & Rachels, 2015). The idea of relational-autonomy, in which persons are considered to exist within their social environments and make decisions interdependently, is founded on ethics of care beliefs (Gordon, 2012; Hall, 2012; Kretzmann & McKnight, 1993). As will be illustrated below, the notion of protection for vulnerable adults from a relative-autonomy perspective can be facilitated through the use of safeguards within the
vulnerable adults’ social support networks (Nidus, 2012e, 2012h). For instance, a vulnerable person may elect a monitor within a representation agreement who will provide protection for the vulnerable person by ensuring the representative is acting in accordance with the vulnerable person’s wishes (Nidus, 2012e, 2012h). Therefore, on this continuum from ethics of justice to ethics of care, I believe the assisted and substitute decision-making options are situated as follows: committees (i.e., committees of person, committees of estate, statutory property guardians), temporary substitute decision-makers, enduring power of attorneys, advanced directives, and representation agreements.

Committees

Guided by the Patients Property Act (1996), committees can be appointed to manage the PWDs’ financial and legal affairs (committees of estate) or committees can be appointed to manage the PWDs’ health care and personal care affairs (committees of persons). Private committees are appointed after the Supreme Court of British Columbia (Supreme Court) deems the PWDs incapable of managing their financial and legal affairs and/or their health care and personal care affairs (Canadian Bar Association British Columbia Branch, 2016; Government of BC, 2016; Nidus, 2016b; Patients Property Act, 1996; PGT, 2016). Public committees are appointed after a certificate of financial incapability is issued and the PGT is appointed as the PWD’s statutory property guardian; the PGT’s powers are therefore those of a committee of estate for the PWD (BC Ministry of Health & PGT, 2016; Nidus, 2016b; PGT, 2015). Committeeship is the most intrusive option for PWDs, as their legal rights within certain domains (financial and legal or health care and personal care) are entirely assumed by their committees (Nidus, 2012g; PGT, 2015). The adult guardianship reform brought about amendments to the Patients Property Act (1996) such as Section 18(2) which states, “a
committee must, to the extent reasonable, foster the independence of the patient and encourage the patient’s involvement in any decision making that affects the patient” (p.11). Despite this aspect, which aligns with the reform movement and an ethics of care approach, the committee’s primary responsibility is to act based on their perceived best interest for the PWDs (Patients Property Act, 1996). This aligns strongly with an ethics of justice approach.

**Private committees of persons and committees of estates.** Committees of estate and committees of persons are assigned to PWDs when the Supreme Court deems them incapable of formal decision-making in certain domains (Canadian Bar Association British Columbia Branch, 2016; Government of BC, 2016; PGT, 2014a, 2014b, 2016). These rulings of incapability are largely based on clinical evidence, provided by two physicians, which suggests the intellectual abilities of the PWDs are insufficient for managing their own affairs in the specific domains being assessed (e.g., financial and legal or health care and personal care) (Hall, 2012; Patients Property Act, 1996; PGT, 2014a). Oftentimes these assessments are referred to as assessments of cognitive functioning (O’Connor et al., 2009). However, these assessments are largely focused on intellectual functioning, which is only one component of cognitive functioning (i.e., intellect, emotionality, control) and therefore they cannot be considered holistic (O’Connor et al., 2009). Persons (e.g., family members, friends) will apply to the Supreme Court to be assigned as the domain-specific incapable PWDs’ committees (Patients Property Act, 1996; PGT, 2014a). This process can result in the Supreme Court assigning committees for the domain-specific incapable PWDs that they may not have chosen for themselves.

Private committee membership is an intrusive option because the assessment process is based on the persons’ intellectual abilities and rulings of incapability result in the PWDs’ legal and financial or health care and personal care rights being entirely controlled by their committees (O’Connor...
et al., 2009; PGT, 2015). Committees are aligned with the ethics of justice approach, because the
definition of capacity is based on ideas of liberal autonomy. For instance, committees have the
power to make decisions for the domain-specific incapable PWDs based on their perceived best
interest, and committees assigned may not be persons the incapable PWDs would choose for
themselves (Patients Property Act, 1996; PGT, 2015). This being stated, private committees
appointed to PWDs are unpaid persons known to the PWDs, while public committees are
strangers to the PWDs prior to appointment and paid for their services.

**Statutory property guardians.** Guided by the Adult Guardianship Act (1996), statutory
property guardians (i.e., PGT) can be assigned to incapable PWDs when they are being
financially abused, neglected, and/or self-neglected unless the individuals are registered First
Nations adults who live on reserves, in which case Indigenous and Northern Affairs Canada
would manage their financial affairs (BC Ministry of Health & PGT, 2016). Once the PGT has
been assigned, the role of the PGT is that of a committee of estate (BC Ministry of Health &
PGT, 2016; Patient Property Act, 1996).

Abuse is defined within the Adult Guardianship Act (1996), as “the deliberate
mistreatment of an adult that causes…(a) physical, mental or emotional harm, or (b) damages or
loss in respect of the adult’s financial affairs” (p.2). Furthermore, neglect is defined as
any failure to provide necessary care, assistance, guidance or attention to an adult that
causes, or is reasonably likely to cause within a short period of time, the adult serious
physical, mental or emotional harm or substantial damage or loss in respect to the adult’s
financial affairs, and includes self neglect. (Adult Guardianship Act, 1996, p.3)
Similar to neglect, self-neglect defined in the Adult Guardianship Act (1996) is related to the
adults’ care of themselves that causes similar consequences as indicated for neglect.
As with all substitute decision-making options, all persons are presumed to be capable under the law, unless proven otherwise (Adult Guardianship Act, 1996; BC Ministry of Health & PGT, 2016). It should be noted that statutory property guardianship only applies to persons who have been deemed incapable of managing their financial affairs based on receiving a certificate of incapacity (Adult Guardianship Act, 1996; BC Ministry of Health & PGT, 2016). A certificate of incapacity is determined when a designated agency or the PGT investigates a case in which an adult is suspected of and found to be abused, neglected and/or self-neglected and the adult lacks financial capacity (BC Ministry of Health & PGT, 2016). A certificate of incapability is used when less intrusive options to address the vulnerable person’s needs have not been successful (BC Ministry of Health & PGT, 2016). The assessment process to determine financial incapacity, as legislated in the Statutory Property Guardianship Regulations (2014), includes both medical and functional components (BC Ministry of Health & PGT, 2016). A physician conducts the medical component of the assessment and a qualified health care provider (i.e., registered social worker, nurse, psychiatric nurse, occupational therapist, and psychologist) conducts the functional component of the assessment (BC Ministry of Health & PGT, 2016). If a qualified health care provider is unavailable, a physician may additionally conduct the functional component of the assessment (BC Ministry of Health & PGT, 2016; Statutory Property Guardianship Regulation, 2014).

Issuing a certificate of incapability results in the PGT or Indigenous and Northern Affairs Canada gaining control of the PWDs’ financial affairs and making decisions regarding the PWDs’ affairs based on the best interests of the PWDs as perceived by appointed caseworkers (BC Ministry of Health & PGT, 2016). The assessment process for finding incapacity for statutory property guardianship differs slightly from that of private committeeship, as this
process uses an assessment with medical and functional components (Adult Guardianship Act, 1996), while private committeeship uses two medical affidavits (Patients Property Act, 1996). This process retains “the paradigmatically inherent, depersonalizing effects of a finding of projected incapacity…a non-person category” (Hall, 2012, p.24) because it removes the financial and legal rights of the PWDs and appoints PGT or Indigenous and Northern Affairs Canada employees to manage their business affairs. Although adult guardianship is similar to committeeship, these processes differ in assessment protocol.

Due to the diversity of assessment components used in adult guardianship, this process provides better context about the PWDs’ individual situations than private committeeship processes. However, the adult guardianship process still results in paid PGT or Indigenous and Northern Affairs Canada employees who are initially strangers to the PWDs acting as the PWDs’ substitute financial decision-makers. Consequently, both private and public committees are strictly aligned with an ethics of justice approach because the decision-making power is entirely given to the committee and the transfer of power to committees does not require involvement of the PWDs.

Temporary Substitute Decision-Makers

Guided by the Health Care (Consent) and Care Facility (Admission) Act (1996), temporary substitute decision-makers are chosen for PWDs who are incapable of giving or refusing health care consent (BC Ministry of Health, 2013; Nidus, 2012b, 2012d). This substitute decision-making option uses a domain-specific definition of capability, as assessment of the PWD’s ability to make decisions is localized to health care consent (Nidus, 2012b, 2012d). The individual, to assume the role of temporary substitute decision-maker, must meet the qualifications set out in the Health Care (Consent) and Care Facility (Admission) Act (1996) and
must be selected according to the hierarchical list of relationships defined in the act (BC Ministry of Health, 2013; Nidus, 2012d). The temporary substitute decision maker list is as follows:

(a) the adult's spouse; (b) the adult's child; (c) the adult's parent; (d) the adult's brother or sister; (d.1) the adult's grandparent; (d.2) the adult's grandchild; (e) anyone else related by birth or adoption to the adult; (f) a close friend of the adult; (g) a person immediately related to the adult by marriage. (Health Care (Consent) and Care Facility (Admission) Act, 1996, p.10-11)

Temporary substitute decision-makers have limited power as their decision-making abilities only pertain to the specific health care treatment decision at hand (Nidus, 2012d). Additionally, the physicians may supersede the temporary substitute decision makers’ decisions regarding life sustaining health care treatments for PWDs (Irvine, Osborne, & Shariff, 2013; Nidus, 2012b, 2012d).

This default decision-making approach aligns with the values of ethics of justice because unless the wishes of the PWDs have been expressed prior to their inability to give or refuse health care consent, the decisions-making for temporary health care decisions follow what the temporary substitute decision-makers and physicians perceive as being in the best interest of the PWDs (Nidus, 2012b, 2012d). Temporary substitute decision-makers must take into consideration wishes expressed by the PWDs prior to being incapable of giving or refusing health care consent (Nidus, 2012b, 2012d). Yet, if health care wishes have not been pre-expressed by the PWDs, decisions then rest with the temporary substitute decision-makers to determine what is best for the PWDs in regards to the health care decisions (Nidus, 2012b, 2012d). Additionally, the temporary substitute decision-maker list is based on the assumption that familial connections result in the closest relationships. This fails to meet the needs of
individuals whose closest relationships are not family members. However, since this default
decision-making approach is domain-specific and the temporary substitute decision-maker’s
power only lasts for one health care treatment decision (Nidus, 2012d), this approach for
decision-making is less aligned with an ethics of justice approach than committees.

**Enduring Power of Attorneys**

Guided by the Power of Attorney Act (1996), an enduring power of attorney document is a
domain-specific personal planning option used to organize an adult’s financial and legal affairs
(BC Ministry of Health, 2013; Nidus, 2012c; PGT, 2014b). Depending on how the document is
written, it may be active while the adult is capable and then when the adult becomes incapable,
or just when the adult becomes incapable (Nidus, 2012c). This document has the most power in
terms of legal and financial planning options and default decision-making approaches, as it is the
only substitute decision-making option that allows the decision-maker (i.e., attorney) to engage
in risky transactions if the adult has written this into the enduring power of attorney document
(Nidus, 2012i). In order to create this document, an adult must fulfill the criteria defined in the
statutory test of capacity through demonstrating understanding of the nature and potential
consequences associated with the agreement (Nidus, 2012c, 2012i; Power of Attorney Act, 1996;
zakreski, 2014). While the law presumes capacity, an adult must be capable of passing the
statutory test of capacity defined in the Power of Attorney Act (1996) for an enduring power of
attorney document to be considered valid. For clarity, a test of capacity is not a test in the clinical
sense, rather it is the qualifications laid out in the legislation or in case law for determining if a
person is considered capable of creating a contract or entering into a certain type of relationship
(Zakreski, 2014). Therefore, a determination of capacity (incapacity) is determined according to
the said qualifications. The criteria a capable adult is required to answer and/or understand to pass the statutory test of capacity defined in the Power of Attorney Act (1996) includes:

(a) the property the adult has and its approximate value; (b) the obligations the adult owes to his or her dependants; (c) that the adult's attorney will be able to do on the adult's behalf anything in respect of the adult's financial affairs that the adult could do if capable, except make a will, subject to the conditions and restrictions set out in the enduring power of attorney; (d) that, unless the attorney manages the adult's business and property prudently, their value may decline; (e) that the attorney might misuse the attorney's authority; (f) that the adult may, if capable, revoke the enduring power of attorney; (g) any other prescribed matter. (p. 6-7)

Thus, PWDs would likely need to create these documents prior to the onset of dementia or in the early stage of dementia. Oftentimes legal professionals help adults create these documents and in these cases, the legal professionals (i.e., lawyers, notary public) would apply the statutory test of capacity, defined above, usually on their first meeting when the legal professionals are receiving instructions from their clients to create power of attorney documents (K. Kramer, personal communication, July 29, 2016; Nidus, 2012c). Even if the legal professionals have no doubt or slight doubt about their clients’ capacity, collecting evidence (e.g., medical evidence, etc.) to support their capacity increases the chance the clients’ wishes will be followed in the future if the validity of the documents are contested (K. Kramer, personal communication, July 29, 2016).

Adults, however, may draw up these documents independently without legal assistance although there may be benefits to legal consultation (Nidus, 2012i).

Enduring power of attorney documents are still aligned with ethics of justice values, as domain-specific capacity is perceived as fixed rather than fluid (Nidus, 2012i). Yet, aspects of
this personal planning option enable self-determination of capable adults by allowing them to
elect adults to manage their financial and legal affairs if they become incapable of independently
managing their affairs in the future (Nidus, 2012c, 2012i). Additionally, this legal planning
option allows capable adults to determine the situations in which the attorneys may act on their
behalf (Nidus, 2012c). Since this legal planning option enables greater levels of self-
determination, it is located approximately in the middle of the ethics of justice and ethics of care
continuum although slightly closer to the ethics of justice side.

**Advance Directives**

Guided by the Health Care (Consent) and Care Facility (Admission) Act (1996), an
advance directive is a health care-specific personal planning option used to arrange adults’ health
care affairs in the case they become unable to give or refuse health care consent (BC Ministry of
Health, 2013; Nidus, 2012a, 2012b). Therefore, domain-specific capacity is required to create
this document (Health Care (Consent) and Care Facility (Admission) Act, 1996; Nidus, 2012a),
because the adult who creates the document must understand the nature of the document and the
consequences that ensue with its creation (Health Care (Consent) and Care Facility (Admission)
Act, 1996; Nidus, 2012a). Hence, this document is applicable only to PWDs who planned in
advance to the onset of dementia or PWDs in the early stage of dementia. Advance directives are
unique among the other personal planning options because they do not require adults to elect
assisted or substitute decision-makers; rather, the document will provide direction to health care
professionals if the adults are unable to give or refuse health care consent for themselves (BC
Ministry of Health, 2013; Nidus, 2012a). While advance directives can be effective when used to
give direction in a specific health care treatment situation (e.g., surgery), advance directives are
less effective when used for long term health care planning. When using advance directives for
long term health care planning, it is challenging for adults to predict the diverse health care situations that may occur throughout their lifetime and predict the medical and technological advances that may occur (Nidus, 2012a). Consequently, if the advance directive instructions are unclear or if the instructions have not taken into consideration medical and technological advances, the health care instructions of the adult may not be followed (Nidus, 2012a). Despite the challenges with advance directives, advance directives may state the adults’ wishes for life-sustaining health care treatments, which unlike temporary substitute decision-makers’ decisions, must be respected and followed by the health care professionals (BC Ministry of Health, 2013; Health Care (Consent) and Care Facility (Admission) Act, 1996; Irvine et al., 2013; Nidus, 2012b). However, advance directives have less power than representation agreements (Health Care (Consent) and Care Facility (Admission) Act, 1996; Nidus, 2012a). For instance, if both documents have been created, the representation agreement supersedes the advance directive (Health Care (Consent) and Care Facility (Admission) Act, 1996; Nidus, 2012a).

Similar to enduring power of attorney documents, advance directives are located slightly off centre of the spectrum between ethics of justice and ethics of care. However, I argue advance directives are slightly closer to ethics of care than enduring power of attorney documents because the decision-making power remains entirely in the PWDs’ pre-emptive written health care wishes (Nidus, 2012a). This personal planning option empowers the voices of the PWDs and entirely preserves their self-determination unless the instructions are unclear and/or fail to take into consideration medical and technological advances that have taken place since the documents’ creation (Nidus, 2012a). However, this personal planning option still remains slightly closer to the ethics of justice side of the continuum because self-determination within an
advance directive is based on a liberal autonomy perspective rather than a relative-autonomy perspective.

**Representation Agreements**

Guided by the Representation Agreement Act (1996), representation agreements (RAs) can be broken down into two types: section 7- standard representation agreements (RA7) and section 9- non-standard representation agreements (RA9). The scope covered by a RA7 includes legal, financial, health care, and personal care decision-making, while the scope covered by a RA9 includes health care and personal care decision-making (Nidus, 2012e; Representation Agreement Act, 1996). The scope of a RA7 is, therefore, much larger than a RA9; yet, the breadth of decision-making available in a RA7 is limited compared to a RA9 (Nidus, 2012f; Representation Agreement Act, 1996). For instance, a RA9 enables the representative to assist in life sustaining health care treatment decision-making while this is not included in the scope covered by a RA7 (Nidus, 2012f; Representation Agreement Act, 1996). Another difference is that a RA7 does not require a PWD to have the ability to pass a legal test of domain-specific capacity, while this is required to create a RA9 (Nidus, 2012e, 2012f). RA7s are to be single planning documents used to cover many decision-making areas of PWDs’ lives that can be used when PWDs “need help today” (Taylor, 2015) and their personal planning options are limited by legal tests of capacity required to create other personal planning documents. Consequently, RA7s provide an alternative to committeeship when PWDs need support with formal decision-making but have limited legal capacity.

Representation agreements are aligned with an ethics of care approach in which RA7s are more aligned with an ethics of care approach than RA9s. Representation agreements adopt a fluid definition of capacity, which allows PWDs to make decisions on days when they are able to
communicate their wishes themselves and allows their representatives to support the PWDs with decision making when the PWDs struggle with communicating their wishes (Gordon, 2012; Nidus, 2012g; Representation Agreement Resource Centre, 2004, 2005). A representative is a facilitator who

is always listening to the individual’s communication (all forms of communication are recognized) to enable them to participate in decision making. A representative not only preserves an individual’s self-determination, they strive to enhance it. A representative does not take the place of the individual, they act as a bridge to help third parties know and interact with the individual. (Gordon, 2012, p.5)

While this is built into the foundation of these documents, RA7s allow for greater flexibility in capacity, as creators of these documents are not judged based on common criteria for determining legal thresholds for formal decision-making (i.e., individual rationality) (Nidus, 2012e). Additionally, this personal planning tool is based on a person-centred approach in which “the relationship is the most important factor, not the instrument” (Representation Agreement Resource Centre, 2002, p.9). Consequently, the desires of the PWDs take precedence over the perceived best interest of their representatives (Nidus, 2012e, 2012f, 2012g, 2014). The PWD is placed at the centre of the equation (Nidus, 2014; Representation Agreement Resource Centre, 2002), as the ethics of care value of relative-autonomy is foundational to these documents (Gordon, 2012). The PWDs’ social support networks are used to ensure the PWDs’ safety and wishes are respected by allowing the PWDs to elect representatives, alternative representatives, and monitors within these documents (Nidus, 2012e, 2012g; Representation Agreement Resource Centre, 2002). While representatives are appointed persons who assist PWDs with domain-specific decision-making, monitors have valuable roles in ensuring the safety and self-
determination of PWDs are respected (Nidus, 2012h, 2014). Monitors do not assist PWDs with decision-making (Nidus, 2012h). Instead, the role of a monitor is to ensure representatives are acting with integrity (Nidus, 2012h). If the actions of representatives are questionable, then the monitor is required to intervene and assist in finding solutions and if necessary, contact the PGT (Nidus, 2012h). Thus, it is through the social support network of the PWDs (i.e., representatives, monitors) that the PWDs can be protected through a relative autonomy approach rather than a liberal autonomy approach (i.e., paternalism). Consequently, of all the personal planning and default decision-making options, RA7s are the most aligned with ethics of care values, as capacity is entirely revolutionized to align with a relative-autonomy approach within this document, with RA9s following closely behind (Nidus, 2012e, 2012f, 2012g). Additionally, these documents also align most closely with ethics of care values because they facilitate the use of the PWDs’ social support networks to enable decision-making abilities of the PWDs (Nidus, 2012e, 2012g; Representation Agreement Resource Centre, 2002).

As illustrated, the substitute decision-making and assisted decision-making options available within BC adult guardianship and planning statutes can be analyzed based on their positions along a philosophical continuum from ethics of justice to ethics of care. While the adult guardianship reform aimed to modernize the adult guardianship legislation so it better respected the rights and self-determination of domain-specific incapable persons, the level of protection for PWDs’ autonomy differs throughout the legislation based on different definitions of capacity.

**Capacity**

It is apparent that definitions of capacity differ based on the review of substitute and assisted decision-making options available under BC adult guardianship and planning statutes. Prior to beginning a discussion on capacity, it should be acknowledged again that the adult
guardianship reform and the current adult guardianship legislation are based on several principles, one being, that under the law everyone is presumed to be capable (Adult Guardianship Act, 1996; Gordon, 2012). Capacity is the legal gatekeeper that allows or restricts the autonomy of PWDs and determines when protection should supersede autonomy (Grisso & Appelbaum, 1998; Zakreski, 2014). This makes the conversation about capacity contentious. From the analysis above, it is clear the epistemological assumptions informing different definitions of capacity have powerful effects on the process for determining PWDs’ domain-specific incapability.

**Definitions of Capacity and Competency**

In the literature, capacity and competency generally refer to autonomy (Shulman, Cohen, & Hall, 2005) and these terms are often defined as “a concept used to determine whether a person is qualified or competent or even just inherently able to make an effective decision, enter into a binding transaction, or form a legally valid relationship” (Zakreski, 2014, p.3). The specific definitions of capacity and competency often differ (Shulman et al., 2005). Capacity often refers to a persons’ medically based cognitive status and competency often refers to legal tests determining a persons’ decision-making abilities (Shulman et al., 2005). Yet, capacity and competency are often used synonymously (O’Connor et al., 2009; Shulman et al., 2005). I use the term capacity (incapacity) to refer to the general idea of a person’s right to autonomy because the purpose of discussing capacity and competency for this report is to explore the epistemological assumptions rather than their technical use in medicine or law.

Prior to entering my practicum, I considered capacity to be categorized as global-capacity, domain-specific capacity, or relative-autonomy where each type of capacity could be placed on a philosophical continuum between ethics of justice and ethics of care. I tended to refer to global-
capacity as absolute, as Nidus (2016b) refers to committeeship and adult guardianship as processes in which “the adult loses his or her decision-making rights… sometimes called ‘civil death.’ In the legal realm, the adult is a non-person” (p.1). Additionally, in regards to PWDs being deemed incapable through the adult guardianship process, Hall (2012) states

Formally, of course, the loss of personhood is no longer considered to follow a finding of incapacity for guardianship purposes in law or in medicine. At the more pervasive social level, however, the taken-for-granted embodiment of autonomy—the rational, independent, and self-maximizing figure of the “autonomous man”—necessarily and automatically works to depersonalize the post-capacity individual. A person found to lack capacity now and for the projected future is effectively and necessarily positioned as a non-person, a failed (and not merely misruled) state. (p.9)

While the perspectives of capacity stated by Nidus (2016b) and Hall (2012) are common in the literature when defining capacity associated with committeeship and adult guardianship, within the first week of my practicum, I became aware that absolute global-capacity is a term of the past, as the idea of global-capacity does not exist within the legislation or in practice (BC Ministry of Health & PGT, 2016). As stated by Zakreski (2014), “there is no single, global test of capacity. Instead, the law has developed many different tests of capacity, each geared to a specific type of transaction or relationship” (p.3). Consequently, a more accurate description may be to use the term involuntary-continuous incapacity, as both the private and public committeeship processes cause PWDs to involuntarily surrender decision-making rights and transfer decision-making power on a continuous rather than a temporary basis from them to their substitute decision-makers.
Involuntary-continuous incapacity determinations are legal processes; however, medical evidence, based on intellectual assessments, is relied on to support claims of involuntary-continuous incapability (Adult Guardianship Act, 1996; Grisso & Appelbaum, 1998; Hall, 2012; Patients Property Act, 1996; Shulman et al., 2005). Since the evidence to support determinations of involuntary-continuous incapacity tend to be measured according to adults’ abilities to engage in higher-level cognitive functions (i.e., frontal and temporal lobe function), this greatly increases PWDs’ chance of being deemed incapable (Grisso & Appelbaum, 1998; Hall, 2012; Shulman et al., 2005). Involuntary-continuous incapacity is, therefore, apparently aligned with an ethics of justice perspective because the process is based on a liberal autonomy definition of capacity. The removal of the PWDs’ decision-making abilities is paternalistic as the PWDs’ involvement is minimal in the removal of their decision-making abilities and in the process of future decision-making by their appointed substitute decision-makers.

Following involuntary-continuous incapacity is involuntary-temporary incapacity in which a temporary substitute decision-maker who is determined by a legislated hierarchical list may be called upon to provide a substitute decision for the PWD with regards to a choice about a health care treatment (Nidus, 2012d). For determinations of involuntary-temporary incapacity, capacity is generally referred to as “an individual’s internal or organic ability to make an informed choice with respect to a certain decision” (Hall, 2009, p.120). Involuntary-continuous incapacity and involuntary-temporary incapacity position themselves similarly in their definition and determination of incapacity, because both assume an ethics of justice definition of capacity based on the idea of liberal autonomy. Consequently, capacity is determined within an individual rather than environmental context, since appointed substitute decision-makers are not selected by the incapable PWDs, and decisions made by the substitute decision-makers are based on the
decision-makers’ perceived best interest for the incapable PWDs. These are characteristics associated with ethics of justice. Despite many similarities between involuntary-continuous and involuntary-temporary incapacity, involuntary-continuous and involuntary-temporary incapacities differ with regard to the contexts of general versus specific decision-making within the decision-making domain. Consequently, since involuntary-temporary incapacity exists for one health care decision, while involuntary-continuous incapacity exists for all the PWD’s domain-specific decision-making, unless a reassessment occurs and finds the PWD no longer deemed incapable (BC Ministry of Health & PGT, 2016; Patients Property Act, 1996), involuntary-temporary incapacity is slightly less aligned with ethics of justice than involuntary-continuous incapacity.

Following involuntary-temporary incapacity on the continuum between ethics of justice to ethics of care is voluntary-continuous incapacity. Similar to voluntary-continuous incapacity, involuntary-continuous and involuntary-temporary incapacities are based on the idea of domain-specific capacity. This perception of capacity is a more humanizing approach used to measure autonomy because autonomy is broken down into specific decision-making areas (i.e., financial, legal, health care) (Hall, 2012; O’Connor et al., 2009). The assessment processes used for determinations of voluntary-continuous incapacity are specific to certain areas of the PWDs’ lives based on the PWDs’ understanding of the personal planning documents and the potential consequences that may ensue from their creation (Power of Attorney Act, 1996).

The primary difference between involuntary-continuous and involuntary-temporary incapacities versus voluntary-continuous incapacity centres on the use of the terms involuntary and voluntary. Involuntary incapacities are associated more closely with paternalism as the PWD has little choice in the legal tool used or the substitute decision-maker selected. However, in
situations associated with voluntary-continuous incapacity, the PWD engages voluntarily in personal planning and the PWD can choose the substitute decision-maker. Despite the wishes of the PWD being better respected with the creation of personal planning documents associated with voluntary-continuous incapacity, the epistemological foundation of voluntary-continuous incapacity is still based on ethics of justice values of individual autonomy and perceived best interest (Hall, 2012; Nidus, 2012i). Thus, voluntary-continuous incapacity is closely aligned with ethics of justice but it is positioned slightly closer towards ethics of care on the continuum than involuntary-temporary incapacity.

Finally, the most revolutionary idea of capacity is voluntary-fluid capacity that is based on an ethics of care approach wherein capacity is considered fluid and decision-making is interdependent (Gordon, 2012; Representation Agreement Resource Centre, 2004). Voluntary-fluid capacity is, therefore, positioned closely with ethics of care on the continuum. While ideas of relative-autonomy have been idealized by the community in its approach to addressing capacity (Gordon, 2012; Representation Agreement Resource Centre, 2004; Taylor, 2015), academics such as Hall (2012) argue that this approach is elitist when applied to the idea of guardianship and does not acknowledge that many persons do not have functional social support networks, such as PWDs who may be experiencing abuse, neglect, and/or self-neglect.

Consequently, Hall (2012) argues that the term capacity should be entirely eradicated and supplemented with the term vulnerability because vulnerability would make the social nature of capacity visible. According to Hall (2012), capacity hides vulnerability behind the language of biomedicine that provides evidence, often perceived as objective rather than socially constructed, for the purpose of involuntary-continuous incapacity assessment processes.
Hall (2012) presents an important point about the social nature of capacity and this needs to be addressed, as these processes greatly influence the rights of PWDs. However, Hall’s (2012) critique of the idea of social support network’s exclusiveness in the context of adult guardianship does not acknowledge the possibility that alternatives to private and public committeeship such as the creation of a representation agreement requires only one trustworthy person to act as the PWD’s representative. While some PWDs may not have a trustworthy person in their lives, acknowledging that their social support network could only consist of one adult makes alternatives to private and public committeeship, such as creation of representation agreements, more accessible for a greater portion of the population.

**Application to Social Work Practice**

Although it appears that an ethics of care approach for defining capacity and assisted decision-making is advantageous for PWDs, especially when engaging in personal planning for PWDs who have trustworthy adults/social support networks to assume positions within representation agreements, within the context of abuse, neglect, and/or self-neglect interventions, ensuring protection often takes priority over maintaining the autonomy of incapable PWDs (Adult Guardianship Act, 1996). Consequently, rapid decisions often must be made to ensure the least amount of harm is inflicted on the PWDs. For this reason, as stated previously, social workers often adopt an eclectic practice approach with an emphasis on ethics of care, but also a consideration of ethics of justice in crisis situations defined by incapability, abuse, neglect, and/or self-neglect (Holland, 2006, 2010).

**Conclusion**

The older adult population and the rate of dementia are rapidly growing in BC (Duffy & Healy, 2011). As public attitudes and societal structures remove self-determination from older
adults with dementia, finding ways to better protect their right to self-determination is important (Gill, 2000; Gordon, 2012; Ray et al., 2009). The adult guardianship reform was a reaction to concerns about the rights, self-determination, and safety of vulnerable populations within the context of adult guardianship and incapacity planning. To address these concerns and modernize the adult guardianship process, the current suite of adult guardianship legislation was developed to incorporate both ethics of justice and ethics of care approaches. Subsequently, personal planning is now promoted as an effective tool for preserving self-determination of PWDs (BC Ministry of Health, 2013; PGT, 2014b; Taylor, 2015). These assisted and substitute decision-making options, and their respective definitions of capacity, can be placed on a continuum between ethics of justice and ethics of care in which the options closer to ethics of care are more supportive of PWDs’ autonomy. As these statutes and their associated epistemologies greatly influence the rights of PWDs, it is important to investigate how legislative and non-legislative processes are being interpreted and operationalized in practice to determine their effectiveness in empowering PWDs by protecting their rights, promoting their self-determination, and preventing abuse, neglect, and/or self-neglect. It is through the connection of theory and practice that legislative and non-legislative processes can be improved to create systems that better meet the needs of PWDs.
CHAPTER FOUR: Practicum Locations and Learning Experiences

As mentioned, my practicum involved placement at Northern Health (approximately three months, two weeks). I received opportunities to spend time with several Northern Health departments (i.e., palliative care, residential care and convalescent care, risk and compliance). While the majority of my time was spent at several Northern Health departments, I was fortunate to also receive opportunities to spend time at BCCEAS and Nidus. Since the topic of adult guardianship and incapacity planning are areas of practice that intersect medicine and law (Hall, 2012), spending time with several departments and organizations throughout my practicum provided opportunities to develop understanding about the legal and medical roles associated with adult guardianship and incapacity planning. In addition, Northern Health, BCCEAS, and Nidus assume roles in interpreting and operationalizing adult guardianship legislation, which was a key focus of my practicum learning goals. While my practicum was composed of many tasks and activities, this practicum report will only provide an overview of experiences directly related to my primary learning goal and identified subthemes.

My primary goal for the practicum was to develop insight into the effectiveness of adult guardianship legislation in empowering PWDs by protecting their rights, promoting their self-determination, and preventing abuse, neglect, and/or self-neglect. To achieve this goal, subthemes were used to separate this goal into several components for reflection. The subthemes include: interpretation and operationalization of legislation in practice; gaps in legislative and non-legislative processes; legislation and empowerment of PWDs; and assisted and substitute decision-making in relation to abuse, neglect, and/or self-neglect of PWDs. It was through the combination of experiences throughout my practicum that I developed a more holistic understanding of adult guardianship legislation and its interpretation and operationalization in
practice. As discussed in Chapter 3, personal planning and the default decision-making options, and their respective definitions of capacity, can be placed on a continuum between ethics of justice and ethics of care. I also make reference to this continuum with regards to my practicum experiences. In addition, I explain how I applied Freire’s (2010) educational framework in order to connect theory and practice and to develop insight about my primary practicum goal and subthemes.

**Practicum Locations**

For my MSW practicum, I was placed at Northern Health and received opportunities to also spend time at BCCEAS and Nidus. Placement at Northern Health with opportunities to spend time at BCCEAS and Nidus provided a holistic experience for understanding the roles of the health care system, legal system, and community-based organizations within the field of adult guardianship and incapacity planning. Here, I provide a brief overview of each of the practicum locations (Northern Health, BCCEAS, and Nidus) and their specific roles in interpreting and operationalizing adult guardianship legislation. It should be noted that while my Northern Health-based practicum supervisor did arrange opportunities for me to spend time at BCCEAS and Nidus to provide other perspectives within the field of adult guardianship and incapacity planning, these organizations were not responsible for supervising me.

**Northern Health**

Northern Health is one of five regional health authorities established under the Health Authorities Act (1996) (Government of British Columbia, n.d.). A large geographic area, smaller population, and rural and remote context distinguishes Northern Health from other health authorities in BC according to the lead for public affairs and media relations at Northern Health (J. Dyck, personal communication, March 14, 2016). Northern Health is also unique, as the
portion of adults (i.e., 55 years and older) served by Northern Health is expanding faster than any of the other health authority service regions (Northern Health, 2013). As stated previously, older adulthood is correlated with increased risk for developing dementia and dementia is a factor that increases the likelihood of older adult abuse (American Psychiatry Association, 2013; Cunningham et al., 2015; O’Connor et al., 2009). Northern Health is therefore an ideal location to explore the effectiveness of adult guardianship legislation in empowering PWDs by protecting their rights, promoting their self-determination, and preventing abuse, neglect, and/or self-neglect.

Northern Health provides diverse services to residents of Northern BC such as acute care, residential care, home and community care, mental health and addictions, and health promotion, which have been arranged according to priority for budgetary spending (Northern Health, n.d., 2015). Based on analysis of budgetary spending, Northern Health emphasizes a down-stream approach (i.e., intervention) with a limited emphasis on an up-stream approach (i.e., prevention), as the majority of funding is spent on health intervention rather than health promotion (Northern Health, 2015).

Under the Adult Guardianship Act (1996) and the Statutory Property Guardianship Regulation (2014), Northern Health has a responsibility to investigate reports of abuse, neglect, and/or self-neglect of vulnerable populations, provide supports and assistance for vulnerable persons experiencing abuse, neglect, and/or self-neglect, and determine if beginning the certificate of incapability process is necessary in cases reported to the health authority (BC Ministry of Health & PGT, 2016). Consequently, Northern Health has appointed three Health Authority Designates, an Abuse and Neglect Specialist, and several qualified health care
providers to assist in fulfilling their legislated responsibilities under the Adult Guardianship Act (1996) and Statutory Property Guardianship Regulation (2014).

Northern Health also assumes roles in the process of educating the public on ACP and collecting information from patients/residents in regards to their assisted and/or substitute decision-makers. These roles have been delegated to various departments of Northern Health rather than to a particular lead with a standardized process applied to all departments.

**British Columbia Centre for Elder Advocacy and Support (BCCEAS)**

BCCEAS is a Vancouver-based, non-profit organization specializing in older adult advocacy, legal representation, and public education to promote dignity for older adults and protection from abuse and/or neglect (BCCEAS, 2016a, 2016c). BCCEAS is committed to bringing about social justice for older adults through advocacy using both up-stream (e.g., outreach, education) and down-stream (e.g., legal representation, abuse and neglect support) approaches.

Since BCCEAS specializes in older adult abuse prevention and intervention, the workshop coordinator often attends events in the community in which information is provided on abuse and related services for older adults. Additionally, the seniors abuse and information line (SAIL) director addresses public callers’ concerns about older adult vulnerability and often directs callers to appropriate services (e.g., health authority adult guardianship workers). While I did not shadow an employee working for BCCEAS’s legal program, the cases assumed by the legal professionals sometimes addressed issues associated with adult guardianship legislation including adult guardianship, capacity, financial exploitation, and abuse and/or neglect (BCCEAS, 2016b). Consequently, BCCEAS interprets and operationalizes adult guardianship legislation through the provision of services used to assist the public in finding appropriate
resources for adult guardianship cases and provide interventions (e.g., legal representation, victim services) to address the violations of the rights of older adults.

**Nidus Personal Planning Resource Centre and Registry (Nidus)**

Nidus is a Vancouver-based, non-profit organization that specializes in the promotion of personal planning with an emphasis on advocating for the use of representation agreements (RA7s and RA9s) and enduring power of attorney documents (Nidus, 2016a, 2016c, 2016e). Nidus provides services and resources focused on educating, supporting, and assisting the public with personal planning (Nidus, 2016e). Most of the resources and services provided by Nidus are based online (e.g., website handouts, webinars, online personal planning document forms, etc.). A unique online resource provided by Nidus is the personal planning registry (Nidus, 2016f). The Nidus personal planning online registry provides a centralized location where British Columbians can store their personal planning documents (Nidus, 2016f). British Columbians with registry accounts can also allow certain persons (e.g., health care professionals, representatives, monitors, attorneys, etc.) access to view their personal planning documents (Nidus, 2016f). Nidus assumes an up-stream approach in the field of adult guardianship and incapacity planning as the organization focuses on proactive personal planning to avoid committeeship (i.e., adult guardianship and private committeeship) (Nidus, 2016e).

Nidus interprets and operationalizes adult guardianship legislation through the provision of resources and services to promote personal planning and prevent committeeship (Nidus, 2016e). Although Nidus does not have a role defined in legislation, Nidus was founded in response to the enactment of the Representation Agreement Act (1996) to promote the provisions of the act (i.e., promote the use of RA7s and RA9s) (Nidus, 2016d). Thus, Nidus assumes an important role in the operationalization of adult guardianship legislation.
Practicum Experiences and Learning Themes

As stated previously, I spent time at Northern Health, BCCEAS, and Nidus throughout my practicum. At Northern Health, where most of my practicum was situated, my time was spent with several teams. My practicum schedule was as follows: four weeks with a Northern Health palliative care team, five weeks with a Northern Health residential care and convalescent care team, two weeks at BCCEAS, one day at Nidus, and five weeks with the Risk and Compliance team (in which the majority of my time was spent with the Northern Health Patient Care Quality Office (PCQO) regional manager and Adult Abuse and Neglect Specialist). I also spent time intermittently throughout my practicum with the Northern Health Abuse and Neglect Specialist when relevant learning opportunities arose related to adult guardianship and to receive clinical supervision, as she was also my practicum supervisor. What follows is a brief description of tasks and activities, related to the topic of interest, completed at each practicum location and the contribution of these experiences for understanding my primary learning goal and subthemes.

Northern Health Palliative Care Team

The activities and tasks I completed with the palliative care team, related to adult guardianship legislation, were focused on ACP. Some of the ACP opportunities I received included learning from a previous ACP project lead, participating in a palliative care ACP webinar, and completing an ACP quality assurance project.

Speaking with a past ACP project lead about her project allowed me to gain insight about Northern Health’s history with ACP and introduced me to past operationalization strategies used by Northern Health to develop employees’ comprehension of the legislation associated with ACP.
Attending the webinar prepared by the palliative care team on ACP provided me with an opportunity to learn about how ACP education is disseminated to the public and health care professionals. This opportunity developed my understanding of this team’s interpretation of adult guardianship legislation and their epistemological stance associated with ACP. The presentation emphasized the importance of having “conversations with family or friends and health care providers about your beliefs, values and wishes” (BC Ministry of Health, 2013, p.8), the initial step of ACP.

The presentation’s emphasis on this first step of ACP was notable, as my research in this field had not focused on the process of ACP but rather on understanding the epistemology embedded within each assisted and default decision-making option and its associated definition of capacity. Also, this presentation introduced me to the importance of focusing on the process of ACP for empowering PWDs. It is through these conversations that PWDs’ social support networks develop context about the PWDs’ values, beliefs, and wishes and be better able to assist in decision-making for PWDs that are aligned with the PWDs’ true wishes in cases in which the PWDs are unable to make decisions for themselves.

Presenters described ACP documents (e.g., advance directives, representation agreements, power of attorney documents, etc.) impartially; thus, taking an ethics of justice approach for document presentation. Yet, through the emphasis on this first step of ACP, an ethics of care approach was also assumed. As stated previously in Chapter 2, ethics of care’s stance on a moral life is defined “as a network of relationships with specific people, and…‘living well’ as caring for those people, attending to their needs, and maintaining their trust” (Rachels & Rachels, 2015, p.154); thus, the presenters’ emphasis on conversations to develop understanding of the advance care planner’s personhood emphasized ethics of care beliefs.
Finally, the ACP quality assurance project allowed me to speak with Northern Health employees across service delivery areas and departments about the current ACP processes (i.e., education, conversations, and collection) used at their worksites to determine their opinions about successes and gaps in these processes. This project further developed my understanding of Northern Health’s interpretation and operationalization of legislation in practice and illustrated the structural constraints experienced by the health care system.

Overall, my time spent with this palliative care team developed my global understanding of the interpretation and operationalization of adult guardianship legislation within this team and across Northern Health, and illustrated strategies for conducting adult guardianship legislation education that may cause greater empowerment of PWDs.

Northern Health Residential and Convalescent Care Team

My time at a residential and convalescent care facility provided me with an opportunity to understand ACP related to PWDs at a local level. The majority of my time was spent assisting with the implementation of an ACP project applied in the residential care facility. The project consisted of several components including education, conversations, document collection, and document storage.

The palliative care quality assurance project illustrated structural challenges limiting ACP implementation processes at Northern Health; however, the residential care ACP project appears to be a step towards developing a formal ACP process that may be transferable to other departments.

Implementation of processes for increasing awareness of the ACP wishes of PWDs and documents of residents in residential care facilities is important, as many residents live with conditions such as dementia. Consequently, assisted and/or substitute decision makers are
frequently called upon to make decisions on behalf of residents and it is important to ensure a
system is in place where health care professionals are aware of the correct decision-makers to
contact when decisions are required.

Although education was provided to residents, their families, and staff about ACP and the
importance of informing health care professionals about residents’ assisted and substitute
decision-makers, opportunities for creating ACP documents were often limited by residents’
level of mental capability across domains. While RA7s were developed as a means for assisting
with decision-making for persons with limited mental capabilities (Gordon, 2012), providing
education about ACP in a residential care setting often brought up questions about the creation of
RA7s for residents living with dementia. While explaining the concept of capacity from an ethics
of care perspective is straightforward in theory, challenges arise in practice. This was an area of
discomfort for myself and other health care professionals. The idea of relative autonomy often
causes challenging situations in practice. Additionally, it was questionable whether it was
appropriate for social workers to interpret legislation within a residents’ context (i.e., apply the
RA7 test of incapability). Yet, these types of questions sometimes arose during presentations and
conversations about ACP within residential care facilities. As representation agreements are
accessible assisted decision-making documents for British Columbians with diverse
socioeconomic statuses (BC Ministry of Attorney General, 2002), advising residents and their
social support networks towards legal professionals often discounts their socioeconomic context.
Additionally, creation of RA7s for residents with limited mental capacity also raised questions
about the residents’ welfare and the potential motives associated with persons who are
encouraging the creation of these documents, as these situations are often encountered by the
PGT and also surfaced with the Risk and Compliance team.
Since the Adult Guardianship Act (1996) brought about the principle of committeeship as the last resort, finding ways for PWDs to have assisted and default decision-makers becomes challenging when there is hesitancy around the use of RA7s as well. In residential care settings, in which PWDs often lack the ability to pass a legal test of capacity for creating power of attorneys and RA9 documents, there are apparently few options for appointing assisted or substitute decision-makers besides committees or representatives appointed through RA7s. However, within these settings, it was common for PWDs, without assisted or substitute decision-makers, to experience challenges associated with personal care decisions and income tax filing. These challenges seemed to increase this population’s need for assisted and substitute decision-makers.

Conversations with residents and their social support networks about ACP documents were also challenging for other reasons, as the topic is often perceived as private. These conversations helped me develop the ability to have difficult conversations with residents and their social support networks. It was through these conversations I learned the importance of setting aside enough time to allow residents and their social support networks to fully process issues associated with this topic. This project illustrated why health care professionals are often hesitant when taking on ACP projects in their departments, as the projects require a substantial amount of time and human resources.

Overall, this ACP project exposed me to the creative initiative taken on by the social workers at this residential care facility for educating residents, families, and staff about the importance of understanding ACP so residents’ wishes can be respected. This project also illustrated several challenges such as limited time for professionals to work on additional projects, the complexities associated with capacity, the time required to have thoughtful
conversations with residents and/or their social support networks, and the ethical challenges associated with collection of this information. These experiences furthered my understanding of the interpretation and operationalization of adult guardianship legislation in practice and illustrated challenges associated with RA7s in practice.

**BC Centre for Elder Advocacy and Support (BCCEAS)**

At BCCEAS, I spent time familiarizing myself with their services and programs, learning the roles of several employees (e.g., workshop coordinator, SAIL director), and developing a better understanding of legal tests of capacity.

These experiences helped me to develop a better understanding of the unique services offered by BCCEAS and enhanced my understanding of adult guardianship legislation interpretation and operationalization. The workshop coordinator invited me to attend a community outreach event in which she provided education about older adult abuse and/or neglect to the public. Additionally, I assisted BCCEAS’s summer student with a community outreach project used to raise awareness about BCCEAS in rural and remote communities in BC. Raising awareness about older adult abuse and/or neglect increases community members’ responsiveness to assist in older adult abuse and/or neglect situations and encourages community members to contact services if they witness situations involving older adults being abused and/or neglected. Through these initiatives, BCCEAS is helping vulnerable populations, in need of protection under the Adult Guardianship Act (1996), to connect with health authorities or the PGT.

Furthermore, the SAIL employees provided information on older adult issues to callers and referred callers to appropriate programs (e.g., BCCEAS victim services, BCCEAS legal clinic, health care authority, etc.) to assist with their needs. This allows programs such as health
authority adult guardianship programs to run more efficiently in delivering services. The SAIL
director often spent time educating callers about the principles of the Adult Guardianship Act
(1996), especially in regards to older adults’ right to live at risk if they are capable. These
experiences highlighted the importance of interconnections between agencies (e.g., BCCEAS,
health authorities, PGT) in ensuring safety and self-determination of the older adult population.
Each agency assumes a crucial role in protecting the rights of older adults and subsequently
PWDs.

While I was at BCCEAS, I was also able to speak with a lawyer about the process for
conducting a legal test of capacity. This conversation illustrated the complexity of domain-
specific capacity, the importance of building a positive attorney-client relationship, and
documentation providing substantial evidence to prove the capacity of clients who live with
diseases associated with cognitive impairment, such as dementia.

My experiences at BCCEAS were associated with the idea of liberal autonomy and
consequently, ethics of justice. For example, education was mostly provided based on the idea of
capacity associated with the Adult Guardianship Act (1996), that being liberal autonomy, and
legal tests of capacity associated with documents predominantly leaning towards the ethics of
justice side of the continuum such as Power of Attorneys, Wills, and Estates.

**Nidus Personal Planning Resource Centre and Registry (Nidus)**

While my time at BCCEAS provided greater understanding of adult guardianship and
incapacity planning associated with ethics of justice, time spend at Nidus provided me with
greater insight regarding relative autonomy associated with ethics of care and the use of RA7s.

Conversing with the executive director of Nidus provided context about the adult
guardianship reform and the community’s desire to create a single personal planning document
integrating all decision-making domains, founded on ethics of care beliefs such as relative autonomy and fluid capacity (J. Taylor, personal communication, July 4, 2016). Representation agreements were developed so persons in need of assisted decision-making such as PWDs, within the health care system would not be left behind and their appointed representative (i.e., their advocate) could be the person to interface with the system ensuring their personhood was respected (J. Taylor, personal communication, July 4, 2016). It was through the creation of the ethics of care definition of capacity that persons who lacked legal capacity for the creation of substitute decision-making documents would have the ability to create a document that specified their preferred advocates. As stated previously, I found the concept of capacity from an ethics of care perspective, when applied to RA7s, to be challenging when applied in practice; however, conversing with the executive director of Nidus taught me the importance of reading legislation carefully. For example, section 8(2) of the Representation Agreement Act (1996) states,

(2) In deciding whether an adult is incapable of making a representation agreement consisting of one or more of the standard provisions authorized by section 7, or of changing or revoking any of those provisions, all relevant factors must be considered, for example: (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions; (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others; (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult; (d) whether the adult has a relationship with the representative that is characterized by trust. (p.6-7)
Consequently, the phrase I overlooked in the Representation Agreement Act (1996) was “all relevant factors must be considered, for example” (p.6). This implies that ideas similar to the examples listed can be taken into consideration. However, the considerations listed are only examples, not necessities. This illustrates the subjective nature of autonomy and PWDs’ right to create RA7s if they can display any form of choice (e.g., desire to create RA7s, positive regard towards the adults being considered for appointment as representatives, etc.).

Spending time at Nidus helped to develop my understanding of the role of Nidus in empowering PWDs through the interpretation and operationalization of adult guardianship legislation and the complexities associated with protecting PWDs’ rights to self-determination.

Northern Health Risk and Compliance Team

Many of the contentious cases faced by Northern Health are forwarded to a member of the Risk and Compliance team. During my time with this team, the PCQO regional manager and the Adult Abuse and Neglect Specialist addressed several cases involving concerns associated with adult guardianship, assisted or substitute decision-making, and PWDs. These opportunities provided me with insight about ethical dilemmas and risks associated with assisted and substitute decision-making.

Northern Health Patient Care Quality Office regional manager. Spending time with the PCQO regional manager exposed me to the legislated complaint process used by Northern Health. Throughout my time with the PCQO regional manager, I learned how to accept various forms of complaints (e.g., phone, email, in person), input complaints into the database, and compose letters for complainants. I also observed the PCQO regional manager action items out to appropriate Northern Health managers to investigate the complaints.
Spending time at the PCQO exposed me to some contentious cases, which were occasionally associated with adult guardianship, personal planning, and PWDs. As illustrated in the literature, personal planning is promoted as means for preserving self-determination of PWDs (BC Ministry of Health, 2013; PGT, 2014b; Taylor, 2015); however, spending time at the PCQO exposed me to cases where assisted and substitute decision-making situations were potentially resulting in disempowerment of vulnerable populations. Oftentimes these cases overlapped with other members of the Risk and Compliance team. For complaints associated with adult guardianship legislation, the Adult Abuse and Neglect Specialist often addressed other aspects of the cases such as finding appropriate support and assistance for the vulnerable persons. Consequently, it was interesting to learn how each of these roles contributed to the resolution of these cases.

As stated previously, the palliative care webinar presenters emphasized the first step of ACP. However, understanding the magnitude of this step’s importance in preventing social support network breakdown became apparent during my time with the PCQO and Adult Abuse and Neglect Specialist when the PWDs had relative autonomy but were unable to express their wishes for certain decisions. There were cases in which personal planning documents existed, but different persons within the PWDs’ social support networks contested the beliefs, values, and wishes of the PWDs. I realized sufficient conversations about the PWDs’ beliefs, values, and wishes may not have occurred prior to creating the personal planning documents and the cognitive changes experienced by the PWDs. Lack of understanding of the PWDs’ beliefs, values, and wishes places the social support networks and the health authority in difficult situations when decisions are required and there is conflict around decisions for PWDs. Deciphering what the PWDs would self-determine if they could express their wishes is nearly
impossible for social support networks and the health authority to determine, especially for personal care decisions. These decisions require intimate knowledge of the PWDs’ beliefs, values, and preferences. Consequently, choosing personal planning documents as a means for preserving self-determination, even if the documents are based on ethics of care’s beliefs such as relative autonomy, are only as effective as the conversations that have occurred to illustrate the meaning of self-determination prior to PWDs’ loss of ability to express their wishes for certain decisions. The ideas of ethics of care and relative autonomy are ideal in theory; however, in practice the subjective nature of relative autonomy may cause conflict about the PWDs’ wishes between members of the social support networks. The result of this conflict can be disempowerment of the PWDs, because the decisions made for the PWDs may not be the choices the PWDs would have made for themselves. Additionally, for personal care decision-making, intimate knowledge about the PWDs’ personhood is required. This makes it nearly impossible for public institutions to assist in ensuring the self-determination of the PWDs is respected.

Even if health care and personal care substitute decision-makers are appointed, well informed, and “advocate for the rights and self-determination” (Nidus, 2016g, p.3) of the PWDs, health care system limitations (e.g., resource and staff shortage) can result in concerns about the system’s ability to support the pre-expressed wishes of the PWDs. An ethical substitute decision-maker will stand by the wishes of the PWD and advocate as though the PWD was speaking. While this behaviour is ethical and appropriate for a substitute decision-maker, the health care system is responsible both to individual patients and to the general population. Consequently, the system can be resistant to following the wishes of the assisted and/or substitute decision-maker if following the PWD’s wishes may cause an unmanageable workload for staff that may result in
lesser care for other patients or if following the wishes of the PWD may cause high risk for staff members.

Consequently, spending time at the PCQO provided greater insight about challenges associated with adult guardianship legislation and difficulties with operationalizing adult guardianship legislation in practice, which can cause disempowerment of PWDs.

**Northern Health Adult Abuse and Neglect Specialist.** Most of my time with the Adult Abuse and Neglect Specialist involved shadowing her at adult guardianship presentations, educational events in which raising adult guardianship awareness opportunities potentially arise, and adult guardianship consultations. Shadowing her provided me with a better understanding of her role and duties as the Adult Abuse and Neglect Specialist.

The Adult Abuse and Neglect Specialist also gave me opportunities to respond to several callers on the adult protection line. While I felt I had a solid grasp of adult guardianship legislation, answering callers’ questions was challenging as they were often inquiring about availability and access to programs, rather than questions directly related to legislation and theory.

Time spent with the Adult Abuse and Neglect Specialist enabled me to observe the operationalization of the Adult Guardianship Act (1996) and Statutory Property Guardianship Regulation (2014) at Northern Health. Adherence to the principles defined in the Adult Guardianship Act (1996) was notable. Those being,

(a) all adults are entitled to live in the manner they wish and to accept or refuse support, assistance or protection as long as they do not harm others and they are capable of making decisions about those matters; (b) all adults should receive the most effective, but the least restrictive and intrusive, form of support, assistance or protection when they are unable to
care for themselves or their financial affairs; (c) the court should not be asked to appoint, and should not appoint, guardians unless alternatives, such as the provision of support and assistance, have been tried or carefully considered. (Adult Guardianship Act, 1996, p.4-5)

Adherence to principle (a) was recognizable because it was common for me to hear professionals, especially social workers and physicians, educating the public and their colleagues about a capable person's right to make poor decisions even if this places the adult at risk.

Principle (b) was also followed and most notable during my time spent with the Adult Abuse and Neglect Specialist. It became apparent that professionals actively involved in adult guardianship cases were deeply committed to principles (b) and (c). Although the Adult Guardianship Act (1996) states that “all adults should receive the most effective, but the least restrictive and intrusive, form of support, assistance or protection when they are unable to care for themselves or their financial affairs” (p.4), professionals specializing in adult guardianship are faced with the challenge of operationalizing this principle. Oftentimes the public or other professionals would advocate for the health authority to assume a more protective role; however, the Adult Abuse and Neglect Specialist often assisted health care professionals in connecting formal supports and mobilizing clients’ social support networks instead of using more intrusive and protective measures. Frequently, the Adult Abuse and Neglect Specialist creatively worked through systematic barriers to access least intrusive options for clients (e.g., home and community care services to clients living outside the service boundaries, assisting in application processes for pension trusteeships, etc.). Holland (2010) argues that in the field of adult guardianship “care can be balanced with autonomy…Social workers can support both autonomy and care by taking responsibility for reaching out, by slowing down and gathering the narrative puzzle pieces to complete a fuller picture, and waiting to discover the solution that will open up
to the middle ground” (p. 128-129). When I reflect on the experiences I observed in which health care professionals provided “most effective, but the least restrictive and intrusive, form of support, assistance or protection” (Adult Guardianship Act, 1996, p.4) to clients, I believe I was observing the phenomena described by Holland (2010).

While professionals in the adult guardianship field are dedicated to principle (b) of the Adult Guardianship Act (1996), systematic challenges cause difficulties in adhering to this principle. For instance, adult guardianship professionals are often required to navigate through federal and provincial systems to find least intrusive supports for clients. However, challenges around privacy issues occasionally restrict access to information sharing between provincial and federal services about adult guardianship cases. These accessibility issues result in long wait periods and uncertainty of whether the client will receive services. These factors create barriers for social support networks of adult guardianship clients from accessing least intrusive supports and assistance, which places the adult guardianship clients at increased risk for guardianship. Consequently, organizations and professionals within this field are often required to advocate at a macro level for changes to make less intrusive options more accessible for future clients.

In situations where conducting an assessment for a certificate of financial incapability was warranted, health care professionals (e.g., physicians, social workers) experienced at conducting these assessments commonly assumed this responsibility. However, some of these professionals were occasionally resistant to participating in this process, as there were concerns about therapeutic relationship breakdown. The professionals who conducted components of the assessment related to financial incapability I observed were not personal health care providers of the client. This, therefore, helped prevent challenges associated with therapeutic relationship breakdown between the client and health care providers. Additionally, receiving the opportunity
to observe the assessment process for the certificate of financial incapability was valuable because, it provided me with a better understanding of how professionals skilfully and respectfulessly conduct these assessments despite their intrusive nature.

While operationalization of the Adult Guardianship Act (1996) and Statutory Property Guardianship Regulation (2014) appears to be effective at Northern Health, operationalization of planning statutes poses challenges. For instance, there appears to be areas of confusion about planning statutes for health care professionals and the public in terms of the decisions made by different substitute decision-makers (e.g., power of attorneys, PGT, etc.) as well as challenges with operationalization of the epistemology guiding the role of assisted decision-makers (i.e., representatives).

Confusion for health care professionals and the public commonly occurred when discussing the difference between advance directives and Medical Order for Scope of Treatment (MOST) forms (i.e., physician orders). Additionally, confusion for health care professionals and the public was prevalent regarding the decision-making domains covered by power of attorneys and decisions covered by the PGT. For instance, it was common for advance directives and MOST forms to be perceived synonymously even though “the MOST form is not a legal document. It is a tool designed for physicians to record treatment options…The MOST form is not part of BC health care consent or personal planning legislation” (Taylor, 2013, p.1). Unlike a MOST form, an advance directive is a legal document that expresses the document creator’s health care consent wishes (Health Care (Consent) and Care Facilities (Admission) Act, 1996). Furthermore, health care professionals and the public often believe power of attorneys have the ability to make health care and personal care decisions, when in actuality their scope of decision-making in BC is limited to financial and legal decisions (Power of Attorney Act, 1996).
Furthermore, as I learned from the Adult Abuse and Neglect Specialist, decision-making assistance from the PGT for domain-specific incapable adults does not extend to personal care decision-making rather the PGT’s scope of decision-making extends only to financial, legal, and health care decision-making for domain-specific incapable adults. The Representation Agreement Act (1996) defines personal care decisions as matters addressing any of the following areas:

(a) the shelter, employment, diet and dress of an adult, (b) participation by an adult in social, educational, vocational and other activities, (c) contact or association by an adult with other persons, and (d) licenses, permits, approvals or other authorizations of an adult to do something. (p.3)

This was an area of confusion for myself and I also found other health care professionals and the public believing the PGT assists with personal care decision-making. While these were common misunderstandings about the role of medical documents versus legal documents and substitute decision-makers, challenges associated with operationalizing the epistemological foundation of representation agreements was also observed during my time spent with the Adult Abuse and Neglect Specialist.

Despite the community effort to create a process for personal planning founded on ideas of relative autonomy (i.e., ethics of care) (Gordon, 2012), operationalizing ethics of care beliefs appears to be challenging. Occasionally, when challenges arise with representation agreements’ ethics of care beliefs, solutions to address these challenges can sometimes result in use of what appears to be strategies founded on best interest approaches (i.e., ethics of justice). Additionally, in cases in which health care professionals have suspicions about the ethic used by
representatives to make decisions for PWDs, the role of the health care system in this process is often unclear and contentious.

As stated previously, determining if PWDs are capable of creating RA7s is challenging. Prior to speaking with the executive director of Nidus, I originally interpreted the Representation Agreement Act’s (1996) “Test of incapability for standard provisions” (p.6) as stating criteria for a legal test of capacity to determine if an adult could create an RA7. However, after speaking with the executive director of Nidus, I realized the legislation states examples of criteria for consideration rather than explicit criteria. Therefore, the total range of criteria considered is up to interpretation, which can create ambiguity and uncertainty in determining if a PWD is capable of creating a RA7. I encountered situations during my practicum in which health care professionals encouraged social support network members of PWDs to create RA7s if they wanted to be able to make personal care decisions for the PWDs such as consent to admission to residential care facilities. Since RA7s are founded on ethics of care beliefs where PWDs are placed at the centre of the conversation (Gordon, 2012), it is questionable whether RA7s are being utilized appropriately if they are being used for the sole purpose of admitting PWDs into residential care facilities. While interpretation of the “Test of incapability for standard provisions” (Representation Agreement Act, 1996, p.6) is subjective, ethics of care strongly opposes the exclusion of PWD from the conversation to focus on managing the business needs of PWD through creation of legal documents (Gordon, 2012). My conversation with the executive director of Nidus clarified that representatives are meant to be the voices and advocates of PWDs (J. Taylor, personal communication, July 4, 2016). Despite this being the case, encouraging members of a PWD’s social support network to create a RA7 to achieve a certain outcome seems
to be in opposition to the intent of the legislation, as this approach is aligned with paternalism rather than self-determination.

Furthermore, despite the adult guardianship legislation’s emphasis on acceptance of diverse communication forms, some health care professionals focus on traditional communication forms which discount the idea that PWDs who employ unconventional means of communication are still communicating through a different delivery style (e.g., nonverbal communication, behaviours demonstrating affection, behaviours demonstrating distress, etc.). It appears that health care professionals take this stance because in times of conflict regarding the PWDs’ wishes from social support network members, evidence to support the PWDs’ wishes is subjective and can easily be misinterpreted, making it hard, if not impossible, to validate. Consequently, health care professionals prioritize considerations for the PWDs’ health care risk and safety associated with the representatives’ decision-making, rather than concerns relating to PWDs’ personhood (i.e., personal care decisions). Thus, when the personal care wishes made for PWDs by their representatives are contested by members of the PWDs’ social support network, determining if the representatives are making choices aligned with ethics of care is hard to prove because the evidence used to illustrate the PWDs’ wishes is often subjective.

Although the law now supports relative autonomy, unless representatives understand ethics of care and its beliefs (i.e., relative-autonomy, assisted decision-making) and commit to employing actions in alignment with this ethic, PWDs’ self-determination will continue to be jeopardized. Since the personhood of PWDs’ and their choices based on values, beliefs, and wishes are intimate, relying on health authorities to determine if representatives are making decisions based on the PWDs’ true wishes is nearly impossible. Challenges associated with the operationalization of ethics of care, which representation agreements are founded upon,
sometimes results in disempowerment of PWDs. However, challenges associated with abuse and/or neglect perpetrated by assisted and substitute decision-makers also causes disempowerment of PWDs.

Although organizations encourage the public to engage in personal planning as a means of preserving self-determination if their capacity becomes questionable in the future (PGT, 2014; Taylor, 2015), literature linking personal planning and abuse, neglect, and/or self-neglect prevention is minimal. While it is rare to witness success stories in which adult abuse, neglect, and/or self-neglect cases have been prevented by personal planning, it is easier to observe cases in which assisted and/or substitute decision-makers are abusing their powers. These are the cases reported to the PGT and the Northern Health Adult Abuse and Neglect Specialist. Consequently, my practicum made me aware of cases in which assisted and/or substitute decision-makers are misusing power and taking advantage of vulnerable adults. Common cases tended to involve assisted and/or substitute decision-makers with addictions issues accessing the vulnerable adults’ assets to fulfill their needs. As stated previously, these observations are limited as I am unable to comment about cases in which personal planning may have prevented abuse, neglect, and/or self-neglect of a vulnerable adult. However, it appears personal planning documents should be created cautiously as disempowerment and harm to PWDs may also be caused by the creation of these documents.

Above all, spending time with the Adult Abuse and Neglect Specialist provided me with the opportunity to develop a better understanding of interpretation and operationalization of the adult guardianship legislation in a health care setting. These experiences also assisted in my understanding of challenges associated with adult guardianship legislation which cause the disempowerment of PWDs. Finally, time spent with the Adult Abuse and Neglect Specialist also
assisted in developing more insight about risks associated with personal planning and the default decision-making options for PWDs.

**Conclusion**

Overall, placement at Northern Health and time spent at BCCEAS and Nidus provided invaluable opportunities for developing my understanding of the effectiveness of adult guardianship legislation in empowering PWDs by protecting their rights, promoting their self-determination, and preventing abuse, neglect, and/or self-neglect. The opportunity to explore this topic in health care and legal settings illustrated the complexities associated with incapacity planning and adult guardianship; as well as, the necessity for contributions from agencies providing both upstream and downstream approaches for protecting the self-determination and safety of PWDs. Additionally, each facet (i.e., multiple practicum locations) of the practicum provided me with a deeper understanding of the complexity of interpretation and operationalization of adult guardianship legislation in practice, especially within structural constraints of systems; yet, provided me with opportunities to observe creative projects and strategies used to operationalize this legislation in practice. These practicum opportunities provided me with insight about challenges associated with implementing ethics of care values in practice, especially in cases in which PWDs’ wishes are unclear and conflict arises between social support network members. Additionally, observing how the idealized concept of ethics of care and values such as relative autonomy, created to empower populations such as PWDs through protection of their self-determination, can cause the opposite effect was eye opening. This illustrated some challenging disconnects between theory and practice. Finally, observing cases in which assisted and/or substitute decision-makers were abusing and/or neglecting PWDs illustrated the structural nature of many of these cases. Overall, these practicum experiences
enabled me to connect theoretical understandings with practical experiences (i.e., specific location and limited environments) to develop a more realistic understanding of this topic.
CHAPTER FIVE: Implications for Policy and Practice

By choosing to complete an MSW practicum, I hoped to contribute to the field of social work policy and practice by providing insights into the connection between theory and practice regarding adult guardianship legislation applied to PWDs. My recommendations for social work policy and practice in the field of incapacity planning and adult guardianship include: furthering community-based holistic education; addressing issues with RA7s; clarifying boundaries between individual self-determination and health care responsibilities; and increasing federal and national organization awareness about adult guardianship legislation. All of these recommendations flow from my primary learning goal and subthemes. These ideas are the result of an MSW practicum student’s observations over 560 hours in specific locations and therefore, should not necessarily be implemented without further research and investigation. However, my hope is that these ideas may provide value to the topic of adult guardianship legislation and its interpretation and operationalization in practice.

Community-Based Holistic Education

Based on my practicum experiences, it appears that providing personal planning education while people are still in the community is more effective than providing education to people after they have been admitted to the hospital or residential care facilities. Education in the community allows members of the general public to be exposed to the idea of personal planning prior to experiencing health care crises. Exposing the general public to the idea of personal planning prior to illness enables them to take the time to determine their values, beliefs, and wishes, and then communicate their wishes thoroughly and continuously with those persons they are considering appointing as assisted and/or substitute decision-makers. This pre-emptive approach also allows people to verify that their assisted and/or substitute decision-makers want to assume
these roles and clearly understand their obligations. In addition to providing personal planning education to the community, it would also be beneficial for personal planning to be a subject added to secondary school education curriculum. Providing education about personal planning to youth would allow the population to become familiar with the idea of personal planning at a young age and potentially increase the use of personal planning in the future.

Based on observations and conversations with health care professionals throughout my practicum, it became clear that, in order for assisted and/or substitute decision-makers to effectively advocate for the voices of the PWDs to be heard within systems, the PWDs need to have actively engaged in discussions with the appointed assisted and/or substitute decision-makers, before they require assisted and/or substitute decision-making. PWDs need to have conversations with their assisted and/or substitute decision-makers about their values, beliefs, and wishes in regards to certain situations (e.g., end-of-life care, admission to residential care facilities, relationships based on friendship or common law statuses, etc.). Also, it appears essential that selected substitute and/or assisted decision-makers have integrity and accountability to fulfill their duties in accordance with the PWDs’ expressed wishes. While it is ideal that elected substitute and/or assisted decision-makers have integrity and accountability when providing decision-making supports for PWDs, it is also important to encourage cultivation of coordinated community responses to protect vulnerable populations from abuse, neglect, and/or self-neglect (BC Association of Community Response Networks, n.d.).

Organizations and the Government of BC should encourage personal planning as a means for preserving self-determination if adults become incapable of making domain-specific decisions in the future (BC Ministry of Health, 2013; PGT, 2014b; Taylor, 2015). Yet, more emphasis needs to be placed on the timing of education about this topic. For instance, providing
personal planning education to secondary school students would allow personal planning to become a more natural part of the culture. Additionally, the importance of discussing values, beliefs, and wishes prior to the onset of dementia and the responsibilities assumed by assisted and/or substitute decision-makers needs to be emphasized during these education sessions. The self-determination of PWDs is best respected when assisted and/or substitute decision-makers are informed about the PWDs’ values, beliefs, and wishes. Additionally, the self-determination of PWDs is protected when their assisted and/or substitute decision-makers advocate for the PWDs based on a clear understanding of the values, beliefs, and wishes of the PWDs. At the community level, protection of PWDs’ self-determination can be supported by community members and organizations involvement in community response networks so coordinated responses can be developed to help prevent and address adult abuse, neglect, and/or self-neglect situations (BC Association of Community Response Networks, n.d). Consequently, providing personal planning education to the community and secondary school students, while community members are still well, is advantageous. This educational strategy enables persons and their elected assisted and/or substitute decision-makers the time to clarify the persons’ wishes within the assisted and/or substitute decision-makers’ decision-making domain(s) and ensures the assisted and/or substitute decision-makers are prepared to assume this responsibility.

**Addressing Issues with Standard Representation Agreements (RA7s)**

My practicum highlighted the challenges associated with the operationalization of RA7s. For example, as stated in Chapter 4, on occasion, RA7s were being used to achieve certain outcomes (e.g., admitting PWDs into residential care, preventing certain social support network members from accessing the PWDs, etc.) rather than being used as tools that facilitate the relative autonomy of PWDs. Additionally, some health care professionals also appeared to be
aware of the challenges and risks associated with the implementation of the idea of relative autonomy for PWDs based on their observations of cases in which RA7s are causing oppressive outcomes for PWDs. Health care professionals also apparently wanted clarity about the idea of the Representation Agreement Act’s (1996) “Test of incapability for standard provisions” (p.6). Consequently, RA7s seem to only achieve intended goals (protection of vulnerable populations’ rights, self-determination, and reduced risk of abuse, neglect, and/or self-neglect) when systems and the public understand the epistemology (ethics of care) that supports RA7s and when RA7s are implemented and used with the act’s original spirit and intent that arose from the adult guardianship reform.

RA7s are sometimes used to admit PWDs into residential care, which could be argued in some cases to be the misuse of RA7s; thus, my initial recommendation is for social workers to advocate for the proclamation of the latter half of the Health Care (Consent) and Care Facilities (Admission) Act (1996). This would prevent health care professionals from encouraging social support network members from creating RA7s simply to enable the admission of PWDs into residential care facilities and rather the Health Care (Consent) and Care Facilities (Admission) Act (1996) could guide health care professionals in admitting PWDs into residential care facilities.

RA7s were created to offer populations with limited legal capacity the option of creating a personal planning document to appoint an advocate who could ensure their self-determination was respected by systems such as the health care system (J. Taylor, personal communication, July 4, 2016). However, cases encountered throughout my practicum illustrated that the epistemology supporting RA7s appeared to sometimes be forgotten. Occasionally it was questionable whether social support network members of PWDs or the PWDs were appointing
the social support network members as the PWDs’ representatives. Thus, if it were in case the former, these actions would be aligned with a best interest approach for decision-making, which would be in opposition to the original intent of the Representation Agreement Act (1996) (Gordon, 2012). Additionally, since the Representation Agreement Act’s (1996) “Test of incapability for standard provisions” (p.6) provides examples rather than criteria for determining capability of a PWD for creating a RA7, PWD are placed at greater risk for undue influence and unconscionability. Consequently, when the validity of RA7s are questioned, challenges arise in determining if these inequitable doctrines existed, due to the interpretative nature of the “Test of incapability for standard provisions” (p.6). While these observations were limited, further quantitative and qualitative studies should be conducted to determine if RA7s are being implemented according to the spirit and intent of the legislation. If studies find RA7s are being implemented in discordance with the spirit and intent of the legislation, legislative amendments should be recommended.

**Boundaries between Individual Self-Determination and Health Care Responsibilities**

Although self-determination (i.e., liberal autonomy and relative autonomy) is central to the adult guardianship reform, based on my observations throughout my practicum, ethical dilemmas sometimes result from this principle. For instance, modernization of the adult guardianship legislation and its increased focus on protecting the self-determination of PWDs in need of assisted and substitute decision-making requires health care systems to also assume the ability to accommodate the wishes of the PWDs. However, determining acceptable limitations placed on the wishes of PWDs was a common question that arose throughout my practicum. For instance, if PWDs have admittedly expressed their wishes to never be admitted to residential care facilities or receive pharmaceutical restraints, where does the PWDs’ self-determination end and the
health authority’s ability to provide equitable services to all patients within the constraints of resource and staff shortage begin?

While this is a valid question, approaching this question creatively seems to open some doors. For instance, an idea currently in use throughout Northern Health residential care facilities is DementiAbility Methods. This is a care philosophy applied to PWDs, which is being promoted as an alternative approach to the use of pharmacological interventions to address responsive behaviours (Dementiability Enterprises Inc., 2016; Elliot, Dempsey, & O’Neill, 2016; G. Elliot, personal communication, October 28, 2016). The central concepts of this care philosophy are strengths-based practice paired with a Montessori prepared learning environment (Elliot et al., 2016). It is believed that through the use of these two concepts creative person-centred solutions can be determined to assist in facilitating autonomy and meaning for the PWD (Dementiability Enterprises Inc., 2016; Elliot et al., 2016). Although this care philosophy is mostly being implemented in residential care facilities, this care philosophy could also be applied to PWDs who are being cared for by caregivers at home. While I did not observe implementation of this care philosophy throughout my practicum, and rather observed and learned about this care philosophy through my employment experiences, I believe this provides an example of how the ethical dilemma of a PWD’s right to autonomy and the health care system’s responsibility to provide equitable services could be addressed.

Federal and National Organization Adult Guardianship Legislation Awareness

Since adult guardianship legislation spans the subjects of health care, personal care, financial affairs, and legal affairs, institutions providing services and professionals working in these fields should receive education about adult guardianship legislation. This would enable institutions providing services to develop policies to efficiently and appropriately respond to
adult guardianship investigations and this would enable professionals ease in providing supports to their adult guardianship clients. Challenges arise regarding information exchange between federal and provincial organizations because of jurisdictional divides. Consequently, future educational endeavours focused on raising adult guardianship legislation awareness should be targeted towards federal organizations such as Service Canada.

Also, challenges arise with acknowledgement of assisted and substitute decision-makers, especially representatives, within nationally based organizations (e.g., financial institutions). Therefore, more education focused towards nationally based organizations that interface with adult guardianship legislation should be provided. Consequently, increased education for organizations, especially nationally based organizations, and professionals will increase the chance assisted and/or substitute decision-makers will be able to assume their decision-making roles without unnecessary challenges. Also this will help to ensure that adult guardianship processes (e.g., least intrusive measures, information for assessment of certificate of financial incapability will be able to be collected in a timely fashion) will become more accessible for health care professionals assisting with adult guardianship cases.

**Conclusion**

Based on connecting theoretical learning and practical experiences in the field of incapacity planning and adult guardianship among PWDs, I was able to arrive at some general social work policy and practice recommendations. These recommendations include: providing community-based holistic education about personal planning; addressing issues with RA7s; clarifying boundaries between individual self-determination and health care responsibilities; and interconnecting federal and national organizations with provincial organizations. My primary learning goal and subthemes are intertwined throughout these recommendations, as the
recommendations have been proposed to provide value towards the goal of improving the effectiveness of adult guardianship legislation, and its interpretation and operationalization in practice to better empower PWDs by protecting their rights, promoting their self-determination, and preventing abuse, neglect, and/or self-neglect. While these recommendations have been concluded based on limited time in the field and within specific locations, the hope in providing these recommendations is to contribute ideas for further study and investigation in the field of incapability planning and adult guardianship.
CHAPTER SIX: Conclusion

Due to personal and professional experiences, I became interested in the topic of rights protection and self-determination promotion applied to the populations of persons with disabilities, older adults, and subsequently PWDs. My literature review illustrated how public attitudes and societal structures reinforce ideas of paternalism for these populations (Gill, 2000; Gordon, 2012; Ray et al., 2009) and the need for solutions (e.g., personal planning and default system options) to protect PWDs’ self-determination. As a result, I chose to explore the topic of BC adult guardianship and planning statutes applied to the population of PWDs for my MSW practicum because this legislation was the result of community efforts to create legislation that brought an alternative epistemology (ethics of care) into force that would empower PWDs.

I was fortunate to receive an agency practicum at Northern Health with opportunities to also spend time at BCCEAS and Nidus. It was through the use of Freire’s (2010) education approach that I was able to reflect on my practicum experiences and academic learning to develop insights into the effectiveness of adult guardianship legislation in empowering PWDs by protecting their rights, promoting their self-determination, and preventing abuse, neglect, and/or self-neglect. Reflecting on the literature in this area and my practicum experiences provided greater clarity about my learning subthemes (interpretation and operationalization of legislation in practice; gaps in legislative and non-legislative processes; legislation and empowerment of PWDs; and assisted and substitute decision-making in relation to abuse, neglect, and/or self-neglect of PWDs).

My limited, site-specific observations and experiences helped me to develop an understanding of the complexity of this topic, especially the challenges associated with interpreting and operationalizing adult guardianship legislation in practice. I was fortunate enough to observe dedicated professionals promoting the rights and self-determination of PWDs.
and working to prevent and address abuse, neglect, and/or self-neglect of PWDs. These
practicum experiences illustrated the necessity of having various organizations, professionals,
and community members working towards the empowerment of PWDs. Finally, as a direct result
of reaching my practicum learning goals, I was able to propose several policy and practice
recommendations for the profession of social work. I hope these recommendations and the
learning I gained in this practicum will help protect the autonomy of PWDs and result in positive
changes that promote the ethics of care approach whenever possible. I will advocate for such
changes in my social work practice.
References


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Appendix

MSW Practicum II: Learning Contract

Student: Keya Russell

Practicum Supervisor: Melinda Allison

Academic Supervisor: Dawn Hemingway

Organization: Northern Health Authority

Length of Placement: From: 02/05/2015 To: 08/12/2016

Day/Month/Year Day/Month/Year

Hours of Work: ~8:30-16:30 Monday to Friday excluding statutory holidays and weekend

Learning Objectives

List what you hope to achieve given the opportunities available within the organization and your needs and interests. The learning objectives must be clearly stated.

My practicum will focus on assessing the interpretation and implementation of British Columbia’s adult guardianship and legal planning statutes related to persons with degenerative dementias within Northern Health Authority (Northern Health) and BC Centre for Elder Advocacy and Support (BC CEAS). The main learning goals for my practicum are to determine gaps and strengths of legislative and non-legislative processes; as well as, to develop insight into the effectiveness of legal planning for empowering persons with degenerative dementias and preventing abuse and/or neglect. Under these main learning goals, I have identified the following sub-goals that I will use to measure my progress at my practicum sites:

- learn to reconcile PWDs’ right to self-determination with ensuring they are protected from neglect and abuse;
• observe different health care professionals performing domain-specific aspects of capacity assessments;
• observe legal professionals performing domain-specific capacity assessments;
• understand how different health care professionals in Northern Health interpret the law covering legal planning options;
• learn how legal planning is encouraged in the health care environment and what biases are held by the health care system about the most advantageous approach;
• learn how patients and their families receive information about their options;
• assess what legal planning options are being used more frequently by patients and what makes certain options popular;
• assess the effectiveness of legal planning for PWDs who make contact with the health care system;
• observe the barriers that inhibit a person from legally planning; and
• observe if legal planning decreases the rates of abuse and/or neglect experienced by PWDs.

For each learning objective, specify

i. how you will achieve it (tasks or activities to be completed)
ii. what will be the evidence of achievement

Goal 1: Learn to reconcile PWDs’ right to self-determination with ensuring they are protected from neglect and abuse

i) I will achieve this goal by doing the following:

• observe interprofessional team meetings and record health care professionals’ comments about patients experiencing neglect and abuse;
• analyze comments for patterns (i.e., look for trends in individuals’ comments, look for trends in stance of particular professions); and
• write critical reflections in journal detailing my perspective on situations.

ii) The evidence I will use to determine if I have met this goal includes:
• discuss patterns and personal reactions or responses to situations of abuse and/or neglect with practicum supervisor;
• analyze depth of contextual understanding over time with practicum supervisor; and
• determine if depth of understanding changes throughout practicum.

Goal 2: Observe different health care professionals performing domain-specific aspects of capacity assessments

i) I will achieve this goal by doing the following:
• find opportunities to observe professionals performing capacity assessments;
  and
• request permission to observe professionals conducting capacity assessments.

ii) The evidence I will use to determine if I have met this goal includes:
• use charts (chart 1 and chart 2) to track number of assessments observed throughout practicum; and
• use information from charts (chart 1 and chart 2) to determine if goal has been met.

Chart 1

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Chart 2

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<th>PPA Medical</th>
<th>AD HC</th>
<th>TSDM HC</th>
<th>POA/EPOA Lawyer/Notary Public</th>
<th>RA General</th>
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Goal 3: Observe legal professionals performing domain-specific capacity assessments

i) I will achieve this goal by doing the following:

- look for opportunities at BC CEAS to observe capacity assessments; and
- ask permission of lawyers or notary publics to observe capacity assessments.

ii) The evidence I will use to determine if I have met this goal includes:

- use chart 3 to track number of assessments observed.

Chart 3

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<th>Notary Public</th>
<th>Assessment Type</th>
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Goal 4: Understand how different health care professionals in Northern Health interpret the law covering legal planning options

i) I will achieve this goal by doing the following:

• observe professionals at family meetings, family consultations, and interprofessional meetings; and

• determine how the law is being interpreted in these situations.

ii) The evidence I will use to determine if I have met this goal includes:

• keep track of observations in journal and determine patterns in professionals’ overall understanding of the law.

Goal 5: Learn how legal planning is encouraged in the health care environment and what biases are held by the health care system about the most advantageous approach

i) I will achieve this goal by doing the following:

• review advanced care planning (e.g., My Voice) promotional materials used at Northern Health;

• observe presentation of legal planning options or alternative (e.g., MOST form) in family meetings; and

• observe interprofessional discussions about advanced care planning to determine biases.

ii) The evidence I will use to determine if I have met this goal includes:

• analyze information gathered throughout practicum to determine if there are marketing patterns.

Goal 6: Learn how patients and their families receive information about their options

i) I will achieve this goal by doing the following:
• observe family meetings, family consultations, and interprofessional team
  meetings to determine how information is being disseminated; and
• conduct an environmental scan on advanced care planning throughout
  Northern Health to determine advanced care planning initiatives and barriers
  in different departments.

ii) The evidence I will use to determine if I have met this goal includes:

• discuss findings with practicum supervisor and write report for environmental
  scan.

Goal 7: Assess what legal planning options are being used more frequently by patients and
what makes certain options popular

i) I will achieve this goal by doing the following:

• review residents’ charts at Gateway complex care facility (Gateway) to
determine percentage of residents who have advanced care planning;
• determine percentage of Gateway residents who have different types of
  advanced care planning legal documents (e.g., power of attorney, enduring
  power of attorney, advanced directive, representation agreement (9 or 7)) and
  alternative forms (e.g., MOST);
• review data from environmental scan on advanced care planning and look for
  advanced care planning patterns in documents used; and
• interview employees who work/worked on advanced care planning initiatives
  and determine reasons certain advanced care planning options are/were
  popular.
ii) The evidence I will use to determine if I have met this goal includes:

- review data collected and determine patterns in data to answer question at the end of practicum.

**Goal 8: Assess the effectiveness of legal planning for PWDs who make contact with the health care system**

i) I will achieve this goal by doing the following:

- observe interprofessional team meetings and listen for information about advanced care planning that works well for patients; and
- review environmental scan data to determine strategies used by sectors (e.g., acute, community, residential) with higher rates of advanced care planning.

ii) The evidence I will use to determine if I have met this goal includes:

- analyze information collected to determine if there is enough information to draw a conclusion.

**Goal 9: Observe the barriers that inhibit a person from legally planning**

i) I will achieve this goal by doing the following:

- observe interprofessional team meetings and listen for information related to barriers to legal planning; and
- analyze environmental scan data for barriers to advanced care planning.

ii) The evidence I will use to determine if I have met this goal includes:

- review observations, conversation, and environmental scan data; and
- determine barriers to advanced care planning.
Goal 10: Observe if legal planning decreases the rates of abuse and/or neglect experienced by PWDs

i) I will achieve this goal by doing the following:

- observe interprofessional team meetings and listen for abuse and/or neglect cases;
- ask practicum supervisor for examples of abuse and/or neglect cases;
- learn about high profile abuse and/or neglect cases (e.g., Margot Bentley case); and
- record if these patients have engaged in legal planning.

ii) The evidence I will use to determine if I have met this goal includes:

- analyze information collected and determine if there is enough information to draw a conclusion.

NOTE: I will use a reflective journal to record weekly learning experiences and reflections at my practicum site. I will compare my experiences and reflections to the literature, I reviewed for my proposal and directed readings course. In addition, I will take the perspective of the people accessing the health care system into consideration when reflecting on my experiences. Each weekend I will review my learning objectives, I will then record information (e.g., observations, reflections, analysis) from the week related to the applicable goals. This system will help me determine if each objective is being met throughout the duration of my practicum.