

The Relationship of Spiritual Well-Being to Quality of Life in Adults with Intellectual and Developmental Disabilities

By:

Tonja Renee' Rambow, B.S., M.S.

A Thesis Submitted in Fulfillment of the
Requirements for the Degree
Master of Arts

Department of Applied Arts
School of Humanities
Waterford Institute of Technology
Waterford, Ireland

Supervisor:
Michael Howlett, PhD

Abstract

This study explored and described how adults who experience intellectual and developmental disabilities perceive the significance of their spiritual well-being in relation to their quality of life. Specifically, the relationship between perceived spiritual well-being and quality of life; the difference gender and living situations have on these variables; and the understanding and relevance individuals who experience intellectual and developmental disabilities give these two variables was examined. To answer the research questions, this study utilized a mixed methods sequential explanatory design, consisting of a quantitative phase followed by a qualitative phase. From a quantitative design framework: Phase One utilized associated theories of spirituality and quality of life, along with two standardized questionnaires that were administered to a total of 50 adults who experience intellectual and developmental disabilities living in both urban and rural areas of Alaska. Next: Phase Two utilized a qualitative framework consisting of unstructured, in-depth interviews, participant observation and document reviews involving 15 adults who were a subset of the study sample population. The findings from this research revealed that a significant positive relationship exists between perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities. The qualitative phase provided additional data adding depth and breadth to understanding the significant positive relationship found in the quantitative phase. Five overarching themes emerged from the qualitative data collected that provided a context for understanding the significant positive relationship found between participants' spiritual well-being and quality of life. The emergent themes were: framework for life; identity; sense of inner well-being; opportunity to contribute; and sense of connectedness. The results of the study suggest that adult individuals who experience intellectual and developmental disabilities across genders and living situations, perceive spirituality as an important aspect of life and overall well-being and that most perceive their spiritual needs to be as important as needs in other areas of life. Study findings produced both disability related theoretical implications and service planning and practice policy implications.

Dedication and Acknowledgments

This thesis is dedicated to my Mom and Dad, Dayton and Ruth Keese, for providing me unconditional love and encouragement along with fervent advice throughout my life to never lose sight of the things that matter the most; and, to my wonderful son, Christopher Hyslop, who provides countless reminders of the importance of my parents' wisdom.

Extra special gratitude is extended to my loving husband, Dr. Dave Rambow, for his tireless acts of support and to friends and family close to me who patiently shared the journey with me. Thanks and acknowledgement is given to colleague, Dr. Roy Scheller, for creating pathways for continued professional development and life-long learning. Finally, a sincere and grateful acknowledgement is given to the individuals who participated in this research who allowed me into their lives to bear witness of life experiences and who generously shared their personal stories, giving of their time, energy, and opinions on the research topic.

Table of Contents

Abstract	ii
Dedication and Acknowledgements	iii
Table of Contents	iv
Definition of Terms	ix
Chapter One: Research Rationale and Contributions	1
Statement of the Problem.....	7
Purpose Statement and Research Questions.....	10
Significance of the Study.....	13
Organisation of the Study.....	20
Chapter Two: Review of the Literature on Spirituality	22
Introduction.....	22
Discussion of the Problem.....	23
Understanding Spirituality.....	26
Dimensions of Spirituality.....	32
Evaluating Spirituality.....	46
Spirituality and Intellectual & Developmental Disabilities.....	49
Societal Perspectives.....	52
Perspectives of World Religions.....	56
Disability Theology Perspectives.....	63

Research Associated with Spirituality and Intellectual & Developmental Disabilities.....	68
Chapter Summary.....	73
Chapter Three: Review of the Literature on Quality of Life.....	76
Introduction.....	76
Understanding Quality of Life.....	78
Dimensions of Quality of Life.....	79
Assessing Quality of Life.....	86
Quality of Life and Intellectual & Developmental Disabilities.....	87
Societal Perspectives.....	89
Quality of Life and Influential Theoretical Perspectives.....	91
Quality of Life Conceptual Models and Intellectual & Developmental Disabilities.....	99
Health Related Quality of Life and Intellectual & Developmental Disabilities.....	101
Quality of Life & Influence of Supports & Services Associated with Intellectual & Developmental Disabilities.....	105
Integrating Spirituality and Quality of Life.....	108
Chapter Summary.....	110
Chapter Four: Research Design & Methodology.....	112
Research Type and Design.....	115
Population and Sample/Target Population.....	118

General Sampling Procedures.....	120
Determination of Sample Size.....	120
Selection of Sample Population.....	122
Ethical Considerations with Vulnerable Populations.....	123
Protection of Human Subjects.....	124
Quantitative Research Design.....	126
Quantitative Phase Data Collection.....	128
Pilot Test.....	128
Quantitative Data Collection.....	128
Quantitative Phase Instrumentation.....	129
Quality of Life Questionnaire Reliability & Validity.....	129
Spiritual Well-Being Scale Reliability & Validity.....	132
Quantitative Phase Data Analysis.....	134
Qualitative Research Design.....	137
Qualitative Sampling Procedure.....	138
Qualitative Methodology.....	139
Qualitative Phase Data Collection.....	141
Role of the Researcher.....	141
Data Collection Strategies & Recording Procedures.....	143
Qualitative Coding, Data Analysis, & Interpretation Procedures.....	147
Strategies employed to Validate Accuracy of Qualitative Findings.....	148

Integrating the Quantitative and Qualitative Data.....	149
Potential Limitations of the Study.....	150
Chapter Summary.....	152
Chapter Five: Quantitative Phase Data Analysis and Findings.....	153
Quantitative Phase of Study.....	154
Quantitative Phase Data Collection Procedures.....	155
Presentation of Descriptive Statistics of Participants.....	157
Quantitative Research Questions & Associated Hypotheses....	161
Quantitative Phase Statistical Considerations.....	162
Adequacy of Sample Size.....	162
Unusual Response Patterns, Missing Cases, & Outliers	
Analyses.....	163
Assumptions of Normality.....	163
Effect Size & Statistical Power.....	164
Quantitative Phase Analysis of Data.....	165
Summary of Quantitative Phase Findings.....	195
Chapter Six: Qualitative Phase Data Analysis and Findings.....	198
Qualitative Phase of Study.....	198
Qualitative Sample.....	199
Description of Communities of Qualitative Phase Key	
Participants.....	200
Description of Qualitative Participant Sample.....	203
Qualitative Data Collection Process.....	216

Qualitative Presentation of Themes and Data Analysis.....	220
Summary of Qualitative Phase Findings.....	237
Chapter Seven: Discussion, Conclusions, and Recommendations.....	240
Discussion of the Study.....	240
Discussion of Findings.....	243
Theoretical Implications of the Study.....	289
Policy and Practice Implications of the Study.....	293
Recommendations for Future Research.....	297
Conclusion.....	299
References.....	302
Appendices.....	341
Appendix A: Introduction Letter from Executive Office of Organisation.....	341
Appendix B: Researcher’s Letter and Informed Consent Document....	342
Appendix C: Instrument’s Administrative Guidelines.....	344
Appendix D: <i>Quality of Life Questionnaire</i>	345
Appendix E: <i>Spiritual Well-Being Scale</i>	351
Appendix F: <i>Aide Memoire</i>	352
Appendix G: <i>Interview Schedule</i>	355

Definitions of Terms

Spirituality. There is no universal definition of spirituality however, virtually all definitions, whether offered by theologians, sociologists, psychologists, healthcare providers, or laypersons agree that spirituality is a multi-dimensional and for the most part, a trans-cultural construct (Koenig, McCullough, & Larson, 2001; Macquarrie, 1982; Mogens & Wadland, 1991; Moberg, 1979; Piedmont, Ciarrochi, Williams, & Dy-Liacco, 2009). Research identifies four generally agreed upon concepts that are central to defining the spiritual dimension of the human experience: 1) transcendence (Piedmont, 1999), 2) connectedness (Simpson, Newman, & Fuqua, 2008), 3) meaning and purpose (Jim, Purnell, Richardson, & Golden-Kreutz, 2006), and 4) belief (Kay, Shepherd, Blatz, Chua, & Galinsky, 2010; Zinnbauer, Pargament, Cole, Rye, Butter, Belavich, Hipp, Scott, & Kadar, 1997). The definition of spirituality for use in this study synthesises these concepts to comprise that aspect of humanity that refers to the way individuals seek and express meaning and purpose; experience connectedness to self, others, nature, and the transcendent – the significant or sacred; and is inclusive but not limited to an individual's faith, beliefs and religious expression (Puchalski, Ferrell, Virani, Otis-Green, Baird, Bull, Chochinov, Handzo, Nelson-Becker, Prince-Paul, Pugliese, & Sulmasy, 2009).

Quality of Life. This study utilised the definition of Felce and Perry (1996). They defined quality of life as “an overall general well-being that is comprised of

objective and subjective evaluations of physical, material, social and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values” (p.52).

The concept of *intellectual and developmental disability*: For the purposes of this study, the definition of an intellectual and developmental disability came from the *Developmental Disabilities Act*, section 102(8) (2000), which defines a developmental disability as a severe, chronic disability of a person that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. Is manifested before the person attains age twenty-two;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitation in three or more of the following areas of major life activity: a) self-care, b) receptive and expressive language, c) learning, d) mobility, e) self-direction, f) capacity for independent living, and g) economic self-sufficiency; and
5. Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong extended duration and are individually planned and coordinated. [42 U.S.C. 6001(5)].

Chapter 1

Research Rationale and Contributions

Psalms 139: 13 – 14 reads, “For you created my inmost being; you knit me together in my mother’s womb. I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well” (New International Version).

This Biblical scripture was quoted to the researcher during the qualitative phase of this study by a woman who experiences significant intellectual and developmental disabilities, utilises a wheelchair for mobility, and requires full physical assistance with all activities of daily living. She followed-up the scripture reading by proclaiming, “God does not make mistakes, [pause] I am not a mistake...we are each made with purpose” (Participant 11). Though this woman was able to express aspects of her spiritual life, the significance of the spiritual dimension of life for adults who experience intellectual and developmental disabilities is largely unknown. This researcher approaches the topic of spirituality, quality of life, and intellectual and developmental disabilities from a position that individuals who experience intellectual and developmental disabilities should be acknowledged in their full humanity in the same respect as people without disabilities.

In the eighteenth century, German philosopher Immanuel Kant asserted that all human beings possess moral status and suggested a universality of moral law that applied equally to all human beings (Kant, 1788). Still, such assumptions were based upon a human being’s ability to reason. People who have limited capacity for rational deliberation continue to challenge the thinking on ideas of personhood, equality, and

citizenship (Kittay & Carlson, 2010). Currently, ethicists and bioethicists grapple with topics of personhood in trying to determine the appropriate treatment of persons with cognitive disabilities (Kopelman and Moskop, 1984; Khuse, Helga, & Singer 1985). Philosophers utilise a human being's diminished capacity to argue for the treatment of these individuals in a manner similar to that of non-human animals with comparable intellectual capacity suggesting that human beings with diminished capacity should not have superior status over nonhuman animals (Singer 1995; McMahan, 2003). Theologians argue against all forms of dehumanisation and diminished status as a result of cognitive disability (Hauerwas, 1986; Reinders, 2008). Historically, debates on the topic flourished depending on the philosophical, social, political and cultural contexts of the time. Difference in personal attributes frequently reflected defect, deviance and degradation of character and place for people.

While philosophers and researchers seek to describe the nature and characteristics of *being* human, many citizens who experience disabilities fight for their rights to be acknowledged as *fully* human. History demonstrates that *being* human in and of itself does not assure a person identity, citizenship, or value within society. Portrayals of people who experience disability are found in art, media, literature, and myth most often connote a less than desirable image. One of the earliest representations of disability is associated with the only mythological Greek god with a disability, Hephaestus, who was both ugly and lame and consequentially rejected by his mother and exiled from Mount Olympus (Ebenstein, 2006). Austrian neurologist and founder of psychoanalysis, Sigmund Freud, correlated physical disabilities with deformities of character (Freud, 1958). Additionally, philosophers, who either deny or question the

full humanity or moral status of all human beings, tend to view that moral status is contingent on physical or intellectual attributes or properties of the individual (Rachels, 1989; Singer, 1986, 2011). Norbert Elias, German sociologist, is recognised for his theory of civilizing processes in which he postulates that societies' processes towards civility configure disability as something that should be removed or corrected within society (Elias, 2000). Elias attributes societies' social response to disability to a culture's dislike of imperfection and impairment from which a purist version of normal appearance and behaviour emerges. In Western societies, ideals of perfection, health, strength, and power inadvertently, ridicule and invalidate the lives of people who experience disability. Erving Goffman, sociologist, who studied how people experience and interact in the context of everyday life, observed that people with characteristics defined by others as undesirable are discredited in the eyes of others (Goffman, 1974). Goffman postulates that consequent to the exertion of social control, societies construct social stigmas and that people act in ways that mitigate difference in a desire to be perceived as normal (Goffman, 1986). People who consequently experience cognitive, emotional, and physical disabilities are thus depicted as individuals outside of established norms and frequently outcast from mainstream society. The constructivist view conceives of disability as a complex construct historically utilised as an instrument of power to marginalise some, and privilege others in society with a fabricated determination of *normal* and *abnormal*. Peter Singer, an Australian moral philosopher and ethicist, promotes a preference utilitarian view which further emphasises that rights should be bestowed to the extent that a creature is a *person* and suggests that not all human beings are elevated to the status of personhood (Singer, 1986, 2011). Singer's

ideology is controversial in that it promotes infanticide and euthanasia amongst severely cognitively impaired people claiming that people bearing certain labels do not qualify as *persons* (Drake, 2009; Teichman, 1992). Philosophers, applied ethicists, and disability academics continue to debate the moral status and treatment of those who experience severe cognitive disabilities (Brown & Gothelf, 1996; Carlson & Kittay, 2009; McMahan, 1996, 2008; Wong, 2007).

Such contention in thinking emphasises that within humanity, a derived sense of what it means to be human cannot be presumptive. Philosophers arguing for an *exceptionalism* to human consideration highlight the methodological conundrums evolving from the imagined lines drawn for where personhood begins or ends. Conversely, a philosophical position postulating equality and full moral status of all people on the basis of a co-membership and a shared kinship within broader humanity negates the utilisation of individual differences in attributes as a definitive marker for humanitarian treatment within society (Byrne, 2000; Edwards, 1997). Moral philosopher Thomas Scanlon (1998) asserts that the mere fact that a *being* is born human provides reason to confer that *being* the same status as other human beings. Fundamental to disability studies is a re-conceptualisation of disability, previously informed by the social and political constructivist theories (Lewiecki-Wilson & Brueggemann, 2008). The calling out of these constructionist theories regarding the social construction of the concept of disability is noted as critical and necessary for the transformation of social realities and identity for people who experience disability (Lindblom & Dunn, 2003). Mead focused on the development of self in his theories of Symbolic Interactionism (Blumer, 1969; Mead, 1934). Mead postulated that the

uncovering of *being* was revealed in the perspective of the individual and his or her interactions within the context of the social world around the person. If identity is mediated by interactions within a given social context and culture, then concepts of disability as abnormal and personally deficient, pathologise identity. Disability studies seek to re-negotiate this dynamic through a re-conceptualisation of what constitutes normal (Davis, 1997; Ware, 2001). Inclusive philosophies prescribe a re-acculturation of people who experience disability asserting a new normal is essential to progress society for people with and without disability. The current research is grounded in a paradigm which recognises individuals who experience intellectual and developmental disabilities as sharing the same moral status as people without disabilities.

The human experience of *being* is noted to evolve out of a body-mind-spirit paradigm and encompasses five dimensions: the physical, the emotional, the intellectual, the social, and the spiritual (Bello, 2008; Chan, Ho, Chow, 2006; Finn, 2000; Fosarelli, 2002). As noted, not all humans fully experience these five dimensions of being. The history of individuals who experience intellectual and developmental disabilities chronicles isolation, segregation, devaluation and marginalisation significantly limiting the human experience (Albrecht, Seelman, & Bury, 2001; Carey, 2009). Individuals who experience disabilities have been stereotyped, stigmatised, and treated as less than human (Browning, 1974). Even more dehumanising, some societies' exclusion of individuals who experience intellectual and developmental disabilities went so far as to question these individual's right to life (Friedlander, 2003; Singer 2011). History further records, individuals who experienced an intellectual and developmental disability almost exclusively were forced to reside in institutional

settings apart from mainstream society (Braddock, Emerson, Felce, & Stancliffe, 2001; Braddock & Parish, 2002).

The scientific community contributed heavily to such circumstance. Western medical practices tended to objectify individuals who experienced intellectual and developmental disabilities emphasising the need to *fix* the person's broken parts. Additionally, civilised societies valuation on individual's physical perfection and intellect, as well as concepts of success, tended to look at disability as a social problem to be avoided. Historically, even faith communities applied negative connotations to individuals experiencing disabilities (Ferguson, 1994; Parmenter, 1992). These faith communities believed that somehow God punished the sick and infirmed in some way or affirmed a person's disability to be resultant of the sins of the Father (Abrams, 1998; Black, 2006). All of these factors contributed to the fact that most societies for one reason or another, be it social, political, cultural, or religious ostracised and at times discarded individuals who experience intellectual and developmental disabilities regarding them as less than human (Goffman, 1986; Singer, 2011).

Extending human regard to one another requires acknowledgement of all aspects of a person's humanity to include the physical (body), social/emotional/intellectual (mind) and spiritual (spirit) domains. Such a moral imperative is required to approach all in society as worthy of regard. Acknowledging each person's humanness means knowing a person is both uniquely separate while collectively interconnected to others. Despite many philosophical movements over the last two decades to move towards a shared identity, individuals who experience intellectual and developmental disabilities

frequently live life without opportunity to fully participate in all realms of the human experience. This author asserts that such circumstance reinforces a separatist mentality.

For individuals who experience intellectual and developmental disabilities, the spiritual domain has only recently been explored in the research. A greater understanding of the social, emotional, and spiritual aspects of people who experience intellectual and developmental disabilities is necessary if society is to honour the humanity of individuals who experience intellectual and developmental disabilities. In addition, such understanding is essential for health and human service systems to adequately meet the needs of the people these systems were created to support and assist in living a quality life.

Statement of the Problem

Spirituality represents one aspect of an individual's overall quality of life and applies to all persons whether religious, humanist, atheist, or agnostic (Moberg, 1979; Paloutzian & Ellison, 1982). The spiritual dimension constitutes a person's sense of meaning, purpose, connectedness, transcendence, hope, and understanding of the sacred in life. These variables, along with the physical, social, and psychological aspects of *being* are necessary to form the whole of human experience, well-being and overall fulfilment in quality of life (Ross, 1995). Consequently, this topic has important implications for individuals who experience intellectual and developmental disabilities and their families.

Likewise, it is important to human service systems and provider organisations that deliver supports to improve the quality of life for individuals who experience

intellectual and developmental disabilities, such as disability community support programs, professional healthcare groups, rehabilitation settings, faith-based organisations and religious groups, as well as entities that fund support for individuals who experience intellectual and developmental disabilities. These service systems rely upon acquired knowledge that guide providers in the manner in which their members interact, design, and direct support for individuals. Therefore, it is important for the research community to address the issue of spirituality on behalf of individuals who experience intellectual and developmental disabilities. Universal applicability of spirituality is intrinsic to all people (de Jager Meezenbroek et al., 2010; Koenig, 1998; Macquarrie, 1982; Plianbangchang, 2007).

The acceptance of a body, mind, and spirit concept is ancient. Consequentially, exploring the spiritual dimension may be important to understand the interplay between body, mind, and spirit, and the effect these dimensions have on a person's health, well-being, and quality of life. Additionally, an increasing body of knowledge and research conducted, supports the benefits of spiritual as well as religious practices on an individual's physical and mental health (Fitchett, Rybarczyk, DeMarco, & Nicholas, 1999; Hales & Lauzon, 2010). Spirituality in relation to a person's physical, emotional, and social well-being has been extensively explored in the literature (Koenig, 1997; Koenig & McConnell, 1999; Larson, Sawyers, & McCullough, 1998; Shafranske, 2010; Wills, 2009). There is also strong evidence of the importance spirituality has on an individual's coping (Pargament, Van Haitsma, & Ensing, 1995), rehabilitation and recovery (Fitchett et al., 1999), search for meaning following major life events or crisis (Maugens, 1996), and quality of life (Ellison & Smith, 1991). Despite these findings,

the spiritual life of individuals who experience intellectual and developmental disabilities remains largely unexamined.

Consequently, the spiritual aspects of the human experience has not been readily integrated into healthcare or related human service professional practices connected with individuals who experience intellectual and developmental disabilities. Indeed intellectual and developmental disability support systems minimally acknowledge this dimension in the majority of service provision (Brown, Raphael, & Renwick, 1997; Gaventa, 2001; Goode & Hogg, 1994; Webb-Mitchell, 1996). Theories associated with health related quality of life and personal well-being suggests the spiritual dimension to be a significant influence on life perceptions (Brandt, Fournier, & Mohr, 2009; Brown, Raphael, & Renwick, 2002; Ellison & Smith, 1991; Koenig, 1998; Koenig, et al., 2001). The lack of exploration of this issue for those people who experience intellectual and developmental disabilities propagates the marginalisation of this population resulting in treatment that is less than fully human.

Individuals experiencing intellectual and developmental disabilities have long since been marginalised by mainstream society (Albrecht et al., 2001; Bray, 1992). However, seeing these individuals as fully human and capable of exploring, experiencing, and expressing their spirituality is a developmental process that continues to evolve in society today. To perceive all individuals as fully human requires an acknowledgement of the body, mind, and spirit within each person.

It can be argued that the dismissal of any aspect of one's humanity paves the path for the objectification, marginalisation, and subsequent human rights violations of people within any society. The history of intellectual and developmental disabilities is

fraught with less than humane treatment and subsequent human rights violations (Blatt & Kaplan, 1974; Quinn et al., 2002). An understanding of being fully human requires one to consider both the uniqueness and the commonalities that each individual possesses as citizens of humankind.

Similar sentiments were shared by Martin Luther King, Jr. who touted a shared vision in his “I Have a Dream” speech delivered on August 28th, 1963 at the Lincoln Memorial in Washington D.C. (King, 1963). While King’s message focused on the issue of racism in America, the sentiments hold true for any person or group of people that are treated by a society as less than human and therefore, not entitled to the same rights as other members of society. The *Dream* calls the brotherhood of mankind (regardless of race, gender, religious preference, or level of ability) to acknowledge a reality that the denial of one group’s personal freedoms jeopardises the freedom for all. King stated that “their destiny is tied up with our destiny...that their freedom is inextricably bound to our freedom” (King, 1963, para 8). In parallel, this research attempts to both further understanding and add to a growing body of literature that seeks to enlighten a greater population on the full humanity of individuals who experience intellectual and developmental disabilities. The current body of research neglects spirituality in relation to quality of life in individual’s who experience intellectual and developmental disabilities, as will be shown in Chapter Two, page 22 and following.

Purpose Statement and Research Questions

Existing theories of quality of life operate from a premise that what constitutes quality of life for one person, constitutes quality of life for all persons, with or without

disabilities (Buntix & Schalock, 2010; Felce & Perry, 1996). Within the literature, as stated above, the spiritual dimension of life is noted to be positively associated with a person's identity (Baumeister, 1991; Brandt et al., 2009), mental and physical well-being (Koenig et al., 2001), and sense of connectedness in life (Ashley, 2007; Simpson, et al., 2008). These factors significantly influence a person's evaluation of how good life appears.

Numerous quality of life models focused on life indicators and life domain areas, evolved within the literature in attempts to describe and measure the quality of life of individuals who experience intellectual and developmental disabilities (Brown, Bayer, & MacFarlane, 1988; Cummins, 2005a; Goode, 1988; Schalock et al., 2002; Taillefer, Dupuis, Roberge, & May, 2003). Despite the research on quality of life and intellectual and developmental disabilities, there is insufficient research regarding the spiritual domain of life for individuals who experience intellectual and developmental disabilities.

Research in this area is important. Little is known about the spiritual lives of persons who experience intellectual and developmental disabilities, and how persons who experience intellectual and developmental disabilities understand and relate the importance of the spiritual dimension of life to other aspects of life. In addition from the researcher's perspective, after 30 years of working professionally in the field of intellectual and developmental disabilities, observations suggest that individuals accessing publically funded supports and services may find the spiritual dimension of their life given little consideration in relation to other aspects of life. Community service providers for individuals who experience intellectual and developmental

disabilities in general do not include staff education and training regarding the provision of spiritual supports nor do they inquire about the spiritual needs of individuals beyond identification of a person's religious preference.

The preponderance of evidence suggesting that spirituality is an important aspect for citizens in general challenges a human service system currently devoid of spiritual dialogue in practice for people who experience intellectual and developmental disabilities. Therefore, the time is long awaited for inquiry of this area within research and the incorporation of knowledge gained regarding spirituality and developmental disabilities into community systems of support. The overall approach of this study combined quantitative and qualitative methods to explore and describe how adults who experience intellectual and developmental disabilities perceive the significance of their spiritual well-being in relation to their quality of life. The overall research aim was addressed through four primary research questions across two phases of study. Phase one addressed the first three primary research questions utilising a quantitative approach, followed by phase two that addressed the fourth primary research question, utilising a qualitative approach. The four primary research questions examined in this study were:

Research Question 1.0: What is the relationship between perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities? Additionally, ten sub-questions related to this primary research question were explored and are addressed further in Chapter Three.

Research Question 2.0: What is the difference between males and females regarding perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities?

Research Question 3.0: Is there a difference for individuals who experience intellectual and developmental disabilities in perceived spiritual well-being and quality of life with different levels of support in living situations?

Research Question 4.0: How do adults who experience intellectual and developmental disabilities understand and describe the importance of a spiritual dimension of life to other aspects of life?

The qualitative phase of this study focused on the following generalised areas in an iterative process of exploration with key participants:

- 1) How do adults who experience intellectual and developmental disabilities describe their own spirituality?
- 2) What role does spirituality play in understanding life experiences for adult individuals who experience intellectual and developmental disabilities?
- 3) What are the spiritual support needs of adult individuals who experience intellectual and developmental disabilities?
- 4) What values, beliefs, and behaviours do adults who experience intellectual and developmental disabilities ascribe to a spiritual dimension of their life?

Significance of the Study

The investigation of spiritual/religious factors in relation to a person's health is well established in research as being relevant (Banks, 1980; Bartlett, Piedmont,

Bilderback, Matsumoto, & Bathon, 2003; Bekelman et al., 2007; Koenig & McConnell, 1999). Yet, there is an even more poignant justification for continued investigation of the spiritual dimension of humanity (de Jager Meezenbroek et al., 2010; MacDonald, Friedman, & Kuentzel, 1999; Macquarrie, 1982; Miller, 2010; Piedmont, 1999). That is, considering the notion that giving oneself permission to dismiss an aspect of a person or group of people's humanity lends itself to propagating an uncivilised society. The ideology in the 1930's under the Nazi regime in Germany, supported the enactment of laws calling for the extermination of the handicapped or persons considered to be genetically defective and a financial burden to society (Friedlander, 2003). As a result of such historical accounts, much research and literature (United Nations, 2006; Americans With Disabilities Act, 1990; *Developmental Disabilities Act, Part A*, 2000; Holocaust Encyclopedia: Euthanasia Program; King, 1963) has been devoted to understanding, identifying, and declaring the universality of certain fundamental human rights and freedoms. Furthermore, the spiritual dimension of human nature has been reported across the literature to be a critical component in an individual's life on a variety of levels (Abdel-Khalek, 2006; Armstrong, 1993; Banks, 1980; Brady, Peterman, Fitchett, Mo & Cella, 1999; Cohen & Hall, 2009; Quinn et al., 2002).

It is the spiritual dimension of human existence that explores significant life questions regarding the history of humankind's past, present, and future. Today, many people attribute their personal vision, values, and sense of well-being to flow out of their spiritual dimension, with approximately 80% of the world's population expressing some sort of religious affiliation (Huddleston, 1993; Pew Research Center, 2012).

Equally significant is the recognition that a person's specific spiritual beliefs continue to influence behaviours that follow throughout an individual's lifespan (Cohen & Hall, 2009; Fitchett et al., 1999). Furthermore, positive aspects of spirituality have been reported to provide an individual with a sense of hope, a resource for coping, combating negative emotions, engendering strength and perseverance and for fostering a sense of community and connection (Kim, 2002). Many have discussed the importance of their spiritual life in assisting them in defining meaning and purpose to their life and to life events, as well as in providing confidence and security when facing issues regarding serious illness, injury, or death (Baumeister, 1991; Koenig, 1995; Matzo & Sherman, 2009).

The study of spirituality for individuals with intellectual and developmental disabilities is relevant. With research increasingly illuminating the positive influence of spirituality on an individual's physical and mental health from perspectives of prevention, wellness, recovery, and coping with aspects of chronic conditions, it would seem negligent to ignore this as a possible resource for individuals who experience intellectual and developmental disabilities. Therefore, research in this area is timely and necessary.

Both scientific and philosophical movements call for holistic, individualised, self-directed, person-centred, and culturally relevant standards of care and support across human service fields (Brown et al., 1988; Buntix & Schalock, 2010; Hasnain & Sotnik, 2003; Menchetti & Garcia, 2003). Likewise, human rights and freedoms are considered applicable to all humanity, premising that any action to de-humanise a people begins to weaken the very fabric of society.

Recently, the application of human rights and freedoms for individuals who experience intellectual and developmental disabilities has only incrementally begun to evolve. From a history of objectification and inhumane acts towards individuals who experience disabilities, to a population of people fighting to be seen as equal and valued members of community. A world in which neighbours, citizens, professionals, and educators, to name a few, acknowledge that individuals who experience intellectual and developmental disabilities are thinking, feeling, spiritual beings like any other member of society has yet to be achieved. As a result, individuals who experience intellectual and developmental disabilities continue to fight to be seen as equal and valued members of community.

Regrettably, even among health care professionals and support systems established to assist people who experience intellectual and developmental disabilities, the voice of individuals with a disability often goes unheard, their individuality unacknowledged, their gifts unutilised, and their inner essence largely unexpressed (Rambow & Scheller, 2006). The result of this is a population of people for the most part, invisible to the community at large. The lack of opportunities for individuals who experience intellectual and developmental disabilities may be in part due to the reliance on others for daily living support. Such reliance may diminish a person's opportunities for personal religious or spiritual expression in their life.

Various advocacy groups attempted to shift peoples' thinking and alter outcomes for individuals in recent history. In the United States, laws like the Rehabilitation Act of 1973 (Section 504) and the Americans with Disabilities Act of 1990 (ADA) are products of such efforts. Paradigm shifts in thinking resulted in such movements as

deinstitutionalisation (Emerson, 1985), principles of normalisation (Wolfensberger, 1972), person-centred planning (O'Brien & O'Brien, 1987), community inclusion (Schalock & Verdugo Alonso, 2002), and self-determination (Parmenter, 1992; Wehmeyer & Bolding, 2001).

If one considers Maslow's *Hierarchy of Needs* (1954), as applied to individuals who experience intellectual and developmental disabilities, disability related services and supports began by addressing the very basic human level of providing for persons physical needs. Communities ensured individuals were provided food, clothing, and shelter. Unfortunately, too often pity appeared to be the prevailing attitude towards disability during the middle of the twentieth century (Parmenter, 1992).

From basic survival needs, an awareness grew that acknowledged individuals who experience intellectual and developmental disabilities should be entitled to safe and secure environments. Paternalistic thinking became dominant and still left individuals with intellectual and developmental disabilities as being seen as not fully human and, needing to be cared for. Ideologies promoting integration and inclusion for individuals with intellectual and developmental disabilities catapulted the application of human rights issues for those deemed previously as less than desirable.

The natural progression of thinking, led to relationships for people once isolated. Individuals who experience intellectual and developmental disabilities began to be perceived as thinking, feeling, social beings that should be afforded opportunities in the community to belong and benefit from interacting with others, and meeting social needs. Increased knowledge regarding the physiological, intellectual, and psychosocial aspects of individuals who experience intellectual and developmental disabilities greatly

influenced outcomes for people (Schalock & Verdugo, 2002). People who experience disabilities who were once isolated began to experience the meaningfulness of love, belonging, friends, and family relationships in life. As people with disabilities began to have people to see, places to go, and things to do; so did the opportunities to contribute to the welfare of others and community evolve. The capacities of individuals with disabilities became evident, increasing self-esteem, respect, and acceptance within community.

Despite this progress, little emphasis was given to the inner and spiritual well-being of the individual. The spiritual domain for individuals who experience intellectual and developmental disabilities represents yet another hallmark towards acknowledging the full humanity of all people. No one group escapes this truth. It is this researcher's opinion that each step taken to acknowledge the diversity of humankind, inclusive of all levels of ability, creates a ripple effect in society that over time alters the view of people and allows for a shared interconnectedness and identity in humanity.

Societal rights and attitudes associated with intellectual and developmental disabilities continue to evolve and influence opportunities for people. The *Convention on the Rights of Persons with Disabilities* was adopted December 13, 2006 at the United Nations Headquarters in New York. The *Convention* was entered into force on May 3, 2008. This human rights treaty marked a paradigm shift in both attitudes and approaches for persons who experience intellectual and developmental disabilities in the 21st century on a global level. It documented the alteration of views of individuals who experience disabilities as *objects* of charity and protection, towards a view of people as *subjects* and citizens with rights and freedoms equal to all other members of community

(Assembly, United Nations, 2006). The *Convention* did not seek new rights for persons who experience disabilities, but rather established clarification regarding the existing rights of persons within the context of disability. The *Convention* anticipates and promotes the full participation of persons with disabilities as equal members of society with a hope that such undertakings will result in significant advances in the human, social, and economic development of community and quality of life around the world.

Additionally, professionals today across the fields of Theology, Psychology, Sociology, and Healthcare acknowledge the importance of a Spiritual dimension in an individual's day-to-day life (de Jager Meezenbroek et al., 2010; Hales & Lauzon, 2010; MacDonald, 2000; Miller, 2010; Okulicz-Kozaryn, 2010). As a result, more and more research explores the spiritual nature of mankind increasing understanding of its influence across life domain areas. Cyclically, research outcomes inform future policy, practice, and resources in ever evolving ways for people with disabilities. Professional organisations, advocacy, and religious groups significantly progress in developing resources to educate their own professions and other entities on disabilities (Abrams, 1998; Black, 2006; Creamer, 2006; Ghaly, 2010; Hammond, 2009). Likewise, religious organisations advance materials for individuals who experience a disability to enhance their exploration of a spiritual or faith based lifestyle ("Friendship Ministries," 2011; Merrick, Gabbay, & Lifshitz, 2001; Morad, Nasri, & Merrick, 2001; Pargament, Van Haitsma, & Ensing, 1995). Most importantly, self-advocates demand an increased voice in the planning of supports and services, in directing control over their life, and in researching the issues that impact individuals who experience disability (Gilmartin & Slevin, 2009; Murphy, Clegg & Almack, 2011; Turnbull et al, 1996). This research

specifically seeks to share the voice of individuals who experience intellectual and developmental disabilities regarding spirituality in their life and add to the early knowledge of a growing body of vital and important research.

Organization of the Study

This research is an interdisciplinary work that crosses the traditional discipline boundaries of Theology, Sociology, and Psychology. The context for the study is Alaska, USA. The study is organised into nine chapters. Chapter One includes the introduction, a statement of the problem, the purpose of the study, the research questions investigated, and the significance of the study.

Chapters Two through Four present a review of the literature pertinent to the construct of spirituality, the construct of quality of life, and the interrelationship of spirituality and quality of life. Furthermore, these three chapters review the literature in respect to the purpose and research questions stated in this study. The review of the literature is intended to frame the study and present a review of the literature related to key variables of the study. Chapters Two and Three of the literature review discuss the constructs of spirituality and quality of life from their respective theoretical underpinnings and addresses how these variables are understood and measured by previous researchers within the literature. These two variables are then discussed from a variety of perspectives in relation to individuals who experience intellectual and developmental disabilities. Chapter Three concludes with examination of the interrelationship of spirituality and quality of life and current research regarding individuals who experience disabilities.

Chapter Four describes the *mixed methods sequential explanatory research* design selected for the study. This researcher provides a rationale for the type of design utilised along with the description of the study population. Careful attention is given to the ethical considerations necessary when doing research with vulnerable populations. The quantitative and qualitative phases are discussed in detail and include a description of instrumentation and data collection procedures utilised in each phase of the study.

Chapter Five presents an analysis and discussion of the quantitative findings as determined from research questions one through three posed in Chapter One. Data from the quantitative phase of the study is presented. This chapter includes a discussion of statistically significant findings as well as findings that are otherwise pertinent.

Chapter Six presents an analysis and discussion of the qualitative findings as determined from research question four posed in Chapter One. Data from the qualitative phase of the study is presented. This chapter includes a description of the communities and participants in the qualitative phase; a description of the data collection process; and a presentation of the themes and data analysis for the qualitative phase of the study. Chapters Five and Six provide a discussion of the findings and implications of the quantitative and the qualitative results of the study. Each chapter contains a discussion of the data collected across the respective two phases of the study and implications of the research.

Chapter Seven concludes with an integration and discussion of the data collected across the two phases of study, a summary of the study, conclusions based on the study findings, and a discussion of both theoretical and policy and practice

implications of the research. Chapter Seven concludes with recommendations for future research in the area of spirituality and intellectual and developmental disabilities.

Chapter 2

Review of the Literature on Spirituality

Introduction

This chapter presents the literature and research pertinent to the spiritual dimension within the current study regarding spiritual well-being and quality of life in individuals who experience intellectual and developmental disabilities. Because the literature and research connected with spirituality in the lives of individuals who experience intellectual and developmental disabilities is still relatively new and underdeveloped, an understanding of the broader literature regarding spirituality is essential. In alignment with the overall aim of this research study, particular attention is paid to both theory and research regarding a person's spiritual well-being and the relationship of this dimension of life to other aspects of a person's life. Additionally, this chapter reviewed literature pertinent to societal and theological perspectives influencing spirituality and disability. Based upon the primary research questions and the research design the literature reviewed specifically explored historical information on the construct of spirituality. This researcher sought to gain a clear understanding of how this construct was defined and assessed in earlier research. In addition, literature

was reviewed to increase understanding of the variable of spiritual well-being within the context of intellectual and developmental disability.

Chapter Two is divided into four sections. The first section provides an introduction of this study and a discussion of the problem. The second section focuses on a review of the literature to increase understanding of the construct of spirituality. A historical review of spirituality is presented along with a review of the theoretical underpinnings of a spiritual dimension of life. The precepts by which spirituality was defined and understood heavily implicated assessment of this life domain area. Therefore, an understanding of assessment instruments utilised within research is important in evaluating research implicating the level of spiritual well-being within a person. The second section further examines empirical research on the influence of spirituality and an individual's spiritual well-being on health, social connectedness/belonging, coping/adjustment, and personal/life satisfaction. This section addresses how the spiritual dimension of life may impact other life domain areas. The third section presents a historical examination of research regarding spirituality in a population of individuals who experience intellectual and developmental disabilities. This section reviews research and the major concepts connected with spirituality and disabilities. Additionally, this section discusses both historical and contemporary societal and theological perspectives noted within the literature to influence perceptions and understanding of spirituality and intellectual and developmental disabilities. Section four provides a summary of the chapter with a review of the linkage between previous works and the current research questions.

Discussion of the problem. The acknowledgement and subsequent treatment of all people, requires society to see each individual as fully human (body, mind, and spirit), and entitled to the same rights and opportunities as all other members of society (Assembly, United Nations, 2006). Unfortunately, history records the marginalisation, segregation, exclusion, and objectification by mainstream society of individuals who experience intellectual and developmental disabilities. Furthermore, this population of people is fraught with less than humane treatment (Blatt & Kaplan, 1974; Browning, 1974; Evans, 2001). Therefore, neither the acknowledgement nor treatment of individuals who experience intellectual and developmental disabilities is aligned with the premise that all people are entitled to the same rights and opportunities as other citizens. Civilized society necessitates an examination of this misalignment. This study focuses on one dimension of humanity, the spiritual, in a population of people who have historically been treated as lesser members of society.

Several researchers suggest spirituality represents one aspect of an individual's overall quality of life and applies to all persons, religious and non-religious (Moberg, 1979; Paloutzian & Ellison, 1982; Ellison & Smith, 1991). Furthermore, there is strong evidence suggesting spirituality plays an important role in a person's health (Koenig, 1997), coping (Pargament et al., 1995), rehabilitation and recovery (Fitchett et al., 1999), search for meaning (Maugens, 1996), and quality of life (Ellison & Smith, 1991). However, healthcare and human service professional practices connected with individuals who experience intellectual and developmental disabilities have not readily integrated spiritual aspects of the human experience into supports and services for people with disabilities (Treloar & Artinian, 2001). In addition, it is this researcher's

opinion that faith communities which focus on the spiritual life of people may lack fully inclusive ministries, limiting opportunities of religious and spiritual expression for this population.

Since little is known about the spiritual lives of persons who experience intellectual and developmental disabilities, research in this area is important. Furthermore, research directed towards understanding how persons who experience intellectual and developmental disabilities understand and relate the importance of the spiritual dimension of life to other aspects of life is necessary to progress both theory and practice. Research suggests the construct of *spirituality* and the construct of *quality of life* are separate and distinct from one another though may have areas of overlap and stand in relationship to each other (Bekelman et al., 2010; Beckie & Hayduk, 1997; Sawatzky, 2002). Therefore, this study with a review of the literature associated with the constructs of spirituality and quality of life, and how these two variables relate to each other for people who experience intellectual and developmental disabilities was approached from a transformative-emancipatory framework (Mertens, 2003). Mertens (2003) emphasised the role values play in studying issues connected with disenfranchised groups and outlined a process by which research is conducted. People who experience intellectual and developmental disabilities often live lives outside of mainstream society. Furthermore, within the transformative paradigm, issues associated with consequent social injustice and marginalised peoples are highlighted within the research process where the topic of inquiry contains an agenda for reform (Creswell, 2003). The disability community itself suggests the use of a transformative paradigm in which the disability community walks side by side with nondisabled researchers in

search of social justice and acknowledgement of the value of human rights and the dignity of every human being (Sullivan, 2009).

Consideration of the transformative-emancipatory framework provided a guide in defining the problem and searching the literature; the selection of the research design; the identification of data sources; the selection of participants; the data collection instruments and the analysis, interpretation, and reporting of the results. The transformative paradigm, utilising a mixed-methods approach, provides the researcher with “more complete and full portraits of our social world through the use of multiple perspectives and lenses” (Somekh & Lewin, 2005, p. 275), thereby giving a greater understanding and appreciation for diversity of people and values. This research topic was pursued as a result of dialogue, observations, and personal experiences with the study population. A review of the literature specifically sought to examine research on the topic associated with diverse groups of people within the study population. The mixed methods sequential explanatory design approach selected in this study and described in chapter five, evolved out of the researcher’s familiarity with the study population. This approach will provide voice to the lived narratives of participants regarding the spiritual dimension of life in regards to their quality of life.

Understanding Spirituality

To define what makes a person “human” is a daunting task. Yet, perhaps the ongoing quest to understand what makes a human being human is part of mankind’s innate journey in life. The search for enlightenment as to what makes people who they are dates as far back as there are written recordings and continues into current times

(Goudarzi, 2006; Swer, 2008). There are certain dimensions that are unique to humanity. The Greek philosopher, Plato (427 BC – 348 BC) contended that a human being had three distinct parts: body, mind, and soul (Popkin & Stroll, 1993). Plato suggested the dimension of the soul to be immortal and unchanging; an element that can know and be known. Platonic dialogues acknowledged man's nature inclusive of an eternal *essence* of being. This study is about the spiritual dimension of a person, an individual's internal *essence*.

In support of this consideration, Miller (1998, pp. 979 - 980) summarised that spirituality's distinctiveness lies in its idiographic nature at an individual level; its defiance of traditional conceptual boundaries (transcendence); and its elusive and somewhat obscure characteristics. Whereas religion, in contrast, represents a social phenomenon defined by an organised structure setting clear boundaries with distinctive beliefs, defining rituals and practices, and formal forms of governance. In the simplest terms, spirituality is considered to be "internal" to an individual, and religion is considered to be "external" to the individual. Yet, acknowledgment is given that the development of an individual's spirituality remains encapsulated within most religions and within its membership, keeping the two concepts tightly interconnected. It is generally agreed that spirituality is a construct that is separate and distinct yet, intimately interconnected with religion. Therefore, this section focuses on the abstract of humanity, humanities spiritual dimension.

Spirituality is a topic of both personal wonder and professional study by theologians, philosophers, psychologists, physicians, sociologists, laypersons, and citizens in general across cultures for centuries (Gaventa & Coulter, 2001a; Koenig,

1997; Macquarrie, 1982). The presence of a spiritual dimension within a person is a generally accepted aspect of human existence. Yet, this dimension of life had largely been excluded from pursuits of scientific understanding. It was not until there was paradigm shifts in thinking within major disciplines such as psychology and medicine that there was new consideration regarding spirituality's contribution and science (Koenig & McConnell, 1999; Larson, et al., 1998; Mytko & Knight, 1999; Piedmont, 1999).

In psychology, reductionist tendencies of understanding the human experience was noted in the literature to fall out of favour and be replaced with a growing recognition of alternative ways of knowing and accumulating psychological knowledge. Included in this new understanding was recognition of the multifaceted layers of existence, and the importance of spirituality and meaning in individual life context (Chuengsatiansup, 2003; Polkinghorne, 1994; Sue, Bingham, Porche-Burke, & Vasquez, 1999).

In 1998, the World Health Organisation (WHO) deemed the spiritual dimension of life to be such an integral part of humanity. The Executive Board of the WHO suggested the phrase "spiritual well-being" be included in the definition of health (Plianbangchang, 2007). In January of 2007, at the 1st World Convention on Science and Spirituality, an appeal was made to scientists and practitioners. The appeal sought to broaden scientists' and practitioners' awareness of the various components contributing to the health and well-being of people by not only acknowledging the anatomical and physiological correlates of well-being, but also, the contribution of meditation and spirituality practiced throughout the world for centuries. Fitchette

(1993) suggests that caregivers working with others are more effective if caregivers adequately identify problem areas and needs within the spiritual domain of the lives of people they assist. Canda (1999) suggests for social work practitioners an inclusive understanding of spirituality that takes into account the religious and nonreligious expressions as essential to being effective in working in a human service field. Canda purports that spirituality is a basic aspect of the human experience common to all people, cultures, and religions. Stienstra & Ashcroft (2010), in exploring the human and disability experience, suggested that the *spirit* is a critical, though often intangible, characteristic of being alive and regarded that spirituality must be included in any ontological discussions seeking understanding of the *nature of being*.

Despite this evolution in thinking regarding the spiritual domain of life, there remains no agreed upon universal definition for spirituality. Some of the confusion may be partly explained in what Miller (1998) described as spirituality's distinctiveness, specifically its idiographic nature, and somewhat elusive and obscure characteristics at an individual level. Despite the challenge of solidifying a universal definition for this aspect of the human experience, there is in the literature a general agreement that spirituality is a construct that is both multi-dimensional and trans-cultural. In addition, there is general agreement that the spiritual dimension of life is separate and distinct from religion yet, intimately interconnected with religion (Wing, 1999). To compare and contrast the use of the terms religion and spirituality within the literature Miller (1998), summarises common distinctions:

- Spirituality is idiosyncratic in nature and understood and defined at the individual level while religion is understood at an

organisational level, defining belief, ritual and practice for a group of people.

- Spirituality in its peculiarity defies defined boundaries and broad governance while religion provides defined boundaries and governance regarding specific beliefs and practices.
- Spirituality is more closely associated with personal qualities and individual internal processes while religion is more often associated with external, behavioural manifestations of governed beliefs, practice and rituals. In addition, spirituality may become unclear when rituals, rules and practice become important in their own right and their purpose is forgotten. (pp. 979-980)

Notwithstanding, the ongoing debates, spirituality and religion remain closely interconnected within the literature. What is clear is that research on the topic of spirituality within a context of deepening understanding of humanity, allows for the inclusion of non-religious belief systems and humanistic activities in addition to the religiously-oriented elements. However, this is not the case in the majority of the literature. The notion that this does not readily occur in research was emphasised in 2008. Hwang (2008) focused on religion and spirituality in health and rehabilitation. Hwang found that the research community neglected the spiritual experiences of committed atheists. Narrowly defining spirituality through measurement of religious expression or ideology alone minimises the fullness of the contribution this life domain area has on humanity. Consequently, Hwang's findings recommended that future

research be cautious in this regard when establishing methodology in the exploration of this life domain area.

Additionally, with the pursuit of research in the area of spirituality, gender differences regarding this aspect of humanity emerged within the literature. For example male and female differences associated with the pursuit of spiritual, and religious pursuits and health were noted in relation to mortality rates between men and women (McCullough, Hoyt, Larson, Koenig & Thoresen, 2000; Strawbridge, Cohen, Shema & Kaplan, 1997; Waite, Hawks & Gast, 1999). Gender differences were also highlighted regarding participation in spiritual activities and lifestyle choices in relation to illness and recovery from illness (Nagel & Sgoutas-Emch, 2007). Wills (2009) explored satisfaction and spirituality; he discovered significant differences between males and females. These research findings suggested that females may experience higher satisfaction with their spiritual life than males. Yet, these findings are not accepted without question. Some researchers question how research examines the constructs of religiosity and spirituality in relation to gender suggesting that the existing frameworks and focus of inquiry may contribute to outcome disparities between gender (Bryant, 2007; Simpson, Newman, Cloud, & Fuqua, 2008). For example, Simpson et al., (2008) explored gender in relation to religious participation and spirituality in respect to participation in religious activity verses relational aspects of spirituality. Their findings revealed no statistically significant differences in religious participation between men and women. Additionally, their findings suggested both genders were equally aware of their relationship with God. Mixed results suggest that gender differences in this life domain area are not yet clear. Furthermore, research on the

influence of gender and the spiritual dimension of life with individuals who experience intellectual and developmental disabilities remains unexplored. Therefore, not only is the pursuit of understanding of the spiritual dimension in life important, but also continued exploration of how the spiritual dimension of life may be understood or expressed between genders and amongst different populations of people.

A path of exploring spirituality that was inclusive of both religious and non-religious belief systems and activities, and increased the understanding of the various dimensions within the spiritual domain of life was pursued from the literature reviewed. To further understanding of this element of humanity the dimensions of spirituality are discussed in detail.

Dimensions of spirituality. The literature identifies four generally agreed upon concepts that are central to a person's spiritual dimension. These are the concepts of: 1) transcendence, 2) connectedness, 3) meaning & purpose, and 4) belief (Hawks, 1994; Kim, 2002; Koenig, 1995; Miller, 1995; Moss & Dobson, 2006; Zinnbauer et al., 1997).

Transcendence. The concept of transcendence points to the philosophical and metaphysical aspects of a person. This dimension of life indicates that human beings relate not only to themselves but to a larger reality. This larger reality includes others, nature, history, thought, and spirit (Wisley & Lynn, 1994). One can find many aspects to the idea of transcendence: it is that part of an individual that allows persons to rise above their immediate physical or material world/universe; view life from a larger, more neutral perspective; go beyond the expected; and see the fundamental unity within the diverse strivings of nature (Piedmont, 1999).

As a concept, transcendence indicates that the *spiritual* is something that is distinct from the physical, social, or psychological aspects of life. It would be that part of the individual that allows a person to rise above these other life realms. Konieg (1995) illustrates the concept of transcendence as he describes the “biopsychosocial-spiritual” model of understanding the human experience. In this model, he describes that the spiritual dimension is separate from the biological, psychological, and interpersonal dimensions of life. Konieg asserts that the spiritual dimension heavily influences the other life dimensions and in turn may be influenced by these other aspects of life. Kuhn (1988) discussed the concept of transcendence within the spiritual dimension relaying that it is this dimension that contains those capacities that enable a person to rise above or transcend any experience that they may encounter in life. As such, transcendence inherently interconnects with the metaphysical aspects of life. The metaphysical represents that which cannot be grasped by the human senses of seeing, touching, tasting, hearing, and smelling.

Additionally, transcendence is that part of a human being that seeks answers to the nature of existence and a person’s place and purpose in the universe. Several scholars addressed the significance of transcendence and the spiritual dimension of a person’s life in the literature, and attempted to build a bridge between science and the spiritual (Jones, 1994; Miller, 2010; O’Donohue, 1989; Shafranske, 2010; Wulff, 1997). O’Donohue (1989) wrote for the consideration of the role of a psychologist as metaphysician-scientist-practitioner. Jones (1994) suggested that religion and psychology could actively partner as an applied discipline in exploration of the

metaphysical and spiritual dimension of life. Wulff (1997) in the psychology of religion discussed the “Principle of the Inclusion of the Transcendent” (p. 645).

More recently, Miller (2010) psychologist and professor at Columbia University pointed out the shortcomings of a science that views *legitimate knowledge* as only that knowledge which comes from the empirical sciences. Miller initiated a call to action for a spiritual psychology in which psychology as a discipline and science generate new methods beyond materialism to map the non-material human experience. Shafranske (2010) suggested any approach that collapses spirituality into purely materialistic categories or explains away the person’s spiritual experience as a mere bio-physiological phenomenon, neglects the potency that transcendence may have on a person and thereby becomes greatly obscured.

This researcher’s study aligns with the notion that any aspect of humanity that is significant cannot be dissected and segregated from a continued pursuit of understanding of the nature of mankind as a whole. Dissection and segregation distorts what is really known about humanity, and scientific methodologies may not adequately capture the significant. Sociologist, William Bruce Cameron (1963) shared similar sentiments when he stated “not everything that can be counted counts, and not everything that counts can be counted” (p.13).

In contrast, there are those who oppose a reconciliation of the spiritual/religious and science, and opt for a continued course of separation. Averill (1998) agrees with the importance of spiritual experiences in life. He makes a philosophical argument that suggests that spiritual experiences can be explained in terms of ordinary psychological processes and casts doubt regarding a belief in an ultimate reality in which spiritual

beings might exist. In addition, Averill (1998) espoused a belief that “we invent a transcendental world and populate it with spirits created in the image and likeness of ourselves” (p.121). Furthermore, Averill suggests that his explanation of the spiritual as *psychological concoction* should not diminish the importance of spiritual experiences. Yet, the pretence that a person should not feel diminished by the suggestion that the framework by which some live their life, is purely imaginary, based upon a belief in God or other life force seems a bit naïve. Likewise, neglecting to pursue such areas in research may inadvertently contribute to diminished outcomes for people who rely on the policies and practices ensued from such research. Whether a person is a believer or unbeliever, Christian, Muslim or atheist, the literature remains generally consistent in acknowledging spirituality as an important dimension of life.

In the emphasis of the universal nature of a spiritual dimension of being, the literature references the cross-cultural nature of spiritual transcendence and experiences. Piedmont and Leach (2002) explored the universality of spiritual transcendence. Their research crossed faith traditions and argued that spiritual transcendence represented an intrinsic quality of the individual that is universal and motivates all religious behaviour (Piedmont & Leach, 2002). Likewise within the literature, spiritual transcendence has been shown to influence areas of learning (Smith, 2003); disability (Stienstra & Ashcroft, 2010); health (Haber, Jacob, & Spangler, 2007); end-of-life care (Moss & Dobson, 2006) ; culture (Sue et al., 1999); substance abuse recovery (Piedmont, 2004); and personality (Loury, 2000; Piedmont et al., 2009), thereby adding to concerns presented regarding the segregation of spirituality and the lack of consideration that this aspect of humanity has received within the social and scientific arenas.

Connectedness. The second reoccurring theme in the literature regarding spirituality is the concept of connectedness. The concept of connectedness emphasises that the *spiritual* not only encompasses the individual's internal experiences (connections with self) but also, is what connects people with that outside of themselves, with the community (others), the environment (nature), or a larger reality (higher power) (Simpson et al., 2008). Therefore, connectedness as a component of a person's spiritual dimension is important to discuss further.

In distinguishing spirituality as different than religion, the former is portrayed as something *internal* to an individual while the latter is *external* to an individual. Yet, it is the spiritual dimension of life that is discussed when contemplating that which connects an individual to things outside of self both vertically and horizontally. In the context of spiritual connectedness, the horizontal refers to an individual's connections to nature, self, family, friends, community, and the world around. The vertical refers to an individual's connection with God, a higher power, or a larger reality (Simpson et al., 2008). Therefore, spirituality is represented as a construct encompassing internal and external aspects of *being*.

Representative of the concept of connectedness to nature is the rapidly growing global movement of a nature-based spirituality. This movement has deep ecological roots in which ultimate meaning and transformative power lies in nature (Gottlieb, 2004; Taylor, 2001). Experiences of *nature* spirituality may include such practices of mountaineering, protective earth and environmental activities, and worship rituals associated with the birds, animals, rivers, and trees. Though quite diverse, this neo-

paganism provides the individual a sense of connection and belonging to nature. As in other religious movements, the eco-spiritualist embraces a connection to an ultimate life force be it Nature itself.

Here, God is not perceived as being somewhere in the heavens but rather, is on earth and animated in all things. The spiritual consciousness is that all nature is sacred, being animated by the presence of a cosmic life force within (Nanda, 2004). Whether or not an individual perceives nature as God or nature created by God, there is a general sense that human beings are interconnected with nature and the world around, and often experience similar feelings of awe, wonder, peace, tranquillity, and harmony in consideration of this connectedness across cultures (Ashley, 2007).

A strong representation of a philosophy emphasising a spiritual connection with nature is observed in Hinduism. In the Hindu philosophy, a person is taught to live in harmony with nature and to acknowledge that divinity exists in all elements, including plants and animals. Therefore, the exploitation or degradation of nature is viewed as morally wrong as this perceived interrelationship between ecology and man is an inherent part of the spiritual world view in Hinduism (Olson, 2007).

Another example can be found in the life philosophies of the American and Alaskan Native populations which also emphasise strong spiritual relationships between man and nature. Noah Augustine, a First Nations activist who passed away in November of 2010, poetically painted a picture of this in the following example:

Rather than going to church, I attend a sweat lodge; rather than
accepting bread and toast from the Holy Priest, I smoke a
ceremonial pipe to come into Communion with the Great Spirit;
and rather than kneeling with my hands placed together in prayer, I
let sweetgrass be feathered over my entire being for spiritual

cleansing and allow the smoke to carry my prayers into the heavens. I am a Mi'kmaq, and this is how we pray. (Augustine, 2000, para 2)

These types of spiritual expression should not be overlooked or underestimated in terms of their significance and influence within certain populations of people.

Additionally, the literature speaks to spirituality as having an attribute of connectedness to others. Emphasised here is the importance of an individual's interrelatedness with others, also referred to as community (Hay, 1989). This kind of connectedness points to the human capacity to form meaningful relationships, and connect by both giving and receiving from other human beings. Researchers highlight the importance of interconnectedness, social belonging, and community to personal well-being (Berkman, Glass, Brissette & Seeman, 2000; Fiske, 2004). Furthermore, in times of significant personal stress, an individual's ability to help others is noted to assist not only with the healing of another but also to contribute to the person's own spiritual healing (Hall, 1998). Other writers have also noted the spiritually healing nature of helping others and the relational power of a person's interconnectedness (Debats, 1999; Emdon, 1997; Montgomery, 1991).

Another aspect of the horizontal connectedness is the sense of belonging portrayed by those connected to various faith communities. Within specific faith communities, members regard their interconnectedness with others as facilitating a shared identity, sense of belonging, and meaning and purpose (Coyle, 2002). Levitt (2004) analysed the role faith communities play in increasing individual social belonging and community networking. Levitt's research highlighted the individual benefits of religious affiliation in creating a sense of membership and at times extending

financial, educational, and recreational opportunities on behalf of people affiliated within a faith community. Hayward and Elliott (2009) asserted that there was a connection between religious group membership and personal well-being in that most religious groups practiced the tenets of a spiritual life within a social context of a faith community paving the pathway for belonging and membership. Within Christian doctrine, participation within a faith community is viewed as an essential aspect of living a Christian life (Ryken, 2001). Likewise, some researchers further suggest that the deepest spiritual encounters are those experienced through relationships (Hales & Lauzon, 2010; Matzo & Sherman, 2009; Spaniol, 2002). Positive aspects of relationships serve numerous sources: sustain and comfort; guide decision-making; and grant forgiveness, provide encouragement, acceptance, love, intimacy and celebration along life's journey (Matzo & Sherman, 2009). Being connected with others is acknowledged as a natural way of being. Within the social capital literature, there are themes emerging from the research that suggest the importance of strong connections within community to improved mental well-being (Friedli, 2001; Hepworth & Stitt, 2007). An enhanced sense of belonging, trust, and life satisfaction are associated with people who have strong relationships within community that assist people in a variety of ways (Welsh & Berry, 2009). In addition, the interpersonal connections and reciprocity of relationships within community afford people opportunities to socially bond and link one another to various individual resource needs.

A person's social and spiritual connectedness is associated with the building of both community and individual *emotional resilience*. This association is highlighted in the Public Health and Medical literature, suggesting a strong interdependence of mental,

emotional and spiritual well-being on physical health (Bekelman et al., 2007; Cooper, Arber, Fee & Ginn, 1999; O'Connell & Skevington, 2010). The literature suggests that such improved mental and personal well-being may occur within the context of faith communities (Greenfield & Marks, 2007). This is thought to be largely attributed to faith communities' potentially supportive environment, promotion of healthy lifestyles, and cultivation of belonging and social inclusion (Okulicz-Kozaryn, 2010).

Likewise, the lack of such attributes within a community has been associated with diminished valued outcomes, life satisfaction and well-being for individuals. Throughout the literature, experiences of social isolation, rejection and exclusion are associated with feelings of depression, and poor mental and physical well-being (Fiske & Yamamoto, 2005; Gaventa & Coulter, 2001b; Stillman et al., 2009; Wolfensberger, 1969). The relationship of connectedness within one's context seems essential to the spiritual experience. If a context does not support the formation of personal connection, social networks, trust and mutually reciprocal engagement, then the likelihood of an individual experiencing a sense of 'spirit' within community may be unlikely.

There is also a spiritual connection of an individual to *self*. The sense of connectedness to self enables individuals to reflect on themselves, their motives, desires, and their sense of personal meaning and purpose in the world (Burkhardt, 1994; Coyle, 2002). The spiritual connection to self is critical as it facilitates the understanding and development of a person's self-identity (Brandt et al., 2009; Erikson, 1943, 1963). Therefore, the intrapersonal aspects of spiritual connectedness involve the contemplation of one's inner person and resources. Finally, the spiritual connection to

self represents a personal inquiry to discover and understand the life force within the self.

The second dimension of spiritual connectedness is described as a vertical connection to God, a Higher Power, cosmic life force, or a greater reality. The challenge to know the exact number of people in the world who either believe in God, or a Higher Power, or are self-described as *spiritual*, is due to statistical reporting and definition of terms. Despite such a challenge, the literature does identify that most indigenous peoples and those residing in Asia, Africa, and Latin America believe that spirituality is a life force that provides the fundamental support of their existence in the universe (Harner, 1990; Kim & Berry, 1993; Sue & Sue, 1999). In addition, a 2008 study conducted in the United States found that 92% of Americans believe in God or a universal spirit, and more than half of the Americans polled reported to pray at least once per day (Salmon, 2008). This pervasive statistic included Americans who described themselves as atheist or agnostic, yet these individuals relayed a strong sense of the presence of a higher power or greater reality.

An ideology that suggests that an individual's god reflects something about the essence of the individual is a widely held notion among the religious and nonreligious alike. The Christian Bible states: "And God said, Let us make man in our image after our likeness" (Genesis 1:26). However, some social scientists and psychologists argue for the reverse causal order of this belief, suggesting that individuals reflect cultural values and ascribe desired human characteristics to the idea of the supernatural (Gorusch & Smith, 1983; Ladd, McIntosh, & Spilka, 1998; Peters, 2007; Roberts, 1989). Despite ongoing debates centred around ideas about God, the connectedness

that individuals' ascribe to themselves and God, or a greater life force, remains a powerful influence in life and in one form or another is pervasive across cultures.

Meaning and purpose. The third reoccurring theme in the literature regarding spirituality is the concept of meaning and purpose. Conceptually, meaning and purpose emphasises that the *spiritual* dimension is that part of humanity that provides the individual with the tools to seek answers to questions of personal meaning and purpose in life experience, and in seeking understanding regarding existence both personally and in a broader context (Baumeister, 1991; Buchanan, 2005; Frankl, 1963).

While most scholarly definitions of spirituality include and even emphasise the concept of meaning and purpose as a component of spirituality, a lay sample of definitions of spirituality included this concept in only about 5% of the definitions (Zinnbauer et al., 1997). One explanation of this phenomenon may be that individuals simplify this construct for their own life, while science and scholarly work attempt to understand the construct on a more global level adding complexity. Regardless, spirituality is thought to provide an individual with tools for discovering the answers to important philosophical and existential questions of life in addition to assisting the individual's search for direction, fulfilment, and life satisfaction.

Viktor Frankl emphasised this in his existential theory and clinical practice of *logotherapy* (Frankl, 1955, 1963, 1967). Viktor Frankl's logotherapy is based upon the premise that each human being is motivated by a *will to meaning*. Frankl theorised that each human being is unique in body, mind, and spirit, and possesses an internal drive to find meaning in all of life circumstances.

Abraham Maslow represented this aspect of humanity in his *Theory of Human Motivation* (Maslow, 1943, 1954). Maslow described an individual's seeking meaning and purpose as an innate human need for *self-actualisation*. Maslow theorised that self-actualisation was a fundamental human need or desire to constantly better oneself and become everything that he or she is capable of becoming. Furthermore, Maslow hypothesised that the spiritual life constituted the most essential humanity. He described the spiritual life as 'instinct like'. Maslow, along with other theorists such as Fritz Perls, founder of Gestalt Therapy in the 1940's, and Carl Rogers as one of the founders of Humanistic Psychology and Client-centred Psychotherapy in the 1950's, contributed heavily to the field of Transpersonal Psychology that emerged as an outgrowth of the humanistic psychology movement (Perls, 1969; Rogers, 1951).

The Transpersonal Psychology movement perceived the earlier approaches of psychoanalysis and behaviourism as too pathologising and reductionistic to fully appreciate the experiential fullness of the human being and one's search for meaning. Transpersonal Psychology emerged within the field of psychology specifically to explore human spirituality in its broadest sense (Buchanan, 2005).

More recently, meaning in life was conceptualised as having four dimensions (Jim et al., 2006). The first dimension included positive emotions and feelings of inner peace and harmony. The second dimension consists of feelings and thoughts of life satisfaction both in the present and in the future regarding the meaning assigned to one's own life. This dimension of meaning in life reflects a person's desire for personal growth, learning, and the desire to self-improve. The third dimension of meaning in life references a person's spirituality and beliefs in a purposeful pattern of the universe that

is larger than oneself. This level of meaning of spirituality can have either a religious or non-religious basis. The final dimension of meaning in life is conceptualised to represent the absence of loss of meaning in life and is reflected in negative emotions and a sense of lesser value in life. Contributing to this fourth area may be a person's sense of social exclusion and rejection in life (Stillman et al., 2009). Likewise, Baumeister's model of meaning suggests that the effect of social exclusion on meaning may be mitigated by a person's sense of purpose, value, and self-worth (Baumeister, 1991). Cummins, Eckersley, Pallant, Van Vugt, and Misajon (2003) developed a subjective personal well-being model and suggested that life satisfaction consists of seven different life domain areas. In this model, theoretical consideration was given to the predictive value of spirituality and religiosity as an evaluative measure of life satisfaction (Cummins et al., 2003).

It is evident within the literature humanity's search for meaning and purpose in life provides significance to understanding ways of being. As such, an individual's search for meaning and purpose in the context of life events continues to be explored in research, where spirituality has been shown to be a positive factor in a variety of areas of health (Jim et al., 2006; Kaye & Raghavan, 2002), palliative care (Gilbert, 2006; Lin, 2008), mental health and addiction recovery (Freeman, 2006; Koenig et al., 2001; Moss & Gilbert, 2007), and even in business and organisations (Hart, 2005; Pawar, 2009). The literature remains consistent in acknowledging the relevance of how individual's ascribe meaning and purpose in life, and how this area shapes perceptions, attitudes, and potential outcomes in life events.

Belief. The fourth and final recurring theme in the literature regarding the spiritual dimension of life is the concept of belief. The concept of belief emphasises that the *spiritual* dimension is that part of an individual that allows the person to hold certain truths or principles which provide a framework for their life, guides their behaviour and influences the interpretation of life experiences. Beliefs may contain both religious and non-religious elements (Kay, Gaucher, Napier, Callan, & Laurin, 2008; Kay, Whitson, Gaucher, & Galinsky, 2009; Norris & Inglehart, 2004).

More specifically, an individual's beliefs influence personal actions, decision-making, and performance; shape the individual's understanding and interpretation of life experiences; and influence expectations of self and others. Furthermore, beliefs aid an individual in answering significant universal life questions such as: *Who am I?; Why am I?; Is there a purpose for my life?; Where do I belong?; To whom do I belong?* and; *Why is there suffering and death?* (Gaventa, 2001). Human beings spend much of their lives seeking answers to these and other significant life questions. Ultimately, the truths that a person holds contribute to the person's understanding about life and provide a personal framework by which the individual lives life. Beliefs further contribute to a person's personal sense of control, power, and place in the world. Finally, beliefs and belief systems provide the fundamental building blocks by which individuals, organisations, communities, cultures, and society establish governance (Kay et al., 2010).

One school of thought suggests that such belief systems are essential to human beings. These belief systems give meaning to life. Meaning structures one's life and creates predictability and order rather than chaos (Fry, 2000; Hammond, 1985; Kay,

Gaucher, Napier, Callan, & Laurin, 2008; Kay et al., 2009; Norris & Inglehart, 2004). Hence, individual belief systems assist in making meaning of the world around a person and in organising and understanding life experience.

Evaluating spirituality. The same challenges and trends found in defining spirituality exist in assessing spirituality in a person's life. Therefore, it is important to include a review of the manner in which research has approached assessing this variable. As noted earlier, trends in the literature regarding spirituality tend to define spirituality as a subjective experience, distinct from religion. Despite this, early research tended to focus on external indicators in measuring spirituality such as religious behaviours, religious affiliations, and religious participation (Boivin, Donkin, & Darling, 1990; de Jager Meezenbroek et al., 2010; Hill & Hood, 1999).

Current research studies emphasise subjective indicators such as overall life satisfaction, spiritual experiences, spiritual beliefs, and spiritual quests (Johnstone & Yoon, 2009; Kim, 2002; O'Connell & Skevington, 2010; Sandage, Jankowski, & Link, 2010). A contributing factor to such diversity is the fact that measurement instruments derived from diverse theoretical backgrounds and theological traditions often attempt to measure a variety of differing elements within the spiritual domain. Over the past several decades, research added numerous measures of spiritual and religious assessment instruments to the available inventory. An examination of spirituality instruments unveils an immense variety of operational definitions for measuring spirituality (de Jager Meezenbroek et al., 2010; Hill & Hood, 1999; Larson et al., 1998; MacDonald et al., 1999). The more recent researchers in spirituality incorporate

measurements more meaningful to the holistic and subjective experiences contributing to a person's perceived overall health, well-being and life satisfaction (de Jager Meezenbroek et al., 2010; MacDonald, 2000; Sawatzky, 2002). However, the lack of a unified and clearly defined classification system with empirically validated categories for the spiritual domain creates confusion. Likewise, confounding concepts regarding the spiritual domain challenges a measurements empirical usefulness. Despite the challenges found in measuring spirituality, progress towards developing a unified understanding or framework from which to explore the spiritual domain continues (Buchanan, 2005; de Jager Meezenbroek et al., 2010; MacDonald, 2000).

An underlying premise of the current research suggests that spirituality is part of all humanity. In consideration of spirituality as a universal human dimension, a review of spiritual assessments focused on measurement instruments appropriate for both religious and non-religious populations. In an extensive literature review conducted, there were four, one-dimensional or two-dimensional spirituality questionnaires and six multidimensional questionnaires representing a global perspective regarding spirituality. Instruments reviewed measured spirituality as a personal experience that transcends any particular religion (de Jager Meezenbroek et al., 2010).

Research by de Jager Meezebroek et al., (2010) examined over 800 articles of which 120 articles reported on the development or validity of well over 120 spirituality questionnaires. In an attempt to uncover global measuring instruments, suitable questionnaires were further defined by the following criteria: "(a) suitability to a broad group of people with various religious or secular backgrounds, (b) having a broad scope and (c) at least some psychometric data have been published" (p. 4). All questionnaires

examined revealed some limitations that should be considered by a researcher. However, in an effort to create a practical approach to a researcher's choice of instrument selection, de Jager Meezebroek et al. (2010) suggest researchers desiring a short global measure of spirituality choose between one of the four, one-dimensional or two-dimensional questionnaire options. Researchers seeking to answer specific questions regarding spirituality should choose a multidimensional questionnaire. A multidimensional questionnaire is more likely to facilitate greater understanding regarding the various dimensions of spirituality and how these dimensions play out in a person's life. These instruments are noted below:

One or Two Dimensional Spirituality Scale Instruments

- Spiritual Well Being Scale of the Functional Assessment of Chronic Illness Therapy, *FACIT-Sp-12* (Brady, Peterman, Fitchett, Mo, & Cella, 1999)
- Spirituality Subscale of the Mental, Physical and Spiritual Well-being Scale, *MPS* (Vella-Brodrick & Allen, 1995)
- Self-Transcendence Scale, *STS* (Reed, 1991)
- Spiritual Well-Being Scale, *SWB* (Ellison, 1983)

Multidimensional Scale Instruments

- Prague Spirituality Questionnaire, *PSQ* (Rican & Janosova, 2005)
- Spirituality Assessment Scale, *SAS* (Howden, 1992)
- Spiritual Involvement and Beliefs Scale Revised Version, *SIBS-R* (Hatch, Burg, Naberhaus, & Hellmich, 1998)
- Spiritual Transcendence Scale, *STS* (Piedmont, 1999)
- Spiritual Well-Being Questionnaire, *SWBQ* (Gomez & Fisher, 2003)

- WHOQOL Spirituality, Religion and Personal Beliefs, *WHOQOL SRPB* (O'Connell, Saxena, & Underwood, 2006)

It should be noted that though these questionnaires were determined to be suitable to a broad group of people, questionnaires were not developed with consideration of individuals who experience intellectual and developmental disabilities.

Spirituality and Intellectual and Developmental Disabilities

A historical examination of research regarding spirituality and individuals who experience intellectual and developmental disabilities reveals a dearth of information within the literature. The paucity of research within the area of spirituality and intellectual and developmental disabilities lends credence to the notion that society and the scientific community may not see individuals within this population as the same as all other citizens in this regard. The scientific community appear to see this population of people as, not fully human, and neither capable of nor benefiting from the full range of human experiences. Therefore, a review of the literature focuses on contextual societal perspectives and theological perspectives influencing research. These perspectives are followed by a review of the research within the field of intellectual and developmental disabilities.

Another contributing factor to the lack of information in this area is that research within the field of intellectual and developmental disabilities typically followed alongside societal, political, economic, and legislative processes and pressure. Service providers, health care providers, educators, politicians, and bureaucrats connected to

these areas simply have not held the spiritual dimension of life as within their scope of responsibility for individuals who experience intellectual and developmental disabilities. Therefore, these perspectives over time, and without regard for the spiritual life of individuals with intellectual and developmental disabilities, influenced the shaping and reshaping cycles of disability definitions, professional and lay person's language and labels, and conceptualisations of what the needs of individuals encompassed. It is only within the last twenty years that significant changes occurred within the disability field, and in churches and religious communities where spirituality and disabilities has begun to be addressed. Nevertheless, people today who experience intellectual and developmental disabilities continue to be excluded from religious communities of choice, and service providers continue to neglect addressing a person's spiritual needs in person-centred planning processes (Creamer, 2006). Thus, both structural and attitudinal barriers remain common.

Creamer (2006), who is both a scholar of religion and of disability studies, suggests that part of religious organisations' slow response to disabilities in the United States may be attributable to religious institutions exemptions from the Americans with Disabilities Act (ADA). The ADA, by law, requires covered entities to address four primary types of accommodations. These areas of accommodation address discriminatory admissions policies; business policies, practices and procedures; the provision of auxiliary aids and services for effective communication; and the removal of physical barriers in programs and facilities. Entities not covered under the ADA are able to independently decide whether or not to address these areas on behalf of people who experience disabilities. While many faith communities are beginning to evaluate

their religious organisations for inclusive practices, many others have yet to address associated barriers of attitude, awareness, architecture, and accessibility in any meaningful way (Carter, 2013). Likewise, Creamer (2006) accused the field of disability studies of considering the exploration of religion and disabilities to be “unimportant, uninteresting, or unapproachable” (Creamer, 2006, para. 6). As support for this perception, Creamer highlights the 2001 *Handbook of Disability Studies* in which editors Albrecht, Seelman, and Bury sought to incorporate the rich depth and diversity of existing theory and perspectives found in disability studies (Albrecht et al., 2001). However, Creamer points out that in this text, religion is scarcely mentioned and then only in the context of the history of disabilities and institutionalisation.

An outcome of neglecting any aspect of significance in life, to include the spiritual dimension, perpetuates the devaluing of individuals who experience intellectual and developmental disabilities as whole beings. Religious/spiritual entities and disability-related entities, professionals and paraprofessionals alike must come to realise their interdependency on each other if ever the dream of inclusive communities for all is to be realised.

Therefore, a review of the various perspectives that contribute to an evolving understanding of what it means to experience an intellectual or developmental disability is important. In addition, a review of perspectives contributes to an understanding of why research in spirituality and intellectual and developmental disabilities is an important pursuit. This section will review societal and theological perspectives that contextually added to the way in which people with disabilities are treated, and review what is currently known about the spiritual lives of individuals who experience

intellectual and developmental disabilities. Finally, research within the literature regarding spirituality and intellectual and developmental disabilities will be summarised.

Societal perspectives. Historically, society perceived individuals who experience intellectual and developmental disabilities as incapable, having limited capacity to make decisions, grow, and develop as human beings; or self-manage day-to-day life (Schalock et al., 1994). Since individuals were perceived as incapable and for the most part non-contributing members of society, notions about their spiritual needs did not enter into consideration. People with intellectual and developmental disabilities were largely objectified and perceived as burdens to society.

It is important to note the term *developmental disability* is mostly utilised within the United States and Canada. The term first appeared in U.S. when Congress passed Public Law 91-517 *The Developmental Disabilities Services and Facilities Construction Amendments of 1970* in an effort to improve the dehumanising conditions that existed for people living in State institutions. The law has been amended many times over the years, culminating on October 30th, 2000 with Public law 106-402 *The Developmental Disabilities Assistance and Bill of Rights Act of 2000*. Public law 106-402 was enacted by the U.S. Senate and House of Representatives to improve service systems for individuals. This law calls for the full community inclusion and self-determination of people who experience intellectual and developmental disabilities.

Yet, there remain historical scars from centuries of isolation, segregation, harmful characterisations, social exclusion, forced sterilisations with the list of

atrocities, and dehumanising acts against individuals continuing up through the mid-twentieth century. Until recent times, society percolated through a colander of degrading beliefs regarding individuals who experienced intellectual and developmental disabilities as mentally defective, deviant, sub-human, the consequence of sin, and at times demonised (Barham, 1992; Ferguson, 1994; Trent, 1994).

Initially, the only support for individuals who experienced intellectual and developmental disabilities came through families and religious communities, who, out of pity and a sense of moral responsibility provided primarily protection and shelter (Parmenter, 1992). Later, large institutions were built and individuals were removed from families and placed in large facilities, completely hidden from mainstream society. History paints a picture that society treated individuals who experienced intellectual and developmental disabilities as if they were something to prevent, fix, ignore, isolate, or eradicate. Supports amounted to little more than the provision of basic physical needs such as food, shelter, and clothing. The social, emotional, and spiritual needs of people with intellectual and developmental disabilities went unacknowledged in any meaningful way for centuries. In the late 1960s, a paradigm shift in societal thinking took place and a social model of disability replaced earlier models.

Wolf Wolfensberger was highly influential in shifting professional policy and practice and societal attitudes of the time in the United States and Canada with his pivotal works of *Changing Patterns in Residential Services for the Mentally Retarded* (1969) and *Principles of Normalisation* (1972). This new ideology paved the way for consideration of individuals who experienced intellectual and developmental disabilities as possessing the same human needs and basic rights as other members of society.

Following this new paradigm was the notion that all people belonged in community, which initiated the deinstitutionalisation movement that took place in large scale over the next several decades.

With the removal of barriers, increased training, and educational opportunities, and the advent of concepts, such as social role valorisation, self-determination, and person-centred planning, society and governments more fully acknowledge people who experience intellectual and developmental disabilities as complete beings to include the contribution and gifts they bring to community (Kormann & Petronko, 2002). Societal views awoke to seeing individuals who experience intellectual and developmental disabilities as entitled to the same basic rights as all citizens and capable of experiencing and benefiting from the full range of human experience. This acknowledgement includes a person's right to participate in spiritual and religious activities (Quinn et al., 2002).

However, considering a person to be entitled to the same rights as all other citizens, does not in and of itself ensure that people are able to execute those rights. The *National Organisation on Disability and Harris Interactive, Inc.* conducted a study in which a survey of Americans (n = 2,255) with and without disabilities participated. The survey findings revealed that 84% of respondents with disabilities and 84% without disabilities considered their religious faith to be "somewhat important or very important" to them (Hanson, 2004, p. 21). Yet, this same survey indicated that individuals with disabilities were less likely than individuals without disabilities to attend religious services.

In addition, many adult individuals who experience intellectual and developmental disabilities in the United States are reliant on publicly funded support services to participate in daily community life which includes religious and spiritual activities. The literature suggests that fear and misconceptions by paid supports regarding law and the separation of church and state continues to challenge people's ability to access spiritual and religious activities of choice (Gaventa, 2006).

Commensurate to this is an acknowledgement of a lack of training and staff educational curriculum regarding the spiritual lives of individuals who experience intellectual and developmental disabilities and a staff's role in the provision of spiritual supports (McNair, 2011a; Patterson, 2009). In 2007, the Office of Mental Retardation and Developmental Disabilities in the State of New York conducted a state-wide survey of individuals who experienced developmental disabilities and were receiving state services (Patterson, 2009). The survey sought three objectives: 1) to evaluate staff and administrations interactions with individuals regarding the individual's spiritual needs, 2) to determine current levels of support, and 3) to determine current obstacles that would hinder support systems.

The survey revealed systemic weaknesses within New York's support system in five main areas that hindered peoples' opportunities to participate in spiritual activities and faith communities of choice: 1) staffing levels and attitudes, 2) training and education, 3) information about various faiths, 4) transportation, and 5) community connections. While the survey's results pointed out that the characteristics of residential settings and staffing levels in the disability population influence opportunities for participation, it does not answer the question as to whether or not participation once

supported would be viewed as meaningful or result in improved individual outcomes. Yet, with the discovery of significant areas of needed improvement, the survey information helped to formulate important first steps and emphasised the important role that a faith-based initiative could have regarding designing systems of support for people in which whole lives and full community inclusion may one day be realised.

Perspectives of world religions. Theology and institutes of world religions have long been sources through which people seek answers to major life questions. Such questions encompass a variety of areas within life to include understanding pain and suffering, hope and faith, purpose and calling, and death and afterlife. Regardless of this, personal experience narratives of individuals who experience disabilities, both historically and in modern times, report exclusion and ridicule. This is particularly true in religious communities. Yet despite negative individual experiences, religious institutions, churches and synagogues, remained influential in attempts to understand and support individuals who experience disabilities. Likewise, in recent years various faith communities made formal commitments towards the development of ministries. Additionally, interfaith networks focused on disability issues developed a growing supply of educational resources. Resources include media presentations, training curricula, informational literature, and advocacy forums in support of furthering inclusive ministries and religious communities in support of individuals who experience developmental disabilities (*American Islamic Fellowship*, 2011; *Friendship Ministries*, 2011; *Interfaith Ministries*, 2011). Inclusive faith community initiatives evolved over time in conjunction with doctrinal understandings and culture regarding concepts of

disability. Review of the literature included an examination of major tenets associated with the largest faith communities in an effort to understand how disability may be understood from a faith based group perspective in the research. This section addressing theological perspectives will summarise core elements within the three major world religions in western cultures which have influenced historically and in contemporary times how people interact with individuals who experience intellectual and developmental disabilities. Additionally, participants in the current research may be associated with a variety of religious groups. Therefore, an understanding of the fundamental precepts connected with the major religious groups is important to providing historical perspective and context to lived experiences of people who experience disabilities.

Christianity and disabilities. Christianity is the world's largest religion, representing approximately 33% of the world's population (Pew Research Center, 2012). Christianity is primarily comprised of the Orthodox Church, the Roman Catholic Church, and Protestant Churches.

The Orthodox Church considers itself to be the One, Holy, Catholic and Apostolic Church established by Jesus Christ and His Apostles 2,000 years ago (Hardon, 1981). Though there are variations in language and style of worship, all Orthodox Churches are united by teachings in the Bible where all members profess the same beliefs regardless of race or nationality. The Orthodox Church considers Jesus Christ as the head of the Church and the Church to be His body. In terms of authority, the Orthodox Church believes that God directly passed down authority to Orthodox

bishops and clergy through the laying on of hands as practiced by the apostles historically, such as, apostolic succession (Morris, 2007). The Orthodox Church looks to the New Testament writings along with the canons (regulations and decrees written by those viewed as having church authority).

The Roman Catholic Church's Sacred Scripture is the Catholic Bible which consists of 73 books. The Roman Catholic Church recognises the Pope as having authority on spiritual matters and sees its mission as spreading the gospel of Jesus Christ, administering the sacraments, and exercising charity (Hahn, 2009). Neither the Code of Canon Law or the Roman Catholic Church have an official policy regarding the inclusion of individuals who experience intellectual and developmental disabilities in participation of sacraments and rituals. However, a parallel is typically drawn in relation to *infant communion* and the *age of reason*. The Catholic Encyclopaedia (1913) article on *Communion of Children* states:

In the best-supported view of theologians this phrase means, not the attainment of a definite number of years, but rather the arrival at a certain stage in mental development, when children become able to discern the Eucharistic from ordinary bread, to realise in some measure the dignity and excellence of the Sacrament of the Altar, to believe in the Real Presence, and adore Christ under the sacramental veils. (para. 2)

Additional guidelines were composed for the Catholic Church in relation to disabilities and participation in worship in a publication entitled *Guiding Principles and Strategies for Inclusion in the Liturgy of Catholics with Disabilities* (Federation of Diocesan Liturgical Commissions, 2005). This document presents an inclusive ministry for all people with and without disabilities, and offers a welcoming place for people with disabilities as an essential component within the Catholic Church.

Out of Catholicism came the Protestant perspective taught by Martin Luther. The Protestant Christian Church is comprised of many denominational and nondenominational groups that vary in their interpretation of portions of scripture, religious rituals, and traditions. Beliefs that extend across Protestantism include the Christian Bible which is seen as the sole authority for all Christians, and the belief that salvation comes through faith alone in Jesus as Christ, as opposed to merely by works (Schaff, 1912).

In general, Christians look to their sacred texts and scriptures for guidance in life and how to regard one another in this life. For example, Biblical imperatives such as found in Matthew 22: 37 – 40 (New International Version) which underlie Christian life are found in the Beatitudes and in the Commandments communicated by Christ “‘Love the Lord your God with all your heart and with all your soul and with all your mind.’ This is the first and greatest commandment. And the second is: ‘Love your neighbour as yourself.’” Christians believe that Jesus Christ is the Son of God who came to earth in human form and through his death, burial, and resurrection became the saviour of all humanity. Underpinning the Christian life is the belief that all who follow Christ’s teachings are welcomed into the membership of His Church. Therefore, Christianity is open to all people regardless of race, nationality, gender, or ability level. Though Christianity proclaims an inclusive doctrine, Churches often fall short. Eisland (1994) proclaims, “The persistent thread within the Christian tradition has been that disability denotes an unusual relationship with God and that the person with disabilities is either divinely blessed or damned” (p.70).

Islam and disabilities. Islam is the second largest religion in the world comprising approximately one quarter of the world's population. Likewise, Islam is one of the fastest growing religions in the world (Pew Research Center, 2012). Islam is a monotheistic religion with God being referred to as *Allah*.

The sacred text of Islam is the Qur'an. A person who adheres to Islam is called a Muslim. Muslims consider the Qur'an to be the verbatim word of God along with the Sunnah and Hadith, which are the teachings of the Prophet Muhammad. The Qur'an is considered by Muslims to be the unaltered and final revelation from God. Despite these shared sacred texts, variations in understanding exist within cultures and between countries and even regions impacting perspectives on disability (Turmusani, 2001).

The basic religious concepts and practices include the *five pillars of Islam* which represent the obligatory acts of worship. These acts of worship include: the shahada (creed), daily prayers (salat), fasting during Ramadan (sawm), almsgiving (zadat), and the pilgrimage to Mecca (hajj) at least once in a lifetime. In addition, Muslims follow Islamic law which addresses most aspects of life and society (Pew Research Center, 2012). Islam views disability as part of life and the human condition. Islam distinguishes between those who experience an intellectual disability and a mental disorder, but view both as legally incompetent (Morad et al., 2001). However, a Muslim's duty according to Islam is to protect, assist, and respect persons with intellectual and developmental disabilities, providing them an equal chance in life as all others (Morad et al., 2001). This chance in life is thought by Muslims to begin at conception as a fetus, is considered a human being and is believed to possess legal rights which are noted within Islamic law (Human Rights in Islam, 1999). The sanctity of life

is established in the Muslim's sacred text, "Nor take life, which God has made sacred except for a just cause" (The Qur'an, 17:33). Islam recognises that each person regardless of race, colour, gender, or disability deserves respect and regard as a human being. The social context for Islam is one of a universal brotherhood, consequently opposing the exclusion of any group of people. The Qur'an acknowledges diversities of all kinds and portrays that in the sight of God (Allah) the only true source of honour lies in living a righteous life (The Qur'an, 49:14). Likewise, Islam establishes duty in demonstrating kindness and benevolence to others in need (The Qur'an, 4:37). Islam teaches that all people regardless of ability level deserve love, care and respect and that God's judgement will come from the heart and conduct of a person. In summary, Islamic teachings as well as the life examples of the Prophet Muhammad exemplify the importance, value, and potential of every individual within society. Despite this, in much of the world people who experience disabilities remain marginalised and often invisible. Islamic teachings remain as one source of guidance for people to live more inclusively.

Judaism and disabilities. Judaism is one of the oldest monotheistic religions, dating back more than 3,000 years and influencing both the Islam and Christian Faiths. Judaism is not just a religion but represents a way of life. Judaism holds high a person's obligations to other human beings. The Jewish way of life is rooted in the Biblical teachings that a human being is created in the image of the Divine and as such has a sacred right to life and dignity. Judaism holds as authority the Torah and Jewish law and view these sacred scriptures to be divine in origin, unchangeable, and absolute

(Merrick et al., 2001). Orthodox Judaism holds that the Torah and Jewish law should be strictly followed. Initially, Judaism did not separate belief from performance. In contrast, Reform Judaism took a more liberal approach to the Torah and Jewish law. They view these scriptures more as general guidelines for how one should live their life, rather than a set of restrictions and obligations required of all Jews. While recent time understandings have both softened and changed, the early portrayal in ancient Jewish texts of people who experienced disabilities when contrasted to the desire to reach the ideal of the “perfect priest” (portrayed as embodied perfection) stigmatised those with disabilities.

Rabbi Judith Abrams, in her book *Judaism and Disability*, portrays the evolution of attitudes through the centuries which gradually reduced physical perfection as a prerequisite to a relationship with God (Abrams, 1998). Abrams inquiry reviews five main areas within Judaism that historically impacted individuals with disabilities: 1) ritual purity and the way in which Temple priests functioned; 2) the symbolic use of persons with disabilities for Israel; 3) how the life stories of persons with disabilities were used as object lessons for God’s justice 4) the treatment of persons with disabilities within Judaism; and 5) the way in which people with disabilities were classified. People with disabilities were socially stigmatised and viewed as defective, blemished, and therefore, unacceptable to participate in systems of holiness.

Merrick et al., (2001) suggests that Jewish law and scholars historically stressed the importance of education, acceptance and responsibility towards people who experience intellectual disabilities. Methods were developed by Rabbis to educate those with intellectual impairment in the rituals and edicts of Judaism. This was seen as a

fulfilment to the commandment: “And you shall teach them (words of the Torah) to your children....” (Deuteronomy, 11:19).

History clearly documents how early cultures and attitudes frequently associated physical and mental impairment with spiritual imperfection, sin, and unworthiness. Yet, contemporary Judaism acknowledges that each human life is sacred and valued. Characteristic of Judaism today is the encouragement of all people regardless of their ability level to participate fully in the worship and rituals of the Jewish Faith. Likewise, Judaism now strives to create inclusive communities of worship and belonging which extends out to other aspects of life (Merrick et al., 2001).

Each of the major religions evolved over time in respect to their understanding of individuals who experience disabilities. Christianity, Islam, and Judaism historically demonstrated less than inclusive practice in association with individuals with disabilities. As cultural and social contexts changed so did the interpretation and application of the sacred texts by which people tried to live and interact with one another. These varied understandings influenced dramatically the spiritual opportunities afforded people who experience disabilities to worship and be included within faith communities.

Disability theology perspectives. Arguments have been made both for and against a disability theology. Concerns against viewing theology from various lenses, disability or otherwise believe theology, as the study of who is God, should stand on its own (McNair, 2011b). Behind this premise is the notion that if people really know God, then love and acceptance of all of His human creation will also be understood. Yet, others believe that disability theology models are important in that these models

facilitate greater depth and breadth of theological reflection (Creamer, 2006; Hull, 2003).

Theological reflection is deemed necessary to liberate not only people who experience disabilities but also, a greater population beyond religious arenas. Disability theologies challenge current understandings and images of God when positioned alongside the lived experiences and narratives of people who experience disability (Creamer, 2006). Dialogues of disability among theologians, society, churches, and those who experience disability may foster new insights for all. Swinton (1997) magnifies the challenges faced within faith communities when considering the churches response to individuals who experience profound cognitive disabilities. For example, Swinton acknowledges that some perceive that participation in the giving and receiving of the sacraments without intellectual comprehension is dishonourable to God. While for others, a lack of cognitive ability would preclude any kind of spiritual life. Swinton proposes that a relational understanding of faith and spirituality verses traditional intellectual concepts is necessary if faith communities are to successfully communicate to people with profound cognitive disabilities the God-given gospel message of value and acceptance. Swinton (2001) challenges the Church to act in ways that are meaningful and inclusive. He suggests that people who experience intellectual and developmental disabilities are not problems to be solved but, rather authentic ways of being human that need to be understood, respected, and embraced. Swinton proclaims a theology for all in calling the church to lay aside prejudice and oppression and embrace an uncompromising love of all who were created in God's image.

Similarly, Demmons (2009) challenged theological positions holding that individuals who experience diminished intellectual abilities cannot know God, because God, as an abstract concept, cannot be understood by those with limited intelligence. Demmons research explored doctrinally and pastorally the underlying question of “How might one know the Word of God without words?” (Demmons, 2009, p. 3). Demmons emphasises a relational understanding of God. Demmons’ work explored the incarnation of the Word in various forms to include knowledge of God that is realised through the living experience of loving relationships. The exploration suggests that there is a living knowledge of God that goes beyond the intellectual or cognitive knowing of the Divine and is manifested through the Church and interrelationships that can be inclusive of all people. The relational paradigm highlights that communication and fellowship with one another occur in various mediums and alternate forms be it art, dance, music, and other forms of self-expression. Demmons’ research ultimately concluded that knowledge of God by all persons is not only possible, but may occur in very unexpected ways.

The most influential alternative views challenging current images of God are offered by individuals who live disability. There are three scholars in the literature who are either primary or secondary consumers. They are noted as having developed a disability theology as an alternative to current views of God. The first is: Jennie Weiss Block who proposed the Accessible God (Block, 2002); the second is Kathy Black, who proposed the Interdependent God (Black, 2006); and the third is Nancy Eiesland, who proposed the Disabled God (Eiesland, 1994).

Jeannie Weiss Block is a professional who works in the field of disabilities and purports to be a secondary consumer in that she has a family member who experiences multiple disabilities. Block (2002) proposed a theology of access in efforts to ensure “that people with disabilities take their rightful place within the Christian community” (p.11). Though Block does not herself experience a disability, she presents the disability population not as *special* but rather as an oppressed group by society. She suggests that access and inclusion are based upon biblical mandates and points to the teachings of Jesus in that, all individuals are welcome and have a place in the Christian community. Block points out the hurt and devaluation that the Christian tradition often evokes upon diverse people experiencing disability when excluded from religious gatherings. Utilising a lens of dignity, she suggests that a theology of access is important, because the gospel of Jesus Christ is a gospel of access. Furthermore, Block states that a theology of access mandates participation of people who experience disabilities in decisions that affect their lives. She advocates from a practical stance regarding inclusion as well as a theological stance calling those without disability to admit to their exclusionary attitudes and actions and practice an inclusionary gospel that fosters fellowship and community for all.

Kathy Black experiences a physical disability and is a Professor of Homiletics who has worked for many years in Deaf ministry. Her disability, at times, leaves her completely physically dependent on others for her daily existence. Black (1996) specifically examined the theological perspectives and homiletic approaches associated with the healing narratives in the Gospels of the Bible. Block portrays an understanding of the Christian community as one that is called to “work interdependently with God to

achieve well-being for ourselves and others” (Black, 1996, pp. 37 – 38). She argues against perceptions of God as the great puppeteer, but suggests a God both interconnected and interdependent with people. In 2006, Black proposed a theology of interdependence focused on the nature of relationships between God and people to achieve well-being for themselves and others. Her theology is one of interconnectedness between God, humanity, and nature alike. Black rejects the notion of God as the cause of disability, suffering or natural disasters, and rather presents a God who is present and interconnected with people in the midst of their suffering; a God that offers possibilities for transformation. She depicts the interdependent God as both friend and resource during times of struggle and strife in life. Black suggests that the experience of disability allows a person to see what is often unseen by others thereby being a resource for increasing awareness. Black reflectively examines theology from a lens of disability, personally and experientially, acknowledging the invaluable contribution that people who experience disability provide.

Nancy Eiesland identifies herself as “a woman with disabilities, a sociologist of religion, and a professor at a seminary in the United States” (Eiesland, 1998, p.103). Eiesland (1994) presents a theology of disability in her proposal of a *Disabled God*. Eiesland suggests that traditional images of God viewed disability as either a blessing or a curse and suggested that these images are inadequate for understanding the lived experience of disability. In her theology of disability, Eiesland connects the story of the resurrection of Jesus Christ in which Jesus appears before his disciples revealing his injured and scarred hands and feet (Luke 24:36 – 39). Thus, she rejects such notions of disability as a consequence of sin. She suggests that Jesus Christ in his glory is known

through His broken body. With these concepts, Eiesland reframes disability meanings ascribed in the past. Her theology reveals both divinity and humanity as compatible with the experience of disability. Additionally, Eiesland views expressions of sympathy and pity as not appropriate. Finally, Eiesland suggests theologians re-think Christian symbols, metaphors and rituals to be inclusive of the diverse experiences of embodiment, making them accessible to people who experience disabilities.

Research associated with spirituality, and intellectual and developmental disabilities. Research conducted on spirituality, and intellectual and developmental disabilities intersect aspects of health, sociology, psychology, ecology, and theology. Several research studies in the area of spirituality and intellectual disability have been associated with L'Arche communities. Research interest with L'Arche lie in the fact that this international federation represents a network of spiritual communities where people with and without disabilities live and share life together.

L'Arche [French for "the Ark"] was founded in 1964 by Jean Vanier in response to people experiencing intellectual and developmental disabilities, and living in institutions in France. The L'Arche movement began with Vanier feeling compelled by God to invite two men to leave the institution where they resided and share their lives with him in a real home in Trosly-Breuil, France. L'Arche, with its philosophy of inclusive community, has since spread around the globe into more than 35 countries.

The L'Arche communities call together persons with and without disabilities to share their lives together in mutually transforming and spiritually profound ways (L'Arche, 2011). As a result, researchers explored areas of disability, difference, and

inequality in L'Arche (Cushing, 2003) as well as various aspects of relationships, membership, and belonging in the context of a spiritual community (Elkins, 2008; Reimer, 2009; Webb-Mitchell, 1993). Though issues explored are diverse and the extent to which membership within community is achieved equally for all vary, the lived L'Arche experience presents as a positive force for well-being for those with and those without disability (Reimer, 2009).

Other scholars and researchers examined the personal impact and role spirituality can play in individuals who experience intellectual and developmental disabilities in developing friendships and connectedness with others (Boswell, Hamer, Knight, Glacoff, & McChesney, 2007; Conner, 2010; Gaventa, 2009; Webb-Mitchell, 1994; 1996). Boswell et al. (2007) explored the self-perceptions of adults who experienced severe physical disabilities. This qualitative study sought to explore how individual's (n = 13) with severe physical disabilities understood the interaction of spirituality and disability in their life. In-depth interviews were conducted across an interdisciplinary team of five researchers. Five themes evolved from his research regarding the interactive nature of disability and spirituality in participants' lives: purpose, awareness, connections, creativity, and acceptance. Boswell found that data from both male and female participants indicated that spirituality was an essential, interactive dimension of their life. These findings suggested a positive role spirituality can play in the lives of adult individuals who experience severe disabilities.

Gaventa (2009) emphasises spirituality as a pathway to connections with God, with self, with others, with community, with nature, and with culture for individuals who experience developmental disabilities. He also reinforces the role of spirituality for

persons with developmental disabilities in the exercise of free will, choice, and decision-making. Furthermore, Gaventa encourages direct support providers in human service arenas to foster faith exploration opportunities, talk about important traditions and rituals, and facilitate opportunities for individuals who experience intellectual and developmental disabilities to express their spirituality.

Connor (2010) discusses how a spiritual life can create *connectedness* and affirm presence for young people who experience intellectual and developmental disabilities. Connor suggests through the Christian model, feelings of loneliness and fears of negation on the part of individuals who experience intellectual and developmental disabilities can be addressed. Connor highlights the importance of the practice of friendship and spiritual nurturing that the Christian faith brings to people. Findings suggest spirituality may have a direct and powerful role in the lives of individuals with intellectual and developmental disabilities.

Other researchers focus on spirituality as a coping resource for individuals and families who experience intellectual and developmental disabilities (Bennett, Deluca, & Allen, 1995; Boswell et al., 2007; Ekas, Whitman, & Shivers, 2009; Specht, King, Willoughby, Brown, & Smith, 2005; Weisner, Beizer, & Stolze, 1991).

Bennett et al. (1995) examined religion as a coping resource used by parents of young children who experienced disabilities. The researchers conducted a qualitative study with in-depth interviews of parents (n = 12) to explore the ways that religion was utilised as a coping mechanism across life cycles. The exploratory study found that prayer, church attendance, and specific beliefs were seen as a source of comfort, hope, and strength.

Ekas et al., (2009) conducted a quantitative study assessing religiosity and spirituality and life outcomes with mothers of children (n = 119) who experienced Autism Spectrum Disorder. Research outcomes revealed that religiosity and spirituality were associated with better positive life outcomes and, to a lesser extent, lower levels of negative outcomes. Positive maternal socio-emotional outcomes included variables of higher self-esteem, life satisfaction, positive life events, positive affect, psychological well-being, optimism, and internal locus of control.

Sprect et al. (2005) conducted a qualitative study that examined the self-perceptions of adults (n = 15) who experienced congenital disabilities regarding spirituality as a coping mechanism during crucial times in the persons' life. The research suggests the importance of spirituality as a protective mechanism in life revealing four recurring themes: God as a guiding force, faith as a provider of inner strength, sense of meaning and purpose in life with respect to disability, and appropriateness of the use of spirituality in counselling.

Weisner (2011) studied families (n = 102) of children with developmental delays regarding religion and sense of peace of mind and emotional adjustment. Though individual measures did not differ between parents who were religious and those who were nonreligious, the study found that religious parents more often described their child as an opportunity rather than a burden and emphasised a more nurturing parental role.

Similarly, a positive association with intrinsic religious beliefs and levels of happiness and well-being among parents of children who experience developmental disabilities has been found to exist (Biesinger & Arikawa, 2011; Sullivan, 2008; White,

2009). Positive life associations in regards to spirituality and family life with individuals who experience developmental disabilities were also found to exist in sibling relationships (Pollak, 2008). Finally, levels of religiosity and religious coping among informal caregivers of individuals who experience developmental disabilities have been associated with better mental health and spiritual health in the caregiving experience (Pearce, 2005).

Many positive aspects of spirituality and religion connected with intellectual and developmental disability research is beginning to be documented. However, studies, to date, that include primary consumers, often involve relatively small numbers of individuals, while most studies utilise secondary consumers or caregiver input within research design. A great deal of methodological work is yet to be done that looks at the incorporation of individuals with varying intellectual capacity as primary to the research process. Development of new methodological avenues within research may be essential to giving voice to a population of people largely dependent on others for support in meeting desired outcomes in life. Consequentially, some scholars provide reminders of the challenges that still exist and the bridge that must be built between the religious and disability communities if inclusive societies are to be fully realised (Anderson, 2006; Gaventa, 2006; Kunz, 2011). Additionally, the literature suggests that even though spiritual and religious activities may be a source of comfort and coping to people who experience disabilities, many faith communities and clergy remain unwilling to acknowledge the theological implications of disability or to fully integrate a person with a disability into the activities of the religious organisation (Treloar, 2002). Further complicating matters is that when compassion for people who experience intellectual

and developmental disabilities is present within faith communities, clergy members often report that they are unsure of how to include or provide pastoral care to them (Rose, 1997; Swinton, Mowat & Baines, 2011).

Furthermore, a compounding factor to the social factors posing barriers to participation is environmental factors that challenge the full inclusion of people who experience intellectual and developmental disabilities. Several researchers examined environmental structural contexts that impact persons who experience intellectual and developmental disabilities participation in spiritual and religious activities of choice (Patterson & Vogel, 2003; Thapar et al., 2004; Vierkant, Hollingsworth, & Stark, 2006). Common environmental barriers impacting those with physical and mobility impairments are narrow aisles, lack of ramps, lack of transportation, lack of parking, poorly designed handles, inaccessible bathrooms, heavy doors, uneven surfaces, inadequate hearing systems and lighting. One of the reasons cited for the continued problem in creating environmentally accessible facilities is the wide range of diverse needs within the disability population (Iwarsson & Stahl, 2003). Therefore, optimal accessibility for all people may prove challenging for organisations to achieve and yet, appears to be a worthy endeavour.

Chapter Summary

This chapter reviewed the spirituality literature and research pertinent to the current study regarding spiritual well-being and quality of life in individuals who experience intellectual and developmental disabilities. It was divided into four sections. Section one provided an overview of the problem. Section two presented a review of the literature to increase understanding of spirituality as an important construct in life.

Comment [R1]: Reconsider the numbering of sections, as suggested in Table of Contents.

A historical review of the definitions of spirituality, the theoretical underpinnings of a spiritual dimension of life, and a review of the instruments utilised to assess spiritual well-being was presented. This section further examined the empirical research on the influence of spirituality and spiritual well-being on health, social connectedness/belonging, coping/adjustment, and personal/life satisfaction. The relevance spirituality is given in the literature guided the development of this topic in the current study exploring this life domain area for people who experience intellectual and developmental disabilities. Section three presented a review of the literature regarding spirituality specific to intellectual and developmental disabilities. This section reviewed empirical studies and the major concepts connected with spirituality in relation to persons who experience intellectual and developmental disabilities. Additionally, both the historical and contemporary societal and world religious perspectives noted in the literature to influence perceptions regarding spirituality and intellectual and developmental disabilities were discussed. Finally, section three concluded with a review of current research on spirituality and its influence on other life areas within the study population. Section four provided a summary of the chapter with a review of the linkage between previous works on spirituality and the current research questions.

While the research represents studies in the physical and intellectual dimensions, there is a shortage of information in the dimension of spirit. Though research in spirituality and disability in general is beginning to receive a greater emphasis in the literature, significant gaps remain. For example, the literature addresses little regarding the spiritual lives of individuals who experience intellectual and developmental

disabilities. There is void of research regarding spirituality as an aspect of quality of life for individuals who experience intellectual and developmental disabilities. Questions remain regarding how individuals who experience intellectual and developmental disabilities understand and describe the spiritual dimension of life. Questions remain as to the significance, meaning, and impact of spirituality to individuals who experience intellectual and developmental disabilities and warrants further exploration. Furthermore, whether or not these areas in a largely dependent population are influenced by age, gender, or levels of support provided in life is not definitive in existing research and assisted in providing focus to the current study. Research methods involving first person perspectives regarding the relevance individuals who experience intellectual and developmental disabilities place on spirituality remains crucial. Support systems continue to evolve towards greater holistic and person-centred philosophies and practice. Yet, the shortage of information concerning the spiritual dimension of life may lead to the incomplete or underrepresented needs of a person in planning processes and support systems design. Likewise, the scarcity of addressing this dimension of life for individuals who experience intellectual and developmental disabilities may in fact deny resources demonstrated in the general population to improve the health, well-being, and quality of life of individuals. Chapter three reviews the literature and research pertinent to the construct of quality of life and intellectual and developmental disabilities.

Chapter 3

Review of the Literature on Quality of Life

Introduction

This chapter presents the Quality of Life literature and research pertinent to the current study regarding spiritual well-being and quality of life for individuals who experience intellectual and developmental disabilities. Quality of life as a construct has been explored and discussed in the literature for decades and is generally accepted to refer to the well-being of individuals and societies. Furthermore, it is generally accepted that multiple factors contribute to quality of life (Baker & Intagliata, 1982; Lamb, 2001; Raphael, Brown, Renwick & Rootman, 1997; Rosenburg & Holden, 1997). Quality of life models and measurements vary from multi-dimensional perspectives (e.g., biopsychosocial) to one-dimensional perspectives (e.g., physical or health related) and emphasise from greater to lesser degrees objective verses subjective evaluative criteria. Though quality of life research for the general populations is extensive, the research specific to intellectual and developmental disabilities is less robust. Furthermore, challenges continue to be made in the literature regarding the universality and application of quality of life principles to all populations (Morisse, Vandemaele, Claes & Vandeveldel, 2013). Therefore, in alignment with the overall aim of this research study, particular attention is paid to a historical review of theory and research influencing the understanding of what constitutes quality of life for individuals who experience intellectual and developmental disabilities and to factors somewhat unique to people with disabilities. The importance of research in this area is chronicled

by the acknowledgment that the field of intellectual and developmental disabilities in the United States is heavily modelled from a quality of life framework that supports equality for people with disabilities and freedom from segregation, oppression and marginalisation. While disability research, policy, and practice in general embrace ideas of self-determination, inclusion, empowerment, and independence; the application of these principles in the field continue to occur with wide variability (Nota, Ferrari, Soresi & Wehmeyer, 2007; Stancliffe, Abery & Smith, 2000; Wehmeyer & Metzler, 1995).

Chapter three is divided into four sections. The first section presents a historical review of the definition of quality of life, the theoretical underpinnings of quality of life, and a review of the assessment instruments utilised to measure quality of life in an individual's life. The second section, presents a historical examination of research regarding quality of life in adult individuals who experience intellectual and developmental disabilities. Furthermore, the second section examines empirical studies and factors associated with quality of life in adult individuals who experience intellectual and developmental disabilities. This section reviews the major theories connected with quality of life in the field of disability. The third section discusses the integration of the literature on spirituality and quality of life and the current empirical studies associated with individuals who experience intellectual and developmental disabilities. The fourth section provides a summary of the chapter with a review of the linkage between previous works on quality of life and the current research questions. This final chapter section concludes with an examination of the gaps within the spirituality and quality of life literature and a rationale for further research on behalf of

individuals who experience intellectual and developmental disabilities to progress both theory and practice.

Understanding Quality of Life

The concept of quality of life as an area of interest dates as far back as Plato (429 – 347 B.C.E.) and Aristotle (384 – 322 B.C.E.) with their respective investigative ponderings of the central question: what constitutes well-being or happiness? Even today, quality of life in its simplest form refers to how good life is. Yet, when the topic is contemplated more deeply it becomes more difficult to determine *how* good life is or even what constitutes a *good* life.

Both historically and culturally, quality of life became defined in very distinctive ways across the globe. Additionally, gender differences in quality of life are prevalent in the literature (Murtagh & Huber, 2004; Muhwezi, Okello & Turiho, 2010; Kim et al., 2010; Willhite et al., 2008). As a research topic the study of quality of life has been explored as it relates to health, education, rehabilitation, disabilities, medicine, human and social services areas to name a few (Brown, Bayer, & MacFarlane, 1989; Cummins, 2005a; Goode, 1990; Headey & Wearing, 1989; Kerr et al., 2004; Taillefer, Dupuis, Roberge, & May, 2003; Watson, Broemeling, & Wong, 2009). Despite this interest, a current review of the literature suggests that there remains no agreed upon definition or standard for the concept of quality of life (Rojas, 2006; Taillefer et al., 2003). There is however, a general acknowledgement that a person's quality of life is a product of the interaction of multiple factors such as, social, health, economic, and environmental

conditions that interact and affect human and social development at both individual and societal levels (Paramenter, 1992; Robillard, 1999; Schalock & Verdugo Alonso, 2002).

Dimensions of quality of life. There is general agreement that quality of life as a multi-dimensional construct has both subjective and objective dimensions (Robillard, 1999). The literature does suggest that an exploration of quality of life from only one dimension that is objective indicators or subjective indicators, presents an incomplete picture of the true status of one's quality of life. Consequently, objective, subjective, and combined measures are noted in the literature for measuring a person's quality of life (Brown et al., 1989; Cummins, 2005b; Cummins et al., 2003; Dossa, 1989).

The objective dimension of quality of life assesses external, objective indicators that can be observed and measured within the public domain through the evaluation of physical quantities and frequencies. Though the specifics of what aspect of life is being examined in different countries vary, the objective dimension generally includes such variables as material wealth, health, safety, education and social status. For example, in France, the Report by the Commission on the Measurement of Economic Performance and Social Progress (Stiglitz, Sen, & Fitonssi, 2010) evaluates quality of life based upon living conditions, economic strain, health status, social networks, social participation, working conditions and education levels of people. In addition, the Commission's Report suggested that particular attention be paid to the inequalities of people across socio-economic groups, gender, generations of life, and immigrants. Maggino and Ruvigliani (2008), evaluated information from 22 European countries and suggested objective indicators for quality of life is viewed from both the micro and macro levels.

In these researchers view, objective indicators at the micro level included individual living conditions, while objective indicators at the macro level included social, economic and health contexts. In America, objective indicators generally include economic, environmental, social, health, and educational aspects of life (Andrulis, Duchon, & Reid, 2003; Angur, Widger, & Angur, 2011; Morrison Institute for Public Policy, 2008).

The subjective dimension of quality of life assesses the internal, subjective perceptions of a person's life experiences. That is, does a person perceive an overall sense of life satisfaction? Research suggests that subjective perceptions of life satisfaction are associated with beliefs of whether or not the person is living a meaningful life (Chamberlain & Zika, 1988; Ghalkos & Bousinakis, 2010). Baumeister and others distinguish between a person's subjective feelings of a happy life and that of having a meaningful life (Baumeister, Vohs, Aaker, & Gabrinsky, 2012). These researchers suggest that the concept of being happy in life and finding life meaningful should be distinguished separately in evaluating quality of life. Within the literature, a meaningful life is more broadly associated with activities that contribute back to the welfare of others and community (Baumeister et al, 2012; Macgregor & Little, 1998). Keeping these concepts in mind, the subjective dimension exists within the private consciousness of each individual; this dimension verifies through repeated responses provided by the person concerned. An emphasis of the subjective aspects of quality of life focuses on people's self-perceptions regarding their physical, emotional and spiritual well-being; personal development; relationships with others; sense of family and community; and sense of meaning and purpose in life. A person's

interconnectedness with family and others have been linked with concepts of both happiness and meaningfulness in life (Debats, 1999; Lambert et al, 2010).

Despite the lack of a definitive standard or definition of quality of life, there has been extensive research undertaken on the topic for more than half a century. The literature regarding the concept of quality of life generally flows out of three major branches of science: Economics, Medicine, Humanities, and the Social Sciences (Cummins, 2005a). The lack of alignment regarding a quality of life framework for evaluation and lack of method for measuring is attributed to the fact that each of these major disciplines approach the topic of quality of life from differing perspectives (Cummins, Lau, & Stokes, 2004; Michalos, 2004).

In the United States, Thomdike (1939) was one of the first scientists to study quality of life. Thomdike approached the topic from a social tradition studying mainly environmentally based social indicators. Researchers within the field of gerontology historically explored quality of life by assessing the well-being and life satisfaction of the elderly (Butler & Ciarrochi, 2007; Edwards & Klemmack, 1973; Requena, Martinez, & Ortiz, 2010; Sarvimaki & Stenbock-Hult, 2000; Schneider, 1975; Spreitzer & Snyder 1974). Other health related areas that have explored quality of life issues are traumatic brain injury (Jacobsson, Westerberg, & Lexell, 2010; Nestvold & Stavem, 2009), mental illness (Pinto-Meza et al., 2009), chronic illnesses (Bartlett, et al., 2003; Harrison, Edwards, Koenig, & Bosworth, 2005), cancer (Krupski et al., 2006) and chronic pain management (Kerr et al., 2004).

In the 1970's – 1990's health economists approached the issue of quality of life by further developing the concept of quality of life adjusted years (QALYs) (Williams,

1985, 1987). This approach applied a value to each healthy year of life expectancy and a diminished value, such as less than one year to each unhealthy year of life expectancy. This approach was then utilised as a measure of cost effectiveness of specific medical interventions for decision making at both macro and micro levels. The QALY approach took on much criticism as it impacted health care, policy, and practice (Brahams, 1991; Carr-Hill, 1989; Loomes & McKenzie, 1989). In addition, this approach by health economists appeared to devalue a population of people in society in terms of decisions made regarding health care interventions and resource allocation.

Another controversial aspect in the literature is the disparity between health care providers' perceptions of an individual's life quality and that of the individual themselves (Anderson & Burkhardt, 1999). The disparity surfaces when objective health status is equated with life satisfaction, or when there is a lack of recognition of the many other dimensions of life that people consider when assessing their own life quality.

The early approaches to understanding quality of life were subsequently evaluated as too simplistic and narrow. Furthermore, the early approaches influenced health literature that favoured valuing the amount of time lived rather than the lives of the individuals. As researchers used various methodological approaches regarding the definition and measurement of quality of life, models for approaching the topic continued to evolve (Goode, 1988). Goode (1988) presented a more comprehensive scheme for quality of life containing seven major categories: social (community and individual), life domains, life events, psychological/psychosocial, overall quality of life, and outcome behaviours. Later, Cummins (2003) and Wills (2009) suggested that life

satisfaction be viewed as a global measure of life as a whole and further contended that life satisfaction should be evaluated with consideration to life domain specific areas. Such life domain areas include marriage (Lucas, Clark, Georgellis, & Diener, 2003), family life, goal pursuit (Emmons, 1986), and social relationships (Helliwell & Putnam, 2004).

Still another approach, connected with the social sciences but, coming out of the field of intellectual disability and later adapted by Schalock (1990), classified studies into either social science or disability categories. The social science approach was subdivided into basically objective measures (social indicators) (Andrews, 1986; Andrews & Whithey, 1976) and subjective measures (psychological indicators) of quality of life (Flanagan, 1978; Flanagan, 1982). When the disability approach described as goodness of fit evolved, social policy incorporated a combined approach of subjective and objective measures for assessing quality of life.

The disability approach recognised that a person's quality of life cannot be inferred solely from objective measures of life circumstance and promoted the importance of including the subjective evaluation of a person's life experience. This view rejected the *medical model* as a philosophical framework of care and adopted a developmental agenda which embraced the humanistic ideas of normalisation, social role valorisation, and empowerment (Wolfensberger, 1969; 1972).

The philosophical and political ideology connected with the deinstitutionalisation movement within the field of intellectual and developmental disabilities, promoted further movement and understanding of the construct of quality of

life. Within the field of intellectual disabilities, a subjective measurement approach to quality of life has been utilised most extensively.

The movement away from the *medical model* became a critical factor in the conceptualisation of quality of life for people and advanced a theoretical framework which included key constructs of cognition (Kahneman, Diener, & Schwarz, 1999) and affect (Russell, 2003). In addition, emerging areas of agreement regarding the quality of life construct comprised four quality of life conceptualisation principles. That is the quality of life construct became viewed as: 1) multidimensional and influenced by personal and environmental factors and their interactions; 2) having the same elements for all people; 3) having both subjective and objective elements; and 4) enhanced by self-determination, resources, purpose in life, and a sense of belonging (Cummins, 2005a). Furthermore, Cummins (2005) unsatisfied with earlier models proposed that the evolving conceptual models of quality of life ensure that the selection of specific life domain components operate in accordance with some fundamental theoretical principle that provides testable theoretical justification and empirical support for the selection of life domain areas. Cummins proposed a theoretical framework towards the advancement of a quality of life construct that provides a synthesis of two approaches to the topic: 1) the identification of indicator variables in terms of core quality of life domains, and 2) a specification of the causal variables in terms of their interrelationships with one another and the indicator variable.

Cummins' approach assumed a hierarchical structure, general to specific, within the indicator variables. An example of domain hierarchy would be characterised as general being *life as a whole* while a more specific indicator might be *friendships*.

Cummins further proposed the idea that subjective well-being as an indicator variable is under the active management of an affective/cognitive homeostatic system (Cummins, 1995, 2003; Cummins & Nistico, 2002). This concept purports that people, in an effort to feel good about themselves, maintain a normal state of well-being, having a set-point for their subjective well-being. Consequently, people under normal circumstance, in concert with their set-point of subjective well-being, will maintain a positive regard and level of life satisfaction. That is maintaining an overall positive view of the self is thought to be a systemic response to sustaining an individual's internal equilibrium and may lead a person to regard his or her own well-being as equal to or higher than that of other people (Headey & Wearing, 1989). This premise adds further support to the utilisation of combined subjective and objective measures when evaluating quality of life.

Recently, following along the principle that quality of life is a multidimensional phenomenon, composed of universal core domains of varied importance, the use of logic models became incorporated into evaluation processes (Foundation, 2001). Programs that support people who experience intellectual and developmental disabilities utilise logic models to link service and support activities to quality of life outcome areas at differing points of time within the delivery of services. The outcome data is then utilised for evaluation and planning. Multiple areas can be addressed at a time allowing for greater emphasis on certain components than others. The utility of these quality of life models are found to guide policy and practice within the health care and social sciences fields (Claes, Van Loon, Van Hove, Vandeveld, & Schalock, 2010; Foundation, 2001; Watson et al., 2009). These models allow for the identification of

potential input predictors that build evaluation capacity in terms of evidence-based practices at both micro and macro levels.

Assessing quality of life. As discussed previously, both subjective and objective measures of quality of life are viewed as valid indicators of life quality regardless of findings that sometimes indicate they can have a weak relationship with each other. To address this, it is suggested that a comprehensive estimate of an individual's quality of life comprise both objective and subjective measures (Cummins, 2000). Accompanying the evolving theories and models of quality of life, have been the development of an overabundance of assessment instruments for quality of life over the last half century (Gill & Feinstein, 1994; Patrick & Bergner, 1990). Sam Salek (1999) documents over 200 instruments that claim to assess quality of life (Salek, 1999). While the *ProQolid, Patient-Reported Outcome and Quality of Life Instruments Database* available on the internet currently contains descriptions of 693 quality of life instruments ("The Patient-Reported Outcome and Quality of Life Instruments Database," 2011). This researcher supports the generally held belief that research consider both objective and subjective aspects of life utilising generic quality of life measurement instruments that are easy to understand, have acceptable reliability and validity, and rate life satisfaction utilising identified life domains important to most people.

Yet, there are far fewer quality of life measurement instruments noted in the literature that have been determined to be appropriate for people who experience intellectual disabilities. Townsend and Pham Tran (2010) conducted a systematic

review of quality of life instruments and found only seven with satisfactory reliability and validity that were designed for use with individuals who experience intellectual disabilities (Townsend & Pham Tran, 2010). This finding suggests that there may be a greater challenge to measuring quality of life considering certain populations as there is a much narrower group of appropriate instruments available. That is, instruments that would truly satisfy the principle that quality of life has the same elements for all people and that measurement instruments of a generic type can be validly utilised with any human group regardless of culture, socio-economic status or disability.

Quality of Life and Intellectual and Developmental Disabilities

In terms of the general disability population, a noteworthy study through The National Organisation on Disability conducted an interactive survey comprised of 2,255 Americans with and without disabilities. Findings suggest a significant gap between those with and those without disabilities in significant quality of life indicator areas (Hanson, 2004). Likewise, this study indicated a continued trend that life satisfaction in general for people who experience disabilities is lower than life satisfaction levels reported by people without disabilities.

These findings were not unexpected. Report trends indicated that individuals with disabilities are less likely than those without disabilities to attend religious services, socialise, or go out to restaurants as compared with the non-disabled population. In addition, people with disabilities as opposed to those without disabilities were twice as likely to have inadequate transportation, three times as likely to live at poverty level, and more likely to go without needed health care services. Though this

study incorporated a broader disability population which included individuals with higher functional skills, it is reasonable to assume that individuals who experience intellectual and developmental disabilities would also experience similar trend lines.

The majority of the recent quality of life research with intellectual and developmental disabilities originates from either a health or social/ecological perspective. The current direction and relative themes found within the literature will be discussed and summarised. It is important to note that models and the construct of quality of life continue to be refined. The term *refined* is proposed over *transformed* or *changed* as emerging models for the most part contain the same core elements discussed in earlier less sophisticated models.

It is also worth repeating that the concept of quality of life outside of bureaucratic and scientific domains still notably refers simply to how *good* life is. In examining the literature on the topic of quality of life from Plato's time forward, a question of progress should be evaluated. Considering the global levels of poverty, inadequate health care, and social inequality in existence today, the verdict on our moral civility may still be out. Yet, the topic of quality of life is regurgitated time-and-time again, with greater sophistication, greater complexity, while adding ever more distinctive processes for specific populations. The quality of life prism has been turned and viewed from many perspectives and yet, the essence of the question regarding what constitutes a *good* life remains the same after centuries of exploration. Perhaps a shift in focus to enhance the utility of information along with policy and practice development is a worthy pursuit.

Societal perspectives. The concepts and ideas of what constitutes quality of life for individuals who experience intellectual and developmental disabilities historically evolved out of social, political, philosophical, and economic forces (Parmenter, 1992). The changing ideologies paralleled changing societal and cultural views regarding disability in general. This evolutionary process reflected in the progression of international conventions established guidelines and policies on a global level, such as *Universal Declaration of Human Rights* (1948); the *Declaration on the Rights of Mentally Retarded Persons* (1971); *Declaration on the Rights of Disabled Persons* (1975); *Convention concerning Vocational Rehabilitation and Employment (Disabled Persons)* (1983); *The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (1993); and, the *United Nation's Convention on the Rights of Persons with Disabilities* (Assembly, United Nations, 2006).

Consequently, the implementation of policies and practice shaped the life opportunities available for an entire group of citizens. On the one hand, the application of quality of life principles have been a freeing agent to physical, psychological, social, and spiritual isolation experienced by individuals who experience intellectual and developmental disabilities. Conversely, the same quality of life principles have been utilised as justification for the valuation of *life* resulting in at times the withholding of medical care and necessary services. As a result, careful consideration of the utility of both theoretical and empirical must be fully contemplated as subsequent actions lay shape to not only the life of an individual but also, societies and culture. For individuals

who experience intellectual and developmental disabilities, this impact has been significant (Baumeister, 1981; Emerson, 1985; Parmenter, 1991).

Research in the area of quality of life and intellectual and developmental disabilities has a much abbreviated history compared to the history of the topic in general. Yet, the field of disabilities drew much from earlier research regarding quality of life. For individuals who experience intellectual and developmental disabilities, distinctive timelines framed life possibilities and outcomes for people.

Knoll (1990) attempted to describe the evolutionary process occurring for individuals who experience intellectual and developmental disabilities within the United States. He described the first evolutionary phase as the era of institutional reform occurring from approximately 1965 to 1975. During this timeframe, standards of care were minimal and primarily focused on safety and the protection of people who experience disabilities. The recorded harsh treatment of institutionalisation led to a humanistic awakening (Blatt & Kaplan, 1974). This awakening acted as a catalyst for social change on behalf of individuals who experience intellectual and developmental disabilities.

The second evolution came with the deinstitutionalisation movement occurring in the United States approximately 1976 to 1986. During this timeframe, the focus shifted from defining standards of care to defining and establishing quality programs (Knoll, 1990). The next timeframe occurred from approximately 1987 into the late 1990's. This timeframe ushered in the era of community membership. This era focused on integration and inclusion of individuals who experience intellectual and developmental disabilities within community.

The community membership era evolved to the current focus, a focus that encompasses full community inclusion, enhanced quality of life, individualised and person-centred supports, choice, and self-determination (Buntix & Schalock, 2010; Knoll, 1990; Schalock, Bonham, & Verdugo, 2008; Shogren et al., 2009). New concepts emphasised the ecological perspective of intellectual and developmental disabilities focused on interaction of person-environment for enhanced personal outcomes. Understanding the dynamic process between theory development and public policy that ultimately shapes outcomes for people is important for the future disability paradigm. Therefore, influential theoretical models that are foundational within the field of intellectual and developmental disabilities are discussed in the following section.

Quality of life and influential theoretical perspectives associated with intellectual and developmental disabilities. Alongside the changes occurring in the lives of individuals who experience intellectual and developmental disabilities were changes in the theoretical models impacting the disability field. The evolutionary process that occurred for those experiencing disabilities, though connected, was somewhat distinct from the general population. The disability journey within community settings began with the previously described person-environment fit or goodness-of-fit model proposed by Murrell and Norris (1983).

This model hypothesised that the better the fit of the individual to his or her environment the higher a person's quality of life (Murrell & Norris, 1983; Schalock, 1990). This model shaped social policy regarding disabilities and community living,

precipitated ideologies supporting communities for all, and promoted self-determination of services and supports.

With the evolving models, a paradigm shift moved thinking from evaluating quality of life based upon objective data, observed adaptive behaviours, and the physical environment to personal life satisfaction, meaningful relationships, and engagement in community. With the initial integration of individuals out of institutional settings and into community settings both research and policies focused more on the evaluation of programs and program standards versus the thoughts, feelings, and desires of individuals to determine quality of life. This type of scientific approach, though quantifiable, was somewhat misleading regarding the quality of life that people who experienced disabilities actually lived (Emerson, 1985).

Despite the controversial aspects, the scientific approach was both socially and politically driven with the development of legislation and social policy requiring specific program outcomes as the justification for the ongoing funding of services and supports to people (Goode, 1991). The result of this paradigm highlights a continuing need for researchers to engage in bureaucratic, administrative program, and political processes that ultimately reveal the humanistic questions to ask. Without the relevant humanistic questions being asked, human service programs may fail to address the needs of their primary customers in any meaningful manner. Program integrity, quality and services enhancement, valued outcomes, and indicators of success may be unappreciated from a person-centred perspective.

As previously noted, disability specific quality of life models began to emerge in the mid-80's. A summary of the predominant influences follows. The first influential

quality of life model for persons who experience intellectual and developmental disabilities was developed by Goode (Goode, 1984, 1988, 1991). Goode suggested a process model, drawing upon social research theory and policy, and emphasised a nonlinear, person-centred view with interactive subjective and objective variables. Likewise, Goode preferred an ethnographic methodological perspective for assessment, emphasising observation versus a reliance on scientifically valid and reliable instrumentation for understanding quality of life. Goode believed it important that professionals become close to the people they study so as to assure that objective data is truly reflective of a person's actual *self* (Goode, 1984).

Underlying this model is an operating premise that an individual's quality of life is a by-product of a person's relationships and living environment. Thereby, holding an endorsement that, in relationships, the quality of life for a person who experiences an intellectual and developmental disability is reciprocated by the quality of life of friends, family, and others providing support (Powers & Goode, 1986). This model proved to be a springboard to future research regarding the quality of life of family and care providers of individuals who experience intellectual and developmental disabilities.

A second influential model Halpern, Nave, Close, and Nelson (1986) developed, a multi-dimensional model of community adjustment that emphasised four dimensions of community living. The four dimensions were client satisfaction, occupation, residential environment, and social support/safety. The authors developed a battery of tests that incorporated within the four dimensions a total of 12 variables. They field tested the model for internal consistency and reliability as part of a larger study of adult individuals who experienced developmental disabilities living in semi-independent

settings across four western states in the United States. The community adjustment model utilised both objective and subjective variables along with aspects of the person's living environment. Ultimately, the psychometrics demonstrated empirical validity to the independent dimensions of community adjustment lending support to the overall strength of the model, and its contribution in understanding quality of life for persons who experience disabilities. The model continued to be a framework from which future research regarding transitions and community living for individuals with disabilities emerged (Bruininks, Chen, Lakin, & McGrew, 2002; Halpern et al., 1986; McGrew, Bruininks, & Thurlow, 1992).

A third influential model of quality of life for people who experience developmental disabilities emerged out of the Quality of Life Project in Canada 1988 – 1999. The Quality of Life Project goals included evaluating and improving the quality of life of people with developmental disabilities, evaluating and improving social policy related to disabilities, acquiring demographic and descriptive information about individuals who experience developmental disabilities, and developing a *Quality of Life Instrument Package* (Brown, Renwick, & Raphael, 1999). Incorporated into the goals for this project were commitments to focus on people's abilities and competencies rather than their limitations. Additionally, this project emphasised that individuals were potentially the best judge of the quality of their own life, to incorporate a variety of means for data collection, and to provide clear evidence of the reliability and validity of data (Brown, Raphael, & Renwick, 1997a). To accomplish these goals of this project, multifarious data was incorporated into the assessment process.

Model development consisted of a combination of objective and subjective measures (Brown et al., 1989; Brown, Bayer, & MacFarlane, 1988). Objective measures included the quality of environment, growth and mastery of skills, health, and economic stability. Subjective measures included life satisfaction and psychological well-being which included income, environment, health, and growth and persons' perceptions of skills and needs. The model further included multiple variables under each area as an expansion from previous models.

This model addressed areas on the macro and micro levels of individuals who experienced developmental disabilities. At the macro level, the assessment of the social, economic, and political attitudes were conducted along with the support systems for individuals. At the micro level the assessment of areas of personal safety, neighbourhoods, worksites, and leisure activities were considered. The development of instrumentation and measurement resulted in a multi-method, multi-source approach to assessing quality of life. The application of this approach required a trained assessor to spend a full day assessing each focus person including an additional 90 minutes with a significant other person who knew the individual well.

Measurement methods included interviews, checklists, and observations along with a significant other person and the trained assessor. Instrumentation examined nine life domain areas seen as important to all people. These nine life areas are incorporated within a context of a person "being, belonging and becoming" (Brown, Raphael & Renwick, 2002, pp. 2 - 3). Additionally, evaluations included an individual's perspective of how the person saw themselves as a person, how they perceive they fit in with other people, and what activities they do that define who they are as a person. The

initial research assessed the quality of life for adults, n = 504, who experience intellectual and developmental disabilities in 23 areas throughout Ontario Canada (Brown, Raphael, & Renwick, 1997b). In addition, subsequent follow-up assessments of 184 participants were conducted as part of a longitudinal segment to the overall study.

The Quality of Life Project fulfilled its purpose by highlighting areas in the lives of individuals with developmental disabilities in a more comprehensive manner than previous attempts. Also noteworthy of this approach is that this assessment, *Quality of Life Profile: Adult Version* explicitly acknowledged the spiritual aspect of a person's *being* in the assessment process for quality of life (Brown et al., 2002).

The multi-method, multi-source approach provided a more comprehensive look at whole life aspects for individuals who experience intellectual and developmental disabilities; however, some provider groups might challenge the practicality of its utility in the field, opting for a more expeditious manner of evaluation. To address this concern, a *Short Version* of the Participant Interview and the Other Person Questionnaire was developed and validated. However, convenience and practicality in and of itself does not necessarily make up for the contribution that the more comprehensive approach yields on behalf of people, planning, and support systems in general (Brown et al., 2002).

A fourth influential model for understanding quality of life is the symbolic-interactionist model developed by Parmenter (1988). Parmenter suggests that the issue of disability itself directly and heavily impacts a person's quality of life. He proposes a sociological/ecological approach with an exploration of the concept of disability and

how this is mediated and interpreted within a human beings life experiences. The view of the self is portrayed as being interactive with context with the idea of disability evolving as a societal creation based upon perceived physical or psychological impairments (Bogdan & Kugelmass, 1984).

This model theorised that consequential ideologies relating to deviance, stigmatisation, stereotyping, and labelling can fundamentally shape ascribed meaning for life in persons who experience disability (Burbach, 1981). Specifically, people who experience developmental disabilities may find themselves in continual conflict to validate the existential nature of who they are if not aligned with the social nature of their lived experience. The symbolic-interactionist model proposed three essential elements in a quality of life model: the individual's perception of self, the individual's behaviour in response to environmental factors (i.e., societal influences), and the subsequent responses from the environment to the person (Parmenter, 1992).

A fifth major influential model for quality of life with individuals who experience developmental disabilities was offered by Robert Schalock (1991). Schalock (2004) proposed a multi-dimensional quality of life model that suggested "that a person's perceived quality of life results from three aspects of life experiences: personal characteristics, objective life conditions, and the perceptions of significant persons" (p. 2). Schalock further suggested that these aspects were reflected in measurable indicators of satisfaction, competence/productivity, empowerment, independence, social belonging, and community integration. In addition, Schalock suggested in his model that a person's life experiences were firmly fixed within the context of culture, such

cultural context included: values, legal foundations as reflected in public laws, and community equity, inclusion and empowerment.

An underlying premise to this model is that individuals who experience intellectual and developmental disabilities should be given the same opportunities to live within community as every other citizen. Schalock and colleagues further developed, field-tested, revised, and standardised a 40-item rating scale, titled the *Quality of Life Questionnaire*. They designed this questionnaire to measure the overall quality of life of a person who experiences intellectual and developmental disabilities (Schalock & Keith, 2004; Schalock, Keith, & Hoffman, 1990).

A perceptual element within the model is the recognition of the importance of both subjective and objective evaluations in measuring quality of life. These researchers found that objective data of life circumstance alone was insufficient to understand quality of life, and that the perspective of the individual is integral in any assessment of a person's quality of life.

The theoretical models discussed thus far provide the foundation from which research regarding the quality of life of individuals who experience intellectual and developmental disabilities continues to emerge. Common to each of the models is an emphasis on the utilisation of both objective and subjective information in the evaluation of a person's quality of life. Furthermore, the interaction of the individual who experiences a disability within the contexts of environment and personal relationships are considered critical variables in understanding perceptions of quality of life. A discussion highlighting current research in the area of quality of life and intellectual and developmental disabilities follows. The current research on this topic

will summarise the literature highlighting studies occurring in three general areas regarding quality of life as it relates to individuals who experience intellectual and developmental disabilities: 1) conceptual models, 2) health related quality of life, and 3) supports and services as it relates to quality of life.

Quality of life conceptual models and intellectual and developmental disabilities. This study is built upon the premise that for individuals who experience intellectual and developmental disabilities, quality of life for one citizen constitutes quality of life for all citizens, with or without disabilities. Schalock, Keith, Verdugo, and Gomez (2010) in addition to embracing this premise, further emphasise that quality of life indicators within life domain areas are culturally sensitive, and may vary individually from person to person in both value and importance. Noted in the literature is an appeal to move beyond the conceptual stages of quality of life for individuals who experience intellectual and developmental disabilities to its application in life. Aiding in this endeavour is the recognition that there is now an international consensus beginning to emerge within the literature. Consensus regarding an aligned conceptual and measurement framework by which professionals should utilise in their interactions with individuals who experience intellectual and developmental disabilities and incorporate into their professional practices and standards (Buntix & Schalock, 2010).

Buntix and Schalock (2010) reiterate the three primary types of models historically utilised for assisting individuals who experience intellectual and developmental disabilities: 1) human functioning/disability models, 2) quality of life models and, 3) supports models. They propose a synthesis of information; this synthesis

suggests a relationship among these three models in regards to each model's primary components; the role each model plays in providing a professional holistic assessment and intervention framework for organisational practices in developing a system of support.

Furthermore, these models support the notion that in working with individuals who experience an intellectual and developmental disability that knowledge of each area is necessary but, not sufficient in and of itself to provide assistance to an individual in a manner that supports meaningful outcomes. For example, within human functioning/disability models, significance is placed on diagnosis and assessment of intellectual and developmental disability. Human functioning/disability models emphasise that to provide assistance one should have an understanding of an individual's limitations, abilities, and adaptive skill levels. Though this is acknowledged as essential information, it generally does not address areas connected with daily life circumstance, life satisfaction level or the resources available to provide an adequate system of support within a given context for an individual. Buntix and Schalock (2010) proposed that knowledge of all three areas is essential for a holistic framework that maximises both individual and organisational planning, supports, services, and valued outcomes. Though Buntix and Schalock did not dictate measurement and assessment instruments, they did propose metric options to utilise as part of a synthesised model. Despite the desire of many for a synthesised holistic model for quality of life for persons who experience disabilities, some researchers focus more specifically on a unilateral approach to quality of life for people who experience intellectual and developmental disabilities suggesting that quality of life may be different for those with disabilities

than those without disabilities. Such unilateral approaches to quality of life most often concentrate on a person's physical status, the mind – body interconnectedness, environment, and the level of dependency on others a person with disabilities experiences in order to meet daily life needs. This alternate view of quality of life perspectives for individuals who experience intellectual and developmental disabilities is discussed separately from the holistic models.

Health-related quality of life and intellectual and developmental disabilities.

The connection of health and physical well-being to quality of life continues to gain strong attention in the literature for both the general population and individuals who experience intellectual and developmental disabilities. Recent literature shows increased efforts to understand quality of life domain areas in respect to individuals who experience severe and profound intellectual and developmental disabilities.

The literature calls into question whether or not the basic life domains historically represented within quality of life models is relevant to individuals who experience profound and multiple disabilities. Methodology for this population generally incorporated the utilisation of proxies or direct observation or video-observation when participants were not able to provide direct response on their own behalf (Goode & Hogg, 1994). However, it is important to keep in mind that proxy approaches in quality of life assessment are not considered valid as an indication of a person's self-perception (Schalock et al., 2002). Petry, Maes, and Viaskamp (2005) conducted a qualitative study (n=76) that analysed the quality of life of individuals who experienced profound and multiple disabilities based upon the five domains of quality of

life proposed by Felce and Perry (Felce & Perry, 1995, 1996a, 1996b). This study utilised both parents and support staff as respondents with results supporting the multidimensionality of quality of life as being the same for individuals experiencing profound disabilities as is for the general population (Petry et al., 2005).

An additional study was later conducted by the same researchers which focused on the objective components of quality of life within people who experienced profound multiple disabilities utilising a self-developed questionnaire specifically for people who experience profound multiple disabilities (Petry, Maes, & Vlaskamp, 2009). This investigation focused on the association between quality of life, and both personal and environmental characteristics.

In terms of personal variables, characteristics connected with a person's medical condition were most strongly associated with quality of life while characteristics such as age, gender, motor limitations, and sensory limitations did not have a significant effect on quality of life – profound multiple disabilities (QOL-PMD) scores.

In terms of environmental variable analysis, characteristics associated with the location of the setting and the staffing level demonstrated a significant effect on the QOL-PMD scores. Though further review of the metrics is warranted, these and other studies lend credence to health related quality of life perspectives and the significance of contextual supports in populations who experience severe and profound disabilities (Petry et al., 2009; Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2010). Furthermore, an understanding of whether the levels of support or the level of disability is the greater factor in perceptions of a person's quality of life. Studies thus far suggest that the relationship of support levels in respect to quality of life warrant additional

investigation within the research beyond health related perspectives and across other life domain areas. The current research seeks to add to the body of knowledge regarding perceptions of quality of life in respect to the provision of differing levels of support beyond health related areas of life.

Health related quality of life continues to be explored within the disability population and its influence in overall life satisfaction. A recent study by Koritsas and Iacono (2011) evaluated (n = 659) individuals who experience intellectual and developmental disabilities. Koritsas and Iacono suggested in their study that the average number of secondary health conditions experienced within this population to be 11.3 in addition to their primary disability. Three of the most recently cited secondary conditions in this study were communication difficulties, reading difficulties, and physical fitness-conditioning problems. Additionally, ranking high within secondary conditions were weight problems, personal hygiene problems, dental and oral hygiene problems, depression, joint and muscle pain, bowel and bladder dysfunction, and a host of other health impacting conditions. This research highlights the prominent health issues faced by this population.

Likewise, many individuals who experience intellectual and developmental disabilities are dependent upon formal and informal supports to receive assistance with health maintenance. James and Shireman (2010) examined the quality of a person's health care as a component of the quality of life of an individual who experiences developmental disabilities. This study suggests that staff who assist individuals in maintaining health, accessing appropriate medical services, and managing ongoing health related conditions demonstrate a weaker knowledge base in this arena than many

other support areas. Additionally, the researchers discuss barriers in accessing health related services on behalf of individuals who experience intellectual and developmental disabilities aligning their findings with others (James & Shireman, 2010; Lewis, Lewis, Leake, King & Lindemann, 2002).

Gillberg, Billstedt, Sundah, and Gillberg (2010) examined risk factors and causes of death in young adults (N = 120) who experience Autism. This study found death rates higher among this population as compared to the general population. Additionally, death rates were highest among females and individuals who experienced Autism with associated disorders such as epilepsy, and other intellectual and developmental disabilities. This study emphasises the significant impact of chronic health issues on a persons' quality of life.

Additional research conducted among individuals who experience Autism Spectrum Disorders and other related conditions examined significant health related issues affecting a person's overall quality of life in the areas of functional behaviour (Chowdhury, Benson, & Hilier, 2010; Stade, Stevens, Ungar, Beyene, & Koren, 2006), leisure activities and stress (Garcia-Villamisar & Dattilo, 2010), and long term psychotropic medication use (Esbensen, Greenberg, Seltzer & Aman, 2009). These studies suggest a continued lack of adequate education, and training and support regarding the health care needs of individuals who experience intellectual and developmental disabilities. Inadequate health care negatively influences a persons' quality of life. In addition, throughout the literature it is suggested that within the general medical community an individual who experiences intellectual and

developmental disabilities may still face barriers with access to basic medical care and with the medical communities' valuation of a person's worthiness for treatment.

Quality of life and influence of supports and services associated with intellectual and developmental disabilities. The significant role that services and supports play in the daily lives of individuals who experience intellectual and developmental disabilities has been clearly established in the literature. Individuals who experience intellectual and developmental disabilities often depend on others, that is, natural/informal supports or paid/formal supports for meeting basic life needs on a daily basis. Therefore, it stands to reason that if supports are either inadequate, poorly designed and implemented, inaccessible, or not available then a person's life opportunities may be dramatically affected. A great deal of emphasis in the field of disabilities places a need to understand the health issues of individuals and translating those health issues into the design of systems to meet these issues. As the understanding of people and their health needs increased, so too has the understanding of people's abilities. This expanded knowledge resulted in changes to the demand and delivery of supports and services across a wide variety of settings and communities. For example, research examining differences in community living verses institutional living situations suggests that community options support greater personal freedom, social activities, and family and friend connections (Horner, Stoner & Ferguson, 1988; Stancliffe, 2005; Stancliffe & Lakin, 1998). These changes in the service delivery arena are therefore, largely attributed to an evolution of societal and cultural understandings of what it means to experience disability coupled with a growing acknowledgment of people's

gifts, capacities, and contribution within community. Subsequent to societal, political, and cultural changes were corresponding changes to how services are designed, developed, and evaluated. Likewise, a review of the literature indicates an association between a person's quality of life, and the quality of services and supports in his or her life (Kozma, Mansell, & Beadle-Brown, 2009; Powers & Sowers, 2006; Schalock et al., 2008; Walker et al., 2011). What is not clearly established is the effectiveness of certain strategies within service planning and implementation processes to evidence-based outcomes in a person's life. These findings foster increased pressure for the development of more extensive evaluative tools within programs and service delivery.

In response, a recent study examined the extensively used person-centred planning approach in 108 studies and evaluated the effectiveness of this approach in terms of outcomes or results in a person's life (Claes, Van Hove, Vandevelde, Van Loon, & Schalock, 2010). The researchers cautioned against the generalisation of information due to reported methodological issues connected to some of the studies reviewed. However, they did make some interesting observations. First, person-centred planning relates to improved social networks for people; second, person-centred planning also develops closer contacts with family and friends; and third, person-centred planning creates greater involvement in group activities and community involvement (Claes et al., 2010; Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Robertson et al., 2006). Additionally, there was a positive effect of a person-centred planning approach on a person's expression of personal preferences and choice-making noted in several studies (Green, Middleton, & Reid, 2000; Hasnain & Sotnik, 2003; Holburn et al., 2004; Menchetti & Garcia, 2003). Consequently, Claes et al. (2010) suggested that

the person-centred planning approach be further evaluated using a quality of life and measurement framework examining outcomes related to personal development; self-determination; interpersonal relations; social inclusion; rights; and emotional, physical, and material well-being (Schalock, Verdugo, Bonham, Fantova, & van Loon, 2008). Furthermore, Claes et al. (2010) recommended further investigation consider a process that evaluates the development and utilisation of a program quality of life logic model with the person-centred planning approach. Claes et al. (2010) suggested that a quality of life logic model process could facilitate the evaluation of the underlying theoretical assumptions, the connections between inputs and outcomes, and the development of a path towards future desired outcomes on behalf of people who experience disabilities.

Kaiser and McIntyre (2010) point out the importance of utilising evidence-based practices across treatment and services for individuals who experience intellectual and developmental disabilities. Evidence-based practices have been previously noted as industry standard in medicine (Institute of Medicine, 2001), in psychology (American Psychological Association, 2002, 2005), and in education (U.S. Department of Education, 2008). Therefore, a call for evidence-based practices within the field of intellectual and developmental disabilities is equally essential. Recent empirical advancements and demonstrated efficacy support treatment, training and support in medical (McCracken et al., 2002), in behavioural (McDougle et al., 2005) and in educational (McIntyre, 2008) arenas within the disability population. As a result, these and many other studies indicate improvement not only in behavioural outcomes for individuals, but also in the overall quality of life of individuals and families in recent years. Therefore, the ongoing advancement of research facilitating the development of

evidence-based standards for services and supports is strongly encouraged. In addition, supports and services fostering the voice of the individual and self-determination within the design and delivery of services appears to result in enhanced outcomes and perceived quality of life for people (Kaiser & McIntyre, 2010; Schalock et al., 2008).

Integrating Spirituality and Quality of Life

The literature reviewed provides evidence of the importance of both spirituality and quality of life for people. Several researchers attempt to understand these two constructs in relationship to each other (Bekelman et al., 2010; Beckie & Hayduk, 1997; O'Connell & Skevington, 2010; Sawatzky, 2002; Sawatzky, Ratner & Chiu, 2005). Though theoretical frameworks are not fully aligned with how these two constructs interrelate, there is general agreement that these constructs are not the same and should be recognised distinct from each other. O'Connell and Skevington (2010) suggested that the spiritual dimension of life is distinct from other life dimensions yet makes an independent significant contribution to a person's overall quality of life. Furthermore, the influence of spirituality and religion within cultures and in respect to the internal and external worldview of people warrant ongoing consideration within the research (Peterson & Webb, 2006).

In looking at people holistically, Brady et al. (1999) suggested spiritual well-being as having a strong association with quality of life. Brady et al. (1999) found spiritual well-being's association with quality of life to be important to the same degree as a person's physical well-being, which is a life domain area of indisputable importance to quality of life. Spirituality is positively associated with improved health

outcomes in the literature (Balboni et al., 2010; Chang, Casey, Dusek & Benson, 2010; Hilbers, Haynes & Kivikko, 2010). And yet, investigation regarding spiritual well-being and health outcomes for individuals who experience intellectual and developmental disabilities, a population known to be at higher risk for health issues, is unexplored. Adebola (2006) suggested that spirituality is an essential element to look at in relation to quality of life and personal wellness overall. And yet, spirituality as a topic is largely absent in explorations of quality of life for individuals who experience intellectual and developmental disabilities. Shah et al. (2011) in studying the emotional well-being of people found spirituality and religiosity to have significant influence on quality of life. In particular, Shah et al. (2011) suggested spirituality assists a person with inner peace and coping with chronic suffering. And yet, most publicly funded human service programs supporting people with intellectual and developmental disabilities do not address the spiritual dimension of life or connect the topic only superficially in practice at best. Questions remain to be answered as to the role of the spiritual dimension of life in personal wellness, coping, and quality of life for persons with intellectual and developmental disabilities. Furthermore, understanding the role variables such as gender or levels of support play in regards to perceptions of spiritual well-being and quality of life remain essential to adequate planning, design, and implementation of appropriate services and supports. In summary, despite the literature suggesting the importance of addressing these two constructs in people's lives, little has been done within the literature and research to analyse the relationship between these two constructs in the lives of people who experience intellectual and developmental disabilities. The current research study is a step towards filling this gap in the literature

and advancing the knowledge of understanding of the needs of individuals who experience intellectual and developmental disabilities. Indeed it would be unlikely to effectively understand or address the needs of individuals who experience intellectual and developmental disabilities and ignore the aspect of life that gives meaning, purpose, and direction in life.

Chapter Summary

Section one presented a review of the literature to increase understanding of quality of life as an important life construct. A historical review of the definition of quality of life, the theoretical underpinnings of quality of life, and a review of instruments utilised to assess quality of life was presented.

Section two presented a historical examination of research regarding quality of life in individual's who experience intellectual and developmental disabilities. The empirical studies and concepts connected with quality of life in adult individuals who experience intellectual and developmental disabilities were examined. This section presented a review of the major theorists connected with quality of life in the field of disability. Of note was a lack of research addressing the spiritual domain of life in relationship to concepts associated with quality of life for individuals who experience intellectual and developmental disabilities. The concepts associated with both of these variables aided in the formulation of research questions in the current study and facilitated researcher reflection during the qualitative phase of the current study.

Section three presented an integration of spirituality and quality of life within the literature. The theoretical frameworks by which these two constructs are related were

discussed and guided the current study in exploring these variables in relationship to each other in the study population. Additionally, a rationale for integrating these two constructs within research was provided. The review of the literature demonstrates theoretical and humanistic gaps of knowledge exist regarding spirituality and quality of life for individuals who experience intellectual and developmental disabilities. Both the theoretical and humanistic gaps call for additional research to be undertaken in this critical area on behalf of people who experience disabilities. The topic of spirituality and individuals who experience intellectual and developmental disabilities remains in infancy stages of development. Further research is necessary to better understand the nature and relevance of spirituality for individuals who experience intellectual and developmental disabilities and the level of significance a person places on this aspect of life in relation to other aspects of life.

Chapter 4

Research Design and Methodology

This study combines quantitative and qualitative methods to explore and describe how adults who experience intellectual and developmental disabilities perceive the significance of their spiritual well-being in relation to their quality of life. Each section in this chapter describes how the mixed methodology utilised supports the study's purpose statement and addresses the research questions.

This study utilises a mixed methods sequential explanatory design. The mixed methods sequential explanatory design incorporates two distinct phases that is, a quantitative phase followed by a qualitative phase (Creswell, et al., 2003). In this design, the quantitative (numeric) data is collected and analysed first. The second phase occurs sequentially, and collects and analyses qualitative (text) data to provide a more thorough understanding of the topic and explains the results that were obtained in the first phase. The two phases are connected in the intermediate stage of the study with the second qualitative phase expanding upon the first, quantitative phase. The rationale for this approach is that the quantitative data and subsequent analyses provide a broad understanding of the research aim. The qualitative data and subsequent data analysis conducted in the second phase further explains the statistical results by providing a more in depth look into the life and views of key participants (Creswell, 2003; Rossman & Wilson, 1985; Tashakkori & Teddlie, 2003).

Phase one of this study utilised the *Quality of Life Questionnaire* (Schalock & Keith, 2004) and the *Spiritual Well-Being Scale* (Paloutzian & Ellison, 1991). A

statistical analysis of individual scores from both instruments across sub-scales was conducted during phase one. Phase two of this study utilised qualitative unstructured in-depth interviews, participant observation, and document reviews. The qualitative component of the study was utilised to add context associated with the quantitative findings, and explore the depth and breadth of understanding of a spiritual dimension of life to other aspects of life for adults who experience intellectual and developmental disabilities. The overall aim of the study was to explore and describe how adults who experience intellectual and developmental disabilities perceive the relevancy of their spiritual well-being in relation to their quality of life. The overall research aim was addressed through four primary research questions:

Research Question 1.0: What is the relationship between perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities?

Research Question 2.0: What is the difference between males and females regarding perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities?

Research Question 3.0: Is there a difference for individuals who experience intellectual and developmental disabilities in perceived spiritual well-being and quality of life with different levels of support in living situations?

Research Question 4.0: How do adults who experience intellectual and developmental disabilities understand and describe the importance of a spiritual dimension of life to other aspects of life? The qualitative phase of this study focused on

the following generalised areas in an iterative process of exploration with key participants:

- 5) How do adults who experience intellectual and developmental disabilities describe their own spirituality?
- 6) What role does spirituality play in understanding life experiences for adult individuals who experience intellectual and developmental disabilities?
- 7) What are the spiritual support needs of adult individuals who experience intellectual and developmental disabilities?
- 8) What values, beliefs, and behaviours do adults who experience intellectual and developmental disabilities ascribe to a spiritual dimension of their life?

This chapter describes the research design and explains the rationale for selecting this particular research design. Following the design and rationale presentation is a discussion of the population considered by this study and ethical considerations. The remainder of the chapter is organised to provide a detailed discussion of the respective quantitative and qualitative methods utilised. A quantitative section of this chapter describes the sampling procedure utilised in the quantitative phase of the study. In addition, the quantitative section discusses the data collection instruments, including the reliability and validity information of these instruments, and a discussion that outlines the data collection procedures utilised in the quantitative phase. Finally, a description of quantitative data analysis procedures is provided.

Next, this chapter describes the qualitative phase of the project. This section identifies the researcher's role during qualitative inquiry, and describes the process by which key participants were selected and the context from which data was gathered. The qualitative section then describes the qualitative data collection strategies and data

recording procedures utilised. Following the description of data collection strategies is a description of the coding process and data analysis procedures. Finally, this section concludes by discussing interpretation procedures and strategies employed to verify or ensure the validity of the findings.

This chapter concludes with a chapter summary describing the strategies utilised to integrate the quantitative and qualitative findings. Closing chapter remarks include an identification and discussion of limitations within this study.

Research Type and Design

This research study utilises a mixed methods sequential explanatory design to answer the stated research questions. The mixed methods approach as a research strategy emerged as a third methodological movement during the 1980's and has been extensively utilised within the social and behavioural sciences (Bryman, 2001; Creswell, 2003; Tashakkori & Teddlie, 2003). In addition, combining quantitative and qualitative methods in a single study gained broad appeal in public health research as well (National Institutes of Health, 1999). The mixed methods approach provides four distinctive advantages to generate detailed data: First, the mixed method provides a more comprehensive account of the self perceptions of adults who experience intellectual and development disabilities regarding the topic of study than either a quantitative or qualitative approach alone could provide; second, the mixed method fosters methodological triangulation, minimising any inherent bias in the data instruments, data gathering method or the investigator (Bryman, 2001, Bryman & Cramer, 2001; Jick, 1979); third, the mixed method adds scope and breadth to the study

by having an opportunity through participant interviews, observation and document review to go beyond answers on a standardised instrument and probe further to clarify participants personal experience; and fourth, the mixed method enhances the validity of the study, through corroboration of data, adding credibility to the integrity of the findings.

The sequential explanatory approach within a mixed methods design is appropriate when a researcher needs qualitative data to explain or expand on quantitative results (Creswell, et al., 2003). The current study explored from a design framework that was quantitative, utilising associated theories of quality of life and spirituality, and standardised questionnaires along with a qualitative phase consisting of unstructured, in-depth interviews, participant observation and documents review. The quantitative phase of data collection occurred with each participant over the course of four months, from January 2010 – April 2010. Data collection connected with the second phase of the study occurred over the course of six months from June 2012 – November 2012. The unstructured in-depth interviews and participant observations component allowed the participant to provide a personal account of self-perception's regarding the significance of and accessibility of spirituality in their life. In essence, the participant was able to share the personal story regarding the spiritual dimension of their life. Each method used to explore research questions in this study will be discussed separately in respective quantitative and qualitative sections of this chapter.

The mixed methods design facilitated triangulation within the research. Triangulation is a term which speaks to the strength of a study (Creswell, 2003). In this research study the qualitative component seeks to add depth and breadth to the

quantitative component. In quantitative research, the concepts of reliability and validity are essential. In qualitative research, the concepts of creditability, transferability, and trustworthiness are utilised in relationship to triangulation (Denzin, 1978; Golafshani, 2003; Patton, 2002). Denzin (1978) discussed the different types and purposes of triangulation. This study triangulates through 1) triangulation of methods and 2) triangulation of sources.

The triangulation of methods seeks to add consistency of findings through the use of different data collection methods. Olsen (2004) suggests that triangulation is not aimed at merely seeking validation of research findings; triangulation also provides deeper and wider understanding. Flick (1992) suggests that mixed methods approaches are useful to achieve innovation of conceptual frameworks. Still others suggest that the utilisation of parallel or mixed methods approach in exploring a topic of study may well be necessary for a more holistic insight of a topic and key to understanding processes occurring (Jick, 1979; Mark, Feller & Button, 1997). The qualitative phase of this research sought to expand on what was made known through the use of standardised instruments by allowing participants to share personal stories regarding the meanings associated with the spiritual dimension of life.

In summary, it is this researcher's intent that the utilisation of both quantitative and qualitative methods will create a deeper understanding of the spiritual lives of adult individuals who experience intellectual and developmental disabilities by exploring various aspects of this phenomenon. A triangulation of sources seeks to improve the analysis and understanding of people on a topic. This study utilised survey data,

individual interviews, participant observations, contextual information, and document reviews to gain a more holistic understanding of the topic of study.

Population and Sample/Target Population

Individuals who experience intellectual and developmental disabilities affects about 2% of the population within the United States as well as most western countries (Larson, Lakin, Anderson, Lee, Lee, Anderson, 2001). The studied population resides in the State of Alaska, USA, where according to a 2009 report there was an estimated 12,235 individuals or 1.8% of the population who experience a developmental disability (The Alaska Mental Health Trust Authority, 2009).

The Alaska State law, AS. 47.80.900 (7), defines the term Intellectual and Developmental Disability (IDD) as a severe, chronic disability that:

Is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: self care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; economic self-sufficiency; and reflects the person's need for a combination and sequence of special, interdisciplinary, or generic assistance, supports or other services that are of lifelong or extended duration and are individually planned and coordinated. (p. 3)

Examples of types of intellectual and developmental disabilities are mental retardation, cerebral palsy, autism, and seizure disorder. Mental illness and Fetal Alcohol Syndrome may also be developmental disabilities. Among this population, approximately 2,636 Alaskans received developmental disability services during the same timeframe in 2009 (Alaska Mental Health Board, Advisory Board on Alcoholism and Drug Abuse, 2010).

Participants in this study came from one state-wide developmental disability provider organisation. This provider organisation was selected based on three criteria: First criteria, the level of access the researcher had to the organisation, critical documentation, and the support recipient population; second criteria, the organisation's characteristics as a comprehensive state-wide provider with a diverse service population serving over 1000 individuals who experience developmental disabilities across the State of Alaska and; third criteria, the organisation's commitment as a learning culture, desiring outcomes that contribute towards continuous quality improvement in the lives of individuals who receive services and supports. The entire organisation's census population was initially screened for participant eligibility criteria (see below) utilising the organisational census database of over 1000 support recipients. There were a total of 156 individuals who met all of the studies qualifying criteria. Of the 156 eligible participants, 53 individuals were purposively selected utilising maximum variation sampling and personally contacted regarding participation in the study. Maximum variation sampling was utilised to ensure that a diverse range of perspectives relating to the research topic was captured from those who met the study population selection criteria (Creswell, 2003; Teddlie & Yu, 2007). Only three of the initial 53 individuals contacted declined to participate, leaving a total of 50 who consented to participate in the study.

The criteria listed below were utilised in selecting the study population participants:

- 1) Adults, age 18 years of age or older.

- 2) Individuals who served as their own guardians and able to provide informed consent.
- 3) Individuals who experienced an intellectual and developmental disability as defined in Alaska state law (AS. 47.80.900).
- 4) Individuals who had a 5th grade reading or receptive/expressive language skill level commensurate with the utility of the instruments utilised in the research study.
- 5) Individuals who were receiving residential and ancillary support services.

The levels of exposure and/or previous life experience in spiritual or religious activities were not a consideration for participation in this study nor were there any exclusion criteria for this study.

General Sampling Procedures

Determination of sample size. A research study should be of adequate size, relative to the goals of a study. It is critical that a sample size of a study be “big enough” that an effect of such magnitude as to be of scientific significance will also be statistically significant (Lenth, 2001). Therefore, this aspect of the research was addressed prospectively to data collection and in conjunction with research design.

In addition, economic factors of time, expense and travel costs were considered in regards to sample size determination. That is the researcher sought to achieve statistical power of the test for useful results, not seeking additional participants for data collection beyond the achievement of these results. Parameters for determining sample size and usefulness of the data were based upon a combination of α value (*probability of*

a Type I error, i.e. probability of rejecting a null hypothesis that is true), $p\tilde{}$ value, and a standardised effect size. The alpha value was set consistently at $\alpha = .05$. For the Pearson product-moment correlations a power of the test was set at $p = .80$ along with a medium effect size. Utilising Cohen d's table of Power of the test, determined that a sample size population of 46 participants would have a Power of test of .88, which exceeded .80 (Cohen, 1988). Therefore, the researcher determined that a sample population of 50 participants would produce a power of test greater than .80.

Finally, ethical considerations were incorporated by the researcher regarding sample size to the extent that the researcher desired to advance knowledge yet, ensure that individuals were not requested to participate without clear benefit to that effect. The U. S. National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (1978) submitted to the President a report entitled *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. These guidelines obligate researchers ensure both respect for persons and beneficence in that research protect individuals by maximising anticipated benefits and minimising possible risks of harm. Conservatively, the foundation for the protection of human subjects in research is established in research design, methodology and planning stages of a study which include decision-making in determining adequate sample size. Additional considerations for the protection of human subjects are discussed later in this chapter in a section discussing ethical considerations with vulnerable populations.

Selection of sample population. Fifty-three participants were recruited from the 156 active support recipients who met the selection criteria and received supports from one private not-for-profit organisation in Alaska. The researcher utilised a maximum sampling technique to ensure a diverse range of perspectives were included in the sample population. The researcher sought to achieve a cross-section within the sample population in respect to gender, geographic location (nine communities representing both urban and rural Alaska), and age range of the sample population. An initial letter of introduction from the organisations executive management was provided to eligible participants (Appendix A). This initial letter provided information to potential participants that executive management supported research in this area as well as assured eligible participants that their participation or non-participation was completely voluntary and would in no way impact their current services. A second letter from the researcher along with a Consent Form (Appendix B) was either hand delivered or sent via the U.S. Postal Service to the same list of eligible participants. This second letter explained the research project, purpose of the research, general procedures, benefits of the research, rights of the participant, confidentiality, and the minimal risk associated with participation in the study if they chose to participate.

All written information provided to potential participants was written at a 5th grade reading skill level, verified by Flesch-Kincaid grade level software in Microsoft Word 2003©, aligning with the receptive/expressive language skill level of the target population. Follow-up telephone calls and personal visits were conducted by the researcher to confirm whether or not an eligible participant was willing to be a part of the study. Informed consent was obtained in writing from each participant. All

participants in this study were their own guardians and deemed able to provide informed consent in such circumstance. Once confirmation and informed consent to participate were established, the researcher scheduled interview times and places with the participants.

Ethical Considerations with Vulnerable Populations

The ethical considerations within research utilising human beings and in particular participants who are considered to be of a vulnerable population continue to receive increasing attention in the literature (Aman & Handen, 2006; Arscott, Dagnan & Kroese, 1998; Fisher, 2003). Areas such as safety and risk, unequal balance of power or coercion, voluntariness, informed consent, and confidentiality of information are identified as essential topics within the scientific community to address in the design and implementation of ethical research (McDonald & Kidney, 2012; National Disability Authority, 2002, Dalton & McVilly, 2004). Additionally, in the United States, disability activist groups tout “nothing about me without me”, emphasising an ideology of an individual’s right to be included in all activities that may ultimately impact the lives of individuals who experience disabilities (Charlton, 1998). The current research by design emphasised the importance of the inclusion of individuals who experience intellectual and developmental disabilities in a research process that directly concerns the population of people who experience intellectual and developmental disabilities. Furthermore, the researcher who worked in the field of disabilities for over 30 years and who developed close relationships with the focal population, advocates for inclusion and choice for all people. This researcher was intentional in pursuing a path of exploration

that would give voice and understanding of the relevance of the topic from the direct perception of the participants. The following paragraphs describe the safeguards utilised in consideration of the vulnerable population who participated in this research.

Protection of human subjects. Prior to implementing this study, the researcher submitted the research proposal for review and approval by the Ethics' Committee for the private not-for-profit organisation. The Ethics Committee of the organisation served as a duly constituted body of demonstrated expertise, formulated to discuss, analyse, and render decisions on any and all matters and issues brought before the body of a clearly ethical nature. This included, but was not limited to, value conflicts, human and civil rights issues, and proposed projects and research connected with support recipients of the organisation. In addition, the researcher submitted the proposal to the Waterford Institute of Technology Research Ethics Committee.

Once approval of each entity was received, the fieldwork phase of the research study began. In an effort to address any perceived coercion on the part of potential participants, a letter from the executive office of the hosting organisation was provided to potential participants. The letter communicated support for the study, the voluntary nature of any participation with the study and provided reassurance that a person's services would not be affected by a decision to participate or not participate in the study. Furthermore, the researcher emphasised to each potential participant, both in writing and verbally in face-to-face conversations, that participation in the study was voluntary, that their personal information would be kept confidential. Their decision to participate or not participate in the study would have no impact to the person's ongoing services

with the organisation. Though the researcher gained initial written informed consent from a participant, informed consent was viewed by this researcher as an ongoing, emergent process that was verbally addressed with participants throughout each phase of the study. This approach ensured continued consent and voluntary nature of participants' involvement in all aspects of the research process (Cameron & Murphy, 2006; Dalton & McVilly, 2004; Ramcharan, 2006). Individuals were informed that even if they initially consented to participate in the study, they could choose to end their participation at any time and not have the data utilised.

There was minimal risk of harm associated with participation in this research study. The anticipated minimal risk of harm associated with participation was described to each eligible participant in writing and verbally by the researcher prior to an individual's consent to participate being given. Minimal risk of harm amounted to possible times during the interview process where an individual might remember something of an emotional nature that made him or her feel either happy or sad. Likewise, this researcher was familiar with the potential participants and paid particular attention to both verbal and nonverbal communication signals of participants to evaluate the comfort level of participants with topics of discussion. Follow-up contact information was provided to each participant in the event that a participant had questions or desired further communication regarding the research once the study was completed. Finally, each research participant was informed of the availability of feedback regarding the research findings following the completion of the study.

Quantitative Research Design

To answer research question number one, a quantitative, descriptive, correlational research approach was developed. This research design employed a descriptive statistical analysis of data collected across variables. A quantitative design views reality as objective, independent of the researcher, and measurable using various data collection instruments (Creswell, 1994). A quantitative approach allowed for the measurement of two variables. The variable of perceived spiritual well-being and the variable of perceived quality of life, both the magnitude and direction of the relationship of these two variables within adults who experience intellectual and developmental disabilities were examined.

Johnson (2001) identified a study as *descriptive* if the primary objective of the study satisfies two questions: 1) “was the researcher primarily describing the phenomena?” and 2) “was the researcher documenting the characteristics of the phenomena?” (p. 9). Additionally, Cooper and Schindler (2006) further identified a study as descriptive if the primary objectives 1) described the phenomena or characteristics associated with a study population, and 2) discovered a relationship among different variables. This study sought to describe the relationship between the variable of perceived quality of life and the variable of perceived spiritual well-being. Additionally, this study assessed the magnitude and direction of the relationship. That is, this study sought to evaluate the strength (magnitude) of a relationship and whether the relationship of the two variables was positive or negative (direction) in nature. In a correlational research approach, the relationship of variables would be considered to be positive if representative scores on both variables were high. A negative relationship of

the variables is indicated by high scores on one variable and low scores on the other variable.

Additionally, no manipulation of variables took place to measure the magnitude and direction of the relationship between the variables of perceived quality of life and perceived spiritual well-being. When variables are not manipulated in a descriptive study, the term descriptive, non-experimental research is applied (Johnson, 2001). Kerlinger (1979) stated that in non-experimental research “there is ‘no manipulation,’ no deliberate control attempt to produce different effects by different manipulations. The relations among phenomena are studied with no experimental intervention” (p.3).

This study analysed the relationship of perceived quality of life and perceived spiritual well-being with no interference, intervention, or manipulation by the researcher. A non-experimental research approach is a frequently used mode of research within the social sciences (Belli, 2007). This approach allowed the two variables to occur and be explored naturally.

A cross-sectional design further supported the non-experimental approach. Gay and Airasian (2003) stated, “Correlational research involves collecting data to determine whether, and to what degree [magnitude], a relationship exists between two or more quantifiable variables. The degree [magnitude] of a relationship is expressed as a Correlation Coefficient” (p. 311). Additionally, Charles (1998), Johnson (2001) and Pedhazur (1997) agree that correlational research can be used to examine the possible existence of causation. A correlational research method examines the problem of causal relationship in terms of magnitude in the relationship between the identified variables (Johnson 2001). Correlational data cannot prove causality; however, correlational data

can reveal a causal relationship exists (Aronson, Ellsworth, Carlsmith, & Gonzales, 1990).

Quantitative Phase Data Collection

Pilot test. A pilot-test was conducted during December 2009, utilising four individuals who were representative of the sample population. Standardised instruments were utilised in this phase of the research and therefore, field testing for reliability and validity was not necessary. However, information gathered in pilot testing was utilised to evaluate interview session format, the time needed for each participant to complete the questionnaires, and to identify potential areas where clarifying questions might arise from participants. Participants in the pilot-test were not included in this study.

Quantitative data collection. The components of the quantitative data collection phase occurred concurrently with each participant over the period of January 2010 through April 2010. Times for participant structured interviews and instrument administration ranged from forty-five minutes to one hour and forty-five minutes across participants. Determination of interview locations and time with participants was carried out in alignment with the preference of the participant. At no time did the researcher impose upon a participant where an interview could occur but, rather agreed to meet the participant in any location requested by the participant.

Interview locations varied from the researcher's office, a public restaurant, or in the individual's place of residence. The interview location breakdown was as follows: a) two interviews took place in the researcher's office, b) two interviews took place at local public restaurants, and c) forty-six interviews took place in the individual

participant's place of residence. The interview format was conducted in accordance with the administration guidelines (Appendix C) of the two instruments utilised in this study. Interviews consisted of the administration of the *Quality of Life Questionnaire* (Schalock & Keith, 2004) (Appendix D) and the *Spiritual Well-Being Scale* (Paloutzian & Ellison, 1991) (Appendix E) to each participant.

All data was collected utilising a verbal interview format with the researcher marking the participant's response on the score sheets of the instruments. Each instrument allowed for either a written or verbal administration of survey questions; however, a verbal administration was chosen as it afforded additional confirmation as to the understanding of the questions by each participant and facilitated a rapport and relationship between the researcher and the participant. Each participant was provided with a paper copy of the *Quality of Life Questionnaire* and the *Spiritual Well-Being Scale* to follow the interview. The researcher repeated questions and provided clarifying statements if needed. At the end of each interview the participant was provided with a follow-up contact e-mail address and phone number if the participant had additional questions, comments or concerns regarding the research study and their interview. Additionally, the researcher inquired as to participants' willingness to share more of their thoughts and experiences on the topic in the future.

Quantitative Phase Instrumentation

Spiritual Well-Being Scales reliability and validity. The *Spiritual Well-Being Scale* (Paloutzian & Ellison, 1991) (Appendix E) has a 20-item rating scale, designed to be utilised as a general indicator of an individual's spirituality. The instrument can be

administered either as a paper-pencil instrument or orally in an interview manner. Each of the 20-items is answered on a 6-point Likert scale. The endpoints of the scale are anchored with the phrases: “Strongly Agree” and “Strongly Disagree” with appropriate gradations in between.

The *Spiritual Well-Being Scale* provides an overall measure of the spiritual quality of life of an individual, as well as subscale scores for both Religious and Existential Well-Being. The *Religious Well-Being Subscale* provides a self-assessment of the person’s relationship with God or a ‘Higher Power’. The *Existential Well-Being Subscale* provides a self-assessment of a person’s sense of life purpose and life satisfaction. There are 10-items on the *Religious Well-Being Subscale* and 10-items on the *Existential Well-Being Subscale*.

The authors of this instrument were contacted regarding the utilisation of the instrument with individuals who experience intellectual and developmental disabilities. Prior to the current study, this instrument had not yet been utilised on behalf of individuals who experience intellectual and developmental disabilities; however, the authors substantiated its use across populations in which a respondent possesses a 5th grade receptive/expressive language skill level. The 5th grade receptive/expressive language skill level within the USA education school system is equivalent to the same receptive/expressive language skill level within the European education school system. Despite the instruments wide use among mental health and health care populations, the absence of utility of such an instrument in regards to the current study population was consistent with the present lack of knowledge regarding the spiritual lives of individuals

who experience intellectual and developmental disabilities and the need for additional research in this area.

The use of the *Spiritual Well-Being Scale* includes clinical practice, health care, nursing, outcome evaluation, congregational or group assessment, and research across disciplines. This particular instrument was chosen for this study because it was non-sectarian and provided application for people from a wide range of beliefs and backgrounds. Likewise, the *Spiritual Well-Being Scale* is one of the most researched measures of religiosity and spirituality available having been included in over 200 published and unpublished studies (Ellison, 1983; Ellison & Smith, 1991; Monod et al, 2011). A substantial number of studies have been conducted in health based research settings and was shown to be consistently related with a significant number of variables indicative of the health and psychosocial well-being of an individual (Bufford, Paloutzian, & Ellison, 1991).

In terms of the reliability of the instrument, the *Religious Well-Being Subscale (RWBS)*, *Existential Well-Being Subscale (EWBS)*, and *Spiritual Well-Being Total Scale (SWBS)* all achieved high reliability. The *RWBS*, test-retest reliability coefficients across four studies, with 1 – 10 weeks between testings were .96, .99, .96, and .88 respectively. For the *EWBS*, the reliability coefficients were .86, .98, .98, and .73 respectively. For total *SWBS*, the reliability coefficients were .93, .99, .99, and .82 respectively. The index of internal consistency, coefficient alpha, also shows a high reliability. Across seven samples the internal consistency coefficients ranged from .94 to .82 (*RWB*), .86 to .78 (*EWB*), and .94 to .89 (*SWB*) (Bufford et al., 1991).

In terms of the validity of the instrument, the *SWBS* has strong face validity as is evident by the content of the items. Research reveals that the items cluster as expected into the *RWB* and *EWB Subscales*. Research further reveals that the overall *SWBS* is an effective general indicator of well-being, and is especially sensitive to a lack of well-being (Paloutzian & Ellison, 1991). *SWB*, *RWB*, and *EWB* are correlated positively with a positive self-concept, sense-of-purpose in life, physical health, and emotional adjustment. Likewise, *SWB*, *RWB*, & *EWB* are negatively correlated with ill health, emotional maladjustment, and lack of purpose in life (Bufford et al., 1991).

Quality of Life Questionnaire reliability and validity. The *Quality of Life Questionnaire* (QOL.Q) (Appendix D) has a 40-item rating scale specifically designed to measure the overall quality of life for a person with mental retardation or related conditions. The *QOL.Q* was selected as it was the most extensively researched instrument currently available for assessing the quality of life of people who experience intellectual and developmental disabilities and was based upon more than a decade of work in this area.

In addition, a subjective verses objective measurement approach to assessing quality of life for individuals who experience developmental disabilities was most extensively used in the developmental disability field (Borthwick-Duffy, 1990; Edgerton, 1975; Goode, 1990; Harner & Heal, 1993; Heal & Sigelman, 1990). Likewise, a subjective approach was aligned with the researcher's personal belief that an individual's personal experience of life is the most appropriate source of measurement of one's quality of life.

Five conceptual basis and assumptions connected with the *QOL.Q*'s development are presented (Schalock & Keith, 2004): 1) Quality of life is necessarily subjective and cannot be inferred from objective measures of life conditions; 2) Quality of life is essentially the same for persons with and without disabilities; 3) Quality of life is basically a social phenomenon and a product primarily of interactions with others; 4) Quality of life is the outcome of persons meeting basic needs and fulfilling basic responsibilities in community settings; and 5) Quality of life can be assessed on a standardised instrument through either subjective report or ratings made by persons who know the individual very well.

The *QOL.Q* was the recommended instrument utilised in research to explore correlates of perceived quality of life and cross-cultural components of perceived quality of life. The utilisation of an instrument that was sensitive to cross-cultural aspects of quality of life was determined to be important as a result of the diverse population within Alaska and the study population. Likewise, the current study sought to explore first-hand information of a person's self-perception of life experience which was aligned with the *QOL.Q* instrument development and subsequent administration protocol.

The *QOL.Q* provided an overall measurement of the participant's subjective evaluation of life experience in four outcome measure areas: 1) Satisfaction; 2) Competence/Productivity; 3) Empowerment/Independence; 4) Social Belonging/Community Integration. Measures of reliability evaluating the test-retest reliability were reported in the *QOL.Q* 1993 Manual as ranging from .80 to .96 (Schalock & Keith, 2004).

Three measures of validity were reported for the 1993 *QOL.Q*: face validity, construct validity, and concurrent validity. In respect to the *Face Validity*, the *QOL.Q* items were generated from a number of published sources on well-being (Andrews & Whitley, 1976; Baker & Intagliata, 1982; Campbell, Converse, & Rogers, 1976; Goode, 1990; Zautra & Goodhard, 1979); independence (Flanagan, 1978; Hoffman, 1980; Yerxa, Burnett-Berulieu, Stocking, & Azen, 1989) and community integration/social belonging (Flanagan, 1978; Lehman, 1988). In respect to *Construct Validity*, the *QOL.Q* score behaves in accordance with previous expectations that among the intellectual and developmental disability population that quality of life increases with more independent living environments and decreases with the severity of the disabilities (Schalock & Keith, 2004). In respect to *Concurrent Validity*, the *QOL.Q* was found to be related to measures of similar constructs (Harner & Heal, 1993).

Quantitative phase data analysis. Borg, Gall, and Gall (2005) warned that the right statistical technique does not ensure an accurate interpretation of data. To validate the correct statistical model and correct interpretation of data were achieved; a separate statistician verified that the correct statistical model was used. The statistician further validated the results attained from the model, using an alpha value of .05 throughout the research, were computed correctly.

To answer research question number one, the researcher reviewed all data to ensure only complete data sets from the *QOL.Q* and the *SWBS* instruments were entered into the Statistical Package for the Social Science (SPSS) version 18.0 data view table. Since data entry could result in input error, a double check was conducted using

minimum/maximum scores in SPSS 18.0 to ensure that the data input was within the bounds of the instruments used. Additionally, a data view table from SPSS was printed and an independent agent verified accuracy of data entry (Gay & Airasian, 2003).

All statistical analysis of data employed SPSS version 18.0 software. Statistical analysis of data set an alpha (α) value of 0.05. Analyses were conducted to ensure that data met the assumptions for a valid Pearson r Product Moment Correlation, independent t test, and an independent analysis of variance (ANOVA). Data from the total scores of each instrument as well as each instruments subscale scores were included in the analysis process.

To answer research question number two, an independent t -test was conducted to examine gender differences within this population in relation to the variables of perceived spiritual well-being and quality of life. A review of the literature suggests that gender differences play a role in perceptions of well-being in relation to health, work, social, leisure, and spiritual domains (Azevedo et al., 2007; Maselko & Kubzansky, 2006; Schumaker & Hill, 1991; Williams, 1989). Therefore, consideration of gender in relation to perceptions of spiritual well-being and quality of life for adults who experience intellectual and developmental disabilities was incorporated for analysis. The independent t -test is utilised to establish whether the mean of two independent groups differ significantly (Field, 2005). The independent t -test is a *parametric test* and assumes the normal distribution of data across two groups. Field (2005) explains that the independent t -test assumes that variances within the two groups are roughly equal and scores are independent because they come from different people. This study compared the mean of male scores to the mean of female scores on both

instruments in the study to determine if a difference existed between the two gender groups in both perceived spiritual well-being and quality of life.

To answer research question number three, an independent analysis of variance (ANOVA) was conducted to examine three different levels of support: 1) 24- hour supports, 2) daily interim supports, 3) and weekly intermittent supports. These three levels of support were representative of combined residential and ancillary supports received by participants in the study population. The means of the three levels of support were analysed against the mean variable of perceived spiritual well-being and the mean variable of quality of life. Previous research indicates the significant role that services and supports play in the daily life of individuals who experience intellectual and developmental disabilities (Kozma, Mansell, & Beadle, 2009; Powers & Sowers, 2006; Schalock, et al., 2008; Walker, et al., 2011). Therefore, levels of support provided in relation to perceptions of spiritual well-being and quality of life were analysed in this study. An ANOVA statistical analysis allowed the researcher to identify more than one independent variable, identified as the varying levels of support, and compare to the dependent variables, identified as the measurement of perceived spiritual well-being and quality of life scores on standardised instruments utilised in this study.

The ANOVA uses the *F*-test to determine whether or not there are significant differences between the means of the groups examined. Once the *F*-test statistic is calculated, the *p*-value, tells how likely it is to find differences between the means of the groups in the study sample as compared to the larger population.

Qualitative Research Design

To add to the overall quantitative framework utilised to answer research questions one through three, a qualitative phenomenological approach was utilised to answer the fourth question of this research study. The qualitative phase of this study met general characteristics of qualitative research assumptions in the following ways: 1) the research occurred in natural settings connected with locations that participants live, work, worship and recreate; 2) the researcher was the primary instrument in the data collection (Eisner, 1991; Fraenkel & Wallen, 1990); 3) the data that came out of the qualitative fieldwork phase was descriptive and reported in words (Fraenkel & Wallen, 1990; Marshall & Rossman, 1989; Merriam, 1988); and 4) The focus of this phase of the research was on the participants reported perceptions, personal experiences and meaning in his or her life (Fraenkel & Wallen, 1990; Merriam, 1988).

The utilisation of a qualitative approach is appropriate when little is known about the topic, as in the spiritual lives of individuals who experience intellectual and developmental disabilities, and there is a need to explore and describe the phenomena further for theory to develop (Creswell, 1994; Morse, 1991). The intent of the qualitative component of this study was to gather additional data that was not a part of the information gathered in the quantitative components of the study and provide further explanation for the statistical results.

Qualitative inquiry seeks to describe the human experience utilising data collection techniques that gather information primarily in the form of spoken or written language. Qualitative data is then converted into written text (text-based) for analytic use rather than utilising numbers, mathematical calculations, and statistical processes

(Polkinghorne, 2005). The qualitative component of this study sought to add depth and breadth to the understanding of the research topic by capturing the meaning of the lived experience in the spiritual dimension of life for individuals who experience intellectual and developmental disabilities. Data collection sought to acquire first person accounts of the self-perceptions of personal beliefs, experiences, and relevancy of spirituality in participants' life. The qualitative design, methodology, and data collection are further described below.

Qualitative sampling procedure. A purposive sampling technique was utilised to identify a representative cross-section of participants from the quantitative phase of the research study as participants in the qualitative phase. Purposive sampling is identified as an appropriate technique to utilise when a researcher a) seeks to include participants that represent a broader group of cases as closely as possible, or b) set-up comparisons among different types of cases (Teddlie & Yu, 2007). To ensure a sample group offered a diverse range of information, the following criteria was utilised by the researcher to select key participants in the qualitative phase: 1) participants' geographic location; 2) participants' ability to generate information rich data resultant of participants' level of involvement across community and spiritual activities, or events; 3) participants' availability and willingness to share personal thoughts, feelings, and life experiences over a period of time.

Polkinghorne (1989) recommends that 5 to 25 individuals who have all experienced the phenomena of study be interviewed when conducting phenomenological research. Utilising purposive sampling and the previously stated

selection criteria, fifteen participants or 30% of the original fifty participants of the research study population were identified. The researcher conducted face-to-face visits to verbally explain the qualitative phase of the research study and gain the individuals' verbal consent to participate. The researcher explored each participant's willingness to allow the researcher to spend time and essentially 'walk along side' the participant across settings over a several month timeframe to learn more about the spiritual dimension of each participant's life in relation to other aspects of the participant's life. Informed consent was treated throughout this phase of the study as emergent and ongoing with each visit. Participants were frequently reminded of the voluntary nature of their participation, and their ability to discontinue at any time. Individual participants were selected from four of the original nine communities represented in the quantitative phase to be inclusive of participants in both urban and rural geographic settings.

Qualitative methodology. The researcher utilised a phenomenological framework consisting of unstructured, in-depth interviews, participant observations and documents review associated with the sample population. Phenomenology has philosophic and scientific roots developed largely from the work of philosopher and mathematician, Edmund Husserl (1859 – 1938), and primarily seeks to describe rather than explain phenomena (Husserl 1970). Husserl emphasised what is called the *intentionality of consciousness*. That is that consciousness is directed toward an object and the reality of that object is intimately entangled in the individual's consciousness of it.

Husserl believed that human beings could only know what they experienced and that meaning to an experience was assigned through an internal dynamic interpretative interactive process only after the experience passed through the individual's internal filtering system (Creswell, 1998; Moustakas, 1994). Therefore, Husserl rejected the subject-object dichotomy proposed by Cartesian duality believing that a person first perceives the phenomenon and then filters the perception through the person's own experience before meaning could be assigned.

This phase of the study focused on describing the meaning spirituality has for participants. Phenomenology as an approach studies experience from the view of the participant, holding aside traditional assumptions and bias (Lester, 1999). Husserl considered the suspension of a researcher's preconceptions essential in the study of phenomena in order to adequately hear or observe what others are saying (Husserl, 1965). Husserl referred to the strategy as *epoche* (or bracketing).

Bracketing as a strategy does not claim that the researcher is free from bias or preconception. Rather it requires the researcher to critically reflect and identify preconceived notions and consciously place these notions aside to allow the study populations' personal and contextual data to emerge. The researcher made every attempt possible to set aside researcher preconceptions and allow participants to share stories with minimal interruption. The researcher was deliberate in engaging in self-dialogue and critical reflection and maintained a journal of identified areas of personal bias arising from researcher experiences. In addition, the researcher engaged in peer debriefing to dialogue regarding presuppositions and further guard against a loss of perspective by the researcher. Such an approach emphasises the importance of

participants' subjective experience, personal perspective, and interpretation of situations.

By design, the phenomenological approach gives voice to individuals' personal lived experience and meanings evolving from the concept of study. The qualitative phase of this study specifically looked at the meanings attached to the spiritual dimension of life of adults who experience intellectual and developmental disabilities.

The qualitative phase of this research followed the phenomenological procedural guidelines outlined by Moustakas (1994). Specifically, a phenomenon for inquiry was identified, researcher bias was bracketed out, and data was collected from participants who experienced the phenomena. The information was reviewed, analysed, and themes identified. The researcher then developed individual *textural* (what participants experienced) and *structural* (how participants experienced it in terms of context) descriptions of the experience resulting in an overall summary or *composite* description of the *essence* of the lived experience of participants.

Qualitative Phase Data Collection

Role of the researcher. The researcher, in alignment with qualitative inquiry, was the primary data collection instrument (Denzin & Lincoln, 2003). The researcher approach was one of open disclosure and sincere engagement with participants in this study. Open disclosure was viewed from both a values base of respect for the individual, and a necessity in rapport and relationship building for honest dialogue to occur. During the qualitative phase, the researcher took an emic (insider) view of activities and events in an attempt to 'walk along side' participants in their day-to-day

life. This type of approach resonated both personally and professionally with the researcher.

People who experience intellectual and developmental disabilities have often been subjected to the actions of well-intentioned systems of support absent of considerations towards individual choices or preferences. Professionals within their respective field of expertise are called upon to make recommendations that they believe to be “in the best interest” of others within vulnerable populations. Therefore, an approach to inquiry that fostered an equalising interaction was deemed essential to this researcher.

Likewise, this researcher as a professional working in the field of disabilities has observed the evolution of the humanisation of service systems through various models of support and consequently the gradual humanisation of people who access systems of support. Yet, as a professional in the field, the researcher is acutely aware of the advancements human service delivery systems must achieve in interacting with people who experience intellectual and developmental disabilities as fully human in all respects.

In terms of researcher bias and the topic of exploration, this researcher’s own sense of spirituality is foundational to life. The researcher’s spiritual dimension throughout life has been a source of resilience, strength, comfort, and coping. This researcher’s Faith is couched within a Christian context and provides a guide for a daily walk. This researcher both recognises and respects the individually and culturally diverse expressions of the spiritual dimension of life and views Religion and Faith practices as personal choice that must be individually driven.

Additionally, this researcher's work and professional experiences required an open attitude and acknowledgment of the spiritual dimension in varying forms in other people's lives. Completing a Bachelor's degree in Psychology and a Master's degree in Counseling Psychology; being a human service professional for over thirty years; and living, traveling and working in a variety of countries around the world, this researcher has come to understand the power behind "seeing" a person in all respects. It is this researcher's intent and desire that the current study merely aide others to be "seen" more wholly through illumination within a research process.

Data collection strategies and recording procedures. Qualitative phenomenological inquiry utilises unstructured, in-depth inquiry as a primary strategy of data collection. The definition of unstructured interviews varies; Minichiello, Aroni, Timewell & Alexander (1990) discusses unstructured interviews as interviews in which neither the question nor the answer categories are predetermined. Punch (1998) describes the unstructured interview as an appropriate method in understanding the complex behaviour of people as it relies on the social interaction between the researcher and the informant without limiting the field of inquiry. Patton (2002) argues that unstructured interviews rely entirely on the spontaneous generation of questions within the natural flow of interactions between the researcher and the participant, and are a natural extension of participant observation. The unstructured interview format allowed this researcher to flow in and out of exploration of the topic of spirituality utilising spontaneously generated questions in a natural flow of conversation within a variety of contextual situations experienced by the participant.

The in-depth, unstructured and informal interviews were utilised as part of an iterative process aimed at exploring and describing the lived narratives of the spiritual life of individuals who experience intellectual and developmental disabilities. The researcher generated questions based upon the interviewees' narration. Interview questions were directed in general to the participant's experiences, feelings, beliefs, behaviours, and convictions regarding spirituality. In-depth interview notes focused on capturing rich detailed contextual descriptions and to the meanings, interpretations, and explanations individuals ascribed to the spiritual dimension of life and life experiences.

The researcher utilised an *aide memoire* (Note: the *aide memoire* can be found in Appendix F) or agenda as a general guide to topic issues that might be covered in the interview (Minichiello et al., 1990; Briggs, 2000; McCann & Clark, 2005). The *aide memoire* is an open-ended and flexible interview guide though; it did not determine the order of the conversation and was subject to revision based upon the responses of the interviewee (Burgess, 1984). Utilising the *aide memoire* or agenda allowed this researcher to achieve a balance between a need for both flexibility and consistency across participants and interview sessions. Data collection with the in-depth interviews and the participant observations occurred simultaneously as part of the qualitative component of the study. Data collected from participants was organised into a written text representing both the individual and the community level of what was observed and recorded by the researcher, and what was told to the researcher during interviews (Lapan, Quartaroli, & Reimer, 2012).

Participant observation was conducted in a manner consistent with a qualitative field study in which the researcher both observed and participated at the same time

allowing for the collection of data at the individual and community level throughout the life of the qualitative phase of the study (Lapan, 2012). Researcher emphasis during the qualitative phase was placed upon the building of a rapport and relationship with each participant. The relationship was open, mutual and interactive. The purpose of the participant observation was to experience life events in the manner in which the study population experienced the events.

Participant observation, as a tool in qualitative research, allowed the researcher to have a role in the life experience of the situation being observed in an effort to discover the nature of participants' social reality, self-perceptions, and interpretations of the world around the participant (Macionis & Plummer, 2005).

Additionally, participant observations allowed this researcher to gain insight into what an individual verbally portrayed and what the participant was observed to experience. The level of flexibility, conversational, and non-intrusive characteristics of the unstructured, informal interview, and participant observations as a methodology for data collection were particularly appropriate for utilisation in this study in consideration of the setting, participant idiosyncrasies, and the long term association of the researcher with the study population.

Participant interviews and observations occurred in four separate rounds of one to eight hour blocks of time. Interview occurred across a variety of natural settings within the community and home environments in which participants lived, worked, recreated, and worshiped. Additionally, interview and observation occurred at various times of day, days of the week, and months of the year within a six month timeframe. Interview and observation data was recorded in written field notes. Data collection continued until

theoretical saturation was reached. Theoretical saturation was representative of the point in data collection when new data no longer brought additional insight into the research questions (Corbin & Strauss, 2008).

Data review and analysis was conducted in conjunction with data collection. Written interview notes and field notes were utilised to record information from interviews and field observations. Field notes were reviewed and analysed to identify emerging themes as part of an on-going inductive and open coding process (Bentz & Shapiro, 1998).

A data collection method called 'memoing' was utilised to capture in the researcher's field notes, thoughts, and reflections in the moment regarding what was observed, seen, and felt by the researcher during participant and contextual data collection opportunities (Miles & Huberman, 1984). Immediately following a participant field experience the researcher reviewed memos and finalised a detailed written textual description of the interview, observations, and experience. Extensive note taking and or audio recording was not conducted during direct time spent with a participant so as not to corrupt the natural and informal nature and flow of communication and relationship with the participant.

Qualitative research acknowledges that all inquiry is encumbered with values (Mertens, 2003). Therefore, a form of 'bracketing' that is, the temporary identification and setting aside of researcher assumptions and bias, was incorporated into the data collection and analysis processes (Kvale & Brinkmann, 2009). This researcher was deliberate in the utilisation of bracketing throughout the fieldwork phase to self-reflect

and evaluate researcher bias and set aside preconceptions until data analysis was complete.

Qualitative coding, data analysis and interpretation procedures. Following each round of participant interviews, observations, and document reviews, text-based data from field notes was read line by line, coded, compared, and integrated into themes and patterns utilising *Dedoose*. *Dedoose*© is an electronic web application for managing, analysing, and presenting qualitative and mixed method data (Dedoose, 2012). Codes were categorised into themes and sub-themes that contained similar ideas, feelings, material, or language in the interviews and participant observation data. In addition, relevant participant documentation was reviewed to include participants' current Plan of Care, adding to the contextual information. The Researcher verified codes and the emerging patterns and themes with participants during each subsequent round of interviews. During the coding process, specific participant quotes were identified that particularly reflected the emergent themes.

Data analysis incorporated a review of significant statements, the generation of meaning units, and the development of an "essence" description (Moustakas, 1994). Descriptive summaries were written for each theme and provided the basis for the qualitative data analysis and interpretation of the coding categories (Lapan, 2012).

A summary of findings was completed arranging themes and topics that highlight key issues discussed by participants. Direct quotes were captured to illustrate key points. A discussion section was included as well as a section discussing themes and implications evolving from the qualitative phase of the research.

Strategies employed to validate the accuracy of qualitative findings. The concepts of reliability and validity are familiar terms in research. However, quantitative and qualitative paradigms experience contentious dialogues resulting in various typologies regarding what constitutes legitimacy and or establishes appropriate scientific rigor in the course of an investigation (Creswell, 2003; Creswell & Miller, 2000; Lincoln & Guba, 1985; Morse et al, 2002; Onwuegbuzie, 2003). Though efforts to bridge both the understanding and the gaps between the thinking across the two paradigms continues to evolve, the steps taken in the qualitative phase of this study to ensure the *verification* of findings is discussed.

Verification in qualitative inquiry consists of strategies utilised during the research process to check, confirm, make sure of findings thereby, contributing to the reliability and validity (rigor) of a study (Morse et al., 2002). These verification strategies were interlaced into each step of inquiry to create a quality product that allowed for the identification and correction of errors which could potentially undermine analysis (Creswell, 1998; Kvale, 1989). Several verification strategies were utilised in the qualitative phase of this project and are described below.

Methodological coherence is said to occur when the research question remains congruent to the component of the method utilised (Morse et al., 2002). This researcher moved back and forth between the design and implementation stages to ensure that methodological congruence was maintained throughout the implementation of the study. A specific time to think and reflect was designated to allow the researcher to remain sensitive to the evolving notions of codes, categories, and themes. Data was systematically reviewed and checked between each round of interviews to evaluate data

fit, sampling sufficiency, and alignment with the overriding research question. This researcher was intentional in the inclusion of negative cases, that is, participant views that were atypical, for completeness of data. Member checks for consistency, coding, and concept clarification was ongoing throughout data collection and analysis activities.

In terms of sampling sufficiency, Morse (1991) suggests that the *sampling adequacy* is evidenced by saturation and replication. Saturation was demonstrated in the replication of codes and categories, leading to the resultant themes. Data collection was determined to be sufficient once saturation was achieved.

Finally, Lincoln & Guba (1985) proposed that in a qualitative paradigm the terms of reliability and validity be substituted with such concepts as “trustworthiness” which was comprised of credibility, transferability, dependability, and confirmability. In qualitative inquiry, ‘trustworthiness’ is context specific and represents the relative truthfulness of the ultimate multiple realities that emerge from the data and the analysis (Lincoln & Guba, 1985). Meaning is considered ‘trustworthy’ when it develops from and is based upon those making meaning. In this study, trustworthiness was regularly checked for both the researcher and participants through ongoing researcher reflection and member checks with participants as data emerged. Furthermore, activities such as prolonged participant engagement, persistent observation, and triangulation as discussed earlier in this chapter were incorporated into this phase of the research to enhance the credibility of inquiry.

Integrating the Quantitative and Qualitative Data

Creswell (2003) offers three overall strategies for mixing quantitative and qualitative data in a mixed methods approach; *merging data sets*, *embedding data at the*

design level, and connecting from data analysis to data collection. Connecting the two data types, quantitative and qualitative, was determined to best suit this study and was incorporated into this study. A mixed methods, explanatory sequential design was utilised with the data types first connected by the primary research questions. The first question asked ‘what’ is the relationship between two variables, and the fourth question explored “how” the research participants understand and describe this relationship between the two variables. The research began with the collection and analysis of quantitative data pertinent to the first question. This first, quantitative, phase of the research was followed by the second phase in which there was a subsequent collection and analysis of qualitative data further informing the quantitative results.

Potential Limitations of the Study

This study was restricted to a particular population of adult individuals who experience intellectual and developmental disabilities living in the State of Alaska, USA and receiving services from one not-for-profit, secular organisation. The data collected, analysed, and interpreted may not represent the entire population of adults who experience intellectual and developmental disabilities in other geographic locations. However there was purposive sampling method utilised in order to ensure that a diversity of viewpoints and experiences were represented from across the State of Alaska.

Within the sample population (n = 50), individuals who participated resided in a variety of regions within Alaska and residential living situations, represented adult individuals across the adult lifespan, and incorporated a substantial number of individuals from each gender. The findings and opinions expressed are specific to the

individuals and settings involved. Another limitation addresses culture and life specific influences; participants' views could be shaped by the cultural, local, and life specific influences, and therefore, cannot generalise to the greater population.

Additionally, the research conditions and instruments limited this study:

- 1) Only adult individuals who experienced intellectual and developmental disabilities with a certain level of receptive/expressive language skill ability were included in the study. Therefore, information may not be representative of individuals with intellectual and developmental disabilities who have language skills of differing ability or are significantly lower functioning in adaptive daily living life domain areas.
- 2) Only individuals who were their own guardians thereby having maximum control legally for self-determination were included in the study and therefore, may not represent individuals who have appointed guardians and do not have the same level of control over life decisions.
- 3) Only individuals were invited to participate who access publicly funded services and further research would need to be conducted to determine if this population is different from individuals of the same criteria who do not access any public funded community support services.
- 4) The *Spiritual Well Being Scale* has been utilised with disability related populations, its' specific utility with an intellectual and developmental disability population had not previously occurred.

Chapter Summary

This chapter described the use of a mixed method, sequential explanatory research design. Within this design, a purposive sampling technique was used in both a quantitative and qualitative phase by specifically selecting adult individuals who experience intellectual and developmental disabilities across the State of Alaska. The two instruments that were utilised in this study during the quantitative phase were the *Quality of Life Questionnaire (QOL.Q)* and the *Spiritual Well-Being Scale (SWBS)*. During the qualitative phase, the researcher was “instrument” and utilised unstructured in-depth interviews, participant observation, and document reviews. A detailed discussion presented the rationale for selecting the research design and instrument use, as well as a detailed description of each instruments reliability and validity.

A detailed discussion was presented regarding each phase of the research on data collection processes, procedures to analyse data, and means by which quantitative and qualitative findings would be verified. Additionally, a timeline outlined critical activities, dates, and resources that supported the data collection plans. Finally, this chapter closed on a detailed discussion of limitations inherent to this study. Chapters five and six present an analysis of the quantitative and qualitative data and discusses how the analysed data answered the four primary research questions.

Chapter 5

Quantitative Phase Data Analysis and Findings

As evidenced in the literature review, there is a prevalent body of knowledge and research regarding the benefits of spirituality in relation to a person's physical, emotional, and social well being (Abdel-Khalek, 2006; Borg, Andree, Soderstrom, & Farde, 2003; Koenig, 1997, 1998; Koenig & McConnell, 1999). There is also strong evidence of the importance of spirituality in an individual's coping (Pargament et al., 1995), rehabilitation and recovery (Fitchett et al., 1999), search for meaning following major life events or crisis (Maugans, 1996), and quality of life (Ellison & Smith, 1991). Despite these findings, a review of the literature reveals an absence in research examining the relationship of spirituality and quality of life in adults who experience intellectual and developmental disabilities. Therefore, this study aims to advance the knowledge of the self-perception of the spiritual dimension of life for individuals who experience intellectual and developmental disabilities through the exploration and description of how adults who experience intellectual and developmental disabilities perceive the relevancy of their spiritual well-being in relation to their quality of life. The overall research aim was investigated utilising a mixed methods sequential explanatory design study that addressed four primary research questions.

Chapters Five and Six present the main findings from a systematic analysis of the data collected in two phases of study. The findings from each phase are presented separately in respective quantitative and qualitative chapters. Phase one was quantitative and analysed data from two questionnaires completed by 50 adults who

experience intellectual and developmental disabilities and is discussed in Chapter Five. Phase two was qualitative and analysed data collected from unstructured in-depth interviews, participant observation, and document reviews of 15 adults from the original study sample and is discussed in Chapter Six. All 50 adult individuals received supports and services from one private not-for-profit organisation in the State of Alaska, USA. The study population was representative of individuals living in a variety of residential environments in both urban and rural areas across Alaska. Following review of the proposed research and approval to proceed by the Research Ethics Committee of Waterford Institute of Technology, and a review and recommendation by the not-for-profit organisations Ethics Committee, Executive Management granted permission to conduct this study.

Quantitative Phase of Study

Two data collection instruments provided data for analysis in phase one of the study : 1) the *Quality of Life Questionnaire* (Schalock & Keith, 2004) and 2) the *Spiritual Well-Being Scales* (Paloutzian & Ellison, 1991). With the *Quality of Life Questionnaire*, data from *QOL.Q Total* scores were analysed along with four subscales: 1) Satisfaction; 2) Competency/Productivity; 3) Empowerment/Independence; 4) Social Belonging/Community Integration. With the *Spiritual Well-Being Scales*, data from the *SWBS Total* scores were analysed along with two subscales: 1) the *Religious Well-being Subscale* and 2) the *Existential Well-being Subscale*. The interpretation of data provides important information for health and social service providers, administrators, religious organisations, social service policy makers and funding sources connected with the intellectual and developmental disability population.

Quantitative phase data collection procedures. Utilising the methodology described in chapter four, the researcher established five criteria to identify participants in this study: 1) participants must have been adults, age 18 years of age or older; 2) participants must have been their own guardians and able to provide informed consent; 3) participants must have experienced an intellectual and developmental disability as defined in Alaska State Law Definitions (Alaska Statute 47.80.900); 4) participants must have had a 5th grade reading or receptive/expressive language skill level commensurate with the utility of the *Spiritual Well-Being Scales* utilised in the research study; and, 5) participants who were receiving residential and ancillary support services.

A purposive sampling technique was used, since participants came from a population of individuals supported by one not-for-profit state-wide organisation in Alaska. The organisations total support recipient census was over 1000 individuals at the time of the study. The researcher determined that of the 1000 support recipients, 156 individuals met the first three criteria for inclusion in the study. Of the 156 eligible participants, 53 individuals also met the 4th and 5th criteria in that, these individuals also had a 5th grade receptive/expressive language skill level, and were receiving both residential and ancillary support services from the organisation. Each of the 53 individuals were personally contacted either face-to-face or telephonically by the researcher regarding participation in the study. Three of the initial 53 individuals contacted declined to participate, leaving a total of 50 or a 94% participation rate that consented to participate in the study. The relatively large response rate was felt to be in

part due to the interest in the topic, method of distribution and inquiry that is, face-to-face contact with the participant, and a personal desire to “help out” the researcher.

Of the 50 individuals who participated in phase one of the study, three individuals met *outlier* criteria and were eliminated as not representing the sample population. The following procedure was used to determine outliers: First, the data set from questionnaire responses was checked for extreme observation using quartiles. Computing the interquartile range, upper and lower fences were established. Data outside the upper and lower fences were considered outliers and not used. Of the original 50 participants who participated in the study, three met the outlier criteria and were eliminated as not representing the sample population. Data from the 47 final participants was utilised for further analysis during the study. Phase one of data collection was conducted directly by the researcher during face-to-face interviews in which the *SWBS* and the *QOL.Q* was administered to each participant from January 2010 through April 2010. Analysis of the data began with a demographic review of the participants in phase one of the study. Next, each research question was analysed through outlining pertinent statistics. Last, a summary of the total group responses is presented.

It was this researcher’s observation from both participant comments and behavioural responses that, in general, participants were very supportive of this type of research being conducted and happy to share their thoughts, feelings and experiences regarding the topic. This was also supported by the fact that 94%, that is 50 of 53, of persons approached to potentially participate in the study, agreed to be a part of the study.

Presentation of descriptive characteristics of participants. The study sample population consisted of 47 adults who experience intellectual and developmental disabilities ranging in age from 23 to 60 years old. Of the 47 individuals who participated in the study, 26 or 55% were female and 21 or 45% were male. Thirteen participants or 28% were representative of individuals living in rural areas of Alaska and 34 or 72% of participants were representative of individuals living in urban settings of Alaska. Participants resided in nine communities across the State of Alaska.

Participants resided in a variety of living environments within their respective communities. Of the sample population, 8 participants or 17% lived in an Apartment Cluster environment; 14 or 30% of participants lived in an Assisted Living Home environment; 20 or 43% of participants lived in Independent Living environments; 2 or 4% of participants lived in a Natural Family Home environment; and 3 or 6% of participants lived in a Supported Living environment. Because of the history of intellectual and developmental disabilities having been excluded and often removed from communities particularly in Alaska (The Western Interstate Commission for Higher Education, 2009), whether or not participants had a history of institutional living was explored. Within the study population 8 or 17% of participants of the study population had a history of institutionalisation, while 39 or 83% of participants of the study population had no history of institutionalisation.

Additional factors such as ethnicity and religious preference were also explored. Participants were representative of diverse ethnic backgrounds with 1 participant or 2% of the sample group being African American; 9 participants or 19%, Alaska Native; 2 participants or 4%, Asian-Pacific Islander; and 35 participants or 74%, Caucasian. In

terms of religious preference, the sample population reported to be 2 participants or 4%, Atheist; 1 participant or 2%, Bahai; 4 participants or 9%, Catholic; 32 participants or 68%, Christian Protestant; and 8 participants or 17% without a specific religious preference. Table 5.1 through 5.7 represents the demographics of the 47 individuals in this study:

Table 5.1

Gender

Gender	Frequency	Percent	Cumulative Percent
Female	26	55.3	55.3
Male	21	44.7	100.0
Total	47	100.0	

Table 5.2

Primary Diagnosis

Diagnosis	Frequency	Percent	Cumulative Percent
Cerebral Palsy	9	19.1	19.1
Duchennes Muscular Dystrophy	1	2.1	21.3
Fetal Alcohol Syndrome (FAS)	2	4.3	25.5
Mental Retardation	28	59.6	85.1
Pervasive Development Disorder	2	4.3	89.4
Seizure Disorder	2	4.3	93.6
Spina Bifida	1	2.1	95.7
Spinal Muscular Atrophy	1	2.1	97.9
Traumatic Brain Injury	1	2.1	100.0
Total	47	100.0	

Table 5.3

Ethnicity

Ethnicity	Frequency	Percent	Cumulative Percent
African American	1	2.1	2.1
Alaska Native	9	19.1	21.3
Asian Pacific Islander	2	4.3	25.5
Caucasian	35	74.5	100.0
Total	47	100.0	

Table 5.4

Participant Geographic Locations within Alaska

Locations	Frequency	Percent	Cumulative Percent
Anchorage	33	70.2	70.2
Eagle River	1	2.1	72.3
Juneau	1	2.1	74.5
Kenai	1	2.1	76.6
Kodiak	3	6.4	83.0
Petersburg	1	2.1	85.1
Soldotna	3	6.4	91.5
Wasilla	1	2.1	93.6
Willow	3	6.4	100.0
Total	47	100.0	

Table 5.5

Living Situation

Situation	Frequency	Percent	Cumulative Percent
Apartment Cluster	8	17.0	17.0
Assisted Living Home	14	29.8	46.8
Independent Living	20	42.6	89.4
Natural Family Home	2	4.3	93.6
Supported Living	3	6.4	100.0
Total	47	100.0	

Table 5.6

Religious Preferences

Preferences	Frequency	Percent	Cumulative Percent
Atheist	2	4.3	4.3
Bahai	1	2.1	6.4
Catholic	4	8.5	14.9
Christian-Assembly of God	1	2.1	17.0
Christian-Baptist	7	14.9	31.9
Christian-Church of God	2	4.3	36.2
Christian-Methodist	2	4.3	40.4
Christian-Non Affiliation	20	42.6	83.0
No Preference	8	17	100.0
Total	47	100.0	

Note: For the purposes of the study. Participant preferences for religious preferences were summarised in the following categories: Atheist = 4.3%, Bahai = 2.1%, Catholic = 8.5%, Christian Protestant = 68%, No Religious Preference = 17%.

Table 5.7

Previous Institutional History

Institutional History	Frequency	Percent	Cumulative Percent
No	39	83.0	83.0
Yes	8	17.0	100.0
Total	47	100.0	

Quantitative research questions and associated hypotheses. This chapter section proposes to answer three primary research questions:

- 1) What is the relationship between perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities?
- 2) What is the difference between males and females regarding perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities?
- 3) Is there a difference for individuals who experience intellectual and developmental disabilities in perceived spiritual well-being and quality of life with different levels of support in living situations?

To test the first research question, a Pearson Product-Moment (r) statistical model was utilised to explore if there was a correlational relationship between the two variables of perceived spiritual well-being and quality of life. To test the second research question for gender differences within the variables of spiritual well-being and

quality of life, an independent *t-test* was conducted. To test the third research question, an *independent analysis of variance* (ANOVA) was conducted to examine three different levels of support: 1) 24 hour supports, 2) daily interim supports, and 3) weekly intermittent supports in comparison with participants perceived spiritual well-being and quality of life. The ANOVA test allowed the researcher to examine differences between more than one independent variable, identified as the varying levels of support, as compared to the dependent variables, identified as the measurement of perceived spiritual well-being and quality of life scores.

Quantitative Phase Statistical Considerations

Before conducting correlation analyses, data were subjected to a number of critical assessments to determine whether various assumptions underlying data analysis procedures were not violated. Specifically, analysis of data determined adequacy of sample size, unusual response patterns, missing cases, outliers, and compliance with assumptions of normality. Statistical Software for Social Science (SPSS) Version 18.0 was utilised in computing statistical tests.

Adequacy of sample size. Parameters for determining sample size and usefulness of the data were based upon a combination of α value (*probability of a Type I error, i.e. probability of rejecting a null hypothesis that is true*), p value, and a standardised effect size. The alpha value was set consistently at $\alpha = .05$ for a one-tailed test. For the Pearson product-moment correlations, a power of the test was set at $p = .80$ along with a medium effect size. A Cohen **d** table of power of the test, $\alpha = .05$ one-tailed test determined that a sample size population of 46 participants would have a power of test of .88 (Cohen, 1988).

Therefore, the research population sample consisting of data from 47 individuals met statistical criteria for data usefulness.

Unusual response patterns, missing cases, and outliers analyses.

Unusual response patterns arise from participants' incomplete responses on assessment instruments. Such unusual response patterns include extreme scores, inaccuracies in scoring measurements, or missing data cases. Regardless of the source, unusual response patterns create skewed distributions, and possibly violate the assumptions of normality for parametric processing procedures.

To minimise the problem of unusual response patterns, descriptive statistics were computed on all variables. The data check revealed no unusual response patterns. Additionally, missing cases significantly influence data analysis results. Frequency computation on all descriptive data checked for missing data. Analysis revealed no missing data.

Assumptions of normality. Many statistical tests function under the assumption of normality. The assumption of normality leads to test that are mathematically tractable and powerful compared to tests that do not make the normality assumption. However, real data sets seldom achieve absolute normality.

The skewness and kurtosis values of data distributions serve as indicators to how well variables are normally distributed. To determine if data in this study met assumption of normality, assessments of data were computed for both the *QOL.Q* and the *SWBS* to obtain values for skewness and kurtosis. The amount

of skewness and kurtosis in data serves as indicators of how variables distribute normally on the univariate level.

Data with an excessive skew can be transformed to normal data distribution (Field, 2005). To determine if data in this study met assumptions of normality, diagnostics were conducted to obtain values for skewness and kurtosis. From the separate values obtained in skewness and kurtosis the values were divided by their corresponding standard error and checked for significance. Tabachnick and Fidell (1996) recommend that any skewness and kurtosis results greater than a z -score of ± 3.29 indicates excessive skewness or kurtosis in data. Data values computed for skewness ranged from .55 *SWBS* to -.58 *QOL.Q*, and kurtosis ranged from -.46 *SWBS* to -1.31 *QOL.Q* respectively.

Effect size and statistical power. Effect size is intrinsically linked to three statistical properties: 1) sample size, 2) probability level to support statistical significance, and 3) statistical power ($1 - \beta$). For this study, the sample size was $N = 47$; the statistical significance was set at alpha equal to .05 ($\alpha = .05$).

For statistical power, Cohen (1988) suggests the maximum acceptable probability for a Type II error is 0.2, or 20%; the value .2 is called the β level. The corresponding level of power he recommends is 0.8, or $1 - \beta$. Therefore, there is a 0.2 probability of failing to detect a genuine effect and a .8 level of power, or an 80% chance of detecting a genuine effect.

To understand the effect size of the statistical tests for correlation conducted in this study, Cohen's d statistical power values must be converted to

correlation coefficient values. Effect sizes (Cohen **d**) are classified as small (.20), medium (.50), and large (.80). Cohen (1988) provides a table that converts Cohen **d** effect sizes into correlation coefficients effect sizes. Table 5.8 presents conversion values for correlation coefficient **r** effect sizes.

Table 5.8

*Conversion of Cohen **d** effect sizes to correlation coefficient **r** effect sizes*

Effect Size	Cohen d values	Correlation Coefficient r
Small	.20	.10
Medium	.50	.30
Large	.80	.50

For this study, correlation statistical test effect sizes were categorised as small (0.1), medium (0.3), and large (0.5) (Cohen, 1988; Green & Silkind, 2005). Correlation coefficients produced effect sizes in seven of nine correlations in this study that ranged from .268 (medium) to .488 (large). With a sample size of $N = 47$ and the significant levels for all statistical tests set an alpha ($\alpha = .05$, one-tail) the correlation statistical tests achieved statistical power values ranging from .67 to .98. Of the eleven correlations, seven correlations met or exceeded Cohen's recommended Cohen **d** value of .8 level of statistical power for detecting genuine effects.

Quantitative Phase Analysis of Data

This study sought to learn more about the spiritual dimension of adults who experience intellectual and developmental disabilities. A description of the measurement of perceived spiritual well-being in the study sample population utilising

the *Spiritual Well-Being Scale (SWBS)* scores is described. The *SWBS* provides three primary scores of measurement of perceived well-being in the spiritual dimension of life: 1) *Spiritual Well-Being Total Score* and, 2) *Religious Well-Being Subscale Score* and, 3) and *Existential Well-Being Subscale Score*.

SWBS Total Scores ranges are interpreted as follows: Scores in the range of 20 – 40, indicate low spiritual well-being; scores in the range of 41 – 99, indicate moderate spiritual well-being; and, scores in the range of 100 - 120, indicate high spiritual well-being.

SWBS Religious Well-Being Sub-scale Scores are interpreted as follows: Scores in the range of 10 – 20, indicate an unsatisfactory relationship with God; scores in the range of 21 – 49, indicate moderate religious well-being; and, scores in the range of 50 – 60, indicate a very positive view of a persons' relationship with God.

SWBS Existential Well-Being Sub-scale Scores are interpreted as follows: Scores in the range of 10 – 20, indicate a low satisfaction with life and a lack of clear purpose in life; scores in the range of 21 – 49, indicate a moderate level of life satisfaction and purpose; and, scores in the range of 50 – 60, indicate a high level of satisfaction in life and clear sense of purpose (Paloutzian & Ellison, 1991).

For the study population (N = 47); 23% (n = 11) of participants *SWBS Total Scores* fell between 100 – 120, high range of spiritual well-being; and 78% (n = 37) of participants *SWBS Total Scores* fell between 41 – 99, a moderate range of spiritual well-being.

On the *SWBS Religious Well-Being Subscale*, 34% (n = 16) of participant scores fell between 50 – 60, high range of religious well-being; 61% (n = 29) of participant

scores fell between 21 - 49, moderate range of religious well-being; and 4% (n = 2) of participant scores fell between 10 – 20, an unsatisfactory range of religious well-being.

On the *SWBS Existential Well-Being Subscale*, 21% (n = 10) of participant scores fell between 50 – 60, indicating a high level of life satisfaction and purpose; and, 78% (n=37) of participant scores fell between 21 – 49, indicating a moderate level of life satisfaction and purpose. .

In learning more about the spiritual dimension of life in adults who experience intellectual and developmental disabilities, this study looked at the spiritual dimension of life in relationship to the individual's quality of life. Utilising the *Quality of Life Questionnaire (QOL.Q)* a description of the measurement of the overall perceived quality of life, *QOL.Q Total Score*, in the study sample population is described. Furthermore, the *QOL.Q* provides four outcome area measurement scores that comprise the individual's subjective evaluation of life experience: 1) *Life Satisfaction Subscale Score*, 2) *Competence/Productivity Subscale Score*, 3) *Empowerment/Independence Subscale Score*, and 4) *Social Belonging/Community Integration Subscale Score*.

The *QOL.Q* has a 40-item rating scale, comprised of 10 questions within each of the four *QOL.Q Subscales*. Each *QOL.Q* item has a 3-point scoring system. The score from each of the *QOL.Q Subscales* can range from 10 – 30. The higher the score the greater the level of satisfaction, competence/productivity, empowerment/independence, and social belonging/community integration. This researcher evaluated where participant scores fell in respect to percentile ranks with the *QOL.Q Total Score* and each of the subscale scores.

For the study population (N = 47), participants *QOL.Q Total Scores* fell between 71 – 110; 32% (n = 15) of participants *QOL.Q Total Scores* ranked within the lower quartile score range for quality of life; 34% (n=16) of participants scores ranked within the median quartile, representing a moderate score range for quality of life; and 34% (n=16) of participants scores ranked within the upper quartile, representing a high score range for quality of life.

On the *QOL.Q Satisfaction Subscale Scores* for participants fell between 13 - 29; 15% (n = 7) of participants *Satisfaction Subscale Scores* ranked within the lower quartile score range for life satisfaction; 53% (n= 25) of participants scores ranked within the median quartile, representing a moderate score range for life satisfaction; and 32% (n=15) of participants scores ranked within the upper quartile, representing a high score range for life satisfaction.

On the *QOL.Q Competence/Productivity Subscale Scores* for participants fell between 10 - 30; 36% (n = 17) of participants *Competence/Productivity Subscale Scores* ranked within the lower quartile score range for competency/productivity; 40% (n= 19) of participants scores ranked within the median quartile, representing a moderate score range for competency/productivity; and 23% (n=11) of participants scores ranked within the upper quartile, representing a high score range for competency/productivity.

On the *QOL.Q Empowerment/Independence Subscale Scores* for participants fell between 15 - 29; 17% (n = 8) of participants *Empowerment/Independence Subscale Scores* ranked within the lower quartile score range for empowerment/independence; 62% (n= 29) of participants scores ranked within the median quartile, representing a moderate score range for empowerment/independence; and 21% (n=10) of participants

scores ranked within the upper quartile, representing a high score range for empowerment/independence.

On the *QOL.Q Social Belonging/Community Integration Subscale Scores* for participants fell between 15 - 29; 28% (n = 13) of participants *Social Belonging/Community Integration Subscale Scores* ranked within the lower quartile score range for social belonging/community integration; 57% (n= 27) of participants scores ranked within the median quartile, representing a moderate score range for social belonging/community integration; and 15% (n= 7) of participants scores ranked within the upper quartile, representing a high score range for social belonging/community integration.

Research question 1.0. What is the relationship between perceived spiritual well-being and the quality of life in adults who experience intellectual and developmental disabilities? Research question 1.0 was answered by the data collected from participant responses to the *Spiritual Well-Being Scale* and *Quality of Life Questionnaire*.

A Pearson's product-moment correlation coefficient statistical analysis was utilised to explore this question. Both magnitude and direction of relationship between perceived spiritual well-being and quality of life scores in individuals who experience intellectual and developmental disabilities were analysed. A total of eleven correlations were conducted. Two *QOL.Q* subscale score areas, that is *Competence/Productivity* and *Empowerment/Independence*, showed no significant relationship with *SWBS* scores. In addition, the *QOL.Q* Total scores and *Life Satisfaction* subscale scores showed no

significant relationship with *SWBS, Religious Well-Being* subscale scores. Seven of the eleven correlations suggested a significant positive relationship.

Based upon a preponderance of research conducted on various populations that suggests a significant role of spirituality on various aspects of health and well-being, one-tailed significant tests were used for all correlations. Each research question, hypothesis and associated correlation is presented:

Hypothesis 1.0: A significant positive relationship exists between perceived spiritual well-being and the quality of life in adults who experience intellectual and developmental disabilities.

Correlation 1.0: The Pearson product-moment correlation coefficient was used to examine the *Total* scores of each participant for the *SWBS* and the *QOL.Q*. The correlation analysed both magnitude and direction of the relationship between the self-perceptions of adults' spiritual well-being and adults' quality of life. A significant, positive correlation ($r = .358$, $r^2 = .13$, $p < .01$) was found. The effect size produced a Pearson $r = .358$, which indicates a moderate correlation, and further suggests that adults who experience intellectual and developmental disabilities quality of life increases as their perception of spiritual well-being increases. The value of r^2 (.13) indicates that 13% of the variability in quality of life in adults who experience intellectual and developmental disabilities is accounted by their perceived spiritual well-being.

The hypothesis was accepted at $r = .358$, a level of significance of $p < .01$. There is a significant positive relationship between a participants' reported spiritual well-being and reported quality of life. Figure 5.1 represents the linear relationship of the *SWBS Total Scores* and the *QOL.Q Total Scores*.

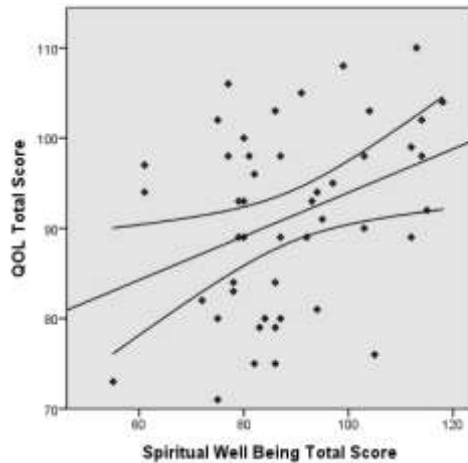


Figure 5.1. Linear relation between *Spiritual Well-Being Total Scores (SWBS)* and *Quality of Life Questionnaire Total Scores* in adults who experience intellectual and developmental disabilities.

In addition, the *Spiritual Well-Being Scales* and the *Quality of Life Questionnaire* instruments have subscales as listed. The *Spiritual Well-Being Scales* contained two subscale scores for both *Religious Well-Being* and *Existential Well-Being*. The *QOL.Q* contained four subscales providing an overall measurement of the respondent's subjective evaluation of life experience in four outcome measure areas: 1) *Life Satisfaction*; 2) *Competency/Productivity*; 3) *Empowerment/Independence*; and 4) *Social Belonging/Community Integration*. From these subscales the following ten sub-questions were analysed to further examine primary research question one:

Research question 1.1. What is the relationship between perceived spiritual well-being and life satisfaction in adults who experience intellectual and developmental disabilities?

Hypothesis 1.1: A significant positive relationship exists between perceived spiritual well-being and life satisfaction in adults who experience developmental disabilities.

Correlation 1.1: Pearson's Product-Moment Correlation Coefficient analysis for *Spiritual Well-Being Scale Total Scores* and *QOL Satisfaction Subscale Scores*. The correlation analysed both the magnitude and direction of the relationship between participants' perceived spiritual well-being and perceived life satisfaction. A significant, positive correlation ($r = .271$, $r^2 = .07$, $p < .05$) was found. The effect size produced a Pearson $r = .271$, which indicates a moderate correlation between spiritual well-being and life satisfaction in adults who experience developmental disabilities. The value of $r^2 (.07)$ indicates that 7% of the variability in adults who experience intellectual and developmental disabilities level of life satisfaction is accounted by their perceived spiritual well-being.

The hypothesis was accepted at $r = .271$, a level of significance of $p < .05$. A significant positive relationship exists between reported life satisfaction and reported spiritual well-being in adults who experience intellectual and developmental disabilities. However, the magnitude of the relationship between these two areas is moderate. Figure 5.2 represents the linear relationship of the *SWBS Total Scores* and the *QOL.Q Satisfaction Subscale Scores* for life satisfaction.

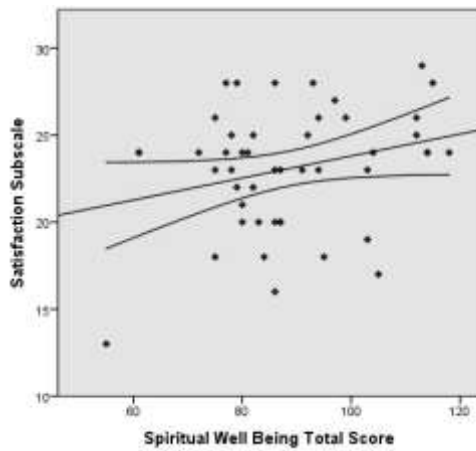


Figure 5.2. Linear relation between *Spiritual Well-Being Total Scores (SWBS)* in adults who experience intellectual and developmental disabilities and *Quality of Life Questionnaire, Life Satisfaction Subscale Scores*.

Research question 1.2. What is the relationship between perceived spiritual well-being and competency/productivity in adults who experience intellectual and developmental disabilities?

Hypothesis 1.2: A significant positive relationship exists between perceived spiritual well-being and competency/productivity in adults who experience intellectual and developmental disabilities.

Correlation 1.2: A Pearson Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between *Spiritual Well-Being Scale Total Scores* and *QOL.Q Competency/Productivity Subscale Scores*. Specifically this correlation analysed the relationship between two variables: 1) participants' reported self-perceptions of spiritual well-being and 2) reported self-perceptions of competency and productivity. The Pearson Product-Moment Correlation Coefficient produced no significant correlation ($r = .140$, $r^2 = .02$, $p > .05$). The

hypothesis was rejected. Figure 5.3 represents the linear relationship of the *SWBS Total Scores and the QOL.Q Competency/Productivity Subscale Scores*.

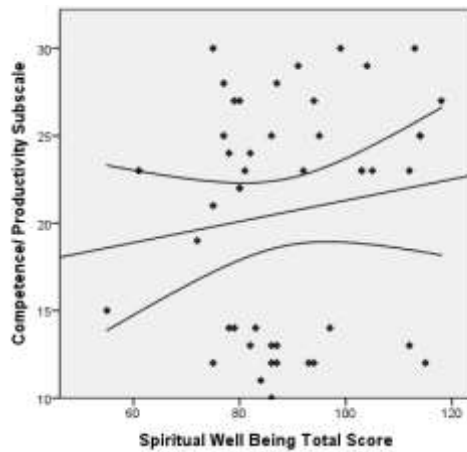


Figure 5.3. Linear relation between *Spiritual Well-Being Total Scores (SWBS)* and the *Competency/Productivity Subscale Scores* in adults who experience intellectual and developmental disabilities.

Research question 1.3. What is the relationship between perceived spiritual well-being and empowerment/independence in adults who experience intellectual and developmental disabilities?

Hypothesis 1.3: A significant positive relationship exists between perceived spiritual well-being and empowerment/independence in adults who experience intellectual and developmental disabilities.

Correlation 1.3: A Pearson Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between *Spiritual Well-Being Scale Total Scores* and *QOL.Q Empowerment/Independence Subscale Scores*. Specifically, this correlation analysed the relationship between the two variables: 1) participants' reported self-perceptions of spiritual well-being and 2)

reported self-perceptions of empowerment and independence. The Pearson Product-Moment Correlation Coefficient produced no significant correlation ($r = .169$, $r^2 = .03$, $p > .05$) between the two variables. The hypothesis was rejected. Figure 5.4 represents the linear relationship of the *SWBS Total Scores and the QOL.Q Empowerment/Independence Subscale Scores*.

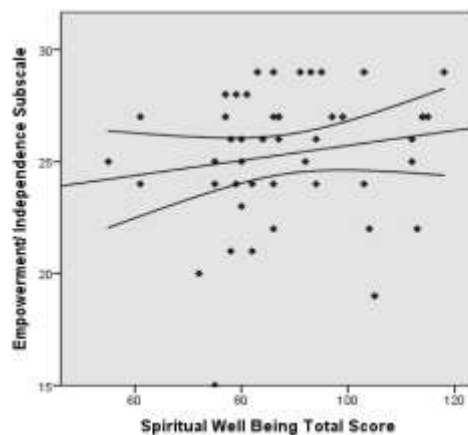


Figure 5.4. Linear relation between *Spiritual Well-Being Total Scores (SWBS)* and *Empowerment/Independence Subscale Scores* in adults who experience intellectual and developmental disabilities.

Research question 1.4. What is the relationship between perceived spiritual well-being and social belonging in adults who experience intellectual and developmental disabilities?

Hypothesis 1.4: A significant positive relationship exists between perceived spiritual well-being and social belonging in adults who experience intellectual and developmental disabilities.

Correlation 1.4: A Pearson Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between *Spiritual*

Well-Being Scale Total Scores and *QOL.Q Social Belonging/Community Integration Subscale Scores*. Specifically, this correlation analysed the relationship between two variables: 1) participants' reported spiritual well-being and, 2) reported social belonging and community integration. The Pearson Product-Moment Correlation Coefficient produced a significant, positive correlation ($r = .361$, $r^2 = .13$, $p < .01$). The effect size produced a Pearson $r = .361$, which indicates a moderate correlation, and further suggests that as adults who experience intellectual and developmental disabilities' spiritual well-being increase so does their perception of social belonging and community integration. The value of r^2 (.13) indicates that 13% of the variability in adults who experience intellectual and developmental disabilities perceived social belonging and community integration is accounted for by their perceived spiritual well-being.

The hypothesis was accepted at $r = .361$, a level of significance of $p < .01$. A significant positive relationship exists between perceived spiritual well-being and social belonging in adults who experience intellectual and developmental disabilities. Figure 5.5 represents the linear relationship of the *SWBS Total Scores* and the *QOL.Q Social Belonging/Community Integration Subscale Scores*.

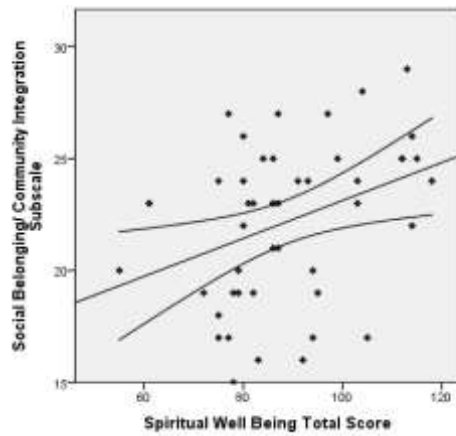


Figure 5.5. Linear relation between *Spiritual Well-Being Total Scores (SWBS)* and *Quality of Life, Social Belong/Community Integration Questionnaire Subscale Scores* in adults who experience intellectual and developmental disabilities.

Research question 1.5. What is the relationship between perceived religious well-being and quality of life in adults who experience intellectual and developmental disabilities?

Hypothesis 1.5: A significant positive relationship exists between perceived religious well-being and quality of life in adults who experience intellectual and developmental disabilities.

Correlation 1.5: A Pearson Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between *SWBS, Religious Well-Being Subscale Scores and the QOL.Q Total Scores*. Specifically, this correlation analysed the relationship between the two variables: 1) participants' reported self-perceptions of religious well-being and 2) reported self-perceptions of quality of life. The Pearson Product-Moment Correlation Coefficient produced no significant correlation ($r = .216$, $r^2 = .04$, $p > .05$). The hypothesis was rejected. Figure 5.6

represents the linear relationship of the *SWBS, Religious Well-Being Subscale Scores* and the *QOL.Q Total Scores*.

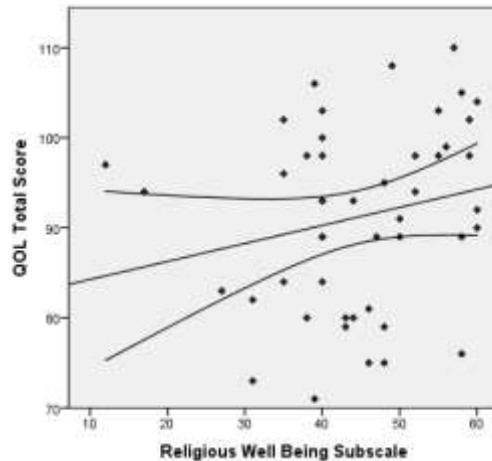


Figure 5.6 Linear relation between *SWBS, Religious Well-Being Subscale Scores* and *Quality of Life Total Scores* in adults who experience intellectual and developmental disabilities.

Research question 1.6. What is the relationship between perceived religious well-being and life satisfaction in adults who experience intellectual and developmental disabilities?

Hypothesis 1.6: A significant positive relationship exists between perceived religious well-being and life satisfaction in adults who experience intellectual and developmental disabilities.

Correlation 1.6: A Pearson Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between *SWBS, Religious Well-Being Subscale Scores* and the *QOL.Q Life Satisfaction Subscale Scores*. Specifically, this correlation analysed the relationship between two variables: 1)

participants' reported self-perceptions of religious well-being and 2) reported self-perceptions of life satisfaction. The Pearson Product-Moment Correlation Coefficient produced no significant correlation ($r = .047$, $r^2 = .002$, $p > .05$). The hypothesis was rejected. Figure 5.6 represents the linear relationship of the *SWBS, Religious Well-Being Subscale Scores* and the *QOL-Q, Life Satisfaction Subscale Scores*.

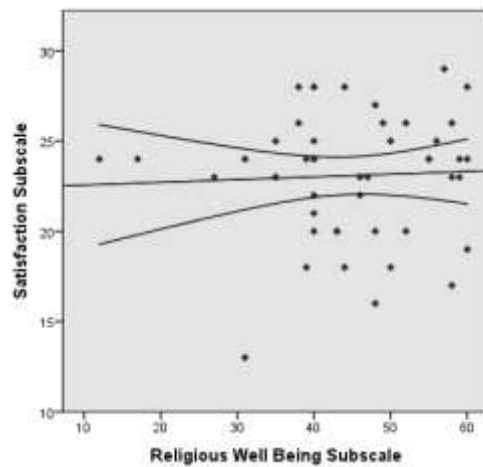


Figure 5.7 Linear relation between *SWBS, Religious Well-Being Subscale Scores* and *Quality of Life, Life Satisfaction Subscale Scores* in adults who experience intellectual and developmental disabilities.

Research question 1.7. What is the relationship between perceived religious well-being and social belonging in adults who experience intellectual and developmental disabilities?

Hypothesis 1.7: A significant positive relationship exists between perceived religious well-being and social belonging in adults who experience intellectual and developmental disabilities.

Correlation 1.7: Pearson's Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between the *SWBS, Religious Well-Being Subscale Scores* and the *QOL Social Belonging/Community Integration Subscale Scores*. Specifically, this correlation analysed the relationship between two variables: 1) participants' reported religious well-being and, 2) reported social belonging/community integration. The Pearson Product-Moment Correlation Coefficient produced a significant, positive correlation ($r = .268$, $r^2 = .07$, $p < .05$). The effect size produced a Pearson $r = .268$, which indicates a moderate correlation. This further suggests that as adults who experience intellectual and developmental disabilities' perceived religious well-being increases, so does their perceived social belonging/community integration increase. The value of r^2 (.07) indicates that 7% of the variability in adults who experience intellectual and developmental disabilities perceived social belonging/community integration is accounted for by their perceived religious well-being.

The hypothesis was accepted at $r = .268$, a level of significance of $p < .05$. A significant positive relationship exists between perceived religious well-being and social belonging in adults who experience intellectual and developmental disabilities. Figure 5.8 represents the linear relationship of the *Religious Well-Being Subscale Scores (SWBS)* and the *QOL.Q, Social Belonging/Community Integration Subscale Score*.

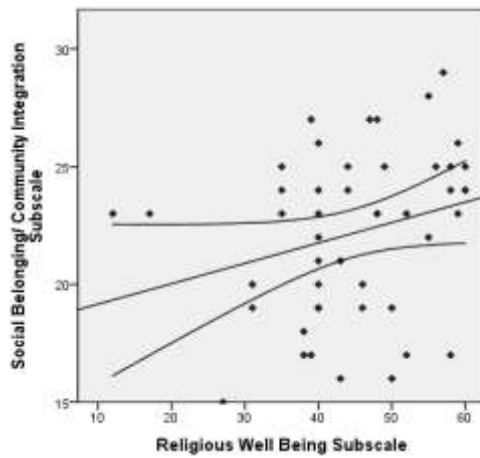


Figure 5.8. Linear relation between *Religious Well-Being Subscale Scores (SWBS)* and *Quality of Life Questionnaire, Social Belonging/Community Integration Subscale Scores* in adults who experience intellectual and developmental disabilities.

Research question 1.8. What is the relationship between perceived existential well-being and quality of life in adults who experience intellectual and developmental disabilities?

Hypothesis 1.8: A significant positive relationship exists between perceived existential well-being and quality of life in adults who experience intellectual and developmental disabilities.

Correlation 1.8: Pearson's Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between *SWBS, Existential Well-Being Subscale Scores* and *Quality of Life Total Scores*. Specifically, this correlation analysed the relationship between two variables: 1) participants' reported self-perceptions of existential well-being and, 2) reported self-perceptions of quality of life. The Pearson's Product-Moment Correlation Coefficient produced a significant, positive correlation ($r = .431$, $r^2 = .19$, $p < .01$). The effect size produced a

Pearson $r = .431$, which indicates a large correlation. This further suggests that as adults who experience intellectual and developmental disabilities' perceived existential well-being increases so does their perceived quality of life increase. The value of $r^2 (.19)$ indicates that 19% of the variability in adults who experience intellectual and developmental disabilities perceived quality of life is accounted for by their perceived existential well-being.

The hypothesis was accepted at $r = .431$, a level of significance of $p < .01$. A significant positive relationship exists between perceived existential well-being and quality of life in adults who experience intellectual and developmental disabilities. Figure 5.9 represents the linear relationship of the *Existential Well-Being Subscale Scores (SWBS)* and the *QOL.Q Total Scores*.

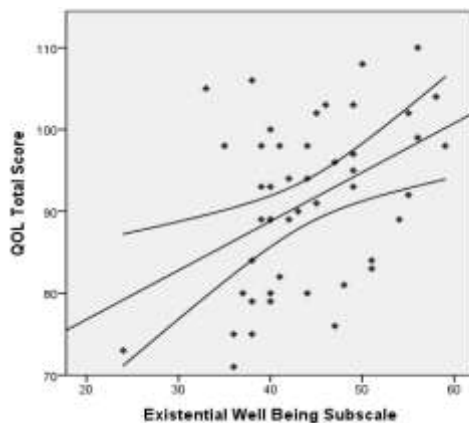


Figure 5.9. Linear relation between *Existential Well-Being Subscale Scores (SWBS)* and *Quality of Life Questionnaire Total Scores* in adults who experience intellectual and developmental disabilities.

Research question 1.9. What is the relationship between perceived existential well-being and life satisfaction in adults who experience intellectual and developmental disabilities?

Hypothesis 1.9: A significant positive relationship exists between perceived existential well-being and life satisfaction in adults who experience intellectual and developmental disabilities.

Correlation 1.9: A Pearson's Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between *SWBS, Existential Well-Being Subscale Scores* and *QOL Satisfaction Subscale Scores*. The correlation analysed the relationship between two variables: 1) participants' reported existential well-being and, 2) reported life satisfaction. The Pearson's Product-Moment Correlation Coefficient produced a significant, positive correlation ($r = .488$, $r^2 = .24$, $p < .01$). The effect size produced a Pearson $r = .488$, which indicates a large correlation. This further suggests that as adults who experience intellectual and developmental disabilities' perceived existential well-being increases so does their perceived life satisfaction. The value of r^2 (.24) indicates that 24% of the variability in adults who experience intellectual and developmental disabilities perceived life satisfaction is accounted by their perceived existential well-being.

The hypothesis was accepted at $r = .488$, a level of significance of $p < .01$. A significant positive relationship exists between perceived existential well-being and life satisfaction in adults who experience intellectual and developmental disabilities. Figure 5.10 represents the linear relationship of the *Existential Well-Being Subscale Scores (SWBS)* and the *QOL, Satisfaction Subscale Scores*.

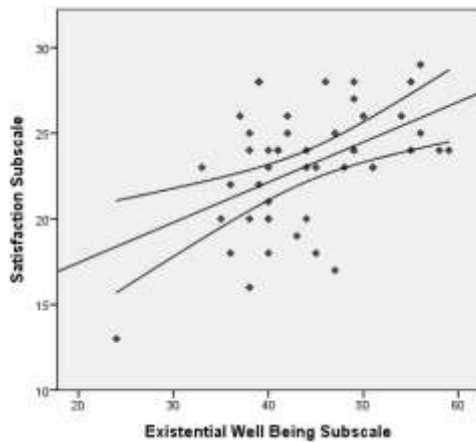


Figure 5.10. Linear relation between *SWBS*, *Existential Well-Being Subscale Scores* and *Quality of Life Questionnaire, Satisfaction Subscale Scores* in adults who experience intellectual and developmental disabilities.

Research question 1.10. What is the relationship between perceived existential well-being and social belonging in adults who experience intellectual and developmental disabilities?

Hypothesis 1.10: A significant positive relationship exists between perceived existential well-being and social belonging in adults who experience intellectual and developmental disabilities.

Correlation 1.10: A Pearson's Product-Moment Correlation Coefficient was calculated to determine the magnitude and direction of a correlation between *SWBS*, *Existential Well-Being Subscale Scores* and the *QOL Social Belonging/Community Integration Subscale Scores*. Specifically, this correlation analysed the relationship between two variables: 1) participants' reported existential well-being and, 2) reported social belonging and community integration. A Pearson Product-Moment Correlation Coefficient produced a significant, positive correlation ($r = .349$, $r^2 = .12$, $p < .01$). The

effect size produced a Pearson $r = .349$, which indicates a moderate correlation. This further suggests that as adults who experience intellectual and developmental disabilities' perceived existential well-being increases so does their perception of social belonging/community integration increase. The value of $r^2 (.12)$ indicates that 12% of the variability in adults who experience intellectual and developmental disabilities level of perceived social belonging/community integration is accounted for by their perceived existential well-being.

The hypothesis was accepted at $r = .349$, a level of significance of $p < .01$. A significant positive relationship exists between perceived existential well-being and social belonging in adults who experience intellectual and developmental disabilities. Figure 5.11 represents the linear relationship of the *Existential Well-Being Subscale Scores (SWBS)* and the *QOL-Q Social Belonging/Community Integration Subscale Scores*.

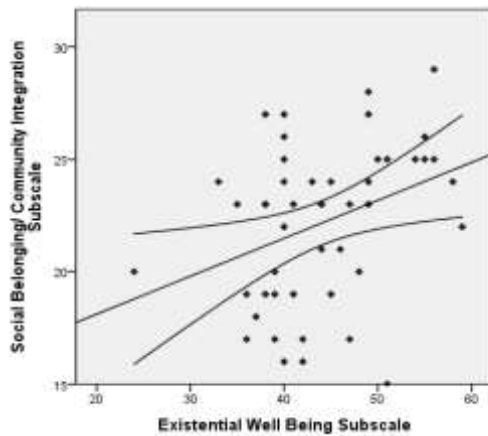


Figure 5.11. Linear relation between *SWBS, Existential Well-Being Subscale Scores* and *Quality of Life Questionnaire, Social Belonging Subscale Scores* in adults who experience intellectual and developmental disabilities.

Research question 2.0. What is the difference between males and females regarding perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities? Research question 2.0 was answered by the data collected from participant responses to the *Spiritual Well-Being Scales* and the *Quality of Life Questionnaire*. An independent *t-test* was utilised to establish whether the mean of two independent groups differ significantly (Field, 2005). Therefore, an independent *t-test* was used to explore if there were differences in the mean total scores of males and the mean total scores of females on the two instruments, the *Spiritual Well-Being Scales* and the *Quality of Life Questionnaire* used in this study.

The review of the literature suggested that gender differences play a role in perceptions of well-being in relation to health, work, social, leisure, and spiritual domains of life (Azevedo et al., 2007; Maselko & Kubzansky, 2006; Schumaker & Hill, 1991; Williams, 1989). Though the literature addresses differences in perceptions of well-being in a variety of populations, gender differences were not established in this area for the study population. This study sought to examine if there were gender differences in relation to perceptions of spiritual well-being and quality of life for adults who experience intellectual and developmental disabilities.

An independent *t-test* was conducted to answer research questions 2.1 and 2.2 which examine if there are mean differences in the total scores of males and total scores of females on the *Spiritual Well-Being Scale* and *Quality of Life Questionnaire*.

Research question 2.1. Is there a difference between *Spiritual Well-being Total Scores* of males and *Spiritual Well-being Total Scores* of females?

Hypothesis 2.1: A significant difference exists between *Spiritual Well-being Total Scores* of males and *Spiritual Well-being Total Scores* of females.

Independent t-test 2.1: An independent *t-test* analysed Group 1, males (n = 21) and Group 2, females (n = 26). An alpha value of $\alpha = .05$ was set. It was hypothesised that there was a difference in mean scores of perceived spiritual well-being in males and females. The independent *t-test* produced a $t(44.98) = -0.66, p = .51$. No significant difference of means existed between males and females. The hypothesis was rejected. The spiritual well-being of males ($M = 87.90, SD = 12.91$) and the spiritual well-being of females ($M = 90.73, SD = 16.42$) showed no difference. The *Box Plot* Figure 5.12 shows the distribution of group one, males and group two, females.

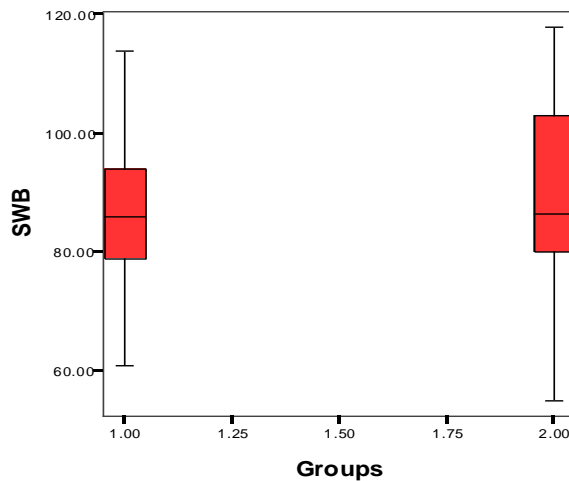


Figure 5.12. Box Plot, Group 1 and Group 2, Spiritual Well-being

Research question 2.2. Is there a difference between *Quality of Life Questionnaire Total Scores* of males and *Quality of Life Total Scores* of females?

Hypothesis 2.2: A significant difference exists between *Quality of Life Questionnaire Total Scores* of males and *Quality of Life Total Scores* of females.

Independent t-test 2.2: An independent *t-test* analysed Group 1, males (n = 21) and Group 2, females (n = 26). An alpha value of $\alpha = .05$ was set. It was hypothesised that there was a difference in mean scores of perceived quality of life of males and females. The independent *t-test* produced a $t(44.23) = 1.35, p = .18$. No significant difference in means existed between males and females. The hypothesis was rejected. The quality of life of males ($M = 92.95, SD = 8.25$) and the quality of life of females ($M = 89.00, SD = 11.76$) showed no difference. The *Box Plot* Figure 5.13 shows the distribution of group one, males and group two, females.

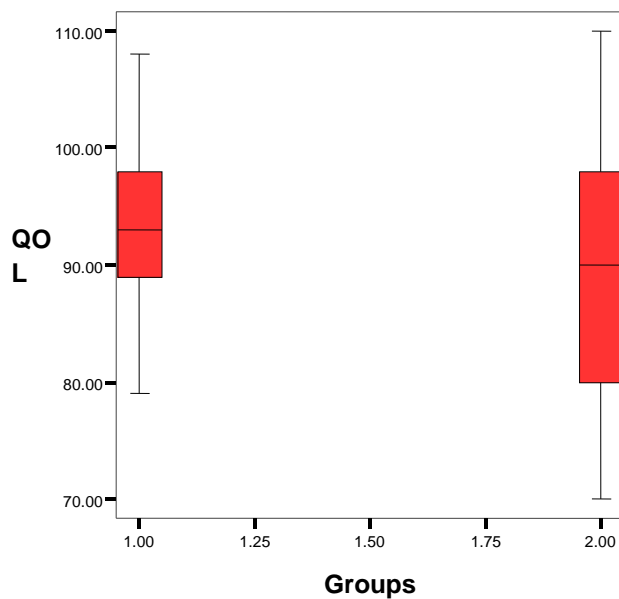


Figure 5.13. Box Plot, Group 1 and Group 2, Quality of Life

Research question 3.0. Is there a difference for individuals who experience intellectual and developmental disabilities in spiritual well-being and quality of life with different levels of support in living situations? An *Analysis of Variance (ANOVA)* test was utilised to explore this question. An ANOVA statistical analysis allowed the researcher to identify more than one independent variable, identified as the varying levels of support, and compare to the dependent variables, identified as the measurement of perceived spiritual well-being and quality of life scores on the standardised instruments utilised in this study.

The review of the literature suggested a significant role that services and supports play in the daily life of individuals who experience intellectual and developmental disabilities (Kozma et al., 2009; Powers & Sowers, 2006; Schalock et al.,

2008; Walker et al., 2011). Individuals who experience intellectual and developmental disabilities are often dependent upon others (paid and unpaid) to meet essential daily life needs across life domain areas. Therefore, the levels of support provided in relation to perceptions of spiritual well-being and quality of life were analysed in this study. As a result of the evolution of the service system within the State of Alaska, participants living situation service categories within an individual support plan, were not definitive of the levels of support (paid and unpaid) that a participant actually received in day-to-day life. This study categorised participants by levels of actual support provided within living situations. The three levels of identified supports within the study population were 24- hour supports, daily interim supports, and weekly intermittent supports. Level of support categories are representative of greatest to least levels of assistance needed in completion of activities of daily living of participants. Sub-research questions 3.1 and 3.2 examined the differences in levels of support and *Spiritual Well-being Total Scores*, and differences in levels of support and *Quality of Life Questionnaire Total Scores* through an analysis of the data.

Research question 3.1. Is there a difference in *Spiritual Well-being Total Scores* with different levels of support in living situations?

Hypothesis 3.1: A significant difference exists between *Spiritual Well-Being Total Scores* of participants with differing levels of support in living situations.

One-way, within subjects, ANOVA 3.1: A one-way, within subjects, analysis of variance (ANOVA) was calculated to compare the *Spiritual Well-Being Total Scores* for participants living within three different levels of support. The study gathered *Spiritual Well-being Total Scores* from participants living in situations receiving three variable

levels of support: 1) 24-hour supports (n = 14), 2) daily interim supports (n = 11), and weekly intermittent supports (n = 22). The mean *Spiritual Well-being Total Scores* for participants living in 24-hour support situations was M = 90.36. The mean *Spiritual Well-being Total Scores* for participants living in situations with daily interim supports was M = 85.91, and the mean *Spiritual Well-being Scores* for participants living in situations with weekly intermittent supports was M = 88.95. Table 5.9 provides central tendency and variance by levels of support, and Figure 4.11 provides a *Means Plot* of the three levels of support.

Table 5.9

Measure of central tendency and variability of spiritual well-being and levels of support

	<i>N</i>	Min - Max	Mean	Standard Deviation	Variance
24 - Hour	14	61 - 115	90.36	17.36	301.37
Daily Interim	11	61 - 114	85.91	14.69	215.80
Weekly Intermittent	22	55 - 118	88.95	14.12	199.37

n= 47

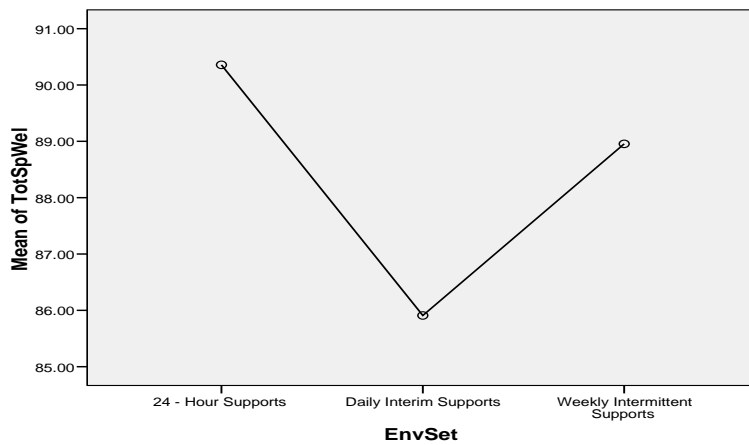


Figure 5.14. Means Plot of the three levels of support

A comparison of the *Spiritual Well-being Total Scores* for participants living within each level of support was conducted using a one-way, within subjects, analysis of variance (ANOVA). The hypothesis (H_1) stated that at least one mean differed from the others. A one-way, within subjects, ANOVA produced no significant difference. The hypothesis was rejected. No significant difference between means was found between 24-hour support ($n = 14$), daily interim supports ($n = 11$), and weekly intermittent supports ($n = 22$), $F(2, 44) = .269, p > .05$. Table 5.10 represents the ANOVA output.

Table 5.10

Differences in mean and three levels of support

Variable and Source	SS	MS	F - ratio	P (two-tail)
Between Groups	125.48	62.72	.269	.77
Within Groups	10267.08	233.34		

Note: $p > .05, N = 47$

Research question 3.2. Is there a difference in *Quality of Life Questionnaire Total Scores* with different levels of support in living situations?

Hypothesis 3.2: A significant difference exists between *Quality of Life Questionnaire Total Scores* of participants with differing levels of support in living situations.

One-way, within subjects, ANOVA 3.2: A one-way, within subjects, analysis of variance (ANOVA) was calculated to compare the *Quality of Life Questionnaire Total*

Scores for participants living within three different levels of support. The study gathered *Quality of Life Questionnaire Total Scores* from participants living in situations receiving three variable levels of support: 1) 24-hour supports (n = 14), 2) daily interim supports (n = 11), and weekly intermittent supports (n = 22). The mean *Quality of Life Questionnaire Total Scores* for participants living in 24-hour support situations was M = 95.00. The mean *Quality of Life Questionnaire Total Scores* for participants living in situations with daily interim supports was M = 90.73, and the mean *Quality of Life Questionnaire Total Scores* for participants living in situations with weekly intermittent supports was M = 89.50. Table 5.11 provides central tendency and variance by levels of support, and Figure 5.15 provides a *Means Plot* of the three levels of support.

Table 5.11

Measure of central tendency and variability of spiritual well-being and levels of support

	<i>N</i>	Min - Max	Mean	Standard Deviation	Variance
24 – Hour	14	76 - 110	95.00	9.78	95.65
Daily Interim	11	71 - 103	90.73	10.90	118.81
Weekly Intermittent	22	73 - 105	89.50	9/56	91.39

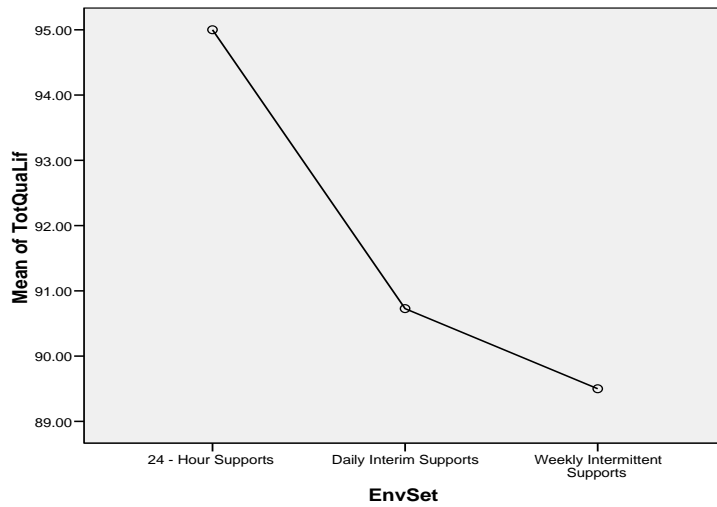


Figure 5.15 Means Plot of the three levels of support

A comparison of the *Quality of Life Questionnaire Total Scores* for participants living within each level of support was conducted using a one-way, within subjects, analysis of variance (ANOVA). The hypothesis (H_1) stated that at least one mean differed from the others. A one-way, within subjects, ANOVA produced no significant difference. The hypothesis was rejected. No significant difference between means was found between 24-hour support ($n = 14$), daily interim supports ($n = 11$), and weekly intermittent supports ($n = 22$), $F(2, 44) = 1.34, p > .05$. Table 5.12 represents the ANOVA output.

Table 5.12

Differences in mean and three levels of support

Variable and Source	SS	MS	F - ratio	P (two-tail)
Between Groups	265.81	132.90	1.34	.27
Within Groups	4349.68	98.86		

Note: $p > .05$, N = 47

Summary of Quantitative Phase Findings

The primary purpose of this study was to explore and describe how adults who experience intellectual and developmental disabilities perceive the significance of their spiritual well-being in relation to their quality of life. The quantitative phase of this chapter presented analyses of data (N = 47) utilising the statistical models of correlation, independent *t* test, and advanced analysis of variance (ANOVA) collected from 47 adult individuals who experience intellectual and developmental disabilities living in Alaska.

The correlation analyses examined the nature and magnitude of relationship between perceived spiritual well-being and quality of life utilising the *Spiritual Well-Being Scales* (Paloutzian & Ellison, 1991) and the *Quality of Life Questionnaire* (Schalock & Keith, 2004). A total of eleven correlations were conducted. With the *Quality of Life Questionnaire*, data from *QOL.Q Total* scores along with four subscales were analysed. With the *Spiritual Well-Being Scale*, data from the *SWBS Total* scores and two subscales were analysed. Analyses of seven of the eleven correlations produced significant positive relationships between perceptions of spiritual well-being

and quality of life. These significant, positive correlations indicated that overall perceptions of quality of life in adults who experience intellectual and developmental disabilities increased as perceptions of spiritual well-being increased. More specifically, the data analyses indicated that within these two variables a significant positive relationship exists between perceived:

- *Spiritual well-being and quality of life* in adults who experience intellectual and developmental disabilities (moderate effect size).
- *Spiritual well-being and life satisfaction* in adults who experience intellectual and developmental disabilities (moderate effect size).
- *Spiritual well-being and social belonging* in adults who experience intellectual and developmental disabilities (moderate effect size).
- *Religious well-being and social belonging* in adults who experience intellectual and developmental disabilities (moderate effect size).
- *Existential well-being and quality of life* in adults who experience intellectual and developmental disabilities (large effect size).
- *Existential well-being and life satisfaction* in adults who experience intellectual and developmental disabilities (large effect size).
- *Existential well-being and social belonging* in adults who experience intellectual and developmental disabilities (moderate effect size).

A significant relationship did not appear to exist between perceived *spiritual well-being* and *competency/productivity*; *spiritual well-being* and *empowerment/independence*; *religious well-being* and *quality of life*; and *religious well-being* and *life satisfaction*.

An independent *t-test* and ANOVA analyses were conducted regarding *Spiritual Well-being Total Scores* and *Quality of Life Questionnaire Total Scores* for gender differences and levels of support in living situations. However, findings revealed no significant differences between scores based upon gender or levels of support within living situations. The quantitative phase of the study examined “what” the relationship was between the two variables and revealed a significant positive relationship in seven dimensions of spiritual well-being and quality of life. The next phase of the study examined *how* participants understand and describe the relationship of these seven dimensions of spiritual well-being and quality of life through a qualitative methodology, providing a more complete picture to the overall research aim. The qualitative methodology utilised unstructured interviews, participant observation, and document reviews. The qualitative data analysis and findings are presented in chapter six.

Chapter 6

Qualitative Phase Data Analysis and Findings

Qualitative Phase of Study

The qualitative section of this chapter describes the findings of the first phase of this study, providing evidence of a significant positive relationship between perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities. To further explain the quantitative findings, a qualitative approach was utilised. The qualitative section of this chapter describes the results of phase two of the study. The primary research question that directed the qualitative phase of the study is presented below:

Research question 4.0: How do adults who experience intellectual and developmental disabilities understand and describe the importance of a spiritual dimension of life to other aspects of life? The qualitative phase of this study adds depth and breadth to understanding the significant positive relationship found in the quantitative component, between spiritual well-being and quality of life in the study population. The qualitative phase focused on the following generalised areas in an iterative process of exploration with key participants:

- 1) How do adults who experience intellectual and developmental disabilities describe their own spirituality?
- 2) What role does spirituality play in understanding life experiences for adult individuals who experience intellectual and developmental disabilities?
- 3) What are the spiritual support needs of adult individuals who experience intellectual and developmental disabilities?

- 4) What values, beliefs, and behaviours do adults who experience intellectual and developmental disabilities ascribe to a spiritual dimension of their life?

Research question 4.0 was answered from data collected in the qualitative phase with participants. Data collection connected with the second phase of the study occurred over the course of six months from June 2012 – November 2012. Again, the intent of phase two of this study was to gather additional data that was not a part of the information gathered using the standardised instruments in phase one of the study. The qualitative phase focused on providing additional data adding further context to the dimensions where a significant positive relationship was found to exist between spiritual well-being and quality of life in the quantitative phase of the study.

Unstructured interviews, participant observations and document reviews were utilised to acquire first person accounts of self-perceptions of personal beliefs, experiences, and relevancy of spirituality in the participant's life. After a description of the qualitative sample, the researcher presents an overview of the sample communities and key participants in phase two. The researcher then describes the data collection processes, provides a presentation of the emergent themes and the data analysis. The section closes with a summary discussion of the qualitative findings.

Qualitative sample. Based upon the quantitative findings and researcher intention to assure a study sample that represented a diverse range of information, the following criteria were used to select the qualitative sample: 1) participants' geographic location; 2) participants' ability to generate information rich data resultant of participants' level of involvement across community and spiritual activities, or events; and 3) participants' availability and willingness to share personal thoughts, feelings, and

life experiences over a period of time. Researcher time, expense, and ability to travel to a community for extended periods of time was also a factor of consideration in final participant selection. Researcher was intentional in identifying key participants who resided in both rural and urban areas of the State of Alaska.

These criteria were selected because Alaska has a variety of cultures within the different geographic regions that experience unique characteristics influencing daily life. The second and third criteria were selected to assure that key participants were individuals who had varied experiences of participation in community and spiritual activities and events and were willing to share thoughts and feelings of these experiences with the researcher over time. The researcher sought in the qualitative phase to obtain a cross-section representation of the original study participants that could provide further explanation to the quantitative results.

Description of communities of qualitative phase key participants. The quantitative sample included participants from nine different communities across three of the five regional areas within Alaska. The qualitative phase sought to select key participants from both urban and rural communities who were representative of the larger sample population. The researcher selected three rural communities and one urban community located within Southeast, Southwest, and Southcentral regions of Alaska. The original study sample did not contain participants who resided in the Northern or Western regions of Alaska. The specific communities selected are referenced by their respective regional area name in an effort to further maintain the confidentiality of participants. General community descriptions are provided to

facilitate a contextual understanding of participant responses and experiences associated with the study topic. Participant community descriptions are as follows:

Southcentral (a) community. An urban community on the Alaska road system with a population just under 300,000 of the 732,000 total population in the State of Alaska. In terms of geography and population density, there are approximately 171 people per square mile. The community can be accessed via the road system, plane, or boat. The racial make-up of the community is reported to be approximately 68% White, 6% Black, 8% Alaska Native/American Indian, 8% Asian, and 2% Native Hawaiian/Pacific Islander, and 8% Hispanic/Latino (U.S. Census Bureau; Department of Commerce). In terms of community population ages, 7 % of the population was below the age of 5; 26% was under the age of 18; 59 % was between the ages of 19 and 64; and, 8% were over the age of 65 years old. The median household income was approximately \$75,000 with 8% of the population represented below the poverty level. In terms of community education level, 92% of adults 25 years and older achieved High School diplomas or higher and 32% of adults 25 years and older achieved Bachelor's degree or higher. As of 2012, there are 344 places of worship in the community, essentially 1 church to every 872 persons (Yellow Pages Group, 2012).

Southcentral (b) community. Southcentral (b) community is a rural community on the Alaska road system with a population of approximately 7,300. In terms of geography and population density, there are approximately 248 people per square mile. The community is accessed by road, boat, or plane. The racial make-up of the community is reported to be approximately 80% White, less than 1% Black, 9% Alaska Native/American Indian, 1% Asian, less than 1% Native Hawaiian/Pacific Islander, 5%

Hispanic/Latino, and 3% multi-racial (U.S. Census Bureau; Department of Commerce). In terms of community population ages, 8 % of the population was below the age of 5; 28% was under the age of 18; 54 % was between the ages of 19 and 64; and, 10% were over the age of 65 years old. The median household income was approximately \$57,000 with 12% of the population represented below the poverty level. In terms of community education level, 92% of adults 25 years and older achieved High School diplomas or higher, and 18% of adults 25 years and older achieved Bachelor's degree or higher. There are approximately 46 places of worship in the community, essentially 1 church to every 158 persons (Yellow Pages Group, 2012).

Southeast community. Southeast community is a rural community with a population of approximately 32,000. In terms of geography and population density, there are approximately 11 people per square mile. The community is accessed only by plane or boat. The racial make-up of the community is reported to be approximately 70% White, less than 1% Black, 12% Alaska Native/American Indian, 6% Asian, less than 1% Native Hawaiian/Pacific Islander, 5% Hispanic/Latino, and 5% multi-racial (U.S. Census Bureau; Department of Commerce, 2011). In terms of community population age, 6 % of the population was below the age of 5; 24% was under the age of 18; 62 % was between the ages of 19 and 64; and, 8% were over the age of 65 years old. The median household income was approximately \$77,000 with 6% of the population represented below the poverty level. In terms of community education level, 96% of adults 25 years and older achieved High School diplomas or higher, and 36% of adults 25 years and older achieved Bachelor's degree or higher. There are approximately 82

places of worship in the community, essentially 1 church to every 402 persons (Yellow Pages Group, 2012).

Southwestern community. Southwestern community is a rural Island community with a population of approximately 6,300. In terms of geography and population density, there are approximately 1,758 people per square mile. The community is accessed by boat or plane. The racial make-up of the community is reported to be approximately 40% White, less than 1% Black, 10% Alaska Native/American Indian, 37% Asian, 1% Native Hawaiian/Pacific Islander, 9% Hispanic/Latino, and 2% multi-racial (U.S. Census Bureau; Department of Commerce). In terms of community population ages, 8% of the population was below the age of 5; 27% was under the age of 18; 56% was between the ages of 19 and 64; and, 9% were over the age of 65 years old. The median household income was approximately \$59,000 with 15% of the population represented below the poverty level. In terms of community education level, 89% of adults 25 years and older achieved High School diplomas or higher, and 24% of adults 25 years and older achieved Bachelor's degree or higher. There are approximately 43 places of worship in the community, essentially 1 church to every 146 persons (Yellow Pages Group, 2012).

Description of qualitative participant sample. Fifteen participants, or 30% of the original study sample were selected by the researcher as a cross-representation to participate in phase two of the study. Each of the fifteen participants were asked by the researcher in a face-to-face conversation as to their willingness to participate further in the study by sharing more of their thoughts and feelings associated with the research topic and allow the researcher to spend time with them over a period of time in learning

more about their views of the topic. Participants were reminded that their participation was voluntary, information shared would be treated as confidential, and that a participant could decide to discontinue participation at any time. Verbal consent was received from all fifteen participants and recorded in the researcher's field notes. The researcher was intentional about not having additional forms signed during the qualitative phase of the study in order to facilitate relationship building and encourage the natural flow of conversations. Even though no one declined to participate initially, informed consent was treated as an ongoing, emergent process throughout phase two of the study and was approached each time the researcher spent time with a participant.

Seven of the participants were from an urban area, that is Southcentral (a) community and eight participants were from a rural area. Of the eight participants from a rural area; four were from Southcentral (b) community, two from Southeast community, and two from Southwest community. The age range of the fifteen participants was from 25 – 63 years old. There were twelve females and three males. Gender was not a criterion for selection in the qualitative phase as there were no differences in scores based upon genders noted in the quantitative phase. In terms of educational background, all fifteen participants were enrolled in Special Education programs throughout primary and secondary grades in completing High School. Two of the fifteen participants had participated in some college courses beyond High School. None of the fifteen participants had completed a college degree. In terms of income levels, all fifteen participants qualified for State and Federal public assistance funding and were represented in each of the community population of citizens who fell below the poverty level. Thirteen of the participants were single and had never been married.

Two of the participants were currently single but had been married in the past. The religious affiliation of the fifteen participants were as follows: one reported to be Atheist; one reported to be Christian, Church of God; one reported to be Christian, Methodist; and eight reported to be Christian without a particular affiliation.

All fifteen participants experienced intellectual and developmental disabilities with many of the participants experiencing multiple co-occurring disabilities and or health related challenges. A general summary of participants' profiles are provided for additional personal contextual information of individual responses during the qualitative phase. Only a general age range verses a specific age is provided in summary profiles for purposes of confidentiality. Each participant was assigned a code number (P1 – P15) in respect to the confidentiality of each participant. The code itself has no relationship to the participant or the order in which participants were interviewed.

Participant profile 1 (P1). P1 was a 35 – 45 year old female who resided in South central (a) community. She lived in a small two bedroom apartment in the community and received weekly intermittent supports. In addition to experiencing an intellectual and developmental disability, P1 experienced both mental and physical health related challenges. Some of these challenges resulted in chronic pain, which she experienced on a daily basis. These challenges periodically placed her independent lifestyle at risk, resulting in P1 focusing considerable personal effort on the maintenance of her health. P1 enjoyed spending time, talking and laughing with people that she trusted. She had a small circle of peers that she considered her friends. She reported to rely on these friends during difficult times in her life. She came from a tumultuous family background and struggled with her familial relationships. Though familial

relationships often caused her stress, she made repeated efforts to stay connected to family. She demonstrated a wonderful sense of humour and readily engaged in conversation about her interests. P1 loved animals, and had two dogs and two cats that she cared about deeply. She participated in a theatre club and liked to volunteer within a variety of community settings. She was viewed by others as a strong advocate for both herself and others who she saw in need of assistance. In terms of her religious preference, P1 shared that she went to church from time-to-time but, described that she “struggles in fitting in.” She reported to be unsure of any personal benefits experienced from times that she went to church. When she did go, she attended a local Christian congregation in her neighbourhood.

Participant profile 2 (P2). P2 was a 55 – 65 year old female who resided in South central (a) community. She lived in a ranch style fully accessible home with three other women and received 24 hours a day, seven days a week of support. In addition to experiencing an intellectual and developmental disability, P2 experienced significant mental and physical health related challenges. P2 was undergoing cancer treatment throughout the course of this study. Despite her need for significant physical assistance in all life areas, she was an active member in her community and operated her own business selling baked goods and craft items. She participated regularly in the arts and theatre community, loved to shop, travel, and socially entertain people in her home. P2 had a significant network of friends and family with which she routinely socialised. She had been married at one time and shared her experiences of a troubled marriage relationship in which she felt taken for granted. She reported that the marriage ended, by her choice, in divorce. Despite the negative marriage experience, she continued to

express her desire to find “Mr. Right.” P2 demonstrated a zest for life and love for animals (particularly dogs), music and the movies. She did not have a dog of her own, however, she frequently encouraged others to bring their pets over to her home to visit. P2 related well to the pain and suffering of others and identified specific social causes within the community that were important to her that she personally invested her time, talent and money. She displayed a kind and generous demeanour. In terms of her religious preference, P2 professed to be “Christian” and affiliated with the Baptist church. She stated on several occasions that she “loves the Lord.” P2 participated regularly in weekly services at a large Baptist church in her neighbourhood and she frequently participated in religious services and activities with her friends at their places of worship. Sadly, P2 passed away from her cancer as this study was coming to completion.

Participant profile 3 (P3). P3 was a 55 – 65 year old female who resided in South central (a) community. She lived in a ranch-style fully accessible home with a housemate and received 24 hours a day, seven days a week of support. In addition to experiencing an intellectual and developmental disability, P3 experienced significant mental and physical health related challenges. These health related challenges resulted in multiple weekly medical treatments and close monitoring on a daily basis. She had participated in end-of-life planning sessions with people who were important to her and had personal advanced directives in place. P3 had worked for many years at a Bookstore until her health no longer allowed her to remain employed. She loved music, crafts, and creating things on the computer. P3 loved animals, had a dog and cat of her own and viewed her pets as part of her family. She had some connection with

extended family that lives out-of-State, however, her primary circle of support was staff, a few close strong friendships, her Pastor and those with whom she attended Church. P3 enjoyed people and emanated a kind, generous, and open nature. She loved to share and give gifts to others. P3 stated that she was a “Christian” and a member of the “Church of God.” P3 reported that attending church was the “highlight of each week.”

Participant profile 4 (P4). P4 was a 25 – 35 year old male who lived in South central (a) community. P4 lived in a one bedroom fully accessible apartment with staff support 24 hours a day, seven days per week. He experienced an intellectual and developmental disability and significant visual and physical challenges. His significant physical challenges resulted in a recent surgery requiring a minimum of 12 months for recovery. Up until his surgery, P4 was a very active person and stayed involved in his community, in work related activities, and in his church. He had taken some college courses but, due to his ongoing health issues he placed his academics on hold. P4 was very close to his family and routinely connected with them and travelled to visit them on major holidays. He enjoyed helping others and looked for opportunities where he could be of assistance to people who were in need. P4 was a proud man who was goal-oriented and spent a great deal of time outlining the steps needed for his future. He dreamed of one day owning his own home and his own business, and was intentional about incorporating others who could assist him to this end. He strongly desired to find a long lasting relationship that would result in marriage and a family of his own one day. In terms of his religious preference P4 described himself as a “Christian” but, did not affiliate himself with a particular denomination. He shared that he looks for a church congregation where the people treat him “like family.”

Participant profile 5 (P5). P5 was a 35 – 45 year old male who resided in South central (a) community. He lived in a small one bedroom apartment and received weekly intermittent supports. P5 experienced an intellectual and developmental disability along with some mental health challenges. He was a very active and artistic person who enjoyed practicing his craft. He worked for a retail company in the community but desired to own his own business some day. He enjoyed all kinds of technology and used it at times to make friends. P5 enjoyed being with people and looked for sharing time with people who had similar interests as his own. He was close to his family and viewed them as supportive and helpful to him in making decisions regarding his life. People had not always been kind in interacting with him and he remained sensitive to negative or hurtful comments that others might make. During challenging times he would seek out support of those close to him. In terms of his religious preference, P5 stated that he was “Methodist” and attended church from time-to-time with his family but, generally did not participate in other activities connected with the church.

Participant profile 6 (P6). P6 was a 25 – 35 year old male who resided in South central (a) community. He lived in a home that he shared with a housemate and had 24 hour staff support, seven days per week. In addition to experiencing an intellectual and developmental disability, he experienced significant mental health challenges. He struggled with negative thoughts and feelings that left him often feeling depressed. He was single but, had been married in the past and had one child. As a result of ongoing relationship challenges, the child was given-up for adoption. Even though P6 voiced that he believed that adoption was the best option for his child, he shared his desire to stay connected, and he continued to be involved in the child’s life. P6 had a job with an

organisation working with computers. He reported that his job was very important to him and that he wanted to do well in his work. He reported that he does not have any college but he expressed a desire to go to college some day. He shared that he had only a few friends and found it difficult to meet new people. He expressed a desire to develop more friendships but, shared that he had to “trust a person first” before he would talk to someone. He further reported that he was a very “private person” who does not go out often to meet people. In terms of his religious preference, P6 relayed that he was a “Christian” and saw himself as “a very spiritual person”.

Participant profile 7 (P7). P7 was a 25 – 35 year old female who resided in South central (a) community. She lived in a small one bedroom accessible apartment of her own and received daily interim supports. She experienced an intellectual and developmental disability with some associated physical health issues. She was an optimistic, friendly person who enjoyed socialising with others. She displayed a wonderful sense of humour and strong communication skills. She described herself as a strong willed person who insisted on making her own decisions regarding her medical and health related needs. Though she required significant physical assistance to complete activities of daily living, she demanded maximum independence in planning and decision-making regarding where she went, what she ate, what she wore, and who she associated with. She wanted decisions about her life to be of her own choosing and was clear about this with others. She often volunteered in the community, participated in recreational and craft activities, and was active with her church. She had a close circle of friends and stayed in close contact with her family. In terms of a religious preference, she voiced that she was “raised Christian Baptist” and that the church had

always been important to her and her family's life. She regularly attended worship services and fellowship activities connected with a large Baptist congregation in her community.

Participant profile 8 (P8). P8 was a 45 – 55 year old female who resided in South central (b) community. She lived in a one bedroom apartment of a large building complex and received weekly intermittent supports. She reported to have recently moved into her apartment and voiced a pride about finally having a “place of her own.” P8 voiced that she “feels safe” at her new apartment and shared that this had not always been the case at places she had lived in the past. In addition to her intellectual and developmental disabilities, she experienced chronic health issues that required special assistance to manage effectively. She displayed a friendly demeanour and maintained a very active social calendar. She was involved weekly with volunteer activities at two different community establishments, worked two days a week for a local retail shop and participated regularly in a variety of recreational and social activities in the community. She had an extended circle of social support comprised of her friends, family, and a variety of community members she affiliated with regularly. In terms of her religious preference, P8 reported to be “Christian,” and to attend church services regularly at a church that she had been a member of for many years. She also noted that she went from time-to-time to different churches with her friends, and especially enjoyed being a part of various fellowship activities when she could get a ride to these activities.

Participant profile 9 (P9). P9 was a 25 – 35 year old female who resided in South central (b) community. She resided in her family home and received 24 hours per day, 7 days per week support. She experienced an intellectual and developmental

disability and significant health issues that frequently placed her life at risk. She was reliant on medical technology and physical assistance in all activities of daily living. P9 expressed that she was a strong willed individual who clearly expressed verbally her wants, needs and opinions regarding matters that affected her life. She readily voiced her desire to be acknowledged for the strengths and abilities that she possessed, and became frustrated when she believed others judged and limited her based upon her physical disabilities. She loved animals and had a variety of pets that lived with her in the family home. She interacted with the animals regularly and shared that her pets are important to her. She viewed herself as an animal rights activist and frequently assisted in rescue animal situations. She attended a local college; and was working towards the completion of a degree. She liked socialising with others and had a strong circle of friends and family from which she received extensive social support. In terms of religious preference, P9 reported that she was an “Atheist.” Regarding spirituality, P9 expressed that “I see myself as a very spiritual person, though I do not believe in God...you do not have to believe in a god to be spiritual.”

Participant profile 10 (P10). P10 was a 55 – 65 year old female who resided in South central (b) community. She resided in her own home which she shared with one housemate and received weekly intermittent supports. She experienced intellectual and developmental disabilities, and significant mental and physical health related issues that at times required an increase to her weekly support needs. She spent a great deal of time and effort managing her mental and physical health related needs. These needs challenged her in all life respects making it very difficult for her to maintain any kind of employment over the years. P10 reported a challenging family history resulting in a

largely estranged relationship without any significant family connection. She also reported a history of abuse and victimisation throughout her life; she had a hard time sharing with others. She related experiencing prolonged times where she socially isolated herself to protect herself and her feelings. She did have a few close friends for which she trusted and spent most of her time. P10 related she enjoyed animals and had two cats that she considered to be great companions. She expressed that she preferred staying home and relaxing to most any other type of activity. In terms of her religious preference, she reported to be “Christian” though she did not specifically affiliate with any particular group. She reported to attend a local Christian church in her community and stated that she believes that her spiritual life is important to her.

Participant profile 11 (P11). P11 was a 55 – 65 year old female who resided in South central (b) community. She lived in a ranch-style fully accessible home which she shared with two other housemates and received 24 hours per day, seven days per week support. P11 experienced intellectual and developmental disabilities that had significant associated physical health issues. She reported that her physical health issues weighed heavy on her mind as she feared losing some of her independence as she physically continued to deteriorate. Most importantly, she expressed that she was at risk of “losing her voice.” She considered herself a staunch advocate for people with disabilities and a general educator to the public. She had spent much of her time to help increase people’s awareness of the needs of people with disabilities. P11 shared that she liked reading and writing and working on her computer. She had a social support group of friends with which she reported to enjoy spending time. In addition, she enjoyed going to the movies, shopping, and volunteering in the community. In

terms of her religious preference, she proclaimed to be a “Christian” and affiliated with a local Baptist group. She relayed that her spirituality was one of the most important areas in her life. She attended church services and Bible studies weekly.

Participant profile 12 (P12). P12 was a 45 – 55 year old female who resided in Southeast community. P12 lived in a home with three other housemates and received 24 hours per day, seven days per week support. In addition to her intellectual and developmental disabilities she experienced significant mental and physical health related issues. She currently struggled with the passing away of a parent with whom she was very close. She reported this as a significant loss in her life that she needed help with adjusting. She volunteered at a local community organisation, and spent leisure time with friends and other family members as often as possible. She voiced a desire to someday have a “place of her own;” however, she relayed that she worried that she might be lonely if she were on her own. She enjoyed “helping people” and believed that this was her purpose in life. In terms of her religious preference, she stated that she was baptised in her early years and was a “Christian.” P12 reported to have attended the same local Christian church in her community for the majority of her life.

Participant profile 13 (P13). P13 was a 25 – 35 year old female who resided in Southeast community. She lived in a two bedroom apartment of her own in the community and received 24 hours per day, seven days per week support. She experienced an intellectual and developmental disability along with significant physical health issues. She required assistance with all activities of daily living. She was currently single and lived alone; however, she dreamed of getting married one day and did have a significant relationship in her life. She expressed a great deal of excitement

about the possibilities of her future. She was a warm and friendly person who openly shared her thoughts, feelings, and desires. She had a significant circle of social support between friends, family, and community members that she routinely associated with. She expressed her enjoyment of a variety of recreational, volunteer, and social activities that kept her busy throughout each week. She purported to love children and animals. She had a dog who she expressed provided her with significant companionship. In terms of her religious preferences, P13 stated that she was “Christian” but, was not currently affiliated with any one church group. She had attended church services at a variety of places over the years, and noted that she and her boyfriend intended to select a place to attend together that they both feel comfortable attending.

Participant profile 14 (P14). P14 was a 25 – 35 year old female who resided in Southwest community. She lived by herself in a two bedroom apartment within a large complex and received weekly intermittent support. In addition to her intellectual and developmental disabilities, she experienced significant mental health related issues. P14 was friendly and reported to enjoy socialising with others. She also professed to be somewhat of “a private person” and was careful with whom she shared information. She voiced that she does not like talking about “private things” in front of others. She had a strong circle of social support, and very much enjoyed spending time with her friends and family. However, she admitted that she did not always choose “good” people to hang around. She relayed that this sometimes got her into trouble. P14 noted that she has struggled in the past with various addictions, but expressed she did better when she “stays busy.” P14 relayed that she tried to be kind and helpful to others. She believed that she does help people and reported to seek out ways to make people’s life

better. She relayed that she enjoyed the out-of-doors, recreation and fishing activities and participated in these as often as she could. In terms of religious preference, P14 relayed that she was “Christian” but, participates in a variety of different church groups. She reported that she did not like to go to just one church but will select where to go depending on how she “feels at the time.” She noted that churches are all different and that she liked learning about their differences. She stated that she does not see “different as right or wrong, (pause) just different.”

Participant profile 15 (P15). P15 was a 55 – 65 year old female who resided in Southwest community. She lived on her own in a small two bedroom apartment within a larger complex and received weekly intermittent support. She experienced an intellectual and developmental disability but, otherwise enjoyed relatively good health. She voiced pride in her apartment and demonstrated a great deal of effort to maintain a well-kept home environment. P15 reported maintaining good relationships with her family and visited with them often. She enjoyed working with children and volunteered in the community in helping children learn new skills. P15 reported that she enjoyed going for walks and exercising regularly. She loved animals and had a dog, which she reported to be a great companion. She liked to go out and walk her dog each day around the neighbourhood. In terms of religious preference, P15 stated that she was a “Christian” and attended worship services at a local “Assembly of God” church.

Qualitative data collection process. The qualitative phase utilised unstructured in-depth inquiry, participant observations, and document reviews carried out by the researcher between June 2012 – November 2012. Interviews were conducted with the aid of an interview guide or *aide memoire* (Note: the *aide memoire* can be found in

Appendix F) and an interview schedule (Note: the interview schedule can be found in Appendix G). Both of these items were treated by the researcher as a general guide that were subject to revision, allowing the researcher to be consistent yet, flexible in interactions with participants throughout the qualitative phase.

Document reviews consisted primarily of an examination of participants' individual support plans, and documents received by participants from various community events where participants were involved. Participants' individual support plans were examined in conjunction with initial participants' encounters and referred back to periodically over the course of the qualitative phase. Planning staff from an agency wrote individual support plans with input from support teams. Each individual support plan contained a personalised snapshot of a participant's life with such information as: 1) participant's functioning levels across life domain areas, 2) description of participant's levels of support and types of services received, 3) level of involvement of family and other natural supports in a participants' life, 4) participant's religious and spiritual preferences, 5) participant's likes and dislikes, and 6) participant's desired life outcomes. An examination of participants' individual support plans provided the religious preference of an individual; this document contained little if any additional substantive information regarding the spiritual life and needs of a participant. In addition to plan document reviews, the researcher examined ancillary documents received from participants' participation in community events, and from religious and spiritual gatherings attended. Ancillary documents included religious documents, brochures and pamphlets, community event flyers, and personal participant papers. As an example, one participant shared with the researcher a certificate of

membership associated with the participant's faith group. This document was dated the day that the participant joined the faith group and acknowledged the participant's membership status with the group. In addition, this personal document included the central tenets by which members of the faith group strived to live their lives.

Participant interviews and observations occurred simultaneously in four separate rounds within each community of one to eight hour blocks of direct time with a participant across the six-month period. The researcher spent a total of 616 hours of direct time with participants in the sample population. The researcher was intentional in creating a variable time schedule with participants to capture diverse life events that occurred across different days of the week and hours of the day. Life events were inclusive of but not limited to such events as meal times, birthday celebrations, neighbourhood walks, volunteer activities, work opportunities, religious events, community events, medical treatments, and end-of-life moments. Participant interviews and observations across a span of time, offered the opportunity for an increasing level of intimacy in the context of relationship and dialogue. Each interview round with a participant built upon the previous. This process allowed the researcher to acquire a greater level of response from a participant and facilitated understanding and development of future themes.

All interview and observation data were recorded in written interview and field notes, and then entered into an electronic database called *Dedoose*©. Field notes consisted of detailed written textual accounts of what was seen and heard at both the community and individual level during participant encounters. Initial jottings, or scratch notes were written in the field during the course of a participant encounter to

capture exact words or details in the moment. Immediately following a participant field experience, a detailed written textual description of the interview, observations, and experience was documented. Memoing was utilised to capture researcher thoughts and reflections in the field notes (Miles & Huberman, 1984). This strategy allowed the researcher to record reflective thoughts and ideas in a field note connected with a participant experience beyond what a code was able to capture. Additionally, the researcher utilised a form of *bracketing* to identify and set aside personal bias and preconception during the field experience (Kvale & Brinkman, 2009). Bracketed information was revisited during the interpretation phase of the study.

Once data was entered into the electronic database, data was coded and organised into themes and sub-themes. On open-coding, line-by-line review process was utilised to identify initial concepts within the raw data. The researcher frequently checked-in with participants regarding consistency of data and interpretations, emerging codes, and concept clarification throughout the data collection and analysis activities. Codes were later grouped into conceptual categories which underwent a continual refinement process that occurred between each round of participant encounters. In addition, the researcher debriefed with a 35 year professional in the field and qualitative researcher regarding participant experiences, and associated codes and concepts to ensure consistency in interpretation and account for any researcher bias. The researcher further utilised the electronic software *Dedoose*© to assist with the identification and organisation of themes and sub-themes. Interviews and participant observations continued until theoretical saturation was reached. Theoretical saturation was considered to be reached when no new information emerged from the data.

Qualitative presentation of themes and data analysis. During the second phase of the study the researcher utilised an iterative process with key participants to provide additional context to significant variable relationships identified in the quantitative phase. The coding process was accomplished by extracting key issues and concepts identified and organised into a thematic framework from which data could be indexed (Pope et al, 2000). The development of the framework was viewed as a dynamic process that underwent continual refinement over the course of data collection, reflective of the iterative nature of qualitative research. The framework organised the material into a hierarchy of five overarching themes and relevant sub-themes associated with the significant quantitative findings. The thematic areas along with participant responses are presented in respect to participants' life experiences. An extract of the thematic framework is presented in Figure 6.1.

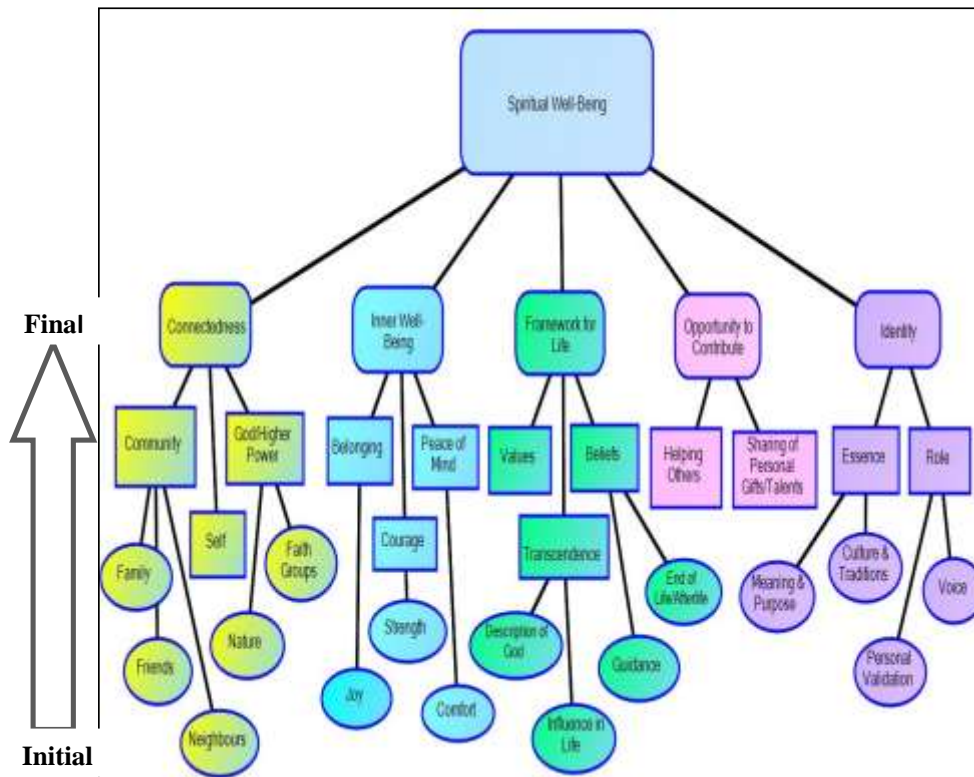


Figure 6.1. Thematic framework, coding process and data analysis.

Quantitative findings 1.0; 1.1; 1.8; and 1.9 suggested that there was a significant positive relationship between participants’ perceived spiritual and existential well-being and perceived life satisfaction and quality of life in adults who experience intellectual and developmental disabilities. That is, the greater the participants’ level of perceived spiritual/existential well-being, so was their perceived life satisfaction and quality of life. Four overarching themes; *Framework for life*, *identity*, *opportunity to contribute*, and *inner well-being* emerged from the qualitative data analysis providing additional context to the relationship between these variables. Similarly, quantitative findings 1.4;

1.7; and 1.10 suggested a significant positive relationship between participants' perceived spiritual, existential and religious well-being, and a participant's self-perception of social belonging. That is, the greater a participant's perceived level of spiritual, existential, and religious well-being so was their perceived social belonging. One overarching theme of *connectedness* emerged in the qualitative data to further explain the relationship between the variables of spiritual, existential, and religious well-being, and perceived social belonging. Note that the connection between the two data sets will be explored further in the Chapter Seven: Discussion. The five qualitative themes are presented in subsequent themed sections.

Theme 1: Framework for life. The concept of having a framework for life from which the participant derived meaning and interpreted life events was an evident theme throughout the data for participants. All fifteen participants discussed spirituality within their life that consisted of individually held beliefs and values (sub-themes) that established a framework by which the participant lived life. The established framework did not appear to be static in participants, but rather evolved over time and life experiences. New experiences were incorporated into future decisions. Several participants shared that beliefs and values contributed to a participant's understanding of life purpose, interpretation of life events, and facilitated life decisions.

Though participants expressed a diverse range of individual beliefs and values, each participant utilised purported beliefs and values in understanding day-to-day interactions and events. Participants shared a variety of thoughts and experiences when asked questions regarding "How do your spiritual beliefs influence your life?" At least half of the participants voiced a belief that God watched over them and shared

experiences in which they felt that they were specifically protected from harm. P4 shared a time when he was administered the wrong medical treatment for an infection he was experiencing yet continued to improve despite the medical error. He relayed that the doctor upon discovering the mistake was baffled by P4's continued state of improvement. P4 relayed "I attributed my improvement to the 'Man Upstairs' [referring to God]." On another occasion, P4 stated, "Sometimes at night, I believe He [God] is speaking to me in my head. I believe that miracles happen, because the right people come into your life...He [God] selects the right people to come into your life." P4 shared several experiences where he believed that special people came into his life at just the time that he needed. P6 reported experiencing comfort from knowing that God watches over him and the people that he cares for. Four participants shared experiences where at different times of life the participant doubted some of their spiritual beliefs and described faith as a journey. P11 shared that she experienced doubts "mostly when I was younger...I am more mature now and I see things that I did not see before. I see how God works in peoples' lives." She went on to say, "Now I see God all around me...I know that I am not alone...I am still growing in my Faith...it is a daily walk." P4 relayed, "Well, I believe He [God] works in crazy ways at times...and it may take me time to know it...spiritual things may appear in the least expected times and places. This is something I had to learn over time."

Several participants discussed their upbringing from childhood and shared how the influence of what they learned as a child continued to impact them in the adult years. A common concept shared by several participants, and linked back to religious or spiritual ideology, was that if they do good, then good things will follow and if they do

bad, then bad things will follow. P3 relayed that she was raised Christian, and that she was taught that she could “correct any bad deeds committed with good deeds.” She further reported that she has tried to live by this understanding all of her life. P3 went on to state, “I am still working on it.” She continued the conversation by sharing a list of recent “good acts” that she has done on behalf of others. Several participants referred to spiritual beliefs in deciding how to respond to important situations and how to treat others in good and bad times. P12 relayed that she was on a lifelong journey. She remarked, “I was baptised at the age of twelve and am able to help others, because God is in my life” (P12). She indicated that her ability to help others during difficult times was a gift that gave her purpose in both personal and work relationships.

Several participants shared thoughts connected to spiritual beliefs regarding end-of-life and afterlife. In general, a belief in the metaphysical appeared to assist participants’ in understanding and coping with the physical loss of friends or family as well as the participants’ understanding of his or her own mortality. Some participants professed a belief that life on earth was only temporary and that at the end of their life, a spiritual transcendence of some kind would take place. P14 shared that she does not believe that God directly influences life “except when He decides to take you.” P14 shared she believes that only God decides when it is time for you to go [meaning leave this earth or die]. She believed that such occurrences were pre-ordained and out of a person’s control. Other participants discussed a spiritual transcendence from a personal yet imaginative perspective. These participants shared stories of what they envisioned life after physical death would be like. P4 shared, “I believe in Heaven I will be ‘walking’ [pause], but if I am in a wheelchair, well that is okay too.” He went on to

express that at times he wondered if God might utilise a wheelchair as well, because he embraced the belief that man was created in “His image”(P4). Later, when P4 was asked how he understands God in relation to issues of disability? He remarked:

I may use a chair, but, the chair does not define me. Faith keeps me from going insane...It keeps me grounded...keeps me from reaching too far, too quickly. It allows me to realise that I do have limits but – it is not the physical limits – the real limits in my life are not of a physical nature.
(P4)

He went on to describe that limits are about attitude and not physical characteristics. This researcher over the course of this study developed a particularly close relationship with P2. P2, who experienced terminal cancer, shared with confidence near the end of her life, “God has a place prepared for me in Heaven and I will need to go.” A short time later while paying last respects, the following was observed:

P2’s breathing [now restricted to bed] was laboured with gurgling sounds as her lungs were beginning to fill-up with fluid, evident signs of her approaching end-of-life. P2’s kidneys were no longer functioning. Hospice supports were in place. Home staff noted that three Pastors of differing faith groups had recently visited to provide assistance and support. Staff at the home were telephoning people who were close to P2 so they could come and say ‘goodbyes’. In the background was the smell of coffee brewing which everyone at the home voiced their appreciation for as several of the folks had been up throughout the night. Friends and family were scattered throughout the home sharing personal stories. I sat in P2’s bedroom with one of her housemates, who sat bedside and gently held P2’s hand. The housemate looked up at me and said, ‘she is my best friend you know.’ Then she looked at P2 and softly began singing ‘You are my sunshine, my only sunshine, you make me happy when skies are grey. You’ll never know, dear, how much I love you. Please don’t take my sunshine away.’

The above encounter provided a powerful demonstration of the role the spiritual dimension of life plays in understanding and assigning meaning to significant life

events. Such an encounter provides a testament to the mysteries of life and hope that people bearing witness seldom forget. P11 summarised her thoughts regarding a spiritual transcendence by stating, “This life on earth and my physical state are just temporary. If it were not for Heaven - what good would this life be?” The majority of participants who expressed belief in an afterlife also seemed to subscribe to an ideology that the next life would be better.

Theme 2: Identity. Most participants associated aspects of his or her spirituality with their *identity* or self-view. Participants inevitably shared self impressions and descriptors of individual essence, innate purpose, or perceived role(s) in life. In addition, important concepts connected with a participant having opportunity to express personal opinions, be personally validated, and honour family and cultural traditions emerged in stories associated with a participants’ sense of identity.

Several participants when asked about their spiritual life touted, “I am a Christian” (P7), or “I am Methodist” (P5) or “I am Atheist” (P9). Other participants shared intimate reference to their inner being and an understanding of identity. P2 stated “I must have got my spirit from one of my ancestors, because having two chronically alcoholic parents is no picnic. Somehow, I knew I was made of finer things.” P9 relayed:

Since I do not believe in God, I do not believe that there is a *force* that we cannot see that guides us [pause]; we are not puppets at someone’s command. I believe in the inner human spirit...it is real...it exists in each person....it is most important above all other things. (P9)

In regards to participants’ understanding of meaning and purpose in life, several participants shared an understanding of his or her own sense of purpose in life. Half of

the participants' shared specific personal goals that aligned with the participants' desire to make a difference in the life of others. P4 shared he believed his purpose was "to be present for someone that believes that things are too rough and to show them another way." He went on to explain:

I have a business that I want to do but, this is what I want to do to make a living. My purpose in life is about helping individuals and families who are challenged...give someone a shoulder of true understanding and let them know that life is not going to end due to a challenge. This for me is real purpose. (P4)

P14 said she would like to have a job "helping people" or "in a restaurant, cleaning, or working with kids." She reported that it was important to her to have a job that she knew helped others and that this would also help her. She relayed that when she is able to help others, she "does not drink, smoke, or do drugs." P11 stated that she finds purpose in using her voice and her experiences to educate and advocate for others. She reported deriving a sense of worth and confidence from actions that are other focused verses self-focused.

Most participants expressed a spiritual need to be acknowledged for who they are. They associated this acknowledgment with opportunities to express personal thoughts and feelings, and participate in individual family and cultural traditions. Some participants relayed feelings of frustration, disappointment, or anger when others had not acknowledged these important aspects in their life. P9 stated:

I do not believe that other people acknowledge my spiritual needs...maybe because I am not religious, but that is no excuse! I require assistance to participate in all aspects of life and people do not necessarily understand that this also means those activities that feed my spirit...music, nature, animals, the ocean [pause]...it is experiencing the ordinary perhaps, but these are all things important to your inner spirit. (P9)

Similarly, P13 relayed that she was often frustrated as she does not believe that others always see her as a spiritual person with spiritual needs. She noted that she requires support and assistance in all areas of her life and that it is important that others learn to see this as well. She said, “this makes you feel like only half a person.” (P13) P11 emphasised that spirituality was individual, personal and unique and stated; “Each person must find their own sense of spirituality in their life. No one can create that for a person. Mine is personal and relational.” She went on to say that people, who really know and care about her, understand this aspect of her as a person.

Several participants discussed that *identity* was not just who a person is on the inside, but where a person comes from. Most participants shared the importance of special events or holiday traditions honoured in specific ways. P14 shared the importance of others acknowledging her need for support during the anniversary of her Grandfather’s death. She relayed that every year she and her family visit her Grandfather’s grave and left food. Afterwards the family gathered together to share stories and celebrate life and memories. P14 described that participation in this event remained important to her understanding of herself and where she comes from.

Theme 3: Opportunity to contribute. A third theme that emerged in connection to participants’ spiritual life was the presence of opportunities or desire for opportunities to contribute. Participants expressed a desire to share personal gifts and talents, and to help and assist others. Most associated opportunities to contribute with having meaning and purpose in life. Some participants reported employment while other participants

reported volunteering at various places in the community. Participant stories indicated that meaningfulness was derived more from activities associated with helping or assisting others, than from receiving a pay check. P12 shared that she elects to remain at her volunteer job rather than move to a paying job, because her personal relationships allow her to help people who she perceives in need. P12 shared numerous occasions that in her volunteer job she was able to help other people who were struggling. She relayed that her ability to help others as God has helped her “is the most important part of my work [volunteer job].”(P12) P11 stated, “I believe that my purpose in life is to encourage others. I do that through my advocacy efforts. I do that through my art. I do that through my poetry and in day to day encounters.” Another participant, P4 stated, “I have my vocal cords...I believe these were a gift from God, which is different than many others who experience CP [Cerebral Palsy]. I have always known my voice to be part of my gifts.” P1 shared her desire to assist in advocating for others who were not able to advocate for themselves. P8 shared that she volunteers with kids, because she enjoys being able to encourage and teach them. She went on to share that she believes she makes a difference in their life.

Theme 4: Inner well-being. The majority of participants associated feelings of inner well-being with the spiritual dimension of their life. In one form or another, participants reported that their spiritual life was associated with feeling comfort, strength courage, acceptance, and belonging. Some associated positive feelings to a personal relationship with God or a Higher Power. A powerful example of self-acceptance was shared by P11 when she was asked how she understood disability in

relation to God. Without any hesitation, she quickly referred this researcher to a scripture in the Bible, Psalm 139: 1 – 14 which was read out loud together and states:

1 You have searched me, Lord,
and you know me.
2 You know when I sit and when I rise;
you perceive my thoughts from afar.
3 You discern my going out and my lying down;
you are familiar with all my ways.
4 Before a word is on my tongue
you, Lord, know it completely.
5 You hem me in behind and before,
and you lay your hand upon me.
6 Such knowledge is too wonderful for me,
too lofty for me to attain.
7 Where can I go from your Spirit?
Where can I flee from your presence?
8 If I go up to the heavens, you are there;
if I make my bed in the depths, you are there.
9 If I rise on the wings of the dawn,
if I settle on the far side of the sea,
10 even there your hand will guide me,
your right hand will hold me fast.
11 If I say, "Surely the darkness will hide me
and the light become night around me,"
12 even the darkness will not be dark to you;
the night will shine like the day,
for darkness is as light to you.
**13 For you created my inmost being;
you knit me together in my mother's womb.**
**14 I praise you because I am fearfully and wonderfully made;
your works are wonderful,
I know that full well.** Psalm 139 (New International Version)

When the reading was concluded, P11 restated with emphasis verses 13 and 14 of the scripture. She then remarked with an assured voice, "God does not make mistakes,

[pause] I am not a mistake...we are each made with purpose...words are insufficient.” Several participants shared similar sentiments. Participants’ expressed for the most part that they believed that God did love, care, and watch over them. Participants shared several stories in which their spiritual life resulted in internal feelings of comfort, strength or courage. Over half of the participants’ shared experiences in which they attributed positive health or personal relationship outcomes to answered prayers. P4 stated, “sometimes I feel things so strongly, I can’t breathe – I can’t sleep. I know I need help and I pray...I see God as someone who gives me strength to handle what life brings.”

Theme 5: Connectedness. The theme of connectedness within a spiritual dimension of life was the most evident of concepts in participants’ lives and was prevalent throughout the data. All fifteen participants discussed spirituality within their life as having to do with connectedness and the relationships within his or her life. Connectedness was important to participants from multiple levels: the self, the community (inclusive of neighbours, friends, family, and faith groups), nature, and the transcendent. Each participant viewed these connections as important to their overall well-being and a desired outcome within life. In addition, this aspect of spiritual connectedness to others appeared to promote reciprocal opportunities with others for support, health, and healing during stressful times.

In terms of connectedness to *self*, some participants voiced the importance of self-reflection in better understanding who they were as a person. These participants discussed spending personal time thinking about their motives and desires in an effort to better understand their inner resources, and how they personally grow and develop. P6

remarked that he often asks himself this question; “How is my spirit doing today?” He said that he reflects on this question often and tries to decide if he is “doing what I should be doing in life.” Another participant, P2, stated that she does not try to “separate out who I am from Cerebral Palsy” as she has come to understand that it is part of “what makes me, me.”

Still other participants represented their connectedness with self as a spiritual journey that they travelled as they developed their own sense of who they are. Several participants’ described a variety of personal experiences connected with accepting themselves as an individual. Some shared emotionally painful experiences of growing up with awareness that they were “different” from other people and described searching throughout life for places in which they felt that they belonged. P4 stated, “I was constantly looked at – ignored by kids, not included, or treated poorly...I now see that time in my life as God’s preparation for me to live on my own...I get it now.” P4 went on to say; “Church has always been a big part of my life since I was a kid. My family first introduced me to the church but participation now is all of my own accord.” Several described their personal faith as something that had helped see them through difficult times such as the loss of a person they cared about, a significant health issue, or a substantial move.

Still other participants voiced a connectedness with self inclusive of experiences of personal achievement and validation. P11 shared a time of personal accomplishment in which she was given an award and shared what a great feeling she had when “they saw beyond the chair [wheelchair].” P4 described a time when he was elected into a leadership position and came to know his own sense of worth and ability to contribute to

others lives in a positive way. At least half of the participants described a personal life goal to have a home of their own, a marriage partner, and children, one day. P4 remarked that he would like “companionship in life” very badly. He relayed that he is a “romantic at heart” and just needs to find someone to see past his physical limitations and “see past the chair, and see who I really am as a human being – the person behind all of this [looking down at his wheelchair].” These intrapersonal aspects of spiritual connectedness appeared to facilitate a participant’s understanding of self, identity, and inner resourcefulness (Brandt et al., 2009).

Another sub-theme of connectedness was the concept of *community*. Hay (1989) referred to community as an individual’s interrelatedness with others. Again, all fifteen participants shared the importance of his or her connectedness within their communities with neighbours, friends, family, or their faith communities. Four participants discussed an extensive network of social support using technology. These cyber relationships were most often referred to by participants as their *Facebook* friends. Participants shared that they had never physically met most of their cyber friends, but consistently shared that staying connected was important to them. P14 shared that it was important for her to share time with friends that keep her busy and out of trouble. That same day, P14 was observed to help decorate a room for a birthday party of a friend, attend the party in the early afternoon, and then later recreate at a local lake with friends kayaking. Several participants shared the importance of knowing who their neighbours are and described their efforts to get to know people who lived around them. P8 shared that she likes to go to the common area within her apartment complex where people often get together to socialise. She was observed on occasions to watch people play cards, talk, or

share a food dish with others during a potluck. P8 stated, "I like it here, because everyone is very nice and I feel safe." Several participants discussed the importance of living in a community where they feel like they belong, where it feels like "home." P11 who had lived in both urban and rural communities in her life described that she prefers living in a "small town because I just feel more at peace when I do."

Many of the participants shared the influence that their faith communities had on their sense of connectedness. Participants repeatedly shared experiences of their faith communities as places where people knew them by name, helped them during difficult times in life, and gave them opportunity to help others in need. Below is a description of one observed encounter with a faith community:

Before we [P11, researcher, and staff] could get out of the van, a church member from the congregation came out of the double glass doors of the church building, smiling and greeted P11 by name. The church member did introductions and relayed that she always likes to be waiting to assist P11 when she arrives. P11 with a big smile greeted the church member back and then turned to greet a couple of other members that walked up soon after. They remarked how happy they all were to see P11 again. [The congregation was small - medium in size, appeared to have between 50 - 75 members]. Everyone seemed to know P11 by name and were warm, welcoming, and friendly in conversation. People made a point to stop and acknowledge P11 and engaged in casual conversation about how she had been doing during the week. Staff did not stay for the service but rather, members of the church community assisted P11 with any support needs during the time she was at the church building. One church member held P11's song book and Bible for her so that she could follow along, another church member assisted P11 with participation in communion service. P11 fully participated in song and worship activities. Just before leaving one of the church members came over to P11 and reminded her of an upcoming event in which several from the church were going to provide help to a special cause and invited P11 to be a part of the assistance effort. P11 readily accepted saying "I'll be there". We loaded up in the van and returned to P11's home.

Participants reported a variety of areas that were important to them when selecting a faith group to affiliate. P12 indicated that church was very important to her, and viewed her faith community as the primary place she meets up with friends and family each week. P14 stated that she attends a variety of churches and has friends and family at each place that she goes. Some participants shared that they liked going to “big” churches with lots of activities, while others reported to like going to “small” churches where everyone knows each other. Most participants sought out a place that was in the neighbourhood of where they lived. However, participants also relayed stories of experiencing rejection or a lack of accessibility with some faith communities. These participants reported that it was most important to find a place where they were comfortable and accepted verses a place nearby. P11 shared an experience in which a neighbouring church had an auditorium that was physically inaccessible to wheelchairs. The inaccessibility required her to be in a separate room from other members during worship times to watch the group via a television monitor. She relayed that she left this place, because she could never fully participate. P14 indicated that she chooses which church to go to depending on how she feels on a given day. She relayed:

In some churches you get to stand up a lot and some churches you sit a lot.” I like both, depending on what I feel like doing. Sometimes I do not always feel like standing a lot...I do always feel better after I go to church. (P14)

Some participants discussed the importance of their connectedness to nature as an important part of their spiritual life. Though this aspect of the spiritual dimension was not as prevalent with participants, three participants shared nature as a very relevant aspect of a spiritual life. P14 shared her experience when accompanying others on a

religious pilgrimage during which she hiked to a “Holy Spring” where she believes holy water flows. She described how people hike to the spring and fill their bottle containers with water believed to promote health and healing for a person. P2 shared numerous personal experiences where she encountered rain, sunshine, oceans, or mountains and associated the experience with her relationship to God. P11 shared experiences of spending time watching birds fly, flowers grow, and seasons change as evidence to her of a Higher Power.

The final sub-theme of connectedness was participants’ personal relationship with God or a Higher Power. The majority of participants voiced that they do believe in God. Participants’ that voiced a belief in God also tended to share thoughts that God watched over them in some manner. Several discussed the experience of feeling love, comfort, or peace of mind associated with a perceived personal relationship with God. Both participants’ life experiences shared with the researcher and direct observations made by the researcher supported the notion that participants perceived relationship with God or a Higher Power was a powerful influence in participants’ lives. Twelve of the fifteen participants relayed that they pray to God as part of a personal relationship with God. Some reported to pray daily while others reported to pray at varied frequency. Participants’ who prayed generally believed that God heard and answered prayers. P4 stated:

I know that God will never give me more than I can handle...the ‘Man Upstairs’ has helped me many times in life when the unexplainable happened...I believe that God does intervene on people’s behalf and that God intervenes on my behalf as well. (P4)

P11 described her relationship with God in the following manner, “God is my ‘pilot’, He sets the direction for my life...He guides me in what to do... He is my ‘anchor’.” P13 spoke to her understanding of God and her prayer life relaying “God stays very, very, very busy answering people's prayers...so, I am careful about when I go to Him in prayer because of His busyness.” P13 went on to share that the content of her prayers were always about the most important things in her life. Other participants saw their relationship with God as less directive yet, still influential in life. P14 stated that she believes that “God does not change what happens in my life, but He helps me better handle the things that life brings...I feel better able to take life when I pray.” Another participant relayed that she sometimes “dreams” or “sees” things that are bad or painful, and prayer helps her feel better because it “helps the thoughts go away” (P10).

Summary of qualitative phase findings. The quantitative phase of the study examined *what* the relationship was between perceived spiritual well-being and quality of life in adults who experience an intellectual and developmental disability. Phase one of the study revealed a significant positive relationship between seven dimensions of spiritual well-being and quality of life. The qualitative section of this chapter described the findings from phase two of the study in answering the following primary qualitative research question: How do adults who experience intellectual and developmental disabilities understand and describe the importance of a spiritual dimension of life to other aspects of life? A qualitative methodology comprised of informal in-depth interviews, participant observations, and document reviews provided rich descriptive data regarding the relationship between the two variables through first person accounts

of life experiences associated with the topic. As the fieldwork during phase two progressed, repetitive visits with participants occurred. During this iterative process, the level of dialogue between researcher and participant moved from generalised to more specific and intimate. In the early stages of the fieldwork, conversation tended to deal primarily with what people did and where they went. For example, “I go to church” or “I pray.”

Participants often talked about identities that they applied to themselves spiritually, for example, “I am a Baptist” or “I am Christian.” These conversations evolved where participants talked about innermost thoughts and feelings regarding how they were raised; who was influential during developmental years; challenging situations or experiences that they encountered in general community moments, or connections with faith communities. As conversations continued to evolve participants shared more about why they engaged in certain behaviours, for example, “prayer” or “giving support to a social cause.” Ultimately, participants shared thoughts and feelings regarding the personal meanings that they assigned to these meaningful activities. Participants shared life experiences and described the role that spirituality played in understanding life situations, making decisions, and evaluating his or her place in the community around them.

Throughout the evolution of these dialogues, participants shared glimpses of the meaning and relevance of spirituality in their life. Insights gained and the evolving understanding of spirituality for participants were further coded into providing context regarding the significant relationship identified in the quantitative phase of the research.

Five overarching themes emerged from the data collected that provided a context for understanding the significant positive relationship found between participants' spiritual well-being and quality of life within the seven positively correlated areas. The next chapter, Chapter Seven, *Discussion, Conclusions, and Recommendations* brings the quantitative and qualitative results together and discusses the study findings, implications, and contributions of this research.

Chapter 7

Discussion, Conclusions, and Recommendations

This chapter discusses findings, conclusions, and recommendations for a mixed methods study in the self-perceptions of spiritual well-being in relation to quality of life in adults who experience intellectual and developmental disabilities. Chapter seven is divided into six sections. Section one presents a brief overview of the entire study. Section two discusses the primary research questions and the key findings of the study. In this particular section the analyses of chapters five and six are presented with discussion of the integration of the quantitative and qualitative data respective to the primary research questions and associated review of the literature. Section three presents a discussion of the conclusions derived from the data analyses. This section conveys the researcher's interpretations derived from consideration of data analyses. Section four discusses the implications of the research. This section communicates the utility of the research outcomes. Section five discusses recommendations for future research, with next steps and future directions proposed. Finally, section six provides summary and concluding remarks.

Discussion of the Study

The aim of this study was to explore and describe how adults who experience intellectual and developmental disabilities perceive the significance of their spiritual well-being in relation to their quality of life, and how this population understands the importance of the spiritual dimension of life to other aspects of life.

The history of this population of people is laden with less than humane treatment and documented violations of human rights (Browning, 1974; Evans, 2001). Furthermore,

individuals who experience intellectual and developmental disabilities often live lives marginalised by mainstream society. This researcher's experiences within the field of disabilities over the past thirty years suggests that the failure to see all people as *fully* human and capable of exploring, experiencing, and expressing each aspect of being human contributes to an ongoing devaluation and dehumanisation of others. Therefore, acknowledgement of the full humanity, body, mind, and spirit of people who experience intellectual and developmental disabilities, is essential. Exploration of the spiritual dimension of life is relevant to understanding the interaction between the body, mind, and spirit, and the affect these dimensions have on the health, well-being, and quality of life of a person (Ellison & Smith, 1991). In addition, an increasing body of knowledge and research supports the benefits of spiritual and religious practices on physical health (Koenig & McConnell, 1999), mental health (Koenig, 1998), coping (Pargament, Van Haitsma, & Ensing, 1995), rehabilitation and recovery (Fitchett, et al., 1999), and understanding of meaning and purpose in life (Maugens, 1996). Irrespective of these findings, the spiritual life of individuals who experience intellectual and developmental disabilities remains largely unexplored.

In an effort to further research in this area, the current study utilised a mixed methods sequential explanatory design to answer four primary research questions. The primary research questions were explored from data collected from a quantitative phase, followed by a second qualitative phase of study. Phase one explored three primary research questions in a quantitative approach utilising Paloutzian & Ellison's *Spiritual Well-Being Scale* (Paloutzian & Ellison, 1991) and Schalock & Keith's *Quality of Life Questionnaire* (Schalock & Keith, 2004). During phase one, the study sample

population was administered both instruments in a verbal interview format. Measurements of each participant's self-perception of his or her spiritual well-being and quality of life were acquired and analysed in respect to the first three primary research questions. Research question number one examined the relationship, magnitude and direction, of the variables of spiritual well-being and quality of life in participants. A total of 11 correlations were conducted. Seven of the eleven correlations produced significance. Findings of significance from these research questions were further explored utilising a qualitative approach in phase two of the study, providing a more complete picture to the relationship between spiritual well-being and quality of life for the study population. The qualitative phase of the research was pursued to provide context to the significant findings associated with phase one of the study. Phase two explored the fourth primary research question utilising qualitative unstructured, informal interviews, participant observation, and document reviews.

Participants in this study came from one state-wide secular Alaskan disability provider organisation in the United States of America. A purposive sampling technique was utilised resulting in a total of 50 individuals who met all of the studies qualifying criteria and participated in phase one of the study. Of the 50 individuals who agreed to participate in the study, 47 were considered to represent the study sample population. Fifteen key participants' were selected as a representative sample from the original study sample population to participate in phase two of the study. Chapters five and six presented analyses of data collected in phase one and two of the study. Data from both quantitative and qualitative phases are discussed in detail in the following section.

Discussion of Findings

Primary Research question 1.0. The study explored the relationship between perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities. The primary research question 1.0 along with ten sub-questions was investigated. From the analysis of the two major variables, the data suggests that there is a significant positive relationship between participants' perceived spiritual well-being and their perceived quality of life. Within the *QOL-Q* instrument, two *Subscale Scores*, *Competence/Productivity* and *Empowerment/Independence* produced no significant relationship with *SWBS Scores*. In addition, *SWBS Religious Well-Being Subscale Scores* produced no significant relationship with either the *QOL Total Scores* or *QOL Life Satisfaction Subscale Scores*. The lack of relationship on these subscales lends support to theories depicting the spiritual dimension of life and quality of life as separate and distinct constructs (Bekelman et al., 2010). Yet, 7 of the 11 correlations produced a significant positive relationship having correlation coefficient produced effect sizes ranging from .268 (medium) to .488 (large) providing additional evidence that these two constructs though independent are significantly interrelated with each other (Cohen, 1988; Green & Silkind, 2005; Sawatzky, Ratner & Chiu, 2005). The theoretical framework proposing spirituality and quality of life as distinct from one another contradicts frequently held theoretical frameworks for quality of life that represent spirituality as a concept falling within a multi-dimensional quality of life construct. Measurement instruments designed from the multi-dimensional quality of life framework presuppose that the various dimensions of quality of life are subject to change in a somewhat predictable manner to the overall quality of life variable. A

presupposition that is not supported by the findings of this study. The opposing distinctive framework treating the variables of spirituality and quality of life as unique, but interrelated is further supported by the moderate magnitude of the relationship.

The *QOL.Q Total Scores* and the *SWBS Total Scores* produced a correlation coefficient effect size of moderate magnitude ($r = .358$). This significant, positive correlation indicates that as adults who experience intellectual and developmental disabilities spiritual well-being increases so does their perception of their quality of life. This finding is consistent with earlier research on the relationship between spirituality and quality of life which suggests a relationship of moderate magnitude between the two concepts (Sawatzky, 2002).

In addition, the lack of relationship between two *QOL.Q* subscales and the *SWBS Scores* and the spread of variance of effect sizes between other *QOL.Q Subscales* and *SWBS Subscales* lends additional empirical support to the idea that the two concepts though related are uniquely distinct from one another (Beckie & Hayduk, 1997; Beckelman et al., 2010; Sawatzky, 2002). This finding leads to the conclusion that these two constructs are not analogous and should be distinguished separately.

In Sawatzky's (2002) meta-analysis of the relationship between spirituality and quality of life, the data suggested that the "conceptual overlap between the two concepts is less than 12% (.34²)" (p. 84). Similarly, the current finding for the *QOL.Q Total Scores* and the *SWBS Total Scores* revealed a value of $r^2 (.13)$, indicating a 13% overlap in perceived spiritual well-being and perceived quality of life in adults who experience intellectual and developmental disabilities. The current study's findings lend additional empirical support to the representation of spirituality as a separate and

distinct construct that stands in relationship to quality of life (Beckie & Hayduk, 1997; Sawatzky, 2002).

O'Connell and Skevington (2010) researched the contrasting models of quality of life to investigate the theoretical frameworks and the contribution of spiritual, religious, and personal beliefs to quality of life in health. Study participants (n = 285) represented a cross-section of religious, agnostic, and atheist beliefs in a heterogeneous sample of sick and well people. O'Connell and Skevington found little evidence to support the model of spiritual quality of life as a superordinate construct overarching all other quality of life domains. The collective data did support spiritual quality of life as an integral part of quality of life overall. These two researchers provided additional evidence to the theory that spirituality is a distinctive dimension that makes a significant, independent contribution to overall quality of life (O'Connell & Skevington, 2010).

Findings from this research project along with O'Connell and Skevington's findings challenge the prevalent theoretical framework that represents spirituality as a concept that falls under a multi-dimensional quality of life umbrella (Mytko & Knight, 1999). Generally, in the multi-dimensional quality of life models, spirituality is depicted as either "1) an independent component of quality of life or 2) as an overarching personal life perspective or world view which influences all quality of life domains (e.g., physical, functional, emotional)" (Mytko & Knight, 1999, p. 445).

The opposing theoretical framework portrays quality of life as a global, uni-dimensional subjective assessment of a person's satisfaction with life (Beckie & Hayduk, 1997). In the opposing theoretical framework, quality of life represents "a

global personal assessment of a single dimension which may be causally responsive to a variety of other distinct dimensions” (Beckie & Hayduk, 1997, p. 22). Though correlational data cannot prove causality, correlational data can reveal that a causal relationship exists (Aronson et al., 1990). The current study findings, with respect to the varied findings of previous research, support a theoretical framework that holds spirituality and quality of life as interrelated yet, distinct from one another.

The question of whether or not people who experience intellectual and developmental disabilities view spirituality as important to their quality of life is simple, yet poignant to establish for a population of people who require support and assistance in addressing daily living needs within a desired lifestyle. Therefore, a definitive answer to this question is significant as spirituality for people who experience intellectual and developmental disabilities have historically been ignored by human service systems. Ironically, experiences gained through this research and thirty years of working in a human service field bears out a reality that this spiritual void often occurs in human service systems which ascribe to a support philosophy of being value-driven, person-centred, consumer directed, and holistic in approach to working with people who experience disabilities. Personal experience reveals that activities associated with the spiritual dimension of life are rarely introduced in planning meetings at either an individual or an organisational level. Topics of religion are often treated as private or taboo and therefore, left out of support dialogues. Training regarding spirituality in general is absent from required learning curriculums for the direct support worker. All of which are indicators that an awakening within the field of disabilities is necessary in

order to align holistic person-centred service philosophies with service delivery practices and to *walk the talk* if you will.

Fitchette (1993), Canda (1999) , and Gaventa (2001) affirm that people not only have biological, psychological, and social aspects to themselves but, spiritual aspects as well. Holistic approaches to working with people must consider all aspects of the person, including persons who experience intellectual and developmental disabilities for philosophy and practice to align. Furthermore, this study's findings suggesting adults who experience intellectual and developmental disability consider spirituality as an important aspect of life, is consistent with research findings that spirituality is an important aspect of life in other populations (de Jager Meezenbroek et al., 2010; Johnstone & Yoon, 2009; Koenig et al., 2001; O'Connell & Skevington, 2010). The current study's findings further reinforce the notion that spirituality is a universal aspect of the human experience and is not dependent on intellectual and functional abilities.

In this study, a majority of individuals interviewed reported believing that spirituality was important to their well-being and overall quality of life. Some participants voiced that their spiritual life was the most important life domain area. Yet, most participants shared that they did not typically discuss religion or spirituality with staff that support them. The majority of participants openly expressed appreciation for talking with them about this area of their life. Examples of comments expressed by participants were: P3 voiced, attending church is the "highlight of each week"; P6 noted, "I am a very spiritual person" and; P9 indicated, "I require assistance in all aspects of life...this also means those activities that feed my spirit." The majority of participants willingly shared views regarding the spiritual aspects of their life. Despite

participant’s willingness to share information, a review of participants individual support plans connected with their daily supports and services, religious or spiritual aspects of life were given only cursory attention if mentioned at all.

The descriptive data collected during the qualitative phase of this study provided a more complete picture to understanding the nature and importance of the spiritual dimension of life to other aspects of life in the study sample population. Five overarching themes emerged as descriptors within a participant’s life associated with spiritual well-being in relation to aspects of a participant’s quality of life. Figure 7.1 depicts within a model the five primary themes of *framework for life*, *identity*, *opportunity to contribute*, *inner well-being*, and *connectedness*.

Figure 7.1. Relationship of Spiritual Well-Being to Quality of Life

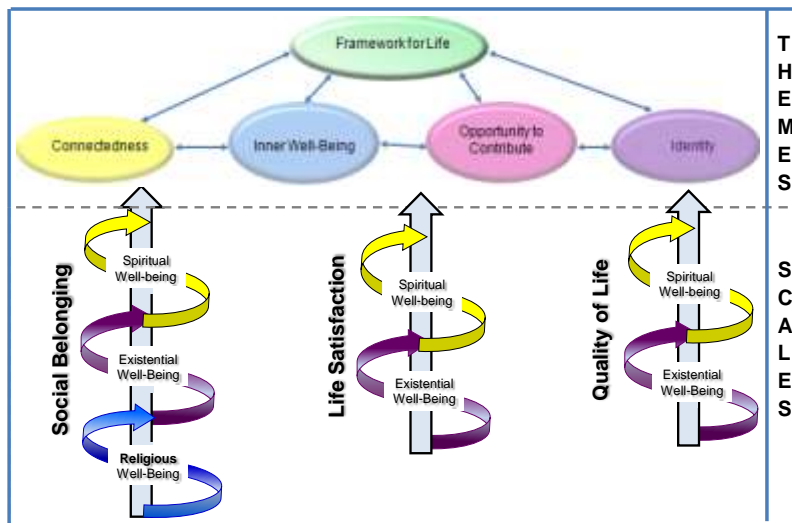


Figure 7.1. Model of the relationship of spiritual well-being to quality of life.

This model was developed by the researcher to show the relationship between these two variables and their influence in participants' lives. This model portrays the relationship of spiritual well-being to quality of life in the study population /and will be discussed along with the fourth primary research question. The lower half of the model depicts the relationship and direction of participant subscale scores on the *SWBS* and *QOL.Q* instruments utilised in this study. As the *SWBS* total scores and *religious well-being* and/or *existential well-being* subscale scores increased, so did the participant's *QOL.Q* total scores and *social belonging/community integration* and *life satisfaction* subscale scores increase. The upper half of the model depicts the themes that emerged from the qualitative phase of the study providing further understanding as to the nature of the positive relationship of the two variables for the participant. Personal stories conveyed by key participants indicated that the five themes, though distinctive were interconnected and often interdependent on each other. For example, most participants voiced a desire to help and assist others, and to know that their actions made a difference in the life of another. Most participants shared that opportunities within a participant's life to contribute in meaningful ways influenced how the participant felt about life in general. The presence of *opportunities to contribute* appeared to afford a participant a personal sense of meaning and purpose, thus positively influencing perceived life satisfaction and overall quality of life. Additionally, assisting others was almost always described in the context of relationships in a participant's life, also linking this aspect with the theme of *connectedness*. It is important to remember the interrelated nature of these themes. The emergent themes as related to the various aspects of spiritual well-being and quality of life will be discussed further in respective

research sub-question finding areas. A discussion of the relationship nature described in an analysis of the data collected from the various *SWBS Subscales* and *QOL.Q Subscales* follows:

Research sub-question 1.1. The study explored the relationship between perceived spiritual well-being and life satisfaction in adults who experience intellectual and developmental disabilities. Utilising a Pearson's Product-Moment Correlation Coefficient to analyse the relationship between the *Spiritual Well-Being Scale Total Scores* and *QOL.Q Satisfaction Subscale Scores*, the analysis found a significant, positive relationship ($r = .271$, $r^2 = .07$, $p < .05$) between these two variables. The effect size produced a Pearson $r = .271$, which indicates a moderate correlation between perceived spiritual well-being and life satisfaction in adults who experience intellectual and developmental disabilities. The value of $r^2 (.07)$ indicates that 7% of the variability in adults who experience intellectual and developmental disabilities level of life satisfaction is accounted by their perceived spiritual well-being.

Wills (2009) examined the contribution of spirituality and religiosity as a new domain to the Cummins et al. (2003) proposed personal well-being model that suggested life satisfaction consists of seven different life-domains. Theoretical consideration was given to the predictive value of spirituality and religiosity to the Personal Well-being Index, an evaluative measure of life satisfaction developed by Cummins et al. (2003). Wills and Cummins noted life satisfaction can be evaluated from domain specific areas such as marriage (Lucas et al., 2003), family life, goal pursuit (Emmons, 1986), social relationships (Helliwell & Putnam, 2004), or as a global measure of life as a whole. In consideration of life satisfaction as a global measure,

Wills (2009) found that spirituality and religiosity were statistically significant ($p \leq 0.00$ and $p \leq 0.05$ levels) predictors of satisfaction with life as a whole.

Clarity regarding the nature of the relationship between overall life satisfaction and a person's satisfaction in specific life domain's remains ill-defined in the research literature (Rojas, 2006). In support of the need for ongoing theoretical refinement in the area of life satisfaction, this study for adults who experience intellectual and developmental disabilities adds additional knowledge to the body of research indicating that spirituality contributes positively to a person's life satisfaction and overall quality of life.

In the current study, though some participants were unsure of how they prioritised life areas, the majority of participants purported to prioritise the spiritual domain of life the same or greater than other life domain areas. Participants' comments included such statements as "This life on earth and my physical state are just temporary. If it were not for Heaven – what good would this life be?" (P11); and P9 emphasised, "I believe in the inner human spirit...It is real [pause]. It exists in each person....It is most important above all other things." The finding that many adults who experience intellectual and developmental disabilities may prioritise their spiritual needs the same or greater than other areas of life is consistent with previous studies conducted with the broader disability population (Hanson, 2004). In the United States, the National Organisation on Disability/Harris Interactive Survey (2004) found 84% of people with disabilities and 84% of people without disabilities rated the importance of their religious faith as either "very important or somewhat important" (Hanson, 2004, p. 21).

In 2007, the Office of Mental Retardation and Developmental Disabilities in the State of New York surveyed individuals across the State who experience intellectual and developmental disabilities, as part of a Faith Based Initiative Program (Patterson, 2009). Though comparisons with the current study are difficult to make due to methodological differences, the findings from the New York study indicated that a significant proportion of the sampled population, approximately 60%, participate in community faith based activities at some level, while approximately 39% of the sampled population reported that they “never” participate in worship or faith related activities in the community. Interestingly, the findings also indicated that a lower percentage of individuals who experience intellectual and developmental disabilities, between 49% – 53%, participate in any residential or facility based worship or faith related activities. Patterson (2009) proposed the following questions as a result of the data collected:

- 1) Are the faith observance experiences due to lack of spiritual/faith experiences?
- 2) Are they due to individual’s inability to communicate faith/spiritual needs?
- 3) Are they due to the individuals being in ‘state’ care?
- 4) Are they due to agency inability to provide consistent opportunity and access, thereby creating apathy for discussions and exploration of individuals’ faith needs? (p. 8)

Patterson’s questions were important to ask in recognition of a population of people who require support in life to meet identified needs. Likewise, these additional questions are necessary to explore if a plan is to be developed to impact policy and program direction regarding supports for the spiritual and faith based needs of individuals. Further exploration with individuals who experience intellectual and

developmental disabilities is necessary to discern what variables contribute to the findings of each study. Individuals who historically lack opportunities to participate or access community activities or experience aspects of life as other citizens may not fully understand opportunities when offered. Similarly, individuals who reside in congregate residential settings may find that opportunities presented for participation in religious or spiritual activities may not necessarily align with personal spiritual preferences, values, and beliefs. In the current study, this researcher found it noteworthy that even though participants relayed that they generally did not discuss religious or spiritual matters with staff, nor did individual support plans address in any depth a person's spiritual life. Participants were often observed to be afforded a wide range of opportunities for personal spiritual expression. For example, P14 described the importance of staff support she received to participate in rituals connected with an annual visit to a Grandfather's grave site and also in participating on a hike with others to a "Holy Spring" while on a religious pilgrimage; P12 shared that the staff support she received on her volunteer job allowed her to help others as God has helped her; and several participants shared stories regarding the staff support received allowing for participation in a variety of church and faith related community activities. Therefore, the informal day-to-day supports provided to a participant in the spiritual domain, were not evident in the formal reporting mechanisms but rather became apparent through informal observation and dialogue with participants. In addition, detailed data that facilitates understanding in this area may not be retrievable through current standardised survey instruments for individuals who experience intellectual and developmental disabilities.

In general, participants indicated that their spiritual life contributed positively to their overall satisfaction in life. Life satisfaction measures generally look at how a person feels about life as a whole. For the most part, participants viewed themselves as similar to others in the community in which they lived and did not perceive themselves to have significantly more problems than any other person. Almost all of the participants indicated that his or her spiritual life contributed to a sense of comfort and peace during both positive and negative life events. For example: P4 following a major illness declared “I attributed my improvement to the ‘Man Upstairs’ [referring to God] while on another occasion remarked, “I see God as someone who gives me strength to handle what life brings”; P6 reported to experience comfort from knowing that God watches over him and the people he cares for; and, P11 shared a story of spiritual celebration when presented an award for her personal achievements; she commented “they [professional organisation] saw beyond the chair [wheelchair].”

Participants espoused personal spiritual beliefs and values that appeared to provide a framework by which life experiences were processed and understood. In addition, most participants referred to aspects of the spiritual domain in formulating a sense of personal identity, value and worth. For example, several participants linked their understanding of who they are as a person and where they came from directly to spiritual ideology. Several participants indicated feelings of being protected and watched over by God or a Higher Power which appeared to lend to feelings of caring and not being alone in life. Many participants seemed to derive an understanding of self-worth from an association with his or her inner spirit as opposed to his or her outer physical characteristics. Finally, participants’ stories frequently suggested that meaning

and purpose in life was associated with participants' opportunity to give back, assist others, or contribute in ways that made a positive difference in their community, church and others.

Research sub-question 1.2. The study explored the relationship between perceived spiritual well-being and competency/productivity in adults who experience intellectual and developmental disabilities. The current study found no significant relationship between perceived spiritual well-being and competency/productivity in adults who experience intellectual and developmental disabilities. This finding supports findings in literature reviewed (Paramenter, 1992; Robillard, 1999; Schalock & Verdugo Alonso, 2002). The general acknowledgement within the literature revealed a person's quality of life is a product of the interaction of multiple factors such as social, health, economic, and environmental conditions. These interactions affect human and social development at both individual and societal levels. Individuals with intellectual and developmental disabilities in general represent the lower economic strata, demonstrate lower educational competencies than the general population, and are less likely to engage in competitive employment. Though having meaning and purpose in life and opportunities to contribute may be individually understood and defined, these factors may be culturally derived as well. In addition, the lack of finding in this area may be attributable to a population of people whose enculturation in the United States regarding their individual value and sense of meaning and purpose emerges from aspects other than personal performance.

Research sub-question 1.3. The study explored the relationship between perceived spiritual well-being and empowerment/independence in adults who

experience intellectual and developmental disabilities. The current study found no significant relationship between perceived spiritual well-being and empowerment/independence in adults who experience intellectual and developmental disabilities. This finding differed from literature reviewed. In particular, the philosophical and political ideology connected with the deinstitutionalisation movement within the field of intellectual and developmental disabilities, promoted a subjective measurement approach to quality of life and embraced a philosophical framework of care that emphasised ideas of normalisation, social role valorisation, and empowerment as necessary for individual well-being (Wolfensberger, 1972). Blatt & Kaplan (1974) in their book, *Christmas in purgatory: A photographic essay on mental retardation*, graphically portrayed what amounted to a soulless treatment of citizens who experienced intellectual and developmental disabilities in America. At the time of the publication, members of the general public found it difficult to believe that the United States treated human beings in such a deplorable and inhumane way. Throughout the literature, disempowered and dependent people within a community have been associated with diminished valued outcomes, life satisfaction and well-being. Additionally, citizens who were socially isolated and rejected experienced feelings of depression, and poor mental and physical well-being (Gaventa & Coulter, 2001b; Stillman et al., 2009; Wolfensberger, 1969).

Participants in this study were fully aware of their dependence on physical supports in their life to meet daily living needs. Still, most participants voiced the importance of access to the Divine as providing inner courage, strength, and resilience when facing life challenges. Additionally, most participants readily shared a personal

understanding of self-acceptance by God that held significance for the person. Participants frequently voiced the importance of being heard by others and acknowledged for who they are as a person. Most participants indicated that the ability to self-direct outcomes in their life was influential in how they felt about life. Participants were observed to experience a high interdependence with those who provided support to implement participants' choices. Yet, participants expressed choices were not always supported by staff. Therefore, the ability to self-direct outcomes in life may be as important as levels of support and reliance on others to achieve those outcomes. These mixed findings suggest that spiritual well-being for individuals who experience intellectual and developmental disabilities may be either unrelated to concepts of independence or are mitigated by opportunities to self-direct life choices irrespective of dependency on others. Human service organisations within the United States are now called upon to protect the civil liberties and human rights for all persons receiving services and supports. Persons who experience intellectual and developmental disabilities are seen as entitled to the same fundamental rights and responsibilities as any other citizen.

Research sub-question 1.4. The study explored the relationship between perceived spiritual well-being and social belonging in adults who experience intellectual and developmental disabilities. A Pearson Product-Moment Correlation Coefficient produced a significant, positive relationship ($r = .361$, $r^2 = .13$, $p < .01$) between these two variables and an effect size that indicates a moderate correlation. The findings suggests that as adults who experience intellectual and developmental disabilities spiritual well-being increases so does their perception of social belonging increase.

Thirteen percent of the variability in adults who experience intellectual and developmental disabilities perceived social belonging is accounted by their perceived spiritual well-being.

Several researchers defined spirituality in terms of the concept of connectedness (Friedli, 2001; Hay, 1989; Montgomery, 1991; Simpson et al., 2008). Connectedness is viewed as essential not only for association with the sacred, but also with family, friends, community, and the environment. The importance of a person's interrelatedness with others along with the capacity to form meaningful and reciprocal relationships is an essential aspect of experiencing a spiritual life. Similarly, quality of life constructs highlight the importance of the concepts of relationships, social inclusion, and belonging in subjective feelings of health, well-being, and life satisfaction (Andrews, 1986; Cummins, 2005; Goode, 1990; Stillman et al., 2009).

The concept of connectedness was the most prevalent theme that emerged from participants during the qualitative phase of the study. All participants highlighted both intrapersonal and interpersonal aspects of life as important to both spiritual and physical life domain areas. Participants reported that feelings of connectedness, membership, acceptance, and belonging between self, others, and the Divine were necessary to participants' overall well-being. For example: P6 in self-reflection asks, "how is my spirit doing today?" and self-evaluates whether or not he is doing "what I should be doing in life"; P8 discussed the importance of being in a place where she felt like she belonged; she stated, "I like it here, because everyone is very nice and I feel safe; P12 viewed her faith community as the primary place she meets up with friends and family each week; and P11 in describing her relationship with the Divine stated, "God is my

‘pilot’; He sets the direction for my life....He guides me in what to do.” All of the participants shared the importance of self-acceptance in relation to the presence of disability. Most participants voiced a desire to not be defined by physical characteristics or limitations, but rather by their inner self. Many participants shared stories of a personal journey of searching for a place to “belong” and “fit in.”

Similar to other research findings, adults who experience intellectual and developmental disabilities in this study voiced the importance of not only having relationships, but also that these relationships were of a reciprocal nature (Friedli, 2001; Montgomery, 1991; Simpson et al., 2008). Faith communities were often highlighted as a place where participants went to socialise and connect with others in meaningful ways. Participants shared a desire to not only receive, but give comfort, support, and healing to others during difficult times. Opportunities to be present for another in need appeared to be additive to a participants’ sense of meaningfulness in life. The current study adds additional support to findings of previous research and reveals relational aspects of a person’s spiritual well-being that contribute to a person’s perceived quality of life (de Jager Meezenbroek et al., 2010).

Research sub-question 1.5. The study explored the relationship between perceived religious well-being and quality of life in adults who experience intellectual and developmental disabilities. The current study found no significant relationship between perceived religious well-being and quality of life in adults who experience intellectual and developmental disabilities. This finding differed from the literature reviewed. Since much of the research overlaps religious well-being with quality of life

and life satisfaction literature discussion for this question will be incorporated into research question 1.6.

Research sub-question 1.6. The study explored the relationship between perceived religious well-being and life satisfaction in adults who experience intellectual and developmental disabilities. The current study found no significant relationship between perceived religious well-being and life satisfaction for adults who experience intellectual and developmental disabilities.

The lack of a significant relationship between the variables of religious well-being and life satisfaction does warrant additional discussion. Koenig et al. (2001) reviewed 100 studies regarding the relationship between religion and life satisfaction. Among the 100 studies reviewed only one study found a negative association between religion and life satisfaction. Eighty percent of the 100 studies reviewed reported a positive correlation; 13% found no association, and 7% found mixed or complex results regarding the relationship between religion and life satisfaction. While the current study found a significant positive relationship between spiritual well-being and life satisfaction, the *Religious Well-Being Subscale* produced no significant relationship with the *QOL Life Satisfaction Subscale* for adults who experience intellectual and developmental disabilities. This outcome suggests that for adults who experience intellectual and developmental disabilities perception of their relationship with God may not be linked to how they feel about life in general. Most participants voiced the importance of their relationship with God or a Higher Power. Perhaps, in a world of exclusion, reliance upon God or a Higher Power brings a sense of security and comfort. Participants expressed comments such as, “I know that God will never give me more

than I can handle” (P4); “He guides me in what to do” (P11); and “He helps me handle the things that life brings.” (P14). This somewhat mixed outcome further suggests relevance in distinguishing the various aspects within the spiritual domain of life in the context of research designed to increase understanding of the constructs relationship to life satisfaction. Consequently, consideration should be given to the variety of measurement tools utilised and the specific variables of exploration. For example, Paloutzian and Ellison’s (1991) *SWBS Religious Well-Being Subscale* focuses on a person’s relationship with God or a Higher Power and distinguishes this relational aspect of the spiritual domain from the existential aspects of spiritual well-being. The *Spiritual Well-being Scale* with its two dimensional conceptualisation of spiritual well-being allowed this researcher to acquire from participants an overall measure of spiritual well-being as well as conduct a differentiated analysis of subscales. Thereby, acknowledging two interrelated yet, distinct aspects of spirituality and analysing each aspect for participants in the current study. The *RWB subscale* conveyed the level a participant perceived having an intimate and positive relationship with God and or their church while the *EWB subscale* conveyed a participant’s perception of having a positive sense of purpose and personal meaning in life. This differentiation may prove helpful in planning supports and services and matching support strategies to identified needs.

Research sub-question 1.7. The study explored the relationship between perceived religious well-being and social belonging in adults who experience intellectual and developmental disabilities. A Pearson’s Product-Moment Correlation Coefficient produced a significant, positive relationship ($r = .268$, $r^2 = .07$, $p < .05$) between these two variables and an effect size that indicates a moderate correlation.

The findings suggests that as adults who experience intellectual and developmental disabilities perceived religious well-being increases, so does their perceptions of social belonging/community integration increase. Seven percent of the variability in adults who experience intellectual and developmental disabilities perceived social belonging/community integration is accounted by their perceived religious well-being.

Levitt (2004) analysed the role of religion in transnational migrants. Levitt asserted that transnational migrants extend and deepen cross-border ties of already global religious institutions by people extending their dual membership in the spiritual arena. Though Levitt's research was aimed at increasing understanding of the political implications for transnational religious migration, an apparent benefit for the individual is social belonging. Religious practices of integration into a receiving community and continued connection to a sending community extends the social network for a person. In addition, religious affiliated social networks may provide temporary financial support, housing, work, recreational, and educational opportunities, in addition to minimising a person's sense of being a stranger in an unfamiliar place.

Hayward and Elliott (2009) explored social attraction as a mechanism by which religious groups affect psychological well-being in members of a faith community. The findings of Hayward and Elliott's study provide support for inclusion of elements of individual-group fit in understanding the relationship between religious group membership and personal well-being. Religion and religious life is largely practiced and lived within the context of social groups within a faith community. Therefore, religious affiliation can be a significant pathway for belonging and membership within a group. Hayward and Elliott (2009) assert from their findings that "believing you fit in

with your neighbours in the pews is as important to your spiritual fulfilment as believing in what you hear from the pulpit” (p. 606).

The positive relationship of the level of social support a person receives as part of an affiliation with a faith community is indicated in several studies (Koenig & Larson, 2001). In addition, personal well-being may be impacted by a person’s sense of involvement with a religious group (Greenfield & Marks, 2007). Finally, researchers in the field of intellectual and developmental disabilities provide emphasis to the significant contribution religious groups make in reconnecting people once disenfranchised from others (Webb-Mitchell, 1994, 1996). However, data from studies in intellectual and developmental disabilities is consistent with data from a national survey of people who experience disabilities which indicated that people with disabilities are less likely than people without disabilities to attend religious services (Hanson, 2004). Similarly, the study conducted by the Office of Mental Retardation and Developmental Disabilities in the State of New York found approximately 18% – 19% of individuals surveyed reported the study population do not get to worship services or faith related activities as often as they would like (Patterson, 2009). The literature supports the findings that people with disabilities may not have the same religious and spiritual opportunities available to them as people without disabilities. Reasons for a lack of religious and spiritual involvement with persons who experience disability are accounted for in exclusionary aspects within environmental, societal, social service, and religious arenas (Iwarsson & Stahl, 2003; Kunz, 2011; Swinton et al., 2011).

In discussing participants’ thoughts about the adequacy of his or her spiritual support, about half of the participants responded that they did receive the supports that

they needed to participate in spiritual activities of choice. For participants who did not believe that their spiritual life was adequately supported, the researcher heard comments like: “I do not believe that other people acknowledge my spiritual needs...maybe because I am not religious but, that is no excuse”(P9); or the lack of spiritual acknowledgement by others “makes you feel like only half a person”(P13). Several participants shared stories of life experiences where a lack of transportation, staff support, or physical accessibility issues resulted in limited opportunity for the participant to attend spiritual and religious activities of choice. These findings support previous studies that indicate that a substantial proportion of individuals who experience intellectual and developmental disabilities perceive they do not receive the support needed to participate in the spiritual activities of their choice.

Outside of participants’ reports of inadequate support at times in the spiritual domain, the current study provides additional support to previous research suggestive of a positive relationship between religious well-being and social belonging. Though some participants did not report all experiences with religious organisations to be positive, most participants maintained an affiliation with a religious organisation as a result of positive experiences. Several participants noted that they affiliated with more than one faith community on a regular basis as a result of both spiritual and social benefits. This researcher observed on numerous occasions with participants the positive impact associated with welcoming strategies implemented within various faith communities for participants. In addition, most faith communities provided other than worship service opportunities for participants to socialise, recreate, and support others within the membership of the faith community. Participants who actively engaged in these

opportunities suggested that these activities kept them busy and helped them not to feel lonely. However, equally important to a participants belonging within a faith community was participants expressed sense of connectedness to the Divine. The *SWBS Religious Well-Being Subscale* emphasises a person's sense of well-being in relationship to God or a Higher Power. Participants in the study who proclaimed a belief in God, or a Higher Power, relayed an importance of this relationship in life and described it as both individual and personal. Most participants who espoused a belief in God relayed that they believed God watched over and protected them. Some participants reported that because of their relationship with God the participant knew that they were never really alone. Many participants reported to turn to their relationship with the Divine when in need of guidance and direction in life. Others discussed the importance of their relationship with the Divine when facing medical and health related challenges or were seeking comfort and strength. Furthermore, several participants attributed his or her personal resilience in times of rejection by others to a spiritual knowing of God's acceptance and valuation of the participant.

Research sub-question 1.8. The study explored the relationship between perceived existential well-being and quality of life in adults who experience intellectual and developmental disabilities. A Pearson's Product-Moment Correlation Coefficient produced a significant, positive relationship ($r = .431$, $r^2 = .19$, $p < .01$) between these two variables and an effect size that indicates a large correlation. The findings suggests that as adults who experience intellectual and developmental disabilities perceptions of existential well-being increase so does their overall perception of quality of life increase. Nineteen percent of the variability in adults who experience intellectual and

developmental disabilities perceived quality of life is accounted by their perceived existential well-being.

Cohen and Hall (2009) researched the relationship between existential beliefs and concerns to well-being in older adults. These researchers specifically explored levels of social satisfaction and existential beliefs between various religious groups as a means for understanding group differences in well-being. Cohen and Hall suggested that religious groups view social satisfaction and connection to a faith community differently. They proposed that Protestant Christians tend to view religious identity primarily as a personal relationship with God, holding participation in a religious community as important but secondary to personal aspects of faith. Catholics and Jews view their religious identity as embedded within a religious community. Research findings suggest that many existential variables exert effects on well-being even when controlling for demographics and social support (Cohen & Hall, 2009). Furthermore, the study indicates that existential beliefs of older adults are important predictors of a person's psychological well-being and sense of usefulness and purpose.

The impetus to assist persons who experience intellectual and developmental disabilities in experiencing opportunities to contribute to community and live meaningful, and productive lives is supported in law in the United States with the Developmental Disabilities Assistance and Bill of Rights Act (H.R. 4920—106th Congress: Developmental Disabilities Assistance and Bill of Rights Act of 2000). Additionally, people who experience intellectual and developmental disabilities proved to be dependable employees and exceptional volunteers. Understanding the relationship

between a person's existential beliefs and their personal sense of well-being appears significant to fostering the quality of life in others who may require support.

The current findings support that the relationship between perceived existential well-being and quality of life is both positive and significant for adults who experience intellectual and developmental disabilities. Similar to other research findings, the existential beliefs expressed by participants conveyed importance to a participant's overall sense of life and personal valuation. Participants voiced the importance of being acknowledged for who they are as a person. Identity factors such as, cultural background, familial ties, faith affiliations, work and volunteer roles, expression of individual talents, and personal characteristics appeared to mitigate disability factors in participant's formulation of self-regard and sense of a meaningful life. In addition, most participants associated opportunities to give back to others through personal reciprocal relationships, and employment and volunteer work experiences as significant to the participants' feelings of how *good* life was. Participants repeatedly shared stories of how opportunities to encourage, assist, teach, advocate or support another human being proved meaningful to their view of self worth and purpose in life. Consequently, when participants expressed they were not acknowledged for whom they are or denied opportunities to contribute, participants expressed such circumstance as *bad* or *dark* times within participants' life resulting in feelings of frustration, anger, or depression.

Research sub-question 1.9. The study explored the relationship between perceived existential well-being and life satisfaction in adults who experience intellectual and developmental disabilities. A Pearson's Product-Moment Correlation Coefficient produced a significant, positive relationship ($r = .488$, $r^2 = .24$, $p < .01$)

between these two variables and an effect size that indicates a large correlation. The findings suggest that as adults who experience intellectual and developmental disabilities' perceived existential well-being increases so does their perceived life satisfaction increase. Twenty-four percent of the variability in adults who experience intellectual and developmental disabilities perceived life satisfaction is accounted by their perceived existential well-being. How a person makes meaning in life and makes sense of his or her existence is worthy of contemplation.

Existential well-being measures focus on a person's perceptions of life purpose and life satisfaction (Paloutzian & Ellison, 1991). People's belief as to whether or not they are living a meaningful life is associated with perceptions of life satisfaction (Chamberlain & Zika, 1988; Ghalkos & Bousinakis, 2010). Baumeister (1991) theorised that the human experience of living a meaningful life was shaped by four needs for meaning; a personal sense of *purpose*, *efficacy*, *positive value*, and *positive self-worth*. First, Baumeister suggested that *purpose* was derived from one's understanding of his or her current activities as the activities relate to possible future outcomes. Second, people's feelings of *efficacy* evolve when people feel capable and perceive they can control outcomes in their life and make a significant difference. Third, feelings of *personal value* emerge when a person perceives he or she is viewed as having *positive value* by others in that their actions are interpreted as acceptable and morally worthy. Fourth, a sense of *positive self-worth* is derived from having established feelings of being a person with desirable traits. Baumeister suggested having a meaningful life could only be achieved by satisfying the needs for *purpose*, *efficacy*, *positive value*, and *positive self-worth* through each person's daily life

experiences (Baumeister, 1991). Baumeister and others went on to distinguish between a happy life and a meaningful life (Baumeister et al., 2012). These researchers suggest that even though being happy and finding life meaningful are overlapping concepts, they are different concepts with distinguishing differences. Two important differences were: 1) happiness was linked to being a taker while meaningfulness was linked to being a giver, and 2) feelings of happiness was largely present-oriented, while meaningfulness integrated past, present, and future. Therefore, it is conceivable that a person could have an unhappy but meaningful life, or happy but meaningless life. A meaningful life within the literature is more broadly linked to activities that express and reflect the self, contribute to the welfare of others, and are valued by culture or community (Baumeister et al., 2012; Macgregor and Little, 1998).

The literature discussing life satisfaction, and meaning and purpose overlap extensively. Furthermore, the implications of factors such as reciprocal relationships, daily life experiences, expressive opportunity, social support, and societal inclusion become particularly salient when considering a population of people who are largely reliant on others to meet day-to-day needs. The idea of social connectedness has been related to concepts of both happiness and meaningfulness in life (Debats, 1999; Lambert et al., 2010). Stillman et al. (2009) examined the impact of social exclusion on global perceptions of life as meaningful. The findings suggested social exclusion led to perceiving life as less meaningful yet, that the effects of exclusion were mediated by a persons' sense of purpose, value, and positive self-worth. Lounsbury (2000) proposed that as spiritual beings and generators of meaning, that human beings can transcend his or

her world of experiences and gain ready understanding of self-worth and human regard, and that such beliefs are powerful and transformative within human beings.

The current study adds additional support to the body of research that indicates there is a strong positive relationship between existential well-being and life satisfaction. Some participants expressed finding purpose in life through disability experiences while others reported having a sense of purpose that was unrelated to disability experiences. Most participants appeared to experience positive feelings following opportunities to assist others. Participants shared feelings of joy and personal satisfaction connected with helping a friend, family or community member. For example: P12 who believed her activities of helping people while volunteering was “the most important part” of her work; or P4 who perceived his voice was a gift from God by which he advocates for those who cannot advocate for themselves; or P11 who teaches others through art and poetry. In general, participants sought ways to share their gifts and talents in a manner that was valued by the world around them. These findings for adults who experience intellectual and developmental disabilities are consistent with other research suggesting that meaningfulness in life is derived over time, involves social support and reciprocity, and is associated with acts of giving verses taking.

Research sub-question 1.10. The study explored the relationship between perceived existential well-being and social belonging in adults who experience intellectual and developmental disabilities. A Pearson Product-Moment Correlation Coefficient produced a significant, positive relationship ($r = .349$, $r^2 = .12$, $p < .01$) between these two variables and an effect size that indicates a moderate correlation. The findings suggest that as adults who experience intellectual and developmental

disabilities perceived existential well-being increases so does their perception of social belonging/community integration increase. Twelve percent of the variability in adults who experience developmental disabilities level of perceived social belonging/community integration is accounted by their perceived existential well-being.

Psychologists and anthropologists repeatedly identified human beings desire to seek connectedness and social belonging as a core element of human behaviour (Berkman, Glass, Brissette, & Seeman, 2000; Fiske, 2004; Fiske & Yamamoto, 2005). The desire of people to live, love, work, and recreate alongside others they know and who know them is fundamental in human beings and relationships. An individual's relationships and sense of social belonging help to form identity, build community and cultural roles, and cultivate feelings of trust and security. Likewise, the psychologically deleterious effects of the absence of social belonging, connectedness, and feelings of being an outcast of society is well documented (Fiske & Yamamoto, 2005). This can also be found in research in existential well-being.

Theorists suggest that existential well-being involves a sense of meaning and purpose, a secure and stable self-identity, and feelings of belonging (Hammond, 1985). Existential well-being measures focus on a person's perceptions of life purpose and life satisfaction (Paloutzian & Ellison, 1991). Therefore, the interconnectedness of community roles, membership within groups, and sense of personal identity contribute significantly to individuals understanding the meaning, purpose, and direction of their life. Fry (2000) examined existential factors and a person's sense of well-being and found "existential measures of personal meaning, religiosity and spirituality contributed more significantly to the variance in well-being than did demographic variables or other

traditional measures such as social resources, physical health or negative life events” (p. 375). Findings from this research support that these factors also hold true for adults who experience intellectual and developmental disabilities.

The concept of connectedness was the most prevalent theme throughout the data collected from participants in the current study. Participant’s interconnectedness with self, friends, family, community, nature, and the transcendent were associated with positive feelings about life in general. A participant’s sense of social belonging appeared to mitigate the negative impact of challenging and difficult times. Consequently, a lack of connectedness appeared to be associated with feelings of depression and isolation with participants. Participants were observed to actively seek out people to see and places to go that engendered a sense of belonging and acceptance and avoid people and places where rejection and judgment were experienced. A participant’s sense of social belonging appeared most prevalent in gatherings where other people knew their name, acknowledged their presence, and included them in the event activities. Faith and religious communities provided several participants a pathway to experience a strong sense of belonging and membership within a group. In addition, several participants’ voiced that their personal relationship with God provided a sense of comfort and inner well-being while diminishing feelings of loneliness. Additionally, some participants voiced the desire and dream of finding someone special who would be a participant’s partner in life in an intimate and mutually committed relationship. Several participants appeared to associate marriage and family as necessary aspects of a truly *complete* life. In a broad view, participants appeared to

formulate a personal sense of meaning and purpose within a context of the various relationships in participants' life.

Primary research question 2.0. The study explored if there was a difference between males and females regarding perceived spiritual well-being and quality of life in adults who experience intellectual and developmental disabilities. A review of the literature and data analysis suggested that gender differences may play a role in perceptions of spiritual well-being and quality of life within the study population. An independent *t-test* was conducted to answer research sub-questions 2.1 and 2.2 to determine if there were mean differences in male and female total scores on the *Spiritual Well-Being Scale* and *Quality of Life Questionnaire*.

The study investigated in research sub-question 2.1 if there was a difference between *Spiritual Well-Being Total Scores* of males and *Spiritual Well-Being Total Scores* of females. An independent *t-test* analysed Group 1, males (n = 21) and Group 2, females (n = 26). An alpha value of $\alpha = .05$ was set. It was hypothesised that there is a difference in the spiritual well-being of life of males and females. The *t-test* produced no significant differences between the spiritual well-being scores of males and the spiritual well-being scores of females.

The current findings indicate that there is no appreciable difference in the spiritual well-being of males and females in adult's who experience intellectual and developmental disabilities. Contrary to this, previous research with other populations suggests males and females may not view spirituality the same. Studies indicate that females tend to attribute a stronger relationship between religion and health than males (McCullough et al., 2000; Waite et al., 1999). In addition, findings of a 28 year

longitudinal study, exploring mortality rates and church attendance, discovered the lowest mortality rates among females reporting the most frequent church attendance (Strawbridge et al., 1997). Finally, Nagel and Sgoutas-Emch (2007) explored the relationship of spirituality, health beliefs, and health behaviours in young adults. Findings indicated that males were more likely than females to drink alcohol, exercise, and believe that illness and recovery from illness was a matter of fate. While females were more likely than males to believe lifestyle was most influential in illness and recovery from illness (Nagel & Sgoutas-Emch, 2007).

Wills (2009) found significant gender differences in satisfaction with spirituality and religiosity. The study sample population (n = 830) consisted of 55.9% females and 44.1% males, ages 18 ≥ 55 years old. Findings indicated females feel a higher satisfaction with spirituality as compared to males. In addition, satisfaction with spirituality and religiosity indicate age differences. Findings suggest satisfaction with spirituality and religion increase with age (Wills, 2009).

Findings from this research for adults who experience intellectual and developmental disabilities found no evidence supporting gender differences in the spiritual well-being of participants. Consideration of gender issues within diverse populations, cultures, and social role formation that influence spirituality may be important considerations within exploratory next steps. Furthermore, people who experience intellectual and developmental disabilities are representative of populations within a population. People who experience intellectual and developmental disabilities are not a homogenous group and within group differences may not be given enough attention. Furthermore, the American Association on Intellectual and Developmental

Disabilities and the ARC jointly developed a position statement in regards to sexuality and the rights of persons with intellectual and developmental disabilities due to decades of treatment as asexual human beings in the United States (Congress of Delegates, The Arc of the United States, November 8, 2008). Though efforts within the United States are being made on a policy and practice level to recognise the need for support to be different across each gender, this researcher frequently observed a gender neutral approach with the provision of supports to participants in this study. The appreciable loss of distinctive gender identity and social role formation experienced by persons with intellectual and developmental disabilities may contribute to the disparate gender related findings regarding spiritual well-being of persons within diverse populations.

Furthermore, the current findings suggest that society's treatment of individuals who experience intellectual and developmental disabilities as asexual beings may have implications across life domain areas in ways yet unexplored and perhaps unintended.

The study investigated in research sub-question 2.2 if there was a difference between *Quality of Life Questionnaire Total Scores* of males and *Quality of life Questionnaire Total Scores* of females. An independent *t-test* analysed Group 1, males (n = 21) and Group 2, females (n = 26). An alpha value of $\alpha = .05$ was set. It was hypothesised that there is a difference in the quality of life of males and females. The *t-test* produced no significant differences between the quality of life scores of males and the quality of life scores of females.

The current findings indicate that there was no appreciable difference in the quality of life of males and females in adults who experience intellectual and developmental disabilities and is consistent with research conducted with earlier studies

for the *QOL-Q* (Schalock, Keith, & Karan, 1989). The norming sample with Schalock & Keith's *QOL-Q* instrument was based upon 552 individuals who experienced intellectual and developmental disabilities in the United States. Though no meaningful gender differences in quality of life among adult males and females with intellectual and developmental disabilities was found in Schalock and Keith's (2004) research, gender differences in quality of life for other adult populations is prevalent in the literature (Murtagh & Huber, 2004).

Murtagh and Hubert (2004) concluded that a greater number of nonfatal physically disabling conditions occurring in older adults, including fracture, osteoporosis, back pains, osteoarthritis and depression, contributed to greater disability and lower quality of life among aging women as compared to men. Similarly, Muhwezi et al. (2010) in a study exploring gender-based profiling of quality of life for persons (n = 446), 18 – 84 years of age, found that women generally reported poorer physical health impacting quality of life outcomes than did men. Kim et al. (2010) explored gender differences in the population of adults recovering from acute stroke. Findings among stroke populations indicate that females (n = 480) experienced greater difficulty than males (n = 575) in recovering from a disabled state after acute stroke impacting quality of life. Among mental health populations gender differences and quality of life outcomes have been widely seen in areas of clinical presentation, psychosocial functioning, and course of illness among adults who experience schizophrenia (Willhite et al., 2008).

The theoretical framework regarding what constitutes quality of life for people with intellectual and developmental disabilities, suggests that what constitutes quality of

life for people with disabilities is the same as people without disabilities. Yet, people who experience intellectual and developmental disabilities experience a higher number of health related co-occurring disorders than the general population (Koritsas & Iacono, 2011). Many of the co-occurring disorders produced gender different quality of life outcomes within non-intellectual and developmental disability populations studied. In the current study, a review of the individual service plans indicated that the majority of participants experienced two or more significant mental or physical health-related disorders in addition to their primary disability though no gender different quality of life outcomes were evident from participant responses on the *Quality of Life Questionnaire*. These findings call into question previously held theoretical frameworks that operate from an assumption that what constitutes quality of life is the same for all people with and without disabilities. It could be hypothesised that, in populations where gender differences are not socially validated or aligned with specific gender role expectations by society, that self-perceptions of quality of life between males and females might be the same. However, this is different than populations and cultures where there is distinct gender role identities and expectations of males verses females.

Primary research question 3.0. The study explored if there is a difference for individuals who experience intellectual and developmental disabilities in perceived spiritual well-being and quality of life with different levels of support in living situations. The findings suggest that as a group, individuals who experience intellectual and developmental disabilities demonstrate support needs in various aspects of daily life. The presence or absence of adequate supports in essential life domain areas directly impact opportunity and quality of life. In the current study, participants' living situation

categories were not definitive of the levels of either paid staff or natural supports that participants received in day-to-day life. Therefore, this study separated participants by levels of support provided within living situations. The three levels of support were 24-hour supports, daily interim supports, and weekly intermittent supports within living situations. Level of support categories are representative of greatest to least levels of assistance needed in the completion of activities of daily living of participants. A one-way, within subjects analysis of variance (ANOVA) was utilised to answer research sub-questions 3.1 and 3.2. Differences in levels of support and *Spiritual Well-Being Total Scores*, and differences in levels of support and *Quality of Life Questionnaire Total Scores* were analysed.

Research sub-question 3.1. The study investigated if there was a difference in *Spiritual Well-Being Total Scores* with different levels of support in living situations. The study gathered *Spiritual Well-Being Total Scores* from participants living in situations receiving three variable levels of support: 1) 24-hour supports (n = 14), 2) daily interim supports (n = 11), and weekly intermittent supports (n = 22). The mean *Spiritual Well-Being Total Scores* for participants living in 24-hour support situations was M = 90.36. The mean *Spiritual Well-Being Total Scores* for participants living in situations with daily interim supports was M = 85.91, and the mean *Spiritual Well-Being Total Scores* for participants living in situations with weekly intermittent supports was M = 88.95.

A comparison of the *Spiritual Well-Being Total Scores* for participants living within each level of support was conducted using a one-way, within subjects, analysis of variance (ANOVA). The hypothesis (H1) stated that at least one mean differed from the

others. A one-way, within subjects, ANOVA was conducted to test the hypothesis. No significant difference between means was found between 24-hour supports, daily interim supports, and weekly intermittent supports.

The current findings indicate that there was no significant difference in *Spiritual Well-Being Total Scores* across levels of support provided within living situations. This finding, coupled with participants' interviews suggested almost half of the participants did not receive the support needed to participate in religious and spiritual activities of choice, suggests that variables other than staff availability may contribute to unmet needs within the spiritual domain. These findings are not surprising considering the lack of attention spirituality was given in people's planning process. The current study provides additional evidence that spirituality is an important aspect in peoples' lives that may not be adequately addressed or supported. A contributing factor may be a lack of understanding by those who support persons who experience intellectual and developmental disabilities in either the importance of this life domain area, or the capacity of people with intellectual and developmental disabilities to benefit from spiritual activities. Research findings in this area have not readily made it into organisational thinking or practice for either religious institutions or community support programs in general. Publicly funded service organisations continue to hold misconceptions regarding the law and the separation of church and state in respect to policy development and practice in supporting the spiritual domain for people (Gaventa, 2006). Service provider direct support training curricula, in general, do not address information regarding the spiritual needs of people who experience intellectual and developmental disabilities. Consequently, attitudes of confusion continue around staff

roles in exploring and assisting individual's who experience intellectual and developmental disabilities in spiritual pursuits (Gaventa, 2006; Patterson, 2009). In order to adequately meet the spiritual needs of a population of people who are dependent on others for support, it is necessary to bridge the gap between research and practice and develop standards of support within organisations that are inclusive of all aspects of life to include spiritual.

Research sub-question 3.2. The study investigated if there was a difference in *Quality of Life Questionnaire Total Scores* with different levels of support in living situations? The study gathered *Quality of Life Questionnaire Total Scores* from participants living in situations receiving three variable levels of support: 1) 24-hour supports (n = 14), 2) daily interim supports (n = 11), and weekly intermittent supports (n = 22). The mean *Quality of Life Questionnaire Total Scores* for participants living in 24-hour support situations was M = 95.00. The mean *Quality of Life Questionnaire Total Scores* for participants living in situations with daily interim supports was M = 90.73, and the mean *Quality of Life Questionnaire Total Scores* for participants living in situations with weekly intermittent supports was M = 89.50.

A comparison of the *Quality of Life Questionnaire Total Scores* for participants living within each level of support was conducted using a one-way, within subjects, analysis of variance (ANOVA). The hypothesis (H₁) stated that at least one mean differed from the others. A one-way, within subjects, ANOVA produced no significant difference between means for those living with 24-hour supports, daily interim supports, and weekly intermittent supports.

Research indicates that lifestyles of persons who experience intellectual and developmental disabilities vary dramatically based upon their residential situation. Various findings within research indicate that community verses institutional living situations promote greater personal freedom, greater levels of social activities, and closer family and friend connections which are all factors associated with quality of life (Horner et al., 1988; Stancliffe, 2005; Stancliffe & Lakin, 1998). Most recently, research examined the sizes and types of living situations and found that smaller community-based services were superior to larger congregate settings for people (Kozma et al., 2009). This was attributed to factors of greater personalisation within planning and supports that afforded an increased level of opportunity within community to pursue individual and social interests. Findings suggest factors other than the basic model of support are important in determining outcomes.

Historically, the availability of supports to individuals experiencing intellectual and developmental disabilities has been a critical factor to access and participation in community. Traditionally, service categories were indicative of the functional abilities of the people who resided in the various residential settings. However, Alaska's community services developed under a philosophical ideology that fostered people receiving the services and supports needed for success in the places the person chose to live, work, and recreate. In the current study, traditional service categories as defined by funding entities were not representative of the functional abilities of the person living in a particular setting. Therefore, the question of whether or not there was quality of life differences based upon the living situation as delineated by the level of supports provided was important to explore.

The findings indicating no significant differences in *Quality of Life Questionnaire Total Scores* for participants across levels of support in living situations suggests that staffing levels alone do not determine quality of life for people. Factors such as having options from which to choose, ability to self-direct outcomes, and staff attitudes in the provision of supports may have a greater influence on perceived quality of life than staffing formulas. Pomeranz, in his *Universal Enhancements* staff training curriculum cautions direct support workers that “an institution is not a place, it’s a state of mind” (Pomeranz, 1992, *para.2*). Such thinking suggests that factors associated with the quality of an individual’s relationships and how they are treated by others is more influential on life outcomes than the physical characteristics of living situations. If professionals concede that a change of address answers the call for inclusion, then the support response will fall short of meaningful outcomes in the life of a person with disabilities. Additionally, the emphasis by the provider organisation in this study, codified in the organisational mission statement to design services and supports in the manner requested by individuals and families may be a mitigating influence in perceived quality of life outcomes. The overriding principle in the organisation’s mission statement is to maximise choice and control of services and supports by the supported individual. Individually driven supports and services that enhance personal freedom, support the formation of meaningful relationships, and are aligned with individual interests and desires may create greater satisfaction in life than a traditional model of supports that are based upon functional limitations and prescribed by a team of professionals.

Primary research question 4.0. The study explored how adults who experience intellectual and developmental disabilities understand and describe the importance of a spiritual dimension of life to other aspects of life. A qualitative approach consisting of unstructured, in-depth interviews, participant observations and documents review associated with the sample population was utilised to answer the fourth question of this research study. Data collection acquired first person accounts of the study population's self-perceptions in regards to personal beliefs, experiences, and relevancy of spirituality in life through the personal story and meaning of participants lived experience.

This study employed a first person account approach. Findings in this study are consistent with other researchers who examined the personal impact and role spirituality plays in individuals who experience disabilities. For example, Specht et al. (2005) examined the self-perceptions of spirituality in adults (N = 15) who experienced congenital disabilities. Specht et al. (2005) suggested the importance of spirituality as a protective mechanism in life revealing four recurring themes: God as a guiding force, faith as a provider of inner strength, sense of meaning and purpose in life in respect to disability, and appropriateness of the use of spirituality in counselling. Specht et al. (2005) specifically sought to gain understanding regarding how persons with disabilities utilised spirituality during challenging times of life. These researchers discovered that participants identified spirituality as a resource and support that provided aide in coping with life challenges and assisted the individual in making meaning of life circumstance and exploring answers to difficult life questions. Research recommendations within a counselling context suggested that professionals tap into a person's spiritual dimension

of life as part of the healing process. Frequently, participants in the current study voiced similar sentiments, presenting a belief that their spiritual life assisted in keeping them out of harm's way, protected them during times of medical intervention, or aided in physical healing.

Boswell et al. (2007), explored how adult men and women (N=13) with severe disabilities perceive the interaction of spirituality and disability in their lives. Five primary themes emerged from Boswell et al.'s (2007) research: purpose, awareness, connections, creativity, and acceptance. Boswell et al. (2007) characterised spirituality and disability as an ongoing interactive process characterised by the five themes interacting with and overlapping each other depending on life circumstance. These researchers highlighted the importance of acknowledging spirituality's influence in life for people who experience disabilities. Furthermore, Boswell et al. (2007) suggested that both rehabilitation professionals and church leaders alike assist individuals who experience disabilities in identifying strategies that promote personal inner strength, utilise creativity and individual forms of self-expression, and support the building of interrelationships and connectivity with others.

Conner (2010) conducted research on faith and pathways to connectedness for young people who experience intellectual and developmental disabilities. Conner suggested that the spiritual life within a Christian model assisted in negating feelings of loneliness and fostered friendship and spiritual nurturing for individuals who experience intellectual and developmental disabilities. Furthermore, Conner advised that regardless of what laws or legislation may be adopted by governments to address barriers, that cultural and societal attitudes deeply entrenched within community may deny the

experience of belonging for those viewed as different. Conner claimed that spirituality fosters connectedness. He further suggested that Christian communities that live their values intentionally engage with others in healing relationships by walking in life alongside both people with and without disability. Similarly, within the organisation associated with the current study, the philosophy of *ubuntu* was adopted as a support strategy and was espoused as part of the corporate culture and in regular staff development training. Desmond Tutu described this life philosophy of *ubuntu* in the following way:

‘My humanity is caught up, is inextricable bound up, in yours.’ We belong to a bundle of life. We say, ‘A person is a person through other persons.’ It is not, ‘I think therefore I am.’ It says rather: ‘I am human because I belong, I participate, I share.’ (Tutu, 1999, p. 31)

Such ideology conveys an understanding of the importance of the interconnectedness of humanity. It is a message of insight that declares that which happens to one person, ripples to the whole of people. Though idealistic in nature, concepts of belonging and membership within the study population’s organisational community was proclaimed for all stakeholders and was often evident by this researcher in observations of employee and support recipient interactions. Much like Tutu’s statement, the concept of membership was not a passive concept but rather, exemplified that a participant was a valued, contributing part of something bigger than themselves. All of the participants in the current study voiced the importance of their interrelatedness with others in relation to participant’s personal well-being, be it family, friends, neighbours, staff, or other community members. Furthermore, participants acknowledged the need for support in accessing and maintaining relationships in their life. When participants shared

circumstance when they were unable to participate in spiritual activities, or lacked social support or personal acknowledgement from others, or were unable to contribute in meaningful ways to others, the participant viewed such occurrences as difficult and lonely times in life. Such findings are suggestive of the importance of establishing pathways of connectedness. Additionally, these findings highlight the importance of the influence support workers may be able to have in fostering quality relationships that result in improved outcomes for individuals supported and the need for support programs to be deliberate and intentional in incorporating relationship building strategies into support provision.

The analysis of data from this study produced five primary overarching themes as descriptors within participants lives associated with spiritual well-being in relation to a participants' quality of life. The five primary themes were *framework for life, identity, opportunity to contribute, inner well-being, and connectedness*. Based upon the analysis of data, the researcher developed a model depicting the relationship between the two variables. Figure 7.1 depicts this model and brings together both quantitative and qualitative data and highlights the relationship of spiritual well-being to quality of life as conveyed by the study population. The lower half of the model, Figure 7.2 provides a visual depiction of the significant positive nature of the relationship of participants' perceived spiritual well-being to aspects of quality of life as measured on the *Spiritual Well-Being and Quality of Life Questionnaire Scales*.

Figure 7.2. Lower Half of Relationship Model

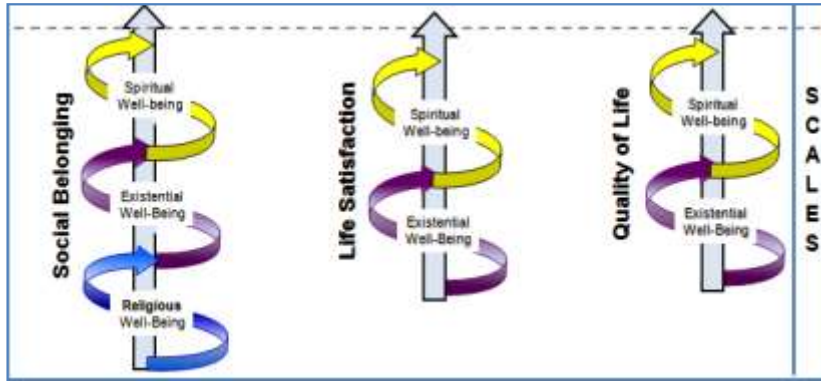


Figure 7.2. Lower half of the relationship model of spiritual well-being & quality of life.

This model depicts that a participants quality of life and in particular, life satisfaction and social belonging, stand in relation to participants' spiritual well-being. Additionally, specific aspects of spiritual well-being, that is, existential and religious well-being, were related to specific aspects of the quality of life construct. The upper half of the model, Figure 7.3 provides a visual depiction of descriptor themes emergent from the relationship of spiritual well-being and quality of life as understood and described by participants.

Figure 7.3. Upper Half of Relationship Model



Figure 7.3. Upper half of the relationship model of spiritual well-being & quality of life.

Furthermore, the model communicates the distinctive yet, interdependent and interrelated thematic experience cultivated within a participant's life by the interplay of spirituality and quality of life.

The majority of participants described their spiritual life as being very important to life in general. All of the participants interviewed discussed spirituality in their life that consisted of beliefs and values which provided a framework by which life events were interpreted and decisions were made. For example: P4 stated, "Sometimes at night, I believe He [God] is speaking to me in my head. I believe that miracles happen"; or P11 who stated "I see how God works in peoples' lives....Now I see God all around me." Several participants voiced the critical role spirituality played for them in understanding life experiences and how they should behave in life. For example: P3 was raised from a Christian ideology and stated that she was taught that she could "correct any bad deeds with good deeds" and therefore, ensures that she does "good" deeds on behalf of others to stay spiritually well. Many participants voiced a belief that God or a

Higher Power provided both protection and guidance in life. Several participants pointed to their spiritual life for comfort and coping in difficult times as well as avenues of protection and guidance. Finally, participants highlighted concepts of connectedness as prevalent within their spiritual life. Participants repeatedly shared stories of their relationship with self, friends, neighbours, community and God. These relationships were described as central and vital to participants overall well-being and feelings about life in general.

Theoretical Implications of the Study

In the review of the literature, it was presented that there was a void of information on spirituality in relation to quality of life for individuals who experience intellectual and developmental disabilities. This research establishes a pathway that links this topic and information regarding people who experience intellectual and developmental disabilities with the general population. The most significant finding this study revealed is that spirituality represents an important life dimension for adults who experience intellectual and developmental disabilities. The analysis of data collected in the quantitative phase demonstrates a significant, positive relationship exists between spiritual well-being and the quality of life within the study population. Furthermore, the magnitude, and positive direction of this relationship appears to benefit people who experience disabilities in several ways. The data collected during the qualitative phase of this research was fundamental to exploring the manner in which the study populations' spiritual life benefited other aspects of their life. Findings from this research suggest that spirituality increased feelings of social belonging and overall life satisfaction. Spiritual and religious activities present avenues for community

engagement and enhanced quality of life. Spirituality, as a pathway to connect self with others, with nature, and with a greater life force, is well supported within the literature for people with and without disabilities. A majority of adults who experience intellectual and developmental disabilities highlighted spirituality as an important means of connection to family, friends, community, nature, and a higher power.

Additionally, participants in this study viewed their spiritual domain of life as a means to cope with life circumstance and manage through difficult times. Findings further suggest a strong, positive relationship between a participant's existential understanding of life purpose, meaning, and direction, and how adults who experience intellectual and developmental disabilities feel about their life in general.

Study findings underscored that participants viewed spirituality as an important dimension of life. A majority of the participants in the study perceived spirituality as essential to their overall health and well-being. The significance of their perceptions is that this dimension does not appear to be contingent on intelligence or functional ability, and lends support to theories of the universal and relational nature of spirit. Additionally, findings align with theories that regard the spiritual dimension of life as a separate and distinct construct from quality of life versus a subordinate component within the quality of life construct (de Jager Meezenbroek et al, 2010; Sawatzky, 2002). Given the spiritual as a universal human dimension further requires that spiritual assessment instruments take into consideration the full array of human diversity and both religious and non-religious populations (de Jager Meezebroek et al. 2010).

Strongly refuted by study findings are early theories that placed people who experience intellectual and developmental disabilities as incapable of experiencing the

spiritual aspects of life. Furthermore, there is a need to review theological positions that claim that individuals who experience diminished intellectual abilities cannot know God because God as an abstract concept cannot be understood by those with limited intelligence. Demmons (2009) begins to ask these and other critical theological questions regarding spirituality and intellectual disabilities. Demmons' research explored doctrinally and pastorally the underlying question of "How might one know the Word of God without words?" (Demmons, 2009, p. 3). Demmons' research ultimately turns the theoretical prism to conclude that knowledge of God by all persons is not only possible, but may occur in very unexpected ways. This type of thinking is consistent with theological views suggesting knowledge of God can be gained from personal, experiential, and relational paths. For example, Swinton suggests that a relational knowing of God may be represented in the "quality of our relationships, rather than the quantity of our intellect" (Swinton, 1997, p. 25). Swinton (2001) emphasised that within Christianity, community and relationships are central to a faithful walk within a Christian life. Pathways for a relational or experiential knowing of God that are less cognitively-based may be more inclusive of persons with intellectual and developmental disabilities.

Additionally, study findings challenge current understandings of the images of God as portrayed in the lived narratives of individuals who experience intellectual and developmental disabilities. Similar to Eisland's research (1994), participants in the current study viewed images of God in relation to his or her disability as being neither blessing nor curse. P4 who utilised a wheelchair, hypothesised that God might utilise a wheelchair as he understood that he was created in "His [God's] image." (P4) P11

thought of God as her “pilot” and relied on a personal relationship with God for guidance and direction in life irrespective of her disability. P2 understood her relationship with God through intimate personal encounters in nature associated with the sun, rain, and seasons. Furthermore, study findings suggest that participants experienced their spiritual life and faith as something that was dynamic, ever growing and deepening over the years through varied life experiences. The theoretical implications of the study highlight the importance of spiritually focused assessment instruments that are inclusive of diverse levels of functioning and allow for varied expressions of spirituality that acknowledge a more ecumenical understanding of this life dimension.

In regards to quality of life, early quality of life models for individuals who experienced disabilities prioritised the health status of a person over other aspects of life, study findings suggest factors such as opportunities for self-determination and social support, may act as equalising forces to significant health issues and overall perceptions of well-being and quality of life. Study findings lend support to theoretical models that emphasise the utilisation of both objective and subjective information in the evaluation of individuals’ quality of life both with and without disabilities. A critical variable in understanding a participant’s perception of quality of life was the observed interactive nature of the participant within the context of the participant’s environment and personal relationships. Personal encounters occurring within the quality phase of the study provided a richer understanding of the influence of the spiritual life domain for a participant.

Finally, study findings corroborate research with other populations that indicate that the spiritual dimension of life for people who experience intellectual and developmental disabilities may be as important as physical well-being or other life domain areas (Adegbola, 2006; Brady et al, 1999; Shah et al, 2011). The spiritual dimension of life assisted participants with exploring significant life questions; providing individual vision, values and sense of well-being; and, assisted in making meaning of life experiences and individual purpose. Therefore, intentional, deliberate, and purposeful actions to address the spiritual well-being of individuals who experience intellectual and developmental disabilities is a necessary next step within the field of intellectual and developmental disabilities.

Policy and Practice Implications of the Study

Study findings suggest that most participants perceived their spiritual needs to be as important as needs in other areas of life. Adults who experience intellectual and developmental disabilities described spirituality as a source of hope and strength in the present and for the future. Participants expressed that their spirituality helps them make decisions, maintain a positive attitude, and manage fears they experienced. In addition, some participants pointed to their faith community as a primary connection to others outside of the disability field.

Despite the significance that participants placed on spirituality, a majority of the participants perceived that their spiritual needs are not adequately acknowledged and supported by others. This finding is consistent with the literature suggesting that disability populations may not have equal access or adequate levels of support to participate in faith communities and spiritual activities of choice. A contributing factor

in the United States may be the fact that the healthcare industry that funds services for individuals who experience intellectual and developmental disabilities does not have provider standards specific to addressing the spiritual needs of those accessing services. Societal and political perceptions still largely hold spirituality as a private matter verses public. Consequently, confusion remains around professional roles and practice in respect to the separation of church and state. The resultant lack of alignment between support philosophies that establish holistic, person-centred services and the absence of provider standards for this life domain area, contributes to the confusion regarding the role of support workers in the field of disabilities. Rectifying the disparity requires an awakening on the part of government and funding entities, service planning, and provider organisations alike as to the relevance of the spiritual domain of life to a person in regards to his or her overall well-being. Rationales for including spiritually relevant supports are: the provision of holistic life supports; the honouring of personal choice, culture, values, and belief systems; supporting people in the manner in which the person makes meaning and copes in life; and tapping into the power of what people hold as sacred or divine. Therefore, the establishment of specific provider standards and guidelines for planning processes and the delivery of supports and services associated with the spiritual domain of life are necessary.

The implications of these findings suggest that the first step begins with assessing members of the intellectual and developmental disability populations as to the relevance of spirituality to these members' quality of life. The development of appropriate assessment instruments is needed to address the spiritual well-being of

people of all functional abilities. Assessment methodologies should be inclusive of diverse abilities, and avenues of self-expression.

Information gathered in the course of the first step then leads to the second step, incorporating the spiritual dimension of life in person-centred planning processes. Though person-centred planning processes are industry standard in service provision within the United States and many other countries, the spiritual dimension of life is not readily included as best practice. The development of best practices that incorporate spirituality as an essential aspect of life planning for people who experience intellectual and developmental disabilities is essential to holistic life planning. Plans of support for individuals who experience intellectual and developmental disabilities that afford opportunities to explore important life questions; address issues of identity and culture; identify personal inner strengths; support a variety of avenues of spiritual self-expression; and foster connections between self and others may facilitate more meaningful outcomes in support contexts.

In regards to service planning, a review of participants' individual service plans provided corroborating evidence that planning processes for needed supports and services do not readily address supports to meet this population's spiritual needs. The planning format along with required documents are dictated by State government and funding source regulations in Alaska which are under the authority of the national health industry statutes and regulations in the United States. Planning documents should expand beyond the simple mention of a person's religious affiliation to be inclusive of a person's cultural and spiritual beliefs and values; faith rituals and practices; avenues for seeking authority and guidance in life; and, sense of the sacred and Divine. Current

planning processes appear biased within a medical and developmental context that prioritise support and assistance in physical and mental/intellectual life skill areas.

Additionally, training curricula for state funded Care Coordinators give little regard if any to a planner's role in addressing the spiritual needs of individuals with disabilities. Therefore, it is not surprising that there is a lack of attention within the planning process regarding the spiritual domain of life. The absence of acknowledging this life domain area in a planning process may inadvertently eliminate available resources for a person, misalign service approaches from personal or cultural values, and result in diminished outcomes for the person overall. Care Coordination, education and training regarding the spiritual needs of individuals who experience intellectual and developmental disabilities is necessary to facilitate a more holistic planning process.

Step three ensures incorporation of the spiritual dimension by developing service delivery support guidelines and training. In order for spiritual supports to be adequately implemented within systems of support, it is equally important to develop implementation guidelines and staff development programs for human service providers, and training regarding spirituality. Future community support program development should include staff and clergy training curriculum and education regarding the spiritual lives of individuals who experience intellectual and developmental disabilities. Training curricula should also incorporate information on various faith traditions, culture, and lifestyles of people. Specific to faith groups, training curriculums for clergy should broaden perceptions that view people who experience intellectual disabilities as a ministry to that of members who can do ministry

within the congregation. Staff and clergy training curriculums should clearly define respective support roles, responsibilities, and boundaries in this arena.

The final step seeks to achieve full community inclusion. To the same degree as provider training, cross-education with faith communities regarding intellectual and developmental disabilities is important to promoting inclusive faith communities. Education should include how to assist individuals who experience intellectual and developmental disability to answer spiritual questions for their own life. In addition, to curriculum development, education, and training should address spirituality across the lifespan and incorporate a variety of topics relevant to spiritual aspects of life to include, aging and end of life planning for intellectual and developmental disability populations.

Recommendations for Future Research

Exploration of the spiritual dimension of the lives of individuals who experience intellectual and developmental disabilities represents an emerging horizon on a changing landscape. The current study implicates the need for future research in theory development in spirituality and continued refinement of theory regarding what constitutes quality of life for persons who experience intellectual and developmental disabilities. Specific areas that need further study are in the identification of the characteristics of the relationship between spirituality, overall life satisfaction, and specific life domain areas; assumptions regarding how these relationship work; and, the presumption of an additional predictive feature of quality of life domains to overall life satisfaction. Furthermore, research is needed in the measurement and assessment of spiritual well-being for religious and non-religious individuals of all functional abilities.

Formal assessment instruments are not available for individuals with significant intellectual disabilities and limited ability to verbally communicate. Methodologies that allow for the exploration of diverse expressions of spirituality in life need development.

Additionally, a review of the literature and analysis of the data indicates the need for further exploration regarding gender differences and levels of support among participants. Confounding outcomes within research regarding spiritual well-being and gender requires further investigation. Additional exploration in the current study found no gender difference between the spiritual well-being of adults who experience intellectual and developmental disabilities and quality of life. However, the health related literature suggests that gender differences are a factor in quality of life within other populations. In addition, there are mixed findings within the literature regarding gender differences, and expressions of spiritual beliefs and values. The lack of research in this area for individuals who experience intellectual and developmental disabilities suggest further research is needed to understand the role gender differences play in the spiritual lives of individuals within the intellectual and developmental disability population. Research to understand the impact of social expectations and subsequent treatment of a population of people as largely dependent, asexual beings who historically were segregated from community to the evolving inclusive philosophies with community services may prove helpful in understanding current disparities in the literature across variables.

Historically, the literature suggests that levels of support and living situations greatly impact the ability of persons who experience disability to access and engage in desired community activities. However, a review of support levels and living situations

of participants in this study suggested that in addition to staff availability, other factors such as staff training and organisational practice may play a significant role in whether or not a person is supported in desired spiritual pursuits. Research to explore various provider models and outcomes would be beneficial to future organisational efforts for quality improvement.

Finally, further research is needed to explore the impact of culture, gender, ethnicity, health, co-occurring disorders, level of functioning and living circumstance on spirituality for people who experience intellectual and developmental disabilities. The current study was exploratory and descriptive in nature and represents early efforts to understand the spiritual domain, a dimension of life largely neglected for people who experience intellectual and developmental disabilities within the social sciences.

Conclusion

This study explored and described how adults who experience intellectual and developmental disabilities perceive the significance of their spiritual well-being in relation to their quality of life. The quantitative portion of the study described the direction and magnitude of the relationship between participants' spiritual well-being and quality of life. The findings revealed a significant, positive relationship between spiritual well-being and quality of life for participants.

The qualitative portion of this study described the relevance that participants place on the spiritual domain of life in regards to other aspects of life. Findings from the qualitative portion of the study suggested that participants consider spirituality as an important aspect of life. Furthermore, the spiritual domain contributed to a participants'

life framework, identity, opportunity to contribute, sense of well-being, and sense of connectedness to the world around them.

Despite the spiritual domain remaining somewhat obscure, research indicates that people in general view spirituality as a source of hope, comfort, and strength. Additionally, most people highlight a spiritual connectedness to family, friends, community, nature, and the sacred as an important aspect of overall well-being. Moreover, the participation in spiritual and religious activities is considered avenues for enhanced social and community inclusion. The current study found these aspects held true for participants who experience intellectual and developmental disabilities.

To exclude such evidence from human services practices and ignore a critical aspect of personhood for those experiencing intellectual and developmental disabilities, is to propagate the objectification and dehumanisation of human services. The spiritual well-being in relation to the physical, emotional, and social well-being of people who experience intellectual and developmental disabilities must be addressed within service systems and provider organisations if person-centred planning, supports, and services are to be realised.

In consideration of the evolving research, extending human regard to the spiritual life of people who experience intellectual and developmental disabilities provides forward movement on the journey to honour the full humanity of people who experience disabilities. Furthermore, exploring the spiritual nature of individuals who experience intellectual and developmental disabilities creates a new frontier of investigation that holds promise to uplift all people, potentially broadening perspectives and deepening understanding of the interconnectedness of life and the universality of a

shared human identity. Finally, opportunities for individuals who experience intellectual and developmental disabilities to fully participate in all realms of the human experience is important to individuals and essential to a cultivation of inclusive communities. This study closes with the remarks from a visionary, Martin Luther King, Jr., who at the *Salute to Freedom* celebration stated: “All Labour that uplifts humanity has dignity & importance and should be undertaken with painstaking excellence.” (March 10, 1968).

References

- Abdel-Khalek, A. (2006). Happiness, health, and religiosity: Significant relations. *Mental Health, Religion & Culture*, 9(1), 85 - 97.
- Abrams, J. Z. (1998). *Judaism and disability*. Washington D.C.: Galludet University Press.
- Adegbola, M. (2006). Spirituality and quality of life in chronic illness. *Journal of Theory Construction & Testing*, 10(2), 42 - 46.
- Alaska Statute, Title 47, Chapter 80, Section 900, Definitions.
- Albrecht, G., Seelman, K., & Bury, M. (Eds.). (2001). *Handbook of disability studies*. London, UK: Sage.
- Aman, M. G., & Handen, B. (2006). Reactions to “Ethical challenges and complexities of including people with intellectual disability as participants in research” by Dr. Teresa Iacono. *Journal of Intellectual and Developmental Disability*, 31(3), 180-182.
- Americans with Disabilities Act (1990).
- Anderson, K. L., & Burkhardt, C. S. (1999). Conceptualization and measurement of quality of life as an outcome variable for health care intervention research. *Journal of Advanced Nursing*, 29(2), 298 - 306.
- Anderson, R. C. (2006). Faith in access: Bridging conversations between religion and disability. *Disability Studies Quarterly*, 26(3).
- Andrews, F. R. (Ed.). (1986). *Research on quality of life*. Ann Arbor, MI: The University of Michigan, Institute for Social Research.
- Andrews, F. R. & Whithey, S. B. (1976). *Social indicators of well-being: Americans' perceptions of life quality*. New York: Plenum Press.
- Andrulis, D. P., Duchon, L. M., & Reid, H. M. (2003). *Dynamics of race, culture and key indicators of health in the nation's 100 largest cities and their suburbs*. SUNY Downstate Medical Center.
- Angur, M., Widger, R., & Angur, S. (2011). Congruence among objective and subjective quality-of-life (QOL) indicators. *Alliance Journal of Business Research*, 4-07-2011, pp. 47 - 54.
- Armstrong, K. (1993). *A history of God: The 4,000 year quest of Judaism, Christianity & Islam*. New York, NY: Ballantine Books.

- Aronson, E., Ellsworth, P., Carlsmith, J. M., & Gonzales, M. (1990). *Methods of research in social psychology* (2nd ed.). New York, NY: McGraw-Hill Publishing Co.
- Arcott, K., Dagnan, D., & Kroese, B. S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 11(1), 77-83.
- Ashley, P. (2007). Toward an understanding and definition of wilderness spirituality. *Australian Geographer*, 38(1), 53 - 69.
- Assembly, United Nations. (1948). Universal declaration of human rights. *Resolution adopted by the General Assembly*, 10(12).
- Assembly, United Nations, (2006) *The convention on the rights of persons with disabilities*. Retrieved: <http://www.un.org/disabilities/default.asp?id=150>
- Augustine, N. (2000). "Grandfather was a knowing Christian". *Toronto Star*. December 2000.
- Averill, J. R. (1998). Spirituality: From the Mundane to the Meaningful - and Back. *Journal of Theoretical and Philosophical Psychology*, 18(2), 101 - 126.
- Azevedo, M., Araujo, C.; Reichert, F., Siqueira, F., Da Silva, M., & Hallal, P.(2007). Gender differences in leisure-time physical activity. *International Journal of Public Health*, 52, 8 - 15.
- Baker, F. & Intagliata, J. (1982). Quality of life in the evaluation of community support systems. *Evaluation and program planning*, 5(1), 69-79.
- Balboni, T. A., Paulk, M. F., Balboni, M. J., Phelps, A. C., Loggers, E. T., Wright, A. A., Block, S. D., Lewis, E. F., Petet, J. R. and Prigerson, H. G. (Jan 20, 2010). Provision of spiritual care to patients with advanced cancer: Associations with medical care and quality of life near death. *Journal of Clinical Oncology* 28 (3), 445 – 452.
- Banks, R. (1980). Health & the spiritual domain: Relationships & implications for professional preparation programs. *The Journal of School Health* (April), 195 - 202.
- Barham, P. (1992). *Closing the asylum: The mental patient in modern society*. UK: Penguin Press.
- Bartlett, S. J., Piedmont, R., Bilderback, A., Matsumoto, A. K., & Bathon, J. M. (2003). Spirituality, well-being, and quality of life in people with rheumatoid arthritis. *Arthritis & Rheumatism: Arthritis Care & Research*(49), 778 - 783.
- Baumeister, A. A. (1981). Mental retardation policy and research. The unfulfilled promise. *American Journal of Mental Deficiency*, 85, 449 - 456.

- Baumeister, R. F. (1991). *Meanings of life*. New York, NY: Guilford Press.
- Baumeister, R. F., Vohs, K.D., Aaker, J. L., & Garbinsky, E. N. (2012). Some key differences between a happy life and a meaningful life. *Forthcoming in Journal of Positive Psychology*. Retrieved from <http://faculty-gsb.stanford.edu/.../SomeKeyDifferencesHappyLifeMeaning>.
- Beckie, T. M., & Hayduk, L. A. (1997). Measuring quality of life. *Social Indicators Research*, 42(1), 21 - 39
- Bekelman, D. B., Dy, S. M., Becker, D. M., Wittstein, I. S., Hendricks, D. F., Yamashita, T. F. (2007). Spiritual well-Being and depression in patients with heart failure. *Journal of General Internal Medicine*, 22(4), 470 - 477.
- Bekelman, D. B., Parry, C., Curlin, F. A., Yamashita, T., E., Fairclough, D. L., & Wamboldt, F. S. (2010). A comparison of two spirituality instruments and their relationship to depression and quality of life in chronic heart failure. *Journal of Pain Symptom Management*, 39(3), 515 - 526. doi: 10.1016/j.jpainsymman.2009.08.005
- Belli, F. (2001, November). Finite state testing and analysis of graphical user interfaces. In *Software Reliability Engineering, 2001. ISSRE 2001. Proceedings. 12th International Symposium on* (pp. 34-43). IEEE.
- Bello, A. (2008). Edmund Husserl and Edith Stein: The question of the human subject. *American Catholic Philosophical Quarterly: Journal of the American Catholic Philosophical Association*, 82(1), 143 - 159.
- Bennett, T., Deluca, D. A., & Allen, R. W. (1995). Religion and children with disabilities. *Journal of Religion and Health*, 34, 301 - 311.
- Bentz, V. M., & Shapiro, J. J. (1998). *Mindful inquiry in social research*. Thousand Oaks, CA: Sage.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E., (2000). From social integration to health: Durkheim in the new millennium. *Social Science and Medicine*, 51, 843 - 857.
- Biesinger, R. & Arikawa, H. (2011). Religious attitude and happiness among parents of children with developmental disabilities. *Journal of Religion, Disability & Health*, 11(4), 23 - 34.
- Black, K. (1996). *A healing homiletic: Preaching and disability*. Nashville, TN: Abingdon Press.
- Black, K. (2006). Unbinding the broken hearted Biblical and theological reflections. *Journal of Religion, Disability & Health*, 9(3).

- Blatt, B. & Kaplan, F. (1974). *Christmas in purgatory : A photographic essay on mental retardation*. Human Policy Press.
- Block, J. W. (2002). *Copious hosting: A theology of access for people with disabilities*. New York, NY: Continuum.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Bogdan, R., & Kugelmass, J. (1984). Case studies of mainstreaming. In L. Barton & S. Tomlinson (Eds.), *Special education and social interests*. London: Croom Helm.
- Boivin, M. J., Donkin, A. J., & Darling, H. w. (1990). Religiosity and prejudice: A case study in evaluating the construct of validity of Christian measures. *Journal of Psychology and Christianity*, 9, 41 - 55.
- Borg, J., Andree, B., Soderstrom, H., & Farde, L. (2003). The serotonin system and spiritual experiences. *American Journal of Psychiatry*, 160, 1965 - 1969.
- Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology*, 62(1), 17.
- Boswell, B., Hamer, M., Knight, S., Glacoff, M., & McChesney, J. (2007). Dance of disability and spirituality. *Journal of Rehabilitation*, 73(4), 33 - 40.
- Braddock, D. & Parish, S. (2002). Chapter 1: An institutional history of disability. In D. Braddock (Ed.), *Disability at the Dawn of the 21st Century* (pp. 1 - 62). Washington D. C.: American Association on Mental Retardation.
- Braddock, D., Emerson, E., Felce, D., & Stancliffe, R. J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the united states, canada, england and wales, and australia. *Mental Retardation and Developmental Disabilities Research Reviews*, 7(2), 115-121. doi: 10.1002/mrdd.1016.
- Brady, M. J., Peterman, A. H., Fitchett, G., Mo, M., & Cella, D. (1999). A case for including spirituality in quality of life measurement in oncology. *Psycho-Oncology*, 8, 417 - 428.
- Brahams, D. (1991). Rationing health care: Ethical and legal considerations and QALYs. *Medico-Legal Journal*, 59, 4.
- Brandt, P. Y., Fournier, C. A., & Mohr, S. (2009). Self-identity and religion/spirituality. In P. Huguelet & H. G. Koenig (Eds.), *Religion and Spirituality in Psychiatry* (pp. 158 - 172). Cambridge: Cambridge University Press.
- Bray, N. W. (1992). *International Review of Research in Mental Retardation* (Vol. 18). San Diego, CA: Academic Press, Inc.

- Briggs, C. (2000). Interview. *Journal of Linguistic Anthropology*, 9(1 – 2), 137 – 140.
- Brown, F. & Gothelf, C. (1996). Community life for all individuals in *People with disabilities who challenge the system*. D.H. Lehr and F. Brown (Eds.). Baltimore: Paul H. Brookes Publishing Co., 175 - 188.
- Brown, I., Raphael, D., & Renwick, R. (1997). *Quality of life - dream or reality?: Life for people with developmental disabilities in Ontario*: Quality of Life Research Unit, Centre for Health Promotion, University of Toronto.
- Brown, I., Raphael, D., & Renwick, R. (2002). *Quality of Life Profile: Adult version*. Toronto: Quality of Life Research Unit, University of Toronto.
- Brown, I., Renwick, R., & Raphael, D. (1999). *Quality of life and life changes for adults with developmental disabilities in Ontario: Final report from the Quality of Life Project* (pp. 1 - 88). Toronto: University of Toronto
- Brown, R. I., Bayer, M. B., & MacFarlane, C. (1988). *Quality of life amongst handicapped adults*. In R. I. Brown (Ed.), *Quality of life for handicapped people*. London: Croom Helm.
- Brown, R. I., Bayer, M., & MacFarlane, C. (1989). *Rehabilitation programmes: Performance and quality of life of adults with developmental handicaps*. Toronto: Lugus Productions.
- Browning, P. L. (1974). *Mental Retardation: Rehabilitation and Counseling*. Springfield, IL: Charles C. Thomas.
- Bruininks, R. H., Chen, T. H., Lakin, K. C., & McGrew, K. S. (2002). Components of personal competence and community integration for persons with mental retardation in small residential programs. *Research in Developmental Disabilities*, 13(5), 463 - 479. doi: 10.1016/0891-4222(92)90003-O
- Bryant, A. N. (2007). Gender difference in spiritual development during the college years. *Sex Roles* 56(11 – 12), 835 – 846.
- Bryman, A. (2001). *Social research methods*. Oxford: Oxford University Press.
- Bryman, A., & Cramer, D. (2001). *Quantitative data analysis with SPSS release 10 for Windows: a guide for social scientists*. Philadelphia, PA: Routledge.
- Buchanan, J. (2005). *Openness: Spirituality in a Process Psychology*. Paper presented at the Wuhan Conference on Science and Spirituality, Wuhan, China.
- Bufford, R. K., Paloutzian, R. F., & Ellison, C. W. (1991). Norms for the spiritual well-being scale. *Journal of Psychology and Theology*.

- Buntix, W. H. E. & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in Intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*
- Burbach, H. J. (1981). The labeling process. A sociological analysis. In J. M. Kauffman & D. P. Hallahan (Eds.). *Handbook of special education*. Englewood Cliffs, NJ: Prentice-Hall.
- Burgess, R. G. (Ed.). (2011). *The research process in educational settings: Ten case studies* (Vol. 168). Philadelphia, PA: Routledge.
- Burkhardt, M. a. (1994). Becoming and connecting: Elements of spirituality for women. *Holistic Nursing Practice*, 8, 12 - 21.
- Butler, J. & Ciarrochi, J. (2007). Psychological acceptance and quality of life in the elderly. *Quality of Life Research*, 16(4), 607 - 615.
- Byrne, P. (2000). *Philosophical and ethical problems in mental handicap*. New York, NY: Palgrave.
- Cameron, W. B. (1963). *Informal sociology: a casual introduction to sociological thinking*. New York, NY: Random House.
- Cameron, L. & Murphy, J. (2007). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, 35(2), 113-120.
- Campbell, A., Converse, P. E., & Rodgers, W. L. (1976). *The quality of American life: Perceptions, evaluations, and satisfactions* (Vol. 3508). Russell Sage Foundation.
- Canda, E. R. (1999). Spirituality sensitive social work: Key concepts and ideals. *Journal of Social Work Theory and Practice*, 1(1), 1 - 15.
- Carey, A. C. (2009). *On the margins of citizenship: Intellectual disability and civil rights in twentieth century America*. Philadelphia, PA: Temple University Press.
- Carlson, L. & Kittay, E., (2009). Introduction: Restthinking philosophical presumptions in light of cognitive disability. *Metaphilosophy*, 40, 307 - 330.
- Carlson, L. (2009). Philosophers of intellectual disability: A taxonomy. *Metaphilosophy*, 40, 552 - 566.
- Carr-Hill, R. (1989). Assumptions of the QALY procedure. *Social Science and Medicine*, 29, 469 - 477.
- Carter, E. W. (2013). Supporting inclusion and flourishing in the religious and spiritual lives of people with intellectual and developmental disabilities. *Inclusion*, 1(1), 64 - 75.

- Chamberlain, K., & Zika, S. (1988). Religiosity, life meaning, and well being: Some relationships in a sample of women. *Journal for the Scientific Study of Religion*, 27, 411 - 420.
- Chan, C, Ng, S., Ho, R., & Chow, A. (2006). East meets west: Applying Eastern spirituality in clinical practice. *Journal of clinical Nursing*, 15(7), 822-832.
- Chang, B. H., Casey, A., Dusek, J. A. & Benson, H. (August, 2010). Relaxation response and spirituality: pathways to improve psychological outcomes in cardiac rehabilitation. *Journal of Psychosomatic Research*, 69 (2), 93 – 100.
- Charles, C.M. (1998). *Introduction to educational research* (2nd ed). White Plains, NY: Longman.
- Charlton, J. I. (1998). *Nothing about us without us without us: Disability, oppression and empowerment*. University of California Pr.
- Chowdhury, M., Benson, B., & Hilier, A. (2010). Changes in restricted repetitive behaviors with age: a study of high-functioning adults with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 4(2), 210 - 216.
- Chuengsatiansup, K. (2003). Spirituality and health: an initial proposal to incorporate spiritual health in health impact assessment. *Environmental Impact Assessment Review*, 23(1), 3 - 15. doi: 10.1016/S0195-9255(02)00037-9
- Claes, C. M., Van Loon, J., Van Hove, G., Vandeveld, S., & Schalock, R. L. (2010). Predictor of quality of life in persons with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 23(5).
- Claes, C., Van Hove, G., Vandeveld, S., Van Loon, J., & Schalock, R. L. (2010). Person-centered planning: Analysis of research and effectiveness. *Intellectual and Developmental Disabilities*, 48(6), 432 - 453.
- Cohen, A. B., & Hall, D. E. (2009). Existential beliefs, social satisfaction, and well-being among Catholic, Jewish, and Protestant older adults. *The International Journal for the Psychology of Religion*, 19, 39 - 54. doi: 10.1080/10508610802471088.
- Cohen, J. (1988). *Statistical power and analysis for the behavioral science* (2nd ed.). New York, NY: Academic Press.
- Congress of Delegates, The ARC of the United States, (November 8, 2008). Sexuality: Joint position statement of AAIDD and The Arc. Retrieved from <http://www.aaid.org>.
- Conner, B. T. (2010). Affirming presence: spiritual life and friendship with adolescents with developmental disabilities. *International Journal of Children's Spirituality*, 15(4), 331 - 339. doi: 10.1080/1364436X.2010.533479

- Cooper, H., Arber, S., Fee, L., & Ginn, J. (1999). *The Influence of Social Support and Social Capital on Health*. London: HEA.
- Cooper, D. R. & Schindler, P. S. (2006). Business Research Methods, empirical investigation". *Journal of Service Research*, 1(2), 108-28
- Coyle, J. (2002). Spirituality and health: towards a framework for exploring the relationship between spirituality and health. *Journal of Advanced Nursing*, 37(6), 589 - 597.
- Corbin, J. & Strauss, A. (Eds.). (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.
- Creamer, D. (2006). Theological accessibility: The contribution of disability. *Disability Studies Quarterly*, 26(4).
- Creswell, J. W. (1994). *Research design*. Thousand Oaks, CA: Sage publications.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed-methods approaches*. (2nd ed.) Thousand Oaks, CA: Sage Publishing.
- Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.
- Creswell, J. W. & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into practice*, 39(3), 124-130.
- Cummins, R. A. (1995). On the trail of the gold standard for life satisfaction. *Social Indicators Research*, 35, 179 – 200.
- Cummins, R. A. (2000). Objective and subjective quality of life: an interactive model. *Social Indicators Research*, 52, 55 - 72.
- Cummins, R. A. (2003). Normative life satisfaction: measurement issues and a homeostatic model. *Social Indicators Research*, 64, 225 - 256.
- Cummins, R. A. (2005a). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, 49, 699 - 706.
- Cummins, R. A. (2005b). Normative Data for the Personal Well-being Index - Australia Retrieved January 2, 2011, 2011
- Cummins, R. A. & Nistico, H. (2002). Maintaining life satisfaction: the role of positive cognitive bias. *Journal of Happiness Studies*, 3, 37 - 69.
- Cummins, R. A., Eckersley, R., Pallant, J., Van Vugt, J., & Misajon, R. (2003). Developing a national index of subjective wellbeing: The Australian Unity Wellbeing Index. *Social Indicators Research*, 64, 159 - 190.

- Cummins, R. A., Lau, A. L. D., & Stokes, M. (2004). HRQOL and subjective wellbeing: noncomplementary forms of outcome measurement. *Expert Reviews in Pharmacoeconomics Outcomes Research*, 4, 413 - 420.
- Cushing, P. B. (2003). *Sharing the moral imagination of caregivers: Disability, difference & inequality in L'Arche*. PhD, McMaster University, Hamilton, ON.
- Davis, L. J. (1997). the bell curve, the novel, and the invention of the disabled body in the nineteenth century. In L.J. Davis (Ed.). *The disability studies reader* (pp. 9 - 28). New York, NY: Routledge.
- de Jager Meezenbroek, E., Garssen, B., van den Berg, M., van Dierendonck, D., Visser, A., & Schaufeli, W. (2010). Measuring Spirituality as a Universal Human Experience: A Review of Spirituality Questionnaires. *Journal of Religion and Health*, 1-19. doi: 10.1007/s10943-010-9376-1
- Debats, D. L. (1999). Sources of meaning: An investigation of significant commitments in life. *Journal of Humanistic Psychology*, 39, 30 - 57.
- Dedoose. Version 4.5.98, web application for managing, analyzing, and presenting qualitative and mixed method data (2012). Los Angeles, CA: SocioCultural Research Consultants, LLC. <http://app.dedoose.com/>
- Demmons, T. A. (2009). *Being in encounter toward a post-critical theology of knowledge of God for persons with intellectual disabilities: With special reference to Karl Barth's Church Dogmatics III:2*. P.h.D Doctor of Philosophy, University of St Andrews, St Andrews, Scotland, U.K. Retrieved from <http://researchrepository.standrews.ac.uk/bitstream/10023/758/3/Tracy%20A.%20Demmons%20PhD%20thesis.pdf>
- Denzin, N. (1978). *The research act: A theoretical introduction to sociological methods* (2nd ed.). New York, NY: McGraw-Hill.
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2003). *Strategies of qualitative inquiry* (Vol. 2). Thousand Oaks, CA: Sage
- Developmental Disabilities Act, Part A*. (2000). Retrieved from <http://www.acf.hhs.gov/programs/add/ddact/DDA.html#>.
- Dossa, P. A. (1989). Quality of life: Individualism or holism? A critical review of the literature. *International Journal of Rehabilitation Research*, 12, 121 - 136.
- Drake, S. (2009, July 17). Peter Singer in the NY Times: Disabled lives worth less, hypothetically. *the New York Times*. Retrieved from <http://www.notdeadyet.org/2009/07/peter-singer-in-ny-times-disabled-lives.html>.

- Ebenstein, W. (2006). Toward an archetypal psychology of disability based on the Hephaestus myth. *Disability Studies Quarterly*, 26 (4), Retrieved August 31, 2013.
- Edgerton, R. B. (1975). Issues relating to the quality of life among mentally retarded persons. In Begab, Michael J. (Ed); Richardson, Stephen A. (Ed), (1975). *The mentally retarded and society: A social science perspective*. Baltimore, MD: University Park Press.
- Edgerton, R. B. (1990). Quality of life from a longitudinal research perspective. *Quality of life: Perspectives and issues*, 149-160.
- Edwards, J. N. & Klemmack, D. L. (1973). Correlates of life satisfaction: A re-examination. *Journal of Gerontology*, 28, 497 - 502.
- Edwards, S. (1997). The moral status of intellectually disabled individuals. *The Journal of Medicine and Philosophy*, 22, 29 - 42.
- Eisner, E. W. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. New York, NY: Macmillan Publishing Company. Eisner, E. W. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. New York, NY: Macmillan Publishing Company.
- Eisland, N. (1994). *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville, TN: Abingdon Press.
- Eisland, N. (1998). Things not seen: Women with physical disabilities. In D.Ackerman & R. Bons-Strom, eds., *Liberatingfaith practices: Feminist practical theologies in context*, pp. 103 – 127. Leuven, Holland: Peeters.
- Ekas, N. V., Whitman, T. L., & Shivers, C. (2009). Religiosity, spirituality, and socioemotional functioning in mothers of children with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*, 39(5), 706 - 719. doi: 10.1007/s10803-008-0673-4
- Elias, N. (2000). *The civilizing process: Sociogenetic and Psychogenetic investigations*, (2nd ed.). Oxford: Blackwell.
- Elkins, J. C. (2008). Living out: A study exploring the experiences of live out assistants in L'Arche. from ProQuest: Dissertations & Theses
- Ellison, C. W. (1983). Spiritual Well-Being: Conceptualization and Measurement. *Journal of Psychology and Theology*, 11(4), 330 - 340.
- Ellison, C. W., & Smith, J. (1991). Toward an integrative measure of health and well being. *Journal of Psychology and Theology*, 19, 35 - 48.
- Emdon, T. (1997). Spirituality: cry freedom. *Nursing Times*, 93, 35 - 38.

- Emerson, E. B. (1985). Evaluating the impact of deinstitutionalization on the lives of mentally retarded people. *American Journal of Mental Deficiency*, 90, 277 - 288.
- Emmons, R. A. (1986). Personal strivings: An approach to personality and subjective well-being. *Journal of Personality and Social Psychology*, 51, 1058 - 1068.
- Erikson, E. H. (1943). Observations on the Yurok: childhood and world image. *University of California Publications in American Archaeology & Ethnology*.
- Erikson, E. H. (1963). *Childhood and society* (2nd ed.). New York, NY: WW Norton & Company.
- Esbensen, A. J., Greenberg, J.S., Seltzer, M.M., Aman, M.G. (2009). A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(9), 1339 - 1349.
- Evans, Suzanne E. (2001). *Forgotten crimes: The Holocaust and people with disabilities*. Disability Rights Advocates. Oakland, CA. Retrieved from: http://www.dralegal.org/publications/forgotten_crimes.php
- Federation of Diocesan Liturgical Commissions Liturgical Arts and Music Committee (August, 2005). *Guiding Principles & Strategies for Inclusion in the Liturgy of Catholics with Disabilities*. Retrieved from: <http://www.disabilitiesandfaith.org/resources/guidebooks/GuidingPrinciplesInclusionLiturgy.pdf>
- Felce, D. & Perry, J. (1995). Quality of life: its definition and measurement. *Research in Developmental Disabilities*, 16, 51 - 74.
- Felce, D. & Perry, J. (1996a). Exploring Current Conceptions of Quality of Life: A model for people with and without disabilities. In R. Renwick, I. Brown & H. Nagler (Eds.), *In: Quality of Life in Health Promotion and Rehabilitation Conceptual Approaches, Issues and Applications* (pp. 51 - 62). London: Sage Publications.
- Felce, D. & Perry, J. (1996b). Assessment of quality of life. In R. L. Schalock (Ed.), *In: Quality of Life. Vol. I: Conceptualization and Measurement* (pp. 63 - 72). Washington, DC: American Association on Mental Retardation.
- Ferguson, P. M. (1994). *Abandoned to their Fate: Social Policy and Practice toward Severely Retarded People in America, 1820 - 1920*. Philadelphia: Temple University Press.
- Field, A. (2005). *Discovering Statistics Using SPSS* (2nd ed.). Thousand Oaks, CA: Sage.
- Finn, S. C. (2000). Big ideas for the 21st century. *Journal of Women's Health & Gender-Based Medicine*, 9(2), 97 - 99.

- Fiske, S. T. (2004). *Social beings: A core motives approach to social psychology*. New York: Wiley Press.
- Fiske, S. T. & Yamamoto, M. (2005). Coping with rejection: Core social motives, across cultures. In K. D. Williams, J. P. Forgas & W. von Hippel (Eds.), *The social outcast: Ostracism, social exclusion, rejection, and bullying* (pp. 185 - 198). New York: Psychology Press.
- Fisher, C. B. (2003). Goodness-of-fit ethic for informed consent to research involving adults with mental retardation and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(1), 27-31.
- Fitchett, G. (1993). *Assessing spiritual needs: A guide for caregivers*. Minneapolis: Augsburg/Fortress Press.
- Fitchett, G., Rybarczyk, B. D., DeMarco, G. A., & Nicholas, J. J. (1999). The role of religion in medical rehabilitation outcomes: A longitudinal study. *Rehabilitation Psychology*, 44, 333 - 353.
- Flanagan, J. C. (1978). A research approach to improving our quality of life. *American Psychologist*, 33, 138 - 147.
- Flanagan, J. C. (1982). Measurement of quality of life: Current state of the art. *Archives of Physical Medicine and Rehabilitation*, 63, 56 - 59.
- Flick, U. (1992). Triangulation revisited: Strategy of or alternative to validation of qualitative data. *Journal for the Theory of Social Behavior* 2: 175-197.
- Fosarelli, P. (September 2002). Fearfully wonderfully made: The interconnectedness of body-mind-spirit. *Journal of Religion & Health*, 4 (3), 207 - 229.
- Foundation, W. K. K. (2001). Logic Model Development Guide. *Using Logic Models to Bring Together Planning, Evaluation, & Action* (pp. 72). Battle Creek, Michigan.
- Fraenkel, J. R. & Wallen, N. E. (1990). *How to design and evaluate research in education*. New York: McGraw-Hill.
- Frankl, V. (1955). *The doctor and the soul*. New York, NY: Knopf.
- Frankl, V. (1963). *Man's search for meaning*. Boston, MA: Beacon.
- Frankl, V. (1967). *Psychotherapy and existentialism*. New York, NY: Washington Square Press.
- Freeman, D. R. (2006). Spirituality in violent and substance -abusing African American men: An untapped resource for healing. *Journal of Religion & Spirituality in Social Work*, 25(1), 3 - 22.

- Freud, S. (1958). Some character-types met with in psycho-analytic work. In Newlson, B. (Ed), *On creativity and the unconscious*. New York: Harper and Row. pp 84 - 110.
- Friedlander, H. (2003). The origins of Nazi genocide. In N. Levi & M. Rothberg (Eds.), *The holocaust: Theoretical readings* (pp. 96 - 102). New Brunswick, NJ: Rutgers University Press.
- Friedli, L. (2001). Social and spiritual capital: Building 'emotional resilience' in communities and individuals. *Political Theology*, 2(4), 55 - 64.
- Friendship Ministries. (2011). Retrieved 3/19/2011 from <http://www.friendship.org/>
- Fry, P. S. (2000). Religious involvement, spirituality and personal meaning for life: Existential predictors of psychological wellbeing in community-residing and institutional care elders. *Aging & Mental Health*, 4(4), 375 - 387.
- Garcia-Villamizar, D. A., & Dattilo, J. (2010). Effects of a leisure programme on quality of life and stress of individuals with ASD. *Journal of Intellectual Disability Research*, 54(7), 611 - 619.
- Gaventa, W. (2006). Signs of the times: Theological themes in the changing forms of ministries and spiritual supports with people with disabilities. *Disability Studies Quarterly*, 26(4).
- Gaventa, W. (2009). Spirituality and spiritual connections. Assess it, train it, and practice it., *Frontline Initiative*.
- Gaventa, W. C. (2001). Defining and assessing spirituality and spiritual supports: A rationale for inclusion in theory and practice. In W. C. Gaventa & D. L. Coulter (Eds.), *Spirituality and intellectual disability: International perspectives on the effect of culutre and religion on healing body, mind, and soul* (pp. 29 - 48). New York, NY: The Haworth Press, Inc.
- Gaventa, W. C. & Coulter, D. L. (Eds.). (2001a). *Spirituality and intellectual disability: International perspectives on the effect of culture and religion on healing body, mind, and soul*. New York: The Haworth Press, Inc.
- Gaventa, W. C. & Coulter, D. L. (Eds.). (2001b). *The theological voice of Wolf Wolfensberger*. New York: The Haworth Press, Inc.
- Gay, L. R. & Airasian, P. (2003). *Educational research: Competencies for analysis and application*. (7th ed). Upper Saddle River, NJ: Pearson Education.
- Ghalkos, G. & Bousinakis, D. (2010). The effect of stress and satisfaction on productivity. *International Journal of Productivity and Performance Management*, 59(5), 415 - 431.

- Ghaly, M. (2010). *Islam and Disability: Perspectives in Theology and Jurisprudence*. New York: Routledge.
- Gilbert, R. B. (2006). Spirituality and the search for meaning. *Illness, Crisis & Loss*, 14(2), 99 - 199.
- Gill, T. M. & Feinstein, A. R. (1994). A critical appraisal of the quality of quality-of-life measurements. *Journal of the American Medical Association*, 272, 619 - 631.
- Gillberg, C., Billstedt, E., Sundah, V., & Gillberg, I. C. (2010). Mortality in autism: A prospective longitudinal community-based study. *Journal of Autism and Developmental Disorders*, 40(3), 352 - 357.
- Gilmartin, A. & Slevin, E. (2009). Being a member of a self-advocacy group: Experiences of intellectually disabled people. *British Journal of Learning Disabilities*, 38, 152 - 159.
- Goffman, E. (1974). *Frame analysis: An essay on the organization of experience*. New York, NY: Harper & Row.
- Goffman, E. (1986). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster.
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8(4), 597-607.
- Gomez, R. & Fisher, J. W. (2003). Domains of spiritual well-being and development and validation of the spiritual well-being questionnaire. *Personality and Individual Differences*, 35, 1975 - 1991.
- Goode, D. A. (1984). Socially produced identities, intimacy and the problem of competence among the retarded. In L. Barton & S. Tomlinson (Eds.), *Special education and social interests*. London: Croom Helm.
- Goode, D. A. (1988). *Quality of life for persons with disabilities: A review and synthesis of the literature*. New York: Mental Retardation Institute, Westchester County Medical Center.
- Goode, D. A. (1991). *Quality of life research: A change agent for persons for persons with disabilities*. Paper presented at the Paper presented to the 1991 American Association on Mental Retardation National Meeting, Washington, D.C.
- Goode, D. A. (Ed.). (1990). *Thinking about and discussing quality of life*. Washington, DC: American Association on Mental Retardation.
- Goode, D. A. & Hogg, J. (1994). Towards an understanding of holistic quality of life in people with profound intellectual and multiple disabilities. In D. A. Goode (Ed.), *In: Quality of Life for People with Disabilities: International Perspectives and Issues* (pp. 197 - 207). Cambridge: Brookline Books.

- Gorusch, R. L. & Smith, C. S. (1983). Attributions of responsibility to God: An interaction of religious beliefs and outcomes. *Journal for the Scientific Study of Religion*, 22(4), 340 - 352.
- Gottlieb, R. S. (Ed.). (2004). *This sacred Earth: religion, nature, environment* (2nd ed.). New York, New York: Routledge.
- Goudarzi, S. (2006). The Future of science: A conversation with Alan Lightman. 1 - 5. Retrieved from http://www.livescience.com/strangenews/060215_alan_lightman.html
- Green, C., Middleton, W., & Reid, D. (2000). Embedded evaluation of preferences sampled from person-centered plans for people with profound multiple disabilities. *Journal of Applied Behavior Analysis*, 33, 639 - 642.
- Green, S. B. & Silkind, N. J. (2005). *Using SPSS for Windows and Macintosh: Analyzing and Understanding Data* (4th ed.). Upper Saddle River, NJ: Pearson, Prentice Hall.
- Greenfield, E. A. & Marks, N. F. (2007). Religious social identity as an explanatory factor for associations between more frequent formal religious participation and psychological well-being. *International Journal for the Psychology of Religion*, 17, 245 - 259.
- Haber, J. R., Jacob, T., & Spangler, D. J. C. (2007). Dimensions of Religion/Spirituality and Relevancy to Health Research. *International Journal for the Psychology of Religion*, 17(4), 265 - 288.
- Hahn, S. (2009). *Signs of life: 40 Catholic customs and their biblical roots*. New York, NY: Doubleday.
- Hales, D. R. & Lauzon, L. (2010). The spirit of health and wellness *An Invitation to health* (pp. 430 - 449). Toronto: Nelson Education, Ltd.
- Hall, B. A. (1998). Patterns of spirituality in persons with advanced HIV disease. *Research in Nursing and Health*, 21, 143 - 153.
- Halpern, A. S., Nave, G., Close, D. W., & Nelson, D. J. (1986). An empirical analysis of the dimensions of community adjustment for adults with mental retardation. *Australia and New Zealand Journal of Developmental Disabilities*, 12, 147 - 157.
- Hammond, M. (2009, Fall 2009). Training faith-based organizations on how to be more welcoming and accessible. *AAIDD Religion and Spirituality Division Newsletter*.
- Hammond, P.E. (Eds.) (1985). *The sacred in a secular age: Toward revision in the scientific study of religion*. University of California Press.

- Hanson, K. (2004). NOD/Harris Surveys: 2004 Gaps Survey (pp. 1 - 25). New York: NOD/Harris Interactive Inc.
- Hardon, J. (1981). *The Catholic Catechism: A contemporary catechism of the teaching of the Catholic Church*. New York, New York: Doubleday.
- Harner, M. (1990). *The way of the shaman*. San Francisco: Harper & Row.
- Harner, C. J. & Heal, L. W. (1993). The Multifaceted Lifestyle Satisfaction Scale (MLSS): Psychometric properties of an interview schedule for assessing personal satisfaction of adults with limited intelligence. *Research in Developmental Disabilities, 14*(3), 221-236.
- Harrison, M. O., Edwards, C. L., Koenig, H. G., & Bosworth, H. B. (2005). Religiosity/spirituality and pain in patients with sickle cell disease. *Journal of Nervous and Mental Disease*(193), 250 - 257.
- Hart, D. W. (2005). Spirituality and archetype in organizational life. *Business Ethics Quarterly, 15*(3).
- Hasnain, R. & Sotnik, P. (2003). Person-centered planning: A gateway to improving vocational rehabilitation services for culturally diverse individuals with disabilities. *Journal of Rehabilitation, 69*, 10 - 17.
- Hatch, R. L., Burg, M. A., Naberhaus, D. S., & Hellmich, L. K. (1998). The spiritual involvement and beliefs scale. Development and testing of a new instrument. *Journal of Family Practice, 46*, 476 - 486.
- Hauerwas, S. (1986). *Suffering presence*. South Bend, Ind: University of Notre Dame Press.
- Hawks, S. (1994). Spiritual health: Definition and theory. *Wellness Perspectives, 10*, 3 - 13.
- Hay, M. W. (1989). Principles in building spiritual assessment tools. *American Journal of Hospice Care, 6*, 25 - 31.
- Hayward, R. D. & Elliott, M. (2009). Fitting in with the flock: Social attractiveness as a mechanism for well-being in religious groups. *European Journal of Social Psychology, 39*(4), 592 - 607.
- Headey, B. & Wearing, A. (1989). Personality, life events, and subjective well-being: toward a dynamic equilibrium model. *Journal of Personality and Social Psychology, 57*, 731 - 739.
- Heal, L.W. & Sigelman, C.K. (1990). Methodological issues in measuring the quality of life of individuals with mental retardation. In R.L. Schalock (Ed.), *Quality of life: Perspectives and issues* (pp. 161-176). Washington, D.C.: American Association on Mental Retardation.

- Helliwell, J. F. & Putnam, R. D. (2004). The social context of well-being. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 359(1449), 1435 - 1446.
- Hepworth, C. & Stitt, S. (2007). Social capital & faith-based organisations. *The Heythrop Journal*, 48(6), 895 - 910. doi: 10.1111/j.1468-2265.2007.00348.x
- Herbermann, C. G., Pace, E. A., Pallen, C. B., Shahan, T. J., & Wynne, J. J. (Eds.). (1913). *The Catholic encyclopedia: an international work of reference on the constitution, doctrine, discipline, and history of the Catholic Church* (Vol. 9). Encyclopedia Press, Incorporated.
- Hilbers, J., Haynes, A.S. & Kivikko, J. J. (March, 2010). Spirituality and health: An exploratory study of hospital patients' perspectives.. *Australian Health Review*, 34 (1), 3 - 10.
- Hill, P. C. & Hood, R. W. (1999). *Measures of Religiosity*. Birmingham, AL: Religious Education Press.
- Hoffman, E. (1980). The Kabbalah: Its implications for humanistic psychology. *Journal of Humanistic Psychology*, 20(1), 33-47.
- Holburn, S., Jacobson, J., Schwartz, A., Flory, M., & Vietze, P. (2004). The Willowbrook futures project: A longitudinal analysis of person-centered planning. *American Journal of Mental Retardation*, 10(9), 63 - 76.
- Holocaust Encyclopedia: Euthanasia Program. from <http://www.ushmm.org/wic/en/article.php?ModuleId=10005200>
- Horner, R. H., Stoner, S., & Ferguson, D. L. (1988). An activity-based analysis of deinstitutionalization: The effects of community re-entry on the lives of residents leaving Oregon's Fairview Training Center. Eugene, Oregon: Fairview Training Center.
- Howden, J. W. (1992). *Development and psychometric characteristics of the spirituality assessment scale*. UMI Dissertation Services, Ann Arbor: Texas Woman's University.
- H.R. 4920—106th Congress: Developmental Disabilities Assistance and Bill of rights Act of 2000. (2000). In www.GovTrack.us. Retrieved November 3, 2013, from <http://www.govtrack.us/congress/bills/106/hr/4920>
- Huddleston, J. (1993). Perspectives, purposes, and brotherhood: A spiritual framework for a global society. In S. Bushrui, I. Ayman, & E. Laszlo, *Transition to a global society* (pp. 142 - 150). Oxford, England: Oneworld Publications Ltd.
- Hull, J. M. (2003). A spirituality of disability: The Christian heritage as both problem and potential. *Studies in Christian Ethics*, 21 -35.

- Husserl, E. G. (1965). *Phenomenology and the crisis of philosophy: philosophy as rigorous science, and philosophy and the crisis of European Man*, translated by Quentin Lauer. New York, NY: Harper & Row.
- Husserl, E. G. (1970). *The crisis of European sciences and transcendental phenomenology: An introduction to phenomenological philosophy*. Northwestern University Press.
- Hwang, K. (2008). Atheists with disabilities: A neglected minority in religion and rehabilitation research. *Journal of Religion, Disability & Health*, 12(2), 186 - 192. doi: 10.1080/15228960802160704
- Institute of Medicine (US). Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century*. National Academies Press.
- Iwarsson, S. & Stahl, A. (2003). Accesibility, usability and universal design-positioning and definition of concepts describing person-environment relationships. *Disability and Rehabilitation*, 25, 57 - 66.
- Jacobsson, L. J., Westerberg, M., & Lexell, J. (2010). Health-related quality-of-life and life satisfaction 6 - 15 years after traumatic brain injuries in northern Sweden. *Brain Injury*, 24(9), 1075 - 1086.
- James, A. S. & Shireman, T. I. (2010). Case managers' and independent living counselors' perspectives on health promotion activities for individuals with physical and developmental disabilities. *Journal of Social Work in Disability & Rehabilitation*, 9(4), 274 - 288.
- Jick, T. D. (1979). Mixing qualitative and quantitative methods: Triangulation in action. *Administrative science quarterly*, 24(4), 602-611.
- Jim, H. S., Purnell, J. Q., Richardson, S. A., & Golden-Kreutz, D. M. (2006). Measuring meaning in life following cancer. *Quality of Life Research*, 15(8), 1355 - 1371. doi: 10.1007/s11136-006-0028-6.
- Jim, H. S., Richardson, S. A., Golden-Kreutz, D. M., & Anderson, B. L. (2006). Strategies used in coping with a cancer dagnosis predict meaning in life for survivors. *Health Psychology*, 25(6), 753 - 761.
- Johann Jakob Herzog & Philip Schaff, A. (1911). The New Schaff-Herzog Encyclopedia of Religious Knowledge (pp. 419).
- Johnson, B. (2001). Toward a new classification of nonexperimental quantitative research. *Educational Researcher*, 30(2), 3 - 13.
- Johnstone, B., & Yoon, D. P. (2009). Relationships between the brief multidimensional measure of eligiousness/spirituality and health outcomes for a heterogeneous rehabilitation population. *Rehabilitation Psychology*, 54(4), 422 - 431.

- Jones, S. L. (1994). A constructive relationship for religion with the science and profession of psychology. *American Psychologist*, 49, 184 - 199.
- Kahn, M. Z. (1999). *Islam & Human Rights*. Islamabad, Tilford: Raqueem Press.
- Kahneman, D., Diener, E., & Schwarz, N. (Eds.). (1999). *Well-being: The foundations of hedonic psychology*. New York, NY: Russell Sage Foundation.
- Kaiser, A. P., & McIntyre, L. L. (2010). Editorial: Introduction to special section on evidence-based practices for persons with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 115(5), 357 - 363.
- Kant, I. (1788). *Critique of practical reason*. Translated by Werner S. Pluhar; Introduction by Stephen Engstrom (2002). Indianapolis, IN: Hackett Publishing Company, Inc.
- Kay, A. C., Gaucher, D., Napier, J. L., Callan, M. J., & Laurin, K. (2008). God and the government: Testing a compensatory control mechanism for the support of external systems. *Journal of Personality and Social Psychology*, 95, 18 - 35. doi: 10.1037/0022-3514.95.1.18.
- Kay, A. C., Shepherd, S., Blatz, C. W., Chua, S. N., & Galinsky, A. D. (2010). For God (or) country: The hydraulic relation between government instability and belief in religious sources of control. *Journal of Personality and Social Psychology*, 99(5), 725 - 739.
- Kay, A. C., Whitson, J. A., Gaucher, D., & Galinsky, A. D. (2009). Compensatory control: Achieving order through the mind, our institutions, and the heavens. *Current Directions in Psychological Science*, 18, 264 - 268. doi: 10.1111/j.1467-8721.2009.01649.
- Kaye, J. & Raghavan, S. K. (2002). Spirituality in Disability and Illness. *Journal of Religion and Health*, 41(3).
- Kerlinger, F. N. (1979). *Behavioral research: A conceptual approach*. New York, NY: Holt, Rinehart and Winston.
- Kerr, S., Fairbrother, G., Crawford, M., Hogg, M., Fairbrother, D., & Khor, K. E. (2004). Patient characteristics and quality of life among a sample of Australian chronic pain clinic attendees. *Internal Medicine Journal* 34(7), 403 - 409.
- Khuse, H. & Singer, P. (1985). *Should the baby live? The problem of handicapped infants*. Oxford: Oxford University Press.
- Kim, J. J. (2002). *Spirituality and the Disability Experience: Faith, Subjective Well-Being, and Meaning and Purpose in the Lives of Persons with Disabilities*. PhD, Northwestern University.

- Kim, J.-S., Lee, K.-B., Roh, H., Ahn, M.-Y., & Hwang, H.-W. (2010). Gender differences in the functional recovery after acute stroke. *Journal of Clinical Neurology*, 6(4), 183 - 188. doi: 10.3988/jcn.2010.6.4.183
- Kim, U. & Berry, J. (Eds.). (1993). *Indigenous psychologies: Research and experience in cultural context*. Newbury Park, CA: Sage Publications.
- King, M. L. (1963). I have a dream Retrieved 5/1/2011, from <http://www.mlkonline.net/dream.html>
- Kittay, E.F. & Carlson, L. (2010). *Cognitive disability & its challenge to moral philosophy*. Malden, MA: Wiley-Blackwell.
- Knoll, J. A. (1990). Defining quality in residential services. In V. J. Bradley & H. A. Bersani (Eds.), *Quality assurance for individuals with developmental disabilities. It's everybody's business*. Baltimore, MD: Paul H. Brookes.
- Koenig, H. G. (Ed.). (1995). *Religion and health in later life*. Minneapolis, MS: Fortress Press.
- Koenig, H. G. (1997). *Is Religion Good For Your Health?: The Effects of Religion on Physical and Mental Health?* Binghamton, New York: Haworth Press.
- Koenig, H. G. (Ed.). (1998). *Handbook of Religion and Mental Health*. San Diego, CA: Academic Press.
- Koenig, H. G. & Larson, D. (2001). Religion and mental health: Evidence for an association. *International Review of Psychiatry*, 13(2), 67-78.
- Koenig, H. G., McCullough, M. E., & Larson, D. B. (2001). *Handbook of religion and health*. New York, NY: University Press.
- Koenig, H. & McConnell, M. (1999). *The Healing power of Faith*. New York, NY: Simon & Schuster.
- Kopelman, L. & Moskop, J. (Eds). (1984). *Ethics and mental retardation*. Dordrecht: D. Reidel.
- Koritsas, S. & Iacono, T. (2011). Secondary conditions in people with developmental disability. *American Journal on Intellectual and Developmental Disabilities*, 116(1), 36 - 47.
- Kormann, R. J. & Petronko, M. R. (2002). Crisis and revolution in developmental disabilities: The dilemma of community based services. *The Behavior Analyst Today*, 3(4), 434 - 443.
- Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential setting for people with intellectual disability: A systematic review *American Journal on Intellectual and Developmental Disabilities*, 114(3), 193 - 222.

- Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential setting for people with intellectual disability: A systematic review *American Journal on Intellectual and Developmental Disabilities*, 114(3), 193 - 222.
- Krupski, T. L., Kwan, L., Fink, A., Sonn, G. A., Maliski, S., & Litwin, M. (2006). Spirituality influences health related quality of life in men with prostate cancer. *Psycho-Oncology*(15), 121 - 131.
- Kuhn, C. C. (1988). A spiritual inventory of the medically ill patient. *Psychiatric Medicine*, 6, 87 - 99.
- Kunz, R. (2011). You have not forgotten us: Towards a disability - accessible church and society. *Journal of Religion, Disability & Health*, 15(1), 20 - 33.
- Kvale, S. (1995). The social construction of validity. *Qualitative Inquiry*, 1(1), 19-40.
- Kvale, S. & Brinkmann, S. (2009) *Interviews: Learning the craft of qualitative research interviewing*, Los Angeles, CA: Sage.
- Ladd, K., McIntosh, D. N., & Spilka, B. (1998). Children's God concepts: Influences of denomination, age and gender. *International Journal for the Psychology of Religion*, 8(1), 49 - 56.
- Lamb, G. S. (2001). Assessing quality across the care continuum. In L. S. Noelker & Z. Harel (Eds.), *Linking quality of long-term care and quality of life* (pp. 27 – 41). New York: Springer.
- Lambert, N, M. Stillman, T. F., Baumeister, R. F., Fincham, F. R., Hicks, J. A. & Graham, S. M. (2010). Family as a salient source of meaning in young adulthood. *Journal of Positive Psychology*, 5, 367 - 376.
- Lapan, S. D., Quartaroli, M.T., & Riemer, F.J. (Eds.), (2012). *Qualitative research: An introduction to methods and designs*. San Francisco, CA: Josey-Bass.
- L'Arche. (2011). L'Arche USA: History Retrieved March 20, 2011
- Larson, D. B., Sawyers, J. P., & McCullough, M. E. (1998). Scientific research on spirituality and health: A report based on the Scientific Progress in Spirituality Conferences. New York: John M. Templeton Foundation.
- Larson, S., Lakin, K., Anderson, L., Lee, N., Lee, J., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, (May, 2001), 106(3), 231 – 252.
- Lehman AF. 1988. A quality of life interview for the chronically mentally ill. *Evaluation Program Plan* 11:51-62.

- Lenth, R.V. (2001). Some practical guidelines for effective sample size determination. *The American Statistician* 55, 187–193.
- Lester, S. (1999). *An introduction to phenomenological research*. Taunton UK, Stan Lester Developments. Retrieved at www.sld.demon.co.uk/resmethv.pdf accessed October 7, 2013.
- Levitt, P. (2004). Redefining the boundaries of belonging: The institutional character of transnational religious life. *Sociology of Religion*, 65(1), 1 - 18.
- Lewiecki-Wilson, C., & Brueggemann, B. J. (2008). Introduction. In C. Lewiecki-Wilson, C. & B. J. Brueggemann (Eds.), *Disability and the teaching of writing: A critical sourcebook* (pp. 1 - 9). Boston: Bedford/St. Martin's.
- Lewis, M. A., Lewis, C. E., Leake, B., King, B., Lindemann, R. (2002). The quality of health care for adults with developmental disabilities. *Public Health Reports*, 117(2), 174 – 184.
- Lin, H. (2008). Searching for meaning: Narratives and analysis of US-resident Chinese immigrants with metastatic cancer. *Cancer Nursing*, 31(3), 250 - 258.
- Lincoln, Y. S. & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic inquiry*, 289-331.
- Lindblom, K. & Dunn P. A. (2003). The roles of rhetoric in constructions and reconstructions of disability. *Rhetoric Review*, 22(2), 167 - 174.
- Loomes, G. & McKenzie, L.(1989). The use of QALYs in health care decision making. *Social Science and Medicine*, 28, 299 - 308.
- Loury, G. C. (2000). Social exclusion and ethnic groups: The challenge to economics. Retrieved: www.bu.edu/irsd/files/socialethnic.pdf.
- Lucas, R. E., Clark, A. E., Georgellis, Y., & Diener, E. (2003). Re-examining adaptation and the set-point model of happiness: Reactions to changes in marital status? *Journal of Personality and Social Psychology*, 84, 537 - 539.
- MacDonald, D. A. (2000). Spirituality: Description, measurement, and relation to the five factor model of personality. *Journal of Personality* 68, 153 - 197.
- MacDonald, D. A., Friedman, H. L., & Kuentzel, F. G. (1999). A survey of measures of spiritual and transpersonal constructs: Part one-research update. *Journal of Transpersonal Psychology*, 31, 137 - 154.
- MacGregor, I. & Little, B. R. (1998). Personal projects, happiness, and meaning: On doing well and being yourself. *Journal of Personality and Social Psychology*, 74, 494 - 512.

- Macionis, J. & Plummer, K. (2005). *Sociology: a global introduction*. Edinburg Gate: Pearson Education, Essex.
- Macquarrie, J. (1982). *In search of humanity*. London: SCM Press Ltd.
- Maggino, F. & Ruviglioni, E. (2008). Methodologies to integrate subjective and objective information to build well-being indicators. Retrieved: http://old.sis-statistica.org/files/pdf/atti/Atti%20pubblicati%20da%20Cleup_383-390.pdf
- Mark, M. M., Feller, I., & Button, S. B. (1997). Integrating qualitative methods in a predominantly quantitative evaluation: A case study and some reflections. *New Directions for Evaluation*, 1997(74), 47-59.
- Marshall, C. & Rossman, G. B. (1989). *Design qualitative research*. Thousand Oaks, CA: Sage.
- Maselko, J. & Kubzansky L. (2006). Gender differences in religious practices, spiritual experiences and health: Results from the US General Social Survey. *Social Science & Medicine*, 62(11). 2848 - 2860.
- Maslow, A. (1943). A theory of human motivation. *Psychology Review*, 50, 370 - 396.
- Maslow, A. (1954). *Motiation and Personality*. New York: Harper
- Matzo, M. & Sherman, D. W. (2009). *Palliative care nursing: Quality care to the end of life* (3rd ed.). New York, NY: Springer Publishing Co.
- Maugens, T. A. (1996). The SPIRITual history. *Archives of Family Medicine*, 5, 11 - 16.
- Maugens, T. A., & Wadland, W. C. (1991). Religion and Family Medicine: A Survey of Physicians and Patients. *Journal of Family Practice*, 32, 210 - 213.
- McCann, T. & Clark, E. (2005). Using unstructured interviews with participants who
- McDonald, K. E., Kidney, C. A., & Patka, M. (2012). 'You need to let your voice be heard': research participants' views on research. *Journal of Intellectual Disability Research*.
- McCracken, J. T., McGough, J., Shah, B., Cronin, P., Hong, D., Aman, M. G., Arnold, L.E., Lindsay R., Nash, P., Hollway, J., McDougle C.J., Posey D., Swiezy N., Kohn, A., Scahill, L., Martin, A., Koenig K, Volkmar, F. Carroll, D., Lancor A., Tierney, E., Ghuman, J., Gonzalez N.M., Grados M., Vitiello, B., Ritz, L., Davies, M., Robinson, J., McMahan, D. (2002). Risperidone in children with autism and serious behavioral problems. *New England Journal of Medicine*, 34(5), 314 - 321.
- McCullough, M. E., Hoyt, W. T., Larson, D. B., Koenig, H. G., & Thoresen, C. (2000). Religious involvement and mortality: A meta-analytic review. *Health Psychology*, 19(3), 211 - 222.

- McDonald, K. E., Kidney, C. A., & Patka, M. (2012). 'You need to let your voice be heard': research participants' views on research. *Journal of Intellectual Disability Research*.
- McDougle, C. J., Scahill, L., Aman, M. G., McCracken, J. T., Tierney, E., Davies, M., et al. (2005). Risperidone for the core symptom domains of autism: Results from the study by the Autism Network of the Research Units on Pediatric Psychopharmacology. *American Journal of Psychiatry*, *162*, 1142 - 1148.
- McGrew, K. S., Bruininks, R. H., & Thurlow, M. L. (1992). Relationship between measures of adaptive functioning and community adjustment for adults with mental retardation. *Exceptional Children*, *58*. 517 – 529.
- McIntyre, L. L. (2008). Parent training in young children with developmental disabilities: A randomized controlled trial. *American Journal on Mental Retardation*, *113*, 356 - 368.
- McMahan, J. (1996). Cognitive disability, misfortune, and justice. *Philosophy and Public Affairs*, *25*, 3 - 31.
- McMahan, J. (2003). *The ethics of killing: Problems at the margins of life*. Oxford: Oxford University Press.
- McMahan, J. (2008). Challenges to human equality. *The Journal of Ethics*, *12*, 81 - 104.
- McNair, J. (2011a). Message from the President. *AAIDD Religion and Spirituality Division Newsletter*, March 2011.
- McNair, J. (2011b, March 4). Theology awakened by disability.
- McVilly, K. R. & Dalton, A. J. (2006). Commentary on Iacono (2006): "Ethical challenges and complexities of including people with intellectual disability as participants in research". *Journal of Intellectual and Developmental Disability*, *31*(3), 186-188.
- Mead, G. (1934). *Mind, self & society*. Chicago: University of Chicago Press.
- Menchetti, B. & Garcia, L. (2003). Personal and employment outcomes of person-centered career planning. *Education and Training of the Mentally Retarded*, *38*, 145 - 156.
- Merriam, S. B. (1988). *Case study research in education: A qualitative approach*. San Francisco, CA: Jossey-Bass.
- Merrick, J., Gabbay, Y., & Lifshitz, H. (2001). Judaism and the person with intellectual disability. In W. C. Gaventa & D. L. Coulter (Eds.), *Spirituality and intellectual disability: International perspectives on the effect of culture and religion on healing body, mind, and soul* (pp. 49 - 63). New York: The Haworth Press, Inc.

- Mertens, D. M. (2003). Mixed methods and the politics of human research: The transformative-emancipatory perspective. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social & behavioral research* (pp. 135 - 164). Thousand Oaks, CA: Sage Publishing.
- Michalos, A. C. (2004). Social indicators research and health-related quality of life research. *Social Indicators Research*, 65, 27 - 72.
- Miles, M. B. & Huberman, A. M. (1984). *Qualitative data analysis: A sourcebook of new methods*. Beverly Hills, CA: Sage Publishing, Inc.
- Miller, L. (2010). Watching for light: Spiritual psychology beyond materialism. *Psychology of Religion and Spirituality*, 2, 35 - 36.
- Miller, M. A. (1995). Culture, spirituality, and women's health. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 24, 257 - 263.
- Miller, W. R. (1998). Researching the spiritual dimensions of alcohol and other drug problems. *Addiction*, 93, 979 - 990.
- Minichielle, V. Aroni, R., Timewell, E. & Alexander, L. (1990). *In-depth interviewing research people*. Melbourne: Longman Cheshire.
- Moberg, D. O. (1979). Development of social indicators of spiritual well-being for quality of life research. In D. O. Moberg (Ed.), *Spiritual well-being: Sociological perspectives*. Washington D. C.: University Press of America.
- Monod, S., Brennan, M., Rochat, E., Martin, E., Rochat, S., & Bula, C.J. (2011). Instruments measuring spirituality in clinical research: A systematic review. *Journal of General Internal Medicine*. November 2011, 26 (11), 1345 - 1357.
- Montgomery, C. (1991). The care-giving relationship: paradoxical and transcendent aspects. *Journal of Transference and Psychology*, 23, 91 - 104.
- Morad, M., Nasri, Y., & Merrick, J. (2001). Islam and the person with intellectual disability. In w. C. Gaventa & D. L. Coulter (Eds.), *Spirituality and intellectual disability: International perspectives on the effect of culture and religion on healing body, mind, and soul* (pp. 65 - 85). New York, NY: Haworth Press, Inc.
- Morisse, F., Vandemaele, E., Claes, C., Claes, L., & Vandavelde, S. (2013). Quality of life in persons with intellectual disabilities and mental health problems: An explorative study. In *The Scientific World Journal*, 2013, Article ID 491918, 8 pages.
- Morse, J. M. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research*, 40, 120-123.
- Morris, J. (2007). An Orthodox Response to the Recent Roman Catholic Declaration on the Nature of the Church. *The Word magazine*.

- Morse J. M., Barrett M., Mayan M., Olson K., & Spiers J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods* 1(2), Article 2.
- Morrison Institute for Public Policy. (2008). Arizonans like their lives, but worry too. *AZ Views*, 1(4), 1 - 7.
- Morrisroe, P. (1908). Communion of Children. In *The Catholic Encyclopedia*. New York: Robert Appleton Company. Retrieved May 5, 2013 from New Advent: <http://www.newadvent.org/cathen/04170b.htm>
- Moss, B. & Gilbert, P. (2007). Flickering candles of hope: Spirituality, mental health and the search for meaning: Some personal perspectives. *Illness, Crisis & Loss*, 15(2), 179 - 191.
- Moss, E. L. & Dobson, K. S. (2006). Psychology, Spirituality, and End-of-Life Care: An Ethical Integration. *Canadian Psychology*, 47(4), 284 - 299.
- Moustakas, C. (Ed.). (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Muhwezi, W. W., Okello, E. S., & Turiho, A. K. (2010). Gender-based profiling of quality of life (QOL) of primary health care (PHC) attendees in central Uganda: a cross sectional analysis *African Health Sciences*, 10(4), 374 - 385.
- Murphy, E., Clegg, J., Almack, K. (January, 2011). Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24(1), 61 - 73.
- Murrell, S. A. & Norris, F. H. (1983). Quality of life as the criteria for need assessment and community psychology. *Journal of Community Psychology*, 11, 88 - 97.
- Murtagh, K. N. & Huber, H. B. (2004). Gender differences in physical disability among elderly cohort. *American Journal of Public Health*, 94(8), 1406 - 1411.
- Mytko, J. J. & Knight, S. J. (1999). Body, mind and spirit: Towards the integration of religiosity and spirituality in cancer quality of life research. *Psycho-Oncology*, 8, 439 - 450.
- Nagel, E. & Sgoutas-Emch, S. (2007). The relationship between spirituality, health beliefs, and health behaviors in college students. *Journal of Religion and Health*, 46(1), 141 - 154.
- Nanda, M. (2004). Eco-Spirituality, neo-paganis, and the Hindu right: The dangers of religious environmentalism. *Women & Environments International Magazine*, 19 - 22.

- National Disability Authority. (2002). *Buildings for everyone*. British Library Cataloguing in Publication Data
- National Institute of Health, (1999). Office of Behavioral and Social Science Research. *Qualitative Methods in Health Research. Opportunities and Considerations in Application and Review*. Washington, DC: National Institute of Health.
- Nestvold, K. & Stavem, K. (2009). Determinants of health-related quality of life 22 years after hospitalization for traumatic brain injury. *Brain Injury*, 23(1), 15 - 21.
- Norris, P. & Inglehart, R. (2004). *Sacred and secular: Religion and politics worldwide*. New York, NY: Cambridge University Press.
- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. L. (2007). Self-determination, social abilities, and the quality of life of people with intellectual disabilities. *Journal of Intellectual Disability Research*, 51, 850 – 865.
- O'Brien, J. & O'Brien, C. L. (Eds.). (1987). *A little book about person centered planning* Toronto: Inclusion Press.
- O'Connell, K. A., & Skevington, S. M. (2010). Spiritual, religious, and personal beliefs are important and distinctive to assessing quality of life in health: A comparison of theoretical models. *British Journal of Health Psychology*, 15(4), 729 - 748. doi: 10.1348/135910709X479799
- O'Connell, K. A., Saxena, S., & Underwood, L. (2006). A cross-cultural study of spirituality, religion, and personal beliefs as components of quality of life. *Social Science and Medicine*, 62, 1486 - 1497.
- O'Donohue, W. (1989). The (even) bolder model: The clinical psychologist as metaphysician-scientist-practitioner. *American Psychologist*, 44, 1460 - 1468.
- Okulicz-Kozaryn, A. (2010). Religiosity and life satisfaction across nations. *Mental Health, Religion & Culture*, 13(2), 155 - 169.
- Olsen, W. (2004). Triangulation in social research: qualitative and quantitative methods can really be mixed. *Developments in Sociology*, 20, 103-118.
- Olson, C. (2007). *Hindu primary sources: a sectarian reader*. Rutgers University Press.
- Paloutzian, R. F., & Ellison, C. W. (1991). *Manual for the Spiritual Well-Being Scale*. Nyack, NY: Life Advance Inc.
- Paloutzian, R. F., & Ellison, C. W. (Eds.). (1982). *Loneliness, spiritual well-being and the quality of life*. New York, NY: Wiley.
- Paramenter, T. R. (1992) International Review of Research in Mental Retardation. Vol. 18. *Quality of Life of People With Developmental Disabilities* (pp. 247 - 309): Academic Press.

- Pargament, K. I., Van Haitsma, K., & Ensing, D. S. (1995). Religion and coping. In M. A. Kimble, S. H. McFadden, J. W. Ellor & J. J. Seeber (Eds.), *Aging, spirituality, and religion: A handbook* (pp. 47 - 67). Minneapolis, MN: Fortress Press.
- Parmenter, T. R. (1988). An analysis of the dimensions of quality of life for people with physical disabilities. In R. Brown (Ed.), *Quality of life for handicapped people*. London: Croom Helm.
- Parmenter, T. R. (1991). Has social policy left research behind? *Australia and New Zealand Journal of Developmental Disabilities*, 17, 1 - 6.
- Parmenter, T. R. (1992) International Review of Research in Mental Retardation. Vol. 18. *Quality of Life of People With Developmental Disabilities* (pp. 247 - 309): Academic Press.
- Patrick, D. L., & Bergner, M. (1990). Measurement of health status in the 1990's. *Annual Review of Public Health*, 11, 165 - 183.
- Patterson, C. (2009). State-wide faith based inclusion study. *AAIDD Religion and Spirituality Division Newsletter*, 7 - 11.
- Patterson, E. A. & Vogel, N. A. (2003). *Accessible Faith: A Technical Guide for Accessibility in Houses of Worship*. Chicago, IL: The Retirement Research Foundation.
- Patton M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Pawar, B. S. (2009). Individual spirituality, workplace spirituality and work attitudes: An empirical test of direct and interaction effects. *Leadership & Organization Development Journal* 30(8).
- Pearce, M. (2005). A critical review of the forms and value of religious coping among informal caregivers. *Journal of Religion and Health*, 44(1).
- Pearls, F. (1969). *Ego, hunger, and aggression: The beginning of Gestalt Therapy*. New York, NY: Random House.
- Pedhazur, E. J. (1997). Multiple regression in behavioral research: Explanation and prediction (3rd ed.). Orlando, FL: Harcourt
- Peters, T. (2007). Christian God-talk while listening to Atheists, Pluralists, and Muslims. *Dialog: A Journal of Theology*, 46(2), 84 - 103.
- Peterson, M., Webb, D., (2006). Religion and spirituality in quality of life studies. *Applied Research in Quality of Life*, 1 (1), 107 - 116.

- Petry, K., Maes, B., & Viaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities, 18*, 35 - 46.
- Petry, K., Maes, B., & Vlaskamp, C. (2009). Measuring the quality of life of people with profound multiple disabilities using the QOL-PMD: First results. *Research in Developmental Disabilities, 30*(6), 1394 - 1405.
- Pew Research Center, (December 2012). *The global religious landscape: A report on the size and distribution of the world's major religious groups as of 2010*. Retrieved from: <http://www.pewforum.org/global-religious-landscape-exec.aspx>.
- Piedmont, R. L. (1999). Does spirituality represent the sixth factor of personality? Spiritual transcendence and the five-factor model. *Journal of Personality, 67*, 985 - 1013.
- Piedmont, R. L. (2004). Spiritual Transcendence as a Predictor of Psychosocial Outcome From an Outpatient Substance Abuse Program. *Psychology of Addictive Behaviors, 18*(3), 213 - 222.
- Piedmont, R. L. & Leach, M. M. (2002). Cross-cultural generalizability of the Spiritual Transcendence Scale in India: Spirituality as a universal aspect of human experience. *American Behavioral Scientist, 45*, 1888 - 1901.
- Piedmont, R. L., Ciarrochi, J. W., Williams, J. E. G., & Dy-Liacco, G. S. (2009). The Empirical and Conceptual Value of the Spiritual Transcendence and Religious Involvement Scales for Personality Research. *Psychology of Religion and Spirituality, 1*(3), 162 - 179.
- Pinto-Meza, A., Fernandez, a., Fullana, M. A., Haro, J. M., Palao, D., Luciano, J. V. (2009). Impact of mental disorders and chronic physical conditions in health-related quality of life among primary care patients: results from an epidemiological study. *Quality of Life Research, 18*(8), 1011 - 1018.
- Plianbangchang, S. (2007, January 13, 2007). [1st World Convention on Science and Spirituality, New Delhi, 13 - 14 January 2007: Message From the Regional Director].
- Polkinghorne, D. E. (1989). Phenomenological research methods. In *Existential-phenomenological perspectives in psychology* (pp. 41-60). Springer US.
- Polkinghorne, D. (1994). A path of understanding for psychology. *Journal of Theoretical and Philosophical Psychology, 14*, 128 - 145.
- Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of counseling psychology, 52*(2), 137.

- Pollak, S. J. (2008). Attitudes and emotions of Orthodox Jews who have siblings with disabilities: Religious correlates and social context. *Journal of Religion, Disability & Health*, 12(2), 154 - 185.
- Pomeranz, T. (1992, April). Living in new kinds of situations. *ANCOR Links*.
- Pope, C. Ziebland, S. & Mays, N. (2000) Qualitative research in healthcare: analyzing qualitative data. *British Medical Journal*; 320: 7227: 114 - 116.
- Popkin, R. H. & Stroll, A. (1993). *Philosophy Made Simple* (2nd ed.). New York, NY: Batnam Doubleday Dell Publishing Group, Inc.
- Powers, J., & Goode, D. A. (1986). *Partnerships for people: Enhancing the quality of life of persons with disabilities through incentives management*. The Rose F. Kennedy Center, Albert Einstein College of Medicine. Bronx, NY.
- Powers, L. E., & Sowers, J.-A. (2006). A Cross-disability analysis of person-directed, long term services. *Journal of Disability Policy Studies*, 17(2), 66 - 76.
- Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., Chochinov, H., Handzo, G., Nelson-Becker, H., Prince-Paul, M., Pugliese, K., & Sulmasy, D. (2009) 'Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference' *Journal of Palliative Medicine*, Volume 12, Number 10, pp. 885- 904.
- Punch, K. F. (1998). *Introduction to social research: Quantitative and qualitative approaches*. London: Sage
- Quinn, G., Degener, T., Bruce, A., Burke, C., Castellino, J., Kenna, P. (2002). *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability*. New York and Geneva: United Nations.
- Rachels, J. (Ed.). (1989). *The Right Thing to Do*. New York, NY: Random House.
- Rambow, T., & Scheller, R. (2006). *Realizing the Dream by Committing to the Journey: Social Inclusion & the Honoring of One's Cultural & Spiritual Paths*. Paper presented at the AAMR Summit: Social inclusion, are we there yet?, Montreal.
- Ramcharan, P. (2006). Ethical challenges and complexities of including vulnerable people in research: Some pre-theoretical considerations. *Journal of Intellectual & Developmental Disability*, 31,183–185.
- Raphael, D., Brown, I., Renwick, R., & Rootman, I. (1997). Quality of life: What are the implications for health promotion? *American Journal of Health and Behavior*. 21(2), 118 – 128.
- Reed, P. G. (1991). Self-transcendence and mental-health in oldest-old adults. *Nursing Research*, 40, 5 - 11.

- Reimer, K. S. (2009). *Living L'Arche: Stories of Compassion, Love, and Disability*. Collegeville, Minnesota: Liturgical Press.
- Reinders, H. (2008). *Receiving the gift of friendship: Profound disability, theological anthropology and ethics*. Grand Rapids, MI: Eerdmans.
- Report of the Commission on the Measurement of Exonomic Performance and Social Progress. (2010). <http://www.stiglitz-sen-fitoussi.fr/en/index.htm>
- Requena, C., Martinez, A. M., & Ortiz, T. (2010). Vital Satisfaction as a Health Indicator in Elderly Women. *Journal of Women & Aging*, 22(1), 15 - 21. doi: 10.1080/08952840903488872
- Rican, P. & Janosova, P. (2005). Spirituality: its psychological operationalization via measurement of individual differences: A Czech perspective. *Studia Psychologica*, 47, 157 - 165.
- Roberts, C. W. (1989). Imagining God: Who is created in whose image? *Review of Religious Research* 30, 375 - 386.
- Robertson, J., Emerson, E. B., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., Joyce, T. (2006). Longitudinal analysis of the impact and cost of person-centered planning for people with intellectual disabilities in England. *American Journal on Mental Retardation*, 111, 400 - 416.
- Robillard, L. (1999). *Quality of Life - A Concept Paper: Defining, Measuring and Reporting Quality of Life for Canadians*. Treasury Board of Canada Secretariat.
- Rogers, C. (1951). *Client-centered therapy: Its current practice, implications and theory*. London: Constable.
- Rojas, M. (2006). Life satisfaction and satisfaction in domains of life: Is it a simple relationship? *Journal of Happiness Studies*, 7, 467 - 497.
- Rose, A. (1997). 'Who Causes the Blind to See': Disability and the quality of religious life. *Disability & Society*, 12, 395 - 405.
- Rosenberg, G., & Holden, G. (1997). The role of social work in improving quality of life in the community. *Social Work in Health Care*, 25(1/2), 9 - 22.
- Ross, L. (1995). The spiritual dimension: Its importance to patients' health, well-being and quality of life and its implications for nursing practice. *International Journal of Nursing Studies*, 32(5), 457 - 468.
- Rossman, G. B. & Wilson, B. L. (1985). Numbers and words combining quantitative and qualitative methods in a single large-scale evaluation study. *Evaluation Review*, 9(5), 627-643.

- Russell, J. A. (2003). Core affect and the psychological construction of emotion. *Psychological Review*(110), 145 - 172.
- Ryken, P. G. (2001). *The communion of saints: Living in fellowship with the people of God*: P & R Publishing.
- Salek, S. (1999). *The Compendium of Quality of Life Instruements*. Hoboken, New Jersey: John Wiley & Sons, Inc.
- Salmon, J. L. (2008, Tuesday, June 24, 2008). Most Americans Believe in Higher Power, Poll Finds, *The Washington Post*.
- Sandage, S. J., Jankowski, P. J., & Link, D. C. (2010). Quest and spiritual development moderated by spiritual transformation. *Journal of Psychology & Theology*, 38(1), 15 - 31.
- Sarvimaki, A., & Stenbock-Hult, B. (2000). Quality of life in old age described as a sense of well-being, meaning and value. *Journal of Advanced Nursing*, 32(4), 1025 - 1033.
- Sawatzky, R. (2002). *A meta-analysis of the relationship between spirituality and quality of life*. MS, The University of British Columbia, Vancouver.
- Sawatzky, R. Ratner, P. A., Chiu, L. (2005). A menta-analysis of the relationship between spirituality and quality of life. *Social Indicators Research*, 72, 153 – 188.
- Schaff, P. (1912). *The new Schaff-Herzog encyclopedia of religious knowledge: embracing Biblical, historical, doctrinal, and practical theology and Biblical, theological, and ecclesiastical biography from the earliest times to the present day* (Vol. 12). Funk & Wagnalls Company.
- Scanlon, T. (1998). *What we owe each other*.Cambridge, MA: Harvard University Press.
- Schalock, R. L. (1990). Attempts to conceptualize and measure quality of life. In R. L. Schalock (Ed.), *Quality of life: Perspectives and issues*. Washington DC: American Association on Mental Retardation.
- Schalock, R. L., & Keith, K. D. (2004). *Quality of Life Questionnaire Manual*. Ohio: IDS Publishing Corporation.
- Schalock, R. L., Keith, K. D., Verdugo, M. Á., & Gómez, L. E. (2011). Quality of life model development and use in the field of intellectual disability. In *Enhancing the Quality of Life of People with Intellectual Disabilities* (pp. 17-32). Springer Netherlands.

- Schalock, R. L. & Verdugo Alonso, M. A. (2002). *Handbook on Quality of Life for Human Service Practitioners*. Washington, DC: American Association on Mental Retardation.
- Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning, 31*(2), 181 - 190.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for people with intellectual disabilities: Report of an international panel of experts. *Mental Retardation, 40*, 457 - 470.
- Schalock, R. L., Coulter, D. L., Polloway, E. A., Reiss, S., Snell, M. E., & Spitalnik, D. M. (1994). The changing conception of mental retardation: Perspectives in change. *Mental Retardation, 32*, 181 - 193.
- Schalock, R. L., Keith, K. D., & Hoffman, K. (1990). *1990 Quality of life questionnaire: Standardization manual*. Hastings, NE: Mid-Nebraska Mental Retardation Services.
- Schalock, R. L., Keith, K. D., & Karan, O. C. (1989). Quality of life: Its measurement and use in human service programs. *Mental Retardation, 27*, 25 - 31.
- Schalock, R. L., Verdugo, M. A., Bonham, G. S., Fantova, F., & van Loon, J. (2008). Enhancing personal outcomes: Organizational strategies, guidelines and examples. *Journal of Policy and Practice in Intellectual Disabilities, 5*, 276 - 288.
- Schneider, M. (1975). The quality of life in large American cities: Objective & subjective social indicators. *Social Indicators Research, 1*, 495 - 509.
- Schumaker, S. & Hill, D. (1991). Gender differences in social support and physical health. *Health Psychology, 10*(2), 102 - 111.
- Shafranske, E. P. (2010). Advancing "The Boldest Model Yet": A Commentary on Psychology, Religion, and Spirituality. *Psychology of Religion and Spirituality, 2*(2), 124 - 125.
- Shah, R., Kulhara, P., Grover S, et al (2011). Contribution of spirituality to quality of life in patients with residual schizophrenia. *Psychiatry Research, 190*, 200 - 205.
- Shogren, K., Bradley, V. J., Gomez, S. C., Yeager, M. H., Schalock, R. L., & Borthwick-Duffy, S. (2009). Perspectives: Public policy and the enhancement

- of desired outcomes for persons with intellectual disability. *Intellectual and Developmental Disabilities*, 47(4), 307 - 319.
- Simpson, D. B., Newman, J. L., Cloud, D. S., & Fuqua, D. R. (2008). Sex and gender differences in religiousness and spirituality. *Journal of Psychology & Theology*, 36, 42 – 52.
- Simpson, D. B., Newman, J. L., & Fuqua, D. R. (2008). Understanding the role of relational factors in christian spirituality. *Journal of Psychology and Theology*, 36(2), 124 - 134.
- Singer, Peter. (1996). *Rethinking life and death: The collapse of our traditional ethics*. New York, NY: Macmillan.
- Singer, Peter. (1995). *Animal liberation*. London: Pimlico.
- Singer, Peter. (2011). *Practical ethics: Third edition*. New York, NY: Cambridge University Press.
- Singer, Peter. (Ed.). (1986). *Applied ethics*. Oxford: Oxford University Press.
- Smith, M. J. (2003). Caring, community, and transcendence - Developing spirit to improve learning. *Community College Review*, 28(3), 57 - 69.
- Somekh, B. & Lewin, C. (2005). *Research methods in social sciences*. London: Sage.
- Spaniol, L. (2002). Spirituality and connectedness. *Psychiatric Rehabilitation Journal*, 321 - 322. Retrieved from
- Specht, J. A., King, G. A., Willoughby, C., Brown, E. G., & Smith, L. (2005). Spirituality: A coping mechanism in the lives of adults with congenital disabilities. *Counseling and Values*, 50, 51 - 62.
- Spreitzer, E. & Snyder, E. E. (1974). Correlates of life satisfaction among the aged. *Journal of Gerontology*, 29, 454 - 458.
- Stade, B. C., Stevens, B., Ungar, W. J., Beyene, J., & Koren, G. (2006). Health-related quality of life of Canadian children and youth prenatally exposed to alcohol. *Health and Quality of Life Outcomes*, 4(81).
- Stancliffe, R. J. (2005). Semi-independent living and group homes in Australia. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 129 - 150). Baltimore, MD: Brookes.
- Stancliffe, R. J., Abery B. H., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living –unit size and type. *American Journal on Mental Retardation*, 105, 431 – 454.

- Stancliffe, R. J. & Lakin, K. C. (1998). Analysis of expenditures and outcomes of residential alternatives for persons with developmental disabilities. *American Journal of Mental Retardation*, 102, 552 - 568.
- Stienstra, D. & Ashcroft, T. (2010). Voyaging on the seas of spirit: an ongoing journey towards understanding disability and humanity. *Disability & Society*, 25(2), 191 - 203.
- Stiglitz, J., Sen, A., & Fitoussi, J. P. (2011). Report by the commission on the measurement of economic performance and social progress. 2009. *Dostupné z: www. stiglitz-sen-fitoussi. fr.*
- Stillman, T. F., Baumeister, R. F., M., L. N., Crescioni, A. W., DeWall, C. N., & Fir, F. D. (2009). Alone and without purpose: Life loses meaning following social exclusion. *Journal of Experimental Social Psychology*, 45(4), 686 - 694. doi: 10.1016/j.jesp.2009.03.007
- Strawbridge, W. J., Cohen, R. D., Shema, S. J., & Kaplan, G. A. (1997). Frequent attendance at religious service and mortality over 28 years. *American Journal of Public Health* 87(6), 957 - 961.
- Sue, D. W., & Sue, D. (1999). *Counseling the culturally different: Theory and practice*. New York: Wiley.
- Sue, D. W., Bingham, R. P., Porche-Burke, L., & Vasquez, M. (1999). The diversification of psychology: A multicultural revolution. *American Psychologist*, 54(12), 1061 - 1069.
- Sullivan, M. (2009). Philosophy, ethics, and the disability community. In D. M. Mertens & P. G. Ginsberg (Eds.) *Handbook of social research ethics* (pp. 69 – 84). Thousand Oaks, CA: Sage.
- Sullivan, S. C. (2008). Unaccompanied children in churches: Low-income urban single mothers, religion, and parenting. *Review of Religious Research*, 50(2).
- Swier, G. M. (2008). 'Nature', *Physis*, and the Holy. *Journal for the Study of Religion, Nature and Culture*, 2, 237 - 257. doi: 10.1558/jsrnc.v2i2.237
- Swinton, J. (1997). Restoring the image: Spirituality, faith, and cognitive disability. *Journal of Religion and Health*, 36(1), 21 - 28.
- Swinton, J. (2001). Building a church for strangers: Theology, church and intellectual disabilities. *Journal of Religion, Disability & Health*, 4(4), 25 - 63.
- Swinton, J., Mowat, H., & Baines, S. (2011). Whose story am I? Redescribing profound intellectual disability in the Kingdom of God. *Journal of Religion, Disability & Health*, 15(1), 5 - 19.

- Tabachnick, B.G. & Fidell, L.S. (1996). *Using multivariate statistics*. (3rd Edition). New York, NY: Harper Collins College Publishers
- Taillefer, M. C., Dupuis, G., Roberge, M. A., & May, S. L. (2003). Health-related quality of life models: Systematic review of the literature. *Social Indicators Research, 64*, 293 - 323.
- Tashakkori, A., & Teddlie, C. (Eds.). (2003). *Handbook of mixed methods in social & behavioral research*. Thousand Oaks, CA: Sage.
- Taylor, B. (2001). Earth and nature-based spirituality (Part II): from Earth First! and bioregionalism to scientific paganism and the new age. *Religion, 31*(3), 225 - 245.
- Teichman, J. (1992). Humanism and personism [online]. *Quadrant, 36*, (12): pp. 26-29. Retrieved from <http://search.informit.com.au/documentSummary:dn=058217644415627;res=IELLCC>. [cited 06 Aug 13].
- Teddlie, C. & Yu, F. (2007). Mixed methods sampling a typology with examples. *Journal of mixed methods research, 1*(1), 77-100.
- Thapar, N., Warner, G., Drainoni, M., Williams, S. R., Ditchfield, H., & Wierbicky, J. (2004). A pilot study of functional access to public buildings and facilities for persons with impairments. *Disability and Rehabilitation, 26*, 280 - 289.
- The Alaska Mental Health Trust Authority, (2009). 2009 Annual report: Working for our beneficiaries. Retrieved at <http://www.mhtrust.org>. Trust 2009 Annual Report.pdf.
- The Patient-Reported Outcome and Quality of Life Instruments Database. (2011) Retrieved January 2, 2011
- Thorndike, E.L. (1939). On the fallacy of imputing the correlations found for groups to the individuals or small groups composing them. *American Journal of Psychology, 52*, 122-124.
- Townsend, C. E., & Pham Tran, A. (2010). A systematic review of quality of life instruments for people with ID. *Journal of Applied Research in Intellectual Disabilities, 23*(5), 505.
- Treloar, L. L. (2002). Disability, spiritual beliefs, and the church: the experiences of adults with disabilities and family members. *Journal of Advanced Nursing, 40*, 594 - 603.
- Treloar, L. L. & Artinian, B. (2001). Chapter 19: Populations Affected by Disabilities. In M. A. Nies & M. McEwen (Eds.), *Community Health Nursing: Promoting the Health of Aggregates* (3rd ed.). Philadelphia, PA: W.B. Saunders.

- Trent, J. W. (1994). *Inventing the feeble mind: A history of mental retardation in the United States*. Berkley, CA: Berkley University of California Press.
- Turmusani, M. (2001). Disabled women in Islam: Middle eastern perspective. In W. C. Gaventa & D. L. Coulter (Eds.), *Spirituality and intellectual disability: International perspectives on the effect of culture and religion on healing body, mind, and soul* (pp. 73 - 85). New York: The Haworth Press, Inc.
- Turnbull, A. P., Blue-Banning, M. J., Anderson, E. L., Turnbull, H. R., Seaton, K. A., & Dinas, P. A. (1996). Enhancing self-determination through Group Action Planning. In D. J. Sands & M. L. Wehmeyer (Eds.). *Self-determination across the lifespan: Independence and choice for people with disabilities* (pp. 237-256). Baltimore, MA: Paul H. Brookes.
- Tutu, D. (1999). *No future without forgiveness*. New York: Doubleday.
- U.S. Department of Education (2008). *What works clearinghouse*. Retrieved at <http://ies.ed.gov/ncee/wwc/reports/>
- U.S. Census Bureau. (2011). *State & Country Quickfacts*. Retrieved from <http://quickfacts.census.gov/qfd/states/02000.html>
- U. S. National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. (1978). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. NIH Library. Retrieved at <http://www.archive.org/details/belmontreporteth00unit>
- Vella-Brodrick, D. A. & Allen, F. C. L. (1995). Development and psychometric validation of the mental, physical, and spiritual well-being scale. *Psychological Reports*, 77, 659 - 674.
- Vierkant, K. E., Hollingsworth, H., & Stark, S. L. (2006). Accessible worship: The receptivity of religious buildings in St. Louis. *Disability Studies Quarterly*, 26(3).
- Vos, P., De Cock, P., Petry, K., Van Den Noortgate, W., & Maes, B. (2010). What makes them feel like they do? Investigating the subjective well-being in people with severe and profound disabilities. *Research in Developmental Disabilities*, 31(6), 1623 - 1632.
- Waite, P. J., Hawks, S. R., & Gast, J. A. (1999). The correlation between spiritual well-being and health behaviors. *American Journal of Health Promotion*, 13(3), 159 - 162.
- Walker, H. M., Calkins, C., Wehmeyer, M. L., Walker, L., Bacon, a., Palmer, S. B. (2011). A social-ecological approach to promote self-determination. *Exceptionality*, 19(1), 6 - 18.

- Ware, L. (2001). Writing, identity, and the other: Dare we do disability studies? *Journal of Teacher Education*, 52(2), 107 - 123.
- Watson, D. E., Broemeling, A.-M., & Wong, S. T. (2009). A Results-Based logic Model for Primary Healthcare: A Conceptual Foundation for Population-Based Information Systems. *Healthcare Policy*, 5(Sp), 33 - 46.
- Webb-Mitchell, B. (1993). *God plays the piano, too: The spiritual lives of disabled children*. New York, NY: Crossroad.
- Webb-Mitchell, B. (1994). *Unexpected guests at God's banquet: Welcoming people with disabilities into the church*. New York, NY: Crossroads.
- Webb-Mitchell, B. (1996). *Dancing with disabilities: Opening the church to all of God's children*. Cleveland, Ohio: United Church Press.
- Wehmeyer, M. L., Bolding N. (2001), Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research*, 45: 371-383. doi: 10.1046/j.1354-2788.2001.00342.x
- Wehmeyer, M. L., & Metzler, C. (1995). How self-determined are people with mental retardation? The National Consumer Survey. *Mental Retardation*, 33, 111 – 119.
- Weisner, T. S. (2011). The Ecocultural family interview: New conceptualizations and uses for the study of illness. *Papers in Honor of Vanna Axia*, 166-180.
- Weisner, T. S., Beizer, L., & Stolze, L. (1991). Religion and families of children with developmental delays. *American Journal of Mental Retardation*, 95, 647 - 662.
- Welsh, J. A. & Berry, H.L. (2009). Social capital and mental health and well-being. Paper presented at the Biennial HILDA Survey Research Congerence 16 - 17 JULY 2009. Retrieved August 31, 2013.
- Western Interstate Commission for Higher Education (2009). Western Interstate Commission for Higher Education; Boulder, CO:
- White, S. E. (2009). The influence of religiosity on well-being and acceptance in parents of children with Autism Spectrum Disorder. *2009*, 13(2), 104 - 113.
- Willhite, R. K., Niendam, T. A., Bearden, C. E., Zinberg, J., O'Brien, M. P., & Cannon, T. D. (2008). Gender differences in symptoms, functioning and social support in patients at ultra-high risk for developing a psychotic disorder. *Schizophrenia Research*, 104(1-3), 237 - 245. doi: 10.1016/j.schres.2008.05.019
- Williams, A. (1985). Economics of coronary artery bypass grafting. *British Medical Journal*, 291, 326 – 329.

- Williams, A. (1987). How should NHS priorities be determined? *Hospital Update*, 13, 261 – 263, 341.
- Williams, C. (1989). *Gender differences at work: Women and men in non-traditional occupations*. Berleley: University of California Press.
- Wills, E. (2009). Spirituality and subjective well-being: Evidences for a new domain in the Personal Well-being Index. *Journal of Happiness Studies*, 10, 49 - 69. doi: 10.1007/s10902-007-9061-6
- Wing, S. D. (1999). The diversification of psychology: A multicultural revolution. *American Psychologist*, 54(12).
- Wisley, S., & Lynn, E. (1994). Spirited connections: Learning oto tap the spiritual resources in our lives and work. In J. C. Associates (Ed.), *Spirit at work* (pp. 100 - 132). San Francisco, CA: Josey-Bass.
- Wolfensberger, W. (1969). *Changing Patterns in Residential Services for the Mentally Retarded*. Washington, D.C.: President's Committee on Mental Retardation.
- Wolfensberger, W. (1972). *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation.
- Wong, S., (2007). The moral personhood of individuals labeled 'mentally retarded': A Rawlsian response to Nussbaum. *Social Theory and Practice*, 33, 579 - 594.
- Wulff, D. M. (1997). *Psychology of religion. Classic and contemporary* (2nd ed.). New York, NY: Wiley.
- Yellow Pages: 2011/2012 Religious Organizations [Local Guide Directory]. Yellow Pages Group. Retrieved from http://alaska.localguides.com/ypcyello/religious_organizations.html
- Yerxa, E. J., Clark, F., Ftank, G., Jackson, J., Patham, D., Pietce, D., Stein, C., & Zemke, R. (1989). An introduction to occupational science: A foundation for occupational therapy in the 21 st century. *Occupational Therapy in Health Care*, 6(4),1-17.
- Zautra, A., & Goodhart, D. (1979). Quality of life indicators: A review of the literature. *Community Mental Health Reveiw*, 4(1), 1-14.
- Zinnbauer, B. J., Pargament, K. I., Cole, B., Rye, M. S., Butter, E. M., Belavich, T. G., Hipp, K. M., Scott, A. B., Kadar, J. L. (1997). Religion & spirituality: Unfuzzifying the fuzzy. *Journal of Scientific Study of Religion*, 36 (4), 549 – 564.

Appendix A: Introduction Letter from Executive Office of Organization

Topic: Letter of Introduction

Dear Sir/Madame,

This letter is an introduction to you regarding Ms. Tonja Rambow who is carrying out academic research on the topic of spirituality and disabilities and how a person's quality of life may be affected.

This organization is very supportive of this research project as it will deepen provider agencies understanding of this issue on behalf of people who experience a disability, as well as allow us to improve services to individuals receiving supports.

Ms. Rambow is a senior member of our organization and is therefore someone we know very well. We have reviewed her research proposal and assured ourselves of her ability to maintain confidentiality regarding the information she obtains from individuals who choose to participate in this project.

Please be assured that even though the Agency sees this as important research, your participation or non- participation is completely voluntary. Your services and supports received through this Agency are independent of this project and your participation or non- participation will not impact these services in any way.

If you wish to discuss this letter of introduction or would like further information regarding the organization's support of this research please do not hesitate to contact me.

Sincerely,

Deputy Executive Director

Appendix B: Researcher's Letter and Informed Consent Document

LETTER OF INTRODUCTION

Hello, my name is Tonja Rambow. I work for [Organization's Name] I am also a college student conducting academic research and I need your help.

I would like to know more about how important God or a higher power is to you and your life. Your help may one day let other people with disabilities live a fuller life.

Before you decide to help, you may have questions about my study. I am happy to answer any questions you may have. Here is my phone number (907) 564-7402, or my email at tonja.rambow@yahoo.com.

Sincerely,

Tonja R. Rambow

Researcher

Encl

Release and Consent Form

Self-Perception of Spiritual Well-Being in relation to Quality of Life

In Adult Individuals who Experience Developmental Disabilities:

Informed Consent Statement

Introduction: Your decision to help or not to help is up to you. Even if you first agree to help, but later decide not to help you can stop at any time.

Purpose: To know more about what people who experience disabilities think about God or a higher power. To know more about how to help people live a fuller life.

Procedures: If you want to help with this study, you will be asked to talk with Tonja Rambow and answer questions about yourself. It should take about one hour.

Benefits: Your answers may help those who work with people do a better job.

Rights: It is your choice as to whether to help or not. The services that you currently receive will not change because of your decision to help or not to help. If you do choose to help, you still may choose to stop helping at any time.

Confidentiality: No one will know your answers to the questions asked. What you share will be protected at all times. Your name will not be written on anything as helping out in this study.

Risks: There is little risk to you if you decide to help. Your help is entirely your decision and you are only asked to share as you are comfortable. You do need to know that there may be times where you remember something that made you feel either happy or sad.

Signature of Participant

Date

Signature of Guardian

Date

Appendix C: Instrument's Administrative Guidelines

Quality of Life Questionnaire

The *QOL.Q* is a 40-item rating scale that is designed to measure the overall quality of life of a person with intellectual and developmental disabilities (mental retardation or closely related conditions). The instrument is appropriate for persons 18 years of age or older. The average length of administration time is 20 – 30 minutes for most respondents.

If the individual has sufficient language skills the instrument is administered in an interview format. The examiner and respondent sit at a table or a desk with the respondent providing his/her written or verbal response to each item. Instructions for answering the questions are provided in the *QOL.Q* Manual and are read out loud to the respondent. If the respondent has provided informed consent to proceed, then the examiner proceeds to administer the 40 - items at a comfortable pace for the interviewer and the respondent. Close attention should be paid of the examiner to the exact wording of questions. It is considered acceptable to repeat items if necessary and to paraphrase items to ensure that the respondent understands the item content.

Spiritual Well-Being Scale

The *SWBS* is a 20-item paper-pencil instrument. It takes 10 – 15 minutes to take. The standard method is for the scale to be self-administered. It may be administered orally if that is desirable.

Each item is answered on a 6-point Likert scale. The endpoints of the scale are anchored with the phrases “Strongly Agree” and “Strongly Disagree,” with appropriate gradations in between. Ten of the statements assess Religious Well-Being (RWB) and contain the word “God.” Ten of the statements assess Existential Well-Being (EWB) and have no religious connotation; these statements ask about such things as life satisfaction and direction. Approximately half of the items are worded in the negative direction in order to control for any possible bias.

Appendix D: Quality of Life Questionnaire

EMBARGO

EMBARGO

EMBARGO

EMBARGO

EMBARGO

EMBARGO

Appendix E: *Spiritual Well-Being Scale*

EMBARGO

Appendix F: *Aide Memoire(s)*

Aide Memoire: Initial

The qualitative phase of this study focused on the following generalized areas in an iterative process of exploration with key participants:

- 1) How do adults who experience intellectual and developmental disabilities describe their own spirituality?
- 2) What role does spirituality play in understanding life experiences for adult individuals who experience intellectual and developmental disabilities?
- 3) What are the spiritual support needs of adult individuals who experience intellectual and developmental disabilities?
- 4) What values, beliefs, and behaviours do adults who experience intellectual and developmental disabilities ascribe to a spiritual dimension of their life?

Aide Memoire: (Expanded Version)

- 1) How do adults who experience intellectual and developmental disabilities describe their own spirituality?
 - a. What do you include in the spiritual dimension of life?
 - b. Describe spirituality in your life?
 - c. How does your spiritual life influence other parts of life?
 - d. How do you describe God?
 - e. What importance does God/Spirituality have in your life?

- 2) What role does spirituality play in understanding life experiences for adult individuals who experience intellectual and developmental disabilities?
 - a. Do you believe God/Higher Power influences your life?
 - b. When you think of God/Higher Power, what feelings come out?
 - c. How do your spiritual beliefs influence your life?
 - d. How do your spiritual beliefs influence your day-to-day choices?
 - e. Where do you go for comfort when you feel sad? Feel angry? Feel frightened?
 - f. How does Joy cross over with your spiritual life?
 - g. Where do you get a sense of purpose in life?
 - h. How does spirituality influence your Relationships?

- 3) What are the spiritual support needs of adult individuals who experience intellectual and developmental disabilities?

- a. Who do you turn to when you have spiritual questions?
 - b. What physical support do you need? (ex: transportation)
 - c. What emotional support do you need?
 - d. What other types of support are needed?
- 4) What values, beliefs, and behaviours do adults who experience intellectual and developmental disabilities ascribe to a spiritual dimension of their life?
- a. What are the spiritual rituals you participate in?
 - b. Prayer? Going to Church? Reading? Listening to Music? Being in Nature?
 - c. What family traditions are influenced by your spiritual life?
 - d. How does culture influence a person's spirituality?
 - e. How does spirituality influence relationships?
 - f. How do you understand 'disability' in relation to your spirituality?
 - g. What are your thoughts on death and an afterlife?

Appendix G: *Interview Schedule*

Fieldwork Schedule and Community

Round One:

Week 1	Southcentral (a) Community
Week 2	Southcentral (a) Community
Week 3	Southcentral (b) Community
Week 4	Southwest Community
Week 5	Southeast Community
Week 6	Data Analysis, Reflection and Review

Round Two:

Week 7	Southwest Community
Week 8	Southcentral (b) Community
Week 9	Southcentral (a) Community
Week 10	Southcentral (a) Community
Week 11	Southeast Community
Week 12	Data Analysis, Reflection and Review

Round Three:

Week 13	Southcentral (a) Community
Week 14	Southeast Community
Week 15	Southcentral (b) Community
Week 16	Southcentral (a) Community
Week 17	Southwest Community
Week 18	Data Analysis, Reflection and Review

Round Four:

Week 19	Southcentral (b) Community
Week 20	Southeast Community
Week 21	Southcentral (a) Community
Week 22	Southwest Community
Week 23	Southcentral (a) Community
Week 24	Data Analysis, Reflection and Review