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## Significance of Spirituality Among Individuals with Intellectual and Developmental Disabilities

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SIGNIFICANCE OF SPIRITUALITY AMONG INDIVIDUALS WITH  
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

A MASTER'S THESIS SUBMITTED TO THE GRADUATE FACULTY  
GRADUATE SCHOOL BETHEL UNIVERSITY

BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF  
MASTERS OF SCIENCE IN PHYSICIAN ASSISTANT

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## ABSTRACT

Previous literature has demonstrated a relationship between spirituality and positive health outcomes in the general population. However, little research has been done on the role spirituality plays in the lives of individuals with DD (intellectual and developmental disabilities). The purpose of this study was to identify the prevalence of spirituality in IDD individuals and involvement in spiritual activities. This was done with the goal of identifying potential barriers preventing the optimal practice of spirituality in the lives of those with disabilities. This study targeted IDD individuals living in a residential group home setting by collaborating with ACR Homes, a residential care company based out of Roseville, MN. The relationship between presence of disability and primary means of expression was analyzed using chi-square testing, with statistical significance identified between primary means of expression and presence of spirituality. The highest presence of spirituality was identified in individuals whose primary means of communication was spoken language. Of those identified as spiritual, 57% participated in spiritual activities as often as they desire. Furthermore, lack of staffing or accompaniment was identified as the largest barrier to attending spiritual activities at a rate individual desire. From this study it can be concluded that IDD individuals with higher levels of communication are more often spiritual or perceived as spiritual. No correlation was identified between spirituality and the other studied determinants of disability level.

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## **Chapter 1: Introduction**

### **Introduction**

Spirituality plays a large role in the well-being and health of individuals (Pandya, 2018; Balboni & Balboni, 2018; Johnson et al., 2007; Davison & Jhangri 2013; Park, Lim, Newlon, Suresh, & Bliss 2014; Tuck, McCain & Elswick, 2001; Vallurupalli et al., 2012; Puchalski, Ferrell, Otis-Green, & Handzo, 2017; McCoubrie & Davies, 2006; Nelson, Rosenfeld, Breitbart, & Galietta, 2002). The aim of this study was to investigate the role spirituality plays within the lives of individuals with intellectual and developmental disabilities (IDD). The access individuals with disabilities have to spiritual activities was explored, along with the barriers hindering IDD individuals from these spiritual experiences. The following introduction will overview the history in relation to this question, the problem statement, purpose and significance of the research, the research question, and limitations of this study.

### **Background**

Spirituality is a fundamental aspect of the human experience. It is a highly personal experience which encompasses an individual's search for the meaning and purpose of life. In turn, spirituality influences the way in which an individual experiences a connection to themselves, others, nature, and/or to a sacred realm (Gaventa, 2016). Spirituality is often associated with the enhancement of both an individual's physical and mental health, and there is a growing collection of research which supports this notion (Pandya, 2018; Balboni & Balboni, 2018; Johnson et al., 2007; Davison & Jhangri 2013; Park, Lim, Newlon, Suresh, & Bliss 2014; Tuck, McCain & Elswick, 2001; Vallurupalli et al., 2012; Puchalski, Ferrell, Otis-Green, & Handzo, 2017; McCoubrie & Davies, 2006; Nelson, Rosenfeld, Breitbart, & Galietta, 2002). According to Simon, (2012), the positive correlation between spirituality and mental health does

not require the individual to be rooted in a specific belief in God or religious practice. Rather, spirituality seems to be helpful because it gives a framework for an individual to connect to something larger than themselves and this gives existence a deeper meaning (Simon, 2012).

As mentioned above, spirituality is a complex and multidimensional element of life with numerous personal definitions. Spirituality is able to be expressed in a variety of ways, both inside and outside of the traditional religious experience. While spirituality resides within the individual and their personal beliefs, religion is defined as an organized community-based system of set beliefs (Greenstein, 2016). Religion presents a vehicle for enhancing spirituality by allowing for the creation of deeper connections with others and to self (Simon, 2012). However, while both components play unique roles for an individual in regards to well-being, research has discovered that health benefits are more prominently seen in association with spirituality, rather than religion (Pandya, 2018). As spirituality promotes a sense of expression, whether through mindfulness, meditation, self-reflection, or prayer, it is often also accompanied by increases in positive, calm, and optimistic outlook on life (Pandya, 2018). Positive spirituality also appears to be related to fewer self-destructive behaviors, reduction of stress, decreased blood pressure, and improved immune system function (Simon, 2012). Studies suggest when combined together, spirituality and religion allow an individual to experience an increased sense of belonging and support. Through this sense of connectedness, one is more likely to find meaning, even in the face of suffering, and maintain a positive attitude which often leads to improved overall health (Puchalski et al., 2017).

The relationship between spirituality and well-being is a well-researched topic. In fact, in 2012, a broad analysis looking to discover the prevalence of studies examining this relationship between spirituality and well-being, found over 250 studies focused on this particular topic

(Carter, 2013). However, despite the breadth of research, significantly less attention has been focused on the role spirituality plays in the lives of individuals with intellectual and developmental disabilities (IDD). This lack of research persists, despite past research showing disability to not be a reliable predictor of the importance of spirituality in an individual's life. A widespread study performed by the National Organization on Disability revealed that almost precisely the same percentage of Americans with and without disabilities (i.e., 84% to 87%) expressed their faith as being somewhat or very important to them. With over three million individuals in the United States having the label IDD, it is crucial that research is completed to discover the role spirituality plays within this particular population of individuals and how they can best be supported in pursuing spirituality (Krane & Hanson, 2004; Carter et al. 2015).

In beginning to assess the place of spirituality in the lives of IDD individuals, the National Organization on Disability survey of 1,000 adults with disabilities determined that approximately half the individuals studied reported attending religious activities (Krane & Hanson, 2004). These numbers continued to decrease with increasing level of disability, particularly for individuals that lack a primary means of communication or have impaired mobility. In considering this lack of spiritual involvement, focus must be placed on determining the cause of this discrepancy, and in turn identifying common misconceptions and barriers restricting IDD individuals from experiencing spirituality (Krane & Hanson, 2004; Carter et al., 2015).

### **Problem Statement**

One cannot deny the health benefits of spirituality, which have consistently been shown in numerous research studies (Pandya, 2018; Balboni & Balboni, 2018; Johnson et al., 2007; Davison & Jhangri 2013; Park et al., 2014; Tuck et al. 2001; Vallurupalli et al., 2012; Puchalski

et al., 2017; McCoubrie & Davies, 2006; Nelson et al., 2002). However, there is a significant portion of the population not receiving adequate support and opportunities to experience spirituality in the same capacity as the general population. As there are now more than three million individuals in the United States with the label IDD, failing to assess the topic of spirituality in this population potentially eliminates many individuals from experiencing this essential element of humanity (Gaventa, 2016). Research has shown the positive effects of spirituality on individuals with IDD, however studies still show a significant decrease in attendance in spiritual activities for an individual with a disability compared to that of the general public (Karter & Hanson, 2004; Carter et al., 2015). There is a need for research to assess the presence of spirituality in IDD individuals, along with identifying possible barriers which may be hindering these individuals from receiving opportunities they deserve to promote and enhance their spirituality.

### **Purpose**

The purpose of this study was to identify the spirituality of IDD individuals within the residential setting, as reported by residential supervisors who directly work with and facilitate the care of these IDD individuals. The study was performed in collaboration with a company called ACR Homes, a company based out of Roseville, MN, which organizes, facilitates, and oversees a collection of over 58 residential group homes, made up of 2-6 residents. Overall ACR Homes provides support services for more than 200 individuals with a broad range of intellectual and developmental disabilities (“ACR Homes”, 2018a). To assess the spirituality of these individuals, a survey was distributed to the resident supervisors of ACR Homes, with the goal of determining the presence of spirituality, involvement in community spiritual activities, and potential barriers preventing these IDD individuals from receiving these spiritual opportunities.

By identifying the spirituality profile of residents across the company, researchers sought to identify potential barriers to the optimal practice of spirituality. All was done with the hope of promoting an increased awareness to the impact of spiritual care.

### **Significance of the Problem**

Approximately 12% of the United States population is living with a significant disability, with three million of these individuals also possessing the label IDD (Conroy, Dale, & McCaffrey, 2016; Krahn, Walker, & Correa-De-Araujo, 2015). This population, in particular those with the label IDD, often represent a health disparity. In fact, people with disabilities are four times more likely to report their health as 'fair or poor' in contrast to those without disabilities (Krahn et al., 2015). With one of the core missions of public health being to promote the health of all, much focus needs to be drawn to the IDD population. This includes all areas of care, even spiritual health. Thus, identifying systemic and individualistic barriers which prevent disabled individuals from receiving optimal care in this particular area of health serves as a way to promote health equity and equality for all.

### **Research Questions**

This study explored the following questions:

1. What is the current percentage of individuals with IDD in residential care facilities who identify as spiritual?
2. What percentage of IDD individuals have access to spiritual activities?
3. What are potential barriers preventing IDD individuals from accessing spiritual activities?

## **Limitations and Delimitations**

The organization with whom this research study collaborated with was ACR Homes. ACR Homes is based out of a particular geographic region in the US and only provides care for individuals over the age of 18. Thus, this research study does not provide a true representation of the spirituality of all IDD individuals living in residential care facilities in the United States. Additionally, the resident supervisor of each residential group home were asked to fill out the survey regarding their perception of the residents living in the group home they oversee, in doing this, response bias was introduced into our survey.

## **Definition of Terms**

For the purpose of this study, the following terms are important to understand: intellectual and developmental disabilities (IDD), spirituality, and group home. In regards to IDD, this study adopted the definition placed forth by the ICD (International Classification of Disease) working group, who states an IDD individual is characterized by “significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behavior and skills” (Salvador-Carulla et al., 2011, p. 177). Characteristics of IDD individuals result in decreased levels of knowledge development, verbal comprehension, perceptual reasoning, working memory and processing speed, managing their behavior, emotions, and interpersonal relationships compared to peers of similar age (Salvador-Carulla et al., 2011).

The term spirituality is multidimensional and complex. One important aspect of spirituality is religion. Often the terms spirituality and religion are used interchangeably (Sango & Forrester-Jones, 2018). For the purposes of this study, a distinction was made between the two. Spirituality is defined as “the aspect of humanity which refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the



moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al., 2009, p. 887). Within spirituality, religion is found, and plays a role as an organized community comprised of individuals with similar spiritual beliefs (Sango & Forrester-Jones, 2018). Although religion is often community based, spirituality is encountered at an individual level (Greenstein, 2016). As stated, spirituality can be affected by community. Thus, it is not isolated and often the living situation of an individual can greatly impact the role of spiritual within their life.

Lastly, this research focused on IDD individuals living within a group home setting. Thus, it is important to define what constitutes a group home. The group homes utilized within the study were residential care facilities, described as a family type living situation accommodating between two and six people, where 24-hour staff assist residents with daily cares and activities inside and outside of the home (“ACR Homes”, 2018-a; Clement & Bigby, 2010). This style of care is becoming increasingly popular among IDD individuals, replacing the previous model of large institutionalized settings (Clement & Bigby, 2010).

## **Conclusion**

The role of spirituality within wellbeing has been proven significant through a myriad of previous studies (Pandya, 2018; Balboni & Balboni, 2018; Johnson et al., 2007; Davison & Jhangri 2013; Park et al., 2014; Tuck et al. 2001; Vallurupalli et al., 2012; Puchalski et al., 2017; McCoubrie & Davies, 2006; Nelson et al., 2002). The benefits of spirituality are particularly highlighted in the arena of mental health (Balboni & Balboni, 2018; Puchalski, Ferrell, Otis-Green & Handzo, 2017; Pandaya, 2018; Johnson et al., 2007; McCoubrie & Davies, 2006; Nelson, Rosenfeld, Breitbart, & Galietta, 2002; Tuck, McCain & Elswick, 2001). The purpose of this study was to take what is known within the general population and apply it to IDD

individuals in order to assess barriers to spiritual care in the lives of those with disabilities. In the following chapter, a literature review summarizes studies which assess the benefits of spirituality in the general population along with the little research which has been done within the IDD population.

## **Chapter 2: Literature Review**

### **Introduction**

This study is focused on determining the role of spirituality within lives of individuals with intellectual and developmental disabilities (IDD). Although much research has been done on the relationship between spirituality and overall health and well-being within the general population, little research has been done on the role spirituality plays in the lives of IDD individuals. The following is a literature review which encompasses previous research on the effect of spirituality on health and well-being, along with an overview of research previously done within the IDD population. This includes common misconceptions and barriers the IDD population generally confronts in regards to spirituality and religious experiences.

### **Spirituality Defined**

In the United States alone, there is incredible diversity in religious beliefs, practices, and backgrounds. This diversity can make it difficult to define spirituality in contrast to faith or religion. The term spirituality is often used interchangeably with religion (Sango & Forrester-Jones, 2018). However, for the purpose of this research, spirituality and religion will be differentiated with a particular focus placed on spirituality. Christina Puchalski, MD, Director of the George Washington Institute for Spirituality and Health, defines spirituality as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al., 2009, p. 887). This definition is the one which will be used in this study. The influence of spirituality on an individual must not be minimized, but instead regarded as an essential component of life. Spirituality is a crucial element of the human experience, and as it encompasses the individual’s search for meaning and purpose in life, it also

encompasses the connection one makes with his or herself, others, nature, or to sacred realms, both inside and outside of traditional religion (Gaventa, 2016). When viewed in this light, spirituality is deemed an essential component of quality of life. In fact, many believe spirituality as a vital aspect of humanity: one which is often used as a measure of justice, marked by freedom of populations to express spirituality in the way they wish (Gaventa, 2016).

When considering spiritually, religion is often a component allowing for an individual to create meaning and purpose in the world around them by connecting to a higher power or god (Greenstein, 2016). However, it is important to make the distinction between religion and spirituality in order to adequately assess the spiritual and religious experiences for IDD individuals and discover the ways to best serve both components of spiritual well-being. Within spirituality, religion plays a role as a place where individuals with similar beliefs form organized communities. Religion can be defined as adherence to a specific system, state, or institution (Sango & Forrester-Jones, 2018). While religion tends to be community based, spirituality is expressed at an individualistic level (Sango & Forrester-Jones, 2018). Also, for the purpose of this study, while religion may have cultural ties, spirituality does not. The relationship between religion and spirituality are visualized in Figure 1.



*Figure 1.* Spirituality and Religion. A visual depiction of the relationship between religion and spirituality.

### **Health Benefits of Spirituality**

Not only is spirituality viewed as a vital aspect of humanity, but the health benefits of spirituality are extensive as well (Gaventa, 2016). There are myriads of studies highlighting the health benefits of spirituality, in particular the positive impacts related to emotional and mental health (Balboni & Balboni, 2018; Puchalski et al., 2017; Pandya, 2018; Johnson et al., 2007; McCoubrie & Davies, 2006; Nelson et al., 2002; Tuck et al., 2001). Spirituality may become a key factor in helping individuals cope with illness, negative health conditions, experience

healing, and express the integration of mind, body, and spirit in order to achieve a sense of wholeness (Puchalski, Ferrell, Otis-Green & Handzo, 2017).

The impact of spirituality is extensive and the effects are seen in numerous research studies, in particular those focused on palliative care (Puchalski, 2017; Greenstein, 2016; Balboni & Balboni, 2018). A connection is found between higher levels of spirituality and quality of life, especially in patients with chronic or terminal illness (Park et al., 2014; Davidson, 2013; Nelson, 2002). The populations studied are vast, ranging from advanced cancers, to individuals living with HIV, to patients with chronic kidney disease, all of which demonstrate significant, positive associations between measures of spirituality and quality of life improvement (Park et al., 2014; Davidson, 2013; Nelson, 2002). Patients who report long-standing spiritual and religious struggles were shown to be at an increased risk of difficulties with daily physical functioning and higher indices of pain and fatigue, along with possible associations being found with spiritual distress as a significant predictor of mortality (Balboni & Balboni, 2018). From improved mental, physical, emotional, and social well-being, to protection against end of life despair, the benefits of spirituality are great (Balboni & Balboni, 2018; Puchalski, Ferrell, Otis-Green & Handzo, 2017). A large meta-analysis focused on accessing the complementary religious and spiritual interventions in physical health and quality of life started with 7,070 articles and narrowed down to 30 articles with adequate randomized data (Lucchetti & Vallada, 2017). This meta-analysis found religious and spiritual interventions to have small, positive outcomes, including increased quality of life, pain outcomes, and physical activity (Lucchetti & Vallada, 2017).

Considering spiritual health benefits, the most prominent benefits are seen within the realm of mental health. Studies in various palliative care populations have observed the impact

of a lack of spiritual health or spiritual turmoil. These studies found strong associations between negative spiritual associations and a lowered psychological quality of life, including depression, anxiety, and hopelessness (Balboni & Balboni, 2018). Other studies focusing on individuals with mental illness who have had a positive spiritual intervention have been found to experience significant increases in positive, calm, and forward-thinking outlooks on life (Pandaya, 2018). Spirituality promotes mindfulness, meditation and self-reflection, while prompting expression in any form, and encouraging unity to surroundings (Greenstein, 2016). The key fact is that spirituality accepts any person, whether they are a part of a religion or not, and promotes a sense of belonging in the world (Greenstein, 2016).

Although spirituality is not dependent upon religion, religion is a structure through which a person or group can express their spirituality within a community. In contrast to the significant health benefits of spirituality, studies examining the effect of religion and its association with patient quality of life have found no significant improvement (Balboni, Vaderwerker, Block, Lathan, & Prigerson, 2007; Tarakeshwar et al., 2006; Hebert, Zdaniuk, Schulz, & Scheier, 2009; Sherman, Simonton, Latif, Spohn, & Tricot, 2005). However, through communities based around common beliefs, attitudes, traditions, and relationships, religion is found to play a role in further enhancing spirituality (Patel, Shah, Peterson, & Kimmel, 2002; Vallurupalli et al., 2012). Spiritual communities create an added element of support and social integration for an individual which may aid in bettering their psychological well-being (Greenstein, 2016). Religion can be a crucial component in increasing a sense of belonging, coping with difficult life situations, and providing a trustworthy and safe conduit to gather and connect with others (Greenstein, 2016).

## **Spirituality in IDD Population**

In light of the mass research done on the benefits of spirituality in the lives of the general population, little research has been done to explore the effects of spirituality in the lives of individuals with IDD. With approximately three million individuals in the United States having the label “IDD”, the lack of research on this topic is a grave oversight (Conroy, Dale, & McCaffrey, 2016). Within the research done there is a lack of research on spirituality without the lens of religion (see Figure 1). Previous research has focused mainly on religious involvement, which has shown positive benefits in the lives of IDD individuals, particularly in the realm mental health (Patel et al., 2002; Vallurupalli et al., 2012). Individuals with IDD, when connected to faith communities, can experience decreased feelings of stigma regarding their disability, along with increased self-esteem, and improved social and psychological support. Through religion, IDD individuals report being encouraged in their individual spirituality, while developing friendships and community (Sango & Forrester-Jones, 2018).

When specifically considering spirituality in IDD individuals, the discrepancy in the quantity of research may be due to two common misconceptions of spirituality in IDD individuals: one- individuals with IDD are less likely to be invested in spirituality and faith than other members of the general population, and two- individuals with IDD are not capable of experiencing spirituality at the same capacity (Harshaw, 2016). Regarding the first misconception stating IDD individuals are less invested in spirituality, a survey conducted by the National Organization on Disability in 2004 discovered 57% of all individuals, regardless of the presence of disability, responded “very important” to the question: “How important is your religious faith to you?” (Krane & Hanson, 2004). Similarly, the findings were consistent for all individuals, as 27% responded “somewhat important” to the same question, with no difference



present between individuals with or without disability (Krane & Hanson, 2004). Although this survey focused on religion, researchers expect trends to be similar in regards to the importance of spirituality for IDD individuals, based upon this research study's definition of spirituality.

In regards to the second misconception, IDD individuals are often thought to perceive spirituality in a less profound way than those without a disability. However, a national survey by Liu, Carter, Boehm, Annandale, & Taylor (2014), focused on the significance of faith in adults, based on the presence of a disability, found faith to be expressed and valued in ways which are more similar than different amongst people with and without IDD. Interviews conducted with 20 individuals who have various intellectual disabilities focused on their personal perception and expression of faith. When asked about the importance of their faith and spirituality, common responses included those of personal affirmation, journey of faith, feeling of belonging, source of healing, friendship, and love. Regarding expression of faith, a majority deemed personal prayer as their primary avenue of spiritual expression (Liu et al., 2014). Apart from prayer, spiritual expression occurring within the context of congregational activities, including worship services, Sunday school, and retreats were the next prominent forms of spiritual expression (Liu et al., 2014). Individuals also noted the importance of beliefs and behavior, with several participants noting their beliefs being rooted within a specific faith tradition (Liu et al., 2014). These findings suggest that faith may be valued and expressed in ways more similar than different among individuals, regardless of the presence of a disability.

### **Barriers to Spiritual Involvement in IDD Individuals**

As mentioned previously, much of the IDD population experiences spirituality. However, these individuals are often confronted with barriers when pursuing spirituality, which the general population does not face. This is made clear within the National Organization on Disability

survey, which revealed 85% of Americans, regardless of the presence of a disability, to consider their faith to be somewhat or very-important to them. However, despite 85% of the population claiming to be spiritual, only 45% of individuals who were considered to have a “slight or moderate” disability reported attending religious activities (Krane & Hanson, 2004). This trend of decreased participation in religious activities continued, as further decreases were seen in religious activity attendance as level of disabilities increased, yet the importance of spirituality was not seen to decrease with increased levels of disability (Krane & Hanson, 2004).

Additionally, less than one third of IDD adults with mobility impairments regularly attended religious services (Carter et al., 2015). The consistent finding of religion being deemed as important within IDD individuals, regardless of disability level, suggests the low level of attendance in religious activities is not due to lack of interest, but instead may be the result of various barriers hindering participation (Krane & Hanson, 2004). When considering decreased religious involvement, several potential factors must be addressed regarding the access of disabled individuals to religious services, such as a lack of necessary staffing accompaniment, time, funding, or proper transportation accommodations, along with a lack of spiritual activities which cater to needs of individuals with disabilities (Carter et al., 2015).

Another significant barrier affecting individuals with profound disabilities is the inability to express their interest in spirituality. These individuals are often identified as nonverbal. Nonverbal individuals are unable to communicate through conventional speech, but instead may utilize communication devices, signing, or facial expressions, or in some cases may lack any primary means of communication. Carter et al (2015) showed that IDD individuals with profound non-verbal disabilities (34%) were significantly less likely to attend religious services compared to other IDD individuals (45%) who were able to express themselves (Carter et al.,

2015). This lack of primary communication and subsequent inability to express interest in certain activities, may be a factor contributing to decreased participation in spiritual activities within the IDD population (Carter et al. 2015). Along with the lack of communication, many of the concepts often associated with spirituality are not tailored to the nonverbal community (Harshaw, 2016). For example, the traditional Christian perspective is based on establishing and developing a relationship with God through cognitive responses, repentance, and the verbal expression of belief in Christ. However, for an individual with a profound nonverbal disability, this is inaccessible (Harshaw, 2016).

This research study aims to identify specific barriers inhibiting IDD individuals from accessing and participating in spiritual activities. Although several spiritual and religious programs for IDD individuals exist, many of are unable to accommodate for all levels of disability, and often cease to provide services for after adolescence (Liu et al. 2014). This cessation of disability services is often a result of a lack of training or resources which limit the viability, efficacy, and participation for the IDD individuals. (Liu et al. 2014). Along with other challenges, ranging from inability of individuals in regards to mobility or expression, the lack of access to spiritual spaces, or impairments in reading and spoken word which render nonverbal or those with profound intellectual disabilities becoming prone to having their spiritual preferences and needs overlooked (Carter et al. 2015). Thus, individual-focused spiritual programs are indicated. In fact, interviews conducted by Pandya (2018) of several IDD individuals regarding spirituality and faith expression found spiritual programs customized and tailored to the individual to be more effective than general, open ended spiritual care (Pandya, 2018).

## **Residential Care**

The final important factor that must be considered when determining the quality and level of spiritual care of IDD individuals, is their living situation. Understanding the living situations for individuals with IDD is vital and assists in determining the supports available to an individual, including faith-based services. Today, the United States has moved away from the large-scale institutional care settings of past, towards small, family-like community-based homes with shift staffing (Clement & Bigby, 2010). In order to predict what residential support may resemble in the future, a study was conducted by Conroy, Dale, & McCaffrey (2016) looking at the current and emerging trends of individuals in residential care settings. One of the focuses of this report was to determine the role faith-based organizations may play in residential services in the future. The majority of the responses predict that future residential services funded by public dollars will be unlikely to trend towards faith-based agencies, which confirms the possibility of government funding for community-based activities to prove as a barrier preventing IDD individuals from adequately receiving community spiritual opportunities (Conroy, Dale, & McCaffrey, 2016). In order to continue providing these spiritual experiences, despite the lack of minimal government funding, spiritual activities must be addressed individually by the residential home company and the person-centered care team of each IDD individual to determine if spiritual experiences will be a standard of care for the resident receiving services (Conroy, Dale, & McCaffrey, 2016).

To assess spirituality of residents within the residential group home setting, this study will collaborate with ACR Homes. This is a residential care organization based out of Roseville, Minnesota, that currently runs 58 small family-like community homes, with more than 200 individuals receiving care (“ACR Homes”, 2018a). ACR Homes is equipped to care for

individuals with a wide range of disabilities, age, and culture (“ACR Homes”, 2018a). ACR Homes prides itself on its core values of acceptance, communication, and respect, as is reflected in its name ACR (“ACR Homes”, 2018b). As one of the premier residential care service organizations within the Midwest, Jim Nelson COO, a licensed psychologist, attributes the high standard of care to increased caliber of staff selected through intensive interview processes (“ACR Homes”, 2018a). Amongst all that apply, approximately ten percent are accepted. Upon hire, each employee receives at least 70 hours of initial training, followed by ongoing education in order to best prepare staff members to effectively meet resident needs and agenda (“ACR Homes”, 2018-a).

## **Conclusion**

Spirituality plays a huge role in the wellbeing of individuals, as noted in the literature review above. Particularly, spirituality is known to have significant benefits on mental health (Balboni & Balboni, 2018; Puchalski et al., 2017; Pandaya, 2018; Johnson et al., 2007; McCoubrie & Davies, 2006; Nelson et al., 2002; Tuck et al., 2001). Although much is known about the spirituality and health within in the general population, little research has been done on the spirituality experiences of the IDD population. However, the research which has been done within the IDD population demonstrates how these individuals need spirituality at a level consistent with the general population (Carter et al., 2015; Harshaw, 2016; Lie et al. 2014). Thus, removing barriers which often confront IDD individuals is essential to promote spiritual care. Many of these barriers are associated with the living situations of these individuals, which are often residential care facilities. Therefore, residential care facilities are an integral part of fostering an atmosphere for spirituality and spiritual expression amongst IDD individuals (Carter et al., 2015). This research aimed to look into ACR Homes, a residential group home

organization, to better understand barriers confronted by IDD individuals. The following chapter overviews the methodology of the research project, including study design, sample population, study tools, data collection, data analysis, along with validity, reliability, limitations and delimitations of this study.

## **Chapter 3: Methodology**

### **Introduction**

The purpose of this study was to identify the spirituality of IDD individuals within the residential setting, as reported by residential supervisors who directly work with and facilitate the care of these IDD individuals. By additionally evaluating participation in spiritual activities, this study identified potential barriers which hinder IDD individuals from experiencing spiritual opportunities. This study then explored and analyzed the following questions:

1. What is the current percentage of individuals with IDD in residential care facilities who identify as spiritual?
2. What percentage of IDD individuals have access to spiritual activities?
3. What are potential barriers preventing IDD individuals from accessing spiritual activities?

The remainder of this chapter discusses the study design, sample population, study tools, data collection, data analysis, validity and reliability, and limitations of the study.

### **Study Design**

This study was an observational, cross sectional study, targeting IDD individuals living in a residential group home setting. Although the IDD individuals are the targeted population, the study utilizes residential supervisors to directly take the survey. The residential supervisor, whose role is described in depth later, was instructed to respond to the survey according to their perception of the residents or IDD individuals they oversee. The study aimed to determine the prevalence of individuals with disabilities who perceive spirituality to be of importance to them and whether or not they participate in spiritual activities. The dependent variable was:

significance of spirituality, and the independent variable is: presence and degree of intellectual or developmental disability.

After discussion with the research committee, the study proposal was submitted to the Bethel Institutional Review Board (IRB) as a category one proposal. Category one level approval was required due to the sensitive nature of spirituality, along with the vulnerability of the target population being studied. The IRB committee also reviewed the methodology to ensure the rights and welfare of participants, including the individuals directly taking the survey (the resident supervisors) as well as the targeted population (IDD individuals).

### **Sample Population**

The population targeted within this study were the residents of ACR Homes. ACR Homes is a care facility organization which provides residential support services for over 200 individuals with a wide range of disabilities and support needs. Many of these individuals have mobility limitations or other medical issues requiring extensive support. ACR Homes also serves those requiring behavioral support services, and individuals who have been injured later in life with chronic, degenerative disease, or other significant physical limitations, but are without mental impairment (“ACR Homes”, 2018a). All residents within the company had the ability to be included in the study, regardless of type/significance of disability, race, age, religion, etc., with the goal of equally representing all individuals with disabilities. Thus, the only exclusion criteria was the residents’ supervisors willingness to complete the survey. To combat the lack of willingness of residents’ supervisors to take the survey, researchers offered an opportunity for participants who completed the survey to be entered into drawing to win a commercial gift card valued at \$10. This is explained in greater detail below within the data completion section.



Because the process of completing a survey often presents challenges which hinder individuals with severe cognitive or physical disabilities from being represented, the resident supervisors were selected to complete the survey on behalf of the ACR Homes residents. The residential supervisors were selected to be the direct participants of the study, due to the close relationship they often have with the residents. Within ACR Homes, the job of a resident supervisor is to oversee resident healthcare, safety, interests and choices, perform direct care, and work effectively with the resident themselves, along with their guardians and case managers (“ACR Homes”, 2018c). A resident supervisor oversees and monitors the care of each resident living in the home they supervise, which ranges from three to eight residents in total. Due to the various responsibilities, the resident supervisors spend significant time and often have a very close relationship with the residents they care for. Based off this presumption, the researchers assumed the supervisors would be able to provide an accurate perception of the responses the resident would choose for themselves, if able. Thus, a survey was distributed to each resident supervisor which prompted them to answer questions on behalf of their residents. They were asked to use their close relationship, knowledge, experience, and perception of the resident in which they work with to guide their responses.

### **Study Tool**

Qualtrics survey software was utilized to collect quantitative data regarding the topics of spirituality and participation. An online survey was created by researchers, which initially assessed the spirituality of the participant taking the survey to assess potential bias. The participant was then prompted to input the number of residents living in the ACR Home they supervise, and the appropriate number of question ‘blocks’ were provided to account for each individual resident. At the beginning of each block, the participant was instructed to answer the

following question the way their “1st Resident”, “2nd Resident”, etc. would respond, if able. The remainder of the survey included 4-7 multiple choice questions per resident (Appendix A). The questions first assessed degree of disability of the resident to determine independent variable, followed by questions assessing spirituality, participation in spiritual activities and access to spiritual experiences to determine the dependent variable. The survey was accessed via a hyperlink received through email, and was estimated to take approximately three to five minutes, per resident or ‘block’, to complete. Confidentiality was ensured through the use of a web-based program and no personal information was collected from participants. Participants were instructed to not divulge any personal information or identifiers pertaining to their residents in order to maintain confidentiality. The use of e-mail was thought to increase the response rate of participants.

### **Data Collection**

A hyperlink to the Qualtrics survey was given to the Director of Staff Development at ACR homes, who is responsible for the placement of all direct care staff hired by ACR Homes, thus having regular contact with all resident supervisors (“ACR Homes”, 2018d). The Director of Staff Development then sent the hyperlink to the work email of each resident supervisor employed by ACR Homes. Upon receiving the email, each participant encountered a statement of informed consent, overviewing the purpose of the study (Appendix C). The participant was given the option to then click the hyperlink and proceed with the survey or to exit at any time. The participant was informed that choosing to proceed with the survey indicates their informed consent to participate in the study. The participant was then prompted to specify the number of residents living in the group home he or she oversees, and the appropriate number of survey question ‘blocks’ was provided to account for each resident. The survey first assessed the

disability level of the resident, and then asked questions regarding the spiritual preference of the resident. If a participant responded that the resident(s) would not consider herself or himself to be spiritual or is unsure of their spirituality, the survey was completed for the resident. If the participant responded that the resident would consider herself or himself to be spiritual, the participant was presented with further questions regarding this resident's participation in spiritual activities.

After the initial distribution of the survey, a reminder email was sent two weeks later, with the hopes of increasing participant response rate. After four weeks, survey responses were no longer be accepted. All data from the survey, while being collected and analyzed, was stored on a password-protected computer owned by the researchers. After the completion of the study, the data collected was stored on an external storage device locked in the Physician Assistant office for a minimum of five years, per security requirements for Bethel University's Physician Assistant program.

To combat a possible lack of willingness to participate in the survey, researchers offered a monetary incentive. When each participant received the email containing the informed consent and hyperlink to the survey, they were also given the incentive of having their name entered into a drawing for a \$10 gift card to Target, if they participated in the survey. Following completion of the survey, the participant was able to notify either of the researchers via email, who then entered their name into the drawing by recording the participant's first name and email address onto a google sheet. After completion of the survey period, a random number generator was then used to select the recipient of the gift card. The identity of any participant entered into the drawing was not attached to their survey, thus resident supervisor responses remained anonymous. Once the winner of the drawing was selected and contacted, the google sheet was

deleted along with any identifiable information. Only the researchers had access to this google sheet from the time of its formation until its destruction.

### **Data Analysis**

ACR Homes currently has 58 different group homes, which are overseen by approximately 50 residential supervisors, and serves over 200 IDD individuals (“ACR Homes”, 2018a). The survey was distributed to all resident supervisor within ACR Homes. Researchers expected a response rate of 50 percent, thus resulting in a sample size of approximately 25 resident supervisors. As each resident supervisor typically oversees 4 to 6 residents, it was expected that 100 various IDD individuals would be represented within the research data. Data was to be collected online via Qualtrics survey tool, and then analyzed using Excel and Real Statistics. Independent analyses would be performed for each of the three research questions by gathering frequencies and running chi-square statistical tests. This would include identifying the prevalence of spirituality among IDD individuals receiving care from ACR Homes, participation in spiritual activities, along with the prevalence of spirituality in relation to potential barriers, including resident supervisor spirituality, disability level, and other factors. This final analysis would be used to understand if one area of disability (i.e. language, mobility, behavioral), or other factors serve as a greater barrier to spiritual activity participation for IDD individuals.

### **Validity/Reliability**

Researchers were unable to assess the validity and reliability of the survey instrument before use, as the survey was developed by the researchers for this particular study and had not previously been used. However, researchers consulted an expert panel which consisted of three Bethel PA Program faculty members, a statistician, along with five previous or current employees of ACR Homes who had personal experience interacting with the residents. These

employees did not currently, nor had ever held the role of resident supervisor at ACR. However, due to similar job responsibilities and roles within the company, were able to accurately respond and assess the survey. Utilization of this group also prevented the limitation of future sample size. This panel was utilized to ensure the survey was easy to navigate, and properly assessed research questions, while not limiting sample size.

### **Limitations/Delimitations**

This study relied fully on the resident supervisors for data collection. By having resident supervisors answer survey questions on behalf of the residents living in the ACR home they oversaw, researchers understood a large amount of response bias would potentially be present. Specifically, researchers sought to determine whether personal spirituality correlated with perception of resident spirituality. To combat this, a survey question was used to identify the spirituality of the participants in order to determine whether any significance existed between supervisor spirituality and perceived spirituality of the IDD individuals. Along with this, unwillingness to participate or lack of time presented reasons resident supervisors may have opted out of completing the survey. Researchers intended to combat this with the use of a gift card as a possible incentive to completing the survey, as discussed in detail above. A delimitation of this study included the narrowing of the population to individuals with disabilities receiving care services from ACR Homes, and thus the results of this study cannot be generalized to all individuals with intellectual or developmental disabilities.

### **Conclusion**

The method of this research involved utilizing a Qualtrics survey to collect data reflecting the spirituality of the residents with intellectual or developmental disabilities receiving care from ACR Homes. The survey looked to explore the research questions stated within the introduction,

which were aimed at determining the prevalence of spirituality in IDD individuals, along with identifying potential barriers hindering IDD individuals from accessing spiritual activities. The following chapters analyze the data collected via the previous methodology and discuss and draw conclusions after data analysis is performed.

## **Chapter Four: Results**

### **Introduction**

Chapter Four contains the results and analysis of data provided by the ‘Significance of Spirituality among Individuals with Intellectual and Developmental Disabilities’ survey. Data was organized according to perceived spirituality and then further organized into various determinants of disability level, including primary means of expression, mobility, and behavioral support needs. The relationship between spirituality and previous determinants of disability were then analyzed to determine the presence of statistical significance. Lastly, among those ACR Homes residents who were perceived to be spiritual, the data regarding adequate spiritual participation, as well as potential barriers to participation were analyzed and reproduced into figures.

### **Calculations**

For analysis purposes, the statistical significance of the data was defined as  $p \leq 0.05$ . The three determinants of disability level, primary means of expression, mobility, and behavioral support needs were assessed using chi-square test of independence. Each of these categories was separately analyzed using the Microsoft Excel program. All other data such as perception of spirituality, spiritual participation and barriers to spiritual participation, were analyzed via simple statistical analysis via Microsoft Excel.

### **Survey Population**

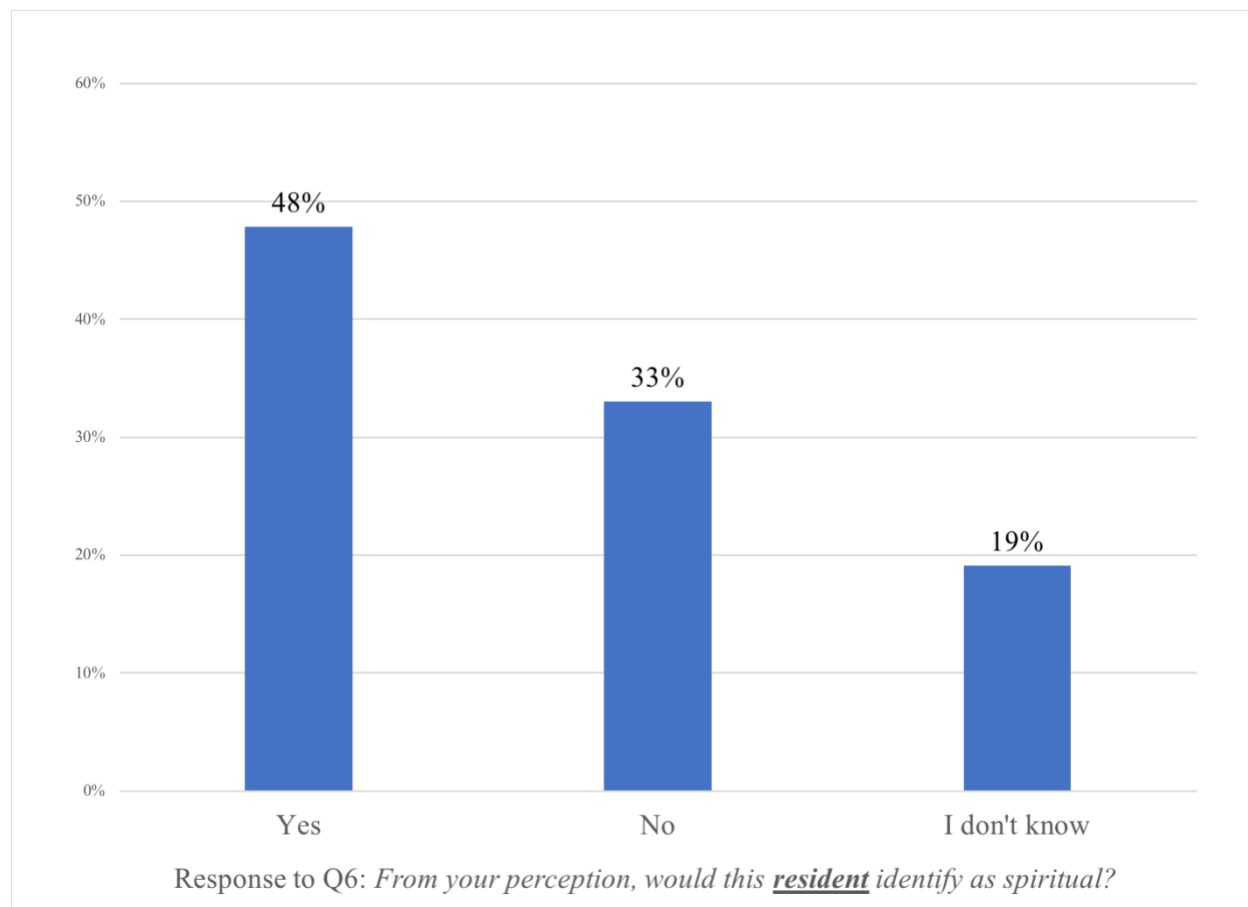
The population surveyed within this study was comprised of ACR Homes resident supervisors. These participants responded to the survey by giving their perception of the residents within the ACR Homes organization, which live in the group homes they oversee as supervisors. In total, there were 30 participants, of whom 26 answered all the survey questions.

Survey participants who did not complete all questions were removed. The data provided by remaining 26 participants included individual survey blocks for each individual resident the participant supervises. The responses equated to data which was representative of 115 different IDD individuals living within various ACR Homes group homes. Researchers sought to assess potential biases of survey participants in regards to personal spirituality. Participants were given the definition of spirituality adopted by this research project and asked to indicate if they themselves would identify as spiritual. Results revealed that 25 of the 26 participants identified themselves as spiritual.

### **Prevalence of Spirituality**

The first research question addressed in this research study was as follows; “What is the current percentage of individuals with IDD in residential care facilities who identify as spiritual?” This question was explored via survey question six which gave Christina Puchalski’s definition of spirituality adopted by this survey: “the aspect of humanity which refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.” The participant was then asked: “From your perception, would this resident identify as spiritual?” Figure 1 contains the responses representative of the 115 residents accounted for in this survey, 48 percent were perceived as spiritual, 33 percent were not, and 19 percent had unknown spirituality. Chi-square testing revealed these values to be statistically significant with a p-value = 0.001.





*Figure 2.* Spirituality among residents of ACR Homes. Various responses are represented as percentages of the total number of residents (n=115) included within study (p=0.001).

### **Relationship between Spirituality and Level of Disability**

In order to identify whether various aspects of disability have an effect on the presence of spirituality, three different demographic questions were asked regarding each IDD individual. These three determinants of disability assessed in this study included primary means of expression, primary means of mobility, and the presence of behavioral support needs. Chi-square test of independence was utilized to individually analyze the relationship between the presence of spirituality and each disability level. Table 1 contains the resultant p-values of each individual analysis. Statistical significance was found between primary means of expression and presence

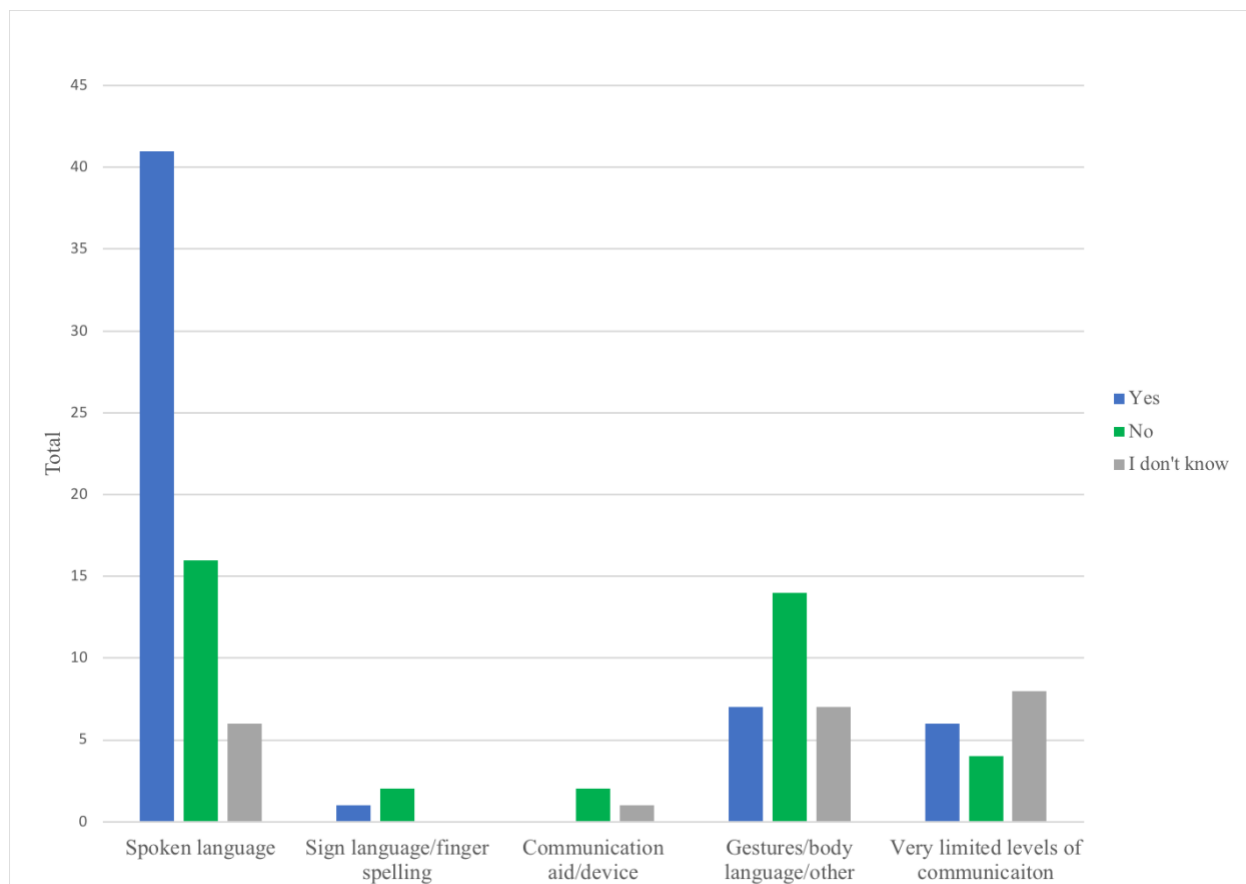
of disability. The other two determinants of disability, mobility and behavioral needs, were both found to not be statistically significant in regards to the presence of spirituality.

<b>Determinant of Disability</b>	<b>P-value</b>
Primary Means of Expression	0.00104
Primary Means of Mobility	0.65544
Behavioral Support Need	0.35007

*Table 1.* Correlation coefficients. Values determined using chi-square statistical testing analyzing the relationship between determinant of disability and the presence of spirituality. Statistical significance was defined as a p-value  $\leq 0.05$ .

### **Relationship between Spirituality and Primary Means of Expression**

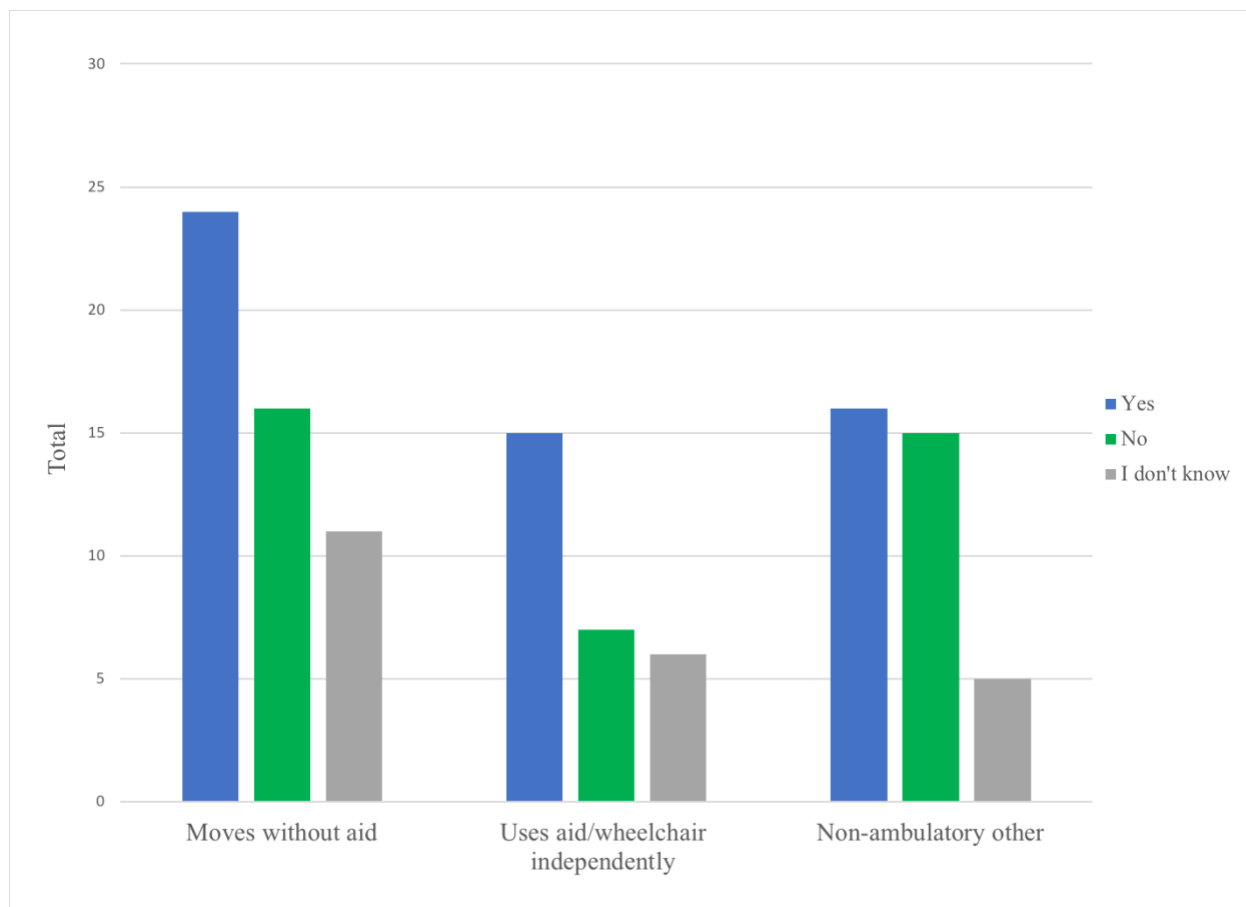
The first determinant of disability addressed, primary means of expression, was divided into five categories; spoken language, sign language or finger spelling, communication aid or device, gestures or body language, and very limited levels of communication. Of the 115 IDD individuals represented within the survey, it was found that 63 used spoken language, 28 used gestures or body language, 18 had very limited levels of communication, and 3 in both sign language or finger spelling and communication aid categories. The highest presence of spirituality was identified in individuals whose primary means of communication was spoken language (65%), followed by sign language or finger spelling and very limited levels of communication (33%). See Figure 3. The relationship between presence of disability and each of the five categories of expression was analyzed using chi-square testing. Statistical significance was found between primary means of expression and presence of spirituality (p-value = 0.001). Thus, it can be concluded that there is a relationship between primary means of expression and the perceived presence of spirituality for IDD individuals who lives at ACR Homes.



*Figure 3.* Relationship between level of primary means of expression within IDD individuals at ACR Homes and spirituality ( $p < 0.001$ ).

### **Relationship between Spirituality and Mobility**

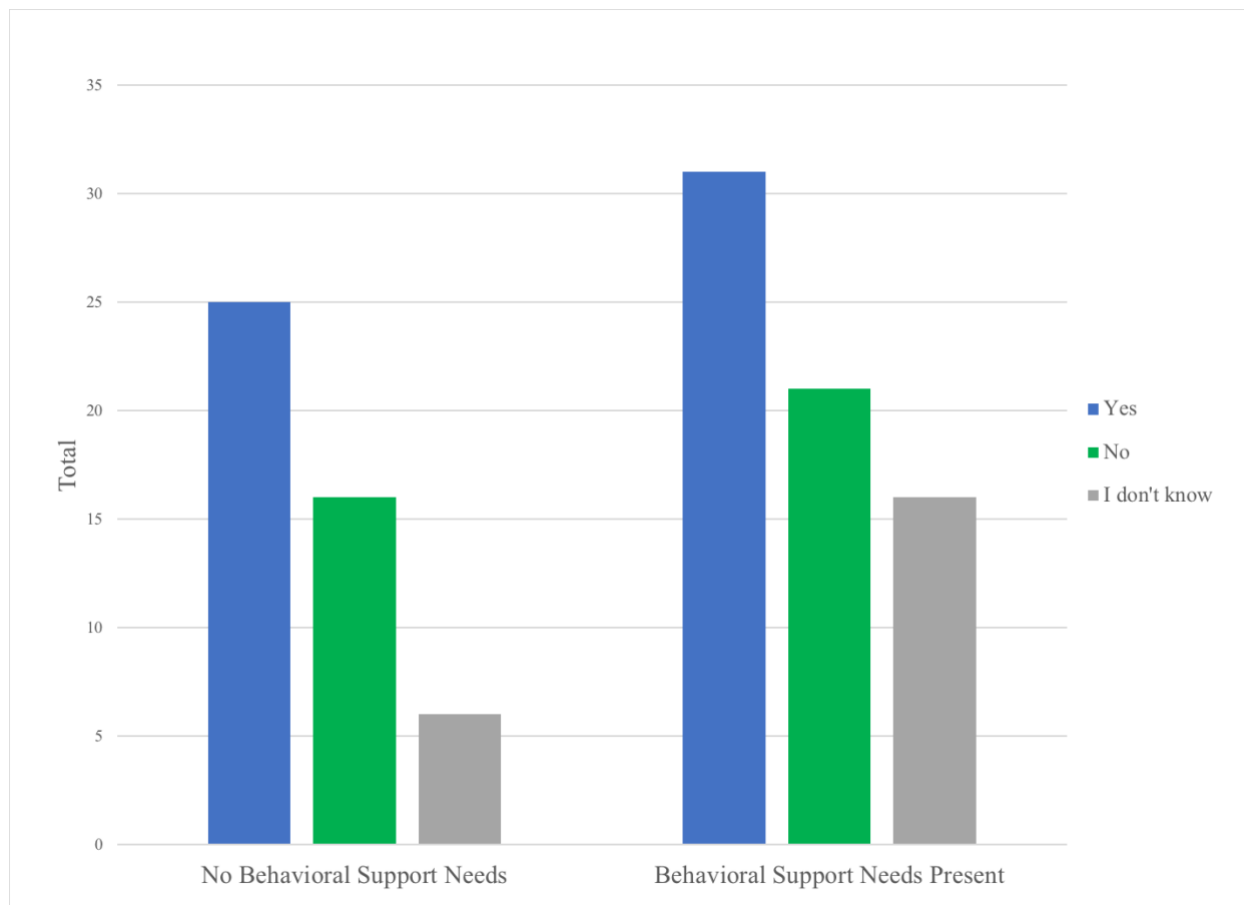
The next determinant of disability, primary means of mobility, was analyzed in regards to perceived spirituality. Mobility was divided into three categories; moves without aids, uses aids or wheelchair independently, and non-ambulatory/other. The highest presence of spirituality was identified in individuals whose primary means of mobility was aide or wheelchair (54%), followed by those who move without aid (47%), and then non-ambulatory individuals (44%). See Figure 4. No statistical significance ( $p = 0.655$ ) was found between primary means of mobility and perceived spirituality.



*Figure 4.* Relationship between IDD individuals at ACR Homes primary means of mobility and the significance of spirituality ( $p=0.655$ ).

### **Relationship between Spirituality and Behavioral Support Needs**

The third determinant of disability, behavioral support needs, was then analyzed to determine whether a relationship exists between the presence of behavioral support needs and perceived spirituality. This was divided into two categories; presence of behavioral support needs, and no behavioral support needs. In this survey, 53% of residents with no behavioral needs present were perceived as spiritual, while 46% of residents with behavioral needs were perceived as spiritual. See Figure 5. No statistical significance ( $p = 0.35$ ) was found between behavioral support needs and perceived spirituality.

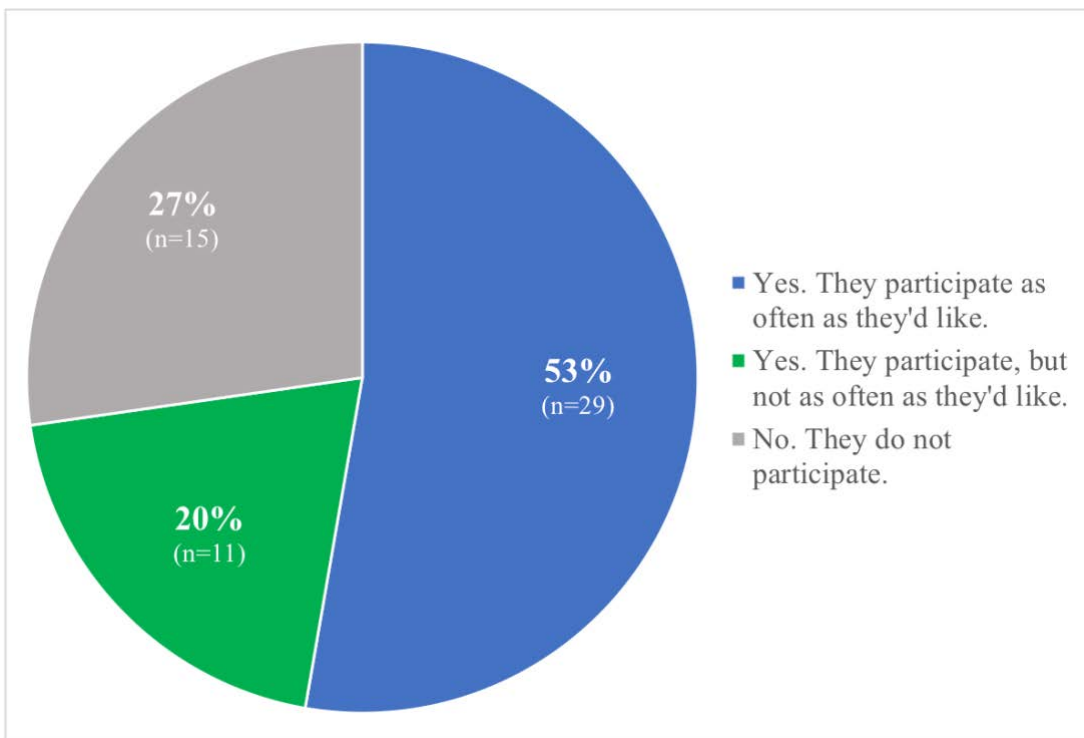


*Figure 5.* Relationship between the presence of behavioral support needs and the significance of spirituality ( $p=0.35$ ).

### **Spiritual Participation**

After initially assessing the overall presence of spirituality among IDD individuals living in ACR Homes group homes, the next question this research study looked to answer was as follows; “what percentage of IDD individuals have access to spiritual activities?” Participants were asked whether or not a resident who was perceived as spiritual participates in spiritual activities. The following examples of spiritual activities were provided: attends religious services or spiritual groups, participates in worship/prayer, etc. If the participant indicated the resident did participate in spiritual activities, additional survey questions sought to identify whether or not these various spiritual activities were accessed as often as the IDD individual would desire. Of

those perceived to be spiritual, 73% participate in spiritual activities. Of those who participate in spiritual activities, 53% were identified to participate as often as they would like, while 20% participates in spiritual activities, but not as much as they would like. The difference in participation in spiritual activities was statistically significant ( $p$ -value = 0.0001). Finally, of the individuals identified as spiritual 27% didn't participate in spiritual activities. See Figure 6.

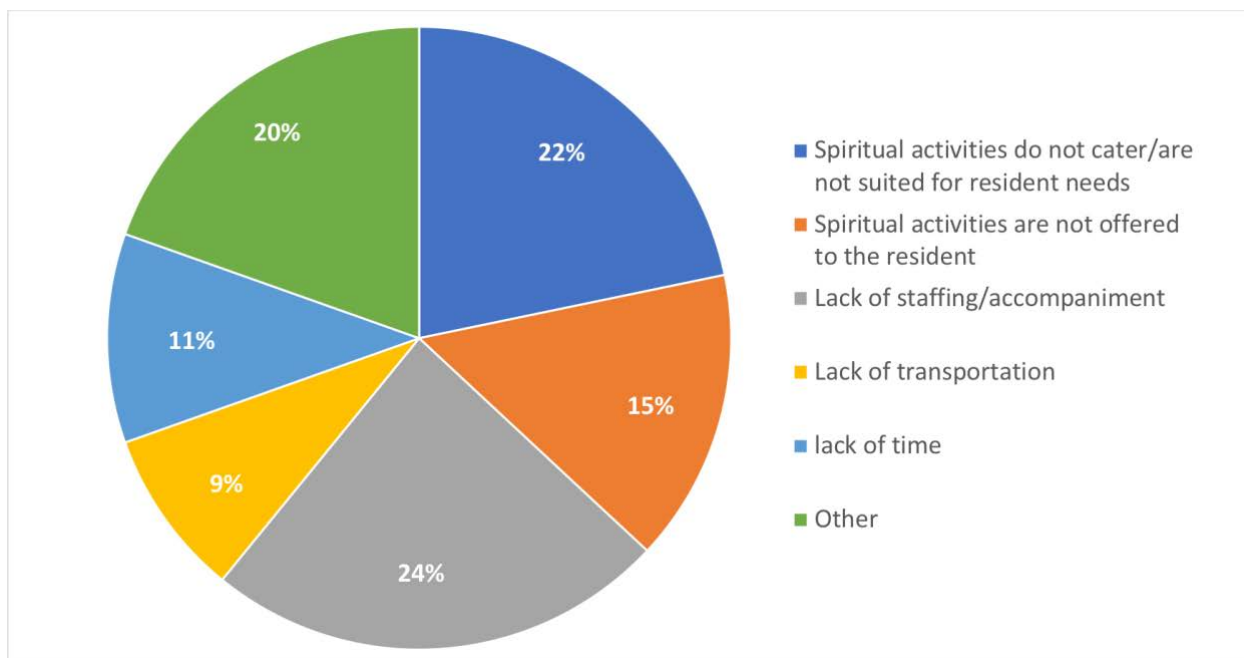


*Figure 6.* Level of participation among 'spiritual' ACR residents. Data is represented as percentages or all individuals identified as spiritual (n=55).

The frequency of the determinants of disability and participation in spiritual activities was evaluated utilizing chi-square statistical testing – independently to evaluate if disability factors limit participation; Expression ( $p = 0.47$ ), mobility ( $p = 0.21$ ), and behavioral support needs ( $p = 0.91$ ) were all found to have no statistical significance in regards to participation in spiritual activities.

## Barriers to Spiritual Participation

The final research question this study sought to answer was; “what are potential barriers preventing IDD individuals from accessing spiritual activities?” If a resident was perceived as spiritual, but either did not participate in spiritual activities as often as they would like or did not participate at all, a final question was asked “Do you think any of these factors may be barriers preventing this resident from participating in spiritual activities? Select all that apply.” The list of potential barriers included: ‘lack of transportation’, ‘lack of staffing/accompaniment’, ‘lack of time’, ‘spiritual activities do not/are not suited for resident needs’, ‘spiritual activities are not offered to the resident’, and ‘other’. The responses were collected and no proposed barrier to spiritual participation was found to be statistically significant. The responses are presented as percentages in Figure 7.



*Figure 7.* Barriers preventing participation in spiritual activities. Data is shown as percentages of a whole (n=26).

## **Overview of Data Analysis**

The research survey was designed to address research questions in sequential order. First, the survey identified spirituality among IDD individuals. Of those perceived to be spiritual, further questions were asked to analyze participation in spiritualities. Of those who did not participate as often as they would like, the final research question sought to determine barriers to spiritual participation. As the survey progressed, population size decreased. An overview of this research design is depicted in Figure 8. Figure 8 outlines how previous figures correlate with the three primary research questions, along with progression of sample size.



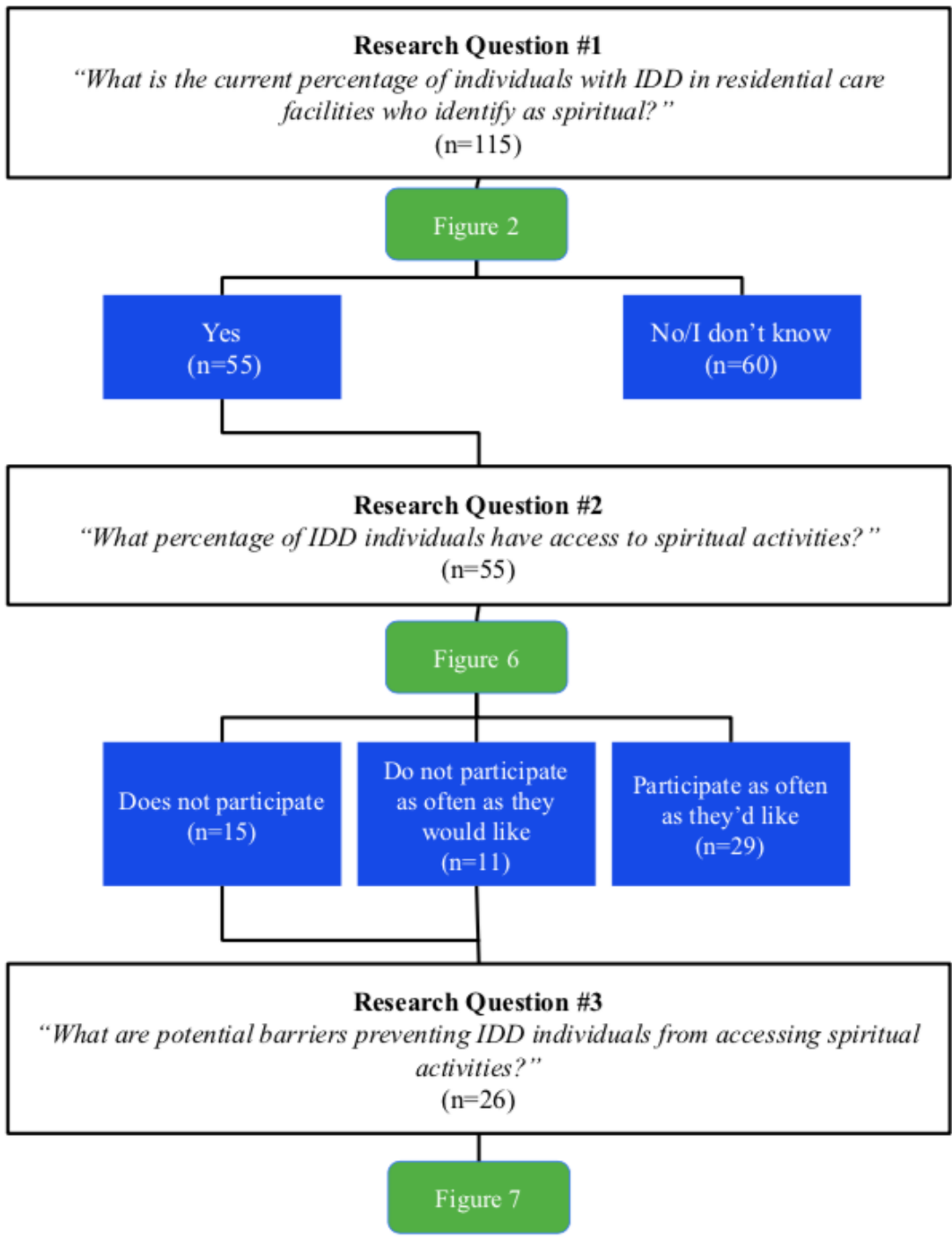


Figure 8. Overview of data analysis. The flowchart depicts how the survey population size changed as each research question was addressed by the survey questions.

**Conclusion**

Data was collected via Qualtrics and later analyzed utilizing Microsoft Excel software. Tables and figures above provide pertinent findings. Statistical significance was found when comparing an individual's perceived spiritually and primary means communication. Chapter 5 contains further analysis of the data by discussing implication of findings, limitations and delimitations of data, along with the need for further research.

## **Chapter Five: Discussion and Conclusion**

### **Introduction**

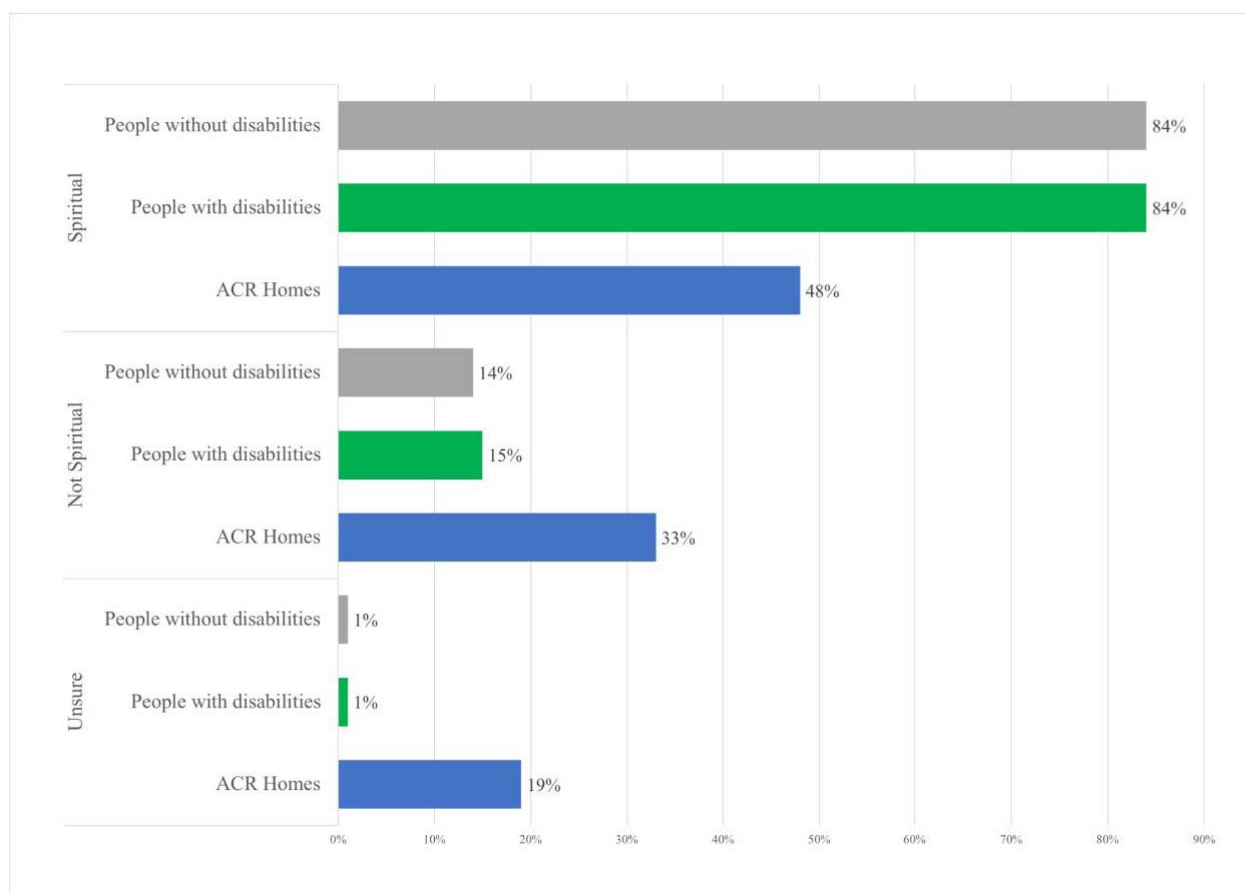
Spirituality is a vital aspect of the human experience as it encompasses an individual's search for meaning and purpose of life. Spirituality is associated with improved well-being, through enhancement of both physical and mental health (Pandya, 2018; Balboni & Balboni, 2018; Johnson et al., 2007; Davison & Jhangri 2013; Park et al., 2014; Tuck et al. 2001; Vallurupalli et al., 2012; Puchalski et al., 2017; McCoubrie & Davies, 2006; Nelson et al., 2002). While the benefits and significance of spirituality have been widely researched in the general population, limited research has been conducted looking primary at the spirituality of the IDD population.

The purpose of this research was to determine the presence of spirituality among IDD individuals, determine the access to and participation in activities which enhance spirituality, and lastly identify potential barriers preventing access and participation in spiritual activities. This final chapter discusses the findings of the research analysis, in regards to these three primary research questions. Additionally, it explores implications brought forth via data analysis and recommendations for future research.

### **Discussion of Findings**

The first aspect of the survey quantified spirituality within ACR Homes. 48% of IDD individuals were identified as spiritual, 33% were perceived to not be spiritual, and the remaining 19% of were identified as 'unsure' in regards to presence of spirituality (Figure 2). The rates of spirituality in ACR residents were then compared to the findings of a 2004 National Organization of Disability (N.O.D) survey of American's with disabilities, which assessed the national prevalence of religion among individuals both with and without disabilities (Krane &

Hanson, 2004). The blue bars within Figure 9 represent the percentage of spiritual individuals based on the results of the data collected in this research study's survey, while the green and grey bars represent information adopted from the N.O.D. survey in 2004. In the N.O.D. survey, participants were asked to respond to the question prompt; "How important is your religious faith to you?" For comparison purposes, participants who responded to this question with either 'Very important' or 'Somewhat important' were classified as 'Spiritual' in Figure 9. Individuals who responded 'Not important at all' or 'Not very important' were classified as 'Not Spiritual' in Figure 9. Lastly answers of 'Don't know' were classified into the group entitled 'Unsure'.



*Figure 9.* Presence of spirituality of IDD individuals of ACR Homes compared to national prevalence. Information on spirituality of the general population of individuals with and without

disability adapted from the 2004 National Survey of Americans with Disabilities (Krane & Hanson, 2004).

As shown in Figure 9, the presence of spirituality was appreciably less amongst ACR Homes residents (48%) compared to that of the national average of IDD individuals (83%). Another significant difference existed in the response of ‘unsure’ in regards to spirituality. The N.O.D. reported only 1% of participants responded with ‘unsure’ when asked the importance of their religion, compared to 19% of ACR Homes individuals whose perceived spirituality was unknown (Figure 9). One factor likely contributing to this discrepancy is the format of the N.O.D. survey being self-reported, compared to this research survey, which relied on the perception of the resident supervisor.

Additionally, within this research study statistical significance was found between primary means of communication and perceived spirituality of ACR Homes residents. This implies that lack of spirituality or unknown spirituality is related to the ability to express oneself in a particular way. For example, as shown in Figure 3, individuals who use spoken language as a primary means of communication are more likely to be perceived as spiritual (63%), compared to the perceived spirituality of those with other means of communication, such as sign language (33%) and gestures or body language (25%). Additionally, participants were more likely to be “unsure” regarding the spirituality of individuals with very limited levels of communication (44%), compared to individuals whose primary means of expression was spoken language (9%). The other determinants of disability studied (mobility and behavior support needs) were not found to be statistically significant in their relationship with the perceived spirituality of the IDD individual. This leads researchers to believe that means of expression plays a large role in the perception of spirituality. For instance, individuals unable to verbally communicate may be

deemed or perceived as unspiritual due to disability, regardless of actual beliefs regarding spirituality.

This research study also intended to explore the access, as well as participation in spiritual activities. Of the ACR Homes residents identified as spiritual, 87% participate in spiritual activities. Of those who participate, only 57% accessed spiritual activities as often as he or she would like (Figure 6). No statistical significance was found between the determinants of disability: expression, mobility, and behavioral support needs and participation in spiritual activities.

The final question of the survey instructed the participant to indicate if any given potential barriers were contributing to that individual not participate in spiritual activities as often as they would like. Among barriers assessed, the top responses were; “lack of staffing/accompaniment” and “spiritual activities to not cater/are not suited for resident needs.’ This led researchers to the conclusion that improvements made addressing these barriers will have the greatest impact on the ability of residents to participate in spiritual activities.

### **Limitations and Delimitations**

Expected limitations entering into data collection included response bias of resident supervisors, as well as their willingness to respond. Response bias was a variable researchers acknowledged and accepted in an attempt to include IDD individuals. This was done because many IDD individuals, including those who are nonverbal, are often underrepresented in research studies or completely eliminated. However, this bias leaves room for more speculation and interpretation in regards to the results.

The expected response rate prior to distribution of the survey was 50% of ACR Homes supervisors (25 resident supervisors), responding on behalf of approximately 100 residents.

Incentive was given to participants through the use of a gift card drawing with the hopes of improving response rate. The actual response rate included 30 participants, following the exclusion of incomplete survey responses, 26 total participants with data on 115 residents. Thus, exceeded and eliminated any concerns regarding validity of data due to decreased sample size.

One delimitation of the study involves the use of resident supervisors as the primary participants. Survey data may have been skewed in the cases when a resident supervisor was unaware of the individual's spirituality or responded according to personal biases. However, researchers recognized this delimitation during the creation of the survey methods and chose the resident supervisors as the sole participants in the study with the primary goal being to collect data on all IDD individuals, regardless of disability level or ability to complete a written or verbal survey. Additionally, researchers sought to explore potential biases of residential supervisors regarding their spiritual beliefs, based on Christina Puchalski's definition of spirituality. Of the 26 participants, 25 identified as spiritual. This significant presence of spirituality among the participants of this research survey may limit the ability to apply this same data to other residential home settings in which the prevalence of spirituality is not as predominant.

Another delimitation of this study includes the use of ACR Homes as the primary IDD population for which data was collected. ACR Homes is a residential group home located within the Midwestern region of the United States, thus the data and analysis of this study can only be directly applied to IDD individuals living within a similar group home setting in the same geographic region.

## **Recommendations for Future Research**

Although this study begins to shed light on spirituality among the IDD population, there is little previous research completed within this population. Thus, leaving ample opportunities for further research. Due to the sensitive nature of this research study, the demographic information collected was limited to only three determinants of disability. While the primary means of expression was identified as a statistically significant characteristic influencing perceived spirituality, many other aspects could be analyzed. Future research expanding upon other aspects of IDD individual identification, including: type of disability, whether the disability was present from birth or acquired later in life, gender, age, ethnicity, along with expand outside of the group home setting to compare with individuals living independently or cared for by personal guardians could further understanding regarding spirituality within the IDD population. Working towards identifying all statistically significant barriers which play a role on the IDD individual's ability to explore spirituality will help to address and expand opportunities for this often-marginalized group to experience benefits associated with spirituality.

In future research, it would also be beneficial to collect demographic information on those directly taking the survey. In this research study, only the spirituality of participants was collected. However, collection of information regarding gender, age, and ethnicity in future studies would deem beneficial in gathering information regarding potential response biases of survey participants responding on behalf of IDD individuals.

## **Conclusion**

Literature review points to positive health outcomes in individuals (Pandya, 2018; Balboni & Balboni, 2018; Johnson et al., 2007; Davison & Jhangri 2013; Park et al., 2014; Tuck et al. 2001; Vallurupalli et al., 2012; Puchalski et al., 2017; McCoubrie & Davies, 2006; Nelson



et al., 2002). However, to researchers best knowledge, there are no previous research studies which assess the spirituality within IDD individuals amongst a broad spectrum of disability type and severity. In particular, those individuals who are nonverbal.

The principle finding within this research study was the significant relationship between primary means of communication in IDD individuals and perceived spirituality. From this study it can be concluded that IDD individuals with higher level of communication are more often spiritual or perceived as spiritual. This was not seen with other studied determinants of disability level. Of those identified as spiritual, 57% participated in spiritual activities as often as they desire. Furthermore, lack of staffing or accompaniment was identified as the largest barrier to attending spiritual activities at a rate individual desire. This was followed closely by spiritual activities not being able to suit or cater to the residents' needs.

Although much further research is indicated to fully understand the prevalence and significance of spirituality within IDD individuals, researchers hope this study acts as a catalyst to further uncover spirituality within the IDD population.

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APPENDIX A

Survey



## Significance of Spirituality among Individuals with Intellectual and Developmental Disabilities

### Survey Flow

**Block: Intro Questions (2 Questions)**

**Block: Resident #1 (7 Questions)**

Page Break

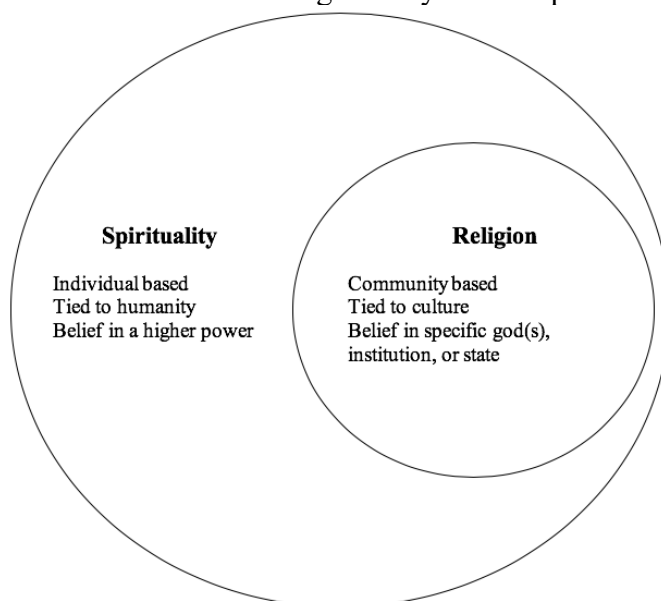
#### Start of Block: Intro question

Q1 Spirituality can be defined as “the aspect of humanity which refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred”.

This may encompass the search for meaning and purpose in life, along with also the connection one makes with his or herself, others, nature, or to sacred realms.

For the purposes of this study, spirituality exists both inside and outside of traditional religion.

The image below overviews how religion may fit into spirituality.



***Based on this definition, would you consider yourself to be spiritual?***

- Yes (1)
- No (2)
- I don't know (3)

*Display This Question:*

*If Q1 = Yes*

*And Q1 = No*

*And Q1 = I don't know*

Q2 How many residents live in the ACR home you supervise?

---

End of Block: Intro question

Start of Block: Resident #1

Please answer the following questions, to the best of your ability, in the way you believe your Field/1 Field/2 would respond if able.

---

Q3 What is the resident's primary means of mobility?

- Moves without aids (1)
  - Uses aid/wheelchair independently (2)
  - Non-ambulatory/other (3)
- 

Q4 What is the resident's primary means of expression?

- Spoken language (1)
  - Sign language/finger spelling (2)
  - Communication aid/device (3)
  - Gestures/body language/other (4)
  - Very limited levels of communication (5)
- 

Q5 Does the resident have any behavioral support needs (self-injury, destructive behavior, disruptive behavior)?

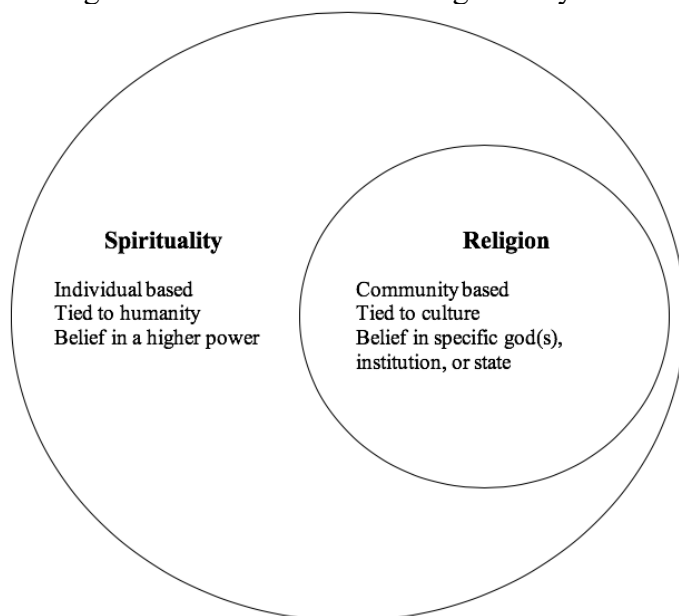
- Yes (1)
  - No (2)
- 

Page Break

Q6 Spirituality can be defined as “the aspect of humanity which refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred”.

This may encompass the search for meaning and purpose in life, along with also the connection one makes with his or herself, others, nature, or to sacred realms.

For the purposes of this study, spirituality exists both inside and outside of traditional religion. The image below overviews how religion may fit into spirituality.



From your perception, would this **resident** identify as spiritual (as defined above)?

- Yes (1)
- No (2)
- I don't know (4)

*Skip To: End of Block If Q6 = No*

*Skip To: End of Block If Q6 = I don't know*

Page Break

Q7 Does the resident participate in spiritual activities (i.e. attends religious services or spiritual groups, participates in worship/prayer, etc.)?

- Yes, they participate. (1)
- No (7)
- I don't know (9)

*Skip To: Q8 If Q7 = Yes, they participate.*

*Skip To: Q9 If Q7 = No*

*Skip To: End of Block If Q7 = I don't know*

Page Break

Q8 If you answered "Yes, they participate"... In your opinion, does this resident have the ability to access these activities as often as they would like?

- Yes, they access them as often as they would like. (1)
- No (2)
- I don't know (4)

*Skip To: Q9 If Q8 = No*

*Skip To: End of Block If Q8 = Yes, they access them as often as they would like.*

---

Page Break

Q9 If you answered "No", do you think any of these factors may be barriers preventing this resident from participating in spiritual activities? **Select all that apply.**

- Lack of transportation (1)
- Lack of staffing/accompaniment (2)
- Lack of time (3)
- Spiritual activities do not cater/are not suited for resident needs (4)
- Spiritual activities are not offered to the resident (6)
- Other (7)

End of Block: Resident #1

---

APPENDIX B

IRB Approval



**BETHEL**  
UNIVERSITY

Institutional Review Board  
3900 Bethel Drive  
PO2322  
St. Paul, MN 55112

April 16, 2019

Sarah Kivisto  
Bethel University  
St. Paul, MN 55112

Re: Project SP-14-19 Spirituality in Individuals with Intellectual and Developmental Disabilities

Dear Sarah,

On April 16, 2019, the Bethel University Institutional Review Board completed the review of your proposed study and approved the above referenced study.

Please note that this approval is limited to the project as described on the most recent Human Subjects Review Form documentation, including email correspondence. Also, please be reminded that it is the responsibility of the investigator(s) to bring to the attention of the IRB any proposed changes in the project or activity plans, and to report to the IRB any unanticipated problems that may affect the welfare of human subjects. Last, the approval is valid until April 15, 2020.

Sincerely,

A handwritten signature in cursive script, which appears to read 'Peter Jankowski'.

Peter Jankowski, Ph.D.  
Chair, Bethel University IRB

APPENDIX C

Permission Correspondence with ACR Homes of Roseville, MN

Bethel PA research project Inbox x**Sarah Kivisto** <sarah-kivisto@bethel.edu>

Thu, Apr 11, 10:20 AM (5 days ago)



to Sarah ▾

Hi Sarah,  
Hope you are well!

In regards to Carlee and my research project, we are in the process of getting approval from the IRB (Institutional Review Board) for our research project. One thing we need for our proposal is to provide documentation stating that you, a representative of ACR Homes, has granted us permission to conduct our research study as proposed.

Our proposed research is as follows: We will send an email to you, containing our informed consent statement, information on how participants can be entered into a gift card drawing, if they so choose following their completion of the survey, and lastly the email will contain a hyperlink to our survey. We then will have you forward this email to all RS's employed by ACR Homes, who will have the opportunity to proceed with the survey. The RS will be prompted to respond to the survey with their perception of each resident they oversee, in regards to spirituality and participation in spiritual activities. Following data collection, analysis will be performed to identify the spirituality of the residents receiving care from ACR, along with also seeking to identify potential barriers that may be preventing residents from accessing spiritual care and activities.

If you have any concerns regarding our proposed methodology, please let us know!

Thank you,  
Sarah and Carlee

**Sarah Abbott**

8:25 AM (28 minutes ago)



to me ▾

Hi Sarah,

Permission granted to proceed! Thank you!!



APPENDIX D

Informed Consent

Initial E-mail to Participants

Dear Participant,

You are invited to participate in a study to explore spirituality within individuals with disabilities. This is a Master's thesis research project by Carlee Hunter and Sarah Kivisto in associated with Bethel University's Physician Assistant program. You may access this survey by clicking the hyperlink below. By choosing to move forward with the survey, you are indicating consent to participate in this study. This research study does involve sensitive information as it asks about the thoughts and perceptions regarding spirituality of individuals with intellectual and developmental disabilities. Participation in this survey is strictly voluntary, and your decision whether or not to participate will not affect your future relations with ACR Homes or Bethel University in any way. As a participant, you may choose to discontinue participation at any time, without penalty by exiting from the site. The answers you give will be confidential so that in any written reports or publications, no one will be identified or identifiable.

Limited research has been performed on the significance of spirituality among individuals with intellectual and developmental disabilities. Your input will guide us in making recommendations to the public and residential care organizations like ACR Homes.

At the end of your survey participation, email either one of the researchers for a chance at winning a **\$10 gift card to Target.** Your first name and email will be recorded onto a secure google sheet this is only accessible to the researchers. At the close of the study, the winner will be contacted and all other identifiable information will be deleted.

This research project has been approved by ACR Homes and the Institutional Review Board of Bethel University. Please contact either of the stated researchers below if you have any questions or concerns about the research and/or research participants'. We greatly appreciate your help and taking the time to help in our investigation.

Sincerely,  
Sarah Kivisto PA-S & Carlee Hunter PA-S

Contact Information:  
Sarah Kivisto PA-S; sarah-kivisto@bethel.edu, 320-262-9225  
Carlee Hunter PA-S; carlee-hunter@bethel.edu, 612-250-6537

APPENDIX E

Informed Consent

Follow-Up E-mail to Participants

Dear Participant,

If you have not already, you are invited to participate in a study to explore spirituality within individuals with disabilities. This survey will expire in two weeks.

This is a Master's thesis research project by Carlee Hunter and Sarah Kivisto in associated with Bethel University's Physician Assistant program. You may access this survey by clicking the hyperlink below. By choosing to move forward with the survey, you are indicating consent to participate in this study. This research study does involve sensitive information as it asks about the thoughts and perceptions regarding spirituality of individuals with intellectual and developmental disabilities. Participation in this survey is strictly voluntary, and your decision whether or not to participate will not affect your future relations with ACR Homes or Bethel University in any way. As a participant, you may choose to discontinue participation at any time, without penalty by exiting from the site. The answers you give will be confidential so that in any written reports or publications, no one will be identified or identifiable.

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This research project has been approved by ACR Homes and the Institutional Review Board of Bethel University. Please contact either of the stated researchers below if you have any questions or concerns about the research and/or research participants'. We greatly appreciate your help and taking the time to help in our investigation.

Sincerely,  
Sarah Kivisto PA-S & Carlee Hunter PA-S

Contact Information:  
Sarah Kivisto PA-S; sarah-kivisto@bethel.edu, 320-262-9225  
Carlee Hunter PA-S; carlee-hunter@bethel.edu, 612-250-6537

[https://bethel.qualtrics.com/jfe/form/SV\\_9zvoXbineJ7kM3r](https://bethel.qualtrics.com/jfe/form/SV_9zvoXbineJ7kM3r)