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“There was some sort of missing middle”: Lived Experiences of Jewish Youth With Intellectual and Developmental Disabilities

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Lived Experiences of Jewish Youth With Intellectual and Developmental Disabilities

by

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Well, I guess I am at the finish line! Thank you all, and many more cheerleaders, for your endless support.

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Abstract

“THERE WAS SOME SORT OF MISSING MIDDLE”: LIVED EXPERIENCES OF JEWISH YOUTH WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

By Aliza Lambert

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Major Director: Dr. Abigail Conley, Associate Professor Counseling and Special Education

Though religion and spirituality contribute to overall well-being (Koenig, 2012; Koenig & Cohen, 2002), social support (Biggs & Carter, 2016; Koenig & Cohen, 2002; Taub & Werner, 2016), quality of life (QOL; Myers & Sweeney, 2000), coping strategies (Krok, 2008), and lower rates of depression and anxiety (Brown et al., 2013; Young et al., 2000), religion and spirituality are seldom included in curriculum in counselor education and supervision doctoral programs (Adams et al., 2015; Henriksen et al., 2015). In the present study, the researcher uses a multiple-case study design to describe the lived experiences of Jewish youth with intellectual and developmental disabilities (IDD). The researcher used proposition building and cross-case synthesis to analyze data. Findings showed how youth with IDD make meaning of Jewish experiences and what their lived experiences are of Jewish rituals and practices. Conclusions include recommendations and implications for religious clergy, religious leaders, counselor educators, counselors in training, and researchers.

Keywords: Jewish, religion and spirituality, youth, IDD, counselor educators

Chapter One: Introduction

Background

My colleague Angie shared a personal experience she had with a resident named Andrew. Angie was the director of a group home for adults with intellectual and developmental disabilities and provided support to her clients in different ways. She recalled that after Andrew was bar mitzvahed in his mid-20s, he requested going to temple for Shabbat. One Friday, Andrew's family was unavailable to take him to services, so Angie volunteered to take him. Angie sat next to Andrew in the service, and when it was time for volunteers to lead a reading, Andrew raised his hand. Angie asked if Andrew would like for her to read for him, and Andrew nodded "yes." Angie and Andrew stood up, and Andrew put his hand on Angie's shoulder. Angie spoke the words from the prayer book, and she recalled the feeling of understanding the whole congregation had. By Andrew placing his hand on her shoulder, she was now his voice for the prayer. Angie felt energy from Andrew after they sat back down—and a feeling of community all around them.

This personal example is an outward display of community, connection to Judaism, and connection to prayer for an individual with intellectual and developmental disabilities (IDD). However, this anecdote is a stark contrast to the history of individuals with IDD in the United States, which is riddled with institutionalization and sterilization. The construct of disability has changed over time, yet theory and research continue to remain nearly void of disability narratives. The lack of disability narratives is particularly apparent in lived experiences regarding religious and spiritual experiences, which are often hegemonic narratives from white Christian parents/guardians (Ault et al., 2013; Boehm et al., 2015; Boehm & Carter, 2019). Historically, disability narratives in the US were shaped by legislation steeped in colonialism (Barnes, 2012; Corker 1999b; Green & Loseke, 2019; Nielsen, 2012), and war (Blackie, 2014; Liachowitz, 1988). Conceptualization of disability is dominated by the biomedical model of disabilities (Kafer, 2013; Lau & Weiss, 2020; Liachowitz, 1988; Pfeiffer, 2002; Smart, 2006, 2016) hindering access to education (Aron & Loprest, 2012; Gerber, 2011) and religious institutions (Blanks & Smith, 2009). As a result, problematic narratives impede access to religious institutions, and perhaps religion and spirituality in general, for individuals with disabilities.

Spiritual wellness is central to overall wellness (Ohrt et al., 2018), yet research on spiritual wellness among individuals with IDD has been geared to determining *if* individuals with IDD can in fact be religious and spiritual (Vogel & Reiter, 2004). Therefore, the purpose of this study is to explore the lived experiences of Jewish youth with IDD. By conducting this study, I aim to contribute to the field of counselor education by applying a critical lens to research surrounding religion and spirituality for Jewish youth with IDD. This will be achieved through applying theory such as Disability Critical Race Theory (DisCrit).

Theoretical Framework

DisCrit is a theory founded on the notion that disability and race are social constructs (Annamma et al., 2013). DisCrit researchers are known for using critical terminology when navigating race and disability (Jaulus, 2020), which provides an intersectional framework that extends beyond education (Annamma et al., 2013) and makes disability equity a societal plight for justice. In education, DisCrit researchers provide space for authentic relationships and mutual understanding of oppression and how this oppression manifests in the system of education (Migliarini & Annamma, 2019). The tenets of DisCrit that are at the core of this dissertation are

(a) multidimensional identities are valued (e.g., religion and disability), (b) voices of marginalized populations often exempt from research are prioritized, and (c) activism and resistance are required and supported (Annamma et al., 2013). My intention as a researcher in this study is to elevate the meaning-making experiences of Jewish youth with IDD.

Statement of Problem

Religion and spirituality contribute to well-being (Koenig, 2012; Koenig & Cohen, 2002), quality of life (QOL; Myers & Sweeney, 2000), social support (Biggs & Carter, 2016; Koenig & Cohen, 2002; Taub & Werner, 2016), coping strategies (Krok, 2008), and lower rates of depression and anxiety (Brown et al., 2013; Young et al., 2000). However, religion and spirituality are seldom included in curriculum in counselor education and supervision doctoral programs (Adams et al., 2015; Henriksen et al., 2015). Counselor educators feel that religious and spiritual competencies are important (Cashwell et al., 2007) but feel unprepared to address religion and spirituality with clients (Adams, 2010; Cashwell et al., 2007). In fact, counselor educators tend to not explicitly address religion and spirituality with clients at all (Cashwell et al., 2013).

The religious and spiritual experience is particularly important for youth with IDD because they experience additional challenges compared to their neurotypical peers as they transition into adulthood (Forte et al., 2011). Narratives about individuals with disabilities and their experiences with religion and spirituality are often told by their parents and caregivers (Carter & Boehm, 2019; Carter et al., 2017; Nurullah, 2013; Poston & Turnbull, 2004; Uhrman, 2017) rather than by individuals with IDD. There are limited studies of lived experiences surrounding faith from the perspective of individuals with IDD (Liu et al., 2014; Sango &

Forrester-Jones, 2018; Turner et al., 2004), and although some research has shown that youth do place high importance on religion (Liu et al., 2014), nuances of religion and spirituality and how they are experienced need to be explored.

Centering lived experiences of Jewish youth with IDD in the home can increase knowledge of how Jewish youth with IDD engage in rituals and practices, which can inform recommendations for synagogues, temples, Jewish organizations, disability organizations, counselor educators, counselors in training, and researchers.

Purpose Statement

The purpose of this multiple-case study is to describe how Jewish youth with IDD experience Jewish rituals/practices in the home. As mentioned previously, the narrative of disability is not often told by the individual with disabilities. I will build from theoretical propositions and use strategies such as plain language (in assent and consent procedures and in the summary document for member checking strategies), accessible interview questions and format as determined by the participants, and observations of real-life experiences in their homes. By using these strategies, I will gather data from Jewish youth with IDD and describe phenomena within the context of the case study (Yin, 2003) that honors and represents these narratives.

Research Question

The research question that this study sought to answer was:

What are the lived experiences of Jewish youth with IDD as they participate in Jewish rituals/practices in the home?

Methodological Overview

A multiple-case study method will be used to begin to describe the phenomena and to develop a deeper understanding of the phenomena (Harrison et al., 2017). Because the case is bound in multiple ways (i.e., age, disability, and religion), I will use the multiple-case study method to conceptualize the different ways these cases exist in the home. Data about lived experiences will be collected through two semi-structured, in-person interviews; an observation of the participants' chosen Jewish home ritual/practice; and researcher case notes from the observation. The participants in the study will be between the ages of 15 and 24 (further referenced as *youth*); have a diagnosed IDD; consider themselves Jewish; and live in Maryland, Massachusetts, Michigan, New Jersey, New York, Ohio, Virginia, or Washington D.C. I will use purposeful sampling and reach out to the synagogues, temples, Jewish organizations, and disability organizations, so that I can get a diverse range of Jewish orientations. For data explication, I will build from theoretical propositions (Yin, 2018). I will also use pattern matching, which is a technique that helps to answer the "how" and "why" of experiences (Yin, 2018). I will use the chain of evidence proposed in Chapter 3 to analyze data collected from interviews, observations, and case notes (Yin, 2018). In summary, I will use methods that help me as a researcher to centralize the narratives of Jewish youth with IDD.

Study Significance

Instead of experiences with religious practices and rituals being told by caregivers, which is often the case for this population (i.e., Ault, 2013; Carter, 2017; Norlin & Broberg, 2013; Nurullah, 2013; Poston & Turnbull, 2004), stories will be told by the participants with disabilities themselves. Centering marginalized voices in research is a major tenant of DisCrit

(Annamma et al., 2013) and is a core way I will create a platform for input and personal narratives in the present study. Not only are narratives generally told by parents and caregivers, but there is also a dearth of research on spirituality and religion for youth with IDD. In a systematic literature review by Oakes et al. (2020) on health disparities for post-secondary education students with IDD, researchers found studies about coping and support needs, transition experiences and worries, and mental health. There was a lack of literature and research surrounding spirituality and religion for youth with IDD. The present study contributes to awareness and understanding about health disparities regarding religion and spirituality for youth with IDD.

Counselor educators are aware of the importance of religious and spiritual competencies (Cashwell et al., 2007) yet avoid conversing about religion and spirituality with clients (Cashwell et al., 2013). Furthermore, research involving wellness for individuals with disabilities and their families has generally been deficit focused (Weiss et al., 2018) and is generally lacking in counselor education (Rivas & Hill, 2018). The present study illuminates the lived experiences of youth with disabilities, which can expose counselor educators to religious and spiritual experiences for individuals with disabilities and prepare counselor educators to address such needs with their counselors in training.

Implications from this dissertation can inform future research involving spirituality for individuals with IDD. Of the five wellness domains (i.e., mind, body, spirit, emotion, and connection), this research can specifically enhance understanding of spirit and how individuals make meaning of self and purpose (Ohrt et al., 2018). Spirituality is often cited as being a core part of wellness (Myers & Sweeney, 2008), yet models of faith development, such as faith development theory (Fowler, 1981), do not include people with significant disabilities.

The results from this research can inform religious clergy, religious leaders, counselor educators, and researchers. Counselor educators can gain insight on meaningful rituals and practices in the home that enhance religious, spiritual, and cultural connections to Judaism. Meaning drawn from this research can affect how Jewish families with youth with IDD think about and enact rituals and practices in their homes. Findings from this research can also have an impact on clergy members and other community service providers in how they think about supporting Jewish youth with IDD.

Definition of Key Terms

The following terms are used throughout the dissertation and are defined for context.

Ableism- "A system that places value on people's bodies and minds based on societally constructed ideas of normality, intelligence, excellence, desirability, and productivity" (Lewis, 2021).

Bar/Bat Mitzvah- Bar (for boys) and bat (for girls) mitzvah traditionally occur between 12 and 13 years old and is not only considered a rite of passage but also symbolizes the responsibility to uphold the word of the Torah and follow Jewish law (Glicksman, 2011).

Cognitive Disability-The former term for intellectual disability (Ohio Coalition for the Education of Children with Disabilities, n.d.).

Family Quality of Life (FQOL)- When family members have their needs met, enjoy their lives together, and do things that are of importance to them (Poston & Turnbull, 2004).

G-d- Some Jews choose to write G-d out of respect and as an interpretation of Deuteronomy 12:3-4 as to not erase or destroy G-d's name (Appell, n.d.; Shurpin, n.d.).

Hebrew- The language of the Torah and the primary language spoken in modern Israel (My Jewish Learning, n.d.a.).

Intellectual and Developmental Disabilities (IDD)- "Limitations in intellectual functioning, behavioral limitations in adapting to environmental demands, and early age onset" (American Association on Intellectual and Developmental Disabilities, n.d.). Some common diagnoses under this umbrella term include autism spectrum disorder (ASD), Down syndrome, traumatic brain injury, Prader-Willi syndrome, and Fragile X syndrome (U.S. Department of Health and Human Services, n.d.). Though IDD includes variations (ID, DD, ID/DD), I selected IDD throughout the dissertation for consistency.

Jewish- A person who identifies as being a part of the peoplehood and religion of Judaism (Washofsky, 2002)

Judaica- Ritual objects used in Judaism (My Jewish Learning, n.d.b).

Judaism- A religion, tradition (Cohen et al., 2003), or ethnic identity (Dubow et al., 2000).

Lived Experiences- A person experiencing moments of meaningfulness (van manen, 2017). In this dissertation, lived experiences are interpreted by the researcher to conceptualize the significance of the experience (Frechette et al., 2020).

Practices- Ethnic and cultural experiences based on religious and spiritual values (Ohrt et al., 2018).

Quality of Life (QOL)- Values for the individual that lead to self-determination and empowerment. QOL is continuously changing and should be discussed to individualize supports (such as assistive technology, accommodations, or caregivers), goals, and the environment (Verdugo et al., 2015).

Religion- An organized system of beliefs shared with others and belief in a higher power (Ohrt et al., 2018).

Ritual- A repetitive behavior that is related to a religious belief or custom. Rituals can be performed individually or as a group (George et al., 2013).

Shabbat- The day of rest as commanded by G-d and the Seventh day of the Jewish week; takes place from Friday at sundown to Saturday at sundown. It is a day to remember and to observe (Jewish Virtual Library).

Spirituality- "A deeply individual lived experience that is connected to one's academic, physical, emotional, social, and hence human development" (Boskovich et al., 2019, p. 217).

Youth- Individuals who are between 15 and 24 years old (United Nations, 2013).

Chapter Summary

Although Jewish youth with IDD are religious and spiritual, information on how they experience rituals and practices in the home is lacking. Thus, the lived experiences of Jewish youth with IDD as they engage in rituals and practices in the home is of interest. Deficit narratives of disability through America's convoluted history and the biomedical model of disability have shaped institutions of education and religion and hindered access to services beyond functional and medical ones. A needed shift in research is facilitated through a DisCrit lens, creating a platform for honoring lived experiences and enacting change in how disability is viewed regarding religious and spiritual practices. In the next chapter, I will review research on religion and spirituality among families and youth, and particularly Jewish families and Jewish youth, with IDD.

Chapter Two: Literature Review

Overview

In Chapter 2, I will establish the importance of studying lived experiences of rituals and practices for Jewish youth with IDD in the home. I will do this by delineating the history of disability in the United States, defining disability and theory, and summarizing educational and religious institutions in America. Subsequently, I will give a synopsis of relevant literature pertaining to religion and spirituality in family, community, and youth with disabilities. I conclude with a review of specific literature on Jewish youth with IDD and how they experience rituals and practices.

History of Disability in the United States

Disability history in this country begins before there were United States of America, with the Indigenous people. This makes defining such history complicated as there are more than 500 different tribal and native groups (Weaver et al., 1997). As cited in Nielsen (2012), Jennie Joe (Navajo) and Dorothy Lonewolf Miller (Blackfeet) suggested some Indigenous people refer to disability as relational rather than bodily, meaning that the disability only existed between people and not within the individual. The mind, body, and spirit were connected as one (Nielsen, 2012) and the individual found different and important ways to be a part of the community.

Disability was next described by colonial laws dating back to 1636, which ascribed communal responsibility to care for wounded soldiers that were returning home. There was a shift from social and public responsibility to functional and service responsibility in the 1690s. In 1776, the first legislation was passed on disability, and it was centered on soldiers' abilities to function in society and remain useful (Liachowitz, 1988). This legislation passed during the time of the Revolutionary War, which spanned from 1775 to 1783, to support and recognize the wounded and injured veterans (Blackie, 2014). Congress defined disabled as being "either fully or partially incapable of laboring for a living" (Blackie, 2014, p. 18), and put national pension laws in place for veterans.

By World War I, there were significantly improved medical procedures and wider availability of those procedures. This improvement, combined with the prevalence and visibility of wounded soldiers, led to a larger congressional response (Liachowitz, 1988). The Disabled Veterans' Rehabilitation Act of 1943 was established to provide vocational rehabilitation programs to disabled veterans, which resulted in job training for 621,000 disabled veterans from World War II (VA History in Brief, n.d.). Though there was protection for disabled veterans, it was not until the late 1960s that individuals with "severe" disabilities had support beyond institutionalization (Barnes, 2013). Life expectancy went from 67.2 years to 70.8 years from 2000–2005 to 2010–2015 (World Populations Prospects, 2017), showing a rise in life expectancy for the general population. There are multiple theories about this increase in life expectancy and include a combination of advances in medicine (Freedman et al., 2016) and higher standard of living (Smart, 2006).

The dominating paradigm in the Western world highlights independence and labor productivity (Green & Loseke, 2019). In Western culture, disability has been framed as a personal and individual medical tragedy (Barnes, 2012). This is apparent in the Nazi strategy to create an Aryan race by involuntarily sterilizing people with disabilities and ultimately carrying out Operation T4, which was the authorization of euthanizing people with disabilities with gas—which later became the "final solution" for all Jews (United States Holocaust Museum, n.d.). An in-depth review of institutionalization and the eugenics movement is beyond the scope of this dissertation (for an understanding of institutionalization and the eugenics movement, see resources such as Albrecht, 2001; Appleman, 2018; and Block, 2000), yet it is important to note the intersection of race, disability, religion, and sexuality in these movements when understanding disability history. In this section, I provide a scoping and abridged review of the national landscape of disability through a historical context. It is apparent with changing legislation (i.e., after both world wars) that the definition of disability shifted as societal needs changed. Thus, in defining the major constructs of disability, I further merge disability history.

Disability Defined

Though defining disability is necessary for critically interpreting theory and empirical works surrounding disability, defining disability has been a formalized process of oppression in the United States to identify individuals using medical diagnoses (Dirth & Adams, 2019). In the context of this dissertation, *disability* is defined as being "based on social and functional criteria" (Charlton, 1998, p. 7) and is a "condition imposed on individuals based on society" (Charlton, 1998, p. 8). This means disability is socially constructed, that if a society deems a person as having a disability, then they have a disability, and that society itself places functional limitations on people (Charlton, 1998).

There is a clear distinction, however, between this definition of disability and the legal definition of disability. The language in the Americans with Disabilities Act of 1990 refers to disability as legal rather than medical and defines a disabled person as someone who has substantial limitations in one or more major life activities due to a physical or mental impairment (What is the definition of disability under the ADA?, 2021). *Disability* as defined by the United

States Census Bureau includes individuals who "have difficulty with certain daily tasks due to a physical, mental, or emotional condition" (Young, 2021, p. 2).

The total number of people with disabilities in the United States was 43,227,000 in 2019, which represents 13.2% of the total population (Annual Report on People with Disabilities in America, 2020). Numbers from the American Community Survey reflect self-reports rather than a medical diagnosis. From 2008 to 2019, the percentage of children under 18 with disabilities in the United States increased from 3.9% to 4.3% (Young, 2021), resulting in more than 3 million children with disabilities.

Disability is categorized by three broad categories: physical disabilities, intellectual disabilities, and psychiatric disabilities (Smart, 2019). This way of framing disability is based on disability symptomology and not the cause of disability. This is because the etiology can be unknown or have multiple causes. Even though individuals may have the same disability, how the condition affects daily life and how it is experienced differs for each person (Smart, 2019).

The five most common models of disability are the Religious-Moral Model, the Biomedical Model, the Environmental Model, the Functional Model, and the Sociopolitical Model (Smart, 2016). The Religious-Moral Model is the oldest model of disability (Retief & Letšosa, 2018; Smart, 2016) and is centered on the belief that disability is a result of sin (Retief & Letšosa 2018). Though this model is outdated, remnants of this model exist today in popular media archetypes (Donnelly, 2016) in which people with disabilities are depicted as wicked or evil, often attributed to sin (e.g., Jamie Lannister from the *Game of Thrones* losing his hand because of his sins of killing the king and being a Lannister).

A more widely understood and familiar model that has been used to categorize people with disabilities is the Biomedical Model (Smart, 2016). This model has vested scientific support and was conceptualized through medical language, framing disability as a problem that results in a treatment (Liachowitz, 1988; Smart 2006) or cure (Smart, 2016). This model pathologizes people with disabilities, making individual dysfunction the major criterion for the label of disability (Liachowitz, 1988). This model is also known as a deficit model because the medical diagnosis becomes the lens for viewing a person with disabilities (Pfeiffer, 2002). In this medical model, the body is categorized and defined in a stagnant way that does not consider life experiences (Kafer, 2013).

In contrast to the Biomedical Model, the Environmental Model and the Functional Model are interactional (Smart, 2006). In the Environmental Model, the environment itself contributes to the disability and can facilitate barriers (e.g., no ramp, no curb cuts, no closed captioning); thus, the environment can exacerbate disability (Smart, 2006). The Functional Model is how the functions of the person define disability (Smart, 2016). Thus, disability is viewed as a functional limitation based on lifestyle or the result of unequal physical access to infrastructure, transportation, and content (Farber et al., 1972). In a seminal study regarding children's ability to apply the Functional Model to conceptualizing individuals with and without disabilities, children were able to differentiate and articulate how disability would affect an individual specific to the function of the task (Langer et al., 1985). For some children, this meant seeing no difference in ability to do a job based on disability and even having an advantage in certain activities when having a disability.

Emerging in 1976, the Sociopolitical Model is the most recent contribution to largely acclaimed disability models (Smart, 2006). At one time, this model was referred to as the Minority Model. The Minority Model, significantly influenced by the civil rights movement, emerged in the late 1970s and was based on experiences of marginalized people (Connor et al., 2008). Disability, steeped in racism and classism, has been used as a device to "other" individuals who do not conform (Ferri & Bacon, 2011). This model stands in contrast to alternative models because it is centered on the larger landscape of society (Dirth & Adams, 2019), language (Williams, 2013), and an appreciation for the disability experience (Dirth & Adams, 2019).

Through this section, it is clear there is not a singular definition of disability because the definition changes over time. How people have come to define disability has commonly been broken down into the five categories of the Religious-Moral Model, the Biomedical Model, the Environmental Model, the Functional Model, and the Sociopolitical Model (Smart, 2016). These models face many criticisms (i.e., the Biomedical Model being used to pathologize people and the Functional Model being used to create unequal access) and are exhibited through legal definitions (Young, 2021) of disability and legislature (Liachowitz, 1988) for people with disabilities. Just as the definition of disability changes, how disability is studied must also change.

Disability Studies

Disability studies (DS) formally emerged in academia in 1982 with the creation of the Society for Disability Studies (Connor et al., 2008). In the 1980s and 1990s, DS activists and scholars challenged the medical deficit framework and emphasized that disability is socially (Depoy & Gilson, 2008; Taylor, 2006), culturally (Taylor et al., 2006), and politically (Kafer, 2013; Taylor et al., 2003) constructed. Thus, rather than being disabled, social and cultural contexts are responsible for giving meaning to disability (Taylor, 2006). An example of these constructs is the Willowbrook study in the 1950s and 1960s, where an entire state institution for students with intellectual disabilities was used as a control setting for an experiment with hepatitis. All children in the facility were injected with hepatitis. Although parental consent was given, participants did not know about the study and were not given information after the data were collected (Hays & Singh, 2012). Policies were not in place to protect people with disabilities permitting people to not inform the children with disabilities about the hepatitis they were being injected with.

Because DS is not discipline specific, it is viewed as an area of inquiry (Taylor et al., 2003). DS theorists within education have advocated for non-segregated settings, including disabled people in developing theory surrounding disability, to understand that disabled lives are meaningful lives and to recognize the societal discourses that create “normal” and “othered” lives (Connor et al., 2008).

A major criticism of DS is the need for deeper cultural and historical contributions to DS, both collectively and individually (Albrecht, 2001). Critical disability studies (CDS) emerged as activists, scholars, and advocates challenged the binary nature of disability (Vehmas & Watson, 2014), galvanizing around broadening the structure that oppresses disabled people and their experiences (Corker, 1999a). Theory cannot bolster the experiences of all disabled people and upholding theory often creates an exclusionary reality of both ideal experiences. Thus, a gap remains between experiences and theory, which can be exacerbated in different power structures (Corker, 1999a). For example, the power structure of language regulates and standardizes, which naturally creates a majority-minority group model (Corker, 2000).

The progression of the emancipatory work of CDS activists, scholars, and advocates led to continued rejection of boundaries placed on disabled people, even by the theory of DS (Corker, 1999a). The critical interrogation of DS by CDS can be equated to the similar rejection of the medical model of disability and replacement with the social model of disability (Vehmas & Watson, 2014). In a continued effort to eradicate ableism, CDS is expanded through the merging of Disability Studies and Critical Race Theory as delineated in the next section.

DisCrit

DisCrit is a theoretical framework that researchers and activists use to critically analyze how people are racialized and disabled by society. DisCrit is a theory where researchers can push past the limitations within DS. In DisCrit, disability is viewed as a social construct like race (Smith, 2004), and this overlap is evident through the seven tenets of DisCrit (from Annamma et al., 2013):

1. Normalcy is upheld by the forces of racism and ableism, and their forces are often invisible.
2. Identity is multidimensional, and DisCrit theorists challenge singular notions of identity.
3. Even though race and ability are social constructs, there are both material and psychological manifestations of being labeled, and it “others” people outside of Western norms.
4. Marginalized populations are centralized in research.
5. Rights of citizens have been denied through historical and legal constructs due to race and ability.
6. Whiteness and ability are recognized as assets, and the advances for people with disabilities are a result of interest from white, middle-class citizens.
7. Activism and resistance are required and encouraged.

These tenets serve as guiding principles to critically expand the field of disability.

DisCrit has become the medium for all disciplines to see disability as a social construct rather than as a special education issue (Annamma et al., 2013). This is apparent in conversations around disability and Judaism related to religious obligations for individuals with disabilities. For instance, Julia Watts Belser (2014) sheds a light on her experiences as a disabled rabbi.She talks of an experience where she was at her temple waiting in line for kiddush when a visitor asked "What's wrong with you?" (Belser, 2014, p.27). This question was common for Belser, so the retort of "I have a disability" (Belser, 2014, p.27) followed. However, she did not feel that was really the truth because of what the questioner was asking. Belser talked about how that question was hinting more at objectification and pity than at physicality. Herein lies the crux of ableism, the positionality of better than or normal (i.e., insinuating that any other life is less than or other).

Belser also spoke of experiences she had with disability and religion. A student of hers asked about a specific prayer called "Asher Yatzar" (Belser, 2014, p.27), in which Jews pray to G-d[1] for the blessing of the body. Belser shifted into a space where she talked of this question as an inner dialogue to which she experiences prayer. She thanked G-d for "crafting this holy house of skin and blood: these clear eyes and bony hips, this leg a bit shorter than the next, this hip unwilling to bear weight." (Belser, 2014, p. 27). She spoke of the sound of her own step, how she loved the offbeat sound as a child.

Finally, Belser discussed religious communities gravitating toward openness in recent years. In fact, synagogues that invested in religious education, specifically for children with intellectual disabilities, have helped to develop community standards around amplification of sound on Shabbat and provide large-print siddurim (prayer books) to congregants (Belser, 2014). This effort makes disability singularly an access issue and one that needs to be solved rather than welcoming disability culture and celebrating disability as a “radically different way of moving through the world” (Belser, 2014, p. 28). Moving through the world provides a context to think about specifically moving through systems and institutions.

Application to Institutions

For individuals with disabilities in America, institutions more broadly have been a longstanding reality spanning from psychiatric hospitals, nursing homes, segregated schooling, prisons, and group homes (Ben-Moshe, 2013). Institutionalization has remained a common fight for disability advocates who challenge discrimination and demand full citizenship (Saxton, 2013).

Education Institutions

Formal education institutions often act as a pathway to regular interaction with professionals who serve children (Aron & Loprest, 2012). Educating children with disabilities in the late 1800s and early 1900s was motivated by humanitarian efforts and resulted in ungraded classes and selectively enforced attendance laws (Gerber, 2011). As values shifted, because of World War II, there was a stronger emphasis on academic achievement, and the government took a more direct role in public education (Gerber, 2011). Yet it was not until the 1970s that federal legislation legally protected both civil and constitutional rights of individuals with disabilities through Section 504 of the Rehabilitation Act of 1973 (Aron & Loprest, 2012). Section 504 of the Rehabilitation Act of 1973 is broad in its protection of civil rights, expanding beyond the educational institution (Guernsey, 1989). In 1970, the Education of the Handicapped Act (EHA) built on the foundation of the Elementary and Secondary Education Act of 1965 by including funding specifically to train and educate teachers of students with disabilities (Yell et al., 2017).

To create more specific protection for students with disabilities, the Education for All Handicapped Children Act (EAHCA; 1975) was passed (Guernsey, 1989) as an expansion to the EHA (Yell et al., 2011). Under EAHCA, all students were entitled to a free and appropriate education, with federal funds, pending proof that the school's educators were in accordance with the law (Yell et al., 2011). Several amendments to the law were passed. Of particular importance was the Individuals with Disabilities Education Act (IDEA) of 1990, proving to be the most significant legislation for students with disabilities (Yell et al., 2011).

When IDEA was passed in 1990, transition planning became part of every student's individualized education program (Yell et al., 2011). IDEA has since been reauthorized in 1997 and 2007, extending services to ensure quality education and measurable outcomes (Yell et al., 2011). Prior to the 1975 passage of IDEA, one in five students with disabilities attended public schools (Aron & Loprest, 2012). As an early core principle of EHA, the question of how best to teach and work toward inclusion still guides educational decisions as policies are amended (e.g., IDEA and the American with Disabilities Act of 1990 [ADA]) (Kauffman et al., 2011).

The Rehabilitation Act of 1973 was expanded by ADA (Schloss & Gunter, 2011). Though ADA was significantly powerful in addressing access to "schools, transportation, public accommodations, telecommunications, and state and local government operations" (Schloss & Gunter, 2011, p. 474), protection of civil rights was not expanded to include access to religious institutions with staff capacity exceeding 15 employees (Anderson, 2006).

Religious Institutions

Educators are often reluctant to discuss religion when working with children with IDD citing the division of church and state, yet religion is quite evident in public school vacation calendars (Blanks & Smith, 2009). In private religious institutions, the same guiding principle of maintaining a division between church and state is upheld by these institutions not participating in federally funded programs (Eigenbrood, 2004). Religious education occurs in places of worship. In fact, six in 10 teenagers say they have participated in religious education, and 29% of these teenagers still participate (Diamant & Sciupac, 2020).

Religious institutions help preserve culture through “customs, rituals, mythology, signs and symbols” (Charlton, 2006, p. 219). The clergy in religious institutions can play a large role in the level of support families with children with disabilities feel in the congregation (Annandale & Carter, 2014), but welcoming congregants with disabilities is not enough (Haythorn, 2003). Support can be felt in physical spaces of worship, in education, and through resources within religious institutions (Haythorn, 2003).

So far, I have provided an overview of the history of disability in the United States, defined disability, explained the progression of theory, and applied these concepts to both educational and religious institutions. In the following sections, I present empirical evidence about religion, spirituality, Judaism, and youth with disabilities. I apply DisCrit and critique the past and current research, then I formulate the need for the unique research I am presenting.

Religion and Spirituality

Since the turn of the century, memberships in churches, synagogues, and mosques have declined more than 20% and in 2020 was at 47% (Pew Research Center, 2021). Though more than seven in 10 Americans are affiliated with an organized religion, less than half of these individuals have a formal membership to a place of worship (Pew Research Center, 2021).

In this dissertation, *religion* is defined as “a belief in a higher power, usually a G-d or G-ds, organized by a system of beliefs shared by others. Religions are creedal, dogmatic, and governed by institutional rules of worship" (Ohrt et al., 2018, p. 94). Religion includes the practices and beliefs that are based in sacred text and experiences (Boyatzis, 2013).

Religion is a tenet of the larger category of spirituality. Spirituality is described as "developmental in nature, meaning that it is a shared experience among all people that grows and changes over time" (Ohrt et al., 2018, p. 94). It results in "increased *mindfulness* (nonjudgmental awareness of present experiences), *heartfulness* (experiences of compassion and love), and *soulfulness* (connections beyond ourselves)" (Cashwell et al., 2007). Spirituality is not inherently linked to religion, meaning it can develop outside of a religious context (Cashwell et al., 2007). This is an important distinction because it blends the possibility of religious development and spiritual development to occur together but also separately. Spirituality is individualized (Glicksman, 2011) and is a search for wholeness and meaning (Hage et al., 2006), which includes self-transcendent experiences that are sacred and involve relationships and practices (Boyatzis, 2013). Ultimately, spiritual development is a personal journey that helps inform the meaning of the world and how people move through it. Though religion and spirituality are personal experiences (Boyatzis, 2013), faith is often rooted in family of origin and home practices (Boehm & Carter, 2019).

Judaism

Turning now specifically to Judaism, it is important to first give an overview of the Jewish people and religion. Jews "are a group who share a common religious, cultural, and ethnic background" (Selekman & Zavadivker, 2021, p. 557). Jewish identity includes the Jewish people, all of whom share an ancestry and a history. Cultures and communities have formulated all over the world and contribute to the shared identity of what it means to be a Jew.

Because Judaism is complex and diverse, it is important to look at the demographic breakdown of Jews throughout the world. According to DellaPergola (2010), one in every 510 people in the world identifies as a Jew. North America alone constitutes 39.3% of the total Jewish population in the world, second to Israel at 42.5%, followed by France at 3.6%. The total number of Jews in America is speculative for a variety of different reasons. Not only are there multiple competing studies, some of which are social surveys without a focus on religion, but also Jews being a minority group has led to problematic survey collection and trust (DellaPergola, 2010). In the United States, the largest concentration of the Jewish population falls within the age range of 45–64, with the average Jew in America being 41.5 years old (DellaPergola, 2010). Recent numbers, according to the Jewish Virtual Library (2021), show that there are 7,153,065 Jews in the United States, which translates to Jews making up 2.2% of the American population. The diminished Jewish population in the United States is attributed to the many pogroms (antisemitic violence mainly in Russia in the late 1800s; Ratzabi, 2018) and the Holocaust (Eisen, 2009).

Within Judaism, there are three major denominations: Reform, Conservative, and Orthodox. Additionally, there are Secular Jews who identify with Judaism culturally and identify as a Jew but have no religious affiliation. Regarding all three sects of Judaism, it is important to acknowledge that there is no singular religious figure that all Jews look to; instead, Jews follow the guidance and supervision of their rabbis, cantors, and other religious clergy. Rabbis lead services and the congregation, and they are the main figures in the synagogue/temple (Selekman & Zavadivker, 2021).

The following is a cursory review of the three sects of Judaism. For a full review, see Selekman & Zavadivker (2021). Reform Judaism is a movement that is progressive in nature and integrates Jewish law (also known as *halakhah* in Hebrew) into daily living that promotes the integration of social justice and gender equality. Reform Jews do not typically perform daily religious practices but do observe holidays and still engage in Jewish rituals and practices (e.g., bar/bat mitzvah and circumcision/baby naming). Conservative Judaism as a movement preserves Jewish law and emphasizes Jewish education and engages in weekly Jewish traditions such as Shabbat. Conservative Jews often follow kosher laws (food preparation and consumption in accordance with Talmudic instruction) and encourage same faith marriage. Orthodox Jews strive to live a halakhic life and follow daily prayer, modest dress, and holiday and Shabbat observance. There also are ultra-Orthodox Jews, and this population tends to live in close communities and neighborhoods central to the synagogue, kosher markets, and kosher restaurants. Ultra-Orthodox Jews tend to reject popular culture in strict observance of the Jewish law (Selekman & Zavadivker, 2021).

In this section, I defined Judaism, gave the demographic overview on the global scale, and came back to an overview of what Judaism looks like according to the three sects of Judaism. It is important to note that, though Judaism has a shared history and has categorical sects, it is still individual in how it is experienced. In fact, Friedman et al. (2005) studied Jewish identity in a phenomenological study where participants emphasized the fluidity of their Jewish identity throughout their lives. There is a strong need to study how these cultural, ethnic, religious, and spiritual people experience disability.

Faith Development Theory

Faith Development Theory is a stage theory that is in line with other developmental theories (e.g., Cognitive Developmental Theory, Psychosocial Development Theory, and Moral

Development Theory) yet extends these structural traditions and adds a range of knowledge building through faith (Fowler, 2004). In 1981, Fowler published the first iteration of the *Stages of Faith* and added four major dimensions to constructing knowledge: 1) Locus of Authority, how one processes and responds to authority; 2) Bounds of Social Awareness, the capacity of a person to deepen perspectives of others; 3) Form of World Coherence, the conceptualization of a meaningful world; and 4) The Symbolic Function, how humans shape and respond to "symbols, narratives, and rituals that invite participation in the sacred and that touch the deepest dimensions of our relatedness to the Holy" (Fowler, 2004, p. 413). Though the contributions expanded developmental theories, a major criticism of Faith Development Theory remains. Faith Development Theory is a stage theory that has a prescribed hierarchy of stages. Categorizing faith development subjectively as "healthy" creates the dualism of a child's development being healthy or unhealthy (Streib & Keller, 2018). In fact, the critique of defining parameters of how a person is religious holds true in defining disability in a religious and spiritual context.

Disability in Religious and Spiritual Contexts

For people with and without disabilities, religion is one of the many ways people make sense of the world (Imhoff, 2017). Though disability literature includes Christian theologians and their movement to include people with disabilities in religious traditions and resources, a critical lens has scarcely been taken to the intersection of religion and disability (Imhoff, 2017). Judaism has often been at the crux of religious critique. Critics cite the Old Testament as being prohibitive and not being improved and rid of cultic ways until Christianity and Jesus made change (Imhoff, 2017). Other insights about Judaism and disability have delineated disability as being deserved and resulting from sin. In fact, many references to the portrayal of people with disabilities derive from the Old Testament (the known Jewish text). Disability is seen as a result of G-d bringing it down on a person as a result of transgression. However, with Christianity and the enlightenment of the Jewish people, the narrative shifts from people with disabilities being sinners to people with disabilities being cured through Jesus (Imhoff, 2017).

Though many religious groups in the United States provide disability programming and have affiliated organizations to address needs of individuals with disabilities (Glicksman, 2011), there does not seem to be a collective stance on inclusion and integration of congregants and community members with disabilities. Religion can shape belief systems and provide community through rituals, worship, and traditions. Examining literature about religion and its purpose for individuals with intellectual disabilities reveals two fields of thought: one relates to religion and spirituality as a method for stress and coping for parents of individuals with intellectual disabilities, and the other focuses on how to include people with disabilities in congregations and rituals (Glicksman, 2011). Both neglect the meaning of spirituality and religion for the individual with disabilities.

Glicksman (2011) suggested the lack of literature and focus on spirituality and religion for individuals with intellectual disabilities is due to the abstractness of concepts. For example, in Judaism there are concepts like eternity (there was always a G-d and will always be a G-d) and omnipresence (G-d is all around you). The biases and perspectives of disability obscure the route to understanding such complex concepts by religious leaders making assumptions that a person with an intellectual disability cannot understand. The religious framework is one that can guide decision-making, provide comfort in terrible times, and help make meaning. By denying individuals with intellectual disabilities the religious pathway to these supports, we are denying them a human right and widely accepted framework for understanding.

It is a tradition for Jewish people to uphold commandments, but for individuals with IDD, there are often exemptions, which directly impacts the esteem and the very personhood of that individual. Societal expectations and biases are often the limiting factor, not the legal rulings in Judaism. For example, in Israel, Orthodox children with mild impairments often get bar/bat mitzvahed, but for secular families, this is not traditional. Even further, in the Conservative Movement, laws in Israel permit children with disabilities to be called to the Torah (Vogel & Reiter, 2003). Jewish tradition and expectations can include involving individuals with disabilities, which expands the religious and spiritual community and creates opportunities for inclusion.

Religious Communities and Disability

Congregations aim to serve the needs of their community and people with disabilities and their families are both part of the congregation and the surrounding community. This section includes three of the most important studies that center on disability and community.

The focus of the first study was on community for families that have a child with disabilities, (Carter et al., 2017). This qualitative study included community conversations and addressed three research questions:

1. What are the emergent strategies when intentional dialogue occurs about expanding belonging and inclusion for people with disabilities?
2. How do community members view congregational commitment and support of participation of people with disabilities?
3. How do participants view community conversations?

Community conversations occurred over a two-hour period and included 175 participants from three faith communities who were split between two different community events. Participants included family members of a person with a disability (29.1%), disability service providers (18.3%), persons with a disability (9.7%), clergy members (9.1%), disability ministry volunteers (8.0%), religious educators (8.0%), other congregational staff (6.9%), faith-based community group member (5.7%), residential provider (1.7%), worship leader (1.7%), or a different role not mentioned (23.4%; e.g., students, advocates). The percentages total more than 100% because participants could select more than one role. Participants sat at tables of five to eight (and had an additional table facilitator) and had conversations split across three rounds of questions for the first hour. For example, in round one, participants discussed what can be done to include people with disabilities and their families in faith communities. After the first two rounds of questions, participants switched tables, but table facilitators stayed in the same spot. At the beginning of each round, the study staff announced the question to all participants. During each round, the table facilitators maintained their focus and took notes as participants were answering the question. After the three rounds, participants and researchers gathered for a whole group discussion in which participants were invited to share responses or correct the researchers' notes.

A total of 24 sets of notes were collected from the conversations, and the research team coded the notes and determined 23 categories of action and five overall themes (disability-specific efforts, internal activities, external activities, influences, and resources), and each category split into more specific themes. The most prevalent theme, encompassing 38.3% of coded material, was disability-specific efforts that included supports and actions that were designed for individuals with disabilities and their families. According to the participants, intentional supports met family needs or even enabled families to participate in the congregation.

In review of congregational life, participants described intentional efforts that would enact reflection and planning. Some of these efforts included a “needs assessment,” “physical inventory,” “accessibility audit,” or “church report card” (Carter et al., p. 586). Additionally, internal activities were means to create meaningful friendships and social interactions for individuals with disabilities and their families. Some participants emphasized the idea for people with disabilities to “serve and use their gifts” (Carter et al., p. 587), which translated into volunteer capacities within the congregation to assist in greeting, reading scripture, and engaging in mentorship and leadership opportunities. Some participants suggested creating individualized plans to determine the supports in religious experiences (e.g., Sunday school, confirmation). Families and individuals with disabilities used external agencies at an infrequent rate. Some participants suggested requesting information from agencies to assist with congregational training or offering physical space to invite these agencies in to connect with the community.

The outcomes of the study included findings related to emergent strategies when intentional dialogue occurs surrounding including and belonging for individuals with disabilities, community members’ views of congregational commitment to inclusion of individuals with disabilities, and participants’ views of community conversations. During the community conversation, participants shared nearly 1,000 strategies about expanding belonging and inclusion for people with disabilities. Disability-specific efforts emerged as the primary avenue for expanding belonging and inclusion. This included efforts by the congregation such as focused reflection and training regarding awareness. Additional recommendations included congregations supporting access to religious events and activities that spanned beyond the sanctuary and the classroom. These findings suggest that strategies to increase belonging and inclusion involve activities that are disability specific and expand beyond the physical places of worship. Thus, more research is needed to describe spaces beyond places of worship (e.g., homes) and the strategies individuals use to experience religious activities.

Community members had mixed views on congregational commitment and support of participation of people with disabilities. More than half of the participants noted current efforts of accessibility and awareness, yet far fewer felt commitment to youth and adults through congregational programming. The lack of commitment felt by community members mirrors the invisible forces of ableism, which is a core tenet of DisCrit (Annamma et al., 2013). Participants found the community conversations helpful and felt that their participation increased their commitment to inclusion efforts. Participants also expressed elevated views of their congregations and strategies that can be used to include individuals with disabilities.

One major limitation of this study was that each career conversation was held in a large church. Even though the facilities were selected for accessibility and geographical centrality, they were both churches and were not in religiously neutral spaces. An important follow-up study would include additional research on person-centered planning approaches within the congregational context to study more avenues to implement systemic change in the congregation. From the sample, it is not clear whether participants could be from the same household, congregation, or school and how that might impact the safety of sharing experiences. It is critical to control the power differential between clergy and congregation members or parent and child, so all parties have safety in sharing. Ignoring such concerns continues to perpetuate the exclusion of individuals with disabilities and their experiences in the narrative of disability and religion.

The second major study, (Griffin et al., 2012) sought to uncover more about religious communities for families with children with disabilities. The study addressed one research question: What are the characteristics that differentiate faith communities as being more or less inclusive of individuals with disabilities? Researchers conducted a quantitative study and developed a correlational research design. To recruit for this study, researchers sent out emails through local newsletters and flyers through community events. In this study, there were a total of 160 participants (91% White, 5% Black, 2% Asian Pacific Islander, and fewer than 1% other or unreported). The mean age was 43.72 years old, and 86% had completed college or higher level of education. Of the sample, 31% were leaders in their faith communities, and 69% were members. It's worth noting that 23 of the participants had disabilities, and 70 participants were family members of a person with disabilities. The disability type varied but were most often autism spectrum disorder, intellectual disability, depression or other psychiatric disabilities, Down syndrome, or learning disabilities. Religious affiliation was overwhelmingly Christian (*n* = 142). Other affiliations included Other (9), Judaism (6), Missing (2), or Buddhism (1). A survey was developed by the researchers, community members of faith, disability advocates, as well as families that had a member with a disability. The survey was called *Survey on Inclusion in Faith Communities* and was distributed through email and available in print. The survey consisted of 145 items, which included multiple-choice questions, ratings on a 4-point Likert-type scale, and open-ended questions. An example Likert-type question asked respondents to rate the importance of fully including people with disabilities in their congregations. Researchers conducted a factor analysis on 24 outcome items. As a result, three factors emerged as predictors for inclusive faith communities: 1) How welcoming the individual's faith community was to people with disabilities, 2) the roles people with disabilities played, and 3) physical accessibility.

There was a stronger feeling of inclusion by communities that had leaders more committed to disability inclusion. Another finding was that the more inclusive faith communities used education resources that specifically addressed disability-related issues. People in inclusive faith communities portrayed people with disabilities positively in teachings and had strong relationships with disability organizations.

Findings in this study include specific characteristics that differentiate faith communities as inclusive or not. Being welcoming and including people with disabilities, the top indicator of an inclusive faith community, alludes to the third tenet of DisCrit (race and ability are social constructs and the manifestations of labeling people with disabilities in turn others them). By actively welcoming people with disabilities, inclusive faith communities can challenge the material and psychological manifestations of being othered. Because this was a preliminary study, additional research is needed to confirm inclusive practices in faith communities. Additionally, the study included individuals with disabilities, but it was not clear that the study materials were accessible. For the correlational analysis, an exploratory factor analysis was conducted on the 24-outcome items to determine three factors. To improve and confirm these findings, a confirmatory factor analysis should be used on a more diverse sample to see if the factor structure still holds.

The third study (Ault et al., 2013) was designed to gather data from families of faith, specifically concerning congregational participation and supports for children with disabilities. The study sought to answer the following three research questions:

1. In what ways do families with sons or daughters with disabilities participate in their congregational communities?
2. In what ways do the sons or daughters with disabilities participate in these same

communities?

3. What factors do parents identify as affecting their participation—and the involvement of their sons or daughters with disabilities—in their congregation?" (Ault et al., p. 50).

In a mixed-methods study, the authors recruited participants through non-probability and snowball sampling. This was because no such list of parents of individuals with developmental disabilities existed. Researchers used a combination of listservs, flyers, and directly contacting agencies (i.e., TASH, state transition listserv) for recruitment. In total, there were 416 participants in the study. Of the 416 total respondents, 88.1% were mothers, fewer than 5% were Jewish, Mormon, or Buddhist, 89.5% were Christian, and no one identified as Muslim or Hindu. Additionally, 88.2% of the parents' children were under the age of 18, and the majority had autism spectrum disorder of moderate to severe intellectual disabilities.

Participants completed a 29-question paper or electronic survey that consisted of a combination of open- and close-ended questions. The close-ended questions (i.e., yes or no, Likert-type scale) ranged from frequency of participation in religious services or activities to accessibility of the congregation to perceptions of supportiveness of their congregation. The open-ended questions covered perceived contributors to and inhibitors of participation in the religious community. For example, "What, if anything has helped you or your child participate in a religious community?" (Ault et al., p. 53).

To analyze the data, researchers conducted descriptive and correlational statistics on the close-ended responses. The researchers also conducted cross-tabulations and chi-square tests to determine the association between selected variables (e.g., disability type, age, size of congregation, and degree of inclusion) associated with familial participation, type of inclusion experienced, and actions taken by both the families and the faith communities. Open-ended questions were coded using the constant-comparative method (Lincoln & Guba, 1985), but due to the depth of the findings, results were presented in a separate manuscript.

Findings related to the first research question included the following. Families with young adults with disabilities participate in their communities mostly in religious services (96.1% frequency) and education programs (56.0% frequency). These findings were the same in response to the second research question, which sought to answer children's involvement in religious activities. This means both parents and children participated in religious services and education programs with the highest frequency. Additionally, the findings concerning the third research question included factors affecting their (and their child's) involvement in their congregation. Parents reported that the most accessible aspect of their faith communities were the accessible facilities themselves (89.3% frequency) and congregational welcoming attitudes toward individuals with disabilities (81.8% frequency). A total of 81 respondents provided both programs and supports they thought would be helpful toward participation in faith communities. Ault et al., (2013) shared that the result of neglecting such supports and programs have led to nearly one third of parents reporting that they changed their place of worship due to lack of inclusion. More than one half of the parents had never been asked about ways to include their child in religious activities. Parents have suggestions for inclusion in faith communities when given the opportunity to share. For counselor educators, it is important to consider the experiences of these families in religious communities and how this may impact religious and spiritual identity development.

Though this study has multiple findings involving familial inclusion in faith communities, additional research concerning the experiences of the individuals with disabilities is warranted to further these findings. Additionally, a major limitation is that the study itself was hegemonic with the dominant religion in participant demographics being Christianity. Another limitation in this study was through the analysis of using chi-square tests. The researchers collapsed different categories to ensure a greater cell size, but by doing so, some inequalities were created. For example, age was split into three categories: young children under five years of age, school age children and youth ages six to 18, and adults ages 19 and over. These age categories are broad, particularly the adult range, and might exhibit different results if the ages were categorized differently (i.e., splitting adult into young adult, adult, and elderly). Thus, more research and analysis are necessary to expand research to other religious communities regarding disability.

In this section, I reviewed three studies that included community experiences that can support and inhibit families with children with disabilities (Carter et al., 2017), accessibility (both physical and inclusiveness) for individuals with disabilities in places of worship (Griffin et al., 2012), and general involvement for families with a child with disabilities in faith communities (Ault et al., 2013). These studies are general in terms of religious community and were overwhelmingly with majority Christian communities; therefore, a more nuanced review of literature is provided in the next section.

Jewish Community and Disability

One way that Jewish communities differ from other religious communities is in terms of Jewish education. For instance, Uhrman (2017) conducted a qualitative study specific to the Jewish community surrounding education of Jewish children. The key research question of this study was “What are parents’ experiences and perceptions of the broader Jewish community vis-a-vis their child with a disability?” (Uhrman, 2017, p. 6). Uhrman used purposeful sampling and recruited participants from New York City and immediate surrounding areas. Families included in the study had a child with high incidence disabilities enrolled in a Jewish day school or enrolled within the last three years. This included participants that identified as Orthodox (5), Orthodox Conservative (4), Conservative (10), and Reform (1). A total of 20 interviews was conducted over the 2010–2011 school year. Sixteen of the interviews were conducted with mothers alone, two were with fathers alone, and two interviews were with both parents. Two-thirds of the children with disabilities were male, and the majority was 8 to 12 years old, with two teens and four preschoolers. At the time of the study, seven were enrolled in a Jewish day school, and 13 had left the Jewish day school. The methodology for this study included semi-structured, open-ended interviews. Data was analyzed using a coding system and theme development. Data was also analyzed using analytic memoing for emergent ideas.

Findings from the study varied, but some themes were common across all families. For instance, for all 20 families, commitment to the Jewish faith and community was a key reason for seeking out Jewish day school. Families noted the mutual benefits of their child attending a warm and welcoming school all while the parents connected to the larger network and school families. A challenge that was apparent for all parents was the difficulty in obtaining and coordinating services and teams for their child. Parents talked about how difficult it was to navigate the Department of Education yet how necessary this was, particularly in a Jewish day school setting where parents have to dedicate even more time and energy and cost to receive benefits.

There were two key findings related to the research question on parental experiences and perception of the broader Jewish community. First, inclusion and exclusion were consistently brought up. Inclusion and exclusion were emphasized more frequently for the families who removed their child from Jewish day school. These parents expressed feelings of marginalization and isolation. For these parents, exclusive experiences impacted the connection to the broader Jewish community. “With little to no help in facilitating these families’ engagement, parents generally felt at a loss and struggled to determine the nature of their families’ Jewish lives as a result.” (Uhrman, 2017, p.17). This transpired to an impression of a lack of support when families felt opportunities to participate in the Jewish community were limited and hard to navigate.

Second, parents shared that disability was not centrally on the Jewish communal agenda, and efforts did not always address the issues. Parents attributed this to general lack of awareness rather than purposeful and hateful intent. Parents not only felt like outsiders within the Jewish community but also noted how unwelcome they felt and how unaccepting they found community members to be. This harbored feelings for parents that resulted in embarrassment of their child having a disability. Most parents felt closest to other parents who had a child with disabilities, Jewish or not.

In this study, Uhrman explored parental experiences and how these experiences informed perceptions of the broader Jewish community. These findings have important implications for counselor educators regarding how disability is perceived in faith communities. Because this research was conducted with parents, additional research is needed to explore experiences from individuals with disabilities.

A significant limitation of this study was with participant selection. The narrow focus of explicitly Jewish day school experience leaves out an entire population of Jews who did not enroll their children in Jewish day school. Jewish day school is just one way that Jews can engage with community, culture, and religion; thus, it is important to expand beyond the Jewish day school experience. Another limitation was in the sampling process of recruiting solely from the New York City and New Jersey area. This is geographically the largest Jewish community concentration in the United States (Sheshkin & Dashefsky, 2021), and to corroborate findings, this study would benefit from being conducted in less Jewish-centric areas. Jewish community can create a sense of belonging through education and youth organizations, reinforcing the individual and collective connection between Judaism (Bunning & Steel, 2007). In the next section, I will relay how individual and collective religious and spiritual identity impact families.

Religion and Spirituality for a Family with a Child with a Disability

In recent years, there has been an increasing amount of literature on religion and spirituality for families with a child with disabilities (Boehm et al., 2015; Carter 2013; and Carter & Boehm, 2019). Family quality of life (*FQOL*) is defined as when family members have their needs met, enjoy their lives together, and can do things that are of importance to them (Poston & Turnbull, 2004). Because a major contributor to individual quality of life (QOL) is spirituality (Poston & Turnbull, 2004), this study was designed to discover the relationship between religion, spirituality, and disability. Poston and Turnbull (2004) conducted a qualitative study to answer the following research questions:

1. What role do spiritual or religious beliefs and practices play in family quality of life?
2. How can community organizations contribute to the enhancement of families' spiritual well-being? (Poston & Turnbull, p. 97).

Researchers used a variety of sampling methods (i.e., convenience, intensity, purposive, and maximum variation) to recruit participants. Researchers conducted individual interviews and focus groups. Researchers conducted 31 individual interviews with parents (*n* = 18), service providers (*n* = 10), and siblings (*n* = 3). Researchers conducted semi-structured interviews in the focus groups. There were two rounds of questions (each session lasting 1.5 hours, and the second round occurred 4 months after the first round), and the 107 participants were split into focus groups of six to 12 people. The focus group questions ranged in topics surrounding FQOL. For example, parents were asked to share what came to mind when they heard the words “family quality of life.” Parents were also asked to talk about a time when “things have gone really well” in their families and share “what helps things go well” (Poston and Turnbull, 2004, p. 99).

To analyze the data, researchers used the constant comparative method. Researchers created categories and codes and developed themes. The results indicated two major findings related to the two research questions. In response to the first research question about the role of spiritual and religious beliefs in FQOL, faith helped participants make sense of life. Participants shared that spirituality and faith gave them strength, and particularly for families with a child with disabilities, spirituality helped them make meaning of the disability. This result corroborated prior studies and literature regarding spiritual development and the impact it has on FQOL (Poston & Turnbull, 2004). The findings from the second research question were polarized. Some participants felt their religious community was accepting and a place of unconditional love. Other participants felt their child was not accepted and that they did not have support to participate.

Findings from the study by Poston and Turnbull (2004) indicate that families are looking for acceptance, spiritual and emotional support, and support for their child during religious services. When families feel supported in these three ways, they feel accepted and included. Inclusion led to families participating more in their religious institutions, which is a contributor to FQOL. Findings from this study have important implications for my study. Religious communities can serve families with disabilities, but it seems there is a lack of understanding of how to support families. My research can contribute to understanding how to support individuals and their families as they engage in religious rituals and practices. There is potential for counselor educators to work with religious institutions and to translate knowledge about supports and needs of families. Families gravitate toward religious institutions for support and information (Poston & Turnbull, 2004). Counselor educators have potential to disseminate resources to religious institutions regarding local agencies (i.e., vocational rehabilitation) or groups (i.e., autism society, Down syndrome association).

A major limitation in this study was the researchers' theoretical framework. Poston & Turnbull (2004) suggested families set aside time for religious and spiritual practices. This included seeking out childcare, so they can engage in religious practices "rather than caring for children and all the other tasks that usually overwhelm them" (Poston & Turnbull, p. 102). The assumption in this statement is that the individual with disabilities is not to participate in the religious ritual because it would be too distracting for the family. The other assumption is that the individual with disabilities cannot experience the benefits of the religious or spiritual ritual because they have a disability. The researchers upheld ideas of normalcy and did not privilege voices of individuals with disabilities in their research. To challenge the "structural power of ableism" (Annamma et al., 2013, p. 7) more research needs to be done through the theoretical framework of DisCrit. Another limitation in this study was the participants selected. The participants included parents from families with a child with disabilities. This is extremely limiting because it does not include caregivers, siblings, or the individual with disabilities. These perspectives are essential to understanding spirituality and religion because these family members may have different experiences altogether. Further research is required to determine how spirituality and religion are experienced by families with children with disabilities.

Another study regarding FQOL for families with a child with disabilities was conducted by Boehm et al. (2015). This study explored transition age youth (young adults 14 to 16 years of age) with disabilities (Lambert et al., in press). The researchers addressed two research questions in their study: 1) How do parents or caregivers describe FQOL? 2) What child and family factors predict family quality of life during the transition period? (Boehm et al., p. 397). An exhaustive list of Tennessee organizations posted blurbs in their newsletters and emails to recruit participants for this study. The sample included 425 parents that had a child between the ages of 13 and 21 years who had an intellectual disability or autism. Demographics included 82.5% White, 13.5% African American, 1.7% Hispanic or Latino, and 1.9% multiple races. Households were 68.2% married couples, and 38.1% of these families were eligible for reduced-price meals. Additionally, 42.8% of parents indicated their child had autism, 12.2% indicated both autism and an intellectual disability, and 6.8% indicated an “other” disability or did not answer. Notably, 68.7% of the youth and young adults were male.

Researchers developed a 15-page packet that used quantitative measures to assess FQOL, child factors, support needs, and religion and faith. FQOL was assessed using the Beach Center Family Quality of Life Scale (Beach Center Family Quality of Life Scale, 2005), which included 25 Likert-type questions with a scale of 1 to 5. Child factors were assessed by using demographic information, gaining information about communication for the child, and degree of challenging behaviors that occurred outside of the home. The support needs measure was an adapted measure that broke down into seven categories the support needed to function. Some of these categories included participating in activities, health and safety, and advocacy. Another scale that was used was from the Santa Clara Strength of Religious Faith Questionnaire-Short

Form (Plante et al., 2002). Family members responded on a scale of 1 to 4 to statements about prayer, faith, decision making, purpose, and meaning making.

In response to the first question, the following are the findings related to what parents said about FQOL. Parents were overall satisfied with their FQOL (*M* = 3.99, *SD* = .63), were most satisfied with their physical/material well-being (*M* = 4.29, *SD* = .68), and overall had the lowest scores in emotional well-being (*M* = 3.41, *SD* = .97). To answer the second research question, researchers ran a multiple regression analysis to determine which factors predicted FQOL. Researchers found the strongest positive association with FQOL was the strength of religious faith, meaning that strength of religious faith can predict FQOL. The strongest negative association with FQOL were challenging behaviors and greater support needs. The findings from this study have implications for the purpose of my study. Transition age youth is often a salient identity potentially related to FQOL, yet little research has been done with this population (Carter, 2013). My intended research will include transition age youth. This will add to the literature and understanding of families with a transition age youth with disabilities.

A limitation of the study is the use of the Beach Center Family Quality of Life Scale to assess FQOL for the entire family. This scale is a reduced scale that has five domains: “Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Supports” (Boehm et al., 2015, p. 399). The scale is intended for parents to assess their families, and areas such as self-determination and independence are not included in any of these five domains (Beach Center on Disability, 2015). Similarly, one parent was the only family member from the family unit to be studied for each family. This data excludes all other family members, which neglects perspectives, particularly family members with disabilities.

A study by Carter and Boehm (2019) was conducted to explore religious and spiritual experiences for youth with IDD. The researchers examined five research questions:

1. How involved are youth with IDD in congregational activities?
2. What spiritual practices do youth with IDD engage in at home and elsewhere?
3. Who tends to initiate these congregational activities and spiritual practices?
4. How do parents perceive the religious faith of their daughters and sons with IDD?
5. To what extent do the spiritual and religious lives of youth with IDD vary based on child and parent factors? (p. 38).

Families were recruited through invitations that were distributed by 151 disability and faith-based organizations in Tennessee. Participants included 440 parents of youth with IDD that averaged 16.4 years old. Participants shared their child's primary form of communication. In total, 83.9% of youth communicated through speech, 10.7% used gestures/body language/facial expressions, 2.0% had communication devices, 1.8% used vocalization; .9% used manual signs or sign language, .5% used a communication board, and .2% used other methods. Information was collected from packets that included questions such as congregational activities, spiritual practices, strength of religious faith, and child factors. Participants were asked to rate their child's involvement (never, daily, weekly, monthly, yearly, or unsure) in 17 congregational activities. Participants were asked to report on the involvement (never, daily, weekly, monthly, yearly, or unsure) of their child in 26 home rituals/practices (e.g., abiding by dietary laws, praying prior to or in conclusion of mealtime). Parents also completed two versions of the Santa Clara Strength of Religious Faith Questionnaire-Short Form (Plante et al., 2002). One version was for themselves, and the other was for their child. In each form, parents rated five items on a 4-point, Likert-type scale (1 = *strongly disagree* and 4 = *strongly agree*). Data on child factors were collected through various participant information questions regarding support needs, age, functional skills, and communication mode.

Researchers used descriptive statistics to analyze data involving congregational activities, descriptions of who initiates involvement in activities, and perceptions of level of religious strength. Researchers used correlation coefficients to analyze the association between variables. Researchers then conducted a linear multiple regression analysis to parse the factors associated with the three dependent variables (i.e., congregational activities, spiritual practices, youth's strength of religious faith).

Involvement in congregational activities (first research question) included participation (i.e., daily/weekly, monthly, or yearly) in worship services (85.5%), Sunday school (63.0%), or social gatherings (58.7%). Parents mostly initiated involvement (third research question) in social gatherings, leading passages in religious services, local outreach participation, or attending worship services. Youth were most likely to initiate serving as an usher (38.5%), being in youth group (37.8%), and being in the choir (37.2%). The most common engagement in spiritual practices (second research question) included religious holiday traditions in the home, praying before or after meals, listening to religious music, and praying at home with family. Strength in religious faith (fourth research question) included ratings of parents' perceptions of faith. The majority of parents reported that their child enjoyed being around other people of similar faith (72.3%) and considered themselves to be active in the faith congregation (60.6%). Findings associated with religious and spiritual expressions varied based on child and parent factors (fifth research question). Three independent variables correlated with lowered ratings of strength of youth's religious faith. These independent variables were higher support needs, being labeled as autistic, and lower ratings of parent's religious faith.

Factors that impact religious practices are important to my study. In the study by Carter and Boehm (2019), it was apparent that religious and spiritual lives of youth with IDD are dynamic. Most of the youth participated in congregational activities and participated in spiritual practices at home regularly (i.e., daily or weekly). Access to religious experiences (both at home and in the congregation) emerged as an issue for youth with autism. Youths with autism were reported to have lower ratings of strength of religious faith. Other characteristics (e.g., functional skills, communication method, challenging behaviors) impacted participation in religious practices. The combination of the findings provides support for research involving experiences of rituals and practices.

Limitations in this study included that reporting of experiences relied solely on the report of the parents/guardians. Parental and guardian reports restricted the input of the intended focus population and may have misrepresented actual experiences of their young adults. The study was also exploratory and can be confirmed through a confirmatory factor analysis with a sample of youth with disabilities to verify whether the factor structure holds true for individuals with disabilities and not just their parents. Also, the dimensions of spiritual and religious life that were measured included 17 congregational activities, 26 spiritual practices, a short form of the Santa Clara Strength of Religious Faith Questionnaire (Plante et al., 2002) to measure the strength of religious faith, and several child factors. In these categories, not all aspects of religious and spiritual life were addressed in this study for youth (e.g., cooking traditional meals, attending religious camp, observing rituals surrounding birth and death, meeting with elders, or speaking traditional language used in familial religion/culture) narrowing the scope of data collection and possibly leaving out important contributors.

Overall, the results from studies surrounding FQOL by Poston & Turnbull (2004) and Boehm et al. (2015) indicate that faith not only helps parents of a child with disabilities make sense of life but also leads to a stronger FQOL. Moreover, Carter and Boehm (2019) found that families with a child with disabilities are engaged in religious congregations and religious practices (both in the community and at home). In this section, I delineate the familial experiences involving religion and spirituality for families with a child with disabilities. It is noticeable that the youth with disabilities were not part of any study. In the next section, I counter the narrative that is told about people with disabilities without input from people with disabilities, and I emphasize the youth experiences.

Youth With Disabilities

Researchers have studied the transition from childhood to adulthood and found individuals with IDD are exposed to elevated challenges (Forte et al., 2011), making research that involves QOL important to understanding how to support youth during transition times.

Biggs and Carter (2016) conducted a quantitative study to determine QOL factors for youth with varying levels of IDD. Researchers sought to answer three research questions:

1. How do parents interpret quality of life for their youth with disabilities?
2. Do these ratings differ between a normative sample?
3. What factors predict quality of life for transition-age youth with disabilities?

Participants were recruited through 151 networks, groups, and organizations across the state of Tennessee. The networks, groups, and organizations posted fliers and sent out newsletters to recruit participants. Once participants contacted the research team to participate in the study, the research team sent packets through the mail for participants to complete. The participants included 389 parents and caregivers with a child between the ages of 13 and 21.

The packets that participants completed consisted of different measures. The KINDERSCREEN-27 (The KIDSCREEN Group Europe, 2006) is an instrument based on the KIDSCREEN and has 27 questions across five domains (whereas the KIDSCREEN has 52 items over 10 domains). The five domains in the instrument included Physical Well-Being, Psychological Well-Being, Autonomy and Parent Relations, Peers and Social Support, and School Environment. Participants answered the 27 questions using a 5-point, Likert-type scale to report frequency (1 = *never* to 5 = *always*) and intensity levels (1 = *not at all* to 5 = *extremely*). An example of a *Physical Well-Being* question from the study is "Has your child felt that life was enjoyable?" (Biggs and Carter, 2016, p. 195). The packet that participants completed included predictor variables (e.g., race, eligibility to receive free or reduced lunch, and age) and disability-related characteristics (e.g., disability type, communication mode, and support needs). Data on the strength of religious faith was collected through the Santa Clara Strength of Religious Faith Questionnaire-Short Form (Plante et al., 2002). Parents rated five statements on a 4-point, Likert-type scale (1 = *strongly disagree* to 4 = *strongly agree*). An example statement is "My child's faith impacts many of his/her decisions" (Biggs and Carter, 2016, p. 196). Data on self-determination was collected through the American Institutes for Research Self-Determination scale (Wolman et al., 1944). This instrument included six items, which participants rated on a 5-point Likert-type scale (1 = *never* and 5 = *always*). Lastly, data on strengths was collected through the Assessment Scale for Positive Character Traits-Developmental Disabilities (Woodward, 2009). This instrument included 26 items, and parents rated 10 domains (i.e., humor, kindness, resilience) on a 5-point Likert-type scale (1 = *not at all* *characteristic* to 5 = *extremely characteristic*). Researchers used descriptive statistics to analyze data from parents involving the QOL of their children. Next, the researchers compared two subsamples (individuals with intellectual disabilities and individuals with autism) to a normative sample. Researchers used independent sample *t*-tests to compare scores. The researchers conducted Pearson correlation coefficients to determine the association between predictor and dependent variables.

Research question findings related to how parents interpret QOL (first research question) varied across QOL domains. The domain of Autonomy and Parent Relations was rated the highest by parents (M = 50.2, SD = 10.0); whereas, Social Support and Peers was rated the lowest (M = 37.4, SD = 15.2). Individual items were rated the lowest in the domain of Social Support and Peers. For example, 37.8% of parents reported that their child *never* or *rarely* spent time with their friends in the past week. For the second research question, results emerged regarding QOL differences from a normative sample. There was statistical significance for three of the five domains (i.e., Physical Well-Being, Psychological Well-Being, Social Support and Peers). Findings for the third research question indicated that there are strong negative associations with QOL for multiple domains (i.e., more challenging behavior, having autism, higher support needs). There are two significant findings related to the purpose of my study. First, parents of children with autism and IDD rated QOL lower than a normative sample in multiple domains (i.e., Physical Well-Being, Psychological Well-Being, and Peer and Social Supports). This perception is from the perspective of parents and does not include the input of their children with disabilities. Though researchers cited many works that have studied QOL for individuals with disabilities, cited works did not include studies from the perspective of the children with disabilities. Second, the strength of religious faith predicted two QOL domains:

Social Support and Peers and Autonomy and Parent Relations. This finding adds to the limited research that addresses faith and spirituality for individuals with IDD, though more research in this area needs to be done.

Despite research surrounding families with a child with disabilities and religion and spirituality, the youth themselves are not typically the central focus (Ault et al., 2013; Boehm et al., 2015; Boehm & Carter, 2019; Carter et al., 2017; Carter & Boehm, 2019; Nurullah, 2013; Poston & Turnbull 2004; Uhrman, 2017). One study that shed light on the youth experience is by Liu et al. (2014). The two research questions were 1) “What is the place and prominence of faith in the lives of youth and young adults with developmental disabilities?” and 2) “How do these youth view their disability within the context of their faith?” (Liu et al., 2014, p. 389). The study was qualitative and consisted of 20 participants (six female and 14 male). Participants were recruited from a larger sample of 450 parents from Tennessee who had a child with IDD from ages 13 to 21. The study included in-person and semi-structured interviews. Interviews were conducted over a 6-month period and averaged 23 minutes in length. The interviews included questions such as “Do you pray? What is it like when you pray? Does G-d answer?” (Liu et al., p. 391). Researchers transcribed the interviews and coded the transcripts. Initial codes were developed prior to the interviews based on the research questions. Codes were then added as team members read through transcripts and shared findings.

Participants in the study illustrated the place and prominence of faith (first research question) through stories of religious and spiritual expressions and activities. Participants shared stories about the expression of faith, the importance of faith, and their identity (which included having a disability) in the context of faith. One religious experience that participants talked about was personal prayer. For the participants, prayer often took place before meals, to give thanks, or to give blessings. Some participants shared how G-d answered their prayers. For example, "A few years ago, during basketball camp, I was praying previously, I was starting to doubt that He existed. So, I prayed for Him to show me that He did exist." (Liu et al., p. 393). Beyond prayer, faith was also expressed by beliefs and behaviors for many of the participants such as reading scripture and living life to fulfill the Ten Commandments. For many participants, this meant congregational activities like services, camps, retreats, youth fellowships, and Sunday school.

Though less mentioned, five participants emphasized "rites of passage." This included ritual events that transitioned individuals to another status. For some, this meant baptism: "I wanted to accept the Lord. So, I wanted to get baptized." (Liu et al., p. 394). For others, this meant communion: "One of my favorite things about doing communion with my church friends is where I can get to break the bread and we make homemade grape juice." (Liu et al., p. 394).

Another expression of faith was through "social connections." In fact, 11 participants mentioned this context and developed these relationships through organized programming or by being a part of the congregation. It is worth noting, however, that some church friends did not feel as close as actual friends: "I do have a few friends, they're not ... I don't think we're as close to my actual friends, but they're very nice, they're kind. I do sometimes wish that they paid more attention to me, I guess." (Liu et al., p. 394).

Findings from the second research question emerged as participants talked about their journey through their own faith and how important it was to them. Four participants talked about the influence of their family's faith on their own participation. In areas where faith was beneficial to participants, subthemes emerged as 15 youth shared how faith was meaningful for them. These included individuals feeling a sense of belonging, friendship, healing (related to illness, not disability), help, and protection. A final theme was faith and spirituality impacted participants' "views of self." Eight participants shared how G-d knew them because he understood and met their needs. One participant explained that her teacher understood her autism and the understanding was an act of G-d. Another participant explained that G-d was aware of his mistakes and accepted him; for example, "Man, you know, that's just Ethan. He does these things." (Liu et al., p. 397). Participants viewed their disability as something that was accepted by G-d and by G-d's design, and that it was part of their purpose; however, two participants viewed their disability as something that they prayed would be healed.

Findings from Liu et al. (2014) are relevant to my study because participants with IDD recounted their religious and spiritual experiences. The purpose of my research is to centralize voices and experiences of youth with IDD. Centralizing marginalized populations is a core tenet of DisCrit (Annamma et al., 2013). Additional research through a DisCrit theoretical lens is needed to advance notions of identity for youth with IDD. The second tenet of DisCrit is that identity is multidimensional, and researchers need to challenge identity being viewed as singular (Annamma et al., 2013). Thus, more research is needed that explores intersecting and multidimensional identities.

Jewish Youth with Disabilities

Having discussed research involving religion and spirituality for youth with disabilities, I now turn to specifically looking at research surrounding religion and spirituality for Jewish youth. One such study was conducted by Lifshitz et al. (2009). The researchers set two goals for their research: 1) Investigate adolescents and adults with IDD and their ability to fulfill Jewish commandments, and 2) investigate the motives for fulfilling Jewish commandments. Participants were recruited from special education schools and vocational workshops. The study consisted of 89 individuals, 35 adults (*M* = 49) and 54 adolescents (*M* = 19.27) with IDD. Mixed methods were used to collect data. Researchers adapted a questionnaire by Levi et al. (1994) that examined beliefs and fulfillment of Jewish commandments. Participants used a 3-point Likert-type scale (1 = *never*, 2 = *sometimes*, 3 = *always*) to answer the 14 questions in the questionnaire. Participants were interviewed using focused interviews with open-ended questions. Questions asked about feelings and motives toward religious behaviors.

To analyze the results from the questionnaire, researchers conducted a factors analysis. Results indicated that four factors (i.e., supervised commandments, autonomous and unsupervised commandments, observing fast days, observing dietary laws) explained 50% of the variance. In the quantitative analysis, the researchers conducted a 2x2 Analysis of Variance (ANOVA) to see if there were differences between adolescents and adults and the behavioral factors according to their religiosity. Results indicated a significant main effect for age, $F(4,82) = 3.25$ and $p < .05$, and level of religiosity, $F(4,82) = 19.14$ and $p < .000$. In a univariate analysis for age, there were significant differences between both age groups for all factors besides autonomous factors. For adolescents, there were significantly higher means for fulfilling supervised commandments like fasting days and dietary laws. To analyze the focused interviews, researchers conducted a content analysis. Researchers coded sentences and phrases and created central categories and subdivisions.

Findings from the first research question indicated differences among adolescents with IDD and adults with IDD in their ability to fulfill commandments. Researchers found that adolescents fulfilled Jewish commandments at a higher rate than adults. Findings from the second research question yielded results about individuals with IDD and their motives to fulfill Jewish commandments. Researchers found that there are similarities between the general population and individuals with IDD in their ability to fulfill Jewish commandments. In fact, the motivational reasons were also similar for both the general population and for the individuals in the study. Key findings, from the second research question, relate to my study purpose. Rather than assuming all Jewish individuals can uphold commandments, researchers studied *if* people with disabilities were *able* to uphold Jewish commandments. My research is intended to be a form of activism by assuming all individuals with IDD who are Jewish can be religious and spiritual. Findings from my research can contribute to the counselor education field. By using DisCrit I am actively describing religious and spiritual experience and challenging the practice of proving "if" people with disabilities "can" be religious. Religious and spiritual experiences for people with IDD can then be incorporated into counselor education in terms of how counselor educators think about religion and spirituality for people with disabilities and therefore how counselor educators translate this to counselors in training.

Hyman (2009) described the bar mitzvah journey for a child with autism, his family, and the community around him. The purpose of the article was to describe the steps in preparing for the bar mitzvah. Participants included Leon (pseudonym), a 13-year-old boy; his family; and the congregation. The conceptual article by Hyman (2009) followed a quasi-case study structure and included a detailed list of experiences (i.e., Jewish day school education in non-segregated classes, reads Hebrew) and support needs (i.e., sitting and attending, extinguishing under the pants behavior). The article also included supports that built on years of participating in family rituals and practices at home (e.g., memorizing Hebrew readings based on Disney credits). Strategies were implemented to prepare Leon for the bar mitzvah. To become accustomed to stimuli and sensations, Leon wore the Kippah (a sacred cap worn on the head) and Tallis (a prayer shawl worn around the neck and shoulders) regularly. The bar mitzvah ceremony took place during the Monday morning service because it required less sitting, and the service was shorter. Other strategies included a customized and accessible prayer book (which included pictures and larger text) and a timeline in the prayer book (to prepare for proceeding events). An accommodation that was made during the ceremony was that the rabbi announced to the congregation that they can only sing to themselves and not out loud when Leon was leading prayer.

Hyman (2009) recounted the different support needs and strategies put in place for Leon. The strategies made the bar mitzvah accessible for Leon. Successful strategies for inclusive religious rituals and practices have implications for my study. A limitation of this conceptual piece is that it was not empirical. Research regarding strategies for participating in rituals and practices has potential to impact how the counselor educators support individuals with disabilities. With research, evidence-based practices can be shared with students with disabilities and with their families.

Within Judaism exists a vibrant culture that is celebrated through various rituals and celebrations. These religious practices in Judaism are experienced on different levels and serve different meanings depending on that individual's spiritual and religious development. Participating in rituals, such as attending Jewish religious school, celebrates the universality that other Jewish youth experience, creates a forum for belonging, and prioritizes cultural experiences. These experiences, however, exist not only in the community and with community members but also within the home and with family members.

Family Systems Theory

As noted above, theory is a framework for viewing the world. Just as theory can help give researchers context, theory can also limit people to this context. In Family Systems Theory (FST)

(Bowen, 1976), human behavior is defined according to relationships (Kerr et a., 1988), and these relationships are similar to the relationships that occur naturally in the world (Metcalf, 2011). Applying a DisCrit lens to FST, it's important to critically analyze the idea of systems. As mentioned earlier, systems have been used to limit individuals with disabilities politically, socially, and in education. When thinking of the family in terms of systems, it restricts individuals to their roles and their functions in the family. Furthermore, FST is a deficit model that is rooted in eradicating emotional distress, which is believed to be the result of familial systems (Metcalf, 2011). In a systematic literature review on parental stress of having a child with disabilities, Dervishaliaj (2013) found empirical articles about the psychological well-being of parents and how it is strongly impacted by the primary diagnosis of disability, behaviors as a source of stress, and the demands of care. Other research from this review has involved formal and informal support and how lack of support can predict stress by parents. Considering this as emotional distress and as a dysfunctional family pathologizes families that have children with disabilities. Instead, research can be enhanced by researchers taking a strengths-based focus and researching how to best support families and their well-being.

Spiritual Wellness

Wellness is composed of five domains: mind, body, spirit, emotion, and connection (Ohrt et al., 2018). Wellness is an umbrella term that includes social, psychological, and biological aspects, and when these domains align, the harmony that is felt is called well-being (Miller & Foster, 2010). Well-being is personal and collective, which in a family means how well-being is experienced varies.

As mentioned when defining wellness, one major component (and even the original center of the Wheel of Wellness; Whitmer et al., 1998) is spiritual wellness. One study of importance regarding spirituality for individuals with disabilities was by Carter et al. (2015). The researchers conducted a mixed methods study to answer the following five questions:

1. To what extent do adults with IDD participate in religious services or spiritual practices?
2. What individual and contextual factors are associated with variations in this participation?
3. Who accompanies these adults to religious services and how does this compare with other community activities?
4. How does this avenue for community involvement compare to participation in other community activities?
5. Are individuals who attend religious services more likely to engage in other community activities than those who do not attend religious services? (p. 382).

Data came from a secondary data analysis of the interviews from the Adult Consumer Survey (ACS) from the National Core Indicators between the years 2012 and 2013. This sample included individuals with IDD who were 18 years old or older and received at least one service and case management. In total, 12,706 adults across the United States met the criteria. Carter et al. requested data for religious service attendance, health and wellness, and relationships, totaling 181 variables. The ACS included structured, face-to-face interviews with participants. Participants' records were used to gather background information (i.e., demographics, health status, employment data). Notably, just over half (57.1%) of the questions were answered directly by the individual with disabilities.

Religious involvement included questions about participation in religious or spiritual practices (e.g., did you go to a religious service or spiritual practice in the last month?). Descriptive statistics were used to summarize findings related to religious frequency and contextual factors. Data analysis involved a chi-square test of independence to determine which factors were related to attending religious activities once a month. Then, categories that were mutually exclusive were compared to each other.

In terms of the first research question (the extent to which adults with IDD participate in religious/spiritual practices), 48.3% of participants attended either a religious service or spiritual practice at least one time in the past month. Out of those who had attended, 12.6% had an attendance rate of once to twice a month and 34.6% attended three or more times. Variations in attendance (second research question) were associated with multiple factors. For instance, there was a relation in attendance according to gender, x2 (1, $N = 11{,}768$) = 19.05, $p < .001$; race, x2 (4, $N = 11{,}670$) = 14.42, $p < .001$; and age, x2 (3, $N = 11{,}670$) = 14.42, $p < .002$). Religious participation was associated with reported level of disability, x2 (3, $N = 9{,}976$) = 132.24, $p < .001$). The highest level of association was found for individuals with moderate IDD (52.7%). In terms of the third research question, the majority of adults with IDD attended religious activities with friends or family (60.8%). Compared to other community events (fourth research question), adults with IDD were more likely to attend religious activities with friends or family than other activities (i.e., shopping, exercising, going out to eat). Finally, results from the fifth research question indicate that individuals who participated in religious activities also participated in community activities (e.g., shopping, going out to eat, exercising) at a much higher rate.

When looking specifically at the factors associated with religious or spiritual attendance, individuals who used communication devices for their preferred communication mode were less likely to attend religious services. Access to religious institutions is a barrier that counselor educators need to be aware of when connecting individuals to religious and spiritual communities. In terms of wellness activities, adults with IDD were more likely to participate in exercise than religious activities. It is not clear if this finding is due to the availability of religious activities or possibly lowered expectations of community members in ability to engage in religious activities for adults with IDD. Thus, more research is needed to determine inclusive practices for individuals with IDD in religious communities.

The approach to research in wellness for individuals with IDD has been deficit based and focused on negative experiences with wellness. Additionally, research has been centered on parents rather than a whole family systems approach. Even fewer research studies are done with Jewish families and Jewish youth with disabilities regarding wellness.

Taub & Werner (2016) conducted a quantitative study and addressed FQOL through a cultural perspective. The researchers had two purposes for the study: 1) examine FQOL according to religiosity and 2) examine how resources contribute to FQOL. Participants were recruited in collaboration with 17 school principals of schools that had children in special education classes. The participants included 170 Jewish parents with a child with developmental disabilities. The average age for the child with IDD was 7.0 years old. The sample consisted of 52 secular Jews, 19 traditional Jews, 35 religious Jews, and 64 ultra-Orthodox Jews.

Researchers created a survey using the Family Quality of Life Survey (Brown et al., 2006), Multidimensional Scale of Perceived Social Support (Zimet et al., 1988), and the Spiritual Support Scale (Ai et al., 2005). An example question from the questionnaire was “How important are your personal/spiritual/cultural values on your family's quality of life?" (p. 351). The questionnaire took 15–20 minutes for participants to complete. For most of the data analysis, participants were divided into two groups (i.e., secular and religious). Researchers used independent *t*-tests to examine the differences in FQOL between the two groups. Researchers also used Pearson correlations to examine correlations between different domains of FQOL. Lastly, researchers used linear regression models to examine which resources predicted FQOL.

The first purpose of the study was to examine FQOL according to religiosity. Findings indicate that religious families reported higher overall satisfaction with FQOL across all domains than secular families. The second purpose of the study was to examine resources that contribute to FQOL. Findings indicate that three resources positively correlated with FQOL: family relations, social supports, and values.

One finding that is related to the purpose of my study is the importance of family for families with a child with IDD. For both religious and secular Jews, the immediate family was viewed as important. For religious families, spirituality was a guiding factor in having a child with disabilities. Spirituality helped families fulfill their purpose in life and strengthened social networks. Families shared that spirituality helped to relieve the stress of raising a child with disabilities. A limitation of the study by Taub and Werner (2016) is that the researchers' purpose for the study focused on FQOL of raising a child with disabilities. The researchers approached the study from a deficit perspective and proposed this study because "raising a child with disability frequently generates stress and anxiety among all members of the family" (p. 348). Thus, categorizing children with disabilities as "other" (see Tenant 3 of DisCrit; Annamma et al., 2013) and as a contributor to stress rather than a contributor to FQOL. More research is needed that is centralized on the experiences of people with disabilities and the impact of religious experiences on the entire family (including the individual with disabilities).

Collectively, the findings from the studies in this section contribute to the overall understanding of wellness in families, and Jewish families, with a child with disabilities. Though research in this area has been done, the research is largely based on assessing whether individuals can be religious and spiritual and what the level of awareness and understanding is surrounding religion and spirituality. More specifically, individuals engage with religion and spirituality through rituals and practices, and in the next section, I review research about how individuals with disabilities engage in these rituals and practices.

Religious and Spiritual Rituals and Practices for Individuals with Disabilities

There are fewer studies about religious and spiritual rituals and practices for families with a child with disabilities, but some researchers have stated that families experience religious rituals and engage in deep traditions (Hyman, 2009) and that prayer is a part routine and a way to communicate to G-d for these families (Poston & Turnbull, 2004).

Turner et al. (2004) conducted a qualitative study with the primary aim of interviewing individuals with IDD. Researchers inquired about religious experiences to gain an in-depth understanding of experiences and interests surrounding religion. Turner et al. used secondary data from a larger project with adults with intellectual disabilities. Participants included 29 adults (*n* = 16 women, and *n* = 13 men) from various religious backgrounds (i.e., Islam, Hindu dharma, Christian denominations). The study consisted of semi-structured interviews around religious topics (i.e., prayer, description of faith, social life and faith agency). Interviews lasted between 10 minutes and 1 hour. Researchers used thematic analysis to analyze the data. Four themes were developed: faith and understanding, religious practice, faith agencies, and service responses to religion.

Findings from the *religious practice* theme are of particular significance to the purpose of my study. The ritual of prayer was consistent across 22 of the 29 participants. Festivals appeared in every religion as a ritual. Multiple Muslim participants spoke of Eid and the different practices involved in celebrating and observing Eid (such as fasting, wearing different clothes, and having relatives over). A major limitation of the study was that the researchers tried to determine *if* individuals with intellectual disabilities can be religious. By focusing on *if* people with disabilities can be religious, people with disabilities are reduced and “othered” (which is a result of the construct of ability, Annamma et al., 2013). Additional research is needed through a DisCrit theoretical lens to explore religious experiences for people with disabilities, rather than prove if they can be religious.

Sango and Forrester-Jones (2018) conducted a mixed-methods study on religion and spirituality for individuals with IDD. The research question for the study was: “To what extent does the opportunity to exercise religion and spirituality mediate the social lives of individuals with IDD?” (p. 275). Purposeful sampling was used to recruit participants from two residential centers (one faith-based, the other non-faith-based). There was a total of 40 participants with IDD from the United Kingdom in the study. The researchers used a combination of participant observations (which occurred over a 6-month period with multiple observation points) and interviews. The interviews included the questions from three instruments: the Adaptive Behavior Scale (ABS) short form (Hatton et al., 2001), the Social Network Guide (SNG) (Forrester-Jones et al., 2004), and the Spiritual Belief Inventory-15R (SBI-15R; Holland et al., 1998). The ABS was conducted with the participant and a caregiver. Participants answered questions according to three factor scales (e.g., personal self-sufficiency, community self-sufficiency, and personal social responsibility). In the SNG, the participants shared contacts for 10 different areas of life. The SBI-15R measured social support and other mediating variables for coping. Participants rated their responses with smiley faces (which was adapted from "*strongly agree*" to "*strongly disagree*").

Quantitative data analysis included a descriptive analysis and a non-parametric Man Whitney U test. The researchers also used a Spearman Rho correlation to determine whether there was a relationship between the SBI-15R and the SNG data. Qualitative analysis included a thematic analysis of the data. The researchers developed codes and categorized codes into themes.

Findings from the study have implications on the ability of religion and spirituality to mediate social lives of individuals with IDD. The key finding was that participants in the study had a smaller social network size compared to the general population. Participants in the study spoke about gathering with friends and family during holidays and community gatherings. Key findings about beliefs and practices have implications for my study purpose. Participants expressed that prayer serves a purpose for many reasons. Some reasons included prayer to help individuals connect spiritually to deceased parents, make new social networks, help loved ones, and provide comfort. The reasons that the participants listed have implications for the benefits of religious and spiritual practices. A limitation of the Sango and Forrester-Jones (2018) study was that it was done with individuals in group homes. Though this research is important and serves a population of individuals with disabilities, more research is needed in different home contexts for individuals with disabilities.

In this section, I presented two studies that contribute to the knowledge about individuals with IDD and how they experience religious rituals and practices. Religious and spiritual practices and rituals are unique, and a needed area of exploration is within Judaism.

Religious and Spiritual Rituals and Practices for Jewish Individuals with Disabilities

For a Jewish family, when their child reaches bar/bat mitzvah age, this is a celebration and a milestone. The bar/bat mitzvah is often called "the right of passage" (Vogel & Reiter, 2003). It is usually commemorated by a celebration in which the congregation, family, and friends celebrate the entry into the Jewish faith as an adult. It is a lengthy buildup of Jewish education, celebration of holidays, and Jewish experiences that culminate with the entrance to upholding Jewish expectations now independently from familial mandate. When becoming a bar/bat mitzvah is not an expectation, there are serious implications on faith development, familial efficacy, and congregational inclusion (Glicksman, 2011).

Because the ritual of the bar/bat mitzvah is a large milestone in the Jewish faith, there have been many studies on this experience. Fewer studies have been done, however, with Jewish youth with disabilities. Vogel & Reiter (2004) conducted a qualitative study with the purpose to explore the significance of the bar/bat mitzvah for the parents of Jewish children with IDD. Purposeful sampling was used to select participants. The 29 participants were selected from two of the 17 schools that participated in the bar/bat mitzvah program (during 1999–2000). Participants were parents of Jewish children with IDD. The researchers used semi-structured interviewing as the primary data collection method. There were two interviews, one prior to the bar/bat mitzvah process and another one 2 months after the bar/bat mitzvah. Each interview lasted between 3 and 4 hours. The researchers also conducted an observation at the ceremony itself and analyzed artifacts (e.g., photo albums or written letters). To analyze the data, the researchers conducted a content analysis and coded the data. Coding categories were generated by reading transcripts and comparing categories.

Findings related to the purpose of the study included six dimensions of perceived significance for the parents. These dimensions included the bar/bat mitzvah as normative, religious, transitional, and an experience that led to a sense of connectedness, enhancement of self-image, and a peak of life experience. In the interviews with parents after the bar/bat mitzvah, parents talked about their child identifying better with their older siblings and how their child became more self-aware.

The finding of most significance to my study was that parents reported that their children felt a sense of belonging and connectedness from the bar/bat mitzvah experience. Parents spoke about the connection to family, both physically (by families joining together to celebrate their child) and ancestrally (by using family heirlooms during the ceremony), and how this connection resulted in feelings of belonging. Participating in the major life cycle event of a bar/bat mitzvah had implications for the connection to the Jewish community as well. Feelings of connectedness, belonging, and Jewish community reached from the individual level (the child with IDD) to the familial level, and even further to the larger Jewish community. As counselor educators navigate resources and services that are available for families with a child with disabilities, engaging in religious and spiritual rituals and practices can have serious implications. Limitations of the Vogel and Reiter (2004) study include the structure of the interviews; they were 3–4 hours long and did not include the youth with disabilities. Additionally, significance of the bar/bat mitzvah experience came from the parental perspective and not the youth with disabilities. Thus, there is a gap in understanding of rituals and practices and how they are experienced by youth with disabilities. The research on these Jewish rituals and practices is vast, but the research with individuals with IDD and their lived experiences with Jewish rituals and practices is nearly non-existent.

Conclusion

In this chapter, I reviewed the history of disabilities in the United States and defined disability and theory. I reviewed the relevant literature about religion and spirituality for families, communities, and youth with disabilities. In summary, the principal issue throughout the research studies I reviewed was that the research is not being conducted with the individuals with disabilities on their lived experiences. This appeared in research involving religion and spirituality for families with a child with disabilities, the youth and Jewish youth, wellness of people with disabilities, and religion and spirituality and people with disabilities. There are two studies about the experiences of the bar/bat mitzvah; however, the intersection of home and Jewish rituals and practices is not commonly researched. Thus, by conducting research including the lived experiences from youth with disabilities themselves as they experience rituals and practices in the home, I seek to expand the understanding of home rituals and practices for Jewish youth.

Chapter Three: Methodology

Overview

This chapter describes the methodology for the present study and connects how this methodology helped answer the selected research question. This includes the purpose, research question, research design, ethical considerations, and limitations. Lived experiences of religion and spirituality for youth with IDD have historically been told through parental perspectives (i.e., Ault 2010, 2013; Carter, 2017; Nurullah, 2013; Norlin & Broberg, 2013; Poston & Turnbull, 2004) with limited research directly from the perspective of the individual with disabilities (i.e., Carter et al., 2015; Sango & Forrester-Jones, 2018; Turner et al., 2004) and young adults with disabilities (Carter & Boehm, 2019; Liu et al., 2014), and even less research from the perspectives of Jewish young adults with disabilities (Lifshitz et al., 2009). The purpose of this multiple-case study was to describe the phenomenon collectively with the participants (i.e., how Jewish youth with IDD experience Jewish rituals/practices in the home). Education about individuals with disabilities in counselor education programs is often absent (Rivas & Hill, 2018) and mainly limited to multicultural counseling courses (Rivas, 2020). A keyword search of "disability" in the Counseling and Values Journal (the journal for the American Counseling Association division the Association for Spiritual, Ethical, and Religious Values in Counseling), yielded zero articles. The findings from this study can educate counselor educators on lived experiences of religion and spirituality for young adults with disabilities, further preparing counselors to work with this high-needs population. The findings from this study can then be incorporated into courses surrounding wellness counseling and supervision, so that education about individuals with disabilities is no longer limited to multicultural counseling courses. Findings from this study also are relevant to religious clergy and religious leaders because they play a large role in inclusive practices (Annandale & Carter, 2014). Though research exists about inclusive strategies (Carter et al., 2017), more findings from this study can corroborate and build on practices specific to Judaism.

DisCrit and Methodology

DisCrit was the theory that shaped my conceptual framework for this dissertation. In my conceptual framework, DisCrit was the bridge between society and the individual. I used DisCrit throughout my methodology. I used the seven tenets of DisCrit (Annamma et al., 2013) to delineate the connection between my methodology and DisCrit, shown in Table 1.

Table 1: DisCrit Connection to Methodology

DisCrit Tenet	Methodology Connection to DisCrit
Tenet 1: Normalcy is upheld by the forces of racism and ableism, and their forces are often invisible.	By selecting a non-medical definition of IDD and a definition that includes environmental and cultural differences, I am opposing the invisible forces of normalcy.
Tenet 2: Identity is multidimensional, and DisCrit theorists challenge singular notions of identity.	The research question is centered on lived experiences of a marginalized population of intersectional identities (i.e., youth, identifying as having an IDD, and being Jewish). This research question aligns with identity being considered multidimensional.
Tenet 3: Even though race and ability are social constructs, there are both material and psychological manifestations of being labeled, and it others people outside of Western norms.	In my observation protocol, I made a decision to be a passive observer instead of a participant-observer. This is because I am aware of my privilege and power being both white and able-bodied and how these social

	constructs can manifest in material and psychological ways, othering the participants.
Tenet 4: Marginalized populations are centralized in research.	In my procedures, I stated inclusive practices to create opportunities for voices and experiences of individuals with IDD to be heard. This included using semi-structured interviews, so I could interact and engage with the participants and had flexibility to shape the research around the direction they took. I constructed my questions based on my review of literature, but by doing my research with my participants, the participants were centralized, and I gathered the participants' experiences.
	I followed this reasoning to justify modifying my existing interview questions for the second interview based on the video observation. In my procedures, I also included plain language and accessible interview questions and emphasized that I will be asking the participant the questions rather than the family member. This conscious effort

	to address that participant yet again centralized the participants.
	I used member checking. By using this strategy, I centralized the marginalized population in my data explication and asked for correction, verification, and input on my findings.
Tenet 5: Rights of citizens have been denied through historical and legal constructs due to race and ability.	When determining my study participants, I selected a definition of IDD that counters the medical definitions of IDD, which have been used to deny rights of individuals with IDD.
Tenet 6: Whiteness and ability are recognized as assets and the advances for people with disabilities are a result of interest from White, middle-class citizens	In my positionality description, I acknowledged being a White, able-bodied researcher who perpetuates the advancements for people with disabilities.
Tenet 7: Activism and resistance are required and encouraged.	By conducting this research, I actively worked with my participants to create space for voices often excluded from research, which is a form of resistance.

As noted in this section, DisCrit was the theory that informed the development of my methodology and was, therefore, pervasive in each step of the research.

Research Question

This study seeks to answer the following descriptive phenomenological question:

What are the lived experiences of Jewish youth with intellectual and developmental disabilities as they participate in Jewish rituals/practices in the home?

Methodology

The method used for this study is multiple-case study. Case studies are a data collection method that allow researchers to carefully document experiences and stories of participants (Hays & Singh, 2012) and have been used across qualitative paradigms. In this qualitative approach, the intent is to describe a phenomenon by exploring a bounded system through detailed and in-depth data collection (Creswell et al., 2007).

Case study research involves multiple sources of data that provide information on the case (Creswell et al., 2007) where the researcher describes a phenomenon through boundaries of time and space (Prosek & Gibson, 2021). In the present research study, the case was bound in multiple ways, meaning the design for this case study was a multiple-case study. The case was bound by the age because the sample will be youth. It was also bound by specific disability of the individual identifying as having an intellectual or developmental disability. The case was also bound by the context of the family dynamic itself. The case itself had multiple bound systems and operated within the same context of the home. The interaction of these bound systems contributed to the phenomena of youth with IDD and their religious rituals and practices in the home. Because the elements of the case were analyzed as the interaction of these parts, this multiple-case study is embedded (DePoy & Gitlin, 2016).

In this section, I described the methodology I used for my study. This methodology fits my research for multiple reasons. The multiple-case study is a direct route to describing the scope and depth (Yin, 2003) for which the phenomenon resides (Prosek & Gibson, 2021) and to explore "how" and "why" questions (Baxter & Jack, 2008). Additionally, this methodology afforded the opportunity to give space to unheard voices that have been excluded from research. By providing different points and approaches to data collection, multiple-case studies have space for various ways to express how the rituals and practices are experienced.

Researcher Positionality

As an individual who identifies as Jewish (religiously, culturally, and spiritually), Jewish practices and beliefs had an impact on how I interacted with this study. My identity is significantly shaped from my own religious involvement in temple, the centrality Judaism had and has in my familial rearing, and my own exploration of rituals and practices as I incorporate Jewish life into my marriage as a reform Jew. My ablebodiedness not only influenced these Jewish experiences but also is the lens through which I see the world. My biases of disability and how they are experienced cannot be overlooked. In my Jewish education and experiences, the history of Judaism has been separated from the history of disability. Though through the review of literature, I sought out ways to develop the interaction of both Jewish and disability histories, I continuously and consciously worked on merging these histories in my own conceptualization of their shared development.

My professional career was shaped by my secondary education in special education, rehabilitation counseling, and counselor education and supervision. All degrees were void of disability studies/critical race theory. It wasn't until I began working in the field that I re-adjusted my understanding and approach to supporting individuals with significant disabilities. My work became person-centered and strengths-based, and I advocated for familial inclusion in support plans. However, I make a conscious effort every time I work with a client on how I can address the inaccessible systems put in place to bar people with disabilities from consistent access and full participation. I also recognize that my identity as White and able-bodied perpetuates the reality that my interest in disability encourages the advances of people with disabilities and these are both identities of power.

Procedures

In the present research study, I highlighted the lived experiences of Jewish youth with IDD. By focusing on how rituals and practices are experienced, the phenomenon emerged (Peoples, 2021).

Study Participants

Selecting participants a priori allowed the most opportunities to learn about the phenomenon (Hays & Singh, 2012). Research participants were recruited through purposeful sampling after obtaining IRB approval from the university. Initially, I reached out to two identified sites in Richmond, Virginia that served Jewish youth with IDD. Staff at both sites were unable to connect me to potential participants. Because of the difficulty in recruiting participants, I submitted an IRB amendment to expand recruitment criteria to temples, synagogues, Jewish organizations, and disability organizations in Virginia. Next, I sent out recruitment emails to 16 identified sites and still was unable to identify participants. After sending the second reminder email to identified sites, I submitted another amendment to expand to Maryland, Massachusetts, Michigan, New Jersey, New York, Ohio, and Washington D.C. I identified and sent recruitment emails to an additional 44 sites. Two participants were eligible and met the following inclusion criteria: a) youth from 15 to 24 years old who identifies as having an IDD; identifies as Jewish (culturally, spiritually, or religiously); and lived in Maryland, Massachusetts, Michigan, New Jersey, New York, Ohio, Virginia, or Washington D.C. Purposeful sampling allowed for the selection of participants who shared unique characteristics and represented a limited pool of candidates to elucidate the phenomenon of interest (Palinkas et al., 2015).

To focus the data collection and study on youth, participants fell within the age range of 15 to 24 years. Youth is a challenging age range to define because it marks the transition from childhood to adulthood. The United Nations defines youth for statistical purposes as 15 to 24 years and recognizes that this varies all over the world (United Nations, 2013). This age range also fits with the definition of IDD I used for this study. The definition of IDD I used for this study came from the American Association on Intellectual and Developmental Disabilities (AAIDD, 2022). AIDD defined IDD as "a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior" (AAIDD, 2022) that originates prior to age 22. Intellectual functioning includes learning and reasoning skills, and adaptive behaviors are social and practical skills. In conjunction with this definition, the AAIDD website also has ways that people "can" measure intellectual and adaptive functioning but encourages additional considerations such as environment, cultural differences, and the co-occurrence of strengths with limitations, which are neglected in medical definitions of IDD. The selected participants for this study also identified as Jewish. Because Judaism is very diverse, this can include Jews by choice, religious Jews, spiritual Jews, or cultural Jews. This population was selected to gather how rituals/practices are experienced for Jewish youth with IDD.

Data Collection

Data was collected upon instructional review board (IRB) approval from Virginia Commonwealth University (VCU). Data was collected via demographic survey, interview, and observation. In multiple-case study methodology, it is suggested to collect data from multiple sources (Halkias, 2022; Yin, 2018). Because my participants ranged in communication needs, providing multiple opportunities to share information was critical. Therefore, in this research study, I collected data through a demographic survey (Appendix A), two interviews (Appendix D and E), and an observation.

The demographic survey, collected prior to the interviews and observation, included questions about age, disability status, whether they identified as Jewish, and if there was anything else they wanted to share with me. Then, I conducted a semi-structured interview with the primary participants and the family member of their choosing. Semi-structured interviews permit spontaneity (Peoples, 2020) and are recommended to fully capture the interviewee's experience (Hays & Singh, 2012). Because not every interview question has to be asked, there is flexibility for adding interview questions or modifying questions. I asked the interview questions to the participant and not to the selected family member. This was an important part of the research and ties it back to DisCrit and a core tenet that marginalized populations are central in research (Annamma, 2013). If there was need for clarification or support from the family member, that was when they had the opportunity to confirm responses, reword questions, or assist in communicating accessibility needs.

Because this case study occurred in the real world, I created an opportunity for observation (Yin, 2018) that occurred in the home of the primary participant. The primary participant selected a Jewish ritual or practice for me to observe. I developed an observation protocol to guide the procedures of the observation (i.e., how long to observe and what to do in the observation) and collected data through the video observation and the memoing I did during and after the observation. This type of memoing occurred with data analysis and was a way to summarize preliminary findings (Hays & Singh, 2012).

By conducting a direct observation in the home, I created the opportunity to observe in a real-world setting (Yin, 2018). The purpose of the observation was to collect data on lived experiences as they are occurring. I conducted a formal observation where I used a specific protocol that I developed so that I could collect data "during specific periods of time in the field" (Yin, 2018, p. 121–122). I was a passive observer and set up a video camera to record the ritual/practice.

An alternative to being a passive observer is being a participant-observer. The participant-observer engages with the participants and the ritual/practice in accordance with the protocol developed. Major challenges in the participant-observer role include potential biases by supporting the participants being observed and being focused on a specific event and ignoring other experiences (Yin, 2018). I also feel as a researcher participating, I would add a power dynamic to the ritual/practice that could potentially threaten the entire case study. Though, by adding any type of observation, I do introduce bias to the ritual/practice, the major drawbacks of participant-observer made being a passive observer a better fit for this study.

After the observation, there was a follow-up, semi-structured interview with the primary participants and the family member they selected. I modified and edited existing interview questions according to findings from my data analysis of the video observation. Data analysis and collection occurred simultaneously and informed the other. Additionally, modifying questions based on the data analysis of the video content provided the opportunity for triangulation and member checking. Each interview lasted up to 1 hour, which allowed for the interviews to remain open-ended but follow protocol more closely (Yin, 2018).

As the primary student investigator, I collected the data for the present research study. Collecting data included getting informed consent and assent, interviewing the participants, and recording the ritual/practice of each participant's choosing. The initial interview, observation, and second interview were recorded through Zoom and transcribed through Rev.com (IRB approved). I listened and watched the recording to make sure the transcript matched verbatim what the participants said. I uploaded all data (i.e., interview transcripts, observation video and audio) into ATLAS.ti, a data analysis software (IRB approval). Using a database for all data records helped to ensure the chain of evidence.

As mentioned above, collecting multiple sources of data is an essential part of multiple-case studies. Additionally, providing different ways for the participants to communicate and interact with the research was a medium for inclusive research practice.

Sampling Method

For this study, I described two cases which allowed for thick description (Prosek & Gibson, 2021) and replication (Yin, 2018). Purposive recruitment occurred through contacting temples, synagogues, disability organizations, self-advocacy organizations, and Jewish disability organizations. Connecting to these community organizations broadened the recruitment pool to Jews from diverse Jewish backgrounds and from various Jewish community programs. Once I identified eligible participants, I held the consent and assent meetings with the participants.

Trustworthiness

In my study, I used a combination of strategies to establish trustworthiness. These strategies included purposeful sampling, member checking, thick description of experiences, memoing, and triangulation of data methods. In the subsequent paragraphs in this section, I will describe how each of these strategies helped me achieve trustworthiness in this study.

Data was collected and then stored using a computer-assisted qualitative data analysis software (CAQDAS) called ATLAS.ti (IRB approved). This helped to create a distinction between the case study and the data collected, which increased reliability of the case study (Yin, 2018). Using a CAQDAS helps to formulate a chain of evidence so that a reader is able to follow the research study, which helps with overall construct validity (Yin, 2018).

Participants may have been aware of their experiences but not of the expertise in verifying these experiences (Giorgi, 2008), underscoring why mindful practices around member checking were important. Regarding youth with IDD, an accessible way to provide member checking is through sharing findings and asking for feedback. After I collected and analyzed the data, I invited the participants to clarify or contribute any additional information (Baxter & Jack, 2008). I then generated a plain language general findings one-pager and disseminated it to participants after the data analysis.

Using purposeful sampling strategies was important in case study methodology so that I could select participants who fit the multiple ways in which the case is bound (Baxter & Jack, 2008). Throughout the data collection and analysis process, I engaged in strategies like journaling about pre-understandings, expectations, biases, and positionality (O'Hara & Cook, 2018). This encouraged confirmability, which means the results showcase the participants instead of the researchers (Prosek & Gibson, 2021).

Another strategy for trustworthiness was an extended exposure to the phenomena (Baxter & Jack, 2008). This prolonged relationship was established through the three data collection points (two interviews and the observation) and member checking. In this study, I used multiple sources of data methods (e.g., the interviews and the observation), this meant there were multiple lines of inquiry, and when these lines converge, triangulation occurs. Triangulation strengthens construct validity because I used multiple sources of evidence to corroborate the same phenomenon (Yin, 2018).

Explication

The purpose of this multiple-case study was descriptive because I gathered information on the multiple ways in which the system was bound to describe the phenomena of how the bound system informs experiences. To do this, I gathered data from multiple sources and analyzed the data together as a whole, and these data together contributed to my understanding of the phenomena (Baxter & Jack, 2008). My aim in this research study was descriptive and the epistemological orientation was constructivist because I described the phenomenon collectively with the participants (Hyett et al., 2014).

During data collection, I memoed what I observed, my experiences, reactions, and initial interpretations. These data were part of the analysis and were used to contribute to the description. The data analysis included reading through transcribed interviews, watching videos of the observation, identifying meaning units (Peoples, 2020), and coding these meaning units (the meaning units contributed to the construction of themes and concepts). I used the same coding process for coding transcripts and coding video. I started at the beginning of the video and highlighted clips as meaning units emerged. For example, I saw Leye's smile widen as she threw her hands up in the air, and that action emerged as a meaning unit and later on contributed to the subtheme construction of Making a Spiritual Connection During Lived Experiences. I developed predetermined codes based on the literature review (Hays & Singh, 2012) and built on these categories from the data I collected, as shown in Table 2.

Table 2: Predetermined Codes

Predetermined Codes	Meaning	Definition
Pre_Inaccessible_Space+ Place	"Welcoming congregants with disabilities is not enough (Haythorn, 2003). Support can be felt in physical spaces of worship, in education, and through resources within religious institutions (Haythorn, 2003)."	Spaces and events are not created intentionally to be accessible for individuals and families with varying disabilities.
Pre_Inaccessible_Lack of Commitment	Community members had mixed views on congregational commitment and support of participation of people with disabilities (Carter et al., 2017). Parents shared that disability was not centrally on the Jewish communal agenda, and efforts did not always address the issues (Uhrman, 2017).	Apparent lack of commitment from religious institutions result in lack of involvement from families.

Pre_Inaccessible_ResultsIn LowR&S	Access to religious experiences (both at home and in the congregation) emerged as an issue for youth with autism. Youths with autism were reported to have lower ratings of strength of religious faith. Other characteristics (e.g., functional skills, communication method, challenging behaviors) impacted participation in religious practices (Carter & Boehm, 2019).	Lack of access results in lowered participation in religious and spiritual practices.
Pre_Inaccessible_Spiritual Wellness	In terms of wellness activities, adults with IDD were more likely to participate in exercise than religious activities (Carter et al., 2015). It is not clear if this finding is due to the availability of religious activities or possibly lowered expectations of community members in ability to engage in religious activities for adults with IDD. The approach to	Lowered expectations and lower availability of activities have a negative impact on experiences with rituals and practices.

	research in wellness for individuals with IDD has been deficit based and focused on negative experiences with wellness.	
Pre_Accessible_Space+Place	Being welcoming and including people with disabilities, the top indicator of an inclusive faith community, alludes to the third tenet of DisCrit (race and ability are social constructs and the manifestations of labeling people with disabilities in turn others them). By actively welcoming people with disabilities, inclusive faith communities can challenge the material and psychological manifestations of being othered. The most accessible aspect of their faith communities were the accessible facilities themselves (89.3% frequency congregational welcoming attitudes toward	When spaces and places are accessible for individuals with disabilities, they are inclusive.

	individuals with disabilities (81.8% frequency) (Ault et al., 2013).	
Pre_Intersection_Dis+ Judaism	For people with and without disabilities, religion is one of the many ways people make sense of the world (Imhoff, 2017). A critical lens has scarcely been taken to the intersection of religion and disability (Imhoff, 2017).	When disability and Judaism intersect. This intersection is what helps meaning making for the individual.
Pre_IncreasedFQOL_R&S	Researchers found the strongest positive association with FQOL was the strength of religious faith, meaning that strength of religious faith can predict FQOL (Boehm et al., 2015).	FQOL is positively associated with religious faith.
Pre_Home Practices	The most common engagement in spiritual practices (second research question) included religious holiday traditions in the home, praying before or after meals, listening to religious music, and	Most common ways to express faith and experience faith is in the home.

	praying at home with family (Carter & Boehm, 2019).	
Pre_Activities&Expressions_ R&S	One religious experience that participants talked about was personal prayer. For the participants, prayer often took place before meals, to give thanks, or to give blessings (Liu, 2014).”Rites of passage” included ritual events that transitioned individuals to another status (Liu, 2014). Another expression of faith was through “social connections.” (Liu, 2014). The finding of most significance to my study was that parents reported that their children felt a sense of belonging and connectedness from the bar/bat mitzvah experience (Vogel & Reiter, 2004).	Activities (like rights of passage) and expressions (like prayer) lead to sense of belonging and stronger R&S for the individual.
Pre_JewishAdolescents_ HigherR&S	Researchers found that adolescents fulfilled Jewish commandments at	More Jewish activities and expressions as an

	a higher rate than adults (Lifshitz et al., 2009)	adolescent/young adult than as an adult.

I stored these codes in Microsoft Excel™ and used this spreadsheet as the platform for the codebook. The process of building on predetermined codes made the data analysis an iterative process and one that was done with my participants, which was imperative to centralizing the voices of individuals with disabilities (Annamma, 2013). I organized these themes and subthemes in a Microsoft Excel spreadsheet and used this as the platform for my codebook.

The general strategy I used for further analysis was relying on theoretical propositions (Yin, 2018) because these theoretical propositions guided the creation of this case study, research question, and review of literature (Yin, 2018). The following are the propositions that I developed based on the literature and theory review from Chapter 2.

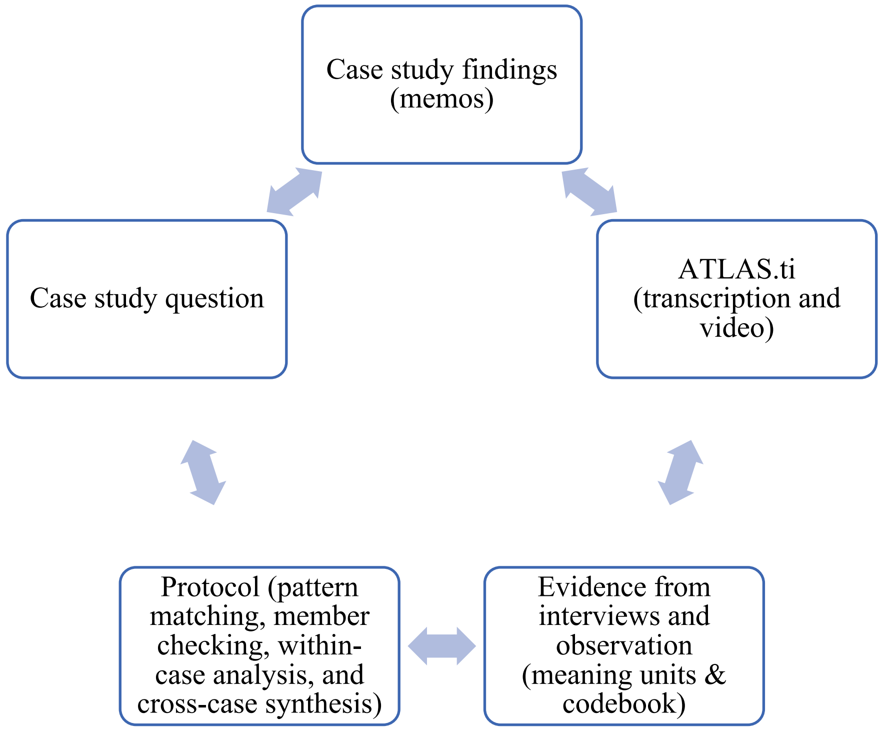
1. This case study will show how Jewish youth with IDD experience rituals and practices in the home, which will highlight the importance of family and Judaism on the identity development of these youth.
2. The case study will also show how the very experience of these rituals and practices influences the connection to Judaism, family, and the community, which influences the overall wellness of these youth.

These propositions represented key issues from the literature review and ultimately led to the research design.

The nature of multiple-case study analysis evolved through the analysis itself (Yin, 2018). However, I used a combination of two techniques. The first was pattern matching for processes and outcomes. This analysis technique involved comparing my proposition to the data collected (Yin, 2018). The second technique I used was cross-case synthesis. The goal of the cross-case synthesis was to develop conclusions about the cases rather than focusing on the individual variables (Yin, 2018). Prior to the cross-case synthesis, I analyzed the within-case results which included the "how" and "why" each participant experienced the phenomena (Yin, 2018). Once I analyzed the individual cases, I analyzed the holistic cases together to understand the real-world experiences (Yin, 2018). I added an additional step of member checking to the data analysis to align with DisCrit and constructivism. To do research with my participants rather than about them, I needed to provide space for alternative explanations and revisions. To do this, I shared my understanding of the propositions and initial themes in the second interview and asked for feedback, alternative explanations, and revisions. My participants helped me to identify alternative explanations of their lived experiences. This helped corroborate the general description from the analysis.

The chain of evidence for the present study included case study findings, including memos from the interviews and observations; ATLAS.ti, which includes the transcripts, evidence from the interviews, meaning units, and codebook; the protocol including the two analysis techniques (pattern matching and cross-case synthesis); then case study questions. This process is depicted in Figure 1.

Figure 1: Chain of Evidence



Note. This figure demonstrates the chain of evidence for this dissertation. The bidirectional arrows indicate that the chain of evidence can be followed in either direction, which indicates the connection between each part of the case study (Yin, 2018).

Ethical Considerations

To ensure participant safety, ethical consideration must be prioritized. This starts at the beginning of the study with participant recruitment. The language in all recruitment materials were approved by the IRB to ensure that participants were not coerced into participating. Because participants were being recruited from Jewish community organizations, the feeling of coercion to participate could negatively impact further participation in these community organizations. Therefore, it was crucial to use a recruitment email that explained the study in plain language so that primary participants and parents/guardians can access the information.

To make sure consent and assent were properly gathered, the assent document was customized to offer visual prompts and verbal cues. Assent is a critical component of the study because the primary participants are the youth with IDD from whom assent is being collected. There were also opportunities for participants to drop out of the study before both interviews and after the observation.

To further ensure participant protection, data was collected and then stored on Google Drive, which was only accessible to the primary investigator on the IRB and the student investigator on the IRB. The information was de-identified after participants were selected for the study. Additionally, the interviews were be recorded through Zoom and then deleted after the study. Because there was an observation, it was clarified to the primary participant and the parent/guardian that the observation was solely to observe how the primary participant interacts with the activity and peers. Peers, organization staff, and family members of peers were not included in data collection, unless they gave consent.

Monetary incentives were not used in this study, again, to protect participants from coercion to participate in the study. Youth with IDD have poorer postsecondary education outcomes than peers without disabilities (Aron & Loprest, 2012) and offering payment could lead to participating out of need versus want, further coercing participation.

Findings from this study were shared with primary participants. These findings were de-identified and in plain language to make the information accessible.

Limitations

A limitation of this study is that, as a researcher, I worked with a vulnerable population that I am not a member of. Though I am Jewish, I am not a member of the disability community. To account for this, I used multiple data methods, such as interviews and observations. I also used a plain language one-pager to perform member checking with the participants. An additional limitation was that the lived experiences recorded in this research were unique to the participants and not transferable. Even though individuals may have the same disability, how they experience their disability and the world around them is unique to their lived experiences. This is an important ethical consideration (Giorgi, 2008) and will be addressed in Chapter 5 by avoiding generalizing individual cases. Though I cannot generalize individual narratives and individual lived experiences, I can generalize propositions (Yin, 2018).

Conclusion

In Chapter 3, I restated the purpose of my study along with my research question, research design, ethical considerations, and limitations. This multiple-case study will be used to answer the research question addressing the lived experiences of Jewish youth with IDD.

Chapter Four: Findings

Overview

The purpose of the present research study was to explore the lived experiences of Jewish youth with IDD as they engage in Jewish rituals and practices in the home. There is a dearth of research from the perspective of youth with IDD themselves, let alone the lived experiences of Jewish youth with IDD. The research question I sought to answer in this study was: What are the lived experiences of Jewish youth with IDD as they participate in Jewish rituals/practices in the home? In Chapter 4, I include the results of the case study analysis. I define the themes and subthemes, and I summarize the findings.

Participant Overview

The multiple-case study consisted of two participants, Rachel and Leye (pseudonyms). Both participants met the inclusion criteria outlined in Chapter 3. I made special considerations regarding data collection for each participant as they both had different communication preferences. For example, Rachel preferred to be contacted using multiple methods (i.e., phone call, text message, email, and Google Calendar invitation); Leye preferred when I texted her, but she preferred to call me. The following section includes a description of the two participants.

Rachel

Rachel is White, 21 years old, identifies with the non-binary pronouns they/them, and lives in Maryland. Rachel was diagnosed with autism spectrum disorder at 20 years old. Rachel grew up with their older brother, mom, and dad. Rachel identified with growing up in the "conservative Jewish movement" and still considers I to be conservative. Rachel and their family attended temple together regularly, decorated their home for different Jewish holidays, and attended Jewish overnight family camp. When Rachel was in high school, they observed Shabbat by refraining from technology use. Rachel also wore a kippah for nearly 3 years of high school. Rachel was an active member in United Synagogue Youth (USY).

Rachel graduated from high school and then attended a private college in a major US city. Rachel shared that they considered college to be home for the last few years. Rachel graduated from college in spring of 2022. At the time of the interview, Rachel lived with their partner and two friends in a house. The house was near public transportation because Rachel did not drive. Rachel's partner is currently undergoing the conversion process to become Jewish. Rachel often educates their partner on Jewish rituals, practices, and beliefs.

Leye

Leye is 22 years old, White, female, lives in Ohio, and has Down syndrome. Leye grew up with her older sister, mom, and dad. Leye attended a reform temple while growing up and, at the time of the interview, still attends the same temple. At the time of the interview, Leye lived at home with her older sister, her mom, and her dad. At home, Leye and her family bake challah every Thursday evening so that it is ready for Shabbat on Friday.

Leye graduated from high school in 2018 and graduated from Hebrew school, at her reform temple, in 2018. Leye enjoys the performing arts and was in several theater productions. She is very active at the Jewish Community Center and participates in a Jewish disability organization. Leye is a young professional and mentioned that she has a new job at a food packaging business.

Case Study Data Explication Summary

Data explication included two general strategies: pattern matching and cross-case synthesis. Pattern matching began even before I collected and analyzed data. Pattern matching included developing propositions based on theory and literature and then revising the propositions based on empirical evidence. I developed the two propositions that were based on theory and the literature review from Chapter 2 (Yin, 2018). The two theoretical propositions were:

1. This case study will show how Jewish youth with IDD experience rituals and practices in the home, which will highlight the importance of family and Judaism on the identity development of these youth.
2. The case study will also show how the very experience of these rituals and practices influences the connection to Judaism, family, and the community, which influences the overall wellness of these youth.

These propositions signify the critical points from the literature review, which informed the research design. After I collected and analyzed the data, I compared the propositions to the empirical evidence and revised the propositions.

The second technique I used was cross-case synthesis. To do a cross-case synthesis, I first did a within-case analysis. I then analyzed the cases together so that I could describe the participants' real-world experiences (Yin, 2018). I added a final step to data analysis that emulated DisCrit, and that was member checking. I shared my findings with the participants and asked for their input. I revised my findings based on their feedback. The following are the results from my data explication.

Results

In this section, I describe the cross-case synthesis of themes and subthemes that emerged during the data explication. The cross-case synthesis included within-case patterns that were generalizable across both cases and developed into themes and subthemes that represent a holistic picture of the cases, shown in Table 3. However, there were clear distinctions that emerged in the within-case analysis. Such distinctions are important to delineate because these distinctions represent the "how" and "why" for the individual experiences that were not generalizable across cases (Yin, 2018).

Table 3: Themes and Subthemes

Theme (Cross-Case Synthesis)	Theme (Within-Case Analysis)	Subtheme (Within-Case Analysis)
Making Meaning of Jewish Experiences	Rachel: Making Meaning of Jewish Experiences	Comparison of Childhood Activities to Youth Activities
		Blended Partner Experiences
	Leye: Making Meaning of Jewish Experiences	Individual Experiences
"I Feel Like There's a Middle That is a Little Bit Missing Maybe"	Rachel: "I Feel Like There's a Middle That is a Little Bit Missing Maybe"	Inaccessible Spaces and Places
		Decision-Making Process
		Merged Experiences

	Leye: “I Feel Like There’s a Middle That is a Little Bit Missing Maybe”	Inaccessible Spaces and Places
		Decision-Making Process
		Merged Experiences
Lived Experiences of Jewish Rituals and Practices	Rachel: Lived Experiences of Jewish Rituals and Practices	Creative Experiences and Creative Space
		Making a Spiritual Connection During Lived Experiences
	Leye: Lived Experiences of Jewish Rituals and Practices	Creative Experiences and Creative Space
		Making a Spiritual Connection During Lived Experiences

The interview questions were geared toward learning about Jewish rituals and practices for the individual and the observation was of a Jewish ritual or practice. Therefore, both cases are both bound by Jewish rituals and practices. Three themes emerged from the cross-case synthesis.

The first theme of making meaning of Jewish experiences materialized when participants reflected and processed their personal Jewish experiences, rituals, and practices. The theme of making meaning of Jewish experiences had within-case differences that could not be generalized across cases. The within-case differences for Rachel included blended partner experiences and comparison of childhood experiences to youth experiences. The within-case difference for Leye included the subtheme of individual experiences.

The second theme that emerged from the cross-case analysis was “I feel like there’s a middle that is a little bit missing maybe.” This theme was a shared feeling of being a Jewish youth with a disability. Middle experiences mean that support needs aren’t met or considered in the creation of Jewish activities, spaces, places, organizations, or events. This theme has three subthemes: inaccessible spaces and places, decision-making process, and merged experiences.

The third and final theme that materialized because of the cross-case synthesis was the lived experiences of Jewish rituals and practices. This theme materialized during the cross-case analysis and included meaningful moments that contributed to the significance of a lived experience. This theme included two subthemes: 1) creative experiences and creative spaces and 2) making a spiritual connection during lived experiences.

I developed themes “to form a composite summary of the phenomenon” (Peoples, 2021, p. 78). To maintain the integrity of each individual case, I compared within-case patterns across the two cases (Yin, 2018). I corroborated the cross-case synthesis with quotes from both participants. In the following sections I describe the overall themes, which I developed based on the cross-case synthesis. I then delineate the within-case analysis and describe the themes and subthemes as they relate to both Rachel and then Leye.

Making Meaning of Jewish Experiences

By reflecting and processing personal Jewish experiences, rituals, and practices, one makes meaning from them. This collective reflection contributes to overall lived experiences in the home.

Rachel: Making Meaning of Jewish Experiences

Making meaning of Jewish experiences contributes to the overall phenomenon of Rachel’s lived experiences of Jewish rituals and practices in the home. For Rachel, being Jewish meant connecting to ancestors and community. In Rachel’s words, “being Jewish means a tie between me and my ancestors, but also between me and like a community of people who either historically have experienced similar oppression or just have the joy of partaking in similar traditions to me.” Rachel spoke of a tie between ancestors and between the community. The tie and connection Rachel felt was how they defined being Jewish and what it means to them.

Rachel distinguished between being Jewish and doing Jewish rituals and practices. Doing Jewish rituals and practices connects Rachel to their ancestors and community. Rachel said:

> It feels nice to be partaking in traditions, and to be sharing them with others, whether it’s those who taught me the traditions or those I just grew up with, or for me to be teaching the traditions to my partner, or to the students at the Sunday School where I worked, for example.

Rachel talked about traditions that were from their ancestors, traditions from people they grew up with, and traditions they taught to their partner. For Rachel, doing Jewish things meant continuing Jewish traditions.

Rachel further elaborated and talked about what it means to be Jewish and have a disability. Rachel said:

> But anyway, me being Jewish and having a disability has meant to adapt different. It’s an extension of the ever-evolving nature of Jewish tradition, which I’ve mentioned has significance in terms of gender and sexuality and stuff. And the

> way that for example, my synagogue now performs marriages for same-sex couples and did not used to do that.

Being Jewish and having a disability meant adaptation. Rachel postulated that adaptation was in fact no different than Jewish tradition. Rachel reflected on the adaptation and the "ever-evolving nature of Jewish tradition" and how significant that is for Judaism and for their own experiences.

The collective reflections Rachel shared all contributed to their making meaning of Jewish experiences, rituals, and practices.

Comparison of Childhood Activities to Youth Activities

Comparison of childhood activities to youth activities emerged as a subtheme for Rachel. This subtheme is defined as distinguishing the differences between childhood activities and young adult activities. For example, Rachel shared about the ritual of preparing for Jewish holidays. Rachel said:

> There's a little storage closet in our house for different Jewish holidays. And so at home, before the holiday, my mom pulls out the box with all the groggers and masks and little Purim-related things, or pulls out the box with the Passover stuff, or the box with the Hamantaschen.

Rachel shared this story of how their family prepared for the holidays at home. Then they shared about their current practices. At the time of the interview, Rachel shared how they now live with their friends and their partner. In Rachel's current home, they still store their Judaica and other holiday decorations. Rachel recounted that their current house has an attic and said, "So, it's just up there, but it's my stuff mainly that I've collected from Hillel over the past year, but then a few things from when I was younger—all in the box." Rachel has added Judaica and other holiday decorations from their college temple, Hillel. Rachel carried on the practice of storing and decorating with Jewish items. Rachel found significance in doing rituals and practices in a way that was different from when they were growing up. Rachel stated, "It's nice to do things in a different way than I did when I was growing up, like doing traditions with family or camp or with my partner or whatever." Rachel distinguished between childhood and adulthood and reflected on the difference.

For Rachel, childhood Jewish activities occurred at a different frequency than how they occur for them as an adult. For instance, Rachel stated, "I used to observe Shabbat when I was in high school. I observed Shabbat by not using my phone at all, or any electronics, or any whatever. And often going to services and things like that." However, as a young adult, Rachel said, "Now I don't really observe it, but maybe … at least once a month … we have challah and grape juice, so I'd say twice a month we have challah and grape juice, but we don't do candles." When Rachel was a child, and lived in their childhood home, Rachel celebrated Shabbat every week. Now that Rachel is a young adult, they celebrate Shabbat differently and only twice a month. Comparing childhood activities to youth activities was part of how Rachel made meaning of their Jewish experiences.

Blended Partner Experiences

Blended partner experiences emerged as a subtheme for Rachel. This subtheme is defined as experiences where the partner and participant have shared and combined experiences. Blended experiences were exemplified when the participant used "we" or "our" to talk about lived experiences. During the interviews and during the observation, Rachel talked about their experiences with their partner. For example, Rachel expressed a shift in how they prepared for holidays. “So ever since my partner and I started living together, we go to everything together, basically.” Rachel’s experiences merged with their partner’s when they began living together.

There was a shift in how Rachel participated in Jewish rituals and practices when Rachel became a young adult. Rachel talked about growing up and celebrating holidays with their family and then transitioned into talking about celebrating holidays with their partner. For their observation, Rachel selected Shabbat because it was something they did frequently with their partner. Rachel said “it’s something that, at the very least once a month, but we try to do it every week, but it happens. But yeah, so because it’s a very common thing for me and my partner to do together.” Rachel selected a common practice that the partners shared together instead of picking a practice or ritual that Rachel did on their own. The shared and combined experiences with their partner helped Rachel make meaning of their past and present Jewish experiences.

Leye: Making Meaning of Jewish Experiences

Leye made meaning of Jewish experiences by processing personal Jewish experiences, rituals, and practices. In Leye’s follow-up interview, I asked if she confirmed that she connected to her people and community by dancing to and listening to Jewish music. The reflections contribute to overall meaning making of Jewish experiences, rituals, and practices.

Individual Experiences

Individual experiences included all experiences that were unique to Leye. Individual experiences were based on Leye’s personal preferences. When the first interview began, Leye talked about her individual experiences. For example, Leye shared her favorite Jewish holiday. Leye said, “I love Rosh Hashanah” and added, “I like to dip apples in honey. It means that it makes you have a sweet new year.” Leye used “I” to talk about her own preferences. Individual experiences included individual choices and autonomy for Leye. For example, when I asked if Leye liked to wear anything Jewish, Leye smiled and said, “I usually wear a necklace and a bracelet, my high heels, and a dress. Yea, I like to dress up every holiday.”

There was an overlap of merged experiences and individual experiences. For example, Leye shared that at home “we celebrate Shabbat together” every Friday. Even though that was a ritual Leye partook in with her family, she expressed an individual experience with celebrating Shabbat. When I asked why she celebrated Shabbat, Leye responded “I love praying a lot.” I asked how it feels when Leye prays, and Leye said, “Um, happy.” Being happy was an individual experience that was unique to Leye and contributed to her overall making meaning of Jewish experiences.

The theme of making meaning of Jewish experiences was apparent for both Rachel and Leye. There was an important difference that remained within each case and that was how each participant made meaning of these Jewish experiences. For Rachel, that included blended partner experiences and the comparison of childhood activities to youth activities. For Leye, that included her individual experiences. Both Rachel and Leye made meaning of their Jewish experiences, and as they did, another theme emerged: “I feel like there’s a middle that is a little bit missing maybe.”

“I Feel Like There’s a Middle That is a Little Bit Missing Maybe”

“I feel like there’s a middle that is a little bit missing maybe” (further referred to as middle experiences) is defined as the feeling of being a Jewish youth with a disability. Middle experiences means that support needs aren’t met or even considered in the creation of Jewish activities, spaces, places, organizations, or events. Having a disability and being Jewish intersected in different ways for Rachel and Leye.

Rachel: “I Feel Like There’s a Middle That is a Little Bit Missing Maybe”

For Rachel, they described the feeling of “middle.” In Rachel’s words, “I feel like there’s a middle that is a little bit missing maybe, because a lot of people who are in the middle of certain things, it’s like they’ve been historically pushed to one side or the other, if that makes sense.” Middle spaces were not intentionally created for young adults like Rachel. Rachel said they kind of just happened.

The middle also existed within Rachel’s family. Rachel talked about their brother, who is 20 months older than Rachel and has autism. Rachel shared that a lot of programs “are more geared toward people who have support needs in the way that my brother does.” In fact, Rachel and their family went to Jewish family camp for children with autism, and Rachel said that it was “my brother being the autistic kid that basically got us into the camp.” Rachel participated in the sibling activities and did not get the same type of support their brother did at camp. Rachel talked more about their diagnosis history and said, “I wasn’t diagnosed until I was 20 because all of my autistic attributes were either not really... They were looked over, because they weren’t as severe or as present as my brother’s.” Rachel expressed that they were “looked over” because they didn’t present the same way their brother did.

Rachel reflected on family decisions that were centered around their brother’s needs. For example, when it was time to have Rachel’s brother’s bar mitzvah, their family decided to do a b’nai mitzvah instead. B’nai mitzvah is the plural of bar mitzvah and occurs when two people share a bar mitzvah. A b’nai mitzvah is common when two family members are coming of age at a similar time (i.e., twins, siblings close in age, cousins close in age) or when a temple or synagogue has a lot of congregants coming of age at the same time (Aspinwall, *B’not vs. B’nai Mitzvah & Bar vs. Bat Mitzvah: Which Is It?*). Rachel mentioned that their brother “would not have been able to do his own bar mitzvah," which is why the family decided to do a b'nai mitzvah. Rachel added, "Instead of doing the normal Saturday morning service, which is at least three hours long at my synagogue, we did the Saturday afternoon service." Rachel talked about the decision to do the Minha service in the afternoon and how the decision was made for their brother first, and then for them second because it "just made sense to squish them together." Rachel said:

> For my brother especially, but also for me at that time, I was only diagnosed with ADHD, but I am also autistic. But even with ADHD, that's the thing, it would've taken away from the meaning to do the full-length morning service, because so much of our energy would've just gone into getting through all of the time that it takes.

Even though support needs were considered for the b'nai mitzvah service, Rachel clarified that their needs were met secondarily to their brother's needs being met.

Inaccessible Spaces and Places

The subtheme is defined as Jewish activities, spaces, places, organizations, or events that are physically or conceptually inaccessible for Jewish young adults with disabilities. Rachel felt spaces and places were inaccessible to them because of expectations. For instance, Rachel reflected on the expectation that all people can drive. Rachel shared, "Jewish things have not been super public-transportation accessible, which is not great, because I don't drive. And there's an expectation of you or someone you're going with will drive." Being able to drive also impacted the ability to belong to or even access a synagogue. Rachel reflected on the idea of belonging to a synagogue:

> So, I don’t know, there might be some sort of synagogue that would be so great for us, but it’s not because I can’t access it, or even in terms of accessing within the synagogue, there are days where I have severe mobility issues, and stairs are not it for me. And some synagogues don’t really have [accessibility]... which is so silly, because so many old people go to synagogues.

Rachel also attended Hebrew school but ended up quitting. Rachel shared, “It was not for me, but the program that they had for autistic students at my Hebrew school was also not for me.” Temple was an inaccessible space for Rachel, which led to dropping out of Hebrew school.

Temple was inaccessible to Leye as well. When I asked who goes to temple with Leye, she said, “my family, because my dad is the driver … because my dad drives. I’m not a driver.” Leye accessed the temple by attending with her family because Leye could not drive herself to attend. It was not clear if Leye would rather attend on her own if she were given the opportunity.

An expectation for Jewish American young adults is that they will attend Birthright Israel (referred to as Birthright), a 10-day heritage trip to Israel. Rachel expressed that, “There’s these things that people my age are doing, like Birthright, that I am not doing right now and maybe I will in the future.” Rachel added, “A part of why I didn’t even consider going before that is because my health is not in a place for me to be able to go on a fast-paced trip like that. Birthright looks intense.” Even though there was an expectation that Rachel would participate in Birthright, they were not able to attend because it was not accessible for them. Wanting to attend but not being able to, due to lack of access to spaces and places, further perpetuated the experience of being in the middle.

Community spaces contribute to feelings of belongingness, but sometimes being at home was more comfortable. Rachel reflected:

> There's certain spaces where I enjoy the sense of community in the sense that it's we are here, and this is a special place to be for a special time, if that makes sense. At a USY convention, or at someone's bar mitzvah, or things like that, there are times where that makes it more special. But, generally, to be at home makes it more comfortable.

Though for certain spaces and occasions, Rachel enjoyed being in the community with others, home continued to be an accessible space and place for Rachel.

Decision-Making Process

A result of feeling "in the middle" is the need to problem solve and make decisions based on personal needs and preferences. Decision making also means having self-awareness to make decisions that best meet needs. For example, Rachel talked about their multiple disabilities and how they had to consider their disabilities when determining which events to go to. Rachel started off by saying, "I guess celiac disease can be considered a disability, because in certain situations it does create a barrier to access. Or I guess if I get gluten, it literally, physically disables me." Rachel continued to talk about the effects of gluten and how that impacts their decision-making process. Rachel said:

> I mentioned about gluten, which a lot of Jewish holidays, it's like, there's stuff that is not gluten-free. So, it just requires a lot more ahead-of-time thought, and sometimes it requires a larger financial cost because gluten-free stuff is just more expensive.

Participating in Jewish activities means having self-awareness. Rachel talked about their decision-making process, "I don't really make spur-of-the-moment decisions. For me, it's a research process." Rachel and their partner also make decisions based on transportation needs.

For example, Rachel and their partner determined which Purim festival to go to based on the festival's proximity to a metro station. Rachel and their partner decided on "the music festival Purim thing, which is literally right next to a Metro stop, and we are a 15-minute walk, 10- to 15-minute walk from a Metro stop." Rachel could not access all Purim events, which created this "middle" that Rachel had to navigate through their decision-making process.

Merged Experiences

Though merged experiences were more evident for Leye, Rachel also had merged experiences. For instance, Rachel made a distinction between childhood and youth experiences. Rachel said, "My participation in Jewish holidays, for example, was more centered around my parents and brother, and now it's still... I participate in some things with them, but it's more so centered around me and my partner." Merged experiences were evident when Rachel mentioned how childhood experiences were "centered" around their parents and brother. Rachel did not mention themselves until they made the distinction between childhood and young adulthood. Now, Rachel has experiences that are centered around their needs and wants.

Leye: "I Feel Like There's a Middle That is a Little Bit Missing Maybe"

There were different instances where Leye's support needs were not met or considered in the creation of Jewish activities, spaces, places, organizations, or events.

Inaccessible Spaces and Places

As mentioned above, this subtheme is defined as Jewish activities, spaces, places, organizations, or events that are physically or conceptually inaccessible for Jewish young adults with disabilities. Leye experienced inaccessible spaces within her home prior to and during the consent/assent meeting. Prior to the consent/assent meeting, I spoke with Leye on the phone. I asked if she wanted any family members to attend the consent meeting, she said she would like her dad to. When the consent/assent meeting took place, Leye's sister, mom, and dad were in attendance. During the consent/assent meeting, Leye's family members told her to speak up and her sister elbowed her to respond to a question I'd asked. Leye immediately started to shake and then she started to cry. Even though Leye was physically able to access the consent/assent meeting, she was not able to conceptually access the meeting.

Decision-Making Process

Leye made decisions based on her personal preferences. Leye celebrates Shabbat every Friday, and when I asked why she celebrates Shabbat, she shared, "I love praying a lot." Leye added that she feels happy when she prays. I asked her if she wears anything Jewish, and she said, "I usually wear a necklace, and a bracelet, my high heels, and a dress." Leye added, "I like to dress up every holiday." Leye's decision-making process was based on her preferences. Making decisions based on preferences created space for Leye to make a connection to her faith.

Merged Experiences

Merged experiences emerged as a theme during data explication. Merged experiences were shared experiences that were indistinguishable from the participant and the family member(s). Merged experiences were particularly evident for Leye. For each data collection point, I gave Leye the opportunity to choose who she wanted in the interview. I shared that it could just be Leye and myself. I also said it could be Leye, Leye's guardian, and myself. Leye said she would like to have her dad attend the first interview. Leye's dad is her legal guardian.

The interview itself became a merged experience. When Leye logged on, she was sitting arm to arm with her older sister. Leye's dad was out of the camera, but next to Leye's sister.

Leye's mom was behind the computer cooking dinner. When I asked Leye how she prepared for Rosh Hashanah at her house, Leye's sister provided support in answering the question. Leye's sister said, "Say it a little louder" and then gave her the prompt of "Well, last year, we did." Leye responded "we made a round challah." I asked if she put anything special into the challah. Leye's mom responded, "Cranberries," and Leye repeated, "Cranberries."

Merged experiences impact autonomous communication. During the interviews, Leye said, "My mind went blank" in response to these five questions:

1. Can you maybe tell me a story about Rosh Hashanah with you and your family?
2. What's it like being Jewish and having a disability
3. What does being Jewish mean to you?
4. Do you do anything in your house now that you are 22 years old?
5. Is there anything else you want to share with me about being Jewish?

When I reviewed the interview, I stopped at each question where Leye responded, "My mind went blank." I noticed family members having visible reactions to the questions, mouthing things to each other, moving around and whispering to each other, and making facial expressions.

Lived Experiences of Jewish Rituals and Practices

This theme means experiencing meaningful Jewish moments that contribute to the significance of a lived experience of the Jewish rituals and practices. This theme emerged from the observation component of the study.

Rachel: Lived Experiences of Jewish Rituals and Practices

The lived experience that Rachel selected for me to observe was the ritual of Shabbat and the practice of eating challah and drinking grape juice.

Creative Experiences and Creative Spaces

This subtheme appeared by creating individualized, personal, and meaningful connections through Jewish rituals and practices. Rachel created experiences and spaces that were meaningful for them. At the beginning of the Zoom call, Rachel was standing outside looking up at the sky. Rachel looked at the camera and said that they were waiting for three stars so that Shabbat could start. Rachel walked inside with their phone and set up the phone in the kitchen. Before the recording began, Rachel and their partner, Ramin, decided to film the observation as if they were making a TikTok. Rachel started off by looking at their partner, smiling, and wishing their partner, "Shabbat Shalom." Their partner smiled and responded, "Shabbat Shalom." Both Rachel and Ramin laughed and looked at each other. Rachel and Ramin created their own meaningful connections through their individualized celebration of Shabbat.

During the Shabbat observation, Rachel continued on with their TikTok and described dipping challah in grape juice. Rachel explained, "It's meaningful because even though challah and grape juice is a thing, there's also different ways. That makes it even more of a micro-tradition, if that makes sense." Rachel liked the ability to individualize the tradition of eating challah and drinking grape juice.

Rachel knew that dipping challah in grape juice was not common practice, but they liked that they could make a personal adjustment to connect to ancestors and the community. Rachel explained why they picked the challah and grape juice ritual. Rachel said:

> Just the fact that it's a tradition that goes back many years and connects me to my ancestors or my cousins or my fifth cousin, all of that kind of stuff. And also I think that the fact that I dip challah in grape juice is something I picked up from a Jewish summer camp when I was younger. And I thought it was more common, but I recently... not super recently, but in high school I discovered that it was not common.

For Rachel, dipping challah in grape juice connected them to their ancestors, to their distant family, and to their community. Rituals became more meaningful when Rachel created a personal adjustment. Rachel shared, "It's meaningful because even though challah and grape juice is a thing, there's also different ways. That makes it even more of a micro-tradition, if that makes sense." Rachel found meaning in the flexibility to be creative and create "micro-traditions."

Additionally, creating space at home to do rituals and practices in the home alleviated the pressure to perform. Rachel said:

> I feel like a lot of the Jewish rituals that there are, there's a lot of pressure to do it the right way. I mean, some people might say like, 'Oh, you didn't do it right because you didn't even say the blessing over the bread. You didn't even say Hamotzi.' But when it's just the two of us, sometimes we do say Hamotzi, but that... In a large, communal setting, I feel like there's a lot more pressure to do things the right way, whereas with two people, you can just focus on enjoying what there is to enjoy about the ritual.

Being in the home eliminated the pressure to perform and allowed for the opportunity to enjoy the ritual. Being with their partner, in addition to being at home, contributed to creativity.

Rachel talked about Shabbat with their partner and how “that’s something that we love, is there’s no pressure. Like the pressure to get the words right or do it in the right order or whatever. You get to be creative at home. “Rachel created individualized, personal, and meaningful connections through Jewish rituals and practices in the home.

Throughout the observation, Rachel and Ramin worked together to create the experience. Toward the beginning of the observation, Rachel gathered different materials that were part of the practice. Rachel moved toward the cupboard to grab the juice glasses and then paused. Rachel then shared:

> I have proposeptive dysfunction as a trait of my autism so when I use the stepping stool, which is right, you can’t see it in the camera, generally I only use it in the presence of my partner or of someone else whom I trust to know about me and my symptoms or just to be able to keep me safe generally.

Ramin placed their hands on both sides of Rachel to guide them on and off the step stool and to be there in case Rachel lost their balance. Rachel dismounted the stepstool and put the glasses on the counter. Rachel put their hands up in the air to catch their balance. Their partner stood across from them, and Rachel said, “I’m good.”

Ramin supported Rachel and assisted in creating the space. For example, at one point in the observation Ramin exited the room and Rachel started looking around and went to grab their bottle of Ritalin. Ramin and Rachel came back into the camera. Ratim said, “Are you sure you should take a Ritalin?” Rachel scrunched their nose and said “yea?” Rachel’s voice fluctuated, and it became visible that they were questioning their decision. Ramin said, “What are you going to do?” Ramin’s question helped to prompt Rachel to think about what they were going to do this evening that would require the effects of Ritalin. Rachel said, “Oh wait, I am waking up earlier tomorrow.” Ramin nodded slowly and said, “That’s what I was saying.” Rachel put the pill back in the bottle, closed the bottle, and said, “I should have taken this two hours ago.” Ramin supported Rachel, and the support helped Rachel make a decision about taking the medicine. Rachel and Ramin worked together to create a space that was safe for this decision-making process.

Rachel and Ramin supported one another in making decisions about the practice. For example, both Rachel and Ramin asked each other questions to support one another. Ramin asked, “Is there anything else we need?” and Rachel asked, “Shall we bring the stool in here … so we can sit?” Rachel moved toward Ramin, and Ramin went to the other room to get the stool. Ramin asked if they should bring in two stools, and Rachel said, “No, just one, we can lean.” Next, Ramin went to get a bowl and Rachel said, “We remind each other to do basic tasks.” Ramin said, “Exactly, that’s how we roll,” and Rachel said, “challah roll.” Ramin said, “challah egg,” and Rachel shook their head from side to side. Ramin said, “Oh snap” and then asked for permission to snap. Rachel said, “Yes, thank you.” Rachel then said, “Snapping is a noise that triggers my SPD sometimes, so they have to ask permission before they snap. And often when I say, ‘oh snap,’ that’s when they tend to ask for permission to snap.” Rachel and Ramin created space that supported Rachel and their needs so that they could access their shared ritual and practice.

Making a Spiritual Connection During Lived Experiences

This subtheme refers to the spiritual connection experienced by the participants during the ritual or practice. Connection is one of five domains that comprise wellness (Ohrt et al., 2018) and was evident in different ways for both Rachel and Leye during the observations. During Rachel’s observation, Rachel and Ramin first assembled all materials for the challah dipping. After Rachel and Ramin assembled the materials, Rachel tore the challah and simultaneously took a deep exhale. Rachel smiled and then put the challah down to look for Ramin. Rachel waited to proceed in the practice so they could share the experience together. Once it looked like Ramin was situated, Rachel said, “Ready?” and then looked at Ramin. It looked like Ramin was ready, so Rachel took their first bite. Rachel closed their eyes then shared, “This has the right taste, but not the right texture.” In the follow-up interview, I asked Rachel about waiting for Ramin to have their first bite of challah. Rachel said, “I think that’s a thing, but I’m not sure why.” Rachel then talked about order in Judaism and order and routines as a trait of their autism. Rachel said, “But maybe just that I think like an autism thing is that you often have those routines, or you have a ritual like that, but it is in a way that is logical to you.” Rachel made spiritual connections in ways that were logical to them.

Leye: Lived Experiences of Jewish Rituals and Practices

The lived experience that Leye selected for me to observe was the practice of listening to and dancing to Jewish music.

Creative Experiences and Creative Spaces

For Leye, creating space meant individually and intentionally creating space for her to move her body (body wellness is one of the five domains of wellness, Ohrt et al., 2018). This subtheme emerged when Leye prepared for the observation. The first thing Leye did in the observation was create her own space. Leye set up the call in her bedroom with the door open. Leye was on her computer and pulled up a YouTube video on her iPad. Leye propped up the iPad, pressed play, and then took her place in front of the laptop.

Leye created her own space and, therefore, created opportunities to problem solve and self-advocate. During the observation, there were multiple instances where the music stopped playing, and it appeared that the music video was buffering. The first time the music paused, Leye looked at the iPad and held her pose until the music started back up. The moment the music started again, Leye continued dancing, and her smile returned. In the second music video, the music stopped two more times. On the second instance, Leye leaned over to the iPad and touched a couple things to get it started. Leye did not leave the room to ask for help. Instead, Leye created her own space and was able to navigate the problem independently.

Leye created a space where she was able to self-advocate. An example of this is when I thought the interview was over before it was. When the song ended, Leye walked back to the iPad. I thought Leye was done, so I turned their camera back on. Leye looked at me and said, "I have one more." Iturned off the camera, and Leye pulled up the next song. When Leye danced, she created her own movements and moved with her own volition.

Making a Spiritual Connection During Lived Experiences

Leye made spiritual connections during her lived experience of the selected Jewish practice of dancing and listening to Jewish music. Leye expressed her connection by moving in different ways. At the beginning of the first song, Leye looked up at the ceiling and raised her hand and pointed one hand to the ceiling. She followed the music and swayed to the other side and pointed her other hand out, shifting her body from one side to the next. The music cut out, and Leye looked at the iPad. When the music started up again, Leye smiled and twirled in a circle. Leye shimmied from side to side and tapped one foot against the other. There was a clear transition from the beginning of the song to the chorus. When the chorus came on, Leye's smile grew even wider, and her movements got bigger. Leye jumped up and down and moved her arms from side to side. Leye moved with her own volition, and her movements looked less calculated and more free flowing. The second song started off slowly and then the beat picked up. When the beat picked up, Leye smiled and started moving faster and clapping her hands on beat. Leye's smile got bigger, and she opened her mouth. She shimmied back and forth and then rolled her hands in circles and swayed side to side. Leye jumped up and down and shimmied forward and backward. In the second song, Leye had a similar transition to free-flowing and less calculated movements during the repeating chorus. These free-flowing moments encapsulated the spiritual connection Leye experienced while dancing and listening to Jewish music.

In the follow-up interview, I summarized Leye's experiences and asked her to tell me if my summaries were right or wrong. I asked when Leye dances, listens to Jewish music, and smiles, does she feel that Jewish connection, and Leye said, "Yea." I continued to summarize and share these with Leye, such as "when you were dancing, your smile got so big. It was like you were really connecting to the music. Is that right or is that wrong?" Leye responded, "That's right." Next I asked, "And when you were smiling, and dancing, and twirling around, and throwing your hands up, did you feel like you were connecting to the music or the Jewish people, maybe both of those?" Leye smiled and said, "Yea."

Both Rachel and Leye made spiritual connections during their Jewish lived ritual and practice. Rachel's spiritual connection was integrated with their partner as they shared challah together. Rachel exhaled when they tore the challah and then waited to experience the challah until their partner was ready. For Rachel, this was part of how they connected to the ritual and practice and how it was logical for them. For Leye, spiritual connection was evident when she engaged with the Jewish music and danced. She made a space where it was just her and where she could engage with the music however was meaningful for her. Leye’s widening smile and big movements showed how engaged with the Jewish music she was.

Revised Propositions

The multiple-case study has additional meaning evidenced in the revised propositions. At the conclusion of my data explication, I went back to the two initial propositions. I developed the initial propositions based on theory and the literature review in Chapter 2. I revised the theoretical propositions and developed empirically based propositions based on the results of the multiple-case study. The empirically based propositions are:

1. This case study showed how Jewish youth with IDD experience rituals and practices in the home, which highlights the importance of connecting to Judaism.
2. The case study showed how the very experience of these rituals and practices influences the connection to Judaism, family, and the community, which influences the overall spiritual connection of these youth.

Because my theoretical propositions and revised empirical propositions are so similar, this indicates strong internal validity (Yin, 2018). The theoretical propositions and empirical propositions are discussed in Chapter 5.

Conclusion

In this multiple-case study, I explored the lived experiences of Jewish youth with IDD as they experienced rituals and practices in the home. In Chapter 4, I presented the results of the study. Results of the study included the various themes and subthemes that emerged for each participant. In Chapter 4, I gave an overview of the participants, briefly summarized the data explication strategies I used to analyze the multiple-case study, defined the themes and subthemes, and delineated the results. In Chapter 5, I will discuss and share implications and recommendations.

Chapter Five: Discussion

Introduction

Narratives about individuals with disabilities and their religious and spiritual experiences are often told from the parent's and caregiver's perspectives (Carter & Boehm, 2019; Carter et al., 2017; Nurullah, 2013; Poston & Turnbull, 2004; Uhrman, 2017). While previous research has shown that youth place high importance on religion (Liu et al., 2014), there are limited studies that highlight the lived experiences of individuals with IDD and their experience of religion and spirituality (Liu et al., 2014; Sango & Forrester-Jones, 2018; Turner et al., 2004). The purpose of this study was to explore how Jewish youth with IDD experience Jewish rituals/practices in the home. In Chapter 5, I give an overview of the study, discuss the major findings, present the implications, share the limitations of the study, and make recommendations for future research.

Overview of the Study

The research question I sought to answer in this study was: What are the lived experiences of Jewish youth with IDD as they participate in Jewish rituals/practices in the home? Eligible participants were youth from 15 to 24 years old who identified as having an IDD; identified as Jewish (culturally, spiritually, or religiously); and lived in Maryland, Massachusetts, Michigan, New Jersey, New York, Ohio, Virginia, or Washington, D.C. This population was selected to gather how rituals/practices are experienced for Jewish youth with IDD.

The study procedures included recruitment, assent and consent, sending out a demographic survey, and conducting the interviews and observation. To recruit, I used purposive sampling, from which I selected two participants who met the inclusion criteria for the study.

Next, I held the assent and consent meetings and immediately followed up with a demographic survey to screen participants and identify any needs or accommodations. Participants then selected a date for the first interview and received the interview questions prior to the interview. Once a date was established, I conducted the semi-structured interviews over Zoom. After the initial interview, I worked with the participants to establish a time for the observation of a Jewish ritual or practice in the home. The observations occurred over Zoom and lasted up to 10 minutes. After the observation, I worked with the participants to do the follow-up interview. In the follow-up interview, I used a semi-structured interview to ask some initial questions and then ask about particular moments in the observation. I concluded the follow-up interview with member checking and asked participants to verify or revise my findings with me.

To analyze the data I collected, I combined two data analysis series (Yin, 2018; Peoples, 2021) and incorporated DisCrit into the analysis.

Step 1: Make an initial (but tentative) explanatory proposition (Yin, 2018)

Step 2: Read the entire transcript/view the entire video (Peoples, 2021, p. 59)

Step 3: Generate preliminary meaning units (Peoples, 2021, p. 59)

Step 4: Generate final meaning units for each interview question (Peoples, 2021, p. 59)

Step 5: Synthesize final meaning units into situated narratives (Peoples, 2021, p. 59)

Step 6: Compare data from case study against the proposition (Yin, 2018)

Step 7: Revise the initial proposition (Yin, 2018)

Step 8: Compare other details of the case against the revision (Yin, 2018)

Step 9: Compare the revision from the first case with the data from the second (Yin, 2018)

Step 10: Member check propositions with participants

Step 11: Repeat this process for each case (Yin, 2018)

Member checking propositions with participants (Step 10) aligns with DisCrit and constructivism and is an additional step that I added to the data analysis series. The data analysis series provided structure and a clear procedural outline for the data explication. The results of the data analysis series were two revised propositions. These propositions were:

1. This case study showed how Jewish youth with IDD experience rituals and practices in the home, which highlights the importance of connecting to Judaism.
2. The case study showed how the very experience of rituals and practices influences the connection to Judaism, family, and the community, which influences the overall spiritual connection of these youth.

These propositions are defined by major findings, themes, and subthemes. Below is a discussion of the findings, the meaning of these findings, and the connection to current research.

Discussion of Findings

To discuss the findings, it is important to understand the general design used. The findings stem from the iterative process of proposition building. The design of the study stemmed from theoretical propositions, which were developed based on the literature review in Chapter 2. Theoretical propositions are one of four general strategies proposed by Yin (2018) for multiple-case study design. The theoretical propositions shaped the overall design of the study and the research question. The initial theoretical propositions that guided this study were:

1. This case study will show how Jewish youth with IDD experience rituals and practices in the home, which will highlight the importance of family and Judaism on the identity development of these youth.

The case study will also show how the very experience of these rituals and practices influences the connection to Judaism, family, and the community, which influences the overall wellness of these youth.

The literature review included experiences of religious community members (Carter et al., 2017), faith leaders and congregants (Griffin et al., 2012), parents of children with disabilities (Ault., 2013; Uhrman, 2017), parents of youth with disabilities (Biggs & Carter, 2016; Carter & Boehm, 2019), youth with disabilities (Liu et al., 2014), adults with disabilities (Carter et al., 2015; Sango & Forrester-Jones, 2018; Turner et al., 2004), Jewish parents of youth with disabilities (Vogel & Reiter, 2004), Jewish service providers (Taub & Wener, 2016), and Jewish adults with disabilities (Lifshitz et al., 2009). Based on these experiences, I determined that the major finding would be about identity development for Jewish youth with IDD.

What I ended up discovering was different. It became evident that there was significant importance of how the participants experienced Jewish rituals or practices in the home, and these experiences were important in connecting to Judaism. I defined "connecting to Judaism" as moments of meaning for the individual that connects them to Judaism. What was salient about "how" these Jewish youth with IDD experienced Jewish rituals and practices in the home was different for each participant. I ended up learning more about how the participants connected to Judaism rather than about the participants' identity development.

I revised the second theoretical proposition to reflect the empirical evidence and results of my data analysis. Originally, I thought I would learn about overall wellness for Jewish youth with IDD. The literature I reviewed included findings about family quality of life (Boehm et al., 2015; Poston & Turnbull, 2004), wellness activities (Carter et al., 2015), and wellness in families with a child with disabilities (Taub & Werner, 2016). Based on these research findings, I determined that the major findings would be about the overall wellness of the Jewish youth with IDD. Rather than overall wellness, the results specifically indicated spiritual connection for Jewish youth with IDD.

In addition to proposition building, I developed themes and subthemes based on a cross-case synthesis (cross-case synthesis is a data analytic strategy suggested by Yin, 2018). There were three themes that emerged from the cross-case analysis. The first theme was making meaning of Jewish experiences that emerged when participants reflected on and processed their personal Jewish rituals, practices, and experiences. In the first theme, there were explicit within-case differences that could not be generalized across the cases (i.e., blended partner experiences, comparison of childhood experiences and youth experiences, individual experiences). For the other two themes, no explicit differences existed within the cases. The second theme was "I feel like there's a middle that is a little bit missing maybe." This theme emerged when participants expressed what it was like being a Jewish youth with a disability. There were three subthemes that emerged: inaccessible spaces and places, decision-making process, and merged experiences. Finally, the third theme was lived experiences of Jewish rituals and practices. This theme emerged when participants shared meaningful moments that contributed to the significance of a lived experience. The two subthemes were: creative experiences and creative spaces, and making a spiritual connection during lived experiences.

Below, I engage with the research, reflect on my own interpretations and experiences of the themes, connect my findings to literature, share threats to trustworthiness, and delineate implications and recommendations.

Theme 1: Making Meaning of Jewish Experiences

I defined the process of "making meaning of Jewish experiences" as reflecting and processing personal Jewish experiences, rituals, and practices. For Rachel and Leye, their collective reflections contributed to overall meaning making of Jewish experiences. However, for Theme 1, there were distinct within-case differences that emerged during the data explication.

Subtheme for Rachel: Comparison of Childhood Activities To Youth Activities

Religion and spirituality are personal experiences (Boyatzis, 2013) yet faith is often rooted in the family of origin and home practices (Boehm & Carter, 2019). Rachel's home practices shifted and adjusted to their preferences and needs as Rachel aged and moved into their own home. Rachel liked this shift and shared, "It's nice to do things in a different way than I did when I was growing up." Connecting to Judaism evolved and changed as Rachel aged and had more onus over their preferences.

Rachel also talked about the tie they felt to their ancestors and community by being Jewish. I found parallels between Rachel's experiences of connectedness to their ancestors and community and the literature. Researchers found ancestral connections led to feelings of belonging for young adults that have a bar/bat mitzvah (Vogel & Reiter, 2004). Rachel consistently referenced the differences between childhood and young adulthood experiences, which impacted how they made meaning of Jewish experiences.

Subtheme for Rachel: Blended Partner Experiences

One of the major distinctions for Rachel was that now they experience Jewish rituals and practices with their partner. Together, Rachel and their partner select which rituals and practices are most meaningful to them. There was a clear connection between Rachel's blended experiences and spirituality. Spirituality involves self-transcendent experiences that are not only sacred but also include relationships and practices (Boyatzis, 2013). The relationship and practices that Rachel shared with their partner were critical to their spiritual connection. The shared experiences influenced how Rachel made meaning of Jewish experiences.

Subtheme for Leye: Individual Experiences

Leye made meaning of Jewish rituals and practices by processing personal Jewish experiences and preferences. Leye's preferences further delineated how she connected to Judaism. For instance, Leye shared that she loves Rosh Hashanah. She added, "I like to dip apples in honey. It means that it makes you have a sweet new year." Leye enjoyed the ritual of dipping apples in honey and resonated with the meaning of having a sweet new year. The combined ritual and meaning reinforced her connection to Judaism. Leye had distinct individual experiences that contributed to how she made meaning of Jewish experiences.

Though there is research on what types of spiritual practices youth with IDD do in the home (Boehm & Carter, 2019) and in group homes (Sango & Forrester-Jones, 2018), my study expands research to encompass the lived experiences of these spiritual practices. Learning about lived experiences contributes to research in a different way because research tends to be centered on familial experiences (Ault et al., 2013; Carter et al., 2017; Griffin et al., 2012) rather than the experiences of youth with disabilities. This study not only adds to existing research but also provides insight into meaning making for youth with IDD. Though some research exists in meaning making for transition age youth (Boehm et al., 2015) this research is done with parents and caregivers of individuals with disabilities rather than with the individuals with disabilities themselves.

Overall, the first theme highlighted the individual experiences of meaning making for Jewish youth with IDD. Though there were clear individual differences, there was a shared theme of the importance of meaning making for Jewish youth with IDD. Based on the theoretical propositions, it was surprising to discover more about participants' connection to Judaism rather than about their identity development. Thus, Theme 1 was critical to arriving at the first revised empirical proposition regarding the importance of experiencing Jewish rituals and practices in the home and the connection to Judaism.

Theme 2: "I Feel Like There's a Middle That Is a Little Bit Missing Maybe"

In addition to learning about the importance of connecting to Judaism (Theme 1), the impact of disconnection because of barriers to accessing Jewish spaces and places emerged as a second area of inquiry. Barriers and the experience of feeling excluded and isolated was a shared experience for Rachel and Leye; however, the wording for the experience emerged mostly from Rachel's interviews.

Subtheme: Inaccessible Spaces and Places

Rachel used the term "middle" to describe their lived experiences of being a Jewish youth with IDD. During the first interview with Rachel, they articulated the profound experience of what it is like to exist in middle space. Rachel started off by identifying the concept of a middle. Rachel situated their experience of being in the middle with experiences of other minoritized groups. Being in the middle impacted many areas of Rachel’s life, especially in their actual autism diagnosis. Rachel was not diagnosed with autism until they were 20 because their autistic traits were not seen as severe as their brother’s. Rachel’s late diagnosis impacted their access to services and supports that exist for people with autism. Rachel explained that “support needs look different than what is traditionally served by organizations that serve autistic youth.” Having unique support needs led to further isolation for Rachel, especially in relation to Jewish programs and institutions. For instance, Rachel quit Hebrew school because the classes were not really for them. They mentioned a middle that was missing and how this experience summarizes what it’s like to be Jewish and have a disability. It seemed like there was no intentional space for Rachel and the result of that was not participating in Jewish activities. The experience of not having intentional spaces for individuals with similar support needs was evident in the literature review. Research showed that when disability was broken down into three levels (mild, moderate, and severe) individuals with moderate IDD were more likely to participate in religious and spiritual practices (Carter et al., 2015). Rachel shared that they identify as having more mild support needs and explained that spaces exist for people with more moderate support needs. Rachel also pointed out the distinction between adult programs and youth programs. Rachel continued, “That’s for adults, and I don’t know of anything that’s on that plane intentionally for youth.” To Rachel, it felt like there really was no organization, no activities, and no space for people like them.

Sometimes inclusion programs are created, but they create a false sense of inclusion. Rachel talked about a Jewish overnight camp that had a program. Rachel explained that programs tend to buddy disabled peers with non-disabled peers, creating a divide.

Rachel continued describing the population that attends such summer camps as “autistic teenagers that have, I guess, generally, more support needs than me—but not by a lot.” In addition to the divide, there is only a specific camper that can attend the program. Rachel said:

> People who attend those programs are able to go to a Jewish summer camp without their parents and stay overnight for at least two weeks. And that is, I think, very much a middle in terms of my brother [who] would not be able to do that.

Until this point, Rachel used the term “middle” to refer to their own experiences. In this example, Rachel used the term to categorize experiences for others. Rachel reflected on their experiences but made connections more broadly to the disability community to explain how a middle exists for everyone with a disability. Even though Rachel’s brother had more significant support needs, he could also fall in the middle when his needs weren’t considered or met. Even though middle is the term that Rachel defined and used to categorize their own lived experiences of being Jewish youth with IDD, Rachel also used this concept to contextualize and conceptualize others’ experiences.

Though Leye did not use the same terminology, she had similar middle experiences relating to transportation. Leye shared that she went to temple with her dad because he was the driver, and then added that she did not drive. The wording Leye used might mean that if there was another way to get to the temple, she would choose to go with someone else besides her dad. Or perhaps Leye could use a rideshare app, use public transportation, or even advocate to get her driver’s license. Research has also shown that individuals with IDD attended religious activities more frequently when family or friends were present (Carter et al., 2015). This could be attributed to transportation needs, accessibility, or communication needs. There are different options for transportation, but somehow existing in this middle space where she is not trusted to make decisions about transportation determines who attends temple with her. Leye's experiences relate to research about inclusive practices for faith communities. For example, Griffin et al., (2012) surveyed religious leaders and families of individuals with disabilities. It is worth noting that 23 of the 160 participants had a disability. Inclusive faith communities had three predictors: welcoming individuals with disabilities, the roles that individuals with disabilities played in the community, and the physical accessibility. Physical accessibility included transportation considerations for Leye, and, because temple was only accessible by transportation from someone else, temple was not accessible for Leye unless she had support from her dad.

A middle exists for Jewish youth with varying abilities and support needs because spaces and places are not intentionally created. Rachel used the term "middle" as a benchmark and defined existing programs, organizations, activities, and experiences as either middle or not middle. This finding is supported by previous literature. Many religious institutions in the United States have programming for individuals with disabilities (Glicksman, 2011), yet there is a lack of consensus regarding inclusion and integration of members with disabilities. Research showed that parents felt disability was not centrally on the Jewish communal agenda (Uhrman, 2017). In fact, there appeared to be two fields of thought throughout the literature review: religion and spirituality are a method of coping for parents of individuals with disabilities, and how do congregations include people with disabilities in congregations and rituals (Glicksman, 2011). Both fields of thought do not consider creating spaces for individuals with disabilities within the community nor the meaning of spirituality and religion for individuals with disabilities.

Subtheme: Decision-Making Process

Previous studies explored expanding belonging and inclusion for people with disabilities (Carter et al., 2017). Disability-specific efforts became the primary suggestion to expand belonging and inclusion. One of these efforts included congregations supporting access to religious events and activities that occurred outside of the synagogue (Carter et al., 2017). Such findings appeared in Rachel's interview. Rachel said, "Jewish things have not been super public-transportation accessible, which is not great because I don't drive. And there's an expectation of you or someone you're going with will drive." As was apparent from Rachel's study, access to activities includes making events and spaces more publicly accessible. Access is a topic that researchers also explore. For instance, Carter et al. (2017) analyzed community practices for families that have a child with disabilities and found a leading recommendation to include finding accessible routes to participating in activities outside of places of worship.

Prior research includes predictive factors for inclusive faith communities (Griffin et al., 2012). The top predictor of inclusive faith communities was how welcoming the individual's congregation was of individuals with disabilities. Congregations can welcome and receive individuals with disabilities in different ways. When congregations do not have the infrastructure in place to include individuals with disabilities, there is a direct impact on belonging, as was apparent for Rachel. For example, Rachel said, "I quit Hebrew school. It was not for me, but the program that they had for autistic students at my Hebrew school was not also for me. There was some sort of missing middle." Rachel felt like they didn't fit in the general Hebrew school class, nor did they fit in the program for autistic students. Even though Rachel's synagogue welcomed congregants with disabilities, there was a *middle* that existed. As a result, Rachel's needs were not met in Hebrew school, and they dropped out. Rachel's experiences overlap with previous research on Jewish youth with disabilities. For instance, one study was specifically about the ability and motivators in fulfilling commandments (Lifshitz et al., 2009). The findings were to prove if Jewish young adults were able to uphold Jewish commandments, which limits the scope of the research to proving functional ability (Smart, 2016). It was apparent that participants made decisions that matched this line of thinking. For instance, Rachel made the decision to drop out of Hebrew school based on ability and their needs not being met.

Research indicates that religious and spiritual lives of youth with IDD are dynamic, yet access to religious experiences (in home and in the community) is an issue for youth with autism (Carter & Boehm, 2019). In fact, youths with autism were reported to have lower ratings of strength of religious faith (Carter & Boehm, 2019). Characteristics such as functional skills and communication methods impacted participation in religious practices (Carter & Boehm, 2019). For Rachel, being in the home afforded access to religious and spiritual experiences. Rachel talked about living in their childhood home and observing holidays as a child. Rachel mentioned "I guess the difference I mentioned earlier is that before my participation in Jewish holidays, for example, was more centered around my parents and brother, and now it's still ... I participate in some things with them, but it's more so centered around me and my partner." Because Rachel was able to center their religious experiences around their needs and their desires, the religious practices were more enjoyable. In fact, Rachel talked about how being in their home with their partner alleviates pressure. Rachel said, "Also, like, to do Shabbat with my partner, and that's something that we love, is there's no pressure. Like the pressure to get the words right or do it in the right order or whatever. You get to be creative at home." Being at home and the ability to create meaningful experiences gave Rachel the opportunity to make rituals and practices that met their needs in the middle.

This was a surprising finding because it was not found in the literature. To learn how prevalent isolating experiences were for Rachel and how pervasive these experiences were in every area of their life. Rachel's middle experiences resulted in their delayed diagnosis, dropping out of Hebrew school, not attending Birthright, not being able to access synagogues or youth events because of transportation, feelings of not belonging, and feelings of not having needs met. Rachel went into an extraordinary amount of detail about being in the middle and how this impacted their everyday life.

Subtheme: Merged Experiences

Though I expected to find experiences of not having needs met, I did not fathom how extensive middle experiences were for Rachel. I also did not anticipate how merged experiences led to limited participation for Leye. The difference between Leye's demeanor and level of comfort when her family was there and when her family was not present was noticeable. Merged experiences impacted how Leye engaged with others, which may also be present in communal spaces.

Research exists that examines the impact of religion and spirituality on social lives for individuals with IDD (Sango & Forrester, 2018), and more specifically the bar/bat mitzvah for youth with disabilities (Vogel & Reiter, 2004). However, a missing factor in current research is the vast impact of not having access to religious and spiritual spaces and places. As was evident with Rachel, inaccessibility led to them not participating in an expected youth activity (Birthright), dropping out of Hebrew school, and not being able to attend different community events.

Rachel and Leye experienced a lack of access to spaces and places, which is a normalcy for individuals with disabilities and is an invisible force of ableism, the first tenant of DisCrit

(Annamma et al., 2013). Additionally, being in the middle sounded similar to being othered, a concept Annamma et al., 2013, denoted as the third tenet of DisCrit. Though race and ability are social constructs, there are material and psychological manifestations of being labeled, and this label leads to othering (Annamma et al., 2013). For Rachel, being in the middle or being othered meant being pushed to the side and not having a space in general.

As Julia Watts Belser (2014) acknowledged, recent efforts in religious communities to include individuals with disabilities highlights that disability is singularly an access issue. My study extends knowledge about the lived experiences of Jewish youth with IDD, which has implications for religious clergy, religious leaders, counselor educators, counselors in training, and researchers. As I discuss in the recommendations sections, counselor educators need more knowledge about discussing religion and spirituality with their students.

Theme 3: Lived Experiences of Jewish Rituals and Practices

Participants experienced meaningful Jewish moments that contributed to their lived experiences of Jewish rituals and practices. Lived experiences of Jewish rituals and practices emerged during the observation portion of the study. Both participants took pride in the space they created for the observation, which led to two subthemes emerging: creating experiences and creative space, and making a spiritual connection during lived experiences.

Subtheme: Creative Experiences and Creative Space

Creative experiences included individualized, personal, and meaningful connections during Jewish rituals and practices. Rachel created a fluid space that started outside, with Rachel looking up at the stars for Shabbat to begin and then moved indoors to their kitchen. Rachel and Ramin decided to make their Shabbat tradition into a TikTok video. They laughed together and smiled at one another as they moved through their shared practice of dipping challah in grape juice. They educated their TikTok audience on Rachel's disability and exhibited how they make supported decisions to access their space. Some of these decisions included having a trusted individual spot them while using a step stool, contemplating appropriate times to take medication, and granting permission for Ramin to snap (which can trigger Rachel's sensory processing disorder). When Rachel reflected on these experiences during the follow-up interview, Rachel expressed that being at home alleviates pressure to perform correctly. Rachel also shared that being at home allows them to make mistakes and create their own "micro-traditions" like dipping challah in grape juice. Rachel and I had a dialogue about dipping challah in grape juice, and Rachel shared how unique of a tradition this was. Rachel liked that their ancestors could use challah and grape juice, their cousins could, and they could, yet Rachel had the freedom to modify the tradition to match their preferences.

I noticed a clear difference in Leye when she was with her family in the interviews and when she was in her own room for the observation. Based on my interactions with Leye, I figured the spaces would be created by her parents. Instead, Leye took pride in the space she created. In the observation, Leye cleared space in her room, a space where she could be herself and move freely. I anticipated that Leye's parents or sister would be in the room with her or would be present to help her get set up, solely based on prior interactions with the family. Instead, Leye was completely on her own and created a space that met her preferences so that she could engage in the practice of listening to and dancing to Jewish music. For both Rachel and Leye, having creative experiences and creative spaces were essential in the lived experience of Jewish rituals and practices.

Subtheme: Making a Spiritual Connection During Lived Experiences

Spiritual connections emerged in unique ways as both participants engaged with Jewish rituals and practices in the home. Leye connected to the Jewish music and dancing in evident ways. Leye smiled, tossed her head back, shimmied from side to side, threw her hands in the air, pointed to the sky, twirled in circles, clapped her hands, and jumped up and down. Leye's smile grew wider and wider as the song picked up and the chorus commenced. The joy and spiritual connection Leye felt was clear from her movements and facial expressions. In the follow-up interview, Leye confirmed that she felt a Jewish connection when she danced to Jewish music. She also confirmed that she felt connected to the Jewish people. Leye made connections in ways that were meaningful to her.

Gathering data with various formats was critical in describing Leye's experiences. I got to not only hear about Leye's preferences and connections to Judaism but also witness them. After the observation, Leye confirmed that she felt connected to the Jewish community when she danced to and listened to Jewish music. The lived experiences of Jewish rituals and practices were evident when participants made a spiritual connection during the lived experience.

My study contributes to the research that shows that youth place a high importance on religion (Liu et al., 2014) and expands research on lived experiences of youth with IDD (Liu et al., 2014; Sango & Forrester-Jones, 2018; Turner et al., 2004). Some researchers conducted studies to determine if individuals with IDD can be religious (Turner et al., 2004). Proving the ability to be religious and spiritual has often meant that there is the assumption that a person with disabilities is unable to be religious or spiritual (which is a result of the construct of ability, Annamma et al., 2013). My study contributes lived experiences of religion and spirituality—not to prove ability, but to exhibit spiritual connectedness so that religious clergy, religious leaders, counselor educators, counselors in training, and researchers can expand their religious and spiritual competencies.

These lived experiences are also important for examples of spiritual connectedness for other youth with disabilities. In general, being a part of the Jewish community contributes to feelings of belonging and reinforces the individual and collective Jewish identity (Bunning & Steel, 2007). As Rachel mentioned, there were no programs that were intentionally created for people like them. This study serves as an intentional space so that other youth with disabilities can have people and experiences that highlight possible lived experiences, which can honor and validate their own lived experiences.

There were clear themes and subthemes that emerged from the within-case analysis and cross-case synthesis. These themes and subthemes shaped empirical propositions that help generalize concepts, principles, and lessons learned (Yin, 2018). Discussion of the findings from the present study have major implications for religious clergy, religious leaders, counselor educators, counselors in training, and researchers.

Implications

The goal of my research study was to describe the lived experiences of Jewish youth with IDD to expand the knowledge of religion and spirituality for religious clergy, religious leaders, counselor educators, counselors in training, and researchers.

Implications for Religious Clergy and Religious Leaders

Based on Rachel's lived experiences of their b'nai mitzvah, there are important considerations for Jewish clergy, leaders, and community members. Bar/Bat/B'nai mitzvah is an important milestone in the Jewish faith (Glicksman, 2011), and this is no exception for youth with IDD (Vogel & Reiter 2003; Vogel & Reiter, 2004). In the study, Rachel shared about the meaningful experience of having a b'nai mitzvah with their brother. Rachel explained how they celebrated with family and friends, and more specifically, gave examples of ways the b'nai mitzvah was accessible for them. Rachel and their brother had their b'nai mitzvah during the Mincha service. The Mincha service is the afternoon prayer and is the shortest daily prayer. Rachel said that having their b'nai mitzvah during the afternoon prayer on Shabbat, rather than in the morning prayer (morning prayer is the typical service for b'nai mitzvah), made the b'nai mitzvah possible for them. Rachel was able to conserve their energy and be present during the ceremony. A recommendation based on Rachel's experiences is for Rabbis to suggest the Mincha service for congregation members who may need a shorter service.

Rachel spoke about the isolation and lack of access they experienced from their synagogue and from other Jewish organizations. A recommendation based on Rachel's lived experiences is to have specific training for Jewish clergy and leaders of Jewish organizations regarding inclusive practices. Julia Watts Belser (2014) shared that religious leaders and clergy communicate inclusivity when synagogues invest in religious education and create standards and practices (i.e., amplifying sound in services and providing large-print siddurim), but evidenced from this study, religious leaders and clergy need training on how to create and implement these practices. It was apparent in Rachel's interview how pervasive being in the middle was for their daily life. Being in the middle existed in many Jewish spaces, synagogues, and Jewish organizations, and this inhibited Jewish experiences (like Birthright and young adult events). The middle space is especially apparent for teenagers, who according to the Pew Research Center (2020), six in 10 teenagers say they have participated in religious education, but only 29% still participate. Additionally, in a study by Ault et al. (2013), parents shared that one-third of parents in the study left their places of worship due to lack of inclusion, and more than one-half had never been asked about ways to include their children with disabilities. This, however, is the parental experience. Though in the study by Ault et al., parents pushed for being asked about ways for their children to be included, I recommend that religious clergy and leaders ask the individuals themselves how they wish to be included. When religious clergy and leaders communicate with individuals with disabilities themselves, they are directly countering the normalcy that is upheld by racism and ableism (Tenet 1, Annamma et al., 2007). Religious leaders and clergy need to be asking individuals how they would like to be involved and what ways they can be supported to better access rituals and practices.

Implications for Counselor Educators

In counselor education programs, students acquire the skills and knowledge to develop professional identities in counseling, supervision, teaching, research, and leadership and advocacy (CACREP, 2016). These five core areas guide the professional identity of doctoral students in CACREP accredited counselor education and supervision programs. Within each of the five core areas, there are broad standards that are covered in the curriculum. Specifically, there are implications in the core area of research and scholarship, Standard l. Standard l refers to "ethical and culturally relevant strategies for conducting research." When I designed my research study, I consulted with experts in the field to ask about ethical considerations for research centered around youth with disabilities. Based on these conversations, I developed the following ethical considerations.

1. I created assent procedures that I wrote in plain language.
2. I asked for assent and consent before every point of data collection (i.e., before the interview, before the observation, and before the follow-up interview).

3. I developed a plain language one-page document to share with the participants.

As I mentioned in the discussion above, I learned a lot about communication with participants with disabilities. I was afraid to communicate with participants beyond an email. I thought I would annoy or frustrate participants, or worst-case scenario, coerce them to be in the study. What I learned from communicating with the participants in my study is that they preferred multiple forms of communication and frequent communication. I felt a dissonance between ethical considerations and culturally relevant considerations. As a field, more research needs to be done that includes individuals with disabilities. Individuals with disabilities need the opportunity to co-create research studies and have a right to be participants in research. Though parameters are in place to protect participants, preferences and needs are of utmost importance to include individuals with disabilities. As counselor educators design research studies and submit studies to IRBs, it is important to advocate for preferences and needs of participants with disabilities.

Religion and spirituality contribute to a client's well-being (Koenig, 2012; Koenig & Cohen, 2002), social support (Biggs & Carter, 2016; Koenig & Cohen, 2002; Taub & Werner, 2016), coping strategies (Krok, 2008), quality of life (QOL; Myers & Sweeney, 2000), and lower rates of depression and anxiety (Brown et al., 2013; Young et al., 2000). Even though counselor educators know that religious and spiritual competencies are important (Cashwell et al., 2007), some feel ill equipped to address religion and spirituality with their clients (Adams, 2010; Cashwell et al., 2007). As a result, counselor educators may circumvent addressing religion and spirituality with clients at all (Cashwell et al., 2013). Comfort in addressing religion and spirituality may come from understanding how rituals and practices contribute to wellness. Wellness includes five domains: mind, body, spirit, emotion, and connection (Ohrt et al., 2018).

Connection is an important part of wellness that emerged throughout the present study. Research has indicated connection and belonging when individuals with disabilities experience their bar/bat mitzvah (Vogel &Reiter, 2004). Rachel shared their b'nai mitzvah experience and the connection they felt. Rachel explained how the camp they attended made the b'nai mitzvah experience accessible and made them and their brother feel a part of the community. Rachel also talked about how gratifying it was to be able to connect to ancestors and family members but still be able to create and make their own micro-traditions. Both Rachel and Leye expressed this deeper connection they felt when experiencing rituals and practices. This deep connection was ancestorial, communal, and individual, truly deepening their overall spiritual connection. Therefore, counselor educators can benefit from learning more about families and family systems that include individuals with disabilities.

Body wellness is another important part of wellness. Spiritual connection and body wellness overlapped for Leye as she listened to and danced to Jewish music. She moved her body, smiled, laughed, clapped, twirled, and moved in ways that were meaningful for her. This chosen practice connected her to her faith and helped her make spiritual connections. Counselor educators can benefit from reading about lived experiences, such as Rachel's and Leye's, so they can better conceptualize the ways in which individuals with disabilities experience religion and spirituality and how that overlaps with wellness. Rachel and Leye shared many ways in which they connect to their ancestors, their community, their families, their religion, and their spirituality. An aspect of DisCrit is learning from marginalized populations themselves to ensure we are not "othering" them or their experiences (Annamma et al., 2007). Counselor educators can incorporate lived experiences, like the ones from the present study, into their wellness counseling courses.

Recommendations from the present study include counselor educators addressing the shared identities of disability and wellness in wellness counseling courses. Education about individuals with disabilities has remained most prevalent in multicultural counseling courses (Rivas, 2020), but there are clear benefits from including education on disability in wellness counseling. Counselor educators can share lived experiences of ways in which individuals with disabilities connect to religion and spirituality and the different barriers they face.

In addition to learning about accessing rituals and practices to facilitate spiritual connection and overall wellness, counselor educators need to be aware of the many barriers that exist in religious and spiritual spaces for individuals with disabilities. In the present study, participants shared the barriers that existed when accessing spaces. For counselor educators, barriers exist for their counselors in training with disabilities and for clients with disabilities. Addressing needs and considerations for individuals with disabilities expands to teaching, counseling, and research. To teach students with disabilities, counselor educators need awareness of the many ways access and the lack of access impact the entire student. This means approaching teaching from a DisCrit lens and acknowledging how ableism impacts normalcy and "others" people. When advising students to connect their clients to religious institutions, counselor educators need to be aware of access issues that exist (i.e., transportation, cost, physical accessibility). Awareness of barriers is not a reason to avoid connecting someone with a religious institution, it is a reason to further understand students and their needs.

Implications for Counselors in Training

Counselors in training can also benefit from larger implications revealed in the present study. As mentioned in the literature review, theories such as faith development theory (Fowler, 1981) do not include individuals with significant disabilities. Because spirituality is developmental, meaning it can grow and change throughout a lifetime (Ohrt et al., 2018), counselors in training need to be aware of the developmental aspect of spirituality. Meaning, if a client does not identify as spiritual or religious or has a complicated relationship with spirituality and religion, this does not mean the client can never have a meaningful connection to religion and spirituality.

It is also important for counselors in training to consider how wellness interacts with spirituality and religion. Spirituality and religion are not inherently linked, meaning that spirituality can develop outside of a religious context (Cashwell et al., 2007). Counselors in training can explore how a client makes meaning of the world, and this exploration can lead to finding areas of growth for additional spiritual connection.

It is important to remember that spirituality is individualized (Glicksman, 2011) and involves both relationships and practices (Boyatzis, 2013) and that faith is often rooted in family of origin and home practices (Boehm & Carter, 2019). Based on these considerations and the findings from the study, individuals connect to people and spaces through rituals and practices, but only when the spaces and places are accessible. Counselors in training need to have conversations with clients about accessibility and in what ways they feel supported or how they feel isolated. Conversations around accessibility are a great way to use person-centered approaches to explore how access impacts different areas in the client’s life (i.e., accessing other services, accessing transportation, accessing education). This finding is echoed in research with families and parents. For example, in a study by Uhrman (2017), parents talked about how difficult it was to connect their children to services when attending Jewish day school. Parents shared that they were not aware of resources and felt marginalized and isolated. The present study expands this finding to individuals with disabilities themselves. Counselors have a critical role in connecting clients to services, especially because services can be hard to navigate.

Implications for Researchers

There are major implications for research with individuals with disabilities, particularly with youth with disabilities. Though recruitment was a major limitation, I think the important question to ask is "why was recruitment a major limitation?" Faith leaders and various staff members from organizations responded to my recruitment email informing me that they could not send the recruitment email out. Some shared that their program attendees or congregants did not meet my criteria. When I asked for feedback on my recruitment, people opened up to me. They shared that they cannot send out dissertation studies because they do not want to subject their families to participating. Others shared that they get so many invitations to do research, so as an organization they say no to all requests. Some individuals responded and thanked me for doing this research but shared that they could not help me. Even though I included a brief positionality statement in the beginning of my recruitment email, my status as (a) being a Jewish researcher and (b) working in the disability field did not afford me access to my sought-after population.

The IRB process protects vulnerable populations and poses an extended process for getting approval to conduct research. Additional considerations need to be made for assent (if a participant is deemed unable to make decisions. This is a formal process when the individual is mandated a guardian by the court system), access to instruments both physically and cognitively (e.g., surveys, questionnaires, open-ended questions), and inclusion in the creation of studies.

Communication With Participants

In addition to my formal data analysis just discussed, another significant finding in my study was the importance of communication preferences and practices. Though communication was a major consideration when developing my protocol for the study because communication is a barrier to religious access (Carter et al., 2015), I did not anticipate the impact of communication on participation. For instance, I thought about how I would communicate with the Jewish community, the disability community, with individuals themselves, and with families. However, I did not consider communication preferences (i.e., calling, texting, emailing, sending Google Calendar invitations) or communication frequency (i.e., using multiple modes of communication or reaching out two or three times) and how this would then impact participation.

Without considering preferences for communication, the research can become inaccessible and can exclude participants who want to be in the study. There were various times that I nearly ended communication with participants because I misinterpreted the situation.

For example, when working with Rachel, I made assumptions as a response to the communication barrier. I thought that because Rachel did not respond to my two emails, they were communicating that they did not want to be in the study. I called Rachel to ask about the scheduling of their first interview and to inquire if they still wanted to be in the study. Rachel thanked me for calling them and expressed that they really wanted to be in the study but completely forgot about the study. I inquired about their communication preferences. I asked if they preferred a phone call, text, email, or a Google Calendar invitation. Rachel said they wanted all of those options. Rachel mentioned that they need to read and hear information in order to remember it. When Rachel was on the phone, we set up their first interview, and they filled out their demographic information. I assumed that Rachel did not want to be in my study because they did not respond to two emails. This assumption nearly led to me moving on without reaching out to Rachel again. Rachel clearly stated to me that they really wanted to be in the study but that they had forgotten about the study. The miscommunication with Rachel is important to consider for future research. For instance, in my study, I would designate a section in the consent and assent meeting to talk about their communication preferences and the various forms of communication.

Another challenge with communication emerged when working with Leye. One challenge that arose in communication with Leye was gaining her input when support people were present. For example, the first phone call I received from Leye was from the director of a youth group she was a part of. Leye and Leye's sister were also on the call. Leye's supervisor and Leye's sister supported her in asking questions. I noticed that Leye was very quiet, and there were long pauses between when someone asked Leye a question and when Leye answered. The next interaction I had with Leye included her, her sister, her mom, and her dad. Her sister was in the frame of the camera, and they were sitting shoulder to shoulder. Leye's dad was out of the camera but was in the same room. Leye's mom was behind the camera and came into the camera a couple of times during the call. At the end of the assent meeting, I shared that there would be an interview, an observation, and a follow-up interview. Leye's dad asked me what it would consist of and how long the observation would be. I shared a couple of examples and said it could even be of Leye making challah. The following is an excerpt from my memo:

When I said I could watch her put yummy things in her dough, Participant 2 smiled. I noticed when mom said she had to speak up and when sister nudged her, she clammed up. She showed me her shaking hands and put her hands on her face. Her sister said, "aww," and Leye started to cry. Her sister said, "no tears." Mom came and put her hand on her sister.

I immediately shared that we can get to know each other more and that this can feel scary and uncomfortable. I let her know that I would hang up and talk with her only when she felt comfortable. I left the assent meeting with a lot of questions. Were there too many people there? Did that make her feel overwhelmed and pressured? A week after the assent meeting, Leye called me, and we talked on the phone for 15 minutes. We talked about things she liked to do, her plans for the weekend, and some of my interests. Communication with Leye has important implications for future research. It is important for the researcher to consider the impact of support and receiving a copious amount of support. A possible option is to share the importance of support and have a dialogue with the participant and the support person. Together they can form a loose contract to follow during communication to ensure the participant is the one being interviewed.

The present research study has implications and recommendations for religious clergy, religious leaders, counselor educators, counselors in training, and researchers. Even though there are a number of implications and recommendations, more research is needed, as described in the following section.

Future Research

There are many barriers to religion and spirituality that exist for individuals with disabilities, especially youth with IDD because they experience confounding challenges compared to neurotypical peers during their transition to adulthood (Forte et al., 2011). Oftentimes narratives about religious and spiritual experiences are told by parents and caregivers (Carter & Boehm, 2019; Carter et al., 2017; Nurullah, 2013; Poston & Turnbull, 2004; Uhrman, 2017) rather than by the individual with disabilities. Furthermore, research tends to end at determining what makes spaces accessible for families that have a child with disabilities (Ault et al., 2013; Carter et al., 2017; Griffin et al., 2012) rather than what makes spaces accessible for youth with disabilities.

There is a dearth of research that highlights the ways in which youth with IDD access religion and spirituality and make spiritual connections. Both Rachel and Leye shared unique and different ways in which they made meaning and made spiritual connections. I will expand this line of research by collaborating with youth with disabilities to determine what kinds of research they want and need. Marginalized voices need to be centralized in research (Annamma et al., 2013) to generate meaningful recommendations for the field and to continue to create accessible spaces and places for religious and spiritual youth with disabilities.

Limitations

A major limitation of this research study became apparent in the recruitment stage of the study. I designed my recruitment procedures with the thought that I was part of the in group. I am a Jewish researcher and have worked as a rehabilitation counselor for five years. I am enmeshed in the Jewish community and have been since I was a child. I grew up going to temple, attending Hebrew school, and going to Jewish day camp and Jewish overnight camp. Throughout my youth and adulthood, Judaism and disability converged for me. I was a Jewish youth group teen president who volunteers with children with disabilities, I was a one-on-one camp counselor for a child with disabilities at a Jewish camp, I worked at a Jewish youth and disability organization, and I spoke with congregants at my own temple about creating more inclusive practices for congregants with disabilities. Because I saw myself as part of the Jewish community and an ally in the disability community, I thought there would be no issue in recruiting participants.

Initially, I reached out to two sites, and after unsuccessfully recruiting participants, I expanded my inclusion criteria and reached out to an additional 16 sites. I was still unable to locate two participants, so I expanded my inclusion criteria again and reached out to an additional 44 sites. In total, I reached out to 62 temples, synagogues, Jewish organizations, Jewish disability organizations, and disability organizations. Eventually, I reached out to a supervisor from a Jewish youth group that I had interned with and asked them for help. They have a vast network and were able to connect me to a participant. The other participant came from a more personal reaction to an email I received. An employee at an organization shared that they could not send out the call for participants. I responded by saying how much the research means to me and how important it is. I asked if they had anyone in their personal network, they could send the call to. Within the hour, I got an email from them with the participant cc'd on it. A key takeaway I learned from recruitment was that sharing personal interest proved to be necessary for recruiting participants. It was not enough to say that I was a Jewish researcher who has worked in the field, I had to give additional information about why I am doing this research and what the impact of the research can be.

Another limitation from my study was that I conducted all consent and assent meetings, interviews, and observations, virtually. Collecting data virtually afforded me the opportunity to interview people from different places in the country without being there in person, but virtual data collection does have limitations. For instance, in the observation, it was very possible that I missed data because I was not in person. Rachel went off screen to retrieve things from other rooms, and Leye navigated the computer and iPad to connect to the internet. During both of these instances, I was not able to observe because I was not there in person. One way I adjusted for being virtual was that I held a follow-up interview with participants to member check. I asked about certain observations I was able to make and asked for more information for things I did not observe.

Multiple-case studies are advantageous because conclusions from two cases are more powerful than findings from a single case and allows for replication of research procedures (Yin, 2018). However, some may believe a major limitation in my study is assumed generalizability to other individuals with similar diagnoses. My participants both have IDD, and they have different lived experiences. The disability community is diverse and vast and even if an individual has the same disability, how they experience the world and their disability will be different. The diversity within this population is a strength, rather than a limitation. Because no two experiences can be the same, there is a need for future research to expand the findings of my study.

Even though I used a combination of strategies in my study to establish trustworthiness, there were still threats to trustworthiness. One threat to trustworthiness was using multiple methods of data collection. When using multiple methods of data collection, it is possible to become inundated with data and actually cause a burden for the researcher (Yin, 2018). When I was collecting data, I found the biggest burden to be scheduling times for each data collection point. To manage the abundance of data coming from various sources, I implemented a few strategies. I used Google Calendar and sent invitations that included the Zoom link to the participants. I also used a CAQDAS called Atlas.ti to create a distinction between the case study and the data collected and to increase reliability of the case study (Yin, 2018). In addition, Atlas.ti was used as a tool to help formulate the chain of evidence, which helps with overall construct validity of the study (Yin, 2018). As apparent through the limitations section, there were evident limitations in the study. Some limitations, such as that no experience of disability is the same for everyone and that I was not able to be in person to observe, lead to the need for future research.

Conclusion

The purpose of the present study was to describe how Jewish youth with IDD experience Jewish rituals/practices in the home. The findings included three themes and two empirical propositions. The empirical propositions were:

1. This case study showed how Jewish youth with IDD experience rituals and practices in the home, which highlights the importance of connecting to Judaism.
2. The case study showed how the very experience of rituals and practices influences the connection to Judaism, family, and the community, which influences the overall spiritual connection of these youth.

Findings from the present study are valuable for religious clergy, religious leaders, counselor educators, counselors in training, and researchers. There is a need for counselor educators to become more comfortable with understanding and broaching religion and spirituality with students (Adams, 2010; Cashwell et al., 2007; Cashwell et al., 2013). Counselor educators can apply the findings to their practices in teaching, counseling, and research, so they can address religion and spirituality for individuals with disabilities. Religious clergy, religious leaders, and religious community members can apply findings from the present study to their understanding of religion and spirituality for individuals with disabilities. A shift in understanding, based on the lived experiences of Jewish youth with IDD, can inform practices to make spaces and places more accessible for individuals with disabilities.

As a Jewish researcher, I hope to expand the line in research for Jewish individuals with disabilities. Hearing the lived experiences of Jewish youth with IDD is just the beginning of making research more common for this population. I plan to partner with Jewish youth with disabilities to determine what their needs and hopes are for research that involves them. So often research is done with their parents and caregivers (Carter & Boehm, 2019; Carter et al., 2017; Nurullah, 2013; Poston & Turnbull, 2004; Uhrman, 2017), and I hope to expand research to centralize their lived experiences.

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Appendix A: Participant Demographic Sheet

Name:

Age:

Race/Ethnicity:

Gender:

Religious/Spiritual Orientation (please circle how you identify):

Reform Jewish Conservative Jewish Modern Orthodox Jewish

Ultra-orthodox Jewish Other:______________________________

Do you have any accommodations you would like study staff to know about?

May we contact you to participate in the study?

How do you want to be contacted?

Phone call Phone text Voice message

Video call (Facetime/Google Hangout/Zoom) Email

What is your phone number?

What is your email?

Is there anything else you would like for us to know about you?

Appendix B: Interest/Disinterest Survey

1. What is your name?

2. What is your email address?

3. What is your phone number?

4. Would you like to be in the study

a. Yes

b. b. No

5. Who referred you to be in the study?

Thank you for completing this survey.

Appendix C: Recruitment Email

Subject Line: Recruiting for a study

Dear [potential participant]

My name is Aliza Lambert, and I am a doctoral candidate at Virginia Commonwealth University in the Counselor Education and Supervision program in the School of Education. I am conducting my dissertation study on lived experiences of Jewish youth with intellectual and developmental disabilities (IDD). You are receiving this email because you have an IDD and identifies as Jewish.

The purpose of this study is to learn from Jewish youth with IDD on their lived experiences of rituals/practices in the home.

The information I learn from this study will help me understand the lived experiences of Jewish youth with IDD. The information I learn from this study will also add to the small pool of research that exists from the perspectives and voices of individuals with disabilities. The information I learn from this study may also lead to more research in the field of counselor education.

To participate, you (or your child) will need to be (1) 15–24 years of age, (2) have access to internet, camera, and a microphone, (3) identify as Jewish, (4) identify as having an IDD, and (5) live in Maryland, Massachusetts, Michigan, New Jersey, New York, Ohio, Virginia, or Washington, D.C.

Participation in the study includes completing the demographic survey attached, a virtual interview, a virtual observation, and a virtual follow-up interview. I will also send you my findings at the end of the study and ask for your input.

If you (or your child) would like to be in this study, please click here (you may change your mind at any time) (hyperlink to RedCap survey)

This link will guide you to an initial recruitment survey where you will provide information (your name, email address, phone number, and interest or disinterest in being in the study).

If you have any questions or concerns, email Aliza Lambert (ahweiss@vcu.edu).

Sincerely,
Aliza Lambert, M.Ed., CRC
Doctoral Candidate - Counselor Education and Supervision

Appendix D: Interview One Questions

Interview One
Assent or Consent  **Yes** **No**
Favorite Jewish holiday  **Rosh Hashanah** **Yom Kippur** **Sukkot**


Simchat Torah **Hanukkah**


Tu Bishvat **Purim**

  **Passover** **Shabbat**
Tell me about how **you** celebrate
Tell me about how you help prepare for the holiday at home

How do other people in your family celebrate with you?

Which family members?

What do you do together?

Share a story about this holiday

Did you do special things at home?

What was that like?

What Jewish things do you do at home?

Does anyone do them with you?

How often do you do them?

Why do you do them?

How does it feel when you do these Jewish things?

Do you wear anything Jewish?

What does being Jewish mean to you?  What’s it like being Jewish and having a disability?
How does your family want you to participate in Jewish things? Has that changed now that you are ____ years old? Do you do anything differently in home now that you are ____years old?
Is there anything else you want to share with me?

Appendix E: Interview Two Questions

Interview Two

Is it alright if I ask you questions as part of my study?

Yes No

2.

3. What ritual/practice did you have me observe?

4.

5.

6.

7.

8.

Why did you choose this ritual/practice?

9.

10. What is meaningful to you about this ritual/practice?

11.

12. How often do you do this ritual/practice?

13.

14. What did you do during the ritual/practice?

15.

What did your family expect you to do during this ritual/practice?

16.

17. What was it like being with family and doing this ritual/practice?

18.

What was it like being at home and doing this ritual/practice?

19.
What is it like being Jewish and having a disability and participating in this ritual/practice? 20.
Is there anything else you want to share with me?

Appendix F: Participant Assent

VCU IRB PROTOCOL NUMBER: HM20023233

Version: 9/28/21

RESEARCH PARTICIPANT INFORMATION AND ASSENT FORM Study Title: Home Practices and Rituals: The Lived Experiences of Jewish Youth with Intellectual and Developmental Disabilities

VCU Student Investigator: Aliza Lambert, Doctoral Candidate Counselor Education and Supervision, Virginia Commonwealth University

About This Form

This form may have some words that you do not know. Please ask me to explain any words that you do not know. You may take this form home to think about and talk to your family about before you decide if you want to be in this study. What is this study about? I am doing this study to learn about your family member's experiences being Jewish and having a disability. I am also doing this study to learn about how they do Jewish things in the home.

What will happen to me if I choose to be in this study?

In this study, you will be asked to: Do a Jewish event at your home with the people you live with and allow a researcher to watch. Will any parts of this study make me feel bad? If you allow a researcher to observe during this study, you may have some stress from being observed.

The following are examples of issues that you may come across that might bother you while the observation is taking place.

You may experience:

· A change in your schedule
· People you are not used to
· Situations you have not experienced before

You can leave the study at any time. If you do become upset and want the researcher to leave, they will leave.

How will this study help me?

Being in this study might help you and your family do more Jewish things in the home and make these Jewish things more enjoyable. However, we cannot promise you that you that either of these things will happen.

What do I get if I am in this study?

No, you will not get paid for being in the study.

Will you tell anyone what I say?

Yes, but when I talk about this study at meetings or in writing, I will never use your name. You can also tell me what things you don't want included. If you tell us that someone is hurting you, or that you might hurt yourself or someone else, by law we have to report that to people or agencies that might help you.

Do I have to be in this study?

You do not have to be in this study. It is up to you. You can say okay now and change your mind later. No one will blame you or get mad at you if you don't want to do this. All you have to do is tell us you want to stop.

Do you have any questions?

You can ask questions at any time. You can ask now or later. Just tell the researcher when you see them, or ask your family member or another adult call Aliza Lambert VCU SOE 907 Floyd Ave, Richmond, VA 23284 (804) 827-1323 ahweiss@vcu.edu

Before you say yes or no to being in this study, we will answer any questions you have now. If you don't want to be in this study, just say so, and don't sign this form. **If you sign here, it means you agree to participate in this study.

____ ________________

Youth Participant's Name (Printed) Date

____ ________________

Youth Participant's Signature Date

____ Name of Person Conducting Assent Discussion (Printed) ____

____

Signature of Person Conducting Assent Discussion Date

____ ________________

Principal Investigator Signature (if different from above) Date

Appendix G: Visual Assent for Participant

Do you want to be in the study?

YES

NO

Appendix H: Participant Consent

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM STUDY TITLE: Home Practices and Rituals: The Lived Experiences of Jewish Youth with Intellectual and Developmental Disabilities

VCU INVESTIGATOR: Abigail Holland Conley, PhD, Associate Professor, Department of Counseling and Special Education

NOTE: In this consent form, “you” always refers to the research participant.

ABOUT THIS CONSENT FORM This form may have some words that you do not know. Please ask me to explain any words that you do not know. You may take this form home to think about and talk to your family about before you decide if you want to be in this study. Your participation is voluntary. You may decide not to participate in this study. If you do participate, you may withdraw from the study at any time. Your decision not to take part or to withdraw will involve no penalty or loss of benefits to which you are otherwise entitled.

AN OVERVIEW OF THE STUDY AND KEY INFORMATION Why is this study being done? I am doing this study to learn about your experiences being Jewish and having a disability and how you do Jewish things in the home. You are being asked to take part in this study because you: 1. Identify as having an Intellectual or Developmental Disability 2. Identify as being Jewish 3. Are between the ages of 15 and 24 4. Live in Maryland, Massachusetts, Michigan, New Jersey, New York, Ohio, Virginia or Washington, D.C. Description of the study and your involvement: If you decide to agree to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

If you decide to take part in this study, you will be asked to participate in a survey. During this survey, we will ask for your name, age, gender, religious and spiritual orientation, who lives at home with you, and how we can contact you. Once in the study, you will have an interview with the researcher and a family member or caregiver of your choosing. This interview will take up to an hour. Then you will choose a Jewish ritual or practice for the researcher to observe in your home. The researcher will not participate, will not evaluate you, and will not evaluate your family. The researcher will record the ritual/practice on the computer, and take notes on how you participate and experience rituals and practices.

After the observation, the researcher will ask you to meet again for a follow-up interview that will last one hour. In this interview the researcher will ask you more detailed questions about the ritual/practice recorded. The researcher will then make a summary of the interview and observation and share it with you for your feedback. As a part of this research study, we will stay in touch with you for a period of 6 months after you enroll in the study. This is so we can do the interview, the observation, and then give you the summary for you to give feedback on. What alternative treatments or procedures are available? The only alternative to this study is to not take part. There are no consequences for saying no to the study. What are the risks of participating? There are no risks beyond what you would encounter engaging in a Jewish practice or ritual at home. These are examples of issues that you may come across: stress from researcher observing, discomfort from answering questions about your disability and Judaism, and varying emotions from engaging in the ritual or practice.

Benefits to you and others: Being in this study might help you and your family do more Jewish things in the home and make these Jewish things more enjoyable. However, we cannot promise you that you that either of these things will happen. Now that you have a general overview of the study, we want to provide the details about what your participation involves. Please read, or have someone read to you, the rest of this document. If there is anything you don't understand, be sure to ask the study staff.

WHY IS THIS STUDY BEING DONE? The purpose of this study is to prioritize voices and lived experiences of youth with intellectual and developmental disabilities. We want to learn from youth themselves instead of about youth. This way, the actual experiences, and ways the individuals make meaning, are prioritized in data collection and analysis. Another goal of this study is to contribute more largely to the counselor education and supervision field. Findings from this study have potential to impact how counselor educators teach about religion and spirituality.

WHAT WILL HAPPEN IF I PARTICIPATE IN THE STUDY? You will get an email from me asking if you would like to participate in the study. If you select yes, you will get another email from me with a demographic survey in it. This survey should take up to 30 minutes to complete. You will talk with me through email to set up a time for your first interview. In the demographic survey I will confirm any accommodations or modifications needed to ensure accessibility to the interview (e.g., closed captioning, transcript of questions sent ahead of time, alternative text descriptions of pictures) and will send the interview questions to you and your family member/caregiver ahead of time. At your first interview (Interview 1), you will be interviewed by the study staff for up to one hour over Zoom.

You will have the opportunity to take as many breaks as needed. At the end of this meeting, we will pick a time to do an observation run-through and the observation. The observation run-through will occur over Zoom and will cover: how to position the camera, my role as an observer, your role as a participant, how I will use the recording, and how the recording will be deleted. The observation will occur over Zoom. The time will vary depending on the ritual/practice you select. It can last from 5 minutes up to 1 hour. I will email you after this observation to set up Interview 2.

Interview 2 will be conducted over Zoom and will last up to one hour with the opportunity for as many breaks as needed. I will reach out to you and your family member/caregiver to schedule the interview. I will confirm any accommodations or modifications needed to ensure accessibility to the interview (e.g., closed captioning, transcript of questions sent ahead of time, alternative text descriptions of pictures) and will send the interview questions to you and your family member/caregiver ahead of time. When I am done with the study, I will send you an email with a one-pager about what I found from the study and will ask you for your input. You can send me back an email with corrections and your input. Non-Physical Risks Participation in research might involve some loss of privacy. There is a small risk that someone outside the research study could see and misuse information about you.

You may learn things about yourself that you did not know before and that could affect how you think about yourself.

CAN I STOP BEING IN THE STUDY? You can stop being in this research study at any time. Leaving the study will not affect your participation in The Friendship Circle of Richmond or the Richmond Jewish Community Center. Tell the study staff if you are thinking about stopping or decide to stop. Your participation in this study may be stopped at any time by the investigator without your consent.

The reasons might include:

- you are found to not be eligible for the study
- the investigator thinks it necessary for your health or safety

HOW WILL INFORMATION ABOUT ME BE PROTECTED? VCU and the VCU Health System have established secure research databases and computer systems to store information and to help with monitoring and oversight of research. Your information may be kept in these databases but are only accessible to individuals working on this study or authorized individuals who have access for specific research related tasks. Identifiable information in these databases are not released outside VCU unless stated in this consent or required by law. Although results of this research may be presented at meetings or in publications, identifiable personal information about participants will not be disclosed. Personal information about you might be shared with or copied by authorized representatives from VCU for the purposes of managing, monitoring and overseeing this study: In general, we will not give you any individual results from the study. Once the study has been completed, we will send you a summary of all of the results of the study and what they mean. We will not tell anyone the answers you give us. However, if you tell us that you may hurt yourself or someone else, the law says that we must let people in authority know. In the future, identifiers might be removed from the information and samples you provide in this study, and after that removal, the information/samples could be used for other research studies by this study team or another researcher without asking you for additional consent.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY? In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact: Aliza H. Lambert VCU SOE 907 Floyd Ave, Richmond, VA 23284 (804) 827-1323 ahweiss@vcu.edu If you have general questions about your rights as a participant in this or any other research, or if you wish to discuss problems, concerns or questions, to obtain information, or to offer input about research, you may contact: Virginia Commonwealth University Office of Research 800 East Leigh Street, Suite 3000, Box 980568, Richmond, VA 23298 (804) 827-2157; https://research.vcu.edu/human-research/ Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

STATEMENT OF CONSENT I have been given the chance to read this consent form. I understand the information about this study. Questions I wanted to ask about the study have been answered.

My signature says that I am willing to participate in this study. Signature Block for Enrolling Adult Participants ____

Adult Participant Name (Printed)

____

Adult Participant's Signature Date

____ Name of Person Conducting Consent Discussion (Printed) ____

____

Signature of Person Conducting Consent Discussion Date

____ _________________

Principal Investigator Signature (if different from above) Date

Signature Block for Enrolling Decisionally Impaired Adult Participants – LAR Consent

____

Name of Adult Participant (Printed)

____

____

Name of Legally Authorized Representative (Printed) Relationship to Participant

____ _________________

Legally Authorized Representative Signature Date

____

Name of Person Conducting Consent/Assent Discussion (Printed)

____ _________________

Signature of Person Conducting Consent/Assent Discussion Date

____ _________________

Principal Investigator Signature (if different from above) Date Signature Block for Enrolling Child Participants - Parent/Guardian Permission

____

Name of Child/Youth Participant

____ Name of First Parent/Legal Guardian (Printed) Study team – verify that this individual is the child's parent or legal guardian.

____ _________________

Required First Parent/Legal Guardian Signature Date

____ _________________

Optional Second Parent /Legal Guardian's Signature Date

Appendix I: Legally Authorized Representative (LAR) Form

RESEARCH PARTICIPANT INFORMATION AND PERMISSION FORM FOR LEGALLY AUTHORIZED REPRESENTATIVE (LAR)

STUDY TITLE: Home Practices and Rituals: The Lived Experiences of Jewish Youth with Intellectual and Developmental Disabilities

VCU INVESTIGATOR: Abigail Holland Conley, PhD, Associate Professor, Department of Counseling and Special Education NOTE: In this consent form, if you are a legally authorized representative, please remember that "you" refers to the study participant.

ABOUT THIS CONSENT FORM You are being invited to participate in a research study. It is important that you carefully think about whether being in this study is right for you and your situation. This consent form is meant to assist you in thinking about whether or not you want to be in this study. Please ask the investigator or the study staff to explain any information in this consent document that is not clear to you. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision. Your participation is voluntary. You may decide not to participate in this study. If you do participate, you may withdraw from the study at any time. Your decision not to take part or to withdraw will involve no penalty or loss of benefits to which you are otherwise entitled.

AN OVERVIEW OF THE STUDY AND KEY INFORMATION Why is this study being done? I am doing this study to learn about your experiences being Jewish and having a disability and how you do Jewish things in the home. You are being asked to take part in this study because you: 1. Identify as having an Intellectual or Developmental Disability 2. Identify as being Jewish 3. Are between the ages of 15 and 24 4. Live in Maryland, Massachusetts, Michigan, New Jersey, New York, Ohio, Virginia or Washington, D.C.

What will happen if your child participates? If you decide to agree to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you. If you decide to take part in this study, you will be asked to participate in a survey. During this survey, we will ask for your name, age, gender, religious and spiritual orientation, who lives at home with you, and how we can contact you. Once in the study, you will have an interview with the researcher and a family member or caregiver of your choosing. This interview will take up to an hour. Then you will choose a Jewish ritual or practice for the researcher to observe in your home. The researcher will not participate, will not evaluate you, and will not evaluate your family.

The researcher will record the ritual/practice on the computer, and take notes on how you participate and experience rituals and practices. After the observation, the researcher will ask you to meet again for a follow-up interview that will last one hour. In this interview the researcher will ask you more detailed questions about the ritual/practice recorded. The researcher will then make a summary of the interview and observation and share it with you for your feedback. As a part of this research study, we will stay in touch with you for a period of 6 months after you enroll in the study. This is so we can do the interview, the observation, and then give you the summary for you to give feedback on. What alternative treatments or procedures are available? The only alternative to this study is to not take part. There are no consequences for saying no to the study.

What are the risks and benefits of participating? There are no risks beyond what you would encounter engaging in a Jewish practice or ritual at home. These are examples of issues that you may come across: stress from researcher observing, discomfort from answering questions about your disability and Judaism, and varying emotions from engaging in the ritual or practice.

Benefits to you and others: Approved by the Being in this study might help you and your family do more Jewish things in the home and make these Jewish things more enjoyable. However, we cannot promise you that you that either of these things will happen. Now that you have a general overview of the study, we want to provide the details about what your participation involves. Please read, or have someone read to you, the rest of this document. If there is anything you don't understand, be sure to ask the study staff.

WHY IS THIS STUDY BEING DONE? The purpose of this study is to prioritize voices and lived experiences of youth with intellectual and developmental disabilities. We want to learn from youth themselves instead of about youth. This way, the actual experiences, and ways the individuals make meaning, are prioritized in data collection and analysis. Another goal of this study is to contribute more largely to the counselor education and supervision field. Findings from this study have potential to impact how counselor educators teach about religion and spirituality.

WHAT WILL HAPPEN IF I PARTICIPATE IN THE STUDY? You will get an email from me asking if you would like to participate in the study. If you select yes, you will get another email from me with a demographic survey in it. This survey should take up to 30 minutes to complete. You will talk with me through email to set up a time for our first interview. In the demographic survey I will confirm any accommodations or modifications needed to ensure accessibility to the interview (e.g., closed captioning, transcript of questions sent ahead of time, alternative text descriptions of pictures) and will send the interview questions to you and your family member/caregiver ahead of time. At your first interview (Interview 1), you will be interviewed by the study staff for up to one hour over Zoom. You will have the opportunity to take as many breaks as needed. At the end of this meeting, we will pick a time to do an observation run-through and the observation. The observation run-through will occur over Zoom and will cover: how to position the camera, my role as an observer, your role as a participant, how I will use the recording, and how the recording will be deleted. The observation will occur over Zoom. The time will vary depending on the ritual/practice you select. It can last from 5 minutes up to 1 hour. I will email you after this observation to set up Interview 2.

Interview 2 will be conducted over Zoom and will last up to one hour with the opportunity for as many breaks as needed. I will reach out to you and your family member/caregiver to schedule the interview. I will confirm any accommodations or modifications needed to ensure accessibility to the interview (e.g., closed captioning, transcript of questions sent ahead of time, alternative text descriptions of pictures) and will send the interview questions to you and your family member/caregiver ahead of time. When I am done with the study, I will send you an email with a one-pager about what I found from the study and will ask you for your input. You can send me back an email with corrections and your input. Non-Physical Risks Participation in research might involve some loss of privacy. There is a small risk that someone outside the research study could see and misuse information about you. You may learn things about yourself that you did not know before and that could affect how you think about yourself.

CAN I STOP BEING IN THE STUDY? You can stop being in this research study at any time. Leaving the study will not affect your participation in your temple, synagogue, or organization (i.e., The Friendship Circle, Autism Society, etc.). Tell the study staff if you are thinking about stopping or decide to stop. Your participation in this study may be stopped at any time by the investigator without your consent.

The reasons might include:

- you are found to not be eligible for the study
- the investigator thinks it necessary for your health or safety

HOW WILL INFORMATION ABOUT ME BE PROTECTED? VCU and the VCU Health System have established secure research databases and computer systems to store information and to help with monitoring and oversight of research. Your information may be kept in these databases but are only accessible to individuals working on this study or authorized individuals who have access for specific research related tasks. Identifiable information in these databases are not released outside VCU unless stated in this consent or required by law. Although results of this research may be presented at meetings or in publications, identifiable personal information about participants will not be disclosed.

Personal information about you might be shared with or copied by authorized representatives from VCU for the purposes of managing, monitoring and overseeing this study: In general, we will not give you any individual results from the study. Once the study has been completed, we will send you a summary of all of the results of the study and what they mean. We will not tell anyone the answers you give us. However, if you tell us that you may hurt yourself or someone else, the law says that we must let people in authority know. In the future, identifiers might be removed from the information and samples you provide in this study, and after that removal, the information/samples could be used for other research studies by this study team or another researcher without asking you for additional consent.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY? In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact: Aliza H. Lambert VCU SOE 907 Floyd Ave, Richmond, VA 23284 (804) 827-1323 ahweiss@vcu.edu If you have general questions about your rights as a participant in this or any other research, or if you wish to discuss problems, concerns or questions, to obtain information, or to offer input about research, you may contact: Virginia Commonwealth University Office of Research 800 East Leigh Street, Suite 3000, Box 980568, Richmond, VA 23298 (804) 827-2157; https://research.vcu.edu/human-research/ Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

I have been provided with an opportunity to read this permission form carefully. All of the questions that I wish to raise concerning this study have been answered. By signing this permission form, I have not waived any of the legal rights or benefits to which I [and/or my child] otherwise would be entitled. My signature indicates that I freely consent to participate and give permission for my child to participate in this research study. I will receive a copy of the permission form for my records. Signature Block for Enrolling Decisionally Impaired Adult

Participants – LAR Consent ____

Name of Adult Participant (Printed)

____

____

Name of Legally Authorized Representative (Printed) Relationship to Participant

____ ________________

Legally Authorized Representative Signature Date

____

Name of Person Conducting Consent/Assent Discussion (Printed)

____ ________________

Signature of Person Conducting Consent/Assent Discussion Date

____ ________________

Principal Investigator Signature (if different from above) Date

Parent/Guardian Permission ____

Name of Child/Youth Participant

____ Name of First Parent/Legal

Guardian (Printed) Study team – verify that this individual is the child’s parent or legal guardian.

____ _________________

Required First Parent/Legal Guardian Signature Date

____ _________________

Optional Second Parent /Legal Guardian’s Signature Date

Appendix J: Research Participant Form: Family Consent

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

STUDY TITLE: Home Practices and Rituals: The Lived Experiences of Jewish Youth with Intellectual and Developmental Disabilities

VCU INVESTIGATOR: Abigail Holland Conley, PhD, Associate Professor, Department of Counseling and Special Education

NOTE: In this consent form, "you" always refers to the family member of the participant. ABOUT THIS CONSENT FORM This form may have some words that you do not know. Please ask me to explain any words that you do not know. You may take this form home to think about and talk to your family about before you decide if you want to be in this study. Your participation is voluntary. You may decide not to participate in this study. If you do participate, you may withdraw from the study at any time. Your decision not to take part or to withdraw will involve no penalty or loss of benefits to which you are otherwise entitled.

AN OVERVIEW OF THE STUDY AND KEY INFORMATION Why is this study being done? I am doing this study to learn about your family member's experiences being Jewish and having a disability and how they do Jewish things in the home. You are being asked to take part in this study because your family member: 1. Identifies as having an Intellectual or Developmental Disability 2. Identifies as being Jewish 3. Is between the ages of 15 and 24 4. Lives in Maryland, Massachusetts, Michigan, New Jersey, New York, Ohio, Virginia or Washington, D.C.

Description of the study and your involvement: If you decide to agree to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you. If you decide to take part in this study, you will be asked to participate in a Jewish ritual or practice for the researcher to observe in your home. The researcher will not participate, will not Approved by the evaluate you, and will not evaluate your family. The researcher will record the ritual/practice on the computer, and take notes on how you participate and experience rituals and practices.

What alternative treatments or procedures are available? The only alternative to this study is to not take part. There are no consequences for saying no to the study. What are the risks of participating? There are no risks beyond what you would encounter engaging in a Jewish practice or ritual at home. These are examples of issues that you may come across: stress from researcher observing, discomfort from your family member answering questions about their disability and Judaism, and varying emotions from engaging in the ritual or practice.

Benefits to you and others: Being in this study might help you and your family do more Jewish things in the home and make these Jewish things more enjoyable. However, we cannot promise you that you that either of these things will happen. Now that you have a general overview of the study, we want to provide the details about what your participation involves. Please read, or have someone read to you, the rest of this document. If there is anything you don’t understand, be sure to ask the study staff.

WHY IS THIS STUDY BEING DONE? The purpose of this study is to prioritize voices and lived experiences of youth with intellectual and developmental disabilities. We want to learn from youth themselves instead of about youth. This way, the actual experiences, and ways the individuals make meaning, are prioritized in data collection and analysis. Another goal of this study is to contribute more largely to the counselor education and supervision field. Findings from this study have potential to impact how counselor educators teach about religion and spirituality.

WHAT WILL HAPPEN IF I PARTICIPATE IN THE STUDY? You will get an email from me asking if you would like to participate in the study. If you select yes, you will participate in a Jewish ritual/practice of your family member's choosing. The observation will occur over Zoom. The time will vary depending on the ritual/practice your family member selects. It can last from 5 minutes up to 1 hour. You will be asked to pretend like I am not there observing. You and your family will then participate in the Jewish ritual/practice. Non-Physical Risks Approved by the Participation in research might involve some loss of privacy. There is a small risk that someone outside the research study could see and misuse information about you. You may learn things about yourself that you did not know before and that could affect how you think about yourself.

CAN I STOP BEING IN THE STUDY? You can stop being in this research study at any time. Leaving the study will not affect your participation in The Friendship Circle of Richmond or the Richmond Jewish Community Center. Tell the study staff if you are thinking about stopping or decide to stop. Your participation in this study may be stopped at any time by the investigator without your consent.

The reasons might include:

- Your family member is found to not be eligible for the study
- The investigator thinks it necessary for your health or safety

HOW WILL INFORMATION ABOUT ME BE PROTECTED? VCU and the VCU Health System have established secure research databases and computer systems to store information and to help with monitoring and oversight of research. Your information may be kept in these databases but are only accessible to individuals working on this study or authorized individuals who have access for specific research related tasks. Identifiable information in these databases are not released outside VCU unless stated in this consent or required by law. Although results of this research may be presented at meetings or in publications, identifiable personal information about participants will not be disclosed. Personal information about you might be shared with or copied by authorized representatives from VCU for the purposes of managing, monitoring and overseeing this study: In general, we will not give you any individual results from the study. Once the study has been completed, we will send you a summary of all of the results of the study and what they mean. We will not tell anyone the answers you give us.

However, if you tell us that you may hurt yourself or someone else, the law says that we must let people in authority know. In the future, identifiers might be removed from the information and samples you provide in this study, and after that removal, the information/samples could be used for other research studies by this study team or another researcher without asking you for additional consent.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY? In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact: Aliza H. Lambert VCU SOE 907 Floyd Ave, Richmond, VA 23284 (804) 827-1323 ahweiss@vcu.edu If you have general questions about your rights as a participant in this or any other research, or if you wish to discuss problems, concerns or questions, to obtain information, or to offer input about research, you may contact: Virginia Commonwealth University Office of Research 800 East Leigh Street, Suite 3000, Box 980568, Richmond, VA 23298 (804) 827-2157; https://research.vcu.edu/human-research/ Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

STATEMENT OF CONSENT I have been given the chance to read this consent form. I understand the information about this study. Questions I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. Signature Block for Enrolling Adult Participants ____

Adult Participant Name (Printed)

____ ________________

Adult Participant's Signature Date

____ Name of Person Conducting Consent Discussion (Printed)

____ _______________

Signature of Person Conducting Consent Discussion Date

____ _______________

Principal Investigator Signature (if different from above) Date Signature Block for Enrolling Decisionally Impaired Adult Participants – LAR Consent

____

Name of Adult Participant (Printed)

____

____

Name of Legally Authorized Representative (Printed) Relationship to Participant

____ _______________

Legally Authorized Representative Signature Date

____

Name of Person Conducting Consent/Assent Discussion (Printed)

____ _______________

Signature of Person Conducting Consent/Assent Discussion Date

____ _______________

Principal Investigator Signature (if different from above) Date Signature Block for Enrolling Child Participants - Parent/Guardian Permission Approved

____

Name of Child/Youth Participant

____

Name of First Parent/Legal Guardian (Printed) Study team – verify that this individual is the child's parent or legal guardian. ____

____

Required First Parent/Legal Guardian Signature Date

____ ________________

Optional Second Parent /Legal Guardian's Signature Date

Appendix K: Plain Language Findings

Jewish Experiences

Youth with intellectual and developmental disabilities

Who was in the study?

Jewish youth with intellectual or developmental disabilities

Why did this study happen?

There isn't a lot of research with youth with disabilities and research is usually with parents and guardians. Research has shown religion and spirituality are important to wellness. The current study adds to research and includes voices of youth with disabilities.

What happened in the study?

The researcher asked the 2 individuals about their experiences being Jewish and having a disability. The researcher observed each individual doing a Jewish ritual or practice in their home. The researcher followed research methods and reviewed the data. The researcher wrote the results and shared them.

What did the researcher find?

1) Jewish experiences have different meanings for each person

2) A middle space exists for youth with intellectual and developmental disabilities meaning their needs aren't always met and can feel left out

3) Being creative and making creative spaces helps to connect spiritually

What can leaders do based on the findings?

Religious leaders and clergy can:

1) Ask youth with disabilities how they want to be included at temple and in the community

2) Ask youth with disabilities how they need to be supported so they can participate

The counseling field can:

1) Talk about disability identity and wellness practices in class

2) Learn more about access to religious and spiritual spaces

Researchers can:

1) Talk to self-advocates to reach individuals with disabilities

2) Ask individuals about how they like to communicate

3) Continue to do research with this population, it’s important!