Inclusion

Enhancing Religious and Spiritual Inclusion of Jewish Youth with Intellectual and/or Developmental Disabilities

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Abstract:	There is a dearth of research surrounding religion and spirituality for individuals with I/DD, and existing studies often solely explore if youth with intellectual and/or developmental disabilities can be religious and spiritual. A better understanding of religious minorities can enhance the inclusion of youth with intellectual and developmental disabilities (I/DD). In this multiple case study, Jewish youth with I/DD participated in two semi-structured interviews and an observation of a Jewish ritual/practice. Three themes and eight subthemes emerged related to accessing religion and spirituality. The implications from this study can help prepare religious leaders, clergy, and researchers to better support, engage, and include Jewish youth with I/DD.

Enhancing Religious and Spiritual Inclusion of Jewish Youth with Intellectual and/or Developmental Disabilities

Abstract

There is a dearth of research surrounding religious minorities regarding religion and spirituality for individuals with intellectual and/or developmental disabilities, and existing studies often solely explore *if* youth with intellectual and/or developmental disabilities *can* be religious and spiritual. A better understanding of religious minorities can enhance the inclusion of youth with intellectual and developmental disabilities (I/DD). In this multiple case study, Jewish youth with I/DD participated in two semi-structured interviews and an observation of a Jewish ritual/practice. Three themes and eight subthemes emerged related to accessing religion and spirituality. The implications from this study can help prepare religious leaders, clergy, and researchers to better support, engage, and include Jewish youth with I/DD.

Keywords: Access, religion, spirituality, Judaism, I/DD, youth

Enhancing Religious and Spiritual Inclusion of Jewish Youth with Intellectual and/or Developmental Disabilities

Researchers have commonly explored ways to promote full inclusion for individuals with intellectual and developmental disabilities (I/DD), often examining areas such as education, employment, and community engagement (Haber et al., 2016; Taylor et al., 2020). One aspect of daily life that is often overlooked for individuals with I/DD is religious and spiritual inclusion (Carter et al., 2017), even though this aspect of their lives is important to mental health and well-being (Biggs & Carter, 2016; Brown & Schippers, 2016; Koenig, 2012; Taub & Werner, 2016).

Research regarding religion and spirituality for individuals with I/DD traditionally is intended to determine *if* individuals with I/DD *can* be religious and spiritual (Vogel & Reiter, 2004). Descriptions of lived experiences regarding religion and spirituality are often relayed by parents and guardians (Carter & Boehm, 2019; Carter et al., 2017; Nurullah, 2013; Poston & Turnbull 2004) rather than by individuals with I/DD. There are limited studies about faith from the perspectives of individuals with I/DD (Liu et al., 2014; Sango & Forrester-Jones, 2018), and many research studies include narratives from white, Christian, parents/guardians (Ault et al., 2013; Boehm et al., 2015, Boehm & Carter, 2019). Although some researchers found that youth place a high importance on religion (Liu et al., 2014), nuances of these experiences remain unexplored among those with I/DD, particularly those with non-Christian religious affiliation. Thus, a deeper understanding of religious minorities, such as Jews, can enhance the overall inclusion of individuals with I/DD in religious and spiritual spaces. Because Jews are a small ethno-religious group, accounting for only about 2% of the U.S. population (Pew Research

Center, 2021), studies of religion and spirituality for those with I/DD are less likely to include this population.

The Jewish people are a collective minority group (DellaPergola, 2010) “who share a common religious, cultural, and ethnic background” (Selekman & Zavadivker, 2021, p. 557). Almost half (47.9%) of the world’s Jewish population (about 15 million) lives in the United States (American-Israeli Cooperative Enterprise, n.d.). Enactment of one’s Jewishness can occur both on an individual or group basis (Rosen, 2018), and in the home or within the community (Ginsberg & Sinacore, 2013). Depending on where a Jewish individual with disabilities lives, there might not be Jewish spaces available or accessible. Regardless of access to Jewish spaces, one Jewish space that can be customizable and adaptable is the Jewish home (Kaplan, 2019). Jewish rituals and practices in the home can be personally meaningful and promote continuity of the Jewish religion and the Jewish people (Kaplan, 2019).

Religious and Spiritual Inclusion

Researchers indicated that religion and spirituality contribute to social support (Biggs & Carter, 2016; Taub & Werner, 2016), less depression and anxiety (Brown & Schippers, 2016), and improved well-being (Koenig, 2012) among individuals with I/DD, regardless of their religious affiliation. Although many religious groups in the United States provide disability programming or have affiliated disability organizations (Glicksman, 2011), there seems to be varied, and potentially conflicting understanding regarding inclusion of those with disabilities.

Religious institutions preserve culture and educate youth on various beliefs and practices. Clergy and religious institutions greatly impact the level of support families and children with disabilities receive in the congregation (Annandale & Carter, 2014). An indicator of inclusion of individuals with I/DD and their families in religious spaces is community members’ views of inclusion. Carter et al. (2017) queried 175 participants from three faith communities to determine how community members viewed the commitment and support of participation of people with disabilities. Using a community conversation model, the researchers gathered nearly 1,000 strategies that enhanced belonging and inclusion for people with disabilities. The predominant strategy to increase belonging and inclusion included disability-specific efforts from the congregation, such as focused reflection and training to raise awareness. Though many strategies were identified, participants still identified a lack of commitment to youth and adults with disabilities in congregational programming.

Carter and Boehm (2019) explored spiritual practices that youth with I/DD are involved with at home and within their congregation by surveying 440 parents of youth with I/DD. The most common spiritual practices included religious holiday traditions in the home, listening to religious music, and praying at home with family. Most parents indicated that their child considers themselves to be active in their faith congregation (60.6%) and enjoyed being around people of similar faith (72.3%). Though parents in this study provided meaningful reports of their child’s religious practices and strength, such research would be enhanced by including the narratives of youth with disabilities themselves. Relying on the input of parents can conflate and misrepresent the actual experiences of their young adults.

Further, religious and spiritual life may include activities like cooking traditional meals, observing lifecycle rituals, connecting to ancestors, and connecting to religious and spiritual music, all experience common among those identifying as Jewish (Fulton et al., 2024). A study of the ways in which youth with I/DD engage in a wider range of spiritual and religious practices may help prepare religious leaders, clergy, and researchers to better support, engage, and include youth with I/DD, and more specifically, Jewish youth with I/DD.

The Intersection of Disability and Judaism

In Judaism there are three major denominations: Reform, Conservative, and Orthodox (for a full review of Judaism as a religion, see Selekman & Zavadivker [2021]). Though there are major differences between the main denominations, each sect prioritizes Jewish rituals and practices to connect to Judaism personally and communally. Jewish rituals and practices are repetitive behaviors related to Jewish beliefs and customs, and practices can be performed individually or shared in a group (George et al., 2013). Rituals and practices can be spiritual, and therefore deeply individual and personal (Boskovich, 2019). Engaging with rituals and practices is a way to connect to being Jewish and a pathway to meaning making. Understanding how meaning is made can help support and engage individuals in their Jewish connection and enactment and having a strong connection to Judaism leads to a sense of belonging (Vogel & Reiter, 2004).

There is strong need to build systems of support in the Jewish community to make Judaism accessible and inclusive for youth with disabilities; however, there is a dearth of research involving Jewish youth with disabilities. The research that does exist explores the religious and spiritual abilities of people with disabilities rather than engaging people with disabilities in the research by learning about their religious and spiritual experiences firsthand. For instance, Lifshitz et al. (2009) investigated the ability and motives of adolescents and adults with I/DD to fulfill Jewish commandments. The researchers found that there were similarities between individuals with I/DD and the general public in their ability and motivational reasons to fulfill Jewish commandments.

A common milestone for Jewish youth is becoming a bar/bat mitzvah. Becoming a bar/bat mitzvah means becoming a Jewish adult as defined within Judaism, typically at age 12 or

13 depending on the denomination. Though many researchers study the bar/bat mitzvah, often referred to as “the rite of passage” (Vogel & Reiter, 2004, p. 294), few researchers studied this experience for youth with I/DD. Vogel and Reiter (2004) conducted a qualitative study with 29 parents of Jewish youth with I/DD. Researchers conducted two semi-structured interviews (one prior to the bar/bat mitzvah and one after), an observation of the bar/bat mitzvah ceremony, and an analysis of artifacts (e.g., photo albums). Parents reported that their children felt connection to ancestors and belonging in the Jewish community as a result of the experience, yet the study did not include exploration of such themes among those with I/DD themselves. Therefore, following is a description of a study examining the experiences of religion/spirituality among Jewish youth with I/DD.

Theoretical Framework

From the perspective of Disability Critical Race Theory (DisCrit), which takes a more multidimensional and intersectional perspective of identity (Annamma et al., 2013), individuals with I/DD exist in the intersection of their disability and other social identities, including religious and spiritual identities. Therefore, the definition of I/DD used for this study was selected to reject the singular notions of identity and includes environmental and cultural differences, which contrasts the medical definition of I/DD.

DisCrit has seven tenets that are commonly used as guiding principles for all disciplines (Annamma et al., 2013). The researchers used the seven DisCrit tenets to further center the voices of individuals. To accomplish this, the researchers: (1) used semi-structured interviews to enhance flexibility in the use of questions; (2) conducted an observation to increase opportunities for individuals with different communication preferences to be able to share their experiences (the researcher was a passive vs. participant-observer due to the power and privilege that the researcher has in their role and identities of being white, cisgender female, and being able-bodied); (3) created and shared plain language and accessible interview questions with the participants; and (4) used member-checking and shared a one-pager summarizing the research findings with the participants.

Purpose of the Study

The purpose of this study is to describe and more deeply understand the lived experiences of Jewish youth with I/DD. More specifically, we aim to highlight the themes and subthemes related to religious and spiritual inclusion to better prepare religious leaders and researchers so they can include and engage Jewish youth with I/DD.

The researchers used a multiple-case study to answer the following research question: "What are the lived experiences of Jewish youth with intellectual and developmental disabilities as they participate in Jewish rituals/practices in the home?" Multiple case studies are used to describe and develop a deep understanding of phenomena (Harrison et al., 2017) offer a mindful way to collect in-depth data (Creswell et al., 2007) and document stories from participants (Hays & Sing, 2012). This study serves as a pathway to work with participants and create space for voices often excluded from research.

Methods

Participants

To recruit participants, the researcher sent emails to 62 temples, synagogues, Jewish organizations, self-advocacy, and disability organizations. To be included in the study, participants needed to meet the following criteria: a) biological age of 15 to 24 years old; b) identify as having an intellectual and/or developmental disability; c) identify as Jewish (culturally, spiritually, or religiously); and d) live in Maryland, Massachusetts, Michigan, New

Jersey, New York, Ohio, Virginia, or Washington D.C. Recruitment criteria for geographic location was based on the heaviest population density of Jewish individuals in the United States

Recruitment resulted in two participants meeting inclusion criteria. Rachel (pseudonym) is 21 years old, White, and identifies with the non-binary pronouns they/them. Rachel lives in Maryland with their partner and roommate. Rachel was diagnosed with autism spectrum disorder at 20 years old. Rachel identifies as conservative Jewish and shared that they grew up in the "conservative Jewish movement" with their older brother, mom, and dad. At the time of the interview, Rachel's partner was undergoing the conversion process to become Jewish.

Leye (pseudonym) is 22 years old, White, and female. Leye lives in Ohio with her older sister, mom, and dad. Leye has Down syndrome and belongs to a reform temple with her family. Leye mentioned that she is very active at the Jewish Community Center and likes to participate in Jewish disability organizations. Leye also shared that her and her family bake Challah together every week for Shabbat.

Data Collection

All study procedures received institutional review board (IRB) approval. Two participants met inclusion criteria for the study and having two participants ensured replication (Yin & Campbell, 2018) and thick description (Prosek & Gibson, 2021). Data collection included multiple sources, which is recommended when conducting a multiple-case study (Halkias, 2022; Yin & Campbell, 2018). Additionally, it was critical to the authenticity of this study to include multiple opportunities for data collection because the participants ranged in communication preferences. Data was collected through a demographic survey on RedCap, two semi-structured interviews, an observation, and memoing. Demographic survey information was collected prior to the first interview and included questions about age, disability status, if they identified as Jewish, and anything else they would like the researcher to know. Once the participants completed the survey, they set up a time to conduct the first interview. The semi-structured interview was conducted over Zoom with captioning enabled. Prior to the start of the interview, the researcher gained consent from Rachel and assent from Leye. Though Leye was over the age of 18, Leye had a legal guardian and therefore was able to provide assent in addition to her legal guardian's consent. The assent process included a plain language description of the study, visuals (e.g. green thumbs up and red thumbs down), and reoccurred before every data collection point to provide opportunities to opt in or opt out of the research.

At the conclusion of the first interviews, participants selected a Jewish ritual or home practice for the researcher to observe to capture the real-world experiences (Yin & Campbell, 2018). The researcher developed a structured observation protocol (i.e., length of the observation, the researcher's role in the observation, camera set up, and how the recording will be deleted) and collected additional data through memoing during and after the observation (Hays & Singh, 2012). To ensure passive observation, the researcher met with the participants ahead of time to discuss the camera and the recording. After the observation, the researcher contacted each participant for a semi-structured follow up interview where the researcher provided the opportunity for member checking.

Data Explication

To analyze the data, the researcher used a combination of two strategies common in multiple case studies: pattern matching and cross-case synthesis. Pattern matching included the development of theoretical propositions based on the literature review and theory (Yin & Campbell, 2018). The theoretical propositions represent the critical points from the literature review, which influenced the research design. Once the researcher analyzed the data, the researcher compared the propositions to the empirical evidence and revised the propositions. The primary outcome of the cross-case synthesis is to develop conclusions about the cases (Yin & Campbell, 2018), often referred to as themes. To gain an overall understanding of the cases and to identify the unique differences between the cases, the researcher analyzed the within-case results. The within-case results included interpretations of "how" and "why" the participants experienced the phenomena (Yin & Campbell, 2018). To align with DisCrit and do research with individuals with disabilities rather than about individuals with disabilities (Annamma et al., 2013), the researcher added an additional step to the case analysis and shared the propositions and initial themes with the participants. Participants helped to identify alternative explanations and clarify their own lived experiences.

Results

Three themes emerged during the cross-case synthesis and then were further differentiated during the within-case analysis, resulting in eight subthemes. However, three themes and two subthemes specifically relate to religion and spirituality inclusion, which is the ultimate purpose of this manuscript. Implications from the highlighted themes and subthemes can help prepare religious leaders, clergy, and researchers to better support, engage, and include Jewish youth with I/DD.

Making Meaning of Jewish Experiences

Rachel and Leye both had collective experiences, rituals, practices, and reflections that contributed to the meaning they made of their Jewish experiences. In this theme, making meaning is defined as the process of reflecting and processing personal Jewish experiences, rituals, and practices. Rachel often made meaning of their Jewish experiences by comparing their

childhood activities to their youth activities. Rachel spoke about the shift they experienced when they moved into their own home and said, “It’s nice to do things in a different way than I did when I was growing up.” Rachel was able to shift their practices to better meet their needs and preferences. Rachel also spoke about the connection they felt to their ancestors and their community. Rachel shared: “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.”
For Rachel, being Jewish meant transcending and connecting generations of Jews through Jewish traditions.

Rachel also talked about their intersecting identities of being Jewish and having a disability. Rachel shared that “me being Jewish and having a disability has meant to adapt different. It’s an extension of the ever-evolving nature of Jewish tradition.” Intersecting identities of being Jewish and having a disability contributed to how Rachel made meaning of their Jewish experiences.

Leye made meaning of Jewish experiences by participating in Jewish rituals and practices in her home. Leye smiled then said “I usually wear a necklace and a bracelet, my high heels, and a dress. Yea, I like to dress up every holiday.” Leye’s experiences were joyful and later in the interview she added “I love praying a lot.” It was clear that Leye made meaning of Jewish experiences by physically participating in Jewish rituals and practices.

Both Rachel and Leye made meaning of Jewish experiences in unique ways. For instance, Rachel made meaning when they transformed childhood traditions into adult rituals and practices that better met their needs. Leye made meaning when she engaged in rituals and practices that commemorated the specialness of Jewish holidays. When Rachel and Leye talked about lived experiences, another theme emerged that alluded to exclusion as a Jewish youth with a disability: “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”

The theme “I feel like there’s a middle that is a little bit missing maybe” (further referred to as middle experiences) emerged when Rachel and Leye expressed their feelings of being a Jewish youth with a disability. Middle experiences meant that support needs weren’t met or considered when creating Jewish events, activities, or spaces. Inadequate inclusion and support considerations resulted in physical spaces, also known as middle spaces, that felt unintentional and at times inappropriate.

For example, Rachel shared that they were not diagnosed with autism until they were 20 because their autistic traits “were looked over, because they weren’t as severe or as present as my brother’s.” Rachel talked about the Jewish milestone of having a bar/bat mitzvah. When it came time for Rachel’s brother to have his bar mitzvah, the family decided for Rachel to join in and make it a b’nai mitzvah to better suit their brother’s needs. When two family members are coming of age at the same time (i.e., twins, siblings close in age) a b’nai mitzvah is common (Aspinwall, n.d., *B’not vs. B’nai Mitzvah & Bar vs. Bat Mitzvah: Which Is It?*).

There were many ways the temple and the congregation accommodated the needs of Rachel’s brother, but Rachel expressed that their needs came second. Rachel said: “For my brother especially… 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.” Rachel shared that though they felt their needs were met by having an afternoon service, their needs were considered second to their brothers, resulting in an unintentional space for Rachel.

Inaccessible Spaces and Places

In this subtheme, inaccessible spaces and places are defined as Jewish activities, spaces, events, or organizations that are physically or conceptually inaccessible for youth with disabilities. Rachel gave specific examples of times that they wanted to attend Jewish events, but could not, due to transportation needs. Rachel commented, “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.” Similarly, to Rachel, Leye also mentioned how temple was not something she attended on her own because she did not drive. When asked who Leye goes to temple with her or if she likes to go alone, she said “my family, because my dad is the driver ... because my dad drives. I’m not a driver.”

Rachel went on to talk about accessing and belonging to a synagogue. Rachel felt that there might be a great synagogue out there but shared that “there are days where I have severe mobility issues” and accessing a synagogue by stairs are “not it for me.” The physical space of the synagogue was not accessible, and Rachel shared other examples of how synagogues were not always inclusive. In fact, Rachel ended up quitting Hebrew school because, they shared, “the program they had for autistic students at my Hebrew school was also not it for me.” Though community spaces can contribute to feelings of belongingness, Rachel felt that being at home was more comfortable. Rachel mentioned that they “enjoy the sense of the community in the sense that it’s we are here, and this is a special place to be for a special time” but in general, “to be at home makes it more comfortable.” For Rachel, Jewish communal spaces and places lacked accessibility, resulting in being more comfortable in their own home.

Decision-Making Process

A result of feeling “in the middle” is the need to make decisions based on needs and preferences. This subtheme emerged when both Rachel and Leye illuded to the process of making decisions based on their needs and preferences. Rachel talked about having disabilities and the process of making decisions to best meet their needs. For instance, Rachel said, “I don’t really make spur-of-the-moment decisions. For me, it’s a research process.” Rachel and their partner used this research process to determine which Jewish activities they wanted to participate in together. Rachel could not just attend Jewish activities, but they had to research which spaces would be accessible to them (i.e., transportation, mobility, dietary).

Leye’s decision-making process was often based on personal preferences. For example, Leye celebrates Shabbat every Friday and stated “I love praying a lot.” And added that she feels happy when she prays. Leye also added that she likes to wear special things when she prays. Leye said “I like to dress up every holiday” and talked about her usual outfit for Jewish holidays: “a necklace, and a bracelet, my high heels, and a dress.” Though Leye’s decision making was often based on personal preferences, there were times when her decision-making was indistinguishable from her family member(s). For example, Leye communicated that she just wanted her dad to attend the interview with her. However, when the Zoom camera turned on, you could see her older sister sitting next to Leye, her dad on the other side, and her mom behind the camera. Throughout the interview Leye answered the question but then would get feedback from her family such as “say it a little louder” or an elbow nudge. The merged decision-making between Leye and her family impacted autonomous communication.

Lived Experiences of Jewish Rituals and Practices

The third theme is defined as the meaningful Jewish moments that contribute to the lived experiences of Jewish rituals and practices. This specific theme emerged during the observation portion of the data collection. Furthermore, the way Rachel and Leye made meaning of Jewish rituals and practices was unique to them. Spiritual connections were evident for Rachel and Leye in different ways. Rachel selected the observation to occur during Shabbat. For the observation, Rachel and their partner decided to make a video together like a TikTok. To start their TikTok, they looked at each other, smiled, and said “Shabbat Shalom.” Next, they assembled the materials to dip the challah in the grape juice. Rachel tore off a piece of challah and simultaneously took a deep exhale. Rachel smiled and put the challah down and waited for their partner, Ramin (pseudonym). Rachel waited to share their experience together. Once Ramin was situated, Rachel said, “Ready?” and then together they took their first bite. Rachel closed their eyes and talked about the taste. In the follow-up interview, the researcher asked Rachel about waiting for Ramin for the first bite of challah. Rachel shared that they weren’t sure why they waited for Ramin and added, “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 talked about order being an important part of Judaism and routine being connected to their autism.

Leye selected the practice of dancing and listening to Jewish music. Leye expressed her spiritual connection by moving her body in different ways. When the song started, Leye looked up towards the ceiling and raised her hands, pointing one at the ceiling. She swayed to the beat and moved her other hand to the side, shifting her body from side to side. Leye smiled and spun in a circle, twirling her whole body. Leye shimmied her shoulders from side to side and tapped one foot to the other. Then, the chorus kicked in and Leye’s smile grew even wider, and her movements got even bigger. Leye jumped up and down and her movements looked like they were free flowing.

In the follow-up interview with Leye, the researcher summarized the observation. Leye indicated to the researcher if the observations were right or wrong. For example, the researcher asked "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." Both Rachel and Leye connected spiritually during their lived Jewish ritual and practice. Rachel exhaled when they tore the challah and closed their eyes as they took their first bite of challah. Leye moved her body effortlessly in tune with the music, threw her hands to the sky, and spun in circles when the chorus kicked in.

Discussion

Revised Propositions

As mentioned above, a common data explanation technique in multiple case studies is using pattern matching (Yin & Campbell, 2018). Pattern matching is the process of creating theoretical propositions based on literature and then revising the theoretical propositions after collecting and analyzing the data (Yin & Campbell, 2018).

The researcher developed the following theoretical propositions:

1. This multiple case study will exhibit the experiences of Jewish rituals and practices in the home, which will indicate the importance of family and Judaism on the identity development of these youth.
2. This multiple case study will exhibit how the experience of Jewish rituals and practices impact the connection to Judaism, family, and the community, which influences the overall wellness of these youth.

The researcher developed the theoretical propositions based on the literature review. The literature reviewed for this study included various experiences from religious community members (Carter et al., 2017), parents of youth with disabilities (Biggs & Carter 2016; Carter &

Boehm, 2019), adults with disabilities (Sango & Forrester-Jones, 2018), youth with disabilities (Liu et al., 2014), Jewish parents of youth with disabilities (Vogel et al., 2004), Jewish service providers (Taub & Werner, 2016), and Jewish adults with disabilities (Lifshitz et al., 2009). Results from the literature review indicated that findings involve identity development and overall wellness for Jewish youth with I/DD. However, through the data explication, it became evident that the major findings involved *how* the participants experienced Jewish rituals and practices in the home and how these experiences were important in connecting to Judaism. Additionally, rather than learning about the overall wellness of Jewish youth with I/DD, results specifically indicate spiritual connection.

Therefore, the revised propositions are:

1. This case study showed how Jewish youth with I/DD 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 the theoretical and revised propositions share many similarities, this indicated a strong internal validity (Yin, 2018).

Access Means Belonging

Connecting to Judaism via rituals and practices in the home reinforced individual and communal Jewish identity. Research shows that connection to a Jewish community contributes to feelings of belonging (Liu et al., 2014) and reinforces Jewish identity (Bunning & Steel, 2007). There were clear individual differences in how Rachel and Leye made meaning of their experiences, indicating more about individual connection to Judaism. For instance, Rachel talked about their immense tie to their ancestors and their Jewish community and Leye made connections in alignment with her own preferred Jewish traditions. Though religion and spirituality are personal experiences (Boyatzis, 2013), faith is ancestral and often originates within home practices (Boehm & Carter, 2019).

Literature indicates that spirituality includes self-transcendent experiences that are sacred and includes relationships and practices (Boyatzis, 2013). There is research on spiritual practices that youth with I/DD do in the home (Boehm & Carter, 2019) and in group homes (Sango & Forrester-Jones, 2018); however, the present study highlights individual experiences and meaning making for youth with I/DD. The observation was an intimate way to witness Leye's proud display of her Jewish identity. Leye's celebration of the Hebrew language and Israeli music displayed Leye's deep connection to her individual and collective Jewish identity. Rachel connected to their Jewish community by engaging with their partner and jointly partaking in a Jewish ritual. Rachel particularly enjoyed the personal touch they could have on the tradition of having challah and grape juice and called this a "micro-tradition" that was shared just with their partner. Rachel felt connected to their Jewish ancestors and community and at the same time reinforced their personal Jewish identity with their partner. The present study adds to the existing research that emphasizes the high importance youth place on religion (Liu et al., 2014) and expands research amplifying lived experiences of youth with IDD (Sango & Forrester-Jones, 2018).

Even though both Rachel and Leye indicated they wanted to be religious and spiritual, both participants shared societal barriers that inhibited their access to religious spaces (e.g., transportation). For example, Rachel shared about having multiple disabilities and how they had to consider their disabilities when selecting Jewish events to attend. Rachel shared about their mobility needs and how important it was for them to look up Metro stop locations before selecting events. Rachel described these events being available but not accessible for them, thus creating a middle space that felt unintentional. Leye also indicated that transportation was a barrier for attending temple and that she attended with her dad because he drives her. It was not clear if Leye would attend temple with friends or others if she was able to get to temple without her dad driving her. The lack of access that both Rachel and Leye communicated resonates with the third tenet of DisCrit, being othered (Annamma et al., 2013) and resulted in a lack of access for both individuals.

Though many religious institutions have programming for people with disabilities (Glicksman, 2011) this programming lacks a consensus and consistency regarding inclusion and belonging for congregants with disabilities. More specifically, research shows that parents feel disability is not centrally on the Jewish communal agenda (Glicksman, 2011). In addition to transportation, another societal barrier that Rachel emphasized was ableism. Rachel described this spectrum of disability that exists and how even when temples create programs, they create the program for one type of disability, which in turn often excluded them. Rachel shared that in their temple there was an autism classroom for Hebrew school. Rachel said they were extremely out of place and felt so discouraged that they dropped out of Hebrew school.

Research indicates that congregation and clergy commitment to and support of members with I/DD is indicative of inclusion and belonging (Carter et al., 2017). In fact, participants in the present study echoed many of the strategies that Carter et al. (2017) identified in their study. Rachel named similar strategies, such as increasing access to religious events and activities beyond the sanctuary and classroom (i.e., Jewish youth/young adult events). Lack of access due to categorizing and othering is an invisible form of ableism and is a normal experience for individuals with disabilities (Annamma et al., 2013). To make religious spaces and programming more inclusive among those with I/DD, it is critical they can share their support needs and ideas.

Implications

Implications for Clergy and Religious Leaders

Based on Rachel and Leye's lived experiences there are numerous implications for making religious spaces more accessible. The bar/bat/b'nai mitzvah is a milestone for Jewish youth (Glicksman, 2011) and this is no exception for youth with I/DD (Vogel & Reiter 2003; Vogel & Reiter, 2004). In the study, Rachel explained the importance of the b'nai mitzvah. Rachel shared the many ways the preparation, the service, and the celebration were accessible to them. Rachel and their brother had their b'nai mitzvah during the Mincha service, which is the shortest daily prayer. Rachel explained that the option to have the service in the afternoon rather than the morning (the typical service for a b'nai mitzvah), made the b'nai mitzvah possible. Based on Rachel's experience, clergy and religious leaders of other faiths can model similar accommodations based on the support needs of their congregants.

Throughout the interviews, Rachel spoke about the isolation and lack of access they experienced in Jewish organizations and their synagogue, particularly surrounding Jewish education. Religious institutions offer religious education for children through teenage years (Diamant & Sciupac, 2020) and this can often act as an access point to religion and spirituality for youth and young adults. Access is often an ableist issue, meaning that people without disabilities aren't considering the needs of people with disabilities when creating spaces or events. A recommendation for clergy and religious leaders based on Rachel's lived experiences is to proactively incorporate individuals with disabilities in planning events and creating spaces.

Belser (2014) stated that religious leaders and clergy can communicate inclusivity by investing in religious education and creating standards and practices (i.e., providing large-print siddurim and amplifying sound in services). Based on Rachel's experiences, religious leaders and clergy can participate in training regarding inclusive practices (Carter et al., 2017). Rachel's middle experiences inhibited participation in young adult events, Birthright, and attending synagogue. In a study by Ault et al., (2013), one-third of left their place of worship because of poor inclusion, and over one-half of parents had never been asked about how to include their children with disabilities. Both the literature and experiences of the participants signal the importance of creating standards and practices to engage youth with disabilities in religious and spiritual spaces.

Future research should include more qualitative studies, with larger samples, from the perspective of the person with I/DD, across more diverse types of I/DD and more diverse religious/spiritual identities. For instance, Muslim families share similar sentiments of home and community in religious spaces (Shikarpurya & Singh, 2021). More research is emerging about the intersection of disabilities and religion and spirituality (Rahman et al., 2024); however, more research can be done from perspectives of individuals with I/DD. Perhaps future studies would benefit from triangulating data from parents, youth with I/DD, family members, and clergy.

Implications for Researchers

Research conducted with youth with disabilities requires additional considerations and safeguards. The IRB process protects vulnerable populations including ethnic minorities, individuals with chronic health conditions, and children. The present study included a participant, Leye, who was over the age of 18 and had a legal guardian. Therefore, Leye was not able to give consent. Even though Leye cannot legally consent, she can give assent. To implement the assent process, the researcher created accessible materials to ask for assent prior to each data collection point in the study (i.e., interviews and observation).

From the beginning of the study, it was clear that both participants preferred different communication modalities (i.e., calling, texting, emailing) and communication frequency. The researcher needs to consider communication preferences or run the risk of perpetuating communication as a barrier to religious access (Carter et al., 2015). For example, during the research study, the researcher assumed that communication was a barrier for Rachel because she reached out to Rachel through email twice and did not receive a response. In a final attempt to schedule the initial interview, the researcher called Rachel. When Rachel picked up, they thanked me for calling and expressed that they wanted to be in the study but forgot about the study. Next, the researcher asked Rachel if they preferred a phone call, text, email, or a Google Calendar invitation for future communication. Rachel said they wanted all those options because they needed to read and hear information to remember it. Rachel clearly expressed the desire to participate in the study and iterated their communication preferences. Future researchers can plan for communication preferences by including space in the consent and assent meeting to indicate preferences for communication frequency and modalities.

Autonomous communication was a barrier for Leye throughout the study. In the consent and assent meeting, Leye sat shoulder-to-shoulder with her sister, her dad sat out of the frame, and her mom stood behind the computer. Leye’s dad asked questions about the study and about the observation. Leye’s sister and mom whispered to each other and gave Leye suggested things to say. One way to encourage autonomous communication could be to dialogue with the participant and their support people to form a loose contract to guide the interview process that enables the participant to be interviewed. It is important for researchers to develop a research protocol that considers different communication needs and preferences.

Future researchers should also utilize some of the varied methods used in this study to gain assent, so that participants can be given greater autonomy and inclusion. Additionally, future research needs to include plain language findings that can be shared with participants and the community.

Limitations

Multiple-case studies are advantageous and allow for replication of research procedures (Yin, 2018) avoid assumed generalizability, because the disability experience is diverse, research is needed to expand the findings of this study. A limitation from the study was that all data collection occurred virtually (assent meeting, the interviews, the observations, and the member checking) to widen geographic recruitment. Virtual data collection has limitations; for instance, in the observation, there were moments that the researcher was not able to collect data (e.g., when Rachel went off screen to collect items from different rooms and when Leye navigated the computer and iPad to connect to the internet). The researcher conducted a follow-up interview after the observation to adjust for not being in-person. In the follow-up interview, the researcher asked about specific moments and was able to member check and gather additional information.

Conclusion

Findings from this study are valuable for religious leaders, clergy, researchers, and Jewish youth with I/DD. Religious leaders and clergy can utilize the findings from this study to expand their understanding and inclusion of Jewish youth with I/DD and enhance the accessibility of Jewish spaces. Researchers can enhance their own practices when partnering with participants in all stages of research to determine needs for research based on individual and community experiences. Engaging youth with I/DD in research centralizes lived experiences and promotes purposeful and meaningful research so we can learn not just whether I/DD youth participate in religious/spiritual activities, but how they can participate fully.

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Dear reviewers,

Thank you for your valuable feedback. The feedback you shared truly enhances the manuscript and helped polish sections. Please see my responses in italics to all reviewer feedback.

Comments from Associate Editor:
This multiple-case study described the religious and spiritual inclusion of Jewish youth with I/DD. The authors offered a rationale for their work, while also clearly describing their multi-faceted study methodologies. The study findings offer a unique contribution to the literature in that the elucidate the experiences of individuals with intellectual and developmental disabilities in their own voice, while also bring forth a perspective from a faith community that has been historically underrepresented. The discussion, including their implications, are well grounded in the available literature and their own findings, which offer the reader important insights for both practice and research.

Abstract, p. 1: I/DD is abbreviated in the first sentence, but later spelled out. Please adhere to the journal guidance regarding abbreviations throughout the manuscript: Abbreviations should be held to a minimum and spelled out in their first use. The names of groups or experimental conditions are usually not abbreviated. The full names of tests should be given when they are first mentioned, with the common shortened form in parentheses with a citation of the source.

I spelled out intellectual and/or developmental disabilities before using the abbreviation.

Abstract, p. 1: The authors stated, "There is a dearth of research surrounding religion and spirituality for individuals with I/DD..." There has been a growing body of literature as it relates to the inclusion of people with intellectual and developmental disabilities as it relates to religion and spirituality; the use of the term "dearth" may not accurately capture the current state of this area of inquiry. It is is recommended that the authors consider revising this statement to reflect the knowledge that has been generated and disseminated to date, while highlight what is the unique contributions of their work. The authors may wish to conduct a further review of the literature and integrate this into their introduction.

I added “religious minorities” as a clarification. You are correct, there is a growing body of work for major faiths, but there is still limited studies regarding religious minorities.

Introduction, p. 3: Please ensure all citations comply with the Publication Manual of the American Psychological Association (APA, 7th edition). Both in-text and the on the reference page, the citation attributed to "Vital Statistics" does not.

I changed the citation and reference to be in APA 7 formatting. Thank you for catching this.

Introduction, p. 3: The following statements may benefit from citations and/or may be more appropriate for inclusion in the discussion, "Enactment of one’s Jewishness can occur both on an individual or group basis, and in the home or within the community. Depending on where a Jewish individual with disabilities lives, there might not be Jewish spaces available or accessible. Regardless of access to Jewish spaces, one Jewish space that can be customizable and adaptable is the Jewish home. Jewish rituals and practices in the home can be personally meaningful and promote continuity of the Jewish religion and the Jewish people."

I added citations to these statements so to keep it in the introduction.

Introduction, p. 3: The following abbreviation is used: U.S. Please adhere to the journal guidance regarding abbreviations throughout the manuscript; specifically, please spell out all abbreviations at their first appearance.

I spelled out United States.

Introduction, p. 4, 5 & Discussion, p. 19: Please reconsider the abbreviation of people with disabilities to PWD. Although this reflects person-first language, it may not be in the spirit of AAIDD's efforts to emphasize the humanity of people with intellectual disability.

This is a great point. I removed the abbreviation.

Introduction, p. 5: Please correct for parenthesis and brackets; it should read: (for a full review of Judaism as a religion, see Selekman & Zavadivker [2021]).

I corrected the parenthesis and bracket.

Introduction, p. 5: The term "proving" may not accurately capture the purpose or aim of this body of literature. Perhaps the terms "elucidate" or "explore" or "describe" would be more appropriate.

I changed the word to be “describing.”

Introduction, pp. 5-6: The authors state, "Rather than assuming that all Jewish people can uphold Jewish commandments, and have similar motivations for doing so, researchers studied if Judaism is enacted similarly for people with and without disabilities. This assumption, that there is a difference in ability and motivation to be Jewish among those with and without disabilities, reveals a potential bias towards ableism in the practice of religion." This claim appears to be interpretative, and it did not appear to be in congruence with the findings of the article cited earlier in this paragraph. It may be worth considering eliminating or revising these statements.

I removed the statements.

Introduction, p. 6: The following statement is hard to follow, particularly the content within parentheses: "A common milestone for Jewish youth is becoming a bar/bat mitzvah (or becoming a Jewish adult as defined within Judaism, typically at age 12 or 13 depending on the denomination)." Revising this sentence to eliminate parentheses and/or as two separate/complete sentences may be helpful to the reader.

I broke this sentence into two sentences.

Introduction, p. 6: Similar to earlier comments, there are portions of the Introduction that appear interpretative and/or commentary, which may be better suited for a discussion. Another example of this is, "A study of the personal enactment and meaning making of spiritual and religious experiences, from the perspective of those with I/DD, would address this gap in the literature more broadly. Focusing on these experiences among Jewish youth with I/DD would contribute to the literature related to minorities with I/DD more specifically. Therefore, following is a description of a study examining the experiences of religion/spirituality among Jewish youth with I/DD." The authors have a subsection on the "Purpose of the Study", which articulates from where the current study emerged and its aims. This is likely sufficient, such that statements like the one cited here may be considered for elimination.

I removed this wording.

Introduction, p. 7: Please correct the typo; this sentence should read: "Multiple case studies are used to describe and develop a deep understanding of phenomena (Harrison et al., 2017), offer a mindful way to collect in-depth data (Creswell et al., 2007), and serve to document stories from participants (Hays & Sing, 2012)."

I corrected the typo.

Introduction, pp. 6-7: The theoretical framework is only briefly described. It may be helpful to the reader to integrate a few additional sentences or a brief paragraph describing the key tenets of the theory. Further, DisCrit is mentioned only in this section of the paper; it is not explicitly referenced in the "Methodology" or "Discussion" sections, which is notable given that the paper explore the intersection of I/DD and identity as it relates to spirituality/religion. It is unclear, as written, how the theory informed the study design and the interpretation of the findings. If it did not, then it may be worth considering if the paper might stand without mention of this theoretical framework.

I added additional mention of DisCrit in my method section. I also added more explanation to the theoretical framework and the discussion section.

Introduction, p. 6-7: Please adhere to the Journal's guidelines for abbreviations. Disability Critical Race Theory can be abbreviated to DisCrit, but this needs to occur at its first appearance in the manuscript.
I spelled out Disability Critical Race Theory before using the abbreviation.

Introduction, p. 8: The following might be better suited to the the subsection on "Theoretical Framework" or the section on "Methodology": "(the researcher was a passive vs. participant-observer due to the power and privilege that the researcher has in their role and identities of being white, cisgender female, and being able-bodied)".

I moved this to the "Theoretical Framework" section.

Methodology, p. 8: It is unclear if a sample size of two participants supports the claim: "...having two participants ensured replication (Yin & Campbell, 2018) and thick description (Prosek & Gibson, 2021)." The authors use of multiple sources of data, however, may support this. Perhaps this phrasing can be revised or move to the "Data Collection" subsection where this is further described.

I moved this to "Data Collection. "

Methodology & Results, p. 8: The term "cross-case synthesis" was sometimes written as " cross case synthesis". Please use consistent phrasing throughout.

I adjusted the phrasing so that it is consistent.

Results, p. 13: Please try to avoid ending subsections with block quotes.

I added a sentence after to avoid ending the subsection with a block quote.

Results, Revised Propositions, pp. 16-7: Both the writing style and content of this section was interpretive in nature. Although it does reflect results from the second phase of the analysis process, it may be better suited for inclusion in the "Discussion" section.

I moved this to the "Discussion" section.

Discussion, p. 19: This sentence is unclear as written: "Rachel this middle space of having events available but not accessible for them."

I rewrote this sentence. Thank you for catching this.

Discussion, p. 20: There is a comma that may not be necessary between "meaning" and "that" in the second sentence of the last paragraph on this page.

I removed the comma.

Discussion, Implications for Clergy and Religious Leaders, pp. 20-21: While the subheading here suggestions implications for leaders from diverse denominations, the recommendations in this section are focused primarily at leaders within Jewish faith communities. The authors efforts to not overgeneralize their findings is appreciated, but I believe their findings do have applicability to leaders from other faiths. Perhaps this section might be re-written (particularly opening/closing sentences to each paragraph) to expand the implications to others.

This is a great point. I struggled with generalizing, as to not assume, but found the material to be quite important for other religious leaders and clergy. I added additional citations and reworded sentences to be a bit broader.

Discussion, p. 21: Reference to a specific IRB is made, but it is unclear why this particular IRB is cited nor is a reference included: "According to Virginia Commonwealth University IRB, vulnerable populations include ethnic minorities, individuals with chronic health conditions, and children." Further, the abbreviation of "IRB" was not included earlier in the manuscript when the term institutional review board was used on p. 8.

I generalized IRB and spelled it out before abbreviating.

Discussion, p. 21: The authors reference the use of consent and assent. While informative to future research and inclusive as a best practice, it may be helpful to include information regarding recruitment of participants in relation to assent/consent within the "Methodology" section.

This is a great suggestion. I made the adjustment in the "Methods" section.

Discussion, Future Research, p. 23: It may be worth considering integrating content from this subsection with the "Implications for Future Researchers", rather than having it as its own stand-alone subsection.

I blended "Implications for Future Researchers" into the "Discussion."

Comments from Reviewer #1:
This paper indicates a very carefully laid out research process. It is well written, and gives the reader a very good picture of the participants, issues involved, and themes coming out. You are right, it would have been great to have more participants, as well as to be able to do the interviews in person.

There are only two very small places that need a revision.

First, on page 15,. taking about dipping the challah in cup and then taking the first "bight." Just a misspelling.

Thank you for finding this misspelling. I made the change.

Second, on page 19, the sentence beginning "Rachel the middle space...." does not make sense as written. Perhaps it was "For Rachel, the middle space....

I rewrote the sentence.

But otherwise, this is a really nice contribution, and helps point the way to do research that carefully listens to the voices of people with intellectual and developmental disabilities.