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A GROUNDED THEORY APPROACH TO RURAL CARE PROVIDER PERSPECTIVES OF DISABILITY AND SEXUAL VIOLENCE

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ABSTRACT

Research involving sexual violence among individuals with disabilities is scarce despite a prevalence rate higher than the general population. The perspectives of care providers regarding their experience working with individuals with disabilities who have experienced sexual violence is even less understood. The purpose of the current grounded theory study was to better understand the experience of care providers working with individuals with disabilities who have experienced sexual violence. Care providers of individuals with disabilities were recruited from disability services agencies and interviewed by the primary researcher. There were ten participants from a variety of direct care, ancillary care, and administrative positions. A grounded theory approach was used to data collection and interpretation to develop a working theory as to the process care providers go through when working with individuals with disabilities who have experienced sexual violence. From ten verbatim transcripts, codes were developed and placed into four related categories: factors leading to sexual violence, affirming experiences, negative experiences, and necessary changes. Additionally, participants provided insight into trauma-informed interviewing practices for future research with individuals with disabilities who have experienced sexual violence. Results from the study added the perspective of care providers working with individuals with disabilities to the existing body of literature. It is important for agencies who employ care providers and the general public to be aware of the process care providers encounter when working with sexual violence in the disability services sector.

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Introduction

There has been a historic call for research conducted on the well-being of Americans with disabilities (Rimmer & Braddock, 2002; Iezzoni & O’Day, 2006). Although studies related to the experiences of individuals with disabilities are necessary, research is also lacking concerning the experiences of care providers of people with disabilities. Care provider research is necessary considering the important role they play in providing direct services to, and advocating for, those with disabilities. Initial research is often conducted with consumers, educators, and care providers as a springboard into understanding the experiences of individuals with disabilities (Morrison et al., 2008).

In general, research concerning care providers has been aimed at understanding the overall negative effects of caregiving such as exhaustion, stress, isolation and others (Bainbridge et al., 2006; McDonald et al., 1999; Rosenzweig et al., 2002). Literature indicates that examining care provider perspectives in a variety of settings may be key to understanding the processes that go into difficult aspects of their job such as mandatory reporting, which further supports the significance and importance of advancing research in this area.

Care providers for individuals with disabilities have numerous duties including maintaining the physical and mental wellbeing of individuals they care for, coordinating medical and other appointments, and in circumstances of suspected neglect or abuse, reporting such instances to the proper authorities (Friesen et al., 2008). Although there is research from the perspectives of care providers and the effects of providing care (i.e. Boerner et al., 2004; Cohen et al., 2002), little is known of their perspectives and experiences with mandatory reporting, especially in instances of sexual violence perpetrated against the individuals they care for.

Power dynamics between care providers and those they provide care for are well documented. Adding complexity to this dynamic is that care providers may also be in a unique position to harm the people they care for (Gil-Llario et al., 2018).

The purpose of this study was to better understand the experience of care providers working with individuals with disabilities who have experienced sexual violence. Specifically, information was gathered through interviews pertaining to care givers experience working with individuals with disabilities who have been victims of sexual violence. Additionally, individuals who have been care providers provided their opinions on existing reporting procedures and provided useful advice on how to effectively and ethically interview individuals with disabilities in a trauma-informed manner. Issues regarding care providers and individuals with disabilities was discussed as well as a review of the literature surrounding sexual violence among vulnerable populations such as those with disabilities. The study examined the posed questions through the use of a qualitative, grounded theory design.

Literature Review

In order to understand the issues related to the current study, literature associated with the topic will be examined before presentation of the methodology. Specifically, disability terms and prevalence of sexual assault was considered followed by care provider reporting and perspectives. Due to the location of the study participants, particular attention was given to perspectives of caregivers in rural settings. Issues surrounding sexual violence and reporting behaviors was also discussed leading to the study's purpose and the initial research questions for the study.

Disability

The term “disability” serves two main functions. Firstly, the legal definition of a disability is someone who has “a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment” (Feldblum et al., 2007). This definition is used in various laws used to make it unlawful to discriminate against a person based on that person’s disability status. Second, although similar, the medical definition of disability covers three areas: impairments, activity limitations, and participation restrictions. The World Health Organization (2016) defines these three areas “an impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.”

Intellectual Disability

Intellectual disability (also known as intellectual developmental disorder) is characterized by three primary criteria. First, an individual must display deficits in intellectual functioning as evidenced by both clinical assessment and standardized intelligence testing. Second, deficits in adaptive functioning must result in a failure to meet developmental or cultural standards for independence without ongoing support across multiple environments. Finally, the onset of both types of deficits must be during the developmental period (American Psychiatric Association, 2013).

Developmental Disability

Developmental disabilities vary widely, characterized by difficulty in a number of different domains including intellectual functioning, emotional-behavioral functioning, and adaptive functioning. (American Psychiatric Association, 2013). Within the category of developmental disability are disabilities such as autism spectrum disorder, fetal alcohol syndrome, and other broadly termed developmental delay or disabilities. Prevalence rates of children ages 3-17 who have ever been diagnosed with a developmental disability increased from 5.76% to 6.99% from 2014 to 2016, and have continued to rise since then (Zablotsky et. al., 2017).

Physical Disability

The breadth of physical disabilities includes a limitation in a person's mobility, dexterity, stamina, or overall physical functioning (WHO, 2016). Within the United States, 61 million adults live with some type of disability, ranging from blindness and hearing loss to issues with mobility or epilepsy (CDC, 2018). Along with such a high prevalence rate of disability, other issues arise to outline the disparities between those with disabilities and those without. Some of these health concerns include:

- 38.2% of those with disabilities have obesity compared to 26.2% of those without.
- 28.2% of those with disabilities smoke compared to 13.4% of those without.
- 11.5% of those with disabilities have heart disease compared to 3.8% of those without
- 16.3 % of those with disabilities have diabetes compared to 7.2% of those without (Okoro et al., 2016).

All in all, it is clear that there are disparities in care and supports between those with disabilities and those without regardless the type of disability. Disparities are evident in healthcare, mental healthcare, and in the criminal justice system

Sexual Violence

Definitions

The definition of sexual assault has been contested due to various definitions (i.e. penetration vs. attempt), however, a commonly accepted definition is “an experience of being pressured or forced by another person to have contact which involved touching of sexual parts or sexual intercourse—oral, anal, or vaginal” (Struckman-Johnson & Struckman-Johnson, 1994). Whereas “sexual assault” implies that a victim has the ability to consent to sex, the term “sexual abuse” is defined as “unwanted sexual activity, with perpetrators using force, making threats or taking advantage of victims not able to give consent” (APA, 2018). Within this definition, a victim is not able to consent due to age, disability status, or a variety of other factors. The term “sexual violence” can be used as an umbrella term to include individual experiences which could include but are not limited to sexual assault, sexual abuse, and/or rape (NSVRC, 2018). Because of differing definitions, prevalence rates of sexual violence vary widely between groups and type of violence (rape, abuse, assault etc.).

Prevalence

Although rates vary, most sources indicate women are more likely than men to be victims of sexual violence. Nearly one in five women report attempted or completed rape and almost 50% of women report sexual violence at some point in their lives totaling over 52 million women in the United States alone (Zang et al, 2018). Although rates for men are significantly lower, they still report many instances of sexual violence. More than one in ten men reports unwanted sexual contact, and around 7% of men indicate that they have been forced to penetrate someone. Ten percent may not seem like a significant number, but when applied to the approximate male population of the United States, this number equates to around eight million men.

For individuals with intellectual disabilities, prevalence rates also vary, although a recent study indicated rates as high as 33% for both males and females (Tomsa et. al., 2021)

Exact numbers are difficult if not impossible to ascertain. They can vary widely due to the populations which are sampled or the method of data collection that is used (surveys vs. self-reports of clinical samples).

Impact

When examining the impact of sexual assault on a survivor, effects can be separated into both short- and long-term. These effects vary widely from person to person, and may be, physical, psychological, social, or a combination. The term sexual assault trauma refers to the impact on a survivor's life in the short term, which may be focused on physical concerns such as injury, sexually transmitted infections, or pregnancy. Effects could also include social/psychological factors such as interpersonal or sexual relationship difficulties or severe psychological problems such as panic or anxiety (RAINN, 2020; Ruch & Chandler, 1983).

Assault trauma on a sociopsychological level is conceptualized into two domains. Firstly, the type of trauma reaction and second, the level of trauma reaction. The type of trauma reaction can vary widely from individual to individual, with some survivors of sexual violence expressing anger while others may be withdrawn and show sadness and other signs of depression. Likewise, the intensity of trauma reaction can vary widely, with some people appearing to be strongly affected by the violence and others showing a relatively mild reaction (McLaughlin et. al., 2019; Ruch et al., 1980).

The long-term effects of sexual assault and abuse are well documented. Many psychobiological symptoms and disorders may arise following a rape or other form of sexual violence including depression, suicidality, self-injury, somatization, sexual behavior problems, dissociative identity disorder, personality disorders, posttraumatic stress disorder (PTSD), and substance abuse (RAINN, 2020; Putnam & Trickett, 1997). While most victims of sexual violence do recover by four months post occurrence, a number do continue to exhibit symptoms of psychological disorders such as depression, fear, and anxiety (Potter et al., 2020; Waigandt, et al., 1990).

Suicidality is much more common in individuals who have been assaulted at 19.2% compared to 2.2% of non-victims (Kilpatrick et al., 1985; Baiden et al., 2020). Along with psychological symptoms, individuals who have been victims of sexual violence are often impacted by physical disturbances.

Medically, victims of sexual violence report having much poorer health than the average population years after an instance of sexual violence has occurred, suggesting that the physical impacts of sexual violence linger long after a sexually violent incidence has occurred (RAINN, 2020; Waigandt, et al., 1990). Individuals with disabilities are found to experience symptoms of PTSD and other negative effects of sexual violence at similar rates to the general population according to both self and caregiver reports (Shabala & Jasson, 2011).

Although individuals with intellectual disabilities likely experience traumatic stress at the same level as other survivors of sexual violence, they may experience additional or different symptoms such as sexually inappropriate behaviors and enuresis/encopresis (involuntary urination/bowl movements) (Sequeira & Hollins, 2003). Due to atypical symptoms, individuals with intellectual disabilities who are survivors of sexual violence may go undiagnosed (Hollins & Sinason, 2000). Overall, diagnosis of post-traumatic stress disorder and other traumatic stress measures may be difficult in the disability community due to the way such diagnoses are made. Symptoms for a diagnosis of post-traumatic stress disorder are gauged largely on self-report of thoughts, feelings, and mood, which may be difficult for some individuals with disabilities (Daveney et al., 2019; McCarthy, 2001).

Vulnerable Populations

Although the occurrence of sexual violence is staggering in the general population, prevalence rates within at-risk populations such as LGBT+ individuals, prisoners, and military personnel are much higher (Cantor et. al., 2015; Beck et. al., 2013; DOD, 2017). Racial minorities are also more likely to be the victims of sexual violence, with Native Americans twice as likely as any other race (Perry, 2004). Rates of sexual violence are especially high among individuals with intellectual disabilities (ID), with prevalence estimates between two to five times above that of the general population (Melcombe, 2003). Of all individuals who have been victims of rape, an estimated 39% have some type of disability (Basile et. al., 2016).

Similar to the general population, the prevalence of sexual violence varies between men and women among individuals with disabilities. Mirroring, the general population, women with disabilities are still much more likely to experience some form of sexual violence than men with disabilities. However, compared to men without disabilities, men with disabilities are at a much-heightened risk for sexual violence, coerced sex, and completed nonconsensual sex (Mitra et al., 2011; Haydon et al., 2011; Macdowall et al., 2013). In general, regardless of gender, sexual orientation, race, or other factors, individuals with disabilities are at a heightened risk for sexual assault—indicating a need for a concerted effort to include them in screening, prevention, and response (Mitra et al., 2016).

Disclosure of Sexual Violence

With such severe psychological and physical impacts which may accompany sexual violence, it may be difficult for a survivor to disclose or report their experiences (Rees et al., 2019). For example, one study of college women found that although 42% of the sample had been victim of some type of sexual coercion or assault, only 28% sought help. Of those who did, 75% sought help from a friend and not from a professional (Ogletree, 1993).

Although reporting is not likely among women, it may be even less likely for a man to report a rape or sexual assault. A similar study found that of a group of men who eventually sought counseling services, only 15% had reported to the police and 79% sought no help after the incident (King & Woollett, 1997). Along with men, vulnerable populations such as racial and ethnic minorities, lgbtq+ individuals, and those with disabilities have a difficult time reporting and are very unlikely to do so (Tillman et al., 2010; Langenderfer-Magruder et al., 2016; Basile et al., 2016).

There are numerous reasons why a survivor of sexual violence may not wish to disclose or report the incidence. Survivors have indicated several barriers to reporting denoted in the following quotations: “afraid of reprisal from offender or other,” “not clear it was a crime,” “did not want the offender to get in trouble,” “police would cause the respondent trouble” (Bachman, 1998). Overall, barriers typically surround concerns of shame, guilt, and embarrassment, with survivors not wanting friends and family to know. Other barriers are concerns about confidentiality and a fear of not being believed. Additionally, regardless of the sex of the survivor, a common barrier is a fear of being judged as gay if the perpetrator is the same sex (Sable et al., 2006).

Disability Risk Factors

The heightened risk of sexual violence in the disability community is due in part to several risk factors. Ideals surrounding sexuality and disability have historically been inherently ableist, sexist, and heteronormative. (Shakespeare, 2014). Due to these biases in recognizing the sexual needs of individuals with disabilities, individuals with disabilities have been excluded from literature and decisions about their own sexuality in an almost political fashion best described by Shakespeare et al., (1996), “it is an industry controlled by professionals from medical, psychological, and sexological backgrounds. The voice and experience of disabled people is absent in almost every case. As in other areas, disabled people are displaced as subjects, and fetishized as objects.” With these ideas in mind, it is important to remember that while the voices of individuals with disabilities must be elevated, researchers must do so in a trauma-informed and ethical manner, which requires the consultation of care providers who work closely with individuals with disabilities.

Individuals with physical disabilities are placed within a double bind. On one hand, they are viewed as asexual beings who have no desire in physical intimacy, and on the other hand, they may be viewed as hypersexual people who engage in sexual activities without constraint (English & Tickle, 2018). Research indicates that the experience of a person with a physical disability can live an exciting and healthy sex life (McRuer & Mollow, 2012; Smith-Rainey, 2011). One example is that individuals who suffer spinal cord injuries may lose sensation in traditional sexual or erogenous zones, they may actually gain sensation in different zones that are not typically viewed as erogenous among individuals who have not experienced spinal cord injuries (Whipple et al., 1996). This stigma that individuals with physical disabilities don’t desire or partake in sex can lead to the myth that they cannot be victims of sexual violence.

Another stigma is that individuals with disabilities may not fit into other groups such as the lgbtq+ community. This view is easily subverted by a 1990’s example of a gay pride parade sign that read “Trached dykes eat pussy all night without coming up for air” (O’Toole, 2000). Since we know that marginalized groups often have higher rates of sexual violence, it is likely that individuals with disabilities who are also members of other marginalized groups may be uniquely at risk for sexual violence.

Although tools and knowledge exist that help individuals with disabilities navigate their sexuality, many barriers to sexual expression are also present in the lives of many people living with disabilities. By far, the largest challenge faced by those with disabilities are the attitudes, beliefs, and stigma held by people without disabilities (Shuttleworth & Sanders, 2010). Care providers of individuals with disabilities often hold a range of attitudes which classify those with disabilities as “asexual infants in need of protection, as undesirable partners, as unfit or unable to have sex or children, and as deviant if they do engage in sexual relations” (Campbell, 2017). This misconception has the potential to lead care providers to miss signs of sexual violence.

Due to misconceptions that individuals with intellectual disabilities may not understand sex and relationships, they are often excluded from sex education. This is compounded by the fact that individuals with disabilities likely have the same sexual and relationship needs as individuals without disabilities. (Eastgate et al., 2011). Without being armed with a knowledge of safe sex practices, consent, and healthy relationship, individuals with intellectual disabilities may be at a higher risk for experiencing sexual violence.

Care Provider Perspectives

When considering and describing care providers for individuals with disabilities, there are numerous occupations which must be considered. Care providers may include nurses, doctors, and other medical professionals as well as family members and those who work in residential settings. The term “caregiver” is defined as an unpaid person (such as a family member) who helps a person with physical care or coping with a disease (Hileman et al., 1992; Hunt, 2003). For the purpose of the current study, the term “care provider” will be used to include medical and residential professionals as well as families and friends who work with individuals with disabilities.

The perspectives of care providers has traditionally been used as the starting point for research involving vulnerable populations such as children, the elderly, or individuals with disabilities (Morrison et al., 2008). This is due to a myriad of reasons including easier access as research participants and the ability for researchers to learn about and navigate ethical considerations such as informed consent with vulnerable populations in their future research. Past literature describes both positive and negative aspects to providing care for those with disabilities.

Positive Experiences

Many positive impacts of providing care to individuals with disabilities exist. Providing care has been shown to strengthen the bond between the care provider and individual receiving care (Boerner et al., 2004). Other positive effects on a care provider (both familial and otherwise) are providing a sense of purpose and direction in life (Cohen et al., 2002), and eliciting positive emotions by helping someone (Redmond & Richardson, 2003). Although some of the impacts could be true for medical or residential providers, they are likely especially true for unpaid family caregivers since they don’t have the same financial benefit that those who are paid to provide care have.

Negative Experiences

Although many positive impacts of providing care for individuals with disabilities have been demonstrated, care providers also report many negative effects. Once again, many of these impacts are specific to individuals who are family or other unpaid caregivers. Live-in care providers often report feeling overall increased levels of stress (Brannan & Heflinger, 2001).

Providing care to vulnerable populations can be an isolating and financially straining undertaking. Care providers report feeling isolated and having financial problems related to caregiving (Earle & Heymann, 2011). Marital strife and other interpersonal difficulties are common among care providers and their families (Redmond & Richardson, 2003). Finally, due to increased physical demands—especially when caring for individuals with physical disabilities, care providers of individuals with disabilities commonly report physical complaints such as back pain and other difficulties due to lifting etc. (Rosenzweig et al., 2008).

Rural Care Providers

With the nature of the research and population of interest (i.e. individuals in South Dakota—a mostly rural state), it is important to explore the unique challenges and experiences of rural care providers—whether they be care providers of individuals with disabilities or other vulnerable populations. Although some research exists, there is a paucity of literature surrounding the experiences of rural care providers (Goins et al., 2009). From what research does exist, it is clear to see that rural care providers are more likely than urban care providers to use informal supports (e.g., untrained workers) than formal supports (e.g., trained support professionals) (Bedard et al., 2004). Such care providers are likely to provide services themselves instead of seeking the assistance of professionals such as occupational and physical therapists. Instead of formal therapies, services are more likely to include the provision of basic necessities such as feeding and bathing (Bedard et al., 2004). Although evidence is inconclusive, rural care providers may experience more severe symptoms of depression due to increased isolation (Goins et al., 2009). In rural areas more than urban areas, care providers of older individuals tend to be older themselves. When added to the physical distance required to access services in rural areas, the age of care providers can be problematic.

In sum, although there is a paucity of research regarding rural care providers, research indicates unique issues, including informal supports, increased depressive symptoms, and an aging caregiving population. Overall, although there is some research surrounding care providers, and some specific to rural populations, very little is known regarding care givers of individuals with disabilities. Research regarding the perspectives of care providers—and especially those of rural care providers, is limited. In instances such as the current study where research is limited, qualitative analyses provide a springboard for future research. Given that there is a lack of research on rural care providers perspectives, this next section will outline common issues associated with the work and supports.

Burnout

The term "burnout" has become increasingly popular when examining workplace stressors encountered by professionals in healthcare and related fields. Vlachou et. al., (2016) describe burnout as varied responses to workplace stressors regarding physical, emotional, and behavioral reactions. Although most occupations include short-term stressors, burnout is unique in that it is considered a prolonged response to the demands of a workplace (Babin, Palazzo, & Rivera, 2012). The dimensions of burnout among care providers include emotional exhaustion, depersonalization, and a lack of personal accomplishment (Maslach et. al., 2016).

A related yet distinct phenomenon to burnout is secondary traumatic stress. Although similar, secondary traumatic stress or "secondary trauma" is related to fields in which workers may interact with individuals who have experienced trauma (e.g., palliative care, healthcare, teaching) (Melvin, 2015). Although burnout symptoms can be severe, those experiencing secondary trauma are more likely to have symptoms akin to those seen in Post-Traumatic Stress Disorder (PTSD) (Cross, 2017). Although current research has not specified the experiences of care providers of individuals with disabilities, it is likely that they have experienced some degree of both burnout and secondary trauma.

Support

While burnout is shown to be prevalent among disability support workers with rates as high as 70% (Sánchez-Moreno et. al., 2014), reports of burnout are uncommon within the profession. Stigma within the healthcare fields decreases the likelihood of workers seeking assistance for symptoms of burnout when compared to other fields (Moll, 2014).

With high levels of burnout, it is clear to see that care providers require supports to be successful and to participate in long-term careers in the field. Perceived social supports have been shown to positively affect both the physical and psychological wellbeing of care providers as well as the health of those they work with (Casale & Crankshaw, 2015). Without adequate supports in place for employees, the demands of a job may exceed the level of supports available, leading to burnout.

Care Provider Reporting

Barriers to Reporting

Care providers are the most likely to report instances of sexual violence for individuals with disabilities and are often required by law to do so. Barriers to care provider reporting are traditionally separated into two groups: 1) the lack of care provider knowledge or recognition of sexual violence, and 2) the decision not to report due to concern of the impact reporting may have (Sege & Flaherty, 2008).

Many care providers report that they do not feel they have adequate training to properly identify instances for which mandated reporting is required (Flaherty et al., 2008). Another barrier is that many policies for mandatory reporting are ambiguous in their definitions (Levi & Crowell, 2011).

Factors that influence care providers decision not to report in cases of neglect and abuse include past negative experiences with reporting concerns and belief that involving the authorities would result in more harm than good (Flaherty et al., 2000). Additionally, some medical professionals report feeling more equipped to deal with concerns directly rather than reporting concerns (Zellman, 1990).

Policy

Each state in the United States, the District of Columbia, American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands has some sort of mandated reporting policy to help ensure the safety of vulnerable individuals such as children, the elderly, and people with disabilities. Although each state includes some version of a mandated reporting law, they vary widely since there is not a federal governance documenting regulation. Discrepancies from state to state lie in questions of: Who is required to report? When is a report required? Where does a report go? What definitions are included? What timing and procedural requirements apply to reports? What information must a report include? (RAINN, 2020).

In general, most states require health and mental health professionals to report instances of sexual violence in vulnerable populations, however there are exceptions to this rule. In Oregon, for example, “A psychiatrist, psychologist, member of the clergy or attorney shall not be required to report such information communicated by a person if the communication is privileged” (Steringer, 1997). States range from having entire handbooks describing which professionals are required to report and how reports should be handled to providing vague language casting a wide net (but not implicating any specific professional). California includes each individual profession which may be implicated, going as far as to mandate reporting by members of the clergy, whereas in Louisiana, those required to report are "any person, including but not limited to a health, mental health, and social service practitioner" (Hankin, 1992; Carter, 2018). Another example of a potentially problematic difference is in the timing requirements of the report. In California, "A telephone report or confidential internet reporting tool report shall be made immediately or as soon as practically possible. If the initial report was made by telephone, a written report must be sent, or an internet report shall be made within 2 working days" (Hankin, 1992). In Louisiana, the revised statute responsible for outlining the timing and procedural requirements for reports following suspected abuse does not specify a time frame or type of report (Carter, 2018).

In states such as Louisiana, where vague language in statutes at the state level make it somewhat unclear on the proper procedure for reporting sexual violence, individual agencies are often tasked with providing their own sets of procedures for reporting (RAINN, 2020).

South Dakota Policy

Since the current study is mainly focused on gathering information from individuals who reside or work in South Dakota, it is important to review the guidelines for mandatory reporting in the state.

South Dakota is somewhat of a hybrid state as far as the level of detail it provides for who is required to report in that it lists individual professions as well as stating "others in healthcare" are mandated to report. Individual professions are first broken into four categories: health care professionals (physician, dentist, nurse etc.), mental health professionals (psychologist, counselor, clinical social worker etc.), state employees (criminal justice, law enforcement etc.), and care providers (nursing facility staff, residential care giver, victim advocate) (South Dakota Codified Law, 22-46-9).

In South Dakota, reports are required when abuse, neglect, or exploitation is suspected. Reports are to be sent to the Department of Human Services office or to law enforcement officers. Any staff of residential treatment facilities is instructed to notify the person in charge of the institution. (South Dakota Codified Law, 22-46-12). The report should be made within 24 hours of obtaining knowledge or suspicion of potential abuse, although individual agencies or residential treatment facilities may require immediate reporting (South Dakota Codified Law, 22-46-9).

In spite of the fact that provisions are set up by the South Dakota Codified Law to ensure that individuals who provide services for those with disabilities report instances of sexual violence in a timely manner, little is known about the experiences individuals encounter when navigating policies and procedures regarding working with individuals with disabilities and reporting instances of sexual violence.

Purpose of the Study

The purpose of this study was to better understand the experience of care providers working with individuals with disabilities who have experienced sexual violence. Collecting this data from the population of interest allowed for a working theory to be developed on the experiences of care providers. Qualitative methods were used due to the extensive gap in the literature considering care provider perspectives on sexual violence in the disability community. Qualitative methods allowed for a more in-depth exploration of the topic.

Research Questions

It is important to note that in grounded theory, research questions evolve as information is gathered, thus the following questions were preliminary in nature. The current study sought to address the following overarching question: What is the experience of care providers who have worked with individuals with disabilities who have been victims of sexual violence? In addition, the following additional questions guided the study:

1. What factors do care providers believe contribute to sexual violence in the disability community?
2. From the perspective of these care providers, what are the common issues with reporting?
3. What ways can we best interview individuals with disabilities about their experiences with sexual violence?

Method

This study was based on a qualitative grounded theory research design. Grounded theory research seeks to move beyond simply describing a phenomenon, to generate or discover a theory or a "unified theoretical explanation" (Corbin & Strauss, 1990). The theory comes from the idea that theory is not gathered in a vacuum, but rather "grounded" in the experiences of the participants in the study. The researcher seeks to uncover a general theory which is gathered through interactions with participants (Creswell & Poth, 2016).

The purpose of this study was to better understand the experience of care providers working with individuals with disabilities who have experienced sexual violence. In a grounded theory approach, the participants are viewed as experts on their own experiences. To this extent, in the current study, providers of individuals with disabilities were seen as experts on their experiences working with the individuals with disabilities and with respect to sexual assault in the disability community. Constructivist grounded theory qualitative research provides a platform to fill gaps in the current literature and creates a basis on which further research may be conducted. The current study sought to provide further understanding of care provider perspectives and experiences working with individuals who have experienced sexual violence within the disability community.

Philosophical Assumptions

One of the central tenets of qualitative research is philosophy, which must be included when working closely with human subjects (Kim & Bonk, 2016). Each qualitative research method stems from pioneers in the scholarly world including Sigmund Freud, Jean Piaget, and Erik Erikson (Kim & Bonk, 2016). Grounded theory is one of five major qualitative approaches first used by these researchers and others and uses methods such as interviewing, memoing, and a simultaneous and iterative data collection process (Cresswell & Poth, 2016; Birks et. al., 2008; Lingard et al., 2008).

An integral component of grounded theory research is using reflexivity to help combat biases that may arise from within a researcher. Within grounded theory research, two divergent pathways have developed concerning the inclusion of a literature review. Because the inclusion of literature inherently provides some preconceived notions, Glaser (1992) insisted omitting literature reviews from grounded theory studies in order to dissuade bias. This approach became known as the classic grounded theory approach. Only after theories begin to emerge may a researcher include information from the literature within this approach, which is a departure from traditional research practices (Glaser 1992). The other approach to grounded theory is that of Strauss, thus called the Straussian grounded theory approach. This approach argues for the use of an initial literature review and suggests that measures can be enacted to circumvent the introduction of bias into a qualitative study (Corbin & Strauss, 1990). This way, existing literature can be used to help guide the research process without clouding the results as they are formulated.

Corbin and Strauss (1990) suggest including a literature review for a number of reasons. Initially, a review can help make certain that a working theory on the process in question does not already exist. In a sense, a thorough examination of the literature can assist a researcher in developing meaningful research questions and provide a guide to the process of sampling. Secondly, many institutional review boards and thesis or dissertation committees require some form of initial review of the literature before a study is approved (Corbin & Strauss, 1990). For this particular study, I had already begun a review of the literature before considering the bias that may be introduced. That paired with the requirement of a literature review by my thesis committee led me to the conclusion that a Straussian grounded-theory approach was best suited for this study.

Reflexivity is one tactic to combat the introduction of bias due to the exploration of previous literature. Instead of avoiding the researcher's viewpoints and past experiences that can lead to bias, the researcher acknowledges them (Gentles et. al., 2014). The researcher both introduces their role in the research with the readers as well as strengthen their own understanding of how their past experiences influence their perception of interviews and other research events through tactics such as memoing. Overall, reflexivity provides an opportunity to face bias head-on, creating the opportunity to include previous literature while still being open to emerging themes that may arise through the course of research. Reflexivity was also implemented in the current study in both the role of researcher and discussion sections.

Interpretive Framework

In addition to philosophical assumptions, qualitative research also requires a frame of reference from which data is interpreted. Interpretive frameworks take a researcher's beliefs and experiences into account when guiding how a study is conducted and which methodological approach is taken (Creswell & Poth, 2016). Due to the nature of the current study, a disability and feminist interpretive lens was the framework for discussion. Disability research originally operated under the medical model where disability was viewed as a sickness in need of a cure. Through transformative disability theory, research has developed to envision disability as a human difference to be celebrated instead of a defect in need of fixing (Mertens, 2007). Within this interpretive framework, researchers take a critical self-reflection on their view of disability and the labels that are applied to it. An emphasis is placed on the research that it must be beneficial to the disability community and reporting of results be respectful (Creswell & Poth, 2016).

A feminist lens takes on the views of marginalized populations and is especially important in work with survivors of sexual violence (Creswell & Poth, 2016). Researchers who take on a feminist lens focus on empowering their findings in a way that is meant to avoid objectifying participants. A feminist lens works well with disability research as well as research dealing with sexual violence considering they both concern power structures and focus on providing resources to confront and remove barriers (Northway et al., 2013).

Role of Researcher

Quantitative and qualitative research methodologies differ greatly in that it is nearly impossible for a qualitative researcher not to bring in perspectives and beliefs that would impact data collection and interpretation. When conducting research, qualitative researchers must be aware that they are members of society with their own culture and thus incapable of completely separating themselves from their past experiences, perspectives, and beliefs (Creswell & Poth, 2016). Approaches to reducing bias in qualitative study vary depending on the methodology, however within each approach, researchers must reflect on their past experiences that led them to be interested in the research and will likely impact the interpretation of results.

Unlike with other qualitative methodologies such as phenomenological research, grounded theory research does not require researchers to set aside or "bracket" their biases or experiences while conducting research. Rather, the researcher takes into account their experiences, values, and research priorities to add to the theory being developed. Since the theory being developed is meant to capture a process and the views of true individuals, the researcher must be aware of their own perspective as well as those of the participants (Creswell & Poth, 2016). This being said, it is important that the researcher identifies their positionality within their study before beginning.

Initially, my interest in conducting research with this population was to improve standards of care within an underserved group and to improve the quality of work experience for my fellow care providers. My research passion has always been working in the area of sexual violence within marginalized populations, and this research combines that interest with my experience working with individuals with disabilities—a passion I have developed during my time in graduate school. I was enrolled as a fellow in the Leadership Education in Neurodevelopmental and related Disabilities (LEND) program and interacted with many individuals with disabilities as well as providers who work with them. Additionally, I currently work at LifeScape—an organization which services individuals with disabilities. Through working with these individuals as well as the disability theory lens, I have come to view disability as another form of human difference such as sexual orientation or gender.

Viewing disability as a characteristic and not as a problem to be solved has helped me to notice injustices the disability community faces on a systemic level. As I have progressed in the clinical program and my graduate training, I have begun to see the link between clinical experiences and research endeavors. My experience working with individuals with disabilities and previous experience researching sexual violence have informed each other and ultimately informed my interest in the current study. In the future, I hope to continue working with individuals with disabilities in a clinical setting and also continue researching injustices in the community through a critical disability lens.

Along with reflecting on my background related to the research topic, it is important to also discuss how my experiences led me to choose a qualitative research approach. In my research training, a colleague in my research lab has conducted qualitative studies. My conversations with her led to an interest in learning about qualitative methodologies. I completed a graduate level qualitative research course with Dr. Lisa Newland in which I learned the importance of qualitative research to substantiate theory and develop the underpinnings that are necessary to conduct quantitative research. With this particular study, a qualitative approach was necessary to develop theory where a working theory did not yet exist. Therefore, I hoped to conduct a quality thesis study to develop a grounded theory on care provider experiences when working with individuals with disabilities who have experienced sexual violence.

Participants

Participants were individuals who are or have previously been care providers of individuals with disabilities.

Sample Size

Qualitative methodologies typically utilize small, carefully selected sample sizes. Within the grounded theory approach, Charmaz, (2014) recommends using a sample size of 20 to 30 to develop a well-saturated theory, although in some cases the number can be much smaller or larger. Purposeful sampling was used in this study to include individuals who work with individuals with disabilities who were willing to discuss their experiences working within the disability services sector. I proposed 20 participants for an initial sample size, however saturation was reached much earlier, resulting in a total sample size of 10 participants. Due to the uncertainty of how many participants would be needed for saturation, 50 participants were requested from the IRB. Saturation in a study is achieved when a phenomenon has been fully described and it is believed that the addition of new participants will not contribute to further elucidation of the phenomenon.

Recruitment

Initial recruitment was done through recruitment flyers sent out by institutions in the disability services sector. Three emails were sent to eligible parties who will be identified through a snowball sampling technique. Due to the nature of the study, the only inclusion criteria was that participants belong to the group outlined above, speak or write in fluent English, and are age 18 and over.

Email correspondences and recruitment flyers were approved by the University of South Dakota’s Institutional Review Board before being sent out to potential participants. The student researcher was in charge of handling correspondences and setting up interview times at the convenience of interested parties.

Data Collection

As is typical among grounded theory studies, data were collected within a single, in-depth, individual interview (Gentles et. al., 2014). As with all qualitative approaches, the interviewer must be adept at interviewing and maintain that the individual they are interviewing is the “expert” and not the researcher themselves (Creswell & Poth, 2018). The student researcher was trained in advanced interviewing techniques and facilitated most of the data analysis, therefore, he conducted all interviews with participants. Interviews ranged from 18 minutes to around 40 minutes with an average of about 30 minutes.

Human Subjects

This study was conducted under strict ethical guidelines put forth by the American Psychological Association (APA) as well as the institutional review board at the University of South Dakota, which is accredited by the Association for the Accreditation of Human Research Protection Programs (AAHRPP). Each individual who works with human subjects or data involved in the current study underwent training with human subjects through CITI research ethics and compliance training modules. The study was proposed to the student researcher’s thesis committee consisting of faculty members with backgrounds in conducting and overseeing research projects. The study was submitted for review to the University of South Dakota’s institutional review board before conducting any recruitment methods for the study. The guidelines of the board were followed to protect participants from undue harm.

Consent

Before data collection begins, participants were introduced to the consent document and asked to give their verbal consent to participate in the study. The researcher read the consent document which outlined the purpose of the study, the protocol for audio recording, the risks and benefits of participation in the study, and the participant's ability to discontinue with the interview at any point in the process. Participants were informed that if at any time they felt uncomfortable, they were free to refuse to answer a question, and there would be no negative consequences to them if they chose to discontinue participation at any point. The student researcher provided each participant with his contact information as well as that of the primary investigator. Participants were offered the opportunity to verify the transcript of their interview at any point. They were also provided with resources for psychological services and information on mandated reporting should they require them.

As approved by the IRB, participants were offered the option of either receiving $20 for their participation or to have a $20 donation be made for an organization focusing on sexual violence and disability. Each of the 10 participants chose to have their $20 donated.

Confidentiality and Anonymity

Participant interviews were conducted over Zoom video conferencing. Interviews were conducted from a private office on the interviewer's side to maximize confidentiality. Each interview was audio recorded as well as being recorded over Zoom. The process for storing and protecting audio files was outlined for the participant and was strictly followed by the student researcher. If participants had any concerns regarding confidentiality or anonymity, they were encouraged to express them. Any identifying information was stripped, and participants were referred to by a pseudonym of their choosing. No identifying information is included in the final document or any publications that may arise from the research. The chosen pseudonym will be included in the transcript and any document thereafter.

Audio Recording

Due to the risk of device failure during interviewing, two recording methods were utilized to capture participant interviews. The student researcher used the audio recording capabilities of Zoom as well as the audio recording capabilities on his phone. Files recorded on both Zoom and the phone were immediately uploaded onto the student researcher's computer and each file was password protected. The files were promptly deleted from the phone once they were uploaded. Once transcribed by the student researcher and other graduate students in Dr. Caraway's lab, files were uploaded onto a password-protected USB drive as a backup method of storage. Only the student researcher and the student's advisor, Dr. Jean Caraway know the password and have access to the files. Once the files are uploaded to the USB drive, they were permanently deleted from the student's desktop and phone. Completed transcripts were password protected and stored on the USB, which will be kept in Dr. Caraway's office. Each file was named according to participant pseudonym and included no identifiable information associated with the participant in the file such as their name, age, or initials. In the consent form and during the beginning of the interview, the student researcher explained the audio recording procedure and asked the participants to consent verbally.

Interview Protocol

Individuals who participate in this study complete a semi-structured interview with the student investigator. The interview took place over Zoom and was recorded on both a recording app on the phone and on Zoom. Each interview lasted approximately 30 minutes, but each interview length depended on the depth of the answers the participants provide during the interview. Creswell & Poth, (2018)   mention that grounded theory research should seek to use a set of interview questions which focus on understanding how individuals experience the process or underlying principle. Through this process, the core phenomenon and related causal mechanisms can be discovered. Each interview began with questions about the participant's history working with individuals with disabilities. Next, questions progressed to address participant's experiences working with individuals with disabilities who have been sexually assaulted, why they believe individuals with disabilities have higher rates of sexual assault, and how their experiences have been in terms of reporting. Finally, participants were asked their perspectives on how best to interview individuals with disabilities about their experiences with sexual violence. Examples of the interview questions are as follows:

1. In what capacity do/did you work with individuals with disabilities?
2. How prevalent do you believe sexual assault or abuse are in the disability community?
3. Have you ever worked with someone with disabilities who has been sexually assaulted or abused?
4. What are the policies and protocols you follow when you become aware that someone has been sexually assaulted or abused?
5. What did you learn about how these cases are handled?
6. What resources were available?
7. What solutions do you think are necessary to combat sexual violence in the disability community?

A full list of questions can be seen in Appendix A.

Data Analysis

Theoretical Sampling

Grounded theory is conducted through an iterative process which includes simultaneous collecting, coding, and analyzing of data (Glaser & Strauss, 1967). Due to the unpredictable nature of data collection, the interview procedure must be guided by the needs of the data. The theory that emerges informs the inclusion of additional subjects in an ongoing process (Glaser & Strauss, 1967).

Theoretical sensitivity. Corbin and Strauss (2008) emphasize the utility of a researcher's skills and insight as having a major role in the process of theory generation within a Straussian grounded theory approach. A systematic approach to research and data collection is still conducted, however unlike other approaches to research, there is less control in the sense that the judgement of the researcher must be used to adjust the methods of data collection as need be. In a sense, a priori theory has little to add to the data gathering process (Glaser & Strauss, 1967).

Theoretical Saturation. When conducting qualitative research with more than one participant, saturation is the end goal of data collection. Saturation is reached when adding participants would not add to the existing theory or knowledge, but rather confirm what has already been established (Creswell & Poth, 2016). Likewise, if saturation has not occurred, additional participants are necessary in order to fully represent the entire extent of a given phenomenon. Saturation can be judged by the richness of a developed theory. A diverse and comprehensive sample should cover any thin theories or theories with several exceptions involved (Glaser & Strauss, 1967). As a starting point, 20 participants was the estimated sample size, although through the iterative sampling process, theoretical saturation in the current study was achieved after 10 participants.

Comparative Analysis

The initial step in grounded theory analysis is to begin analyzing data into units. This process is both comparative and iterative analysis because it involves comparing units to each other as well as to data collected in the next phase of data collection. As mentioned earlier data collection and analysis occur simultaneously within a Straussian grounded theory approach. The researcher begins analyzing data during the first interview through memo writing and continues inductive approaches to research throughout the coding process (Corbin & Strauss, 2008). Corbin and Strauss (2008) recommend following three steps in the coding process. First, open coding, next axial coding, and lastly, selective coding (Strauss, 1987).

Open Coding

To begin the coding process, a researcher must break down data into parts and examine them, comparing and contrasting ideas (Strauss, 1987). Within open coding, phrases, words, or even observations are used to develop concepts. The method of analysis and comparison is constant until the researcher reaches a level of saturation in which additional inclusion of participants would only add existing information to the data. Memo writing is an important feature of open coding. Corbin and Strauss (2008) even suggest interrupting coding in order to write memos to the self that help a researcher to develop theories. A researcher must develop concepts and theories without becoming committed to them too quickly (Creswell & Poth, 2016).

Through the inductive process, the concepts ascertained from open coding were formulated together into categories. Concepts used in categorizing must have both analytic and sensitizing features (Glaser & Strauss, 1967). For a concept to be analytic, it must denote key characteristics of an entity, and to be sensitizing, it must produce a meaningful picture to be able to encourage an individual's understanding in terms of personal experience. Through the open coding process, general themes in the current study began to occur, but were not yet fully developed.

Axial Coding

The term “axial coding” gets its name from the idea that this level of analysis takes place around the axis of one “one category at a time” (Strauss, 1987). Axial coding takes place within a category and involves analysis of the “who, what, where, when, and why” (Strauss, 1987). Once again, axial coding happens in conjunction with open coding, although for axial coding to occur, open coding must also take place. Axial coding differs from open coding in that it involves a more explicit comparison and contrast of categories (Corbin & Strauss, 2008). Ideally, axial coding will continue to become denser until ultimately, the linkages between categories will lead to the discovery of a “core” category. This core category can be thought of as the central tenet of the theory that is being developed (Strauss, 1987). Through comparing codes while also open coding, the student researcher was able to further discern subcategories that began to emerge in the research process.

Selective Coding

With the identification of the core category, the researcher can focus in and conduct the most limited coding process, duly named “selective coding.” This type of coding is systematic in nature and uses the core category to help inform any additional sampling and collection of participant data (Strauss, 1987). As the research process continued, coding phased from more open and axial to almost solely selective coding as the process moves toward the generation of a theory. In the current study, the student researcher was able to selectively code between categories and use memoing to further develop a theoretical model.

Generating Theory

As the name suggests, grounded theory involves the development of a theory that is grounded in data (Creswell & Poth, 2018). Once the coding process begins to develop a core category of related concepts, a researcher can begin developing hypotheses of possible mechanisms. These hypotheses may seem unrelated, however as more categories and relations are developed, hypotheses will also become clearer and more defined, shifting into theory (Glaser & Strauss, 1967). Because of the qualitative nature of data collection, it must be noted that the role of a researcher "is not to provide a perfect description of an area, but to develop a theory that accounts for much of the relevant behavior" (Glaser and Strauss, 1967). What a researcher must do is to identify a working theory that is not set in stone, but rather informative and beneficial for future research.

In summary, the student researcher was able to simultaneously engage in each process of coding and theory development within the data collection process. The research process sought to abstract meaning from minute units to concepts to categories, to a core category to hypotheses, tentative theories and finally to a crystalized theory (Glaser & Strauss, 1967).

Integrity Measures

As with any type of research, the validity and reliability of data is important to the process. These considerations are especially important within qualitative data given the active role of the researcher in each step of the process. Several procedures will be followed within the current study to assure both validation and reliability.

Validation Procedures. The overarching theme in qualitative research is to generate information which is reflective of the voices of the participants and population included in the research. Validation procedures are utilized in qualitative research to assure the preservation and integrity of those involved in the research. These procedures emphasize the importance of representing the participants. Creswell and Poth (2018) outline several ways to validate the data, including self-reflection and reflexivity; seeking participant feedback; peer review; as well as several other types of procedures. In general, it is ideal to use at least two validation procedures regardless of the type of qualitative research methodology being employed.

The first procedure that was utilized is self-reflection or reflexivity. The student researcher attempted to understand and reflect on how personal experiences, background, and biases may have potentially impacted the direction of the research. My reflections have been discussed as part of this study and were included to inform the research process. The memoing process included observed connections between researcher bias and the processes of data collection and interpretation.

The second validation procedure involved debriefing with a fellow colleague in the research lab to verify that the study is being conducted as outlined in this document. By asking tough questions of the researcher, he was able to reflect on the process involved in research and any problems that arose.

Reliability Procedures. Whereas validation is concerned with accurately portraying the voices of individuals in the study, reliability procedures are mainly focused on the accuracy of obtained information by using checks on the coding process (Creswell & Poth, 2018). The main method to reach reliability is through inter coder verification. For the current study, graduate co-researchers were recruited from Dr. Jean Caraway’s research lab. The co-researchers were trained in coding by the student researcher. The student researcher conducted all coding; however, the co-researchers were provided with the preliminary coding from each transcript in order to ascertain their level of agreement with each code. Once 80% agreement was obtained between the student researcher and co-researcher and saturation is achieved, the coding process was concluded (Creswell & Poth, 2018).

Data Representation

The ultimate goal of grounded theory research is to develop a working theory that takes into account interviewees' participation in a phenomenon or process. The final product of this study should be representative of the experiences of the participants. The theory developed from this research should be used to help inform future research to benefit the disability community, as is outlined in the lens of disability theory (Creswell & Poth, 2018).

Findings

This purpose of this study was to better understand the experience of care providers working with individuals with disabilities who have experienced sexual violence. Through this study, I attempted to illuminate the experiences that care providers face. To that end, the following overarching research question guided this study:

What is the experience of care providers who have worked with individuals with disabilities who have been victims of sexual violence?

Additionally, the following research questions were included in order to further elucidate care provider's experiences and to learn from their expertise:

1. What factors do care providers believe contribute to sexual violence in the disability community?
2. From the perspective of these care providers, what are common issues with reporting?
3. What ways can we best interview individuals with disabilities about their experiences with sexual violence?

As stated earlier, within qualitative research, initial research questions adapt to better encapsulate the experience of the participants and thus are guiding questions rather than “answerable” queries. As such, although the interview process was guided from the research questions, the results were guided by participant experiences and responses.

Although in order to protect participants’ anonymity detailed identifying demographic data were not collected other than their gender. Information regarding the participant’s role and length of time working in the disability services sector was also collected. Of the ten participants, eight were female and two were male. One participant identified as a client advocate, two were administrators, three were multidisciplinary health providers (occupational therapists, speech therapists, etc.), and four were direct support professionals. Participant’s amount of time in the field ranged from one year to over thirty years with an average of 12 years.

Although I believe saturation of the data was achieved early on in the data collection process, the addition of participants to reach a total 10 added richness to the data and examples from participant voices that helped to better articulate some codes. In the following section, each participant’s voice is used at least once, pointing to the depth and richness of the data. Although some participants had more insight to provide in certain areas of the research, they each had input into all categories.

In this section, I present categories pertinent to the aforementioned research questions and that emerged from the data obtained from the interview transcriptions. Each interview was analyzed independently. Categories and sub-categories common among interview transcriptions were then identified concerning the research questions. Four data categories emerged from the data analysis process (Figure 1). A full list of categories and supporting codes can be viewed in the codebook (Appendix B).

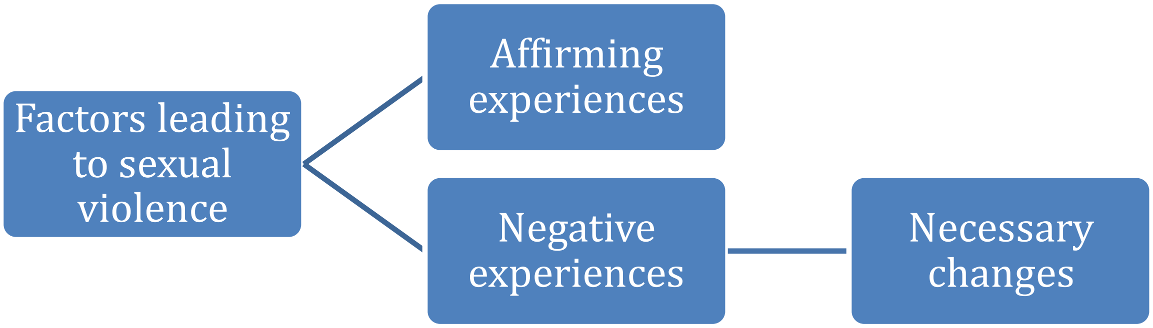

Figure 1: The four key categories

As is typical with qualitative studies, many data were gathered and analyzed from the collected and transcribed interviews. Only a sample of illustrative quotations is presented in this findings section. To ensure the voice and experience of the participants is respected, no existing literature will be included with the results. This presentation style supports the credibility of the research and is a proven grounded theory format (Charmaz, 2014). For the purpose of anonymity and to protect the research participants, each participant has been assigned a pseudonym. Other identifying details have also been omitted from quotations.

Overall, four categories emerged—all of which contained subcategories. The first category was *Factors leading to sexual violence* which contained the subcategories of *Myths* and *Lack of sex education.* The second category was *Affirming experiences* which contained the subcategories *Reporting* and *Policies.* The third category was *Negative experiences* which contained the subcategories of *Frustrations* and *Burnout.* The fourth and final category was *Necessary changes* which contained the subcategories of *Policy* and *Societal.*

Following from the left side of the model, care providers take the lens of their beliefs of *factors leading to sexual violence* to view both their *affirming experiences* and *negative* *experiences*. From those *negative experiences*, participants learn what existing structures and polices are not working and thus can provide insight into the *necessary changes* that are required in order to combat sexual violence in the disability community and negative experiences such as burnout for care providers. Results of each category and samples representing each subcategory will be presented below.

Factors leading to sexual violence

The first category to emerge was related to factors that lead to sexual violence for individuals with disabilities that care providers work with. The two sub-categories that emerged are shown below (Figure 2).

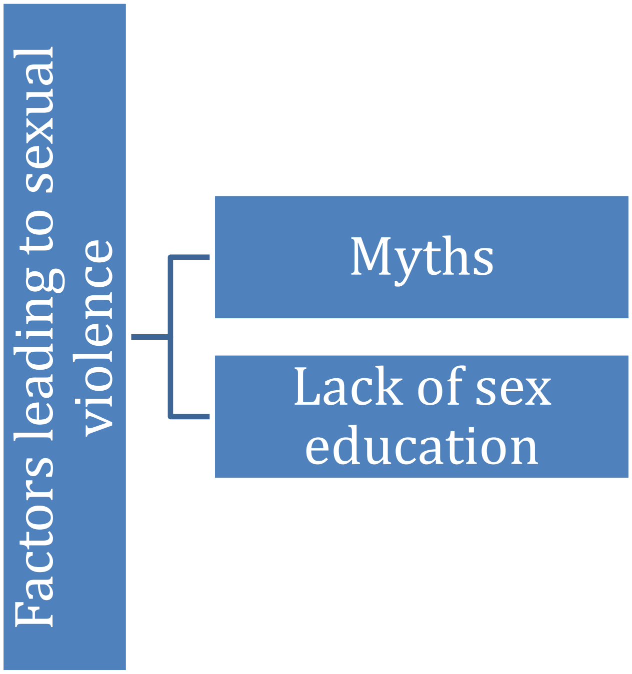

Figure 2: Category one: Factors leading to sexual violence

Participants described several factors leading to sexual violence that were encompassed into sub-categories of myths and a lack of sex education.

Myths

From their combined 93 years of experience in the disability services field, each of the ten participants identified myths that are perpetuated in society that they believe contribute to the rate of sexual violence in the disability community. For example, participant “Allison” articulated:

> People don't necessarily think that people with disabilities have any type of like sexual urges or anything like that, because I do believe that they do. I think that's a pretty normal, common human thing for anybody um and then there's people who believe that even if they do have those that they shouldn't be allowed to do anything, because they have a disability.

This quotation provides evidence that care providers have knowledge of existing societal myths that contribute to sexual violence. The myth that individuals with disabilities do not have sexual desires appears to be well-grasped by most participants in the current study. Participants further voiced that viewing individuals with disabilities as inherently asexual leads to them being objectified and potentially becoming easier “targets” for perpetrators of sexual violence. For example, participant “Jason” stated:

> I think that certainly the stigma and the myth that they are not sexual individuals places them not as a human being--a living breathing person--but as a thing. I think that if someone were to be a predator of some sort logic might tell you that they could see this “thing” as an easier target for their misgivings.

Participants also acknowledged that although individuals with disabilities may be perpetrators themselves, the myth that they are hypersexual and any sexual desire they may have is unnatural is also a contributor of sexual violence. For instance, participant “Carol” recounted the following about her experience working with a male who was sexually aroused:

> One of the myths would be that it's more predatory. A male might want to seek a female attention or is trying to get someone while it just might be a reaction of their body, you know, because you never know, and everyone gets sexually aroused but I don't feel like it's taken into account.

Lack of Sex Education

Along with myths related to individuals with disabilities and sexuality, the other sub-category that emerged was the lack of sex education provided for individuals with disabilities. This lack of education was articulated in a variety of ways ranging from a lack of education in body parts and functions to lack of training in consent and sex practices. This lack of education is shown in the following statement made by “Carol”:

> You know how they don't understand their own privacy or their body or even like not even understanding their own anatomy. I feel that that's concerning to me as well. Sometimes the residents don't use appropriate language when it comes to private parts like penis or vagina. So, when I work with residents, I make sure I say ten thousand times, let's wash your penis, lets wash your vagina so then we just destigmatize the word. Just make it more normal, so then if anything were to happen, they would be able to say “so and so touched me inappropriately” on my vagina.

Care providers had valuable insight to provide, considering some of them have been in the disability services sector for over thirty years. In their experience, factors of myths about sexuality and disability as well as a lack of sex education for individuals with disabilities are both contributors to the occurrence of sexual violence in the disability community.

Affirming Experiences

The second category that emerged centered on affirming experiences care providers had related to working with individuals with disabilities. The experiences participants described were not affirming in the sense that they were overly positive, but rather that they encountered instances where existing structures (e.g., policies/procedures) worked as they were intended to. Although each participant was able to describe certain aspects of policies and existing structures that do work, there was a seeming lack of positive feelings toward most policies. Within affirming experiences, sub-categories of reporting and policies emerged (shown below in Figure 3).

Figure 3: Category 2: Affirming experiences

Reporting

The first subcategory within affirming experiences was care providers experience with reporting. Responses in this subcategory ranged from positive experiences with reporting as well as affirming responses others had following the discovery of a history of sexual violence for individuals that providers served. Related to affirming reporting and discovery experiences, participants indicated that building relationships with the individuals they serve(d) led the individuals with disabilities to disclose a history of sexual violence. For instance, "Hillie" recounts an experience being informed by an individual with Cerebral Palsy about a history of sexual violence:

> This man who was a teenager at the time [he was sexually assaulted] is still an acquaintance and he is in his 40s now. He shared that with me in the way he talks with people who know and love him. He would say "you have no idea what went on."

Although this experience of sexual violence was not reportable as it occurred years in the past, this story highlights the affirming experiences care providers may have being someone those they care for feel comfortable disclosing to as they work and build trust with individuals with disabilities.

With instances that were reportable, care providers in the study described success in both reporting and follow-through. As an example, "Priscilla" shared her experience with reporting a sexual assault and connecting the individual she was working for with resources:

> Well, I made sure they were safe where they were at and provided information on shelter and service agencies because it wasn't in the areas that I live in. It was in another part of the state, I connect them with a provider in the area so they could be there more physically with them, then I would be able to where I'm at.

"Priscilla" further elaborated on her experience with this individual and the success of the system in providing resources for someone who experienced sexual violence:

> They were very, very supportive. The other liaison was perfect to make contact with the person, and was able to help with more information. One of the shelters the person was staying at provided other avenues and information such as where they could go.

In "Priscilla's" role as a client advocate at the time, she was not mandated to report the sexual violence to authorities, but still reported success in sharing resources with other agencies and the individual she supported.

Policies

Along with affirming experiences with disclosure and reporting, participants also spoke of their affirming experiences with policies. Each participant was able to identify to some degree the policies and procedures in place for reporting sexual violence and abuse. In a non-mandated reporting role, "Priscilla" explained her role in situations where sexual violence is disclosed to her:

> We're not mandatory reporters but as a non-attorney client advocate I would go to my supervising attorney and I would say "this was brought to my attention." We have an investigative team that could go in and investigate. We have what they call access authority, which means that we can get in and get things that. Without subpoenas or warrants.

“Priscilla” noted that although policy dictates that she cannot report the incident in her role as a client advocate, policies in place still benefit her clients. For care providers who are mandated reporters, some participants still find policies to be helpful and affirming. For instance, “Megan” noted:

> Every agency has a very team that deals with severe circumstances. The police are contacted and then every agency has acquired quality and compliance so that's where an internal investigation is done. Anywhere from there it's working with that agency to find…you know say it happens in a group home. [We would] find separate placement for that person. And then the agency essentially will take over, you know…if it's a family, or staff member, we kind of collaborate as a team on how we're going to ensure that person continues to stay safe and whether you know, sometimes the police do pursue it sometimes we have to pursue it.

In this quotation, “Megan” outlined the process of reporting to include both internal and external investigations and a stringent focus on the safety of the individual who experienced the incident of sexual violence. “Hillie” provided insight into positive changes in policies and work environment since she began working in the disability services sector:

> This place with the students and the staff was like a family. You know, we did things together and staff took kids home on their weekends who didn't have family nearby and you know there's a lot of that that is absolutely not allowed, rightfully so because of all this. You know, in a way that’s sad but I understand why it's needed to become so much tighter.

In all, affirming reporting experiences and policies played a role in how care providers experience working with individuals with disabilities who have experienced sexual violence. Unfortunately, along with affirming experiences, participants also reported several negative experiences they encountered when working with individuals with disabilities who have experienced sexual violence.

Negative Experiences

The third category to emerge from the data refers to the negative experiences that care providers experience when working with individuals with disabilities. Sub-categories include the frustrations participants reported related to their employer and the disability services sector as well as burnout they face when working with difficult topics such as sexual violence (Figure 4).

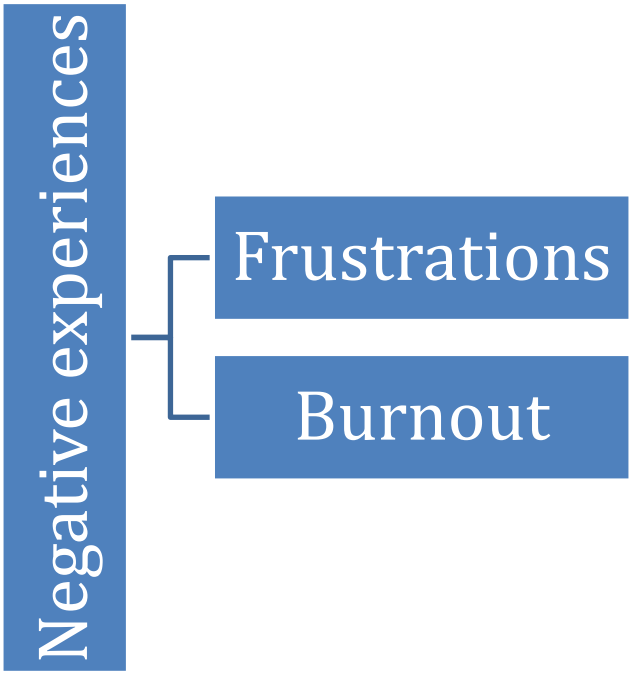

Figure 4: Category 3: Negative experiences

Frustrations

Care providers spoke of several frustrations related to their work with individuals with disabilities. Within the sub-category of frustrations, participants identified frustrations related to their employers. For instance, employers may not take care provider's reports of suspected sexual violence seriously. "Carol" discussed her experience trying to report a suspected instance of sexual violence:

> I don't think it was taken serious with one of the residents, because he would act so weird when it came to wiping him and he would, whenever I would try to clean his penis or just like his anal area, he would cry. It wasn't like a whining cry, it looked traumatizing like

> he was he was triggered. So then I brought it up, and I was like “well this is not normal, his reaction is not normal” I reported it and I don't think anything happened. I think it was really brushed off and I didn't like that at all.

Beyond instances where care providers may not feel supported by their employers or those they report to, participants also identified a general feeling of discomfort related to working with individuals with disabilities who have experienced sexual violence due to staff feeling untrained. “Megan” articulated this sentiment:

> They don't really provide training towards the specific like sexual abuse needs. When you have staff that are trained well there be able to you know ensure that person doesn't go from zero to 100. So instead, they can start recognizing those triggers. You know I honestly didn't even recognize that we don't have that specific training till this meeting.

Burnout

Feeling underprepared to work with individuals with a history of trauma appears to lead to staff burnout and secondary trauma. The second sub-category of burnout relates to both directly working with individuals with disabilities who have experienced sexual violence as well as to work and policy-related burnout. Talking about working with individuals who have experienced sexual violence was sometimes an emotional experience for care-providers. Secondary trauma and burnout were common experiences. “Jason” spoke of his experiences:

> We are tasked over and over and over again, just to be resilient and to be to give give give give give of yourself. Give of your time. Give up your financial resources to propel a mission. And that's taxing. It's really tiring. I had a conversation with a few colleagues about burnout and just you know the constant need to feel like you're invincible.

In addition to burnout/secondary trauma related directly to the work care providers do with individuals with disabilities, they also reported burnout related to their employment. “Carol” for instance, indicated her burnout related to her employer:

> Sometimes I don't see the point in the job that I do because it's not effective. We're not even meeting the basic needs and their [the client’s] trauma’s not taking into account either. So if someone was severely abused for instance, if bath time is a struggle and we don't ever take into account their past and say if they were sexually abused in the bath,

> how are we able to, how are we going to be able to help these residents live a fulfilling life?

Although participants identified self-care related activities such as art, faith, and taking a break to be helpful to combat burnout and secondary trauma, as a whole, they appeared to feel a general deficiency of support from employers and society as a whole.

In all, frustrations and burnout were universal experiences of care providers of individuals with disabilities. It was evident in the data that participants feel a general lack of support in their roles from their employers as well as from society. Although negative experiences were common, care providers used these negative experiences to provide insight into changes that are necessary to mitigate their effects.

Necessary Changes

Along with the indication of negative experiences, individuals who participated in this study also identified changes that could be implemented to combat sexual violence in the disability community and to help negate care provider burnout/secondary trauma. Although a wide range of changes were presented by participants, desired changes emerged into two sub-categories presented below (Figure 5).

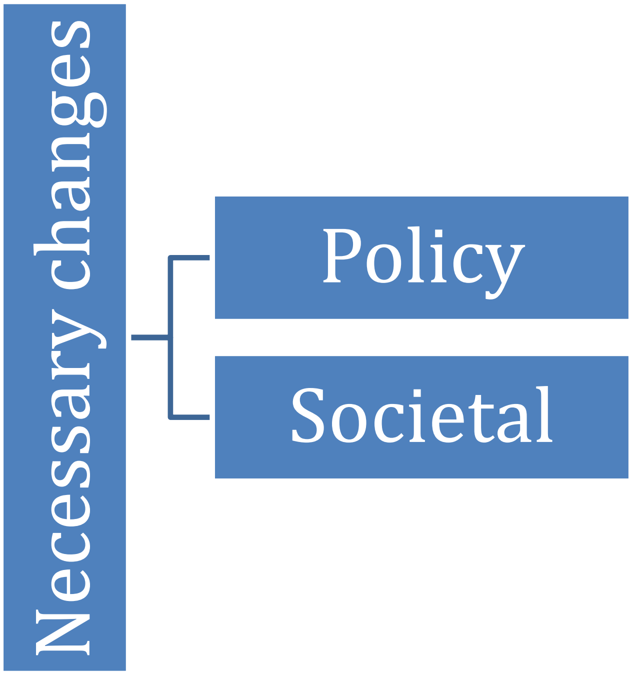

Figure 5: Category 4: Necessary changes

Policy

The first set of desired changes relate to institutional policy changes suggested by care providers who participated in the study. Initially, care providers related their discomfort with working with individuals with disabilities who have experienced sexual violence with a desire for further training to help them better serve those they work with and to avoid burnout. “Carol” indicated the need for further staff training:

> I would like to get training on it and know the proper chain of commands because I know there's like anonymous hotlines, but the way the organization is set up it's a hot mess. Communication is crappy so, if it was situations like this, I would like the communication to be 1,000% and I would want me to feel secure in my position and knowing that I am prepared for any kind of situation, and then I would like that training to go out to everyone else.

“Allison” furthers that training should be continuous as to account for the considerable staff turnover in the disability services sector:

> Continue training for staff. It's hard, because when you hire somebody, you're obviously hoping that they're a decent person and going to be doing what's right and then

> unfortunately, some people are just not. Making sure that there's constant checks, making sure that the other staff, maybe feel comfortable too knowing that if something happens that they should be reporting it.

In addition to the necessity for further staff training to combat burnout and secondary trauma, participants identified a dire need for sex education for individuals with disabilities. Following the myths related to sexual violence, many care providers reported their belief that sex education could help individuals with disabilities become their own sexual self-advocates. This need for sex education relates to the myths and frustrations outlined earlier. “Ella” expressed:

> I think we do a poor job as those who support individuals with disabilities at providing education to them on how to prevent sexual assault, what is sexual assault, what is appropriate touch and not appropriate touch. In particular in children, we aren't forward thinking of how things that we allow them to do at a younger age will be perceived or turned against them when they get older. So, it's very cute when a three-year-old sits on your lap. It isn't cute when the 25-year-old does that and it puts them at risk of a sexual assault because they're still doing that type of behavior.

It was especially apparent in the data that care providers disagree with the myth that individuals with disabilities cannot comprehend sex education and healthy relationships. “Allison” furthered “Ella’s” previous statements:

> I don't think it's something that they should be sheltered from. It should be taught. It should be taught like anybody else like appropriate ways when it's appropriate when it's not. So you just need to have the same education that everybody else does as well. I think they need to be made aware, regardless of what their cognitive level is or physical ability is. and if it happens to you, you can say something to someone, so I think having some resources like that would be helpful.

Societal

Along with changes in institutional policy, care providers believed that societal changes are required in order to better support individuals with disabilities who have experienced sexual violence as well as the care providers themselves. Tangibly, care providers indicated a need for increased funding for the disability services sector. “Ella” pointed out the direct benefit increased funding may have:

> It always comes to funding. More funding so that these individuals aren't in group homes alone with one person only for weeks at a time where there's never an opportunity for another person to be there to observe things--to supervise things. Just the presence of a second person in a home makes a huge difference in decreasing rate of sexual violence.

The other necessary societal change that emerged was the need for awareness of the issue of sexual violence in the disability community. Within the disability services sector, care providers articulated needed changes and further training and education. They further called for broader education and awareness on a societal level as demonstrated by "Jason:"

> It needs to start with social change. I think that everything in our world is about people, and I think we forget that sometimes. And being a person and having wants and needs and then having the realization that someone who happens to have a disability is also a person with wants and needs. Society places them in a box or label them as less than or different than or other than and social change is the only way that we will stop spinning our tires. I think once we're able to tell those stories once we're able to share those experiences on a larger platform.

In sum, participants recognize the needs of care providers and those they care for. They are aware of the need for policy changes such as increased and consistent training as well as the need for sex education for individuals with disabilities. Additionally, care providers reported a dire need for societal changes such as increased funding for the disability services sector and awareness in the general public.

Model

Within the original model of the four emergent categories, some conclusions of the experiences of care providers can be drawn. By revisiting Figure 1, it is evident that the insight providers have relating to the factors leading to sexual violence informs their affirming and negative experiences working in the disability services sector with individuals who have experienced sexual violence. Care providers learn from the negative experiences they encounter to gain perspective into solutions that can benefit their job performance and the individuals they serve.

To reiterate, care providers take the lens of their beliefs of *factors leading to sexual violence* to view both their *affirming experiences* and *negative experiences.* From those *negative experiences*, participants learn what existing structures and polices are not working and thus can provide insight into the *necessary changes* that are required in order to combat sexual violence in the disability community and negative experiences such as burnout for care providers.

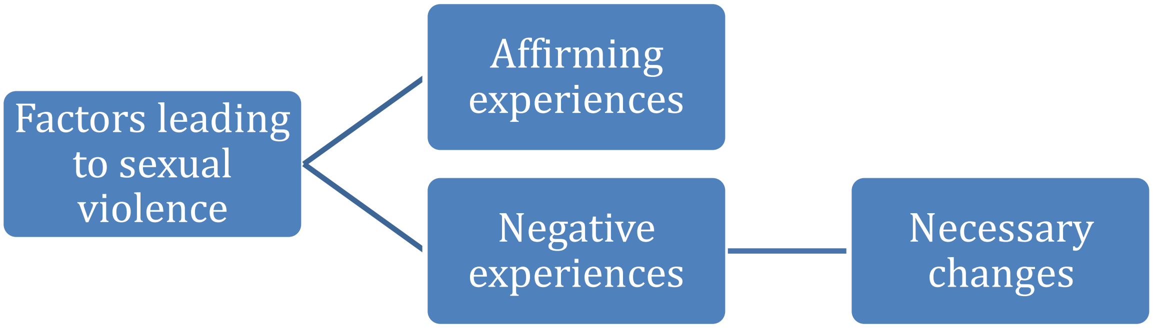

Figure 1: The four categories

In the next section, the findings are discussed in relation to existing literature and within my own work in the disability services sector.

Discussion

Review of Research Questions

The purpose of this grounded theory study was to better understand the experiences of care providers working with people with disabilities who have been victims of sexual violence. This study was designed to give care providers of individuals with disabilities a safe space to describe their experiences working in the disability services sector with individuals with disabilities who may have experienced sexual violence and to develop a model to describe those experiences. Specific research questions were:

1. What factors do care providers believe contribute to sexual violence in the disability community?

2. From the perspective of these care providers, what are common issues with reporting?

3. What ways can we best interview individuals with disabilities about their experiences with sexual violence?

A qualitative, grounded theory analysis was conducted to gather and analyze data collected during in-depth interviews with ten care providers.

Categories emerged that addressed the original research questions. Additionally, themes expanded beyond the direct scope of the initial research questions as is typical within qualitative research. The four data categories: *factors leading to sexual violence, affirming experiences, negative experiences,* and *necessary changes* provided an explanation of the background, experiences, and proposed changes necessary to combat negative experiences for care providers and sexual violence in the disability community. The process of using perspective from experience in the disability services sector, experiencing positive and negative experiences, and using those experiences to articulate desired social and policy changes is supported by existing literature and thus appears to be a useful model for describing the experiences of care providers in the disability services sector.

Although one of the preliminary research questions was meant to explore the experiences with reporting instances of sexual violence, the participants of this study did not collectively focus on reporting itself in their interviews. Rather, they spoke largely of their own experiences working with individuals who have a *history* of sexual violence. As such, the categories that emerged from data focused less on reporting than I speculated. This could be due to the degree to which care providers felt the importance of talking about other experiences such as their own degree of burnout related to work in the field as a whole. Additionally, many care providers in the current study are employed by agencies who work with individuals who have already been identified as survivors of sexual violence and thus additional reporting may not be necessary.

Factors leading to sexual violence

Care providers in the current study provided insight as to the nature and prevalence of sexual violence in the disability community and the factors that lead to such rates. Although most participants of the current study did not specify a rate of sexual violence within the disability community, they generally believed the rate to be higher than in the general population, which is consistent with existing literature (e.g., Melcombe, 2003). With an understanding that the rate of sexual violence among individuals with disabilities is disproportionately high, participants provided insight into factors that contribute to instances of sexual violence.

Myths

Responses from participants elucidated two sub-categories of factors that lead to sexual violence in the disability community. Care providers indicated that myths surrounding disability and sexuality (e.g., the myth that individuals with disabilities do not experience sexual desire) may contribute to the rate of sexual violence in the community. Specifically, care providers recounted many instances of individuals they provide care for being sexual beings with the same desires and needs as typically developing individuals. The beliefs and anecdotes of the participants in this study are supported by existing literature indicating that most individuals with disabilities do in fact experience sexual desire (Campbell, 2017), although the rejection of these attitudes by the care providers in this study does not support the claim that care providers themselves are likely to hold these beliefs themselves. Care providers were also rejecting of the belief that individuals with disabilities are unable to restrain themselves from inappropriate sexual behaviors as described by McRuer & Mollow (2012).

Participants also indicated to a lesser extent their knowledge of the myth that individuals with disabilities can be viewed as hypersexual deviants who display inappropriate behaviors. This myth was capitalized on in discussions participants had about the need for sex education for individuals with disabilities. This understanding of myths is also supported by literature that individuals with disabilities are often viewed as hypersexual (English & Tickle, 2018).

Lack of Sex Education

Along with myths surrounding individuals with disabilities and sexuality, responses from care providers also indicated that the lack of appropriate sex and sexuality education for individuals with disabilities contributes to the rate of sexual violence. Participants shared their experience that individuals with disabilities who they work with currently or have worked with in the past are sorely lacking in the area of sex education. As outlined in the results section, individuals with disabilities are rarely taught proper anatomical terms and the topic of sex is avoided. This belief is also backed by literature outlining the lack of sex education for individuals with disabilities (Eastgate et al., 2011). Care providers in the study reported their belief that individuals with disabilities would be better equipped to understand healthy sexual boundaries and become their own sexual self-advocates with proper sex education.

It is clear that providers have insight into factors that lead to sexual violence in the disability community. The participants in this study identified the scope of the issue and reasons of myths related to sexuality and a general lack of sex education as problems in need of solving.

Affirming experiences

The current study found that care providers of individuals with disabilities encounter some positive and affirming experiences related to reporting instances of sexual violence and existing policies and trainings that are effective.

Reporting

Related to their experiences working with individuals with disabilities who have a history of sexual violence, care providers who participated in the current study felt affirmed and trusted when those they work for disclosed their personal history. Success in reporting and connecting survivors of sexual violence with necessary resources also emerged as an affirming experience for care providers. Most of the participants had not reported instances of sexual violence per se, however, those who had seemed to generally find their experiences to be successful and affirming, contrary to literature that suggests that reporting experiences are often negative for care providers (Flaherty et al., 2000).

Policies

There was certainly an evidenced need for improvement in training and policies that emerged from the data, however, care providers also indicated some degree of success in reporting guidelines and existing policies. Existing state and institutional requirements for mandated reporters were referenced several times by participants in the current study. Although not a universal sentiment, many participants found the existing policies to be useful and effective. Participants who recollected their knowledge of state laws (South Dakota Codified Law, 22-46-9) and other existing policies found them useful as a guideline for what, when, and how to report instances of sexual violence.

Although participants spoke much more of the negative experiences they encountered, they did speak of affirming experiences. Although their experiences were not completely universal, they did each describe something positive about their work in the disability services sector. Even though some positives were mentioned, as a whole, care providers in this study do not appear to feel an overall sense of support from the institutions they work. That being said, there is a sense that although there are changes that are necessary, some policies are working in their existing format to some extent.

Negative experiences

Along with positive and affirming experiences, participants of the current study also shared their frustrations and negative experiences related to working with individuals with disabilities who have experienced sexual violence. As with positive experiences, most negative experiences faced by care providers were not entirely universal, although every participant reported some degree of negative experience.

Frustrations

Within the sub-category of frustrations, care providers reported frustrations with their employers. Some care providers do not feel supported by their employers—with a lack of perceived support being shown to lead to lower physical and psychological wellbeing for providers and a lower quality of care for the individuals they support (Casale & Crankshaw, 2015). Care providers also articulated feeling inadequately trained to work with survivors of sexual violence or understand when reports are necessary. Some participants in the current study disclosed that they and their coworkers may not understand the behaviors of individuals they work with who have a history of trauma and feel that they were not adequately trained by their employers for their current roles. Training (or lack thereof) appears to be a common issue within literature, pointing to difficulties with both work with individuals with disabilities as well as with reporting instances of abuse and neglect (Flaherty et al., 2008).

Burnout

Literature points to burnout rates as high as 70% within the disability services sector (Sánchez-Moreno et. al., 2014). Participants in the current study highlighted their experiences with burnout related to working with individuals with disabilities who have experienced sexual violence as well as general burnout related to their work and inefficient policies. Frustrations with policies and demands that exceeded their emotional capacity reportedly lead care providers to feel the effects of burnout, which became evident in quotations provided by participants. The lack of perceived support from employers and society led participants to feel burnout and a lack of a sense of purpose in their work—to the detriment of the quality of work as well as a reportedly high turnover rate for employees in the disability services sector.

Negative experiences of frustrations and burnout were nearly universal among the care providers in this study. They recounted some serious frustrations with their employers and a general lack of training as well as burnout from difficult work in the disability services sector.

Necessary changes

With two of the categories being factors related to sexual violence and negative experiences, care providers who participated in the study offered their insight into changes that could help combat each. Desired changes varied from participant to participant, however, subcategories did emerge from the data—necessary policy changes and necessary societal changes.

Policy

Policy changes care providers deem necessary to combat burnout focused on more training for staff on working with individuals with disabilities who have experienced sexual violence. This desire for more training stemmed from the discomfort care providers felt working with individuals with disabilities who have a history of sexual violence. Care providers felt that increased and more effective training could help combat burnout and create a safer environment for both care providers and the individuals they serve. Clearer understanding of mandated reporting and increased training on how to provide trauma-informed care are desires that has been articulated in the literature surrounding reporting guidelines (Flaherty et al., 2008).

Care providers also indicated that policies allowing for sex education training for individuals with disabilities would help combat sexual violence as well as decrease potentially problematic behaviors some individuals with disabilities may display (e.g., public vs. private behavior). Participants identified that sex education should include information related to sexual behaviors, and also how individuals with disabilities can prevent sexual assault themselves. The efforts of care providers to suggest sex education as a possible solution for combating sexual violence is supported by literature outlining the lack of existing sex education (Eastgate et al., 2011).

Societal

Along with policy changes, participants of the current study reported desiring social changes. For instance, increased funding for the disability services sector can lead to better support for care providers and thus prevent burnout. Funding increases could also indirectly reduce the instances of sexual violence in the disability community as the number of care providers could grow, increasing the number of workers in residential and related units and helping with oversight. Awareness was another common theme within the sub-category of necessary societal changes. Care providers do not believe that the general public is aware of the issue of sexual violence in the disability community. This is evidenced by myths and misconceptions surrounding sexuality and disability. Literature mirrors the care providers' desire to receive more resources in order to be successful in their work. As mentioned, care providers feel the effects of burnout less severely if they have adequate supports in place (Casale & Crankshaw, 2015).

With increased supports and changes within the disability services sector, care providers believe they can more effectively work with individuals with disabilities and avoid burnout as well as combat sexual violence. They indicated that in order to be successful, policy changes such as increased training for providers and sex education for individuals with disabilities are necessary. Additionally, they indicated a need for societal changes such as increased funding and awareness.

Strengths of the Study

The purpose of the current study was to better understand the perspective of care providers with regard to their experiences working with those with disabilities who have been victims of sexual violence. One major strength of the study was its novelty. As outlined in the introduction section, there have been very few studies looking directly at the experiences of care providers of individuals with disabilities—especially as they relate to sexual violence. Due to the nature of grounded theory research, relationships between the emergent categories could be inferred to create a working theory as to the experience of care providers with regard to working with individuals with disabilities who have experienced sexual violence. The qualitative nature of the study also allowed me to include my reflections and experience from working in the disability services sector to inform aspects of the research. Additionally, the sample—although small—was diverse in aspects of experience level, gender identity, racial identity, and specific job (e.g., occupational therapist, direct support professional, etc.) The diversity of the sample helps to make the study more generalizable.

Another strength of the study comes in the methodology. Even with a small sample size, saturation of data was achieved quite quickly, indicating the experiences of the participants are likely experiences that care providers encounter universally to some extent. With clear insight and solutions relayed by care providers, results and recommendations can be shared with existing disability services agency, pointing to the utility of the results as a strength of the study.

Challenges and Limitations

Although there were many strengths of the current study, there were also some challenges and limitations. One major limitation of qualitative research methodology is that it decreases the generalizability of the study to the geographic region. As mentioned in the literature review, the study focused on rural care providers in South Dakota. As such, care providers in more urban states may have different experiences than those in a rural state such as South Dakota. Additionally, the participants from the study were recruited from a limited number of agencies and may have unique experiences working in certain locations. These participants had experiences that were mostly limited to working with individuals with disabilities who had already experienced sexual violence. As such, many of the participants had not encountered a need to report instances of sexual violence since they occurred in the past.

Another possible limitation of this study is my own professional training and background. I have experience working in the disability services sector and have been trained in the use of clinical interviewing. Therefore, I am aware that interview sessions may have been influenced by my own experiences working with individuals with disabilities and interviewing strategies. For example, probes used in interviews may have influenced care providers’ responses and therefor the data. These limitations were controlled to the extent possible through the use of memos and debriefing throughout the research process.

Recommendations for Future Research

As mentioned in the limitations section, the generalizability of the results from the current study are limited geographically and to a rural sample. Gauging the experiences of care providers in urban areas is an important direction for future research.

In addition to research with care providers of individuals with disabilities, ancillary fields also need further study. For instance, the experiences of lawmakers and advocates who do not provide direct services for individuals with disabilities could add to the existing body of literature. Specific research with families of individuals with disabilities who have experienced sexual violence could help elucidate the differences between care providers who are not related to those who they care for. Although the current study did include an individual who was a family member, gaining a more targeted sample of family members could provide a more nuanced example of experiences. Lastly, it is important as with any research to ensure that diversity within samples is explored. Future research should focus on the intersection of underrepresented identities to gain a more representative sample for the existing body of literature. Additionally, research conducted with individuals with disabilities who are survivors of sexual violence is important to gain a further understanding of their own unique experiences and perspectives.

Implications and Recommendations

With a better understanding of the needs for the disability services sector provided by care providers, there are several implications and recommendations that can be implemented by disability services agencies.

As some care providers do not feel adequately trained to work with individuals with disabilities who have experienced sexual violence, it is important for employers to provide consistent and adequate training for care providers. With high rates of turnover, training should occur often and include topics related to reporting as well as direct, trauma-informed care for individuals with disabilities. When care providers' work expectations exceed their ability to function in their occupation, they may feel the effects of burnout. Employers can better support care providers by providing adequate training and mental health services when necessary—especially during emotionally charged times such as when working with survivors of sexual violence and other traumatic experiences.

Care providers also expressed a need for sex education for those they serve. Currently, South Dakota does not require formal sex education in schools, and individuals with disabilities are even less likely to receive specialized sex education. At the time of this study, I am piloting a trauma-informed, developmentally appropriate sex education and healthy relationship training group at my current role at LifeScape in Sioux Falls, South Dakota. Teaching individuals with disabilities about their bodies, sexuality, and healthy relationships may help to reduce the occurrence of sexual violence and help individuals with disabilities become sexual self-advocates.

As mentioned in the findings section, care providers who participated in this study were asked to provide insight into how researchers could best interview individuals with disabilities who have experienced sexual violence. Care providers indicated that having a trusted individual available to be there during the interview would help interviewees to feel comfortable. They also universally included reverence for the interviewees and emphasized the requirement to focus on the individuals being interviewed as people and not simply as research participants.

Summary and Conclusion

The purpose of the current study was to better understand the perspective of care providers with regard to their experiences working with those with disabilities who have been victims of sexual violence. Through a grounded theory approach, ten care providers were interviewed about their experiences working with individuals with disabilities who may have experienced sexual violence. Four categories emerged to describe the process of care providers' experiences and insight. Care providers provided insight into the factors that contribute to sexual violence in the disability community, used to those insights to inform their positive and negative experiences, and provided recommendations for combating sexual violence and negative care provider experiences.

Care providers included myths of sexuality and disability and lack of sex education as factors that contribute to sexual violence in the disability community. Positive experiences of reporting and effective policies were shown to be affirming for care providers as they worked in the disability services sector. Negative experiences including frustrations and burnout impeded care providers from working to the full extent of their ability but informed their recommendations for necessary changes. Changes included both changes related to policies as well as changes that must take place on a societal level in order to combat the negative experiences of care providers as well as ultimately decrease the rate of sexual violence in the disability community.

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Appendix A
Interview Schedule

(Go through informed consent process)
(**TURN ON Electronic Recording Device**)

With your permission I've begun recording.

In what capacity do/did you work with individuals with disabilities?

- What types of disabilities?
- How long have you been in the field?
- Tell us about your day-to-day role
- What ages were/are they

How prevalent do you believe sexual assault/abuse is in the disability community?

- Explain your opinion.
- What shaped this opinion?
- Why do you think it is as prevalent as it is? (Try to use their words to categorize how prevalent it was)
- What shaped that opinion?
- Are there myths associated with people with disabilities and sexuality?
- What are these?
- Are they related to sexual assault in the disability community?

Without going into specifics, have you ever worked with someone with disabilities who has been sexually assaulted or abused? (If not) Have you ever heard about someone with disabilities who has been sexually assaulted or abused?

- How many people has this happened to? Number of instances? (In general…)
- How did you find out?
- What did you do (if anything)?
- How did others respond?

Given that you work at (place with direct services for people with disabilities) what are the policies and protocols when you become aware that someone has been sexually assaulted/abused?

- Did you or others follow these policies/procedures?
- With what you known now, what changes would you have made?
- Did you discover any issues with the policies/procedures when working with a case? If so, can you explain them?

Given that you work at (place without direct services for people with disabilities) what did you learn about how these cases are handled?

- What resources were available?
- Who became involved with this case (police, advocates, others)?

- With what you know now, what changes would you have made?
- Are there any resources that you would have like to have used that don't exist or are otherwise unavailable?

Frustration, secondary trauma etc.

(If working in a place with direct services and yes to sexual assault) What resources were available?

- Did you utilize these resources?
- Who became involved with this case (police, advocates, others)?
- Did everything go as planned with these procedures?
- Are there any resources that you would have like to have used that don't exist or are otherwise unavailable?

What solutions do you think are necessary to combat sexual violence in the disability community? (Prod for policy/procedure and social changes if needed)

Is there anything else that we haven't talked about today that you would like to share?

The next stage of our research is to talk to people with disabilities who have been sexually assaulted about their experiences. Do you have any advice for how we can make those interviews as supportive as possible for those individuals?

- Are there any precautions we should take?
- Is there any information we should have on hand?
- Is there a specific way we should arrange the room?
- Are there certain objects or materials that we can provide or have them bring with them to make the interview more comfortable?
- Any other thoughts?

Is there anything else that we haven't talked about today that you would like to share?

After I turn off the electronic recording device, I would like to ask for contact information for others we may want to interview for this portion of the research or individuals we could interview in the next portion of the research. (**TURN OFF Electronic Recording Device**)

Appendix B
Codebook

Categories	Subcategories	Evidence
Factors leading to sexual violence	1. Myths 2. Lack of sex education	The majority of participants in this study cited myths related to sexual violence and the lack of awareness of sex and bodily autonomy among individuals with disabilities.
Affirming experiences	1. Reporting 2. Policies	All the participants talked about affirming experiences they have had working with individuals with disabilities who have experienced sexual violence. Many talked of their experience with reporting or learning of sexual violence and others talked of their work with current policies that are working.
Negative experiences	1. Frustrations 2. Burnout	Each participant talked about frustrations they had working in the disability services sector including frustrations with their employer and lack of training working with individuals with disabilities who have experienced sexual violence (i.e., trauma informed care). Participants also recounted their experience with burnout and secondary trauma related to sexual violence.
Necessary changes	1. Policy 2. Societal	Every participant provided guidance on how best to combat sexual violence in the disability community and prevent burnout for care providers in the disability services sector. Many participants noted the need for policy changes including

		sex education and increased training. They also reported the need for more tangible resources such as funding. Other participants noted that awareness and education on a societal level is necessary.