

2016

Experiences of Direct Support Professionals Supporting Sexuality for Individuals with Developmental Disabilities

Elizabeth Senne

University of St. Thomas, Minnesota, senn4010@stthomas.edu

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Experiences of Direct Support Professionals Supporting Sexuality for Individuals
with Developmental Disabilities

by

Elizabeth M. Senne, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St Paul, MN
In Partial fulfillment of the Requirements for the Degree of
Master of Social Work

Committee Members
Catherine L. Marrs Fuchsel, PhD., LICSW, LCSW (Chair)
Sarah Shafer, MSW, LISW
Katie Thune, M.Ed

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

EXPERIENCES OF DSP SUPPORTING SEXUALITY

Abstract

Individuals with Developmental Disabilities (DD) face significant barriers to experiencing relationships and expressing sexuality. While the law recognizes basic human rights, there continue to be societal attitudes that shape how individuals with DD are treated and supported. A qualitative exploratory study was conducted using semi-structured interviews and Grounded Theory to examine how Direct Support Professionals (DSP) experience providing support for relationships and sexuality for persons with DD. From the analysis of this data, six themes emerged: (a) Clarity of DSP Role Around Supporting Sexuality and Relationships, (b) Families or Interdisciplinary Teams as a Barrier for Sexual Relationships and Expression of Sexuality, (c) Lack of Privacy for Individuals with DD, (d) Individual's Overall Cognitive Functioning Level, Capacity to Consent, and Lack of Understanding About Sexuality (e) Safety and Identified Risks, and (f) Access to the Community as a Barrier. The results of this study suggest that there continue to be significant barriers for individuals with DD in expressing sexuality. Further research is needed that would identify these barriers and suggest program and policy changes to reduce these barriers.

Keywords: Intellectual Disabilities, Developmental Disability, Direct Support Professionals, Sexuality, Relationships

EXPERIENCES OF DSP SUPPORTING SEXUALITY

Acknowledgments

I would like to thank my research chair, Catherine Marrs Fuchsel, for her ongoing support, guidance, and dedication to this research process. Her positive spirit, ongoing encouragement, creative problem solving, and thorough feedback continued to be the force that kept this project moving forward. I would also like to thank the members of my research committee, Sarah Shafer and Katie Thune, for contributing to the research process with their wealth of knowledge, helpful feedback and guidance for the duration of this project. I am grateful for their time and dedication, as well as their continued efforts toward social justice in the area of supports for individuals with Developmental Disabilities.

I would also like to thank all of the participants for sharing their time and their experiences of working with individuals with Developmental Disabilities. I appreciate the knowledge and critical observations that each one of them brought to this topic and their continued commitments to supporting individuals with Developmental Disabilities in living life to the fullest. I also would like to acknowledge and thank Hammer Residences, Inc. for their support in allowing this project to take place within their community. I am forever thankful for their dedication and enthusiasm toward continuing to advancing and improving the quality of services for people with Developmental Disabilities.

Last, but certainly not least, thank you to my husband and two beautiful girls for your ongoing patience and support through this project. I am here because of you.

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Experiences of Direct Support Professionals Supporting Sexuality for Individuals with Developmental Disabilities

Individuals with developmental disabilities (DD) continue to face negative societal attitudes and significant barriers toward basic human rights and opportunities, especially in the area of receiving support in their expression of sexuality. In addition to these barriers, individuals with DD who identify themselves as gay, lesbian, bisexual or transgender (LGBT) face an additional challenge in that they are a minority within a minority population (Walker-Hirsch, 2007).

In the U.S. approximately 10.6 million people live with a cognitive impairment and 1.2 million people are diagnosed with a developmental disability (Brault, 2012). For most of this population, their disability alone acts as a barrier to accessing many opportunities such as: a) healthcare, b) education, c) employment, d) housing, e) community involvement, and f) meaningful relationships (Gilmore & Chambers, 2010). Over the last several decades, individuals with DD and disability advocates have fought to break down these barriers.

While research shows that there have been significant shifts in attitudes over the last several decades, and that, generally, attitudes toward sexuality for people with DD are positive, there continue to be barriers that prevent individuals with DD from being able to have opportunities for sexual expression and education (DiGiulio, 2003). These barriers occur on a policy level, as well as at the mezzo and micro levels, ultimately affecting the level of competency in the Direct Support Professional(s) (DSP) who work directly in supporting sexuality and sexual health needs of individuals with DD. A DSP is a paid caregiver whose role is to provide supervision, support, and training to individuals with DD who live in the community, either in their family home, a group home, or in their own home or apartment.

Recent policies for inclusion and deinstitutionalization have guided the push toward community-based services for individuals with DD. There continue, however, to be common misconceptions that are rooted in our culture that affect how we view individuals with DD and their needs (McClelland, et al., 2012). These misconceptions contribute to the exclusion of individuals with DD from mainstreamed sexual education programs and community-based support services that provide competency in areas of sexuality and sexual health (McClelland, et al., 2012). As a direct result of this exclusion, DSP who provide support to individuals with DD are left without the tools to be able to recognize areas of need, ultimately leading to discomfort in addressing sexuality and sexual needs among those with whom they work (Abbott & Howarth, 2007).

This lack of awareness among DSP in the field has led to pervasive attitudes that persons with DD are asexual or that if they are sexual, then they must be heterosexual (Noonan & Gomez, 2011). As a result of this lack of support, individuals with DD continue to feel isolated in community settings because of both their disability and their sexual orientation (Morgan, Mancl, Kaffar, & Ferreira, 2011). As we move into an era of primarily community-based service models for individuals with DD, it is essential that community integration involves a “sense of community,” where individuals are not only receiving supports that acknowledge their sexuality and sexual health needs, but are being included in supportive social structure in the community (Cummins & Lau, 2003). DSP play a critical role in helping individuals with DD to achieve their goals and transform the community.

The current silent and uninformed approach to sexuality and disability will continue unless steps are taken to understand the problem and create educational interventions for both persons with DD and the DSP who work with them in their homes. As social workers working with this vulnerable population, we have the duty to uphold the social work principles for social

justice for participation by promoting that individuals with DD have the right to participate in the “political and cultural life of society” and have equal access to the resources and opportunities that all other non-disabled people do (National Association of Social Workers, 2008).

The purpose of the proposed study is to gain an understanding of how DSP support individuals in the area of sexuality. In this qualitative study, DSP will be interviewed in an effort to gather data that will answer the following research question: What are the experiences of DSP in supporting sexuality for individuals with developmental disabilities?

Literature Review

To better understand the concerns that the DD community faces in regard to support for sexuality, it is critical to explore the previous research that exists regarding the supports in place for individuals with DD in supporting their sexuality. This literature review explores previous research and serves as a base of knowledge to better understand, a) important definitions, b) the history of human rights and community integration for individuals with DD, c) the role of the DSP for individuals with DD, d) the movement into individualized supports and person-centered thinking, e) sexuality as a right for individuals with DD, f) barriers to rights for sexuality and sexual expressions for individuals with DD, g) supporting sexuality for individuals with DD who identify as LGBT, h) barriers for individuals with DD who identify as LGBT, and i) the identification of the problem.

Definitions

Developmental disabilities. In the past, the term “mental retardation” has been used to describe the population of those who were diagnosed with a cognitive impairment that manifested prior to the age of eighteen. In 2013, however, the Social Security Administration (SSA) adopted new terminology to acknowledge and respond to the ongoing concerns from

individuals with DD and disability advocates who vocalized that the word “retardation” now holds a negative connotation and is used as a derogatory term (Daily Journal of the United States Government, 2013).

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability is “characterized by significant limitations in both intellectual functioning and in adaptive behavior” (American Association on Intellectual and Developmental Disabilities, 2010). To be diagnosed with an intellectual disability (ID), individuals must go through IQ tests and adaptive behavior assessments to demonstrate three main criteria: 1) significant limitations in intellectual functioning, 2) significant limitations in adaptive behavior, and 3) onset of disability prior to the age of eighteen (AAIDD, 2010).

The term developmental disability (DD) is an “umbrella term that includes intellectual disability,” but refers to chronic disabilities that may be physical, cognitive, or both (AAIDD 2010). Individuals with a developmental disability may be diagnosed with a physical disability, but may not exhibit signs of cognitive impairment. Examples of this may include cerebral palsy, spina bifida, and epilepsy. To be considered developmentally disabled, individuals must demonstrate the disorder prior to the age of 22 (AAIDD, 2010).

For purposes of this study, the term DD will continue to be used to include both individuals with ID and DD. While both DD and ID are used among the medical profession, the term DD is used more regularly throughout the culture of community-based services for individuals with DD/ID

Sexuality. It is not only important to understand the meaning of the term “sexuality,” but also to understand sexuality in the context of how sexuality is experienced by individuals with DD. The World Health Organization (WHO) posits that sexuality is a bio-psycho-social

experience that is influenced by economic, political, cultural, legal, historical, religious and spiritual factors (WHO, 2010). Sexuality can be expressed in thoughts, desires, beliefs, attitudes, behaviors, practices, roles and relationships and is a central component of human behavior that comprises sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction (WHO, 2010).

Every human being has sexuality, and even individuals with DD experience the physical development of sexuality similarly to individuals without DD (Perrin, Erenberg, La Camera, & Nackashi, 1996). The social, emotional, and developmental stages that a person with DD experiences, however, may not occur in the same timeline or in the same way as individuals without DD, thus delaying their own learning about sexuality. Therefore, the range of experiences for individuals with DD will be significantly more limited than those of peers of the same age who do not have disabilities (Walker-Hirsch, 2007).

History of Human Rights and Community Integration for Individuals with Developmental Disabilities

Community-based services for individuals with DD are wide-spread today; however, this was not always the case. It was only 50 years ago that many children and adults with DD lived in public institutions, where they received inadequate medical care and had few social opportunities. Additionally, there were no community-based supports and few educational opportunities for individuals with DD (The Minnesota Governor's Council on Developmental Disabilities, 2015).

There have been many notable events in U.S. history that document the long passage to community inclusion for individuals with DD. A few of these include: a) Section 504 of the

1973 Rehabilitation Act, b) the Americans with Disabilities Act (ADA) in 1990, and c) the U.S. Supreme Court case *Olmstead vs. L.C.* in 1999.

Section 504 of the 1973 Rehabilitation Act was one of the first acts of legislation that identified people with disabilities as a class, and that as a group, people with disabilities frequently faced discrimination and violations of civil rights (Mayerson, 1992). Section 504 forbid programs and organizations from denying individuals with disabilities the right to equal access of programs and services, including employment services (U.S. Department of Health and Human Services, 2006). Section 504 was a platform for many disability advocates, giving the disability community a voice to be heard all the way up to the Supreme Court. In the 1980's, Section 504 began to lay the groundwork for what would eventually become the ADA (Mayerson, 1992).

After several drafts and revisions, the ADA passed in 1990 under the Bush administration. The ADA expanded beyond simply the prohibition of discrimination of programs and services for people with disabilities: it extended to accessibility in employment, housing, education, transportation, and other public entities and accommodations (U.S. Department of Justice, 2008). The ADA also began to bring change to society in how individuals with disabilities are viewed- not just as charity, but as contributing members of the community who want to work, learn, and experience life just as those without disabilities do.

Nearly a decade later, the ADA was put to the test, in the case of *Olmstead vs. L.C.* in June of 1999. During this trial, two women with disabilities had voluntarily entered the psychiatric unit of a Georgia State Hospital. After completion of their treatment, they were determined by physicians that they were capable of returning to live in the community in a community-based program with services in place. These women, however, were confined to the

institution, where they unnecessarily remained for another two years beyond their treatment. These two women filed a suit under the ADA in order to get a release from the hospital (U.S. Department of Justice, 2008). As a result of this case, state governments across the country have moved toward more community-integrated options for housing and services for individuals with DD.

These events, separately and collectively, played a key role in how society embraces individuals with DD in their communities. Community-based residential services have existed since the 1980s. However, it took the passing of the ADA and the Supreme Court case of *Olmstead vs. L.C.* for states to take action in the deinstitutionalization for its community members with DD. Home and Community Based Services (HCBS) is a waiver program that was established under the Social Security Act 1915(c) in 1981, that allows states to use Medicaid dollars to fund community-based services to keep individuals with DD living in the community (Centers for Medicare and Medicaid Services, n.d.). Prior to 1981, Medicaid long-term care funding was only available in an institutional setting. In 1991, shortly after the passing of the ADA, HCBS waivers only represented approximately 14 percent of Medicaid long-term care expenditures (Shirk, 2006). The passing of the ADA rocketed the HCBS programs and by 2009, over one million individuals with disabilities were utilizing HCBS waiver programs (CMS, n.d.). Through the HCBS programs, individuals with DD are able to live where they want to live within their communities, and receive support from DSP to maintain community living.

The Role of the DSP for Individuals with Developmental Disabilities

Today, as individuals with DD have become more integrated into living and working in the community, the role of the DSP has become a more critical level of support to these individuals. The DSP are the frontline workers who often are the first point of information, the

first to provide immediate support, and often the person who is closest to the individual (Walker-Hirsch, 2007).

The DSP role has changed with the movement into community integration, in that DSP are not just asked to provide physical assistance when needed, but they are asked to be communicators, provide assessments, facilitate other services, provide advocacy, empower, provide crisis intervention, complete documentation, and maintain ongoing training and education (Walker-Hirsch, 2007). Today, DSP are expected to demonstrate competency and a commitment to person-centered supports, promoting physical and emotional well-being, integrity and responsibility, confidentiality, justice and equity, respect, self-determination, relationships and advocacy (National Alliance for Direct Support Professionals, 2011).

As a result of the exceeding demands on DSP and low recognition, they have grown to be among the nation's most vulnerable workers, due to the low paying compensation, limited benefits, and a high turnover rate of 40-50 percent. The American Network of Community Options and Resources (ANCOR), a national non-profit trade association that represents community organizations that support individuals with DD, predicts that with the rising number of people needing long-term services, the need for DSP will grow 48 percent over the next decade (ANCOR, 2014).

The low wages, high turnover, and increasing demands on DSP has created additional strain on this already stressful role. Pressure from state and federal government and organizations that serve individuals with DD has lead the National Alliance for Direct Support Professionals (NADSP) to create credentialing and training programs for DSP across the country, which many states have adopted as provisions for licensed organizations who serve individuals with DD. This has helped states become more accountable for trainings of DSP in

areas such as person-centered thinking and self-determination, which provides the framework through which services are now provided (NADSP, 2011).

The Movement to Individualized Supports and Person-Centered Thinking

The push to community-based supports in the last forty years has challenged the public and policy makers to look at how supports for individuals with DD are designed. There has been a significant shift from the “person fits the system” model of services to the “system meets the individual’s needs” model of services. This shift has pushed programs that support individuals with DD to focus on people’s strengths and abilities while respecting individuals’ choices. This movement has led to a new language called person-centered thinking (or planning), in which programs help individuals with DD to develop interests, opportunities, and relationships that help them to connect with their communities (Walker-Hirsch, 2007).

In response to the shift to an individualized approach to services, many providers are adopting trainings for DSP that focus on working within a person-centered model of support for individuals with DD. Among the 15 competency areas used for credentialing of DSP, the NADSP specifically identifies person-centered awareness and training a requirement of all credentialed DSP (NADSP, 2011). Additionally, the NADSP Code of Ethics states that DSP are responsible for honoring the personality, preferences, needs, and gifts that each individual they support has (NADSP, 2011).

As a DSP, it is highly important to understand the balance between a person-centered approach that gives an individual with DD the right to make their own choices and the potential risks of these choices, especially in the area of relationships and sexuality. Many individuals with DD continue to need support in decision making. One of the roles of a DSP is to help an

individual with DD to balance their basic rights and ability to make decisions, with the understanding of consent, safety, and consequences (Walker-Hirsch, 2007).

Sexuality as a Right for Individuals with Developmental Disabilities

Over the last several decades, and especially since the implementation of the ADA in 1990, policies have been written to ensure that individuals with DD are guaranteed the same rights and access to opportunities as those without DD. In general, as a society, we are increasing our recognition of these rights, especially with regard to sexuality.

Studies have demonstrated an overall awareness and recognition among families and caregivers that sexuality is a basic human right, even among the DD population. In 2001, a study conducted among DSP in an agency that supports individuals with DD showed that over 95 percent of respondents believed that women with DD should have the freedom to express their own sexuality, and that sexuality is an important part of a woman's identity (Christian, Stinson, & Dotson, 2001). Another study in 2004 showed that respondents believed in the importance of autonomy for people with DD, stating that sexuality is a natural part of being a human being and that individuals should have the right to make choices regarding this area of their lives (Cuskelly & Bryde, 2004). In the context of comparing professionals in the field, those who receive a higher training and education in supporting individuals with DD also hold more liberal attitudes toward the expression of sexuality of adults with DD (Saxe & Flanagan, 2014).

In contrast, however, there continue to be many ways in which individuals with DD are not able to fully demonstrate these rights. While there has been significant progress in gaining equal rights to housing, employment, education and access to services, the promotion of sexual rights has not been identified as a basic necessity, and thus has not been given as much priority as other rights for people with DD (Esmail et al., 2010). There continue to be prejudicial

practices that have reinforced negative attitudes toward individuals with DD, and there is still a negative stigma attached to disability and sexuality (Aunos & Feldman, 2002; Esmail et al, 2010). In fact, from a young age, many individuals with DD are taught that their sexuality is not equivalent to those living without a disability (Esmail et al, 2010). One participant indicated that they were only allowed to date someone who also has a disability (Esmail et al., 2010). In a study conducted by Healy et al. (2009), individuals with disabilities reported an awareness that they were not afforded the same rights to relationships as their siblings without disabilities (Healy et al., 2009). The negative social stigma surrounding individuals with DD expressing their sexuality has led to minimizing their sexuality (Healy et al., 2009). These prejudicial practices continue to be one of many existing barriers that individuals with DD experience with regard to sexuality.

In general, there continues to be a belief that individuals with DD are asexual and that they do not have a desire to have healthy, sexual relationships (Morgan, Mancl, Kaffar, & Ferreira, 2011). In a study among special education professionals, nurses, and psychotherapists, Parchomiuk (2012) demonstrated that professionals, perhaps because of these previous prejudices, perceived sexuality of people with DD as an “uncontrolled phenomenon” which is threatening to others and that should be controlled through the use of contraception and sterilization (Parchomiuk, 2012). These beliefs continue to contribute to the existing barriers that individuals with DD face with regard to sexuality and the right for sexual expression.

Barriers to Rights for Sexuality and Sexual Expression for Individuals with Developmental Disabilities

Capacity to consent. A common theme throughout previous research is the concern of individuals with DD expressing their sexuality while maintaining personal safety and the

capacity to consent to sexual interactions. Wilkenfeld and Ballan (2011) identified that knowledge, rationality and voluntariness are major components in evaluating an individual with DD's capacity to consent to sexual activity. Respondents in this study recognized that while it is important to encourage autonomy, as providers we also have a duty to prevent victimization of vulnerable adults. DSP also strongly believe in an individual's right to participate in sexual relationships, as long as capacity for consent was understood and exercised (Wilkenfeld & Ballan, 2011).

Christian et al. (2001) also demonstrated that DSP feel strongly that a person's ability to consent should really determine whether or not they should engage in sexual relationships. The ability for individuals with DD, and, in this study, specifically women, to consent to a sexual relationship had the greatest impact on staff responses and attitudes toward sexuality for individuals with DD (Christian et al, 2001).

A survey among DSP working in residential facilities that supported individuals with DD showed that staff hesitate to support sexual relationships among residents for fear of being disciplined or facing prosecution. Correct understanding of an individual's capacity to consent and reviewing laws surrounding sexual offenses may affect DSP attitudes toward sexual rights for the people they support (Grieve, McLaren, Lindsay, & Culling, 2008).

Presuming a lack of capacity to consent simply due to a cognitive disability, however, can deprive a person of their basic human rights. Walker-Hirsch (2007) suggests that there are four elements to consent for individuals with DD. First, capacity, and evaluating whether an individual with DD has the capacity to be taught and to make relevant decisions. Second, information or knowledge, and evaluating whether that knowledge is enough to provide reasonable safety and to recognize sexual acts versus acts that are not sexual. Third,

voluntariness and the ability to demonstrate reason when making choices. Finally, a person's ability to recognize "right" from "wrong" and the social and moral implications of their choices (Walker-Hirsch, 2007).

DSP, however, face several challenges when it comes to an individual's capacity to consent. Individuals with DD are identified as vulnerable adults, with a higher probability to be victims of sexual abuse (Lackasson, 1992). As caregivers, DSP view their roles as protectors, protecting individuals from potential risks. Often, DSP feel that they have a duty to protect and safeguard. Some may prematurely question an individual's capacity to consent in order to avoid having to manage the risks (Yool & Langdon, 2003). Grieve et al (2008) found that caregivers were worried that they would be disciplined, or even face criminal charges if they allowed physical intimate relationships between individuals with DD that they were supporting (Grieve et al, 2008). Access to appropriate sexuality information and education programs has shown positive impacts on individuals with DD in helping to avoid sexual health problems, sexual exploitation and abuse (DiGiulio, 2003). Reduced access to sexual education, however, continues to be a systemic barrier that individuals with DD face.

Education as a barrier to support. Esmail et al (2010) show that the promotion of sexual rights has been left out of the quest for equal rights for individuals with DD. Sexuality has not become normalized because it has not been discussed in a formal setting. For many individuals with DD, their primary source of education regarding sexuality is from sources outside of their immediate support system (Esmail et al, 2010). In general, the topic of sexuality among people with DD is not mentioned, further perpetuating the societal view that individuals with DD are not sexual beings (Esmail et al, 2010).

Overall, educators feel that individuals with DD should receive the same sexual education curriculum that mainstreamed students do, but one study shows that the majority of teachers did not view educating their students with DD about sexuality as their responsibility (Wilkenfeld & Ballan, 2011). Educators strongly believe that education around sexuality for individuals with DD minimizes risks and enhances functionality (Wilkenfeld & Ballan, 2011). Ironically, however, proper sexual health education has often been denied for those with DD for fear that it may spark more interest in sex and elicit behaviors than it will provide useful information (Szollos, 1995). DSP also agree that individuals with DD should receive the opportunity to receive sex education, and would even feel comfortable implementing such programming. However, few have received such training to be able to provide this education (Christian et al, 2001).

Staff training and policies. Competency, staff education, and agency policies are all concepts that are explored in current research surrounding support for sexuality for individuals with DD. In a health care setting, one provider noted that sexuality is not even addressed in training for many health care professionals that support individuals with DD. In fact, current medical practices focus on functions of reproductive health rather than on sexuality, creating limited exposure and training in the medical professional field (Esmail et al, 2010).

In a survey of DSP, 35% of respondents stated that their confidence in discussing sexuality with the individuals that they support was due to a lack of training or qualifications (Evans, McGuire, Healy, & Carley, 2009). This lack of training and lack of clear guidelines at both an agency level as well as a policy level discouraged paid caregivers from discussing and supporting the development of sexuality for individuals with DD (Healy, McGuire, Evans, & Carley, 2009). Research has shown that although paid staff are comfortable supporting an

individual's needs for sexual expression, few actually receive any formal training in how to provide that support, and even fewer know whether or not their agency actually has a policy regarding sexuality or staff training for an individual's sexuality for the people they support (Christian et al, 2001).

Lack of Privacy. Due to the lack of education and training for both individuals with DD and DSP who support them, DSP often struggle to recognize their role in supporting opportunities to exercise sexuality and sexual expression and allowing them to do so safely and privately. Individuals with DD are often living in group settings in the community, or are being supported in some way at all times. One of the major systemic barriers that individuals with DD face is that a shared living model in and of itself is restricting of one's privacy (DiGiulio, 2003). Individuals living in community group home settings are especially affected by having many shared living spaces, and few areas that are private (DiGiulio, 2003). In the state of Minnesota, one of the goals of the new Olmstead Plan is to create housing opportunities for individuals with DD that will allow for more flexibility of choice on where they live and how they choose to participate in a community setting (MN Department of Health and Human Services, 2015). The Olmstead Plan will force teams and the counties of financial responsibility to look at alternative ways that individuals with DD could be supported in the community that would not be typical licensed group home settings. DHS, however, predicts that this process may continue to take years to accomplish, forcing individuals with DD to continue to live in group settings for the immediate future (MN Department of Health and Human Services, 2015).

In addition to the lack of privacy due to physical accommodations, individuals with DD may be dependent on family or DSP for activities of daily living. Many individuals with DD may not have the capability to arrange their own intimate activities, often relying on caregivers

to assist in making these arrangements, which may include helping them find sexual partners, and arranging visits and transportation to have opportunities for sexual intimacy (Walker-Hirsch, 2007). In a survey of 32 individuals with DD, Healy et al. (2009) revealed that many individuals with DD feel that the services that they have in place actually restrict their ability to have romantic relationships. This same study also concluded that there is an overall view from individuals with DD that DSP should be supporting the development of relationships and should be respecting the privacy and entitlements of the individuals whom they support (Healy et al, 2009).

This lack of privacy forces individuals with DD to explore sexual opportunities outside of the privacy of their own home, often in locations that are unsafe. McLelland et al. (2012), in a study conducted among LGBT youth, concluded that individuals with DD are often forbidden from exercising sexuality in their own home, being explicitly told that they cannot have sex in their own place of residence. These same youth reported engaging in sexual behavior in places in their community that were less safe, and often more public (McClelland, et al., 2012). This risky behavior often leads DSP to feel that individuals lack the capacity to engage in responsible sexual behavior. It is more likely the case, however, that risky sexual behaviors are often the result of individuals with DD being placed in environments where safe expressions of sexuality are impossible (Hinsburger & Tough, 2002).

DSP may also feel that all areas of sexuality must be communicated with the individual's interdisciplinary team members, especially, if the individual with DD cannot act as their own guardian. NADSP states that a DSP role is to "maintain collaborative professional relationships with the [DD] participant and all support team members" (NADSP, 2011). However, DSP may often feel as though an individual's sexuality and behaviors related to sexual expression must be

communicated with all team members to avoid areas of neglect or abuse with regard to health and safety. In a case study among women with DD, Christian et al. (2001) found that in some cases, DSP would request a team meeting to discuss the individual's sexual activities, and may, at times, contact the team directly without the consent of the individual (Christian et al., 2001). In general, DSP continue to be uncertain of individuals' right to privacy and what their responsibility is to maintain privacy for the individual with DD whom they support (Evans et al., 2009). This role appears to become even more ambiguous when DSP encounter same-sex relationships.

Individuals with developmental disabilities under familial or state legal guardianship. In an effort to protect those with DD from exploitation and potential harm, many individuals with DD have an assigned legal guardian- someone appointed by the court that retains the ability to make decisions on the behalf of the individual (Drogin, 2011). Often, legal guardians are family members who maintain a significant role in the person's life. Seeking and maintaining legal guardianship over an individual with DD, however has often been used to have their views control the lives and the wishes of those that they are guardian over (The Arc, 2009).

While parental/familial guardians are said to generally support the sexual rights of their loved one with DD, they continue to demonstrate more conservative attitudes toward the sexual behaviors of their family member (Cuskelly & Bryde, 2004). In a 2009 study which compared family members to paid staff members, a significantly larger proportion of staff members versus family members stated even having discussed sexuality with the individual with DD (Evans et al., 2009). In fact, only 43% of family members believed that all sexual relationships should be reported to the guardian, and only 10% of family members believe that adults with DD should be allowed to have unsupervised sexual relationships (Evans et al., 2009).

Many individuals with DD view this as an inequality between them and other family members of siblings without DD. Healy et al. (2009) interviewed 32 individuals with DD, and discovered that many individuals with DD were aware of the differences in their rights to have relationships versus those of other siblings (Healy et al., 2009). Many of these individuals also noted that they had to deceive family members to be able to exercise their rights to relationships (Healy et al., 2009). This lack of autonomy and privacy is often what discourages individuals with DD from developing intimate relationships with others.

Supporting Sexuality for Individuals with Developmental Disabilities who Identify as LGBT

In the past, caregivers tended to publically approve of homosexual activities, but behind closed doors would privately restrict them (Thompson & Bryson, 2001). Not surprisingly, then, much of the previous research has shown a lack of knowledge and support for individuals with DD who identify as LGBT. McCabe and Schreck (1992) reviewed previously conducted studies regarding sexual knowledge, experience, feelings and needs for individuals with disabilities and found that 86% of caregivers indicated that homosexuality was wrong (McCabe & Schreck, 1992).

More current studies do not demonstrate an outright disapproval for individuals with DD who identify as LGBT, but rather, they tend to show that many people believe in treating everyone the same, rather than acknowledging these differences (Abbott & Howarth, 2007). The problem with treating everyone the same is that assumptions are made regarding the sexuality of individuals with DD- that they are asexual or heterosexual. In a study completed in 2007 by Abbott and Howarth, emotional and sexual health was said to be jeopardized by the failure on the

part of many service providers that support people with DD to talk about or help support same-sex sexuality and relationships (Abbott & Howarth, 2007).

Lofgren-Martenson (2009) reported that personnel, families and caregivers tended to believe that homosexuality is very uncommon within the DD population (Lofren-Mortenson, 2008). Lofgren-Martenson believed that one of the many explanations to these perceptions was that the development of homosexual identity requires a large social support system. For individuals with disabilities, this natural support is very limited (Lofren-Mortenson, 2008).

Barriers for Individuals with Developmental Disabilities who Identify as LGBT

Myths. There are some myths when it comes to the sexuality of individuals with DD which are reinforced through various prejudices that currently exist toward individuals with DD. One myth is that disability implies asexuality. Another myth, is that if an individual does express sexuality, it is always heterosexual (Thompson & Bryson, 2001). These myths continue to perpetuate the negative attitudes and lack of knowledge and educational opportunities for staff and individuals who identify as LGBT.

Lack of knowledge and education among adults with developmental disabilities. One of the most significant barriers for individuals with DD is that even if they have an awareness of their own sexual desires towards members of the same sex, they may not have an understanding or the language of common terms used to describe homosexuality. Burns and Davies (2011) found that only 26% of the individuals with DD that they polled knew that homosexual is a term to describe someone with same-sex feelings (Burns & Davies, 2011).

Morgan et al. (2011) found that many of the resources that are available to LGBT students in an educational setting are not available to students with disabilities (Morgan et al., 2011). The process of identity formation is especially difficult for individuals with DD who

identify as LGBT because they experience isolation and complexities stemming from their identity as a person with DD and as someone who is same-sex oriented or transgender (Morgan et al., 2011).

Dual identity and acceptance of individuals with DD in the LGBT community.

Individuals with DD who also identify as LGBT must somehow integrate their disability identity and their LGBT identity, and must simultaneously maneuver within these two identities (Harley, Hall, & Savage, 2000). While both the disability community and the LGBT community share the fact that they are both stigmatized, the disability community is accepting of homosexuality, whereas the LGBT community is less accepting of disabilities (Appleby, 1994). Appleby (1994) also concluded that among the LGBT community, individuals with DD continue to be viewed as asexual, or access to LGBT events is limited or inaccessible to individuals with DD (Appleby, 1994).

Given that both individuals with DD and individuals who are LGBT face discrimination, it is highly important that the DSP who work with these individuals demonstrate ethical behavior and non-judgment practices while working. DSP need to work to create a culture of inclusion and work to prevent attitudinal barriers (Harley et al., 2000). In a school setting it has been found that LGBT students with disabilities are often not included in many of the common cultural activities where they would normally be able to explore and express sexual identity (Morgan et al., 2011). This leads individuals, and especially young students who are just discovering sexual identity, to feel isolated because of both their disability and their sexual identity (Morgan et al., 2011).

Summary

To summarize the current literature, DSP generally support individuals with DD in exploring sexuality and sexual relationships. In practice, however, many barriers continue to exist for this population. Additionally, there is currently an absence of studies that explore same-sex relationships among adults with DD. Much of the current literature focuses on heterosexuality, or focuses on sexual education and support within the school system. The research has implications for future studies to try to better understand these barriers and to continue to advocate for equal opportunities for individuals with DD. In the following section, the researcher will discuss the methodology of this study.

Conceptual Framework

This section of the research paper identifies and discusses theories through which this researcher views the proposed problem. Discussion of these theories helps to draw out key concepts that are relevant to this study and to help guide the interpretation of the data. In this research study, systems theory and social constructionism theory have been identified as relevant theories through which this problem is viewed.

Systems theory considers the environment as a whole, made up of parts that are interconnected and work well together (Forte, 2007). Much like the body, each system has smaller systems with identifiable functions, which work separately and together to create effective functioning for the whole system (Forte, 2007). It can also be assumed that any change with one part of the system can affect or change other parts of the system, or destroy the whole system and organization (Forte, 2007).

In this research study, systems theory can be used to understand the interconnectedness of the team approach for a person with DD. Individuals with DD who receive HCBS waived services are functioning within many systems which are driven by the state and federal funding

guidelines through which they receive support services. Supporting an individual with DD often requires the coordination of multiple systems, including DSP, families, county case managers, medical providers, employers, day programs, schools, advocacy groups, mental health providers, their community, and possibly multiple other service providers. These interdisciplinary teams consist of team members who know the individual best and can be their biggest advocate (Walker-Hirsch, 2007).

An individual with DD who is supported by multiple systems benefits from the knowledge and advocacy that each person brings as a member of their team. In the area of sexuality, multiple systems can offer their expertise in ways that help an individual with DD achieve his or her lifestyle and personal goals (Walker-Hirsch, 2007).

In the same way, when one system is failing to carry out the function of its role, all other systems are affected, and ultimately, this jeopardizes the individual with DD who relies so heavily on these supports. For example, when the education system and/or family system fails to provide quality sexual health education for individuals with disabilities, this may lead to individuals with DD being at higher risk of victimization, unplanned pregnancy, and sexually transmitted diseases (Wilkenfeld & Ballan, 2011). The result of this lack of education may lead to changing roles of other service providers or team members in how an individual with DD is supported, not only in the prevention of these risks, but the outcomes should they demonstrate risky sexual behaviors. Societal views about individuals with DD shapes these systems and practices.

Social constructionist theory is another framework through which this problem is viewed. This theory helps to provide an understanding of how these societal views are shaped. Social constructionist theory views the understanding of the world is sustained by social processes

(Burr, 1995). Social constructionist theory suggests that the understanding of the world is shaped through social processes and interactions with others that provides the basis for how certain beliefs or phenomena are shaped (Burr, 1995). This theory also posits that language provides structure and meaning to our experiences of the world, and that how we represent our behavior is embedded in our language (Burr, 1995).

Through the social constructionist lens, society's views of people with DD were largely shaped by their social interactions and language. In her book, *The Facts of Life and More*, Leslie Walker-Hirsch (2007) states that the history of the social support system for individuals with DD reflects the attitudes that drove exclusion, separation, and ultimately, the development of institutions (Walker-Hirsch, 2007). Before inclusive services became available, families with children with DD were following the advice of physicians and/or other family members who strongly encouraged them to place their children in institutionalized settings for their care, labeling children as "retarded" or "mongoloids" (Walker-Hirsch, 2007). Families with children with significant challenges were made to feel ashamed of their children with DD, thus keeping them home and not allowing for inclusion of education, support services, or community integration (Walker-Hirsch, 2007).

The language which was used to label individuals with disabilities was often the same that described their limitations (i.e. "profounds" for individuals who were profoundly disabled, "feeds" for individuals who needed feeding assistance or who required tube feeding, "behaviors" for those with more significant behavioral concerns), (Walker-Hirsch, 2007). In this way, individuals with DD were identified solely by their diagnosis, and not by their identity as a human being. The labels and language that were used to describe individuals with DD not only shaped society's views of this population over time, but became integrated into the culture of

support services. The way in which these services are provided and the way DSP have been trained to work with this population has largely been shaped by the social construct in which we have previously viewed individuals with DD.

In this study, both systems theory and social constructionism theory are used to understand the history and the context in which services are provided to individuals with DD and how attitudes of service providers and DSP have been shaped over time. The social work profession, and the human services field in general, is greatly influenced by the systems theory and the social constructionism theory. These theories will be used to guide this study to better understand DSP experiences with sexuality for individuals with DD.

Methods

Study Design

The study design for this research study is qualitative design, seeking to understand the role that a DSP plays in the area of supporting sexuality for individuals with DD. Research was approached through grounded theory methodology, which allows the theory to emerge and be developed from the data (Monette, Sullivan, DeJong, & Hilton, 2014). This study was an exploratory study, with the primary objective of gathering information on this topic to add to the body of existing, but limited knowledge.

Sample and Sampling Procedure

This researcher utilized a nonprobability sample, where the goal was to understand the research topic as it relates to a particular group (Monette et al., 2014). The sample of participants included people who, at the time of the study, were working as a DSP for an agency or organization that provides licensed community residential housing services for individuals with DD. This researcher also required that participants had to have worked in this field for greater

than 3 years. A method of criterion sampling was utilized, a technique in which the researcher asked knowledgeable persons to identify potential participants based on their knowledge of the study criteria (Padgett, 2008).

To recruit respondents for this research study, this researcher enlisted the support of a Twin Cities based non-profit organization, Hammer Residences, Inc. This researcher reached out to the organization and sent a recruitment flier (Appendix A) through email to DSP and Program Managers. Program Managers were asked to dispense the flier and information sheet (Appendix B) and speak to DSP who may be good candidates for participating in this research study. This informational sheet provided, in greater detail, information about this researcher, the purpose of the study, and how the data was gathered.

This researcher provided Hammer Residences, Inc. with a letter of cooperation (Appendix C) that asked them to agree to participate in the study by recruiting participants and allowing this researcher to interview employees.

Protection of Human Subjects

All participants for this study were asked to sign the Information and Consent form (Appendix D). Within this consent form, participants were informed of the risks and benefits to participating in this study. In this consent form, the researcher notified participants that they would be recorded during their interview. All interviews were conducted in a private room, located in the central office space at Hammer Residences, Inc. or at a private location that was convenient to the participant. Names were not used in the recordings, nor were they used in the transcribing of the data or presenting the data. Participants were identified by number (e.g., Participant 1, Participant 2, and Participant 3).

In the participant consent form, this researcher identified specific information about how data would be collected and kept confidential. This researcher used a research assistant to assist in cross-checking coding in the transcribed interviews. The research assistant signed a confidentiality agreement to protect the privacy of participants (Appendix E). All data collected for this study was stored in a locked file cabinet at the researcher's home office, or electronically in a password protected electronic device. Only the researcher, research chair, and research assistant had access to data collected. Additionally, all recordings were deleted from the recording device following completion of this study.

Any correspondence with participants through email or phone calls were stored only on devices that require a passcode. Following the completion of the study, all documentation of correspondence with participants was destroyed or deleted.

Data Collection

Data for this qualitative study was collected through scheduled, semi-structured interviews. A qualitative interview was used to be able to draw out participant's attitudes and feeling toward this particular topic. The objective was to collect information relating to description, explanation, and evaluation of the problem (Monette et al., 2014).

This researcher developed a series of open-ended questions (Appendix F) to prompt discussion of the problem and research topic. Participants were asked a total of 13 questions. These questions were derived from the themes that were identified within previous research. These questions were open-ended in an effort to guide an exploratory study by placing few restrictions on participant's responses (Monette et al., 2014). These questions not only allowed the participants to provide more in depth and contextual information, but it also allowed this researcher to prompt further discussion to draw out information.

Questions in the interview began with basic information relating to each person's role as a DSP. Questions further developed into discussion of providing support for individuals with DD in the area of sexuality, and progressively moved into more in depth discussion about that support. Lastly, questions addressed experiences of DSP supporting individuals who identify as LGBT. Throughout the process of data collection and interviewing, field notes were taken to recall specific details of observations made by the researcher. Each interview was approximately 25-45 minutes. Each participant was compensated with a \$10 gift card to Target.

Data Analysis

All interviews were audio recorded, and data was transcribed by researcher. Grounded theory guided the data analysis by allowing the theory or themes to emerge from within the data (Monette et al., 2014). Each interview was transcribed, and each transcribed interview was read thoroughly to pull out frequently identified patterns within each participant's responses. Content analysis was used to quantify the frequency of responses and themes throughout the data (Padgett, 2008). A process of open-coding was used to pull out emerging themes within the data (Monette et al., 2014). The questions presented at the interview were designed to draw out specific information to help guide the themes that fit within the scope of the theories identified within the conceptual framework.

Validity and Reliability of Data

In this study, the researcher took several steps to ensure that the content analysis, the measurement of the aspects of the content of this research, developed coding schemes that were valid and reliable (Monette et al., 2014). To strengthen the validity, this researcher utilized a research assistant for a reliability check. The data is considered reliable if there are consistent and frequent patterns of use of the coding themes (Monette et al., 2014). The research assistant

read all transcribed interviews and pulled out themes from the data, which were compared to themes that this researcher found.

In addition to a reliability check, this researcher also completed field notes from each interview process, to provide descriptive observations of each interview (Monette et. al, 2014). Field notes not only allowed for an opportunity to note important information that is not included in each interview, but it also allowed this researcher to document feelings and thoughts toward each interview.

Strengths and Limitations of Study

There are some strengths and limitations to this study. One strength lies within the qualitative nature of this study. Conducting a qualitative analysis allowed the researcher to gather information that is more in depth and descriptive, leaving room for elaboration of responses and more emotion and opinions to come from the participants. Another strength is that DSP are often the closest people in the lives of the individuals with DD whom they support. DSP often know very specific details relating to the abilities and needs of the individuals with whom they work. Interviewing DSP allowed this researcher to gather much more specific information relating to the daily support needs and risks of individuals with DD.

One limitation of this study is that the researcher could not interview individuals with DD themselves. While the first hand knowledge and experiences that individuals with DD may have on exploring their own sexuality would be helpful, there were greater risks to using this vulnerable population as participants for this study. Another limitation is that participants from only one agency were used, limiting the diversity of experiences from multiple agencies or organizations that support individuals with DD. The research for this study was limited to the

experiences of DSP who work for one agency, and are only familiar with that agencies' training, policies, and culture of providing services to individuals with DD.

Findings

This research study was designed to explore the experiences of DSP in supporting sexuality for individuals with DD. Within these experiences, this study sought to gain an understanding of the role of the DSP, the barriers that individuals with DD may encounter in having sexual opportunities, and to understand implications for support needs and future policies and programs in providing this support. This researcher distributed emails to over 300 DSP at Hammer Residences, Inc., and received 9 total responses. One interview was unable to be scheduled, and a total of 8 interviews were conducted. Correspondence with each potential participant was made over the phone or through email. The researcher verified that all participants met the required criteria of being over 18 years of age and having worked in the field for over three years. Six out of nine participants are DSP but also have additional administrative duties as part of their job description that serve to help the overall function of the program. The data shared from each DSP included their experiences from the agency they currently work for as well as other agencies they have worked for in the past.

All interviews took place within a three-week span of time, at two locations. The first location was in a private office space, located at Hammer Residences, Inc.'s corporate office. The second location where participants were interviewed was one of Hammer Residences, Inc.'s apartment program locations, in a staff office located within the apartment complex. Interviews varied in length of time, ranging from 25 to 45 minutes. Prior to all recorded interviews, participants were asked to read, agree to and sign a participant consent form (Appendix C). Participants were given a \$10 gift card prior to interviews.

Once the interviews were completed, this researcher transcribed each recorded interview onto a word document. Participants were not identified by name, but rather by “Participant 1”, “Participant 2”, and so forth. Once interviews were transcribed, this researcher did a side by side comparison of each individual question to compare and contrast responses specific to each question. Phrases or concepts were drawn out from each question. When specific phrases or concepts were mentioned frequently, these were identified as strong themes throughout the study. The themes identified in this study are being identified as: (a) Clarity of DSP Role Around Supporting Sexuality and Relationships, (b) Families or Interdisciplinary Teams as a Barrier for Sexual Relationships and Expression of Sexuality, (c) Lack of Privacy for Individuals with DD, (d) Individual’s Overall Cognitive Functioning Level, Capacity to Consent, and Lack of Understanding About Sexuality (e) Safety and Identified Risks, and (f) Access to the Community as a Barrier. This researcher will describe how the collected data led to these themes emerging and how specific participant responses demonstrated the strength of these themes.

Clarity of DSP Role Around Supporting Sexuality and Relationships

One of the themes that emerged from consistent participants’ responses was the concern about the clarity of the role and duties of DSP. Many participants responded that a lack of clarity surrounding their role with regard to supporting sexuality not only hinders their support for individuals in this area, but may lead to possible risks in their employment. All participants in this study were unable to identify specific company policies that related to the DSP role in supporting sexuality and relationships for individuals with DD. Additionally, each participant was asked to provide a list of duties which they are responsible for as a DSP. Participants described the following as duties in their role as a DSP: (a) taking people to medical

appointments, (b) assisting in daily living skills (cooking, cleaning, personal shopping, hygiene, etc...), (c) providing transportation, (d) assisting in passing medications, (e) encouraging community integration, (f) helping them problem solve, helping them find joy in their lives, (g) helping them to maintain personal safety with behaviors and (h) helping them to maintain a healthy and active lifestyle. Among these responses, supporting sexual health, sexuality or relationships was not mentioned.

When participants were asked how they support the sexual health needs of the individuals they support, participant responses did not vary greatly. Many DSP reported that this was either not a part of their job, or that it simply did not present itself in their daily duties as a DSP. In fact, 7 of the 8 respondents reported that supporting individuals in their sexual health needs is not something that they do often. Participant 5 stated, “I don’t [support individuals in understanding their sexual health needs] in this position. It has just never come up.” While some participants stated that they would be comfortable discussing sexual health needs with the individuals they work with, it is not a proactive part of providing support to people. Participant 6 stated, “just talking with them if they bring it up. I’m not one to mention it [sexual health needs].”

The participants interviewed recognized that individuals have sexual health needs and desires as all humans do, but that a DSP role is not to help them to discover or facilitate that for them. Participant 4 described how a DSP duties do not proactively address sexual health needs:

It’s kind of a fine line because I understand that people need human touch in order to feel connected, but here...and at other places I’ve worked, that’s discouraged. So I don’t think that we, unless they have a relationship established that staff had nothing to do to facilitate- unless they already have that, we can help them to set up activities with their

significant other or help them in that way, but we're not going to be the ones to support them in helping them to find something like that.

The data provided also indicated that sexual health and sexuality only comes up when at doctor's appointments. Participant 1 explains "It doesn't come up a lot. Sometimes with [annual] physicals it comes up more often." Another participant explained that sexual health only came up because of specific medical treatments that an individual has in a private area of his body.

Participants also explained that there are risks to them, as employees, because of the sensitive nature of supporting individuals with DD in having sexual relationships. Participant 1 explains "by not reporting something, it would be considered a [vulnerable adult] issue, that I could possibly be fired or written up for not doing something." Participants also felt that supporting individuals with DD in having sexual relationships or expressing sexuality may result in family members or guardians becoming angry with the DSP and the organization as a whole. Participant 5 explained what may happen if a family member or guardian had guidelines regarding intimate relationships that DSP was unaware of:

I think the only risk I see, to me, is if there is a protocol in place and I'm not up on it.

Like if [an individual] has somebody over and I didn't know about it...I think there would be an accountability risk. I guess I'd be afraid, I'd be fearful that I wasn't on top of it.

Other participants also responded by indicating that, as a DSP, it is difficult to know how to support an individual's desire for sexual relationships when families or guardians set guidelines for DSP in providing that support. Participant 1 stated, "I'm not sure [if there are agency policies], I just know the boundaries that we are told by the guardians."

In addition to these potential risks as employees, participants also expressed that they are unaware of clear agency policies and staff training and education on supporting this area in individual's lives. While many of the participants expressed that they believe their agency strongly supports individuals with DD in their expression of sexuality, many were not sure on the organization's policies on supporting individual's sexual health needs and sexuality or if any such policies even existed in their workplace. Participant 5 explained that an individual's Bill of Rights, a standard document included in licensing standards, may include something about sexual relationships, stating "I'm sure there are policies allowing for privacy and consensual relations between individuals," but did not know if those policies were in place in the particular location where they worked.

DSP's roles are often confused, as this is an area that is not often discussed with families and interdisciplinary teams. Some participants also noted that sometimes supporting individuals with DD in their rights for self-determination and following the family's wishes for that person, often makes it challenging for DSP to know what their role is in facilitating this area of their life.

Families and Interdisciplinary Teams as a Barrier for Sexual Relationships and Expression of Sexuality

The strongest and most prevalent theme throughout the data was the role of families, guardians or interdisciplinary teams in how individuals with DD are able to experience sexual relationships or express sexuality. All eight participants reported families or guardians as a significant barrier for individual's having the ability to have sexual relationships or express sexuality. Participant 2 demonstrates how families feel protective over their family member with DD:

It's a touchy subject and because [sex] can be dangerous, and I think people feel protective sometimes of their family members and don't want them to be...I don't know, they don't see them that way. They sometimes see them like a child still, or someone that wouldn't have feelings like that, so it's never even explored...it's been a piece of their life that's just been forgotten.

Participants described families and guardians as having a lot of fear and anxiety regarding this area of life. Participant 3 described that families are “protective and do not know how to just treat [individuals with DD] as an individual and let them experience.”

Every participant indicated that family members and/or guardians typically establish the boundaries or guidelines for their family member with DD to prevent intimate sexual relationships. When participants were asked how, as a DSP, they ensure safety for sexual relationships and sexual health, Participant 1 stated, “I stay within the guidelines of what the guardians want.” Other participants indicated that safety is not really a concern because the individual with DD is never alone with intimate partners, due to guidelines and protocols that guardians and interdisciplinary teams set up for them and request that DSP implement in the residential setting. Participant 1 also explained a situation when an individual with DD wanted to have a friend over, and the DSP were told “can't be alone, her dad's rules.” After a while, it would be addressed with her dad, what would be appropriate in his eyes, as the guardian.

Parents and/or guardians are also seen as imposing personal values and beliefs on their family member, especially if the person with DD identifies as LGBT. Participant 8 explained that families are first and foremost the largest barrier to individuals with DD expressing their sexual identification, stating, “I think a lot of these views are pushed on people, and for

individuals with DD, it's hard for them to stand up for themselves.” Participant 2 describes her encounter with an angry parent:

I got in a conversation one time. I was talking to a mom. One of the people I support, she identifies as a lesbian, and she got on the phone with her father who lives in a different town. He doesn't have guardianship anymore...she had called him and was talking to him about this girl she had a crush on. And out of the blue dad calls the staff office, and I answer the phone...and he all of the sudden started going into how he doesn't agree, and how they're Christians. I was so taken aback. It's sad because she's lonely, and she needs [relationships] too.

Participants also noticed that families, especially older generations, may not feel comfortable talking with their family member with DD about sexual identification as LGBT. Participant 3 described, “I think with their parents being the age they are, they're not going to have those conversations and be able to say ‘Hey, let's go to gay pride, I think you're gay’. I think that's a very, very hard thing.”

Participants in this study indicated that, overall, the role of the family and the interdisciplinary team has a significant impact on the environment in which relationships can be explored for those with DD. Overall, families have the power to determine the amount of privacy an individual with DD can experience in their life.

Lack of Privacy for Individuals with DD

Individuals with DD living in community residential settings face a great challenge that many people without DD do not have to encounter- a lack of privacy for many areas of their lives. The very nature of their living situations, living in a home or apartment setting with others, appears to justify having everyone know every detail about how they choose to live their

lives, including whom with and how they choose to have relationships. Participant 2 described a dormitory style living situation where one room was designated for individuals living in that home to have sexual activity- a shared space where everyone knew what went on when individuals went into that room by themselves or with significant others. Participant 3 described individuals going to a dirty linen room together, as that was the only private space where others who lived in that setting would not be able to see them. Participant 7, who works with four men stated, “[intimate partners] are never really alone together...there have always been other people we serve around or staff, they’ve never been in each other's bedrooms or houses alone.”

Many participants in this study described “alone time”, a term used in licensing documentation that designates a specific amount of time that a person with DD is allowed to be alone, either at home or in the community. As a result of this designated or restricted alone time, many individuals are often supervised on dates or activities with intimate partners. Participant 1 explained, “if they have three hours of alone time with their significant other, or where they can be designated to be when they are hanging out alone...and they are usually not alone, [DSP] are usually there hovering.” Participants in this study also indicated that families often request that staff are present when a person with DD is spending time with an intimate partner. Participant 6 recalled, “I used to go sit in their apartment, I would kind of sit at the dining room table and they were on the couch kissing, and it was quite uncomfortable.”

The data from these interviews also showed that information regarding an individual with DD’s sexual experiences is often shared with many members who are a part of their interdisciplinary team, including family members or guardians. DSP in this study believed that individuals with DD have the right to privacy when it comes to who is privy to personal information about their sexual experiences. Participant 4 believed that only information about

their wishes and hopes may be necessary to share with members of their team. However, others reported that while individuals with DD have the right to privacy, the exception is if there is a risk to safety. Participant 6 shared, “I think [sexual experiences] should be shared with the team so that [individuals with DD] can be protected so that they are not taken advantage of.” Many of the participants also believed that sharing information with the team should be a proactive measure before determining if a sexual relationship is appropriate for that individual.

The data also showed that the guardians often request supervised visits with an individual's intimate partner, based on what they feel the overall risks are to that individual. Risks and safety concerns appear to be strongly tied to how much freedom and privacy an individual with DD receives in their personal relationships.

Individual’s Overall Cognitive Functioning Level, Capacity to Consent and Lack of Understanding About Sexuality

Another theme that was revealed through the data was the cognitive functioning of individuals with DD, how this impacts their abilities in having sexual relationships, and how this impacts their overall understanding of sexuality. Every participant indicated that an individual’s overall cognitive functioning level may directly impact their ability to engage in sexual relationships. The data showed that DSP believe that the functioning level of the individual impacts how much supervision is needed, determined by previous risk factors or by family’s/guardian’s standards. Participant 3 expressed that individuals with DD may receive more staff support for sexual relationships “as long as there is a team agreement...and everyone’s involved, and it’s a safe thing that’s happening, taking into account their vulnerabilities.” Many participants believed that cognitive limitations create barriers for individuals being able to understand sexuality and sexual relationships. When asked what stands

in the way for individuals entering into sexual relationships, Participant 7 explained “well, I think their cognitive abilities in a lot of cases. They are watched so closely and they aren’t able to develop relationships.”

Many discussions with participants regarding an individual’s overall cognitive functioning level naturally lead to further discussions regarding the safety concerns for individuals with DD entering sexual relationships. Capacity to consent was considered a significant concern from DSP who were interviewed in this study. Several participants indicated that individuals with DD may not fully understand consequences of their decisions when it comes to relationships and engaging in sexual activity. Participant 7 explained, “I don’t think they know how to handle [consent], no...they don’t know the dangers of having an intimate relationship and what could happen.” Many participants recognized that the overall cognitive functioning level of an individual may greatly impact their ability to understand and consent to sexual relationships.

Cognitive abilities also appeared to impact how individuals with disabilities understand relationships and sexual intimacy. Many participants noted that many of the individuals they support do not enter into sexual relationships because they don’t appear to understand or be interested in such activities. Participant 8 described how an individual’s cognitive abilities impact how they view sexual relationships: “I guess it differs on everybody’s level. Some people think intimacy is different. Some think it’s holding hands, some think it’s intercourse.” This participant also went on to explain that their level of understanding may also impact their level of desire for relationships.

Another area where lack of understanding or awareness was identified as a barrier for individuals with DD was when discussing individuals with DD who may identify as LGBT.

Very few of the participants in this study had experience working with individuals with DD who also identified as LGBT. In fact, only one participant in this study reported having worked with an individual who openly identified themselves as LGBT. Four of the eight DSP interviewed had instances when they suspected that someone they worked with may be LGBT, but that the individual had difficulty understanding what sexual orientation meant. Many participants attributed the lack of experience in this area to the fact that individuals with DD may have a lack of awareness, experience and education with regard to sexual orientation. Participant 8 stated “I think that people would identify [as LGBT] but they don’t know what that means. They are not exposed; they are not provided literature or education. They are just told ‘this is who you are’.” Other participants noted that individuals with DD are often treated as if they are asexual.

In addition to the lack of awareness and understanding about sexual orientation, DSP also noted that many individuals with DD struggle with identification as a person with a disability, and that a dual identification of DD and LGBT may be quite complex for their understanding. Many participants indicated that individuals with DD already struggle with communication barriers and may not have the communication skills or outlets to be able to express their feelings regarding sexuality or orientation. When asked what would make it difficult for individuals with DD who may identify as LGBT to express sexuality, Participant 5 noted: “maybe feeling isolated, or maybe having feelings of confusion and not knowing who to talk to.” Many participants stated that individuals with DD would need a strong support system in place to help them to navigate sexual and/or gender orientation.

Safety and Risks

While the data in this study also showed that DSP believed that the safety of individuals with DD and identified risks that they can experience are mostly the same as those without DD.

Participants reported that individuals with DD are at risk for unplanned pregnancy, STD's, and exploitation, but that these were risks that they had identified as being risks to anyone involved in a sexual relationship. Many participants in this study believed that individuals with DD would experience the same emotional and physical risks as those without DD. Participant 2 explained that when she discusses safety and risks of sexual interactions with others to individuals with DD, it is very similar to the conversation that she has with her teenage daughter.

The data in this study showed that overall, DSP believe that the risks for individuals with DD are the same or similar to those without DD, there were also some differences. Several participants addressed the concern that individuals with DD are more vulnerable to sexual abuse and exploitation from others, and that as a DSP, it is difficult to advocate for their rights while supporting their safety. Participant 3 described a woman she has worked with in the past who went missing and was sexually abused for several days:

We had one girl who was taken from her home. She was walking, and she was gone for three days, and she was sexually abused...some guy just saw her on the side of the road, pulled up and said 'oh, I need help fixing my bike' or 'oh, I've got pop at my house'.

And then the police found her with her bike, biking around. They asked her 'where were you?' and she was able to point to where the house was.

While this situation may be rare, it was significant, dangerous, and left this participant questioning how to help other individuals with DD and be able to prevent abusive encounters with others.

Another area where DSP felt that individuals with DD may be more vulnerable is around online dating or social media sites. One participant described an event where it was difficult to keep an individual safe due to her demonstrating risky online behavior:

She would just find people online, craigslist, and facebook, and we were pretty sure she ended up being a part of a sex trafficking sting a few years ago...she was bringing men who we didn't know back to the apartment, and it got to the point where we needed to scan visitors ID's, and if they refused, they wouldn't be allowed in the building.

This participant also expressed that the risky sexual behavior that this individual with DD was demonstrating not only presented a safety concern for the individual, but for the staff team who supported her in that particular program.

Many of the participants also provided their thoughts on possible solutions to these safety concerns and potential risks. Much of the data showed that increasing education and decreasing the barriers to gain access to appropriate outlets for safe relationships may benefit this vulnerable population.

Access to the Community as a Barrier

The final theme identified in the data was access to the community as a barrier for sexual relationships. All participants in this study believed that individuals with DD have limitations to accessing the community, which complicates relationships and ultimately limits access for sexual expression. When asked what stands in the way for individuals with DD to have sexual relationships, Participant 2 stated "Access to people. In some ways, the field has come so far because we've integrated [individuals with DD] in so many ways, but other times, they stick with their own or only have a couple of friends." DSP in this study believed that individuals with DD don't have the opportunity to spend time with other people or meet new people outside of their living arrangements. DSP reported that in most cases, it is the DSP role to encourage community integration, but that this often means that individuals are always supervised by staff. Participant 8 noted that "having staff to attend places with them is a barrier" and that individuals

with DD are often attending organized events that are focused on activities within the DD community, and not engaging in their community in natural ways.

For some participants, transportation alone was a major barrier to individuals with DD having opportunities in their community to engage in relationships. Participant 5 described how distance played a major factor in one man's relationship:

For some of our people, the problem for them is developing relationships because they have to rely on us for transportation... We have an individual who talks all of the time about getting an apartment with his girlfriend. I wish we could find a way. He doesn't drive, I mean, and things are difficult. He's motivated, he's trying to make things work... It seems like there a lot of barriers to just getting physically close to this person.

Conclusion

The 8 participants who were interviewed for this study contributed to the data through their recollection of specific details in supporting individuals with DD in sexuality and sexual experiences. The experiences and sentiments that were shared by each participant allowed this researcher to establish the six major themes that were described. The themes identified in this study include: (a) Clarity of DSP Role Around Supporting Sexuality and Relationships, (b) Families or Interdisciplinary Teams as a Barrier for Sexual Relationships and Expression of Sexuality, (c) Lack of Privacy for Individuals with DD, (d) Individual's Overall Cognitive Functioning Level and Lack of Understanding About Sexuality (e) Capacity to Consent, Safety, and Identified Risks, and (f) Access to the Community as a Barrier. In the following section, this researcher will discuss how these findings compare to previous research, add to the body of literature, and have implications for future practice and research.

Discussion

The purpose of this research study was to better understand how sexuality is viewed and supported by DSP who work directly with individuals with DD. The research question of this study is: What are the experiences of DSP in supporting sexuality for individuals with developmental disabilities? This section will discuss how the data found in the current study: (a) compares to previous research, (b) has implications for social work practice, (c) has implications for policy, and (d) has implications for future research. Additionally, this researcher will discuss the strengths and limitations of this study and the impact on the findings.

Comparison with Previous Research

Overall, the data presented in this study supports the body of literature and findings of previous studies. Many of the themes identified in this study strongly supported data provided in the literature review. There were, however, some differences that stood out when comparing this study with previous studies.

Clarity of DSP role around supporting sexuality and relationships. The DSP interviewed for this study provided an extensive list of their job duties. While many of the duties described were relating to supporting individuals with DD in opportunities for community integration and relationships with others, none of the participants explicitly stated that they support individuals with DD in expressing sexuality or exploring sexual relationships with others, nor was it implied among the duties described. Additionally, all 8 participants in this study did not have training in company specific policies regarding supporting individuals with DD in sexuality, and many did not know if such policies existed. This information strongly correlates to the previous studies by Christian et al. (2001) and Healy et al. (2009), who described gaps in staff education and training as it relates to implementation of sexual education

or supporting sexuality for individuals with DD (Christian et al., 2001; Healy et al., 2009). Evans et al. (2009) also concluded that while DSP may feel comfortable discussing sexuality with individuals with DD, many attribute the lack of support in this area to a lack of training and a lack of unclear organizational guidelines (Evans et al., 2009). The data shown in the current study supports the previous literature regarding the clarity of the DSP role and the expectation or training around supporting sexuality for individuals with DD.

Grieve et al. (2008) found that staff who work with individuals with DD often fear disciplinary action from their employer or from the state if they condoned intimate relationships of people they supported (Grieve et al., 2008). The results of the current study found that, while a couple of participants were concerned about their employer's response to DSP supporting sexual relationships among individuals with DD, most were concerned with responses from guardians and family members of the individuals with whom they work.

Families or interdisciplinary teams as a barrier for sexual relationships and expression of sexuality. Each participant in this study indicated that family members, guardians, and interdisciplinary teams present barriers for individuals with DD being able to express sexuality or experience sexual relationships with others. This information strongly correlates with much of the previous research in this area.

Overall, DSP in this study reported that families hold more conservative views regarding individuals with DD expressing sexuality, stating that many families continue to view individuals with disabilities as perpetual children. Aunos and Feldman described that parents of children with DD are restrictive of their activities and generally do not discuss sex with their disabled child (Aunos & Feldman, 2002).

Additionally, participants in this study reported that family members are often setting the “rules” or guidelines for intimacy and privacy in sexual relationships, by which DSP are to follow. This supports the study completed by Evans et al. (2009), which showed that 63% of family members believe that family members should be involved in important decision making when it comes to sexuality and relationships (Evans et al., 2009). Many DSP in this study believed that the guardian’s wishes for the person with DD often impede upon an individual’s basic human rights. Often, it appears that the guardian’s role and rights conflict with a person-centered model of care, leading to significant confusion in how a DSP should provide support for sexuality for those with whom they work.

Lack of privacy for individuals with DD. The data in this study continues to support the literature, showing that individuals with DD experience a significant lack of privacy, which prevents opportunities for sexual relationships and the expression of sexuality. Walker-Hirsch (2007) explains that individuals with DD are often living in community settings, among other individuals with DD, supported by staff members on a consistent, daily basis (Walker-Hirsch, 2007). Many participants in this study described this significant lack of privacy as a result of living in a communal setting. Participant 3 even recalled working in a home with young men and women where there was a specific room of the house that was separated from other common areas of the home and was specifically designated for the personal use of masturbation or sexual activity with a partner. Still, however, this participant also concluded that while the room itself was private, everyone else in the home knew what activities were taking place during that private time.

Studies from both Christian et al. (2001) and Healy et al. (2009) found that DSP often face difficulty distinguishing what information should be shared with family members,

guardians, and interdisciplinary teams regarding an individual's sexual experiences (Christian et al., 2001; Healy et al., 2009). Responses from participants in this study supported previous research. Many DSP believed that individuals have a right to privacy, but when safety or risks were of concern, team members should be notified about information relating to that person's sexual experiences.

Individual's overall cognitive functioning level, the capacity to consent, and lack of understanding about sexuality. The current study revealed that DSP feel that individuals with DD may lack an understanding of sexuality. This may be due to overall cognitive functioning level and overall lack of exposure to education or resources relating to sexuality. These findings are consistent with previous research. Christian et al. (2001), Grieve et al. (2008), Walker-Hirsch (2007), and Wilkenfeld and Ballan (2011) all support that individuals with DD, depending on cognitive functioning level, may not have the capacity to understand sexuality and consent to sexual relationships (Christian et al., 2001; Grieve et al., 2008; Walker-Hirsch, 2007; Wilkenfeld & Ballan, 2011). DSP in the current study also believed that there needs to be an increase in education opportunities for individuals with DD from sources outside their primary support system. This is consistent with Christian et al. (2001), Esmail et al. (2010), and Wilkenfeld and Ballan (2011), who pose that proper education around sexuality increases functionality (Christian et al., 2001; Esmail et al., 2010; Wilkenfeld & Ballan, 2011).

The results of the current study also found that DSP believe that many individuals with DD do not have an understanding or awareness of what it means to be LGBT. The results of the current study are consistent with previous findings of Abbott and Howarth (2007), Lofgren-Martenson (2009) and Thompson and Bryson (2001), who claim that there is an assumption, when working with individuals with DD, that they must identify as heterosexual, or that LGBT

identification is uncommon in the DD population (Abbott & Howarth, 2007; (Lofgren-Mortenson, 2008; Thompson & Bryson, 2001). DSP in the current study also reported that it would be significantly difficult for individuals with DD to comprehend the dual identity of being both DD and LGBT. This is consistent with the work of Appleby (1994), Harley et al. (2000), and Morgan et al. (2011) who believe that the process of identity formation is more challenging for individuals with DD who may identify as LGBT due to lack of awareness or support (Appleby, 1994; Harley et al, 2000; Morgan et al., 2011).

Safety and identified risks. DSP in the current study believed that individuals with DD face similar risks to those without DD when engaging in sexual relationships. However, this contradicts previous research. Lackasson (1992) revealed that as vulnerable adults, individuals with DD are at greater risk for sexual abuse or exploitation (Lackasson, 1992). Walker-Hirsch (2007) suggests that loneliness experienced by individuals with DD may increase their vulnerability to abuse by misidentifying someone as a “safe” person (Walker-Hirsch, 2007). While participants in this study did believe that safety was a large concern, overall, the participants believed that individuals with DD may experience the same safety concerns and risks as those without DD. Many participants agreed that individuals with DD are at risk for unplanned pregnancy, STD’s, emotional abuse, and physical abuse when engaging in sexual relationships, but that these risks are the same for anyone engaged in sexual activity.

Access to the community as a barrier. While individuals with disabilities are experiencing an increase in community integration and increase in opportunities or relationships, access to the community continues to present a barrier to establishing and maintaining relationships. The current study showed that DSP feel that individuals with DD lack the ability to access transportation or rely on social supports to access opportunities to maintain

relationships. This is consistent with the findings of Walker-Hirsch (2007), who explains that individuals with DD may have few friends outside of their families or living arrangements due to major gaps in inclusion and access to the community (Walker-Hirsch, 2007).

Strengths and Limitations

This study sought to better understand the experiences that DSP have supporting sexuality for individuals with DD. There were many strengths and limitations that were factors in the overall data that was collected and shared. One strength of this study was that through qualitative interviewing methods, participants were able to answer questions with more thorough and in-depth explanations. This allowed participants to provide detailed accounts and subjective information about supporting this area of people's lives. Using qualitative methods, this researcher was better able to discuss the complexities of the role of a DSP, especially as it relates to supporting sexuality. This also allowed the researcher to better assess quality programs, support, and overall attitudes as it relates to the subject.

Another strength was the range of experiences of participants in this study. Participants reported experience ranging from 3 years to over 30 years in the field of working with individuals with DD. This wide range of experience allowed this researcher to better understand how attitudes of supporting sexuality for individuals with DD have shifted over time, and what DSP are doing differently today to better understand and support this area of a person's life.

To increase validity and reliability, the data from this study was also analyzed by a research assistant. This research assistant was given transcribed interviews from each participant. In turn, the research assistant provided coding and determined a separate set of themes, which then were shared with this researcher. This researcher then compared the two sets of data, along with themes, to determine the strength of each theme.

One limitation of this study is the small sample size. While the quality of these interviews was exceptional, it only provided the experiences of 8 DSP who are working in this field. Additionally, all DSP worked for the same agency. This did not allow the researcher to get a broader perspective, taking into consideration that each agency has a different overall culture and mission of providing services for individuals with DD.

Another limitation is that individuals with DD themselves were unable to be used in this study. Individuals with DD are considered a vulnerable population, which would have been very difficult to approve through an Institutional Review Board (IRB) for this project. While individuals with DD are the focus and their information would have been perceived as invaluable to the research, information was only to be gathered from professionals working in this field.

Implications for Social Work Practice

The information provided in this study provides value to the social work practice and to the agencies that support the needs of individuals with DD. This study provides many implications to social work practice. With regard to support services for individuals with DD, social workers are often a critical member and assist in mediating and communicating with other members of individuals' interdisciplinary team, assessing an individual's needs, locating and establishing effective support services to meet those needs, and evaluating and working toward improving those direct supports. It is critical that social workers understand the importance and basic human need of human touch and expression of sexuality for individuals with DD. Social workers advocate for an individual's right to sexual expression and helping team members to understand the balance of an individual's right to self-determination and possible outcomes of decisions made.

Additionally, the data provided has implications for education- both for individuals with DD and staff members who work with them. Individuals with DD experience a lack of access to important information regarding sexuality (DiGiulio, 2003). Not only should individuals with DD have access to the same opportunities for sexual education as those without DD, but social workers should advocate for the development of programs that comprehensively accommodate the unique learning needs of each individual with DD.

Not only is education important for individuals with DD and DSP, but social workers themselves may benefit from further education and awareness on sexuality for individuals with DD. When receiving reports of sexual abuse, it is important for social workers, including those working in adult protection, to be able to distinguish between individuals expressing their right to sexuality and relationships, and those who are trying to impose their own personal values on the individual. Additionally, social workers may benefit from learning the skills to listen empathetically and respond respectfully to all reports of sexual abuse from individuals with DD.

Implications for Policy

The information gathered in this study has implications for policy at both the mezzo and macro levels of social work practice. At the mezzo level of social work practice, schools, health care, and community supports should further develop educational programs that address sexual health and sexuality as a basic human need for individuals with DD. These programs should not only help an individual with DD navigate sexuality as it relates to the formation of identity, but also as it relates to personal safety and risk. The findings of this strongly suggest the solution to reducing risks and increasing safety for individuals with DD wanting to engage in sexual activity is to provide comprehensive education and ongoing support. Additionally, family members of

individuals with DD may benefit from receiving education and support regarding sexuality for individuals with DD.

The findings of this study also support implications for macro level policy changes. While services for individuals with DD continue to progress toward more person-centered models of care, the services that are provided for individuals with DD are bound by licensing guidelines and restrictions set forth by the Department of Health and Human Services. As indicated in the data, DSP are bound by these licensing guidelines that are intended to reduce risk and increase personal safety for individuals with DD. These guidelines, however, ultimately lead providers and DSP to restrict an individual's right to privacy and right to choices with regard to sexual relationships for fear of violation of these guidelines. As members of interdisciplinary teams serving individuals with DD, social workers can advocate for individuals by ensuring that individual's basic human rights are not restricted. Additionally, social workers can continue to encourage efforts at a policy level by empowering individuals with DD and their family members to connect with state policymakers to support changes to licensing guidelines that indirectly force restrictions for individuals with DD in the area of sexuality.

The results of this study also suggest that there are significant conflicts between the powers and duties of appointed guardians and the provision of a person-centered model of care for individuals with DD. As written in the State of Minnesota's guidelines for guardianship and conservatorship, a guardian has "the duty and power to exercise supervisory authority over the ward in a manner that limits the person's civil rights and restricts personal freedom only to the extent necessary to provide needed care and services" (Minnesota Conference of Chief Judges, 2013). While in many cases, this supervision is exercised out of concern for health and safety for an individual with DD, these guidelines are also quite subjective. The "extent necessary"

gives guardian's power to make decisions on an individual's behalf that falls in line with their own personal beliefs and values, rather than those of the individuals. There is a great need for further review and revision of these court guidelines to ensure that the rights of the individual are recognized regardless of the personal values of the guardian in place.

Implications for Research

This data found in this study has several implications for possible future research around sexual health and sexuality for individuals with DD. First, previous research has solely focused on sexual health rather than sexuality or sexual identification for individuals with DD. Further research is needed in this area to determine more focused support needs for individuals with DD as they explore sexual identification through their lifespan. Additionally, limited research has been completed to explore the experiences of individuals with DD who identify as LGBT. More research would be useful in understanding how this dual identification adds a layer of complexity to sexual relationships and experiences, for a person who is both DD and as a person who identifies as LGBT. Future studies should include interviews with individuals with DD to better understand how they struggle with this dual identification as a person with DD who may identify as LGBT, or how they are successful in navigating this dual identification. Interviews with individuals with DD may lead to more general information on how individuals with DD understand sexual orientation and gender identification. Interviewing family members of individuals with DD would also be useful, as they offer another perspective and world view as it relates to this topic. Families would be able to share how the sexuality of their family member with DD is affected by their own values and principles, as well as fears and concerns they may have regarding sexual activity.

In addition to implications for research around sexuality and identification, further research is needed to better understand how education is a factor in reducing risk and increasing personal safety skills for individuals with DD. Many participants in this study indicated that more formalized proactive strategies would be helpful as DSP discuss sex and relationships with individuals with DD. Further research is needed in order to develop educational programs that encourage skill building and self-determination, as well as the development of sexual identification.

Further research is needed on the role of caregivers as it relates to supporting this area of a person's life. DSP themselves are often the first point of contact and frontline workers, supporting daily needs for individuals with DD. More research is needed to understand how promoting training and education opportunities for DSP who work directly with individuals with DD may benefit not only the individual and their rights for expression of sexuality, but also the DSP who work with them.

Lastly, the findings of this study imply that more research is needed in understanding how the changing social climate impacts this population of people and their right to expression of sexuality. Previous research explored how a staff member or family member's personal values impact their attitudes toward individuals with DD having sexual experiences or having a sexual identification. As there continues to be ongoing political and societal changes, not just changes for the LGBT community, but also changes in overall attitudes towards individuals with DD, researchers might explore how these shifts in societal attitudes impact how family members and staff relate to individuals with DD with regard to sexual identification and expression.

In conclusion, the results of this study are similar to that of previous research; however, the advancement of services and programs for individuals with DD and the overall changes in

societal attitudes towards individuals with DD indicate that continued research around the topic of sexuality for individuals with DD may be necessary to increase awareness and ongoing support for this population. With over 1.2 million people diagnosed with DD in the U.S. (Brault, 2012), ongoing research is needed to continue to advance services and reduce barriers that will allow individuals with DD to receive support in having sexual relationships and expressing sexuality.

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Appendix A: Recruitment Flier***Recruiting DSP for
Research Study!!***

Looking for Direct Support Professionals to participate in interviews

TOPICS: supporting sexuality for individuals with developmental disabilities

Study purpose: To gain an understanding about how DSP's support individuals with DD in the area of sexuality.

Criteria for participation:

-18 years or older

-must be currently working as a Direct Support Professional

Commitment: a one-time interview, for 60-90 minutes

***Receive a \$10 gift card to Target upon
completion of the interview***

Please call Elizabeth Senne at XXX-XXX-XXXX or XXXX@stthomas.edu to discuss participating in this study.

***If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact Dr. John Schmitt, Chair of the Human Subjects Institutional Review Board, through St. Catherine University at:
(651) 690-7739***

Appendix B: Information Sheet for Participants

INFORMATION SHEET FOR THE STUDY

My name is Elizabeth Senne, and I am a Masters of Social Work student under the direction of Professor Catherine Marrs Fuchsel, PhD., LICSW, LCSW in the School of Social Work, St. Catherine University and University of St. Thomas. I am conducting a research study to explore the experiences of Direct Support Professionals in supporting sexuality for individuals with developmental disabilities. Through this study, I hope to learn what social workers and services providers can do to reduce the barriers that exist for individuals with Developmental Disabilities in being able to express their sexuality, and to learn more about how to support the DD population who identify as lesbian, gay, bisexual or transgender.

I would like for DSP who have more than three years of experience in providing supports to individuals with DD. If you agree to participate, I will ask you to read the information letter and the informed consent before the interview process, to allow time for you to ask any questions you may have. Once you have read the information sheet, and signed the consent, you will move forward with an interview, which includes a total of 13 questions, and will be audio recorded. This study is voluntary and you may choose to stop participating at any time. You may also choose not to answer any of the questions in the interview. The questions in the interview will pertain to your knowledge and experience in supporting areas of sexuality for those you work with. You will be asked questions relating to several topics, including your role in supporting sexuality for individuals with DD, your agency's policies and training that is provided in the area of supporting sexuality for individuals with DD, the risks and barriers for individuals with DD in expressing their sexuality, and your experience in supporting individuals with DD who identify as LGBT. One incentive to you for participating in this study is you will receive a \$10 gift card to Target for your time and commitment.

The information from this study will be published in my thesis and may be published in social science journals. Your name will not be used to identify you and information will be recorded anonymously. The questionnaires will be kept in a locked cabinet at my place of residence as well as on my computer that requires a passcode to access. Only Dr. Catherine Marrs Fuchsel and I will have access to the confidential information. The data will be kept until May 31, 2016 and all reports and notes will be shredded or deleted from the computer. The emails will be permanently deleted after the interviews have been transcribed and coded. Contact information: Elizabeth Senne, XXX-XXX-XXXX, or XXXX@stthomas.edu.

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Dr. John Schmitt, Chair of the Human Subjects Institutional Review Board, through St. Catherine University at (651) 690-7739.

Appendix C: IRB Consent Form

Experiences of Direct Support Professionals Supporting Sexuality for Individuals with Developmental Disabilities

INFORMATION AND CONSENT FORM

Introduction:

You are invited to participate in a research study investigating the experiences of Direct Support Professionals in supporting sexuality for individuals with developmental disabilities. This study is being conducted by Elizabeth Senne, a graduate student at St. Catherine University and the University of St. Thomas under the supervision of Catherine L. Marrs Fuchsel, PhD., LICSW, LCSW, a faculty member in the School of Social Work. You were selected as a possible participant in this research because of your role as a Direct Support Professional working in an agency that provides support to individuals with developmental disabilities. Please read this form and ask questions before you agree to be in the study.

Background Information:

The purpose of this study is to gain an understanding of how Direct Support Professionals support individuals with DD in the area of sexuality. Approximately 6-10 people are expected to participate in this research.

Procedures:

If you decide to participate, you will be asked to meet with the researcher for approximately 60-90 minutes and participate in an interview that will be recorded, transcribed, and shared with other graduate level social work students and social work faculty.

Risks and Benefits of being in the study:

The study has minimal risks.

There are no immediate and direct benefits to you for participating in this research. There may, however, be societal benefits that may produce better outcomes for training and awareness for DSP in supporting sexuality for individuals with DD, as well as possible educational opportunities for individuals with DD in understanding their own sexuality.

Compensation:

If you participate, you will receive a \$10 gift card for Target.

Confidentiality:

Any information obtained in connection with this research that could potentially identify you as a participant will be disclosed only with your permission; your results will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented.

I will keep the research results in a locked file cabinet in my personal home office and only I, Elizabeth Senne, and my advisor will have access to the records while I work on this project. I will finish analyzing the data by May 31, 2016. I will then destroy all original reports and identifying information that can be linked back to you. Taped interviews will be stored in a safe location in a locked file cabinet in my home office. An electronic copy of the transcribed interviews will be kept in a password protected file on my personal home computer. The transcribed interviews will not hold identifying information of the interviewee.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with the St. Catherine University or the University of St. Thomas in any way. If you decide to participate, you are free to stop at any time without affecting these relationships. Should you decide to withdraw, previously collected data will be destroyed and will not be used for future research purposes.

New Information:

If during course of this research study I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings.

Contacts and questions:

If you have any questions, please feel free to contact me, Elizabeth Senne, at XXX-XXX-XXXX. You may ask questions now, or if you have any additional questions later, the faculty advisor, Catherine Marrs Fuchsel, PhD, LICSW, LCSW will be happy to answer them. You can reach Catherine at 651-690-6146. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study.

I consent to participate in the study and agree to have my interview audio taped.

Signature of Participant

Date

Signature of Parent, Legal Guardian, or Witness

Date

Signature of Researcher

Date-

Appendix D: Research Assistant Confidentiality Agreement

Transcriber Confidentiality Agreement Experiences of Direct Support Professionals Supporting Sexuality for Individuals with Developmental Disabilities

I am conducting a study on the experiences of Direct Support Professionals in supporting sexuality for individuals with developmental disabilities.

This study is being conducted by: Elizabeth Senne, under the advisement of my chair, Catherine Marrs Fuchsel, Ph.D., St. Catherine University and the University of St. Thomas.

Confidentiality:

Confidential information includes all data, materials, products, technology, audiotapes, computer programs and electronic versions of files saved to portable storage devices. One-time audio taped interviews lasting no longer than 90 minutes will be conducted by the researcher. The completed audio tapes will be hand delivered to you by the researcher for transcription. No personally identifying information will be attached to the audio tape recordings. Any transcriptions or electronic files produced by you will not include information that will make it possible to personally identify participants in any way. All audio tapes and transcriptions are to be kept in a locked file. No one else will have access to the records. No one else will have access to the computer on which transcriptions and electronic files will be prepared. All tape recordings, transcripts and electronically formatted transcripts will be returned in their entirety to the researcher. Once transcriptions have been completed and an electronic file compiled, you will contact the researcher who will then personally pick them up. Any and all electronic versions of transcripts will be deleted from your files upon delivery of records to the researcher.

Contacts and Questions

My name is Elizabeth Senne. If you have questions, you may contact me at XXX-XXX-XXXX or my research chair, Catherine Marrs Fuchsel, 651-690-6146. You may also contact the St. Catherine University Institutional Review Board at 651-690-7739 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Agreement of Confidentiality:

I, _____, have read the above information and agree to confidentiality as stipulated above. I further agree not to disclose, publish or otherwise reveal any of the confidential information received from the researcher or interview participants.

Signature of Transcriber

Date

Signature of Researcher

Date

Appendix E: Interview Questions

1. Please describe the job expectations that you have as Direct Support Professional (DSP).
2. As a DSP, how do you assist individuals with Developmental Disabilities (DD) in understanding their sexual health needs?
3. As a DSP, how do you support individual's needs or desires for intimate relationships?
4. How do you ensure safety in overall sexual health for the individuals that you support?
5. What are your agency's policies on supporting sexuality for individuals with DD?
6. With regard to their sexual relationships and their sexuality, what do you do to ensure and respect an individual's right to privacy?
7. What information do you believe should be shared with family members, guardians or other interdisciplinary team members regarding the individual's sexual experiences?
8. What do you feel are the risks of individuals with DD having sexual relationships or experiences?
9. What are the risks to you, as a DSP, in supporting an individual's desire for sexual relationships?
10. What do you think stands in the way of individuals with DD being able to experience sexual relationships?
11. What would make it easier for individuals with DD to be able to have sexual relationships?
12. What is your experience in supporting individuals with DD who identify as Lesbian, Gay, Bisexual, or Transgender (LGBT)?
13. What do you think makes it more difficult for individuals DD who identify as LGBT to be able to express their sexuality?