

The University of Maine

DigitalCommons@UMaine

---

Electronic Theses and Dissertations

Fogler Library

---

Summer 8-21-2020

## Direct Support Professionals' Perspectives on Sexuality Issues of Adults with Intellectual Disabilities: A Qualitative Analysis of Interviews with Providers in Maine

Nicole Achey

University of Maine, [nicole.achey@maine.edu](mailto:nicole.achey@maine.edu)

Follow this and additional works at: <https://digitalcommons.library.umaine.edu/etd>

---

### Recommended Citation

Achey, Nicole, "Direct Support Professionals' Perspectives on Sexuality Issues of Adults with Intellectual Disabilities: A Qualitative Analysis of Interviews with Providers in Maine" (2020). *Electronic Theses and Dissertations*. 3248.

<https://digitalcommons.library.umaine.edu/etd/3248>

This Open-Access Thesis is brought to you for free and open access by DigitalCommons@UMaine. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of DigitalCommons@UMaine. For more information, please contact [um.library.technical.services@maine.edu](mailto:um.library.technical.services@maine.edu).

**DIRECT SUPPORT PROFESSIONALS' PERSPECTIVES ON SEXUALITY ISSUES OF  
ADULTS WITH INTELLECTUAL DISABILITIES: A QUALITATIVE  
ANALYSIS OF INTERVIEWS WITH PROVIDERS IN MAINE**

By

Nicole Achey

B.S. University of Maine at Farmington, 2007

M.A. University of Northern Colorado, 2009

A DISSERTATION

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

(in Interdisciplinary Studies in Human Development)

The Graduate School

The University of Maine

August 2020

Advisory Committee:

Sandra Caron, Professor of Family Relations and Human Sexuality, Advisor

Sandra Butler, Professor of Social Work

Allison Carey, Professor of Sociology, Shippensburg University, Pennsylvania

Sarah Howorth, Assistant Professor of Special Education

Daniel Puhlman, Assistant Professor of Family Studies

Copyright 2020 Nicole Achey

All Rights Reserved

**DIRECT SUPPORT PROFESSIONALS' PERSPECTIVES ON SEXUALITY ISSUES OF  
ADULTS WITH INTELLECTUAL DISABILITIES: A QUALITATIVE  
ANALYSIS OF INTERVIEWS WITH PROVIDERS IN MAINE**

By Nicole Achey

Dissertation Advisor: Dr. Sandra Caron

An Abstract of the Dissertation Presented  
in Partial Fulfillment of the Requirements for the  
Degree of Doctor of Philosophy  
(in Interdisciplinary Studies in Human Development)

August 2020

The purpose of this qualitative study was to understand how Direct Support Professionals (DSPs) view and support the sexuality of individuals with mild to moderate ID. Interviews with 24 DSPs (19 females, 5 males) working in Maine focused on several topic areas: sexual attitudes and experiences with consumers' sexuality issues, the factors that influence how they handle various situations, and the impact of gender on their response to consumers. DSPs were also asked to talk about suggestions they have for improving their work with consumers around sexuality. These in-depth, face-to-face interviews consisted of a series of open-ended questions. The participants were primarily recruited using a snowball sampling technique. Straussian grounded-theory method was used to guide the collecting and coding of interview data in order to identify emerging categories within the data.

Sixteen themes emerged from the analysis of the interview transcripts and were organized under the topics of focus for the study. The 16 themes were organized according to the sub-research questions of this study and are the focus of this research, they are: *attitudes and beliefs, experiences in sexuality, influencing factors, gender, and suggestions for sexually related issues*. Three broad categories emerged from a further analysis of the 16 themes and include: *My Hands*

*are Tied, Isolation, and Champions for Sex.* This study revealed that DSPs perceive constraints, limitations, and an inability to act freely when it comes to addressing their consumers' sexuality issues and needs. They often find themselves alone to support their consumers' sexual needs without much training or guidance from their agency. Despite these challenges and frustrations, the DSPs see themselves as the people on the front lines to support and advocate for their consumers' sexuality issues. Implications of the study findings are discussed, including the need for agencies to have a clear policy around sexuality, the use of a team approach which includes the DSPs, and better sexuality training for DSPs and parents to ultimately improve the sexual lives of individuals with ID.

## ACKNOWLEDGMENTS

I would like to thank my Chair, Dr. Sandra Caron for her guidance through each stage of the process. I am forever grateful for Dr. Caron who graciously assumed the role of advisor. I want to acknowledge her impressive commitment in supporting me and her generous availability. I cannot say enough how much I benefited from your mentorship. I am also very thankful for the support and encouragement that my committee members provided from the beginning to the end of my dissertation. Thank you for being a part of my team and helping to shape and polish this work, each of you brought your areas of expertise and made it what it is. You were truly a pleasure to work with, I hope to work with you all again. Finally, I wish to thank the graduate school and my other faculty at University of Maine.

I owe a big thank you to my colleagues at the University of Maine at Farmington for their support and encouragement, especially to my Rehabilitation Services Department colleagues. To Dr. Gina Oswald who provided inter-observer support and served as a sounding board during my analysis process, thank you. To Dr. Karen Barret I also thank you for providing steadfast support, and recognizing when I needed extra encouragement without me even asking for it. To all of the scholars in my circle of friends, I thank you for your time and support when I needed it most to continue my writing. You gave me the seeds of knowledge to keep growing and get better.

I extend my heartfelt gratitude to the participants of this study, the DSPs who trusted me with their stories and for giving me their time. The DSPs are warriors with great compassion and their expressions of humor, fear, frustrations, concern, responsibility, compassion and caring is what makes this study so accessible and compelling.

This accomplishment is shared by my closest and dearest friends and family who stuck by me and supported me from near and far, your words of encouragement and motivation were

so appreciated and needed. I cannot thank you all enough for your years of sacrifice where I was missing from or working through our time together. I am thankful and blessed to have had my friends and family with me during this writing. Your unwavering and generous understanding, is so appreciated, without that and you, I never would have been able to write this.

Lastly, I would like to thank my husband, Shane and daughter, Addilynn. To my husband, you have supported me each day of this journey, for better or for worse, you stood by me pushing me to be my best. Everyone working on their dissertation should be so lucky to have a partner who is willing to accommodate the demands of a PhD and stand in whenever and wherever needed. To my daughter, Addilynn, you have never known your mom to not to be working on her PhD. Thank you for your ongoing patience and your understanding. It is for you and our family that I fought so hard to get here.

## TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	iii
CHAPTER ONE: INTRODUCTION.....	1
Rationale for Study .....	10
Research Questions.....	12
Theoretical Influences.....	13
Definitions.....	15
Summary .....	19
CHAPTER TWO: LITERATURE REVIEW.....	21
Historical Context.....	21
Current Circumstances.....	28
Three Perspectives on Sexuality: Individuals with ID, Parents, and Staff.....	31
Perspectives on Sexuality by Individuals with ID .....	31
Lack of control .....	32
Lack of privacy.....	35
Lack of opportunity.....	36
Lack of understanding.....	38
Perspectives on Sexuality by Parents of Individuals with ID.....	41
Misunderstanding of the child’s sexuality.....	41
Parents’ concerns and fears .....	42
Lack of sex education at home .....	44
Perspectives on Sexuality by Staff of Individuals with ID.....	44
Staff attitudes on sexual expression .....	45

Staff attitudes on parenting.....	49
Staff attitudes and gender.....	50
Staff attitudes and age.....	52
Staff attitudes on sexual diversity.....	54
Staff attitudes on sex education.....	56
Theoretical Influences.....	59
Theory of Planned Behavior.....	59
Feminist Disability Theory.....	60
Gender Theory.....	63
Summary.....	64
CHAPTER THREE: METHODOLOGY.....	68
Purpose of the Study and Research Questions.....	68
Study Design.....	69
Participants.....	70
Recruitment of Participants.....	71
Sampling Procedure.....	73
Informed Consent.....	74
Data Collection.....	75
Interviews and Instrumentation.....	75
Memo Writing.....	77
Data Analysis Process.....	77
Transcribing.....	78
Coding.....	79

Open Coding.....	80
Axial Coding.....	81
Selective Coding.....	81
Risks.....	82
Limitations of the Study.....	82
Ethical Conduct of Study.....	83
Summary.....	84
CHAPTER FOUR: FINDINGS.....	85
The Participants.....	86
Participant Sample Demographics.....	86
The Themes.....	89
Attitudes and Beliefs.....	89
Sexuality is a life experience and for everyone.....	89
Consumers' sexuality is cute.....	92
Sex is their right but not my role.....	94
Attitudes and beliefs summary.....	96
Experiences in Sexuality.....	96
Sex is part of the job.....	97
My job is to keep them safe and appropriate.....	100
We're left to figure it out on our own.....	102
Experiences in sexuality summary.....	104
Influencing Factors.....	105
Parents and guardians dictate what happens.....	106

It depends on the individual and the situation .....	107
My own personal values and experiences play a role.....	110
Influencing factors summary .....	113
Gender.....	114
Everybody is equal.....	115
The sexual double standard is alive and well.....	117
Working with the other gender makes it harder to relate.....	120
Gender summary.....	122
Suggestions for Working with Sexuality-Related Issues.....	123
More sexuality training and education is needed for DSPs .....	123
Consumers need more skills training on sexuality issues.....	125
Parents and guardians need sexuality acceptance training .....	127
Clearer policies are needed on sexuality issues .....	128
Suggestions for working with sexuality-related issues summary .....	130
Three Broad Categories .....	131
My Hands are Tied.....	133
Isolation.....	135
Champions for Sex.....	138
Summary of the Themes and Three Broad Categories .....	139
CHAPTER FIVE: DISCUSSION.....	146
Contributions to the Literature.....	148
My Hands are Tied.....	148
Isolation.....	151

Champions for Sex.....	155
Contributions to Theory .....	159
Theory of Planned Behavior .....	159
Feminist Disability Theory .....	160
Gender Theory .....	161
Limitations .....	162
Implications.....	163
Agency Policy.....	164
Team Approach.....	165
Professional Staff.....	166
Individuals with ID.....	167
Parents and Guardians.....	168
Educational Programs .....	169
Future Research .....	170
Conclusion .....	171
REFERENCES .....	173
APPENDICES .....	187
Appendix A: Letter to Agency Directors for Recruiting Participants .....	188
Appendix B: Letter of Invitation to DSPs.....	190
Appendix C: Informed Consent.....	192
Appendix D: Interview Questions .....	196
BIOGRAPHY OF THE AUTHOR.....	201

## LIST OF TABLES

Table 4.1:	Participant Sample Demographics.....	87
Table 4.2:	Themes for Attitudes and Beliefs, Experiences in Sexuality, Influencing Factors, Gender, and Suggestions for Working with Sexuality-Related Issues ....	90
Table 4.3:	Three Broad Categories to Emerge Across the Themes .....	132

## **CHAPTER ONE**

### **INTRODUCTION**

This chapter provides statistical information related to individuals with intellectual disability (ID), brief historical background, and the study rationale to provide a foundation for the need for this study. Additionally, this chapter will introduce research questions, theoretical influences, and identify pertinent terms related to this study.

According to the American Association on Intellectual and Developmental Disabilities (American Association on Intellectual and Developmental Disabilities [AAIDD], 2019a), approximately 6.5 million individuals are diagnosed with an ID in the United States, and approximately 200 million people from the global population have an ID. That equates to one to three percent of the world's population (AAIDD, 2019a). Estimating the prevalence of adults with ID specifically for the State of Maine is difficult as this population is not regularly included in national health surveys, and many of the available studies are no longer contemporary. In an effort to find current statistics for this dissertation, the Center for Community Inclusion and Disability Studies (CCIDS), Center for Disease Control (CDC), and the Office of Aging and Disability Services (OADS) in the Maine Department of Health and Human Services (DHHS) were consulted. In a 2019 publication in the Bangor Daily News, the CCIDS (2019) stated, 1,580 individuals with Autism and ID were relegated to a waitlist to receive “comprehensive waiver” services from DHHS under MaineCare section 21. The Bangor Daily News article does not state how many people with ID are currently receiving services in the State of Maine and an extensive search did not reveal this specific statistic. However, according to a Biennial Plan (2018) for services to adults with ID or autism written collaboratively by DHHS and OADS in 2016, the combined statistic given for the number of adults with ID or autism in the state of Maine that

received services under the comprehensive waiver was 8,757. The 1915c Waiver Services (Section 21 and Section 29) offer a broad array of services including home support, community support, and work support (Biennial Plan, 2018). Finally, the DHHS (2018a) website was consulted and the most recent statistic available was found in the 2018 Biennial Plan. The CDC (2019) website states a general statistic of 22.1% of adults in the state of Maine have some form of disability. This does not give information that recognizes individuals with ID as a standalone statistic. The OADS (2020) website states their goal is to “assist elders and adults with disabilities over age sixty, to maintain their independence, and to live successfully in their homes and communities” (para. 1). DHHS does not have statistical data that includes all individuals in the state of Maine identified as ID. Furthermore, the Department of Education (DOE) website offers a percentage for students enrolled in public schools who are identified as having an ID, the percentage is .39% of the total 28,247 students in Maine; this percentage is from 2010 and there is no current percentage offered (Maine DOE, 2020).

The inconsistency and inaccuracies in the collection of these data are due to variations in available programs and the number of individuals who choose not to use public services. Additional factors impacting the accuracy of the surveys, according to Snow et al. (2014), involve failure to include institutionalized persons or to consider changes in the classifications and definitions of ID since the surveys were initially administered, which could lead to excluded individuals. Individuals with ID are not included in statistics for a variety of reasons, including; limited studies and censuses being conducted, disability populations being counted together and not identified individually, or certain age ranges being counted exclusively by certain state agencies and not others. Accessing the number of individuals using public services in the State of Maine is another method of estimating the prevalence of ID, yet the accuracy of this method is

also likely inaccurate. To address the issues surrounding the estimation of this population of individuals with ID, the CDC and the National Center on Birth Defects and Developmental Disabilities Health Surveillance Work Group have developed a more robust method of estimating and tracking the adult population with ID, including expanding current survey instruments, developing new ones, and linking available databases (Snow et al., 2014). The most current statistical data found were in Maine's 2010 census results where an estimated 8,426 adults were identified as having an ID (Snow et al., 2014).

An exact count of individuals with ID is a challenge due to data collection, moreover, obtaining accuracy in knowing how many individuals have an ID is perhaps an issue in itself because disability is socially constructed. The ideas, definitions and classifications of individuals with ID have changed significantly over time, and therefore an exact count or way of establishing an accurate count is not available. The fluidity of disability makes it so that accuracy of surveys and criteria by which to capture an individual with ID is not easily accomplished.

Moving from counting individuals with ID to understanding societal perceptions of individuals with ID remains a challenge. Perceptions of individuals with disabilities have been historically negative, paternalistic, and based on fallacies (Cheeseman, 2015; Walker-Hirsch, 2007). In 2003, DiGiulio (2003) stated that the literature lacks acknowledgment that people with ID can understand many topics relating to sexuality and sexual expression including gender identity, safe-sex sexual practices, and contraceptives. While this statement is dated, the limitations DiGiulio highlights remain barriers in 2020.

This dissertation study is focused on the perspectives of sexuality issues with adults with ID. This introduction provides a brief history of the eugenics movement, sterilization, capacity to consent, de-institutionalization, and mainstreaming, as well as inclusion in education and society.

Then, sexuality will be connected to an individual's independence. Additionally, within this section, historical themes in education, legislation, and sexual independence as a civil right will be briefly discussed.

Historically, individuals with ID have been mistreated. In the late nineteenth century, eugenicists believed that eliminating persons with ID would improve the human race by “cleansing” the human gene pool of negative traits found in less desirable people (Disability Justice, 2019; Grenon & Merrick, 2014). In addition to the implications of the eugenics movement and sterilization practices, it was also common to house individuals with ID in institutions. Many individuals with ID who entered institutions experienced a life of institutionalization until death (Cheeseman, 2015). Family members who housed a relative in what they thought to be a safe environment, had the intent of the individual potentially leaving some day (Cheeseman, 2015), and simply followed the advice of physicians or family members who encouraged individuals with ID, especially children with ID, to be institutionalized for their care (Walker-Hirsch, 2007). The eugenics movement of 1880-1940 led to forced sterilization and segregation in institutions and society (Kempton & Kahn, 1991). A historical reference for the warehousing of individuals with disabilities can be found in the photographic essay on mental retardation entitled, *Christmas in Purgatory* compiled by Blatt and Kaplan (1974). This work of photography and literature depicts the horrendous conditions of institutions where people with ID were warehoused. The regulation of sexuality through institutionalization, sterilization, and residential settings to limit reproduction was reported to have oppressed individuals with ID within the United States from the 1880 to the 1970's (Wade, 2002).

Due to an individual with ID's perceived inability to consent, individuals with ID are especially vulnerable to forced sterilizations performed under the auspices of legitimate medical

care or with the consent of others in their name (Human Rights Watch, 2011). According to the Universal Declaration of Human Rights as stated by the United Nations (UN), it is a fundamental human right to have the freedom to decide on one's own consensual adult relationships (UN, 1948). Two forms of non-consensual sterilization can occur: 1) forced sterilization occurs when a person is sterilized after expressly refusing the procedure, is sterilized without knowledge of it, or is not given an opportunity to provide consent; 2) coerced sterilization occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure (Human Rights Watch, 2011). Additionally, the ability or the inability of an individual with ID to consent has been contested throughout history. For example, according to Murphy and Ocallaghan (2004), adults with ID were significantly less knowledgeable about almost all aspects of sex and appeared significantly more vulnerable to abuse, having difficulty at times distinguishing abusive from consenting relationships. Nevertheless, the authors also state that some adults with ID scored highly on all measures of competency and revealed they did have the ability to give consent, especially if they had relatively high IQs and had received some form of sex education. What these authors do not specifically address is the difference between sexual knowledge and sexual ability for these individuals. The authors state that the individuals with ID lacked knowledge and this unknowing is produced by oppressive social structures and this can appear as a lack of ability. The question is raised that if these individuals were taught sexual education in schools or by their family members, would people with ID still lack knowledge and ability?

Also in the 1950s, new treatment philosophies and deinstitutionalization theories were introduced, emphasizing short-term and community-based treatments. Deinstitutionalization has progressed since the mid-1950s, and although moving individuals with disabilities into the

community and work settings has been successful for many individuals, it has been a failure for others (Cheeseman, 2015; Wade, 2002). The period from 1960-1970 was a decade of incredible change in regards to the support and services people with significant disabilities received and generally a period of sexual awakening in society (Wade, 2002). Initial advances in the lives of individuals with ID were made in the 1950s and 1960s based on parent activism (Carey, 2009). Basic human rights for individuals with mental retardation during this era were still not recognized, as evidenced by eighteen states still not permitting such individuals the right to marry (Wade, 2002). However, the period does reflect the movement towards greater civil rights. President Kennedy (who had a sibling with ID) established The President's Panel on Mental Retardation in 1963. Twenty-six members were appointed by President Kennedy in October of 1961 "to combat mental retardation." The President's Panel on Mental Retardation was responsible for the Report of the Task Force on Law, which mandated recommendations concerning research and manpower, treatment and care, education and preparation for employment, legal protection, and development of federal, state, and local programs for individuals with mental retardation (Bazelon & Boggs, 1963). The President's Panel initiated a change in policy and legal approaches, that diffused down to change public opinion. The Kennedy family made additional efforts with programs like the Special Olympics, this program had a great impact on public sentiment towards individuals with ID (Bazelon & Boggs, 1963).

In 1975, the Education for All Handicapped Children Act was passed to guarantee equal access to public education for children with disabilities. This piece of legislation specified that every child had a right to an education, and mandated the full inclusion of children with disabilities in mainstream education classes unless a satisfactory level of education could not be achieved due to the nature of the child's disability (Wright & Wright, 2006). Today, this act is

known as the Individuals with Disabilities Education Act (IDEA) (Individuals with Disabilities Education Act [IDEA], 2004). As a result of mainstreaming children in school and adults into communities and workplaces, attitudes towards individuals with ID have changed dramatically over the last few decades (Inclusion BC, 2019) and there has been a shift in societal, parental, and staff attitudes towards individuals with ID. This shift in attitudes was supported by the 1960s Civil Rights Movement along with the national momentum towards normalization and deinstitutionalization of people with mental retardation (Wolfe, 1997).

In the 1990s, self-advocacy blossomed for individuals with disabilities (Carey, 2009) and after decades of campaigning and lobbying, the Americans with Disabilities Act (ADA) was passed in 1990. It ensured the equal treatment of people with disabilities and equal access to employment opportunities and public accommodations. The ADA intended to prohibit discrimination on the basis of disability in employment, services rendered by state and local governments, places of public accommodation, transportation, and telecommunications services (Anti-Defamation League, 2020). While the signing of the ADA placed immediate legislative demands to ensure equal access and equal treatment of people with disabilities, deep-rooted assumptions and stereotypical biases were not instantly transformed with the stroke of a pen. People with disabilities still face prejudice and bias in the form of stereotypical portrayal of people with disabilities in the movies and in the media; physical barriers to schools, housing, voting stations; and lack of affordable health care (Anti-Defamation League, 2020). The promise of the ADA is yet to be fully realized, but the disability rights movement continues to make great strides towards the empowerment and self-determination of Americans with disabilities.

Individuals with disabilities have been historically disadvantaged, oppressed, and disallowed equal opportunities. Challenges still exist for inclusion, human rights, and equality.

Considering the traditional legal model, Carey (2009) posits, disability is equated with incompetence, and individuals are therefore assumed to have inferior legal status. Exclusion on the basis of disability is widely accepted and viewed as legally justified and morally imperative (Carey, 2009). Current failures in educational and support practices have their roots in the history of segregation and discrimination of this population. Decades of rampant disregard for the humanness of individuals with ID have led to policies that illustrate how states continue to interfere with an individuals' rights to pursue consensual relationships and realize a private life (Wade, 2002). The diminished legal status an individual with an ID is placed under is also apparent in the attitudes of parents and staff in their conservative beliefs, and consequent restrictions, on sexual issues. Studies have shown staff and parents' beliefs towards sexual experiences of individuals with ID can influence either a positive or negative development of sexual identity (Swango-Wilson, 2007). Sexuality is a very important part of the personality of each individual as well as a basic human need, and cannot be separated from other life domains, including quality of life and life satisfaction (Allen, 2008). Individuals with ID represent a particularly disadvantaged group because they are often denied an opportunity to speak about, explore, or develop their sexuality (Chrastina & Večeřová, 2018).

Established laws have done little to increase the likelihood that individuals with ID will realize the same opportunities and access to sexual expression and relationships that their non-disabled peers have (Wade, 2002). Specifically, individuals with ID continue to encounter discrimination with their right to participate in education that will lead to an understanding of their sexuality and opportunities to engage in sexual activity and expression (Wade, 2002). The failure to include sexuality education and expression in the lives of people with ID leads to further discriminatory policies.

Available evidence suggests the values, attitudes, and activities of parents and staff are still conservative regarding the sexuality of individuals with ID, which leads to a possible restriction in the development of individuals with ID in terms of their own social and sexual identity (Frawley & Wilson, 2016). Individuals with ID are often dependent on staff or parents to assist in many meaningful areas that contribute to the quality of life, yet sexuality is often a contentious or neglected area. As a result, sexuality-related care (ie. sex-ed, assistance with sexual health like contraceptives, etc.) is not included in the assistance provided to individuals with ID. Parents and caregivers are considered the primary educators of sexuality education for their children with ID and are not equipped to be fully educated themselves nor are they fully prepared to educate their children (Swango-Wilson, 2009). Furthermore, Menon and Sivakami (2019) posit, that parents of children with ID begin talking about sexuality only when their children exhibit socially unacceptable behaviors and parents' main concerns are the negative behaviors associated with sexuality such as abuse or socially unacceptable behaviors. Parents are in a position where their perspectives contribute greatly to their child's sexual development and what the experiences of sexuality are like for their child (Menon & Sivakami, 2019).

Caregivers, staff, and parents are revealed to restrict the expressiveness of individuals with ID. However, research shows that there have been significant shifts in perceptions over the last several decades. Perceptions and attitudes are becoming more positive though there continue to be barriers that prevent individuals with ID from being able to have opportunities for sexual expression and education (DiGiulio, 2003). Furthermore, Hingsburger and Tough (2002) assert that people with disabilities can develop sexual relationships if they live in healthy environments surrounded by people with appropriate attitudes. Some improvements are being made on behalf of individuals with ID as evidenced by the review of the literature mentioned in Chapter Two.

Many areas of these individuals' lives are still ruled by providers and families because of the perception that individuals with ID likely need assistance, including with their sexuality. The primary barrier to sexual expression by people with ID has been an insufficient effort by caregivers and provider agencies to adequately address sexuality (DiGiulio, 2003). While positive accounts of relationships among people with disabilities do exist, there is still a great discrepancy in desire and opportunity among individuals with ID. A review of the literature, reveals many gaps as well as limited and dated content related to these important issues. The study adds to this area of research.

New studies are needed to reflect on how staff can support individuals with ID as opportunities emerge. Individuals with ID are frequently reliant on support staff, but the existing literature does not reveal how staff practices impact the sexual lives of individuals with ID. Individuals with ID face challenges in gaining equality and independence in many of the areas of basic human rights that others without a disability are given automatically (Cuskelly & Gilmore, 2007; Wade, 2002).

### **Rationale for Study**

All individuals are born to be sexual beings and sexuality is a part of what makes everyone unique (Hock, 2016). With approximately 6.5 million people in the United States identified as having an ID (AAIDD, 2019a). Many individuals with ID are not receiving support or education related to their sexuality (Chrastina & Večeřová, 2018; Frawley & Wilson, 2016). Without an individualized approach, staff dealing with the sexuality of individuals with ID risk reinforcing inequality and falling short of meeting the differing needs related to an individual's sexuality (Chrastina & Večeřová, 2018). This research study explores how DSPs view and support the sexuality of individuals with ID. I investigate DSPs' attitudes toward and experiences

with a variety of sexuality issues involving their consumers (e.g., use of social media and erotica, dating and sexual relationships, use of contraception, masturbation, LGBTQ+ issues), as well as how they see their role in educating, facilitating and supporting their consumers. I also inquire about the factors that shape the way DSPs respond to the sexuality of individuals with ID, how gender influences their perceptions, and any changes DSPs suggest when working with sexuality-related issues of individuals with ID. The DSP's beliefs and values regarding sexuality can have a great impact on the support they provide or do not provide to individuals with ID. However, a review of the literature reveals few studies have addressed staff attitudes and perceptions of the sexuality of individuals with ID. Gender remains an understudied phenomenon, as well as other sexual issues including the LGBTQ+ community. Furthermore, many of the current studies report from nations outside of the United States. This study contributes to the gaps in the current literature.

Currently, we live in a society in which most individuals can purchase contraception and view pornographic materials. Dating and the intimate world of sexual issues have changed dramatically along with how people communicate through technology and "meet online." This contemporary society has at times, afforded greater support and acceptance of marriage equality and the LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Questioning, and Plus) community. Some might say the social landscape is more tolerant, and there are improvements for the LGBTQ+, disability, and other oppressed minority groups, however, these oppressed communities still experience legitimate discrimination. Many minority groups are omitted from sexuality which includes individuals with ID. Individuals with disabilities should have equal rights to sexual and reproductive desires and hopes as non-disabled people, however, society has disregarded their sexuality and reproductive concerns, aspirations, and human rights. People with

disabilities are infantilized and held to be asexual; incapable of reproduction and unfit sexual/marriage partners or parents. Individuals with ID can be denied privacy, their children can be removed on the basis of disability, guardians can control their sexuality and the sexual and reproductive health and rights of people with disabilities continue to be contested, and there are particular concerns in relation to women with disabilities (Addlakha & Heidari, 2017).

For individuals with disabilities, sexuality and related topics are seen as inappropriate and/or unsafe. The paternalistic tendencies of the past are ever-present and looming over this population restricting their access to the same rights and privileges that others have. Gill (2015) questions, to what extent is the denial of the ability to be sexual for individuals with ID connected to the idea that these individuals lack the ability to be sexual or to properly consent? Furthermore, Gill (2015) states, the denial of disability as a worthwhile and meaningful life is evidenced by the paternalistic attitude that family and staff can adhere to, a “we know what’s best” standard of care that regulates aspects related to sexuality.

While the literature review is extensive within this dissertation, the studies are from around the world, and minimally include how gender influences a participant’s attitudes related to sexual issues. Furthermore, this study has an additional focus on attitudes toward LGBTQ+ and other sexually diverse constructs that are underrepresented within the literature. Finally, the State of Maine is not represented in any studies reviewed.

### **Research Questions**

As an understudied phenomenon, this research explored how DSPs perceive the sexuality of those with ID, including their perception of their role, their approach to specific issues and the types of challenges they encounter, their thoughts on the ways to assist those with ID to experience sexual expression, and the influence of their gender on their perception. The primary

research question for this study is: How do Direct Support Professionals (DSPs) view and support the sexuality of those with ID? There are five sub-questions:

- Sub- Research Question 1. *What attitudes and beliefs are held by DSPs regarding the sexuality of individuals with intellectual disabilities?*
- Sub-Research Question 2. *What are the experiences for DSPs in relation to the sexuality of individuals with ID and the DSPs' employment position?*
- Sub-Research Question 3. *What factors influence DSPs' responses to the sexuality of individuals with ID?*
- Sub-Research Question 4. *How does gender (of the DSP and consumer) influence the role, approach, and ideas for ways to assist adults with ID related to sexual issues?*
- Sub-Research Question 5. *What suggestions do DSPs have for working with sexually related issues of individuals with ID?*

### **Theoretical Influences**

As an inductive study, this dissertation explored and built ideas about theory. This study is informed by three theoretical influences. Currently, there is no theoretical framework that specifically addresses the issue of how gender affects DSPs the experiences of sexuality for individuals with ID. The Theory of Planned Behavior, Feminist Disability Theory, and Gender Theory serve as theoretical guidelines when considering disabilities and gender in this study and will be further discussed in Chapter Two.

The Theory of Planned behavior will provide a theoretical guide as to why the staff person does what they do or how they behave in response to the sexuality of individuals with ID.

The sexuality of individuals with ID and other disability groups has been studied in the past, however, as the phenomena of the lived experience that occurs in the providers' lives, combined with how gender influences their decisions and actions related to the sexuality of individuals with ID, has not been studied and does not lie within one singular theoretical framework.

Using a Feminist Disability Theory approach expands the binary focus within Feminist Theory where women, as a gender, are subordinated compared to men. Feminist Disability Theory agrees with, but expands beyond, the unequal treatment of women compared to men. It provides insights on expanding the understanding of what a body is and provides ideas on the range of bodies that women with disabilities have and unique needs they share. According to The body of works within Feminist Disability Theory, women having the freedom of choice and control over their bodies is not enough—accommodations must be made where specific support and accessibility to choice and control are required too. If accommodations and accessibility are not provided to these women, freedom and choice cannot be benefited from.

There are very few theoretical works available that focus on a male's inequality due to gender and disability. Hence, the third and final theory, Gender Theory, is included in this study. Gender Theory provides a theoretical guide when considering both females and males with disabilities. Gender Theory considers gender stereotypes, gender roles, and gendered interactions and will be used to evaluate the staff interviewed for this study their gender, and the gender of consumers. Chapter Two will include a deeper explanation of the use of these theories. The three theories will be used to guide this study and an in-depth review of the literature will provide a theoretical explanation for how this study contributes to the existing literature.

## Definitions

- **Intellectual Disability (ID).** ID is a disability characterized by limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills and originates before age 18 (AAIDD, 2019a). ID is further defined as “impairments of general mental abilities that impact adaptive functioning” across three areas (American Psychiatric Association [APA], 2013, p.1). These areas include the conceptual domain involving skills such as language, writing, reasoning, and memory; the social domain relating to empathy, judgment, communication skills, maintenance of friendships; and the practical domain focusing on self-management, for example, personal care, management of money, and organization of events (American Psychiatric Association, 2013). It is important to note that Developmental Disability is an umbrella term that includes intellectual disability, but also refers to chronic disabilities that may be physical, cognitive, or both (AAIDD, 2019a). The term intellectual disability (ID) is preferred for this study in comparison to the broader definition offered by development disability (DD).
- **Mild or Moderate ID Classification.** Within the medical model of disability, there are four levels of severity for ID, known as mild, moderate, severe, and profound (National Academies of Sciences, 2015). This biologically focused definition provides that people with mild ID are “slower in all areas of conceptual development and social and daily living skills” (National Academies of Sciences, 2015, p.170). However, they are able to acquire “practical life skills” that enable them to function in life with a small amount of support (National Academies of Sciences, 2015, p.170). Individuals with moderate ID are able to “take care of themselves” with moderate support, can travel distances within their

own community, and acquire basic health and safety skills (National Academies of Sciences, 2015, p.170). The current study will focus on staff perspectives of adults with mild to moderate ID.

**Mild or Moderate ID System of Support.** A definition informed by a synthesis of best practices regarding ID, critiques of previous ID definitions, and feedback from the field comes from the 11th edition of the AAIDD Definition Manual. The AAIDD uses a system of support as a means of classification which acknowledges the fluidity of disability. It is the environment an individual is in and not the disability that determines the need for support (Schalock et al., 2010). Classifying individuals with ID through a system of supports assumes that all people have needs and rights such as sexuality and that the level of supports may vary for them to meet their needs and enjoy their rights a political reframing of why we classify people. People are classified in order to provide supports. An example from the AAIDD website definition sheet states team members must “Take into account the individual's cultural and linguistic differences as well as communication, sensory, motor, and behavioral factors;...” (AAIDD, 2019a).

- **Individuals with ID.** Self-Advocated Becoming Empowered (SABE), the national self-advocacy organization, and The American Psychological Association (APA) advocates the use of person-first language (e.g., people with disabilities) to refer to individuals with disabilities in daily discourse and to reduce bias in psychological writing (The Arc, 2018a). Using person-first language eliminates generalizations and stereotypes by focusing on the person rather than the disability. By placing the person first, the disability is no longer the primary, defining characteristic of an individual, but rather one of several aspects of the whole person (The Arc, 2018a). Therefore, the phrase “individual(s) with

ID” is preferred for this study. Person-First Language tends to be a term that a professional working as a service provider may use (S. Gilson, Professor of Social Work, School of Social Work and Coordinator and Professor Interdisciplinary Disability Studies Center for Community Inclusion & Disability Studies, University of Maine, personal communication, July, 2019). The sample for this study is composed of individuals working as service providers for individuals with ID, the use of person-first language aligns with this study.

- **Identity-First Language.** Disability culture advocates and disability studies scholars have challenged the rationale for and implications of exclusive person-first language use, promoting the use of identity-first language (e.g., disabled people). Identity-first language is acknowledged as an important contributor in addressing the concerns of disability groups while promoting human dignity but will not be used within this study for consistency in writing (Dunn & Andrews, 2015).
- **Staff.** Various titles are used in the research studies reviewed to describe the employee and/or family member that provides care for individuals with ID. This literature review will use the term “staff” for consistency, though the reviewed articles may have used their own unique job title. Three of the most common terms used when referring to staff are:
  - 1) **Direct Support Professional (DSP):** A DSP is a paid caregiver whose role is to provide supervision, support, and training to individuals with ID who live in the community, either in their family home, a group home, or in their own home or apartment (Senne, 2016).

- 2) Direct Care Staff (DCS): This term refers to individuals tasked with the care of the elderly or disabled individuals in various settings (Stephenson, 2017).
  - 3) Caregiver: the individual responsible for assisting an individual with an ID with the task of meeting the daily needs of living. “Caregiver” includes paid and volunteer direct care workers who provide direct supervision of daily tasks. Caregiver titles include parent, personal service attendant, day habilitation specialist, job coach, respite providers, and individual service support (Swango-Wilson, 2007).
- **Consumer.** The term “consumer” refers to people with certain types of disabilities who access services by agencies (Baladerian, 2013). The term “consumer” will be used in this study. “Consumer” is a term typically used by service providers and does not reflect a contemporary disability studies perspective (S. Gilson, personal communication, Professor of Social Work, School of Social Work and Coordinator and Professor Interdisciplinary Disability Studies Center for Community Inclusion & Disability Studies, University of Maine, July, 2019). The sample population within this study will be composed of service providers that care for and support individuals with an ID. One of the criteria of the study participants is that research participants need to work in a community or residential setting. Due to the nature of the employee and consumer’s relationship, the term consumer is an encompassing one that fits the scope of this study.
  - **Sexuality.** This concept is influenced by an individual’s values and attitudes and has psychological, biological, and social aspects. A person’s sexuality develops throughout childhood and adolescence, and is a key part of their identity. The way each person understands and interprets their sexuality varies significantly, and often changes over time. Healthy self-esteem and respect for self and others are important factors in

developing a positive sexuality (World Health Organization, [WHO], 2010). Problems arise with the use of the term “sexuality” due to its diverse definitions between people and across contexts. For the purposes of the present study, the term “sexuality” refers to 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).

### **Summary**

Individuals with ID are challenged by the inequality they face related to many basic human rights, including the right to have an intimate relationship, learn about sexuality, and choose to be sexual or not. Staff that work closely with individuals with ID in either community or residential programs are in a unique position to provide education, support, and opportunities for individuals with ID to increase their quality of life and provide access to these basic human rights areas. The beliefs and values related to sexuality that staff have can have a great impact on the support they provide to individuals with ID in the areas of sexuality, sexual identity, and sexual behaviors.

This study reports on an inductive qualitative study in which participants were interviewed using a grounded theory design. The study adds to existing literature, and advances existing theories and methods. This doctoral investigation provides a rich study in which the components bring something new and interesting to the literature, and have a global contribution academically. In-depth, interviews have been conducted as part of this qualitative study. This research contributes to the field and works to fill the gaps in literature and existing theories. Theories have been explored and built upon for ideas. The study is theoretically informed by the Theory of Planned Behavior, Feminist Disability Theory, and Gender Theory.

Staff attitudes are a determining factor in the care an individual receives and this study seeks to discover how staff members respond to sexual issues among consumers with ID. However, the history of the service system cannot be reduced solely to attitudes, although attitudes affect the kinds of services that are delivered. The constitution and legal system, welfare bureaucracies, and economic costs/benefits shape agency policies like sterilization, eugenic attitudes, and other systemic challenges that are unique to individuals with ID. These factors that contribute to service provision are included within this study through the interview questions. A focus on how the staff 's beliefs and how they respond to sexuality issues; their role in facilitating, educating, or supporting their clients' sexual lives; and their perspectives of gender provides a new area of inquiry and makes this study unique.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

To better understand the concerns that individuals with ID encounter regarding staff perspectives on sexuality issues, it is critical to explore the previous research that exists. There are limited studies that focus on individuals with ID and sexuality issues. Furthermore, there are fewer studies published within the past decade, and many of the identified studies are from countries other than the United States. This literature review explores the historical research related to individuals with ID; the perception of sexuality by individuals with ID, their parents, and their staff; as well as the theoretical framework that informs the study.

#### **Historical Context**

In 1883, the term “eugenics” was coined by Sir Francis Galton who loosely defined it as “the cultivation of race,” or “the science of improving stock” (Galton, 1883). Eugenicists believe that the human race can be improved by controlling reproduction as a way of “cleansing” the human gene pool of negative or less desirable traits found in “less desirable” people, particularly those with developmental disabilities, mental illness, or those who were considered ‘immoral’ or who had criminal histories (Disability Justice, 2019). Eugenics is among many late nineteenth century ideologies encompassed by the term “Social Darwinism” (Grenon & Merrick, 2014). As the eugenics movement grew, supporters portrayed feeble-mindedness as a direct cause of poverty, crime, sexual deviance, and moral degeneracy (Carey, 2009). The first eugenic law to be passed in the world allowing “undesirables and defectives,” such as the “feeble-minded,” to be involuntarily sterilized occurred in Indiana in 1907. At this time, terms such as “mental hygiene,” “racial hygiene,” “social hygiene,” and “racial and human betterment” became

prevalent (Grenon & Merrick, 2014). The sexual lives of individuals with ID were dictated by the government and societal views (Disability Justice, 2019).

Numerous books on eugenics emerged between 1912 and 1930, all encouraging young men and women to find “suitable” partners in marriage in order to “improve the human race” (Carey, 2009). These books and manuals also advocated for sterilization of the feeble-minded, degenerate, and criminal (MacMurchy, 1920). In 1929, Gosney and Popenoe (1929) authored a book that detailed 6,000 sterilizations of “idiots” and “other undesirables.” To prevent procreation for those in their childbearing years, institutions were encouraged to implement marriage restrictions and compulsory sterilization for individuals determined to be feebleminded (Carey, 2009). Grenon and Merrick (2014) state, this ideological perspective led to the sterilization of individuals with ID. A review of history shows the statement made by Grenon and Merrick is too simplistic. Not all states with strong eugenicist organizations/leaders ended up with sterilization laws and not all states that had sterilization laws used them equally enthusiastically (Carey, 2003). Trent (1994) and Ladd-Taylor (2017) show that systems of state law and the local welfare policies influenced the actual implementation of sterilization. This is not to say that eugenics practices were not central, but that institutionalization and the prevention of procreation occurred before Galton (1883) and both institutionalization and sterilization lasted after eugenics became unfashionable because there were other motivating factors such as saving the state money and parent wishes/fears that were not necessarily rooted in the idea of or fear of transmitting disability from one generation to the next (Carey, 2003).

At the height of the eugenics movement, a crucial legal decision known as *Buck vs. Bell* was rendered in 1927 (Disability Justice, 2019). The *Buck v. Bell* case focused on an 18-year-old patient named Carrie Buck in the Virginia State Colony for Epileptics and Feeble-minded

(Doerr, 2009). The state of Virginia wished to sterilize her, claiming that her traits of promiscuity and “feeble-mindedness” were genetic and would be passed to her offspring (Reiter & Walsh, 2018). Coinciding with this, on May 2, 1927, the state of Virginia passed legislation that allowed residents to be released from an institution on the condition that they were sterilized first (Doerr, 2009).

The Supreme Court rejected the arguments made by Buck’s lawyers that involuntary sterilization violated the Eighth Amendment (which protects against “cruel and unusual punishment”) and the Fourteenth Amendment (which mandates that states provide “any person within its jurisdiction the equal protection of the law;” (Reiter & Walsh, 2018). The *Buck vs. Bell* decision was one of the first times that the federal courts intervened in a case involving the rights of people with developmental disabilities, and the landmark outcome excluded them from the Constitutional protections provided by the Eighth and Fourteenth Amendments, further limiting their rights (Disability Justice, 2019). Additionally, *Buck vs. Bell* paved the way for 30 other states to enforce similar laws. As a result, more than 60,000 men, women, and children in the United States were sterilized without their consent from the 1920s through the mid-1970s (Disability Justice, 2019). The Supreme Court upheld Buck’s involuntary tubal ligation, and Buck herself did not learn of her sterilization until decades later, as she was originally told that the operation was an appendectomy (Doerr, 2009). In explaining the Supreme Court’s decision supporting involuntary sterilization, Chief Justice Oliver Wendell Holmes, Jr., infamously justified his decision as follows:

“We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world if, instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can

prevent those who are manifestly unfit from continuing their kind. . . . Three generations of imbeciles are enough.” (Doerr, 2009, para 3)

It was later shown that Justice Holmes’s statement, “three generations of imbeciles are enough” was grossly inaccurate as Buck was found to be intellectually competent. At the time of this statement, individuals with ID were characterized as too incompetent or irrational to exercise their rights responsibly (Carey, 2009). This injustice reveals the justification used to deny civil rights to people with ID (Carey, 2009). A final fact stands that the Court’s decision in the *Buck vs. Bell* case has never been overruled (Mutcherson, 2017).

In addition to the eugenics movement and sterilization practices, individuals with ID were housed in institutions as a common practice. Historically, for people with ID, the provision of services rested on the decisions and management of family members, professionals, and policy-makers, which generally resulted in the person residing in a state facility or institution (Cheeseman, 2015). The housing of the “feble-mindedness” and “imbeciles” was historically recommended to protect these individuals, as they were often presumed to be incompetent and it was believed that institutions would give them medical and psychiatric “care” (Wolfensberger, 1969). The institutional care model for persons with ID, in the United States, began in 1846, with the arrival of Édouard Séguin, Séguin was recruited to come to the United States based on his work at the Bicetre Asylum, in France (Cheeseman, 2015). The building of these institutions eventually changed from the concept of schools to train residents for community living because in an increasingly industrial society, employers wouldn't higher nonstandardized or less productive workers, and families had fewer caregivers at home (Carey, 2009) The original concept set for residents deteriorated into a model of pity and charity. The term “school” became asylum, a place where no human rights existed, including marrying and reproducing offspring. This place became one of custodial care. Wolfensberger (1969) states, “The protective model

emphasized benevolent shelter, however, it bore the seeds of three dangerous trends: 1. Isolation, 2. Enlargement, and 3. Economization” (Wolfensberger, 1969, p.29). Institutions grew at an astonishing rate during the years 1904 to 1923, as society’s emerging perception of “feble-mindedness” and “imbeciles” was given more negative attention (Carey, 2009). Many individuals with ID who entered what they thought to be a safe environment with the intent of leaving in the future, were typically housed in an institution until their passing (Cheeseman, 2015).

During the era between the 1940s and 1960s, positive changes in the conception of individuals with ID and an expansion of their rights occurred. This foundational time was mostly based on the work of professionals and parents (Carey, 2009). Professionals began documenting the productive capabilities of individuals with ID and justified their access to rights and services to further develop their abilities (Carey, 2009). This period reflects a movement toward growth with President Kennedy, with his establishing of The President’s Panel on Mental Retardation in 1963. This national plan was to combat negative attitudes towards mental retardation where 26 members were appointed by President Kennedy in October of 1961 (Bazelon & Boggs, 1963). The Presidents Panel on Mental Retardation was responsible for the Report of the Task Force on Law, which mandated recommendations concerning research and manpower, treatment and care, education and preparation for employment, legal protection and development of federal, state, and local programs for individuals with mental retardation in 1963. The purpose of the group was to better meet the needs of individuals with ID. This President’s Panel changed the public’s attitudes towards people with ID. Congress has since passed 116 Acts or Amendments providing support for people with ID and their families (Inclusion BC, 2019).

By the 1960's individuals with ID began to advocate for their right to live as full citizens, which aligned with the civil rights era of the 1960s (Wolfe, 1997). As a result, attitudes towards individuals with ID have changed dramatically over the last few decades (Inclusion BC, 2019) as has the terminology. Similarly, in the evolution of ideology concerning individuals with ID, segregation in schools has been affected by the passing of legislation such as Section 504(a) of the Rehabilitation Act of 1973 which established that

[n]o otherwise qualified individual with a disability in the United States, . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service (Department of Health, Education, & Welfare, 1973, p.142).

In 1975, when Congress passed the Individuals with Disabilities Education Act (IDEA) which mandated free, public education for all children with disabilities and provided all students with disabilities the opportunity to receive a free and appropriate public education in the least restrictive environment (IDEA, 2004). Though the IDEA legislation has been in place since 1975, recent research suggests that sex education in an academic setting for individuals with ID does not typically occur. Nor has the federal budget ever fully funded this legislation, hobbling public school's financial ability to provide these mandated services (National Center for Learning Disabilities [NCLD], 2019). IDEA, for all of its benefits, has actually never been fully funded since its inception. According to the NCLD (2019) that is because there is a difference between what is "authorized" and what is "appropriated." As it stands, IDEA funding is at its lowest ever recorded (NCLD, 2019). Swango-Wilson (2007) writes that education improves knowledge and decision-making skills concerning sexual behaviors, however, McCarthy and Thompson, (1994) state that, "individuals with ID lack sexual knowledge and many sex educational programs teach facts about sex and do not help individuals incorporate fact into

meaning” (p.17). This statement from 1994 argues that individuals with ID are unable to incorporate fact into meaning. Fitzgerald and Withers (2013) claimed that women with ID are unable to conceptualize themselves as sexual beings and consider sex as an activity that is dirty and inappropriate for them. Conversely, Gil-Llario, Morell-Mengual, Ballester-Arnal and Diaz-Rodriguez (2018) study indicated that most of the people with ID evaluated were interested in sexuality and had knowledge and experiences with sexual intercourse and masturbation. Rushbrooke, Murray and Townsend (2014) conclude that sexual relationships are desired and important for people with ID, to satisfy their needs and can have a positive impact on their mental health and well-being. While the provision of services improved, little change occurred in improving the paternalistic approach to services and rights of individuals with ID (Carey, 2009).

Historically, the term “mental retardation” has been used to describe the population of those who were diagnosed with a cognitive impairment that manifested before the age of 18. In 2013, the Social Security Administration adopted new terminology to acknowledge and respond to the ongoing concerns that the terms “retarded” and “mental retardation” held a negative and derogatory connotation (Federal Register, 2013). In addition to legislation and required terminology changes, national organizations, such as the American Association on Intellectual and Developmental Disabilities (AAIDD), have proclaimed equal status for individuals with ID. The Joint Position Statement (Federal Register, 2013) of AAIDD and The Arc asserts that people with ID, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected. Furthermore, the Americans with Disabilities Act Amendments Act (ADAAA) of 2008 was signed on September 25, 2008. The law was intended to clarify the scope of the definition of disability under the Americans with Disabilities Act (ADA) and took effect on January 1, 2009. Congress passed the ADAAA in response to several

Supreme Court decisions that had narrowly interpreted the ADA definition of disability (ADAAA, 2014). The law made a number of significant changes to the ADA definition of “disability” to ensure that it would be easier for individuals seeking the protection of the ADA to establish that they have a disability that falls within the meaning of the statute. The narrow interpretation resulted in the denial of the law’s protection for many individuals (ADAAA, 2014). This denial includes an individual’s sexuality. One example of how the Americans with Disabilities Act Amendments Act (ADAAA) of 2008 worked in improving the sexual lives of individuals with ID was when The 9th United States Circuit Court of Appeals ruled that the ability to engage in sexual relations was a major life activity under the definition of the ADA (ADAAA, 2014).

### **Current Circumstances**

To ensure that the State of Maine follows these national legislative mandates as well as addresses the ongoing concerns of advocates and individuals with ID and their position statements, the State of Maine has enacted regulations for the Department of Health and Human Services (DHHS) that protect the rights of Maine citizens with ID. However, within this DHHS regulations manual (Maine DHHS, 2018b), the sexuality of Maine citizens with ID is not addressed specifically. Sexuality is not mentioned in this set of regulations, however, it does state that relationships are a part of the “overall quality of a person’s life” (p.35). The State of Maine rules that regardless of the level of disability, all residents of the State of Maine have rights that are protected by law. The following information has been identified as relating to the sexual rights of Maines’ citizens with ID. The Maine Revised Statutes, under Title 34-B: MRSA Section 5606, relate to the sexuality of individuals with ID. The statutes dictate that a person with an ID is entitled to humane treatment, private communications, reasonable opportunities for

phone and internet communication, unrestricted rights to visitors during reasonable hours, the right to their own personal property, and a person with an ID may not be sterilized (State of Maine Revised Statutes, 2019). These revised statutes provide guidelines for the agencies that provide support services to individuals with ID in the state of Maine. In short, a parent could not according to these statutes overrule their adult child's human rights, unless guardianship has been awarded to the parent or for safety reasons.

DSPs as part of their employment position are often asked to navigate these challenging relationships and make decisions about their consumers' sexuality. Before a DSP can begin to work with consumers with ID, the State of Maine requires they earn certification as a Maine Direct Support Professional through the Maine College of Direct Support. The State of Maine requires individuals to complete 52 online lessons and 11 live classroom training courses to be completed through the Office of Aging and Disability Services and Maine Department of Health and Human Services (Maine College of Direct Support, 2018). A portion of the required modules includes community inclusion, positive behavior supports, and human sexuality (Maine Department of Health and Human Services, 2018). Of note is the fact that the "human sexuality" module requires only one online lesson and one live classroom session. When by comparison, the "maltreatment" module has 11 online lessons and one live classroom session and the "safety" module has 14 online sessions and no live classroom sessions. A DSP can earn certification as a DSP-I, DSP-II, or DSP-III (Maine College of Direct Support, 2018). Each certification level increases the training that a DSP would have acquired. A DSP-II or DSP-III has demonstrated skills that typical entry level direct support professionals would not have learned and achieved.

The requirements of DSP training vary from state to state. For example, the California Department of Developmental Services (DDS) offers a two-year, 70-hour standardized statewide

competency-based training program. According to the California Department of Education, The DSP training is mandatory for employees and administrators who provide direct care. The 70 hours of training are divided into two equal parts of 35 hours each to be completed in successive years (Direct Support Professional Training, 2019). The state of New York, which uses a national alliance of Direct Care Professionals training for the certification of DSPs, mandates 15 competency areas including a Centers for Medicaid & Medicare Services (CMS) cross-sector set with 12 areas. Some of the competency areas include, Participant Empowerment, Communication, Documentation, and Supporting Health and Wellness National Alliance for Direct Support Professionals (NADSP) Competency Areas (NADSP, 2020). While the CMS cross-sector set areas include but are not limited to; Person-Centered Practices, Crisis Prevention and Intervention, Education, Training, and Self-Development. This information reveals that the state of Maine is relatively consistent with the national training policies of the nation. The Director of Certification and Accreditation for the National Alliance for Direct Support Professionals stated,

In general, most training for DSPs is based on regulatory requirements. Common topics include CPR/First Aid, Fire Safety and Extinguisher Use, Bloodborne Pathogens, and Mandated Reporting of Abuse. Often these are annual or biannual requirements so these same trainings are taken repeatedly throughout a DSP's career. They tend to focus on health and safety and they tend to be focused on some worst-case scenarios (D.Hermreck, Director of Certification and Accreditation for the National Alliance for Direct Support Professionals, personal communication, February, 2020, personal communication, email, 2-15-20).

The President's Committee for People with Intellectual Disabilities (PCPID) released a report in 2017, titled, *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy*. In the report, PCPID describes the current state of the DSP workforce as a "crisis," noting that the average DSP wage is \$10.72, and most DSPs work two or three jobs, and the average annual DSP turnover rate is

45% (Presidential Report, 2017). The job of a DSP is especially difficult and according to Alvey (2018), there is a high rate of burnout for this profession. Burnout is a particularly relevant topic in the field of direct support and is likely a contributor to the current workforce crisis (Alvey, 2018). Furthermore, DSPs also encounter many additional stressors that may increase their chances of burning out, including poor wages, minimal benefits, limited training or education, limited opportunities for career advancement, physically demanding work, isolation from coworkers and supervisors, and high accountability for decisions made (Alvey, 2018; Presidential Report, 2017).

### **Three Perspectives on Sexuality: Individuals with ID, Parents, and Staff**

This section highlights research on sexuality with three groups of individuals: individuals with ID, parents of individuals with ID, and the staff who work with individuals with ID. Some research studies will be referenced in more than one section if their sample included more than one group (e.g., a study of both parents and staff). The first section focuses on research findings for individuals with ID and sexuality-related issues; the remaining two sections focus on parents and staff and their attitudes toward sexuality issues of individuals with ID.

### **Perspectives on Sexuality by Individuals with ID**

A desire for relationships and sexual expression is a fundamental component of the human experience (Allen, 2008; Bazzo, Nota, Soresi, Ferrari & Minnes, 2007; Evans, McGuire, Healy, Carley, 2009; Murray & Minnes, 1994; Yool, Langdon & Garner 2003), yet individuals with ID are not included in this human experience. The idea that individuals are autonomous beings who can choose whom they marry; or choose how many children they wish to have or whether to abort them before birth or create them through artificial means; or choose what kind of sex they have and with whom is a largely western modern world notion (Plummer, 2003). The

experiences of sexual autonomy that individuals with ID experience are vastly different than what Plummer (2003) describes. Through restrictive oversight, a paternalistic staff and organization, a limited environment, and a lack of opportunity, the barriers individuals with ID face are more considerable than those experienced by other populations.

Studies within this literature review revealed four themes that were commonly reported by individuals with an ID. The responses shared by individuals with ID come from studies using various methodologies, yet there were clear themes identified within the literature. The following themes were identified and are discussed below: lack of control, lack of privacy, lack of opportunity, and lack of understanding.

**Lack of control.** The sexuality of an individual with ID has been marked by several myths, stereotypes, and false beliefs. These include stereotypes of asexuality for an individual with ID, the belief that an individual with ID is incapable of consent, a false belief that non-consensual sterilization procedures on individuals with ID are appropriate and necessary, and individuals with ID are victims of sexual violence more often than those who do not have ID. These four themes are found in the literature and exemplify the lack of control an individual with ID has in relation to their sexuality.

Brown and McCann (2018) reported that both men and women with ID, when provided with a legal guardian, have asserted that their views, opinions, needs, and rights to self-determination were, in some cases, not recognized and even ignored. In a related study, Kelly, Crowley, and Hamilton (2009) found that individuals with ID reported they have asserted their right to make choices related to their sexuality. According to Arias, Ovejero, and Morentin (2009) individuals assert their rights to form relationships as they seek ways through which they can gain more control over their lives. It is apparent that some men and women with ID want to

have, and be able to talk about, loving relationships; they seek passion, romance, and intimacy (Wheeler, 2007). Furthermore, individuals with ID want to be more in charge of their sexuality and relationships rather than being controlled by others (Arias et al., 2009). Individuals with ID are a particularly disadvantaged group as they do not have many opportunities to make their voices heard in some areas of their lives, and they are very often excluded from opportunities to actively explore and develop their sexuality.

A common experience shared by research participants is having a lack of control in what information they are provided and therefore able to understand. Specifically, Gil-Llario et al. (2018) reported, in a quantitative study involving 360 adults with ID in Spain that, participants demonstrated a lack of control regarding what sexual information was shared with them. Chou, Lu, and Pu (2015) additionally discussed participants being misinformed of sexual information. When an individual is excluded from certain information or intentionally misguided about content, there is a lack of control in what information a person has access to.

The participants in the Gil-Llario et al. (2018) study reported that their parents and care providers would not permit a steady partner. Two reasons stated within the study were, “that’s not right” and “because you can’t do that sort of thing” (p.75). In the Chou et al. (2015) study, all 100 participants reported they wanted to have an intimate relationship but they did not know how to go about pursuing such a relationship. Some participants reported not having the confidence to speak to their romantic interest, while others reported they were more comfortable loving someone in secret.

The misinformation, direct orders, or the void of information results in a skewed version of the truth for individuals with ID. A female participant in the Chou et al. (2015) study reported that she was told “a man and woman cannot get physically close to each other” (p.671). While

others shared that they had never talked about masturbation or sexual intercourse and a third sentiment was that “this is a very private issue; parents do not talk about it or let us know about it...” (Chou et al., 2015, p.670). Servais (2006) and Chou et al. (2015) found that the sexual needs of adults with ID have been neglected or strictly controlled by their families and service workers.

Finally, individuals with ID are victims of sexual violence more often than those who do not have ID (Hughes et al., 2012). Some research shows that adults with ID have higher rates of sexual abuse (Gil-Llario et al., 2018; Schaafsma, Kok, Stoffelen & Curfs, 2017). Additionally, McCabe and Cummins (1996) conducted a study where sexual knowledge among undergraduate first-year college students’ sexual knowledge were investigated in contrast to adults with mild to moderate ID and their level of sexual knowledge. The results from this study demonstrated that the individuals with ID had less knowledge, more negative attitudes toward sexual issues, and less experience in intimacy and sexual intercourse. Respondents with ID experienced a lower level of sexual experience when compared to the findings from the general population (McCabe & Cummins, 1996). In a similar study, 60 individuals with congenital disabilities living in the community participated in a quantitative study. The results from this study demonstrated that the participants of the study experienced low levels of sexual knowledge and experience, held negative feelings in relation to sexuality and experienced high levels of sexual needs. The low levels of knowledge are of major concern since this has been shown to be associated with high levels of sexual abuse (McCabe, Cummings & Deeks, 2000).

In another study, Chou et al. (2015) reported all of the women in the study’s focus groups had had negative experiences concerning sexuality in their life. Examples of this are one participant was sterilized when she was 14 years old; another said she had been raped twice

when she was in the fourth and fifth grades while another had been peeped on during her shower, and another participant had been forcibly kissed in the workplace by her colleague; and finally, another had been inappropriately touched on the bus. According to Chou et al. (2015), all of these female participants agreed that sexual protection lessons should be included as a priority in the sexuality education of women with ID. The results from these studies demonstrate that individuals with ID can have low levels of sexual knowledge and experiences. The low levels of knowledge are of major concern since this has been shown to be associated with high levels of sexual abuse (McCabe et al., 2000).

**Lack of privacy.** In a survey of 32 individuals with ID, Healy et al. (2009) revealed that many individuals with ID feel the services they have in place restrict their ability to have romantic relationships. Within the Healy et al. (2009) study, the authors concluded that individuals with ID think their care staff should support the development of romantic or sexual relationships and should respect the privacy of individuals with ID. The authors employed a focus group method in which the vast majority of the participants across all age categories reported they did not understand why individuals with ID should be prevented from having relationships and the space to do so.

Individuals with ID often highlight a lack of privacy as a contributing factor that inhibits their opportunities to establish relationships and express their sexuality (Brown & McCann, 2018). In their study, Hingsburger and Tough (2002) reported case studies where individuals with ID shared their personal stories of having a lack of privacy. One couple participating in the study reported: “we can’t have sex in our bedroom or we’d get killed!” (Hingsburger & Tough, 2002, p.9). For this man and his girlfriend, the park was where they engaged in intimate sexual behavior, as the individuals reported it was safer, more private, and away from the staff who

could punish them for their behaviors (Hingsburger & Tough, 2002). Another research participant shared that because of anti-sexual policies and overtly homophobic staff, he and his male partner would meet in the park where they would have sexual encounters until they were permitted a bedroom. Once they had access to a bedroom the individual shared he did not know what to do, as all of their sexual encounters had been quick and with fear they would need to run if they were to be caught in public (Hingsburger & Tough, 2002). Another concern shared by the individuals of this study was that condom use was considered risky. The individuals reported that condoms/wrappers could be found and would be an indication of sexual intent or use and would lead to punishment (Hingsburger & Tough, 2002). Additionally, Feely (2016) interviewed four male service users in a day service program in Ireland. The study participants reported experiences of staff eavesdropping on their conversations, being watched and recorded on CCTV within the agencies' property and other instances of invasions of their privacy. The layout of the property was also described as lacking in intimate spaces where individuals could be unsupervised (Feely, 2006).

**Lack of opportunity.** Positive interpersonal relationships have been found to enhance an individual's quality of life. However, individuals with ID often have restricted social networks, and little is known about their views on close social relationships (Sullivan, Bowden, McKenzie & Quayle, 2015). Wade (2002) interviewed 12 adults with mild to severe ID to understand their social and relationship experiences and the supports they require. The study generated three important findings: (a) individuals with ID do indeed experience healthy and reciprocated intimate relationships, (b) there are systematic barriers limiting their opportunities for sexual expression, and (c) they require constant staff support to maintain successful relationships. Kempton and Kahn (1991) interviewed individuals with ID and found, they had their sexual

needs ignored; their sexual behavior was punished; they were randomly sterilized; and they were closeted in their homes or isolated in large institutions, segregated by sex to prevent them from reproducing. Furthermore, the authors concluded, these individuals with ID were oppressed largely because of their sexuality. The regulation of sexuality through institutionalization, sterilization, and residential patterns to limit reproduction was reported to have oppressed an entire generation of individuals with ID within the United States (Kempton & Kahn, 1991).

In a similar study, Lofgren-Martenson (2004) interviewed 13 “youth and young adults” (p. 199) with ID in Sweden to understand the opportunities and difficulties for young individuals with ID. The themes identified were: (a) social opportunities are often arranged, and individuals with ID are often treated as if they are all the same; (b) self-determination is frequently dependent on the support of staff and other responsible adults, and; (c) since social opportunities and self-determination requires the support of others, sexual expression is significantly influenced by the attitudes and values of those providing support.

In another study, Sullivan et al. (2015) investigated how individuals with ID from Scotland perceived and experienced close relationships. The results of the study concluded that close relationships are valued and desired by individuals with ID, but a variety of barriers inhibit their development and maintenance. These include the failure of others to value, accept, and appropriately support the independence and relationships of individuals with ID. The study identified and explored themes concerning relationships and the struggle for ordinary life and feelings (Sullivan et al., 2015). Similar results were found in the McConkey and Ryan (2001) study from Northern Ireland which concluded that individuals with ID are frequently isolated in the social community and only have opportunities to develop relationships with roommates who also have ID, with their immediate families, and with their staff. Consequently, individuals with

ID have limited experience and skill in developing relationships with “normal” age-appropriate peers (McConkey & Ryan, 2001). Finger (1992) posits sexual oppression can be a source of deep pain for disabled people and individuals, stating that

Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It’s easier for us to talk about and formulate strategies for changing discrimination in employment, education, and housing than talk about our exclusion from sexuality and reproduction. (Finger, 1992, para. 6)

**Lack of understanding.** Individuals with ID often have a lack of understanding of sexuality and limited access to sex education (Saxe & Flanagan, 2014; Sinclair, Unruh, Lindstrom & Scanlon, 2015; Swango-Wilson, 2007), want to know how to start relationships, as well as to understand safe sex practices (Sinclair et al., 2015), and are denied the right to experience sexuality because of a lack of education and information (Esmail, Darry, Walter & Knupp, 2010; Sullivan et al., 2015; Swango-Wilson, 2007). Brown and McCann (2018) refer to this recurring theme as a need for education regarding sexuality and relationships. In their 2018 study, Brown and McCann interviewed individuals with ID who detailed a desire to have an intimate relationship, the need for support in sustaining it, and assistance in addressing and overcoming difficulties that may be encountered.

Sexual knowledge was measured in the identified studies using a variety of instruments and assessments. Researchers used focus groups, individual interviews, and multiple sexuality knowledge scales to measure the acquired knowledge of participants with ID. The studies revealed individuals with ID have less knowledge about sex and sexuality compared to non-disabled individuals (McCabe & Cummins, 1996; Swango-Wilson, 2009).

In an Australian study of ninety-six adults with ID, Galea, Butler, Iacono, and Leighton (2004) administered a four-part assessment and reported that individuals with ID demonstrated inadequate knowledge of sexuality, particularly regarding safe sex practices, sexual health, and legal issues. Similarly, Schaafsma et al. (2017) conducted a study in the Netherlands to assess the perspectives of individuals with ID. The results of the study showed that there was a need for better-quality sex education; the interviewees in the study reported that the frequency of sex education they received was low, that their knowledge regarding sex education was mainly limited to topics such as safe sex, contraception, and STI's, and that it tended to be superficial (para 1). Gill (2015) reports that another barrier to sex education is that sex education materials use "stranger danger" as an attempt to reduce sexual assault rates for individuals with ID. According to individuals with ID, this approach gives individuals the tools to respond only defensively when approached by strangers and an intense focus on harm reduction denies these individuals other perspectives of strangers that could lead to other types of relationships (Gill, 2015).

In a study conducted in 2000, McCabe et al. (2000) found that 50 percent of people living with a disability had not received any form of sex education. McCabe et al. (2000) additionally found that the general population received sex education from parents, friends, and other sources, whereas people with disabilities were most likely to receive information only from 'other' sources. These 'other' sources mainly consisted of media or formal sex education in school.

Many individuals with ID in this literature review reported that formal education about sex was lacking, and those who had received such education had not found it helpful. Saxe and Flanagan (2014) posit that individuals with ID have little knowledge about contraception and have significantly lower levels of knowledge when compared to non-disabled individuals.

Siebelink, de Jong, Taal, and Roelvink (2006) found that only 59 percent of their disabled research participants could correctly identify an image of a condom. Additionally, Schaafsma et al. (2017) stated that knowledge of safe sex did not always translate into safe sex behavior. Finally, many sex education programs teach facts but do not aid individuals with ID to incorporate the presented facts into a concrete meaning of experience (Kelly, Murphy, Sikkema & Kalichman, 1993).

Furthermore, for some individuals with ID, their sex education was described as incomplete because instruction focused on protective measures rather than on enhancing their sexual knowledge (Swango-Wilson, 2007). Cuskelly and Bryde (2004) found that the staff in their study significantly overestimated their clients' knowledge in a number of areas related to sexuality. The authors also concluded that adults with ID lacked sufficient knowledge about sexual matters to protect themselves against exploitation (Cuskelly & Bryde, 2004). Research suggests explanations for this vulnerability are related to a history of reinforced compliance, inadequate social skills, lack of judgment skills, and a lack of practical knowledge provided in formal sex education programs (Sobsey & Varnhagen, 1988; Swango-Wilson, 2007).

Existing sex education programs have historically not involved individuals with ID in the development of the programs. Current sexuality education programs vary widely in the accuracy of content, emphasis, effectiveness, and the programs range from abstinence-only-curriculum to a comprehensive sex education curriculum (Alford, 2020). According to Schaafsma et al. (2017) not involving the target population decreases the likelihood that the sex education program will be effective. Furthermore, Andrews and Veronon (1993) found that courses designed for the general population were used for the ID population. Examples of sex education curriculum and instructional activities specifically designed for individuals with ID are limited. However,

product licenses are available for purchase if an agency or academic program wished to purchase a curriculum. Clinical social worker Lucille Duguay developed Oak Hill's "Positive Choices" curriculum and founded the Center for Relationship & Sexuality Education. Since 2009, the curriculum has been sold across the country, including to colleges and public school districts (Positive Choices (n.d.). Sample curricula from Positive Choices includes 31 instructional units, a wealth of best practice information, suggested extension activities and resources, plus teaching strategies that clearly present desired results, and assessment evidence (Positive Choices (n.d.). The overall ratings and feedback on the Positive Choices program is positive.

### **Perspectives on Sexuality by Parents of Individuals with ID**

A review of the literature revealed few studies that have addressed parents' perception of the sexuality of family members with ID. Included in this section of the literature review are parents' perceptions of their children with ID and sexuality, parents' misunderstanding of sexuality, parents' concerns and fears on the development of sexual identity and sexual expression, and parents' lack of understanding and knowledge of what topics to address and how to approach sex education with their children with ID.

**Misunderstanding of the child's sexuality.** Parents report a range of misunderstanding in regard to the sexuality of their children with ID (Esmail et al., 2010; Swango-Wilson, 2009). In one study, a majority of the parents reported the belief that individuals with ID are asexual (Esmail et al., 2010). In another study, a parent of a child with ID stated to researchers that "their child was not interested [in sex]," even though the parent recognized that sex was an important part of life in general (Swango-Wilson, 2009, p. 226). Furthermore, parents tend not to view their children as appropriate for dating either. In their study, Brown and McCann (2018) observed parental concerns related to fears of their child being exploited sexually or sexually abused.

According to Esmail et al. (2010), when researchers questioned participants without a disability about a relationship with an individual with a disability, the participants responded by saying they would not want to begin a relationship with someone with a disability for fear of becoming a caregiver to the individual with a disability. Individuals with ID face challenges to their sexuality from family members and society.

**Parents' concerns and fears.** Cuskelly and Bryde (2004) conducted a study on parental and familial guardians which showed that while parents and familial guardians are said to generally support the sexual rights of their loved one with ID, they continue to demonstrate conservative attitudes toward the sexual behaviors of their family member with ID. In a related study, Evans et al. (2009) compared family members to paid staff members and found a significantly larger proportion of staff had discussed sexuality with the individual with ID than family members who claimed to have had very few conversations about sexuality. The authors reported that only ten percent of family members believed that adults with ID should be allowed to have unsupervised sexual relationships (Evans et al., 2009). Furthermore, Tamas, Jovanovic, Rajic, Ignjatovic and Prkosovacki (2019) found similar results in their study. The researchers suggest that parents as primary caregivers experience more concern and fear regarding all aspects of the sexual behavior of their children with ID when compared to staff level of concern. The research findings suggest that parents do not feel ready to educate their children on sexuality and are concerned that their children would find it difficult to express their sexuality in a socially acceptable manner or that they would fall victim to sexual abuse (Tamas et al., 2019).

Consequently, parents of persons with ID often avoid talking about sex and are more restrictive when it comes to allowing their children to have sexual experiences. Desjardins (2012) interviewed parents of individuals with ID and found that parents wanted their children to

remain sexual without the threat of reproduction. The parents desired to have their children be liberated from the ability to reproduce but remain sexual. Attitudes towards parenting by persons with ID remain negative, and these attitudes may adversely affect the provision of competency-enhancing supports (Aunos & Feldman, 2002; Cuskelly & Bryde, 2004; Haynes, 2016; Wolfe, 1997). Some parents are willing to support sexual intercourse but prohibit reproduction (Desjardins, 2012). To do this, parents required that their children adopt permanent contraceptive devices. What Desjardins (2012) discusses in his study is “an adapted sexuality” conceived by parents and supported by medical staff and other care staff” (p. 5). The parents recognized that their children could be sexual and in order to remain sexual, parents sought sterilization practices to guarantee their children’s sexual opportunities.

The need for more consistent and appropriate sex education for individuals with ID would seem to be apparent, however, there is minimal consistent research to support parental attitudes regarding sexuality education. Trudel and Desjardins (1992) discuss their study investigating attitudes of parents and professionals towards sex education for individuals with ID. The authors reported that attitudes varied according to age, with younger respondents being more favorably disposed towards sex education, a finding repeated in Murray and Minnes’ (1994) study. Oliver, Anthony, Leimkuhl, and Skillman (2002) also found age to be an influence on attitudes, with older adults having more conservative attitudes about sexual expression than younger adults, both for those with and without a disability. Cuskelly and Bryde (2004) additionally found that age was associated with attitudes, with those aged 60 and above holding more conservative attitudes.

Across studies, special education teachers and university students appear to hold more positive attitudes towards sexuality and sexuality education programs than parents and service workers (Aunos & Feldman, 2002).

Ćwirynkalo, Byra, and Żyta (2017) reported that the staff interviewed in their study referred mostly to environmental barriers, which include certain systemic constraints as well as negative attitudes and incorrect beliefs about individuals with ID held by the families and claimed that the most essential barrier was connected with parental attitudes towards their adult children's sexuality. Beyond that, parental overprotection and/or tendency to control many aspects of their adult children's lives may lead to dependency, withdrawal, infantilism and the adult child's passive acceptance of his or her role as an asexual being. This is consistent with other studies indicating that parents tend to have fairly more conservative and reserved views about the sexuality of individuals with ID when compared to the siblings of individuals with ID and other individuals without an ID (Cuskelly & Bryde, 2004; Ćwirynkalo et al. (2017).

The literature reveals that individuals with ID recognize parents' beliefs about their sexuality as an inequality that exists between themselves and their families (Senne, 2016). Healy et al. (2009) found that many of the individuals with ID interviewed in their study were aware of the difference in their parents' responses to their siblings having intimate relationships and to their own entering into an intimate relationship. This inequity may be related to parents' lack of understanding of how to educate or communicate with their child with ID about sexuality and sex education content.

**Lack of sex education at home.** According to Wilkenfeld and Ballan (2011), there is a lack of understanding of what and how much sex education does or does not occur at home. Research has shown, however, that parents are identified as the primary sex educators for their

children with disabilities (National Information Center for Children and Youth with Disabilities, 2019). Furthermore, parents are the major source of sex education for children with ID through formal and informal communication and through social experiences provided to practice emerging sexuality skills (Walcott, 1997). Swango-Wilson (2007) posits that parents need to be included in the development of sex education and to support the sex education program. What is more, when planning a sex education curriculum, the influence of parents' social beliefs and morality needs to be recognized (Walcott, 1997).

According to Saxe and Flanagan (2014), the denial of sex education to students with ID is often the result of their gatekeepers' fears and insecurities. Parents of those with ID express concern regarding whether sex education encourages the expression of sexual behaviors, for example, "I fear sexual abuse ... he is so trusting" (Swango-Wilson, 2009, p. 226), and "if she had a baby, I don't think I could raise another one" (Swango-Wilson, 2009, p. 226). Parent responses seemed to be more focused on sexual abuse and unwanted pregnancy.

### **Perspectives on Sexuality by Staff of Individuals with ID**

A review of the literature reveals a growing number of studies that have addressed staff attitudes and perceptions of the sexuality of individuals with ID, and most are conducted outside of the United States. A review of staff attitudes towards the sexuality of individuals with ID and how it relates to sexual expression for individuals with ID is included in this section of the literature review. They are as follows: staff attitudes on sexual expression, staff attitudes on parenting, staff attitudes and gender, staff attitudes and age, staff attitudes on sexual diversity, and staff attitudes on sex education.

**Staff attitudes on sexual expression.** Studies have identified the importance of staff beliefs concerning sexual experiences for individuals with ID and the influence that these beliefs

have on the development of sexual identity. Tamas et al. (2019) posit that staff have an important direct influence on the development of the sexual identity of individuals with ID. Differences in values and beliefs related to sexuality can contribute to a lower quality of cooperation between parents and staff, and consequently to confusion and ambiguous expectations for individuals with ID (Tamas et al., 2019). Halstead (2002) found that while the importance of sexual experiences was identified by staff, individuals with ID were rarely left alone and had limited exposure to situations that might lead to a friendship or sexual relationship.

Due to a lack of established laws and policies, staff are left with the responsibility for deciding how their clients' sexual rights and needs are addressed. Because of the staff's potential impact on the lives of individuals with disabilities, attention must be given to their attitudes concerning the sexuality of individuals with ID (Saxe & Flanagan, 2014). Yool et al. (2003) also noted that staff were not aware of their organization's policies with regard to sexuality and individuals with ID and Martino and Perreault-Laird (2019) similarly found staff reported having little knowledge about policies and guidelines in place and staff reported having a hard time remembering what the policies were. This is consistent with the findings of Murray, MacDonald, Brown, and Levenson (1999) who also found that a significant number of staff were unaware of the policies regarding the sexuality of individuals with ID, but that despite the lack of or ambiguous organizational policies, staff hold generally positive attitudes towards the sexuality of individuals with ID. Beyond a lack of clear policy or staff's understanding of the limited policy, Martino and Perreault-Laird (2019) state there is an additional challenge in assessing current providers' attitudes, as the staff were fearful of "getting into trouble" and often do not want to discuss the policy and training their organizations employ (para. 18). Other research studies similarly indicate that staff hold generally positive attitudes towards the sexuality of individuals

with ID (Aunos & Feldman, 2002; Bazzo et al., 2007; Brantlinger, 1983; Cuskelly & Bryde, 2004; Ćwirynkalo et al., 2017; Gilmore & Chambers, 2010; Murray et al., 1999; Murray & Minnes, 1994).

Additionally, Oliver et al. (2002) surveyed staff in the Midwest and determined that there was generally positive support for the sexual expression of individuals with ID. Two results were found to be significant within this study: firstly, most staff understood sexual expression to be a prohibited topic by parents of clients with ID; and secondly, while staff regarded sexual expression issues as part of their jobs, these sexual issues were emotionally difficult for other staff members (Oliver et al., 2002). Conversely, Grieve McLaren, Lindsay and Culling (2009) conducted a similar study with 188 nurses and care staff to assess their attitudes towards sexuality in relation to individuals with ID, and found the staff to feel less positively about individuals with ID having romantic relationships. In fact, Grieve et al. (2009) found staff may often hold attitudes that are likely to be detrimental to the development of the sexual identity and personal relationships of individuals with ID for whom they are charged with caring, despite the fact that staff are also shown to care about the welfare of individuals with ID. Furthermore, Grieve et al. (2009) report that many staff members responded that they did not support individuals with ID kissing or holding hands; these staff attitudes would likely hinder individuals with ID trying to form an intimate relationship.

Further studies also express concerns of staff about individuals with ID and sexuality. For example, Young, Gore and McCarthy (2012) carried out a qualitative study on staff attitudes towards the sexuality of individuals with ID in England which revealed “unfavourable attitudes” overall in relation to sexuality. Staff demonstrated anxiety when discussing individuals with ID and their sexuality. According to the study, staff did not seem to be aware of or committed to

helping support any sexual relationships (Young et al., 2012). Furthermore, Tamas et al. (2019) claim that professionals have a tendency to show fewer positive attitudes towards the sexuality of individuals with ID out of concern for the welfare of their patients; since they are aware of the difficulties individuals with ID can face in areas of sexual functioning, they are therefore prone to shape their attitudes based on concern for the welfare of an individual with ID (Tamas et al., 2019). Additionally, Grieve et al. (2009) and Schaafsma, Kok, Stoffelen, Doorn and Curfs (2014) found that some staff members expressed concerns about other staff members' or parent's reactions if they were to talk to clients about sexuality and were worried about being prosecuted if they attempted to discuss sexuality with their client (Grieve et al., 2009; Schaafsma, et al., 2014). Bazzo et al. (2006) stated their study results suggested that the staff tended to have moderately liberal attitudes and that educational level and role carried out did not produce differences in their attitudes. However, the authors found, a significant difference emerged between those who operated in different services. The staff of the outpatient treatment services revealed the most liberal and positive attitudes towards the sexuality of individuals with ID (Bazzo et al., 2006).

Gilmore and Chambers (2010) conducted a study in Australia concerning individuals with ID and sexuality, using a sample containing disability support staff and leisure industry staff who would have contact with individuals with ID. According to the authors, both support staff and leisure workers considered a higher level of sexual freedom to be appropriate for those developing typically than for individuals with ID.

In contrast, a further review of the literature shows an identified barrier in staff demonstrating a range of misunderstanding in regards to the sexuality of individuals with ID (Esmail et al., 2010; Sinclair et al., 2015; Swango-Wilson, 2009). Parents and caregivers in

multiple studies reviewed held the misperception that individuals with ID/DD are asexual (Esmail, et al., 2010; Gil-Llario et al., 2018; & Harris, 2018). Aunos and Feldman (2002) and Young et al. (2012) posited participants had unfavorable attitudes generally towards the sexuality of individuals with ID. Staff expressed considerable anxiety when considering the sexuality of people with ID and indicated little awareness or commitment to proactively supporting such sexual relationships (Young et al., 2012). Cuskelly and Bryde (2004) reported that in practice, the staff's conservative attitudes directly impact the behaviors and the sexual attitudes of individuals with ID. In the context of such attitudes, it is unlikely that people with ID will be supported to develop meaningful intimate relationships (Young et al., 2012).

**Staff attitudes on parenting.** An additional area of focus within the research concerns attitudes towards individuals with ID becoming parents. Studies have shown negative and conservative attitudes towards parenthood by individuals with ID (Cuskelly & Bryde, 2004; Haynes, 2016; Wolfe, 1997). These attitudes are due to the concerns the study participants have regarding the abilities of individuals with ID to take care of their children, regarding possible genetically transmitted disability and factors such as finances and health which can influence quality of life (Cuskelly & Bryde, 2004). Additionally, Wolfe (1997) conducted a study that involved interviewing staff working with individuals with ID in a school setting (teachers and school administrators) and found that the majority of school staff had a negative attitude towards individuals with ID having the right to parent children. Cuskelly and Bryde (2004), Gilmore and Chambers (2010) and Yool et al. (2003) all conclude that, although staff appear to believe that sexuality is a necessity for individuals regardless of disability, they are least positive about individuals with ID parenting. These negative attitudes towards the parenthood of individuals

with ID echoes the previous discussion in this literature review of non-consensual sterilization (Reiter & Walsh, 2018) to reduce the likelihood of individuals with ID becoming parents.

The issue of individuals with ID and parenting is complex. Questions around parents with ID have changed according to sociocultural shifts in the position and rights of individuals with ID (Schuengel, Kef, Hodes & Meppelder, 2017). McKenzie, Shewan and Wilson (2016) report there is recognition that people with ID have the same rights as others to parent. However, it is apparent that the term ID is applied to a heterogeneous group of people, “some of whom will not have the capacity or ability to parent effectively, even with additional support” (McKenzie et al., 2016, p.88). Additionally, the authors note there is difficulty in isolating the impact of parent(s) ID from other factors, such as parental socio-economic deprivation and social isolation, and, for the mothers, higher risk pregnancies and birth complications. McKenzie et al. (2016) concluded that, while their review found some evidence for poor outcomes for children with a parent with ID, once the other factors, such as those noted were controlled for, the development of their children was consistent with general population norms. They suggest therefore, that children are not inevitably disadvantaged by having a parent with ID. Ultimately, parenting research should become fully inclusive. As theoretical models developed for other at-risk populations prove increasingly helpful for understanding the challenges of parenting with ID, it becomes viable to adapt existing evidence-based parenting interventions and test these for this population (Schuengel et al., 2017).

**Staff attitudes and gender.** The gender of individuals with ID in relationships to attitudes to individuals with ID sexuality has shown to be a minimally investigated phenomenon within the literature. Gilmore and Chamber’s (2010) study found most beliefs about male and female sexuality to be similar, but staff in the study saw men with an ID as having less self-

control over their sexual behavior than women, a perception that was also evident in Cuskelly and Gilmore's (2007) sample. In this particular study staff considered a higher level of sexual freedom to be more appropriate for those developing typically than for individuals with an ID.

In a related study, Gilmore and Chambers (2010) found that less sexual freedom is acceptable or desirable for women with ID than for women without an ID. This perception, according to the researchers, may be related to perceptions about female innocence and the need for greater protection because of increased risks of exploitation and abuse, whereas the same caution does not seem to apply to men (Gilmore & Chambers, 2010). Gilmore and Chambers (2010) found this view was expressed by staff who, on the basis of their experience, the researchers presumed, should have more awareness of the need for women with an ID to access information about sex and to be supported to express their sexuality appropriately and safely. Whereas, Young et al. (2012) found similar data results within their study. Women with ID were described as sexually naive. Subthemes included that they do not think about sex, are more vulnerable to sexual abuse, and consequently need more protection and men with ID are seen as more sexually driven (Young et al., 2012).

Conversely, Meaney-Tavares, and Gavidia-Payne (2012) suggested that there was no relationship between staff gender and their attitudes. The authors did find that staff attitudes were more positive towards the sexual rights, non-reproductive sexual behavior, and capacity for self-control of women with ID in comparison with men with ID (Meaney-Tavares & Gavidia-Payne, 2012). It was suggested that this finding may be related in part to the physical differences between men and women (Meaney-Tavares & Gavidia-Payne (2012). Furthermore, they suggest that this finding could result from staff feeling less confident due to the size and nature of men, and subsequently reporting less positive attitudes (Meaney-Tavares & Gavidia-Payne, 2012).

Tamas et al. (2019) found a similar result in the subsample of staff where there was no statistically significant difference either between average scores on the attitudes towards the sexuality of women and men with ID or on any of the subscales of an attitude questionnaire which was administered to 137 professionals living in Serbia. The authors stated, there is a statistically significant difference in the assessment of the general attitude towards the sexuality of men and women with ID, the attitude being more liberal when men with ID are considered. Upon examining the structure of these differences in the context of individual aspects of sexuality of persons with ID, results yielded significant differences only on the subscale of self-control, the attitudes being more liberal towards the sexuality of men with ID (Tamas et al., 2019). Frawley and Wilson (2016) stated a possible explanation of such findings lies in the stereotyped belief that men with ID have less self-control over their sexual drive, as a result of insufficient knowledge on the subject as well as prejudices. Consequently, the general public's attitude towards the sexuality of women with ID is more positive (Frawley & Wilson, 2016). Generally, in the context of sexuality women with ID are perceived as naïve and helpless, and men as sexually deviant (Tamas et al., 2019).

Finally, a single study specifically investigated the gender of staff and its relation to attitudes to the sexuality of individuals with disabilities. Ryan and McConkey (2000) conducted a study in Northern Ireland which interviewed 150 staff members and found that male staff was more disposed to clients receiving sexuality education and to having children than female staff.

**Staff attitudes and age.** There is evidence that older staff hold more negative attitudes, in line with traditional beliefs and stereotypes (Tamas et al., 2019), and age has been identified as correlated with attitudes toward the sexual rights of individuals with ID within the literature. Trudel and Desjardins (1992) conducted a study investigating attitudes of staff who work with

individuals with ID and reported that attitudes varied according to age, with younger staff being more favorably disposed towards sexuality education, a finding repeated in Murray and Minnes's (1994) study. Younger staff in the 20-year-old age range reported the most positive attitudes when compared with those in the aged 50 and older range; the age-related results are similar to findings that attitudes of younger staff are more positive toward client sexuality (Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007; Murray & Minnes, 1994; Tugut, Golbasi, Erenel, Koc & Ucar, 2016). The results of these multiple studies confirm that attitudes of staff differ dependent on their age, not only towards the sexuality of persons with ID, but also towards a more liberal attitude towards sexuality education for persons with ID, whereby younger participants hold more positive attitudes.

On the other hand, other studies found that the age of the staff did not have an influence on the attitudes toward the sexuality of persons with ID. Gilmore and Chambers (2010) found that, unlike earlier studies (e.g., Cuskelly & Gilmore, 2007; Oliver et al., 2002), attitudes were not associated with staff age or education in their study. The researchers suggest that this result could be due in part to the sample containing fewer older staff and a smaller proportion with a high level of education than in many previous studies (e.g., Cuskelly & Gilmore, 2007). Yool et al. (2003) posit that staff attitudes towards the sexuality of persons with ID is influenced not only by their age but also by the level of disability present in an individual with ID. Tamas et al. (2019) state that staff attitudes are not dependent on their gender but are dependent on age, educational level and, professional role.

According to Schaafsma et al. (2014), in a comparison between parents and staff, the staff were more likely to be younger than the parents, and therefore conflict may arise between these groups when values about sexual behavior do not coincide. Typically, parents hold more

conservative views of their sons' and daughters' sexuality than do support workers (Brown, 1994), with older parents tending to be the most conservative in their views (Schaafsma et al., 2014). Such conflict is likely to lead to some confusion on the part of the individual with ID (Schaafsma et al., 2014). Although older staff members seem to have more conservative attitudes towards the sexuality of their clients than younger staff members (Evans et al., 2009; Gilmore & Chambers, 2010; Meaney-Tarvares & Gavidia-Payne, 2012), the general attitudes of staff members are more liberal and overall more positive towards sexuality among individuals with ID compared to the attitude of family members (Bazzo et al., 2009; Evans et al., 2009; Gilmore & Chambers, 2010).

**Staff attitudes on sexual diversity.** Sexual diversity is an important consideration in sexuality and relationships for individuals with ID. Sexual diversity generally refers to differences in sexual orientation (Malony, 2001). Frawley and Wilson (2016) argue that there is a small body of work that has demonstrated the need to develop an understanding of what is important for individuals with a range of sexual aspirations and identities among people with ID. Furthermore, Frawley and Wilson (2016) suggest that there is a significant gap in research knowledge that includes a focus on sexual identity and the ways that a positive perspective on sexuality can improve staff approaches to support and educate individuals with ID (Frawley & Wilson, 2016).

Though information on gender diversity is available to staff, it is not known, based on this literature review, if staff are aware of the information. The literature reveals that staff often feel as though sexuality and behaviors related to sexual expression of individuals with ID must be communicated with all team members to avoid areas of neglect or abuse with regard to health and safety. Senne (2016) notes that, in a case study among women with ID, in some instances,

staff would request a team meeting to discuss the individual's sexual activities, and might, at times, contact the team directly without the consent of the individual. Furthermore, Evans et al. (2009) observed that staff continue to be uncertain of what the right to privacy is of individuals with ID and what their responsibility is to maintain privacy for the individual with ID whom they support. This role appears to become even more ambiguous when staff encounter same-sex relationships (Senne, 2016).

Further studies delineate the challenges faced by individuals with ID who identify as sexually diverse. Grieve et al. (2009) discuss negative staff attitudes towards same-sex relationships by staff respondents in their research. In an assessment of attitudes towards same sex sexual behavior revealed that nursing home staff possessed significantly more conservative attitudes when compared with community-based staff. In 2011, a forty-one-year-old man "Alan" who had an ID, was banned from participating in sexual relationships with his male partner. The banning came as a judicial ruling from the Court of Protection in the United Kingdom, after the local housing council that provided residential housing and support for Alan brought suit to restrict the relationship (Gill, 2015). This is just one example from available case studies where an "ableist trend" denies the sexuality of individuals with ID based on staff assumptions of incompetence and staff attitudes toward inappropriateness in sexual orientation (Gill, 2015, p. 1). Gill (2015) states, the court ruling raises important questions on the interconnectedness of homophobia and ableism whether intended or unintended. Ableism is defined by Gill (2015) as discrimination or oppression of individuals who are disabled, including, denying the rights of individuals and perpetuating stigma, hatred and othering.

Brantlinger (1983) argues that the rights of individuals with ID are governed not by policy or law, but by the feelings and behaviors of the staff who provide support services. Grieve

et al. (2009) found conservative attitudes are shown to target gay men with cognitive disabilities living in nursing homes as well as medium-secure hospitals. In a more recent study, Saxe and Flanagan (2014) found that homophobia and heterosexism are expressed among some staff. School staff also identify same-sex behavior and anal sex as being inappropriate for individuals with disabilities, even when performed in private (Wolfe, 1997). In several of the reviewed studies, staff members were hesitant to consider individuals with ID as gay or lesbian even though the individuals engaged in same-sex sexual behavior (Abbott & Howarth, 2007; Hellemans, Royeyers, Leplae, Dewaellw & Deboutte, 2010; Lofgren-Martenson, 2009). In a related study, Ryan and McConkey (2000) assert that staff acknowledged that individuals with ID are exposed to sex education, that they were reportedly supportive of marriage and staff appreciated the need for privacy for sexual behaviors, and were tolerant of masturbation by individuals with ID. But, Ryan and McConkey (2000) also found that this liberal attitude did not extend to individuals with ID engaging in same-sex activities or “one-night stands.”

**Staff attitudes on sex education.** Staff that supporting individuals with ID are intimately connected with maintaining, facilitating, and upholding human rights to sexuality. However, the role can be complicated by staff attitudes towards the sexuality and sexual expression of individuals with ID (Martino & Perreault-Laird, 2019). The negative views expressed by staff related to individuals with ID gaining access to sex education can have damaging consequences due to the fact that individuals with ID are very reliant upon their staff (Saxe & Flanagan, 2014). Because individuals with disabilities are less likely than their nondisabled peers to gain information about sexuality from others or parents (McCabe & Cummings, 1998), staff can become the primary sex education providers, whether staff are aware of this or not. Staff belief systems related to the sexuality of individuals with ID are liable to

impact how staff view sex education targeting individuals with ID (Saxe & Flanagan, 2014). Thus, it is important to understand the influence of staff in the lives of individuals with ID, whether through support or prevention of sexual expression and practices (Martino & Perreault-Laird, 2019).

Findings from the Schaafsma et al. (2017) study reveal a need for a better quality sex education for individuals with ID. The Schaafsma et al. (2017) study indicated that the frequency of sex education the participants received was low and that their knowledge regarding sex education was mainly limited to topics such as safe sex and contraception and tended to be superficial. Furthermore, Allen (2008) determined through a 41 item survey, that most staff were comfortable supporting the sexual expression of their clients, but did not have the appropriate training to accommodate the respective issues of individuals with ID. Additional research has identified barriers that may affect staff in providing sex education to individuals with ID (Bazzo et al., 2007; Cuskelly & Bryde, 2004; Evans et al., 2009; Gilmore & Chambers, 2010; Grieve et al., 2009; Healy et al., 2009; Schaafsma et al., 2017). These barriers will be addressed within this section. Young et al. (2012) argue that the results of their study imply that when sex education is provided, it is taught in response to problems, rather than to prevent problems or proactively support individuals with ID.

In a study conducted by Schaafsma et al. (2014) the authors claimed that sex education typically arises for the individual with ID when they ask questions related to sexuality or display inappropriate sexual behavior. The authors argue that this contradicts the reasons why most sex education programs are developed: as a preventive tool and as a way to increase the chances of having a healthy sexual life (Schaafsma et al., 2014). The authors suggest that teaching sex education as a response to negative occurrences can have a negative impact on an individual's

likelihood of having pleasurable and safe sexual experiences (Schaafsma et al., 2014).

Schaafsma et al. (2014) found older staff members seemed to have a more positive attitude towards sex education. This is contrary to what has been reported by authors Evans et al. (2009) and Gilmore and Chambers (2010). Evans et al. (2009) and Gilmore and Chambers (2010) found that older staff members seem to have more conservative attitudes towards the sexuality of their clients than younger staff members.

Saxe and Flanagan (2014) reported that staff raised concerns regarding restrictive and prohibitive parental attitudes they have observed towards the sexual behavior of their children with ID which impacts the ability to provide sex education. Swango-Wilson (2009) reported that staff identified a need for sex education programs that empower and educate individuals with IDs to protect themselves. Furthermore, Servais (2006) declared that although policies guiding staff acknowledge that individuals with ID have sexual rights, a conservative and paternalistic service delivery system negatively impacts sex education for individuals with ID. Concurrently, staff members bring their own perspectives to the work environment, which can be in conflict with the values of the person receiving the service (Allen, 2008).

In summary the staff perspectives of sexuality for individuals with ID are varied, yet there are consistencies found in the literature. A range of misunderstandings in regards to the sexuality of individuals with ID is demonstrated within the studies (Esmail et al., 2010; Sinclair et al., 2015; Swango-Wilson, 2009). Study findings suggest that individuals with ID are commonly viewed as asexual (Esmail et al., 2010; Swago-wlson 2009). Furthermore, there is a lack of consistency in the approach to educating individuals with ID regarding their sexuality, sexual health and their rights related to sexuality (Allen, 2008; Martino & Perreault-Laird, 2019; McCabe & Cummings, 1998; Ryan & McConkey, 2000; Saxe & Flanagan, 2014; Schaafsma et

al., 2017; Sinclair et al., 2015). Another challenge for service providers is the influence of parents and guardians. Parents have been shown in the literature to hold more conservative views or to hold conflicting views when compared to support staff (Brown et al., 1994; Schaafsma, et al., 2014). Oliver et al. (2002) found that parents prohibited sexual expression for their adult children with ID. Staff members encounter a variety of limitations and barriers as they work to support the sexuality of individuals with ID.

### **Theoretical Influences**

For this study, an inductive research methodology approach explores emerging areas in the literature and the contributions to theory from the collected data. This study used existing theories to formulate the research questions explored. The Theory of Planned Behavior, Feminist Disability Theory and Gender Theory are examined for their ability to inform the research questions and for how they are limited in their ability to inform this academic study.

#### **Theory of Planned Behavior**

One of the main theoretical frameworks that guides this study is the Theory of Planned Behavior. This theory links one's beliefs and behavior. The theory states that attitudes toward behavior, subjective norms, and perceived behavior control shape an individual's behavioral intentions and behaviors (Armitage, Conner & Norman, 1999). The Theory of Planned Behavior suggests that staff will be willing to support individuals with ID and issues related to sexuality if they have a positive attitude towards the sexuality of individuals with ID, perceive social support and approval from important others in the work context, and feel confident and capable in providing the intended support around sexuality. The Theory of Planned Behavior is used to predict an individual's intention to engage in a behavior at a specific time and place (Ajzen, 1985). The Theory of Planned Behavior posits that someone with a positive attitude towards a

belief or action would be more likely to perform the behaviors that are required to support the belief or obtain the action (Swango-Wilson, 2007). The Theory of Planned Behavior looks at subjective norms and behavioral control, not just that attitudes influence behavior.

The Theory of Planned Behavior is an appropriate guide for the study's research questions and serves to inform this study because it includes liability, policy, and law. This theory indicates a relationship between an individual and a greater impact like how policy and law shape the perceptions of costs/benefits for providers. Federal laws and state statutes mandate that individuals with ID have sexual rights. These rights are furthermore a human right. However, despite the fact that an individual with ID is guaranteed to equal access to sexuality by law, according to The Theory of Planned Behavior, if the provider does not have a positive attitude towards their consumers' sexuality they are less likely to perform the behaviors that are required to support the sexual needs of their consumer. The Theory of Planned Behavior is not a theoretical explanation for gender. This theory does not include how an individual's gender or the gender of the individual being cared for impacts a person's thinking and actions. The following theories on gender and feminist disability theory address gender and disability respectively but do not speak to the subjective norms and behavioral controls as the Theory of Planned Behavior does.

### **Feminist Disability Theory**

Feminist Theory, practice, and politics are far from unified and cannot be contained within a single definition (Kafer, 2005). However, one of the basic principles of Feminist Theory is a concern with issues of social justice and social change and a commitment to a more just, equitable, and sustainable world. At both a collective and individual level, Feminist Theory and politics have a long tradition of engaging in the dual practice of imagining better futures while

working to transform inequalities in the present (Kafer, 2005). Feminist Theory provides the tools to think through disability and the ways in which assumptions about disability and disabled bodies can lead to resource inequalities and social discrimination (Kafer, 2005). Feminist disability studies guide this study because there is both a focus on sexuality and control of one's body as a key political issue. Feminist Disability Theory provides a lens to explore how inequality affects the body and the enactment of pleasure. It further guides this study by proposing what an ideal of social justice could be and how sexuality and the body could be treated in earnest. Feminist theorists acknowledge the ways that gender is deeply constitutive of the way the world is constructed and how gender is embedded in systems of inequality for women. Feminist disability scholars agree with this, but expand this way of thinking by including the range of what bodies are/can be and include the unique needs of these diverse bodies and how women with disabilities face inequalities and thus the ideals of liberation (Garland-Thomson, 2005).

Feminist Disability Theory is an academic, body of work that aims to change the stereotypes about people with disabilities by challenging assumptions about what life is like with a disability (Garland-Thomson, 2005). Gerschick (2000) posits activists and scholars have successfully applied feminist insights, theory, and methods to the intersection of disability and gender. Feminist disability studies highlight the rights and exclusions made upon individuals with a disability and aspire to retrieve dismissed voices and misrepresented experiences (Garland-Thomson, 2005). Disabled bodies are considered deviant; they are systematically excluded, surveilled, and controlled and are denied access to pleasure when compared to traditional bodies (Garland-Thompson, 1997). Key feminist ideas are to have equal rights for all women and to have access to "traditional" rights like the right to vote or access the workplace to

be productive, be considered an equal citizen, and have freedom of choice and control over their bodies. For women with disabilities the inequality they experience is not just about access to those traditional rights, but also to having access to supports and accessibility to this choice and control. Feminist theorists call for access to traditional rights and equality and further demand non-traditional rights like control over one's own body. A key feminist disability idea is that the law, policies, and supports available to all citizens need to recognize and support the freedom and choice of disabled individuals too, or else those laws, policies, and supports are not working sufficiently or fully. Feminist Theory and Feminist Disability Theory are used as a guide in shaping the development of the broad research question, how do DSPs view and support the sexuality of those with ID, and the research sub-questions.

Studies of masculinity and disability are informative for this study too in that male and female DSPs will be interviewed and it is likely that accounts of individuals with ID who are male and female will be reported upon during interviews. I am aware that the use of gender in this section is binary and does not include individuals who identify with various forms of gender outside of what male and female gender norms offer. For the purpose of this study, the traditional use of gender has been used in evaluating theoretical frameworks for the ability to guide this research study as this is the typical practice within the literature. Studies comparing the sexual attitudes of men and women with ID have been limited (Chou et al., 2015). Chou et al. (2015) state, qualitative data indicates that men and women with ID have different sexual attitudes and experiences and are subject to different expectations from the people around them.

Authors Cuskelly and Gilmore (2009) suggest that attitudes toward the sexual expression of men and women with an ID should be examined separately. This suggestion is valuable to this study in that the authors claim the attitudes to the sexual expression of men and women have

traditionally been different. Another burgeoning area of study that currently is limited is the gender of care providers. This research area has been studied minimally with less focus than the gender of individuals with disabilities receiving the services. There are large gaps in the research and few theoretical foundations that can guide this study. The need for this inductive study is especially apparent here.

### **Gender Theory**

Gender Theory is a methodological approach to the study of human sex differences, which emerged in the 1970s among feminists. Since the 1970s, those who have taken this methodological stand have explored gender as a cultural construction through a wide variety of disciplines and viewpoints (Balius, 2018). Gender Theory remains for many, an important methodological approach to the study of human social life and those interested in both describing and transforming inequality (West, 2015). In an investigation of the contributing factors to staff attitudes on the sexuality of individuals with ID and their consequent behaviors and response to sexual issues, the knowledge of whether gender has an impact is an understudied phenomenon. Gender Theory offers a theoretical explanation for including gender within this study.

Including Gender Theory as a guide in discussing theoretical frameworks will offer empirical knowledge about gendered practices, norms, and discourses (Balius, 2018). The field of gender studies offers a systematic analysis of the meaning of sex and gender in past and present societies and produces notions, methodologies, and theories on how gender categories are entangled in other categories and practices (Balius, 2018). One of the limitations to using gender studies is some participants may be uncomfortable with the binary established by many feminist scholars between masculine and feminine (West, 2015). While this may be true for some gender theorists, Butler (2015) resists binary ideas of gender. Butler, talks about gender as

performance, so that individuals can learn and shift their gender; and the idea that gender is fluid and dynamic.

For the purposes of these theoretical frameworks guiding the development of research questions, Gender Theory does not include disability as a minority group but does offer insights to gender (West, 2015). Feminists theorists often assume the inferior social position of women and the superior social position of men and, to some degree, this occurs for individuals with disabilities, too. Typically, disabled men have more money on average, are more likely to marry, receive more in government benefits than disabled women (Longhi, 2017). However, when considering sexuality and ID, men do not seem to hold a superior social position. Their sexuality is very feared, they seem very controlled, and the rate of incarceration for sexual deviance is disproportionately high (Frawley & Wilson, 2016; Meaney-Tavares & Gavidia-Payne, 2012; Young et al., 2012). The three theoretical frameworks have informed the research questions and guided this academic study.

### **Summary**

Chapter Two has provided a brief overview of the historical and systemic restrictions that continue to impact the expression and freedom of sexuality for individuals with ID. There have been many notable events in United States history during which individuals with ID have had to overcome challenges as they have worked to achieve equality and have advocated for improved community inclusion including, self-advocacy, terminology changes, and educational reforms.

Today, as individuals with ID have become more integrated into living and working in the community, the role of the staff has become a more critical component of support to these individuals. As the review of the literature indicates, there are still improvements and advancements to be made concerning equality. A staff member is often the first point of

information, the first to provide immediate support, and frequently, the person who is closest to the individual (Walker-Hirsch, 2007). As a staff person, it is important to understand the balance between a person-centered approach that gives an individual with ID the right to make their own choices, and the potential risks of these choices, especially in the area of relationships and sexuality (Senne, 2016). The majority of individuals with ID will interact with support professionals and organizations. Often at least one major feature of daily living, including vocational activities, housing settings, and community integration, is administered by staff working in some capacity with the individual with ID. This daily and continual interaction poses an opportunity in which staff can shape certain aspects of the lives of individuals with ID.

Various research studies on the sexuality of individuals with ID reveal three perspectives: those of the person with ID, their parents, and the staff who work with them. A review of the studies that included an individual with ID's perspective revealed individuals with ID often feel a lack of control over their sexuality. The misconception that an individual with ID is unable to consent to sexual expression or relationships is very present within research findings, and this results in a lack of control over their relationships and sexuality decisions. Findings reveal individuals with ID are often denied their sexual rights and right to privacy. Since they may need to rely on others to arrange intimate activities, they may have restrictions placed upon them by others about their own sexual lives. Those with ID also identify a lack of opportunity and a lack of understanding by providers who do not value, accept, or appropriately support the building of skills needed to develop sexual relationships. Other studies have found that individuals with ID report that they are not able to access the community to create new relationships, nor are they included in appropriate sex education.

Research about individuals with ID has also focused on the role of parents. The misunderstanding of their child's sexuality is a common research finding. Parents have concerns and fears and may believe that their child is asexual, that sexual behavior is inappropriate, or that their child is too vulnerable for dating and could be exploited by others. There is also hesitation from family members to provide education on sexually-related issues which leads to a lack of sex education at home. Research reveals parents' fears and insecurities are primary reasons for not educating individuals with ID about sexuality. Furthermore, there are many fears and misconceptions regarding the ability of individuals with ID to be a parent themselves.

The third perspective of research on individuals with ID has focused on staff attitudes toward their sexuality. While some research revealed generally positive attitudes, other studies reported that staff had negative attitudes towards sexuality-related issues for individuals with ID, including concerns that individuals with ID may not have the ability to parent a child. The gender and age of staff varied in each study. The consensus was that males with ID are seen as having less sexual control when compared to women, who are perceived to be more innocent and to need protection. The gender of staff and attitudinal differences remain understudied phenomena. In terms of staff perception of sexual diversity, research suggests staff are unsure and unaware of these sexual issues for individuals with ID. Finally, staff perspectives of sex education were found to be more negative due to a lack of training or policy within their agencies. Furthermore, sex education is provided as a response to a sexually related problem or focused on training against sexual abuse. As this literature review reveals, there is limited qualitative research on staff attitudes toward the sexuality of individuals with ID. There is a need for expanded research to include more of the lived experience in the United States and New England specifically.

This research uses an inductive research methodology approach in which three theoretical frameworks guide the study and inform the research questions. This study used the Theory of Planned Behavior, Feminist Disability Theory, and Gender Theories to formulate the research questions to be explored. These theoretical frameworks aided me in exploring emerging areas in the literature and in making contributions to theory. The theoretical frameworks will be used as a guide to explore how DSPs view and support the sexuality of those with ID. I was interested in learning about DSPs' experiences with and attitudes toward a variety of sexuality issues involving their consumers (e.g., use of social media and erotica, dating and sexual relationships, use of contraception, masturbation, LGBTQ+ issues), as well as how they saw their role. I was also interested in understanding what factors shape the way DSPs respond to the sexuality of individuals with ID, how gender influences their perceptions, and any changes DSPs might suggest when working with sexuality-related issues of individuals with ID.

## CHAPTER 3

### METHODOLOGY

This chapter outlines the purpose of the study, the guiding research questions, and the methodological approach, sampling strategy, data collection procedures, instrumentation, data analysis process, and acknowledgment of the risks and limitations of this study. The research study focuses on staff who work directly with individuals with ID and are referred to as Direct Service Professionals (DSPs). The term DSP will be used in this chapter to represent those who were interviewed for this study.

#### **Purpose of the Study and Research Questions**

This study is designed to explore how DSPs view and support the sexuality of those with ID. I was interested in learning about DSPs' attitudes toward and experiences with a variety of sexuality issues involving their consumers (e.g., use of social media, dating, erotica and sexual relationships, use of contraception, masturbation, LGBTQ+ issues), as well as if they saw themselves having a role in facilitating, supporting or educating about these issues. I was also interested in understanding what factors influence the way DSPs respond to the sexuality of individuals with ID, how gender influences their perceptions, and any changes DSPs might suggest when working with sexuality-related issues of individuals with ID. The DSP's beliefs and values concerning sexuality can have a great impact on the support they provide or do not provide to individuals with ID. This study adds to the understanding of the important role these staff play in the lives of individuals with ID.

The primary research question for this study is: *How do Direct Support Professionals (DSPs) view and support the sexuality of those with ID?* The five sub-research questions include:

- Sub- Research Question 1. *What attitudes and beliefs are held by DSPs regarding the sexuality of individuals with intellectual disabilities?*
- Sub-Research Question 2. *What are the experiences for DSPs in relation to the sexuality of individuals with ID and the DSPs' employment position?*
- Sub-Research Question 3. *What factors influence DSPs' responses to the sexuality of individuals with ID?*
- Sub-Research Question 4. *How does gender (of the DSP and consumer) influence the role, approach, and ideas for ways to assist adults with ID related to sexual issues?*
- Sub-Research Question 5. *What suggestions do DSPs have for working with sexually related issues of individuals with ID?*

### **Study Design**

A qualitative study is well suited to understanding the understudied phenomenon of how DSPs perceive and support the sexuality of those with ID. Qualitative research seeks to establish the meaning of a phenomenon from the views of participants (Creswell, 2018) and derives its findings from activities that do not involve statistical procedures and hypothesis-testing as required in quantitative research. Qualitative inquiry is completed with a small number of participants; this method is used to empower individuals to share their stories (Creswell, 2018). The study's design includes the recruitment of 24 participants who described their lived experiences as a DSP and their working with adults with ID in the state of Maine. The study design is appropriate for this type of one-on-one interview setting where a research participant's story will be heard. Qualitative research investigates the social phenomenon of an individual or

group of individuals who have had the same experience (Creswell, 2018). Furthermore, Leedy and Ormrod (2005) suggest that qualitative research provides a lens to reveal how people perceive and understand experiences.

A qualitative design aligns with the inductive study approach, therefore, the inductive research design of this study will provide an opportunity to answer questions that previous qualitative research has not adequately addressed (Leedy & Ormrod, 2005). Qualitative inquiry is characterized as inductive and emerging (Creswell, 2018).

### **Participants**

The sample of participants included respondents who, at the time of the study, were working as a DSP for an agency or organization located in Maine that provides community or residential housing services for individuals with ID. I also required participants to have worked in this field for greater than six months. The setting for this study was the State of Maine. The United States Census Bureau estimates that the population of Maine was 1,338,400 in 2018 (United States Census Bureau, 2018). The target population for this study will be DSPs working with adults with mild to moderate ID in Maine. Individuals who wish to work as DSPs must earn certification as a Maine Direct Support Professional through the Maine College of Direct Support. At the time of the writing of this dissertation, a report on all currently active learners in the College of Direct Support system, indicated there were approximately 13,141 DSPs in the state of Maine (DHHS Employee, DSP Coordinator for the College of Direct Support system, personal communication, March, 2020, personal communication, email, 3-5-20). This number represents the estimated number of DSPs currently working having completed their required coursework. In an email exchange, the DHHS worker wrote, “In a perfect world this should be an accurate count of how many DSPs are currently working across the state, but unfortunately

not all agencies are good about making people inactive when they leave their employment, so this number is likely inflated. There could also be duplicate learner IDs for one person in some cases” (DHHS Employee, DSP Coordinator for the College of Direct Support system, personal communication, March, 2020, personal communication, email, 3-5-20).

### **Recruitment of Participants**

Originally, sampling locations were solicited through a Provider Directory (State of Maine Aging and Disability Services, 2019) that the State of Maine Office of Aging and Disability Service manages. The State of Maine Office of Aging and Disability Services (OADS) (2019) is the certifying entity for individuals who wish to be a DSP and support Maine citizens with ID. Furthermore, the curriculum through the State of Maine meets the training requirements for MaineCare Sections 21 and 29. Maine citizens with ID receive funding for essential MaineCare services. These services include residential staffing and support for people who need ongoing, in-home supervision and assistance (Section 21) and community support and services for people who need help accessing and integrating into their community (Section 29). DSPs are hired for both Section 21 and Section 29 employment positions (Maine Coalition for Housing and Quality Services, 2019). This provider directory lists agencies that employ DSP workers and was a valuable resource in the inquiring about agency availability to participate in this study. A secondary website source to recruit was additionally used; this website is maintained by the Maine Association for Community Service Providers (MACSP, 2019), a group of Maine agencies that have chosen to be members of this group. MACSP is an association of organizations which provide supports and services to children and adults with ID. According to the website, MACSP works with many bureaus, offices, and departments of the state government to deliver high-quality services to Maine people. In 2020 their membership consisted of

approximately 70 organizations operating in all 16 counties of Maine, providing comprehensive services across the state (MACSP, 2019). The dataset provided contact information for each agency.

Initial correspondence was sent to 45 selected agencies based on their website descriptions or previous knowledge of the populations and services provided. The recruitment letter (see Appendix A) and a copy of the Letter of Invitation to DSPs (see Appendix B) and the Informed Consent (see Appendix C) were all included via electronic mail to the Director of each selected agency. In the email correspondence the administrators were asked to dispense the recruitment letter and informed consent form. These documents provide clarification on the purpose of the study, instructions on how individuals can schedule interviews, and participate in the study, as well as the informed consent letter. Initially, the response rate was quite limited. Agency directors were sent follow up emails and called directly in an effort to encourage participation support, answer questions, and to follow-up to see if the original requesting email was received.

In an effort to secure interview participants, two to three follow up emails or phone calls were made to the administrators. These attempts to recruit participants did not garner many participants. Only four individuals contacted me within a span of a month. I received varied support from administrators; some administrators were nonresponsive while others were supportive. Due to only four participants being identified through the initial recruitment email to administrators and follow up efforts, I contacted these four after the interview through their supplied email. The four original DSPs were emailed to inquire about additional DSPs possibly becoming participants. Based on the low participation rates, a snowball sampling technique was used. In this type of snowball sampling, the first participant is recruited and then that participant

provides multiple referrals. Each new referral then provides more data for referral and so on, until there are enough participants for the sample (Cohen & Arieli, 2011). This sampling technique is used for conducting qualitative research, with a population that is hard to locate (Cohen & Arieli, 2011). Efforts were made to not directly ask the study participants to identify other potential participants by name. Rather, the participants were asked to encourage other DSPs to come forward on their own and seek out information by contacting me. Email, texting, and the use of Facebook messenger proved to be more effective than the recruitment letters. In the end, four original participants were recruited from a recruitment letter disseminated by the administration. The remaining 20 participants could have resulted from the recruitment letters disseminated from the administrators or through snowball sampling techniques. I did not ask where the participant had received the information for the study, nor did I track the names or locations of the agencies. This decision was made consciously so as to maintain the DSPs' confidentiality and not bias me.

This qualitative study design, was approached through grounded theory methodology. This qualitative study relied upon the Straussian grounded-theory model, first developed by Glaser and Strauss (1967) and later refined by Strauss (1987) and by Corbin and Strauss (2015). Within this model, I use constant comparative analysis methods to generate meanings, categories, and grounded theory. Glaser and Strauss (1967, pp. 105-115) described this method of continually comparing concepts with each other as their “constant comparative method.”

### **Sampling Procedure**

Glaser and Strauss (1967) called for use of “theoretical sampling”—a process of deciding what data to collect next while “jointly collecting, coding, and analyzing data” (p. 45). The quality of data can affect the sample size; hence theoretical sampling is recommended when

using grounded theory. The theoretical sampling procedure dictates that the researcher chooses participants who have experienced or are experiencing the phenomenon of the study. The more systematic and widespread the theoretical sampling is, the more completely the conditions and variations will be discovered, permitting greater generalizability, precision, and predictive capacity (Corbin & Strauss, 2015).

Glaser and Strauss (1967) argued that the success of theoretical sampling lies in reaching “theoretical saturation” (p. 61), the point at which no additional data are emerging to enable the researcher to develop further properties. Repeated instances of similar data indicate that a point of saturation has been reached, and data collection in that area can be stopped. At that point, the researcher proceeds to collect data from other groups—or in the study of a single group, from subjects more likely to contribute data to a different category in the study. For this study, the last two DSPs who were interviewed were added because they were male and somewhat spontaneously, as Holstein and Gubrium (1995) suggested could be the case. Theoretical Sampling was attempted to achieve saturation but due to pragmatic issues, there were only five males that participated.

### **Informed Consent**

Permission to conduct research involving human subjects was sought out from the IRB and all subsequent guidelines related to this study were strictly adhered to. I completed the CITI Program as a requirement of the graduate school at the University of Maine at Orono and the institution’s IRB. Interested participants were asked to review an Informed Consent form that states the purpose of the study, procedures, risks, benefits, and assurance of protection of confidentiality (see Appendix C). As part of the Informed Consent, participants were informed that should they become uncomfortable at any time in the interview process, they would have a

choice to not answer the question or to stop the interview for any reason and without any negative consequences. In addition, participants were informed that interviews would be audio recorded. The interview was transcribed without any identifying information and a corresponding number was assigned to the interview. The taped interviews were erased after they were transcribed. Care was taken to assure the confidentiality of all participants and the employment agencies.

## **Data Collection**

### **Interviews and Instrumentation**

Glaser and Strauss (1967) emphasized the need to make data collection rigorous in qualitative research; thus, it is important that an entire interview is conducted within a strong but flexible plan. During an interview, a researcher may observe body language or tone of voice or level of emotional intensity; the researcher should include such observations in the field notes or memos, which become part of the artifacts of the study along with the transcripts of interviews. Memoing will be discussed further in the following section. The interviewer must listen well, use good personal interaction skills, frame questions well, and use gentle probing to elicit valuable and detailed responses (Sunstein & Chiseri-Strater, 2016).

The DSPs were invited to participate in an in-depth interview which explored how they perceive the sexuality of those with ID, as well as how they see their role, and its challenges, and ways to assist those they work with related to sexuality issues. All of the interview settings were based on the preference of the participant. Once permission was obtained, each interview was audio recorded using a personal handheld device with a portable microphone.

Two types of data collection including in-depth open-ended interviews and written documents or memoing were performed within this study (Patton, 2014). An interview guide with several questions (see Appendix D) were used within this qualitative study. The interview

questions were developed based on the reviewed literature. The Young et al. (2012) and Ćwirynkalo et al. (2017) studies served as a primary outline and guide, and the research by Allen (2008) helped to inform the specifics of the interview questions. Open-ended questions facilitated an opportunity for participants to give reflective responses and descriptive examples. The interview schedule was conducted by asking each bulleted question as an independent and distinct question, one at a time. Additional probing questions were asked as clarification when needed. Sample probing questions were; “Can you tell me more about your experiences?,” “Did that incident happen only once or multiple times?,” “Can you clarify what you mean? and, “Was that a consumer with a mild or moderate ID?.”

Patton (2014) describes qualitative data as telling a story by taking the reader to a time and place captured through the words of the individual who has experienced the phenomenon. Open-ended questions were selected for their ability to focus on the wholeness of the experience (Moustakas, 2010), with probes to produce in-depth responses. The interviews have a semi-structured format, which Bogdan and Biklen (2003) suggest allows the narrative to naturally develop through probing conversation. Semi-structured interviews are in-depth interviews during which the respondents answer preset open-ended questions; these types of interviews (unless longitudinal) are conducted once only, and with an individual and generally cover the duration of 30 minutes to an hour or more (Creswell, 2018). The format of this study mirrored the outline of a semi-structured interview in that the semi-structured interviews had a core question and many associated questions related to the central question (Creswell, 2018). When taking into account the prior research and gaps in the literature in understanding the lived experiences of DSP’s, in-depth interviewing was considered the most appropriate method.

## **Memo Writing**

Memo writing is an important part of the open coding process. Its purpose is to interrupt the process with reflection and probing to call into question the efficacy of the concept and both to reveal a more appropriate concept and to move the researcher toward more abstract and theoretical thinking (Glaser & Strauss, 1967). Memo writing is an analytic process considered essential in ensuring quality in grounded theory (Birks & Mills, 2015). I used memoing to analyze and code data, and develop codes into categories early in the coding process. Memos detail why and how decisions were made related to sampling, coding, collapsing of codes, making of new codes, separating codes, producing a category and identifying relationships. Memoing is an ongoing activity that informs the GT findings (Birks & Mills, 2015). Memos vary in form and length according to the stage of the research project and the type of coding one is performing.

Memos are not simply about "ideas." They are involved in the formulation and revision of theory during the research process. Writing memos should begin with the first coding sessions and continue to the end of the research (Strauss, 1987). Birks and Mills (2015) offer the analogy that if data are the building blocks of the developing theory, then memos are the 'mortar' (p. 119). Memos are the storehouse of ideas generated and documented through interacting with data (Corbin & Strauss, 2015). Memos provide detailed records of the researchers' thoughts, feelings, and intuitive contemplations (Birks & Mills, 2015).

## **Data Analysis Process**

Adhering to grounded theory methodology practices, the data for this study was analyzed for patterns and variations. In grounded theory, the data collection is standardized and continually analyzed. The investigator must analyze the first samples of data for cues and the

data must be examined for regularity; finding patterns or regularities helps to give order to the data (Corbin & Strauss, 2015). Conducting the analysis from the start is necessary because it is used to direct the next interview and observations. The carrying out of procedures of data collection and analysis systematically and sequentially enables the research process to capture all potentially relevant aspects of the topic as soon as they are perceived (Corbin & Strauss, 2015). This process is a major source of the effectiveness of the grounded theory approach.

### **Transcribing**

Once each interview was conducted, the audio recording was sent through an online program called Rev.com. Rev employs over 50,000 professionals globally providing transcribing, translating, and closed captioning services. Due to the global setting of this online service, the transcribing services are literally 24 hours a day and seven days a week, with an option to have support provided. This is a speedy and reliable source where transcribing services are purchased and kept in a secure account where the account owner has a unique username and password to log in. Rev.com was recommended to me from two other academics who have used it in their research. The transcripts are kept confidential as the participant's name was never stated, nor the agency where they worked. At the start of each interview the researcher stated the time and date of the interview and each participant was given a number. The assigned interview number is how each transcript was referenced through the coding process. I later assigned a pseudonym to each of the interviewees.

If a participant had mentioned a consumer by name or stated which agency they worked for, the researcher redacted the information from the transcript, concealing the content so it was no longer visible when reading and rereading the transcripts. Transcribing the tapes allowed for ease of data coding and establishment of emergent themes (Creswell & Poth, 2018). Recording

the interview made it easier for me to focus on the interview content and verbal prompts, thus enabling the transcriptionist to generate a “verbatim transcript” of the interview (Creswell & Poth, 2018). The first interview was transcribed and evaluated for quality and accuracy using the online Rev service. Once I determined that the quality, speed of transcription, and overall effectiveness of the transcribing service was acceptable, three more interview audio recordings were requested. The coding began with the first four interviews.

Inter-observer agreement was accomplished with the assistance of a colleague with extensive experience in qualitative coding. A second person coding the transcripts authenticated the data. Lincoln and Guba (1985) described this as having “inquiry credibility” within naturalistic methodological practices. My colleague served as the auditor and reviewed the findings of the primary coder (me) and served as a consultant when questions arose about the strength of certain categories and the placement of ambiguous data points. Of the 24 transcripts, five were randomly chosen and were fully reviewed by the auditor. Auditors are thought to be useful in qualitative analysis as they provide a means of ensuring neutral or unbiased results (Hsieh & Shannon, 2005).

### **Coding**

Coding was the fundamental analytic process used by the researcher. In grounded theory research, there are three basic types of coding: open, axial, and selective. The purpose of coding is to give the analyst new insights by breaking through standard ways of thinking about or interpreting phenomena reflected in the data (Hsieh & Shannon, 2005). This study used a modified approach to open, axial, and selective coding (Strauss & Corbin, 1990) to guide the analysis.

**Open Coding.** Open coding is the interpretive process by which data is broken down analytically. In open coding, events, actions or interactions are compared with others for similarities and differences. Open coding, according to Corbin and Strauss (2015) entails a close examination of the data, breaking it down into parts, making comparisons, and questioning. Open coding occurred at the beginning of the first interview. Coding was completed with the analysis of field notes taken during and after each interview, and what was heard and observed during the interviews. A constant comparative analysis is an analytical process used in grounded theory for coding and category development. This process begins with the first data collected and informs the research process. Incidents are identified in the data and coded (Bricks & Mills, 2015).

Each transcript began with a process of collecting indicators—that is, words, phrases, statements from the data, memos, or observations, (Glaser & Strauss, 1967). Interview statements shared about consumers with severe ID were not included in the open coding process as consumers with severe ID were not the focus of the study. Grounded Theory demands more in analysis than simple inspection of the data. However, Glaser and Strauss (1967) do not instruct the reader in a prescribed mechanism for performing the coding. They describe the conceptualization of coding. Furthermore, there is no consensus on what number of responses equates to a substantive finding. Within this study, open coding occurred two ways; when conducting the interviews and when creating memos. I was able to collapse ideas originally when reading through memos, listening to the audio recordings and reading through the transcript narratives. This provided an opportunity to further focus and construct open codes within the emerging data.

**Axial Coding.** The concepts discovered in the open coding process were first considered provisional. From there, each concept was identified by being present in either the interviews, field notes, and/or observations. The concepts that were frequently present were then given conceptual labels so that all the conceptually similar responses were grouped together to form categories and subcategories, where initial codes are then compared to other codes (Glaser & Strauss, 1967). This repetitive process involves inductive and deductive thinking (Charmaz, 2006). The Rev.com website was then used to do keyword searches in an effort to achieve saturation and exhaust the search for concepts and search for relevant details that could generate new categories. Axial coding was completed once all 24 transcripts were analyzed and the data was no longer generating new categories and had reached saturation.

For this study, a coding category was considered a theme when six or more participants discussed this theme. A total of 16 themes emerged from the axial coding. These themes were then organized under the topics of focus for this study: *attitudes and beliefs, experiences in sexuality, influencing factors, gender, and suggestions for sexually related issues*. These themes will be described in detail in Chapter Four: Findings.

**Selective Coding.** Selective coding is the process of relating the categories from axial coding and realizing the core or broad category(ies) of the study. The goal of selective coding is to integrate the different categories or themes that have been developed, elaborated, and mutually related during axial coding into one cohesive theory (Strauss & Corbin, 1990). A modified approach to open, axial, and selective coding analysis was completed, in that it was not the intention of this study to build theory (Olmstead et al., 2013). Within selective coding, the findings from axial coding are further elaborated, integrated, and validated, selective coding is carried out on a more abstract level (Strauss & Corbin, 1990).

An examination of the connections between the 16 themes revealed three broad categories, which described “the central phenomenon around which all the other categories are integrated” (Strauss & Corbin, 1990, p. 116). These three broad categories include *My Hands are Tied*, *Isolation*, and *Champions for Sex*. The connections between the themes and these three broad concepts will be discussed in Chapter 4: Findings.

### **Risks**

The risks to participants in this study were minimal. Participants read and stated they understand the Informed Consent form (Appendix C) prior to conducting any research; participants were provided a copy of the consent form. Emotional distress was a potential risk as the participants considered sexual issues. Interview fatigue was also a potential risk that was anticipated and minimized. These potential risks include: a minimal physical risk to participants and there was minimal future emotional distress. The participants’ personal or professional time was impacted by agreeing to participate in an interview. Participation in the study was entirely voluntary, and names were not used in the transcription nor in the presenting of the data. No identifying information was included in the transcription after the information was redacted. In the instances where participants discussed identifying information, the content was modified since the consent form stated, “identifying information will not be reported in any publications.” Sieber (1992) stated, researchers typically present confidentiality agreements at the beginning of the data collection process and take steps to protect subject information.

### **Limitations of the Study**

The design of this study was successful in gathering descriptive data from participants during the interview process. However, using interviews as a single data sample source can be a limitation because validity enhancement measures like triangulation are not available (Creswell,

2018). Furthermore, interviews and the self-reported data are limited by the fact that they rarely can be independently verified and there is difficulty in replicating this study since it is based on DSPs in a rural state which is a unique group in unique situations (Creswell, 2018). This study could be replicated in other rural regions or settings but would not be verified in an urban region or setting. In an effort to minimize some of the limitations, an auditor (described earlier) was used in the data analysis to ensure neutral or unbiased findings and, therefore, increase the credibility of the study. Additional limitations are discussed in Chapter Five: Discussion.

### **Ethical Conduct of Study**

Steps were incorporated into the study to minimize the cumulative effect of researcher bias, as well as to best support all ethical standards and tenets of professional integrity (McMillan & Schumacher, 2014). Participation was voluntary and all participants had the option to exit the study at any time without penalty as communicated in the informed consent form (McMillan & Schumacher, 2014). Permission to conduct research involving human subjects was sought out from the University of Maine Institutional Review Board and all subsequent guidelines related to this study were strictly adhered to (McMillan & Schumacher, 2014). Transcriptions were checked for context and content accuracy before analysis began. These precautions and the fact that conclusions drawn are grounded in actual data helps minimize the risk of bias. A real advantage of grounded theory is that analysis starts as soon as data collection begins in the first interview. Charmaz (2006) holds that analysis can start during the first interview if the researcher identifies concepts that are striking at that time. However, it is not sufficient simply to inspect data and label interesting points, the data have to be analyzed in a systematic and rigorous manner to discover the concepts leading to the categories. A working awareness of bias is imperative in all interview research.

## Summary

This qualitative study used grounded theory research methods as a lens to reveal how the study participants perceive sexuality issues of individuals with ID. The interviews were semi-structured format and each of the interviews were recorded and then transcribed. Once the audio recordings were uploaded to the Rev.com website the audio recordings were deleted. Participant confidentiality was ensured, and IRB permission was obtained before beginning data collection. Risks were kept to a minimum. A written explanation of the study was provided to the participant and informed consent was obtained.

This qualitative study used Straussian grounded-theory design to guide the collecting and coding of interview data in order to identify emerging categories. The researcher collected data through open-ended interviews with 24 DSPs who have worked in the State of Maine for at least 6 months with adults with a mild to moderate ID. Data analysis was analyzed by using Strauss and Corbin (1990) coding techniques where the transcribed interviews were coded into themes. The 16 themes were organized according to the sub-research questions of this study and are the focus of this research. The 16 themes were then further organized into three broad categories including, *My Hands are Tied*, *Isolation*, and *Champions for Sex*. There are limitations to this study; however; given the limited amount of qualitative research on this topic, findings within this study are worthy of note.

## CHAPTER 4

### FINDINGS

This chapter will present the findings that illustrate the answer to the overarching research question: *How do Direct Support Professionals (DSPs) view and support the sexuality of those with ID?* The five sub-questions that will be answered are:

- Sub- Research Question 1. *What attitudes and beliefs are held by DSPs regarding the sexuality of individuals with intellectual disabilities?*
- Sub-Research Question 2. *What are the experiences for DSPs in relation to the sexuality of individuals with ID and the DSPs' employment position?*
- Sub-Research Question 3. *What factors influence DSPs' responses to the sexuality of individuals with ID?*
- Sub-Research Question 4. *How does gender (of the DSP and consumer) influence the role, approach, and ideas for ways to assist adults with ID related to sexual issues?*
- Sub-Research Question 5. *What suggestions do DSPs have for working with sexually related issues of individuals with ID?*

Within this chapter, the themes and the three broad categories will be presented. For the themes, each sub-question will be answered in its order of presentation and will identify those themes that emerged from interviews with DSPs regarding their attitudes and beliefs, their experiences, influences, and gender, as well as suggestions for working with sexuality issues. Six or more participants described each theme that is analyzed. Direct quotations from interview transcriptions are provided to the reader throughout this chapter. Each section of the themes

concludes with a summary highlighting the main findings to answer each sub-research question. This will be followed by an analysis of the three broad categories. Finally, a chapter summary will highlight the main findings to answer the overarching research question.

### **The Participants**

Twenty-four DSPs participated in this study. Participants have been given pseudonyms in an effort to best protect their identities (See Table 4.1). Each participant was screened and met the criteria for inclusion at the time of the interview. Specifically, all participants worked in the State of Maine, were employed in residential or day program settings, and had supported adults with mild or moderate ID for at least six months.

There was one in-depth interview consisting of a series of open-ended questions with each participant (see Appendix D). All interviews were face-to-face and lasted approximately 90 minutes. The interview settings were based on the preference of the participant. Individual interviews took place over a two-and-a-half-month period with DSPs working in eight of the 16 counties in Maine. Additionally, all interviews were recorded and transcribed by REV.com an online transcribing service. A summary of the participant sample demographics is provided below. I will then discuss the findings of this study.

#### **Participant Sample Demographics**

Nineteen females and five males participated in this study. According to the United States Bureau of Labor Statistics (2020), females outnumber males in human services and health professions. Therefore, this study's participant sample is reflective of the employment trends in the State of Maine. The Participant Sample Demographics table (Table 4.1) includes their pseudonym, age, gender, highest education level completed, number of years employed as a

Table 4.1 Participant Sample Demographics (N=24)

Pseudonym	Age	Gender	Education	Years employed as a DSP	Years employed at current agency	Number of consumers with mild to moderate ID
Addi	21	Female	In college	2	2	10
Brittney	21	Female	In college	4	1.5	10
Carl	36	Male	Bachelor's	12	8	50
Dianne	26	Female	HS Diploma	7	1	25
Elouise	40	Female	Bachelor's	2	2	8
Finley	24	Female	Bachelor's	6	1	25
Gabby	41	Female	Bachelor's	10	4	15
Harriet	24	Female	In college	6	2.5	10
Ian	24	Male	Some College	1	1	10
Jennifer	21	Female	Some College	1	1	3
Kristin	25	Female	HS Diploma	2	2	40
Lewis	21	Male	Some College	4	4	10
Mary	25	Female	Bachelor's	3	1	6
Natalie	32	Female	Bachelor's	12	8	14
Olivia	35	Female	Associate's	16	7	50
Patricia	40	Female	HS Diploma	15	7	1
Quinn	51	Female	HS Diploma	6	6	6
Rachel	33	Female	Bachelor's	15	15	40
Sarah	54	Female	Associate's	12	12	17
Tiffany	26	Female	Bachelor's	1.5	2	4
Uri	25	Female	Bachelor's	1	1	1
Violet	43	Female	HS Diploma	19	4	12
Weston	30	Male	HS Diploma	11	7	22
Xander	54	Male	Associate's	8	7	12

DSP, years employed at their current agency, and the total number of consumers with mild to moderate ID they have worked with.

The overall age of the participants ranged from 21 to 54 years old, with the average age being 32 years old. All but one identified their race as Caucasian/White; one DSP identified their race as both Black and White. In terms of education, most DSPs had participated in some form of post-secondary education. Specifically, six DSPs had completed at least one college course or were currently in college, three had earned an Associate's degree, and nine had earned a Bachelor's degree. Six of the DSPs reported that they had earned a high school diploma.

Years of employment as a DSP ranged from 1 to 19 years; the average time the participants had worked in this field was 7 years. When asked how long they had been employed in their current position, responses ranged from 1 to 15 years, with the average being employed 4 and a half years with their current employer.

The DSPs had a wide range of experience in terms of the number of consumers with mild to moderate ID that they had worked with. When asked how many consumers they had worked with, the number ranged from 1 to 50; the average number each DSP had worked with was 18 consumers with mild to moderate ID. The total number of consumers served by the 24 participants in this study was 426.

In terms of work setting, most of the DSPs (n=18) were currently employed in a group home/residential setting with one to five individuals living in the home at any time. Five of the DSPs worked in a day program with consumers, and one participant reported that they worked in an individual's own private home. Finally, although an individual's sexual orientation was not asked in the demographic question portion of the interview, four of the participants disclosed that they identify as lesbian women.

## The Themes

The themes presented below are organized around the five sub-questions: attitudes and beliefs, experiences in sexuality, influencing factors, gender, and suggestions for working with sexuality-related issues. The themes that emerged from the interviews for each of the sub-questions are presented within each section below (see Table 4.2).

### Attitudes and Beliefs

In this section, I describe the DSPs' attitudes and beliefs about working with their consumers on sexuality issues. I answer the first sub-research question: *What attitudes and beliefs are held by DSPs regarding the sexuality of individuals with intellectual disabilities?* To answer this research question, participants were asked what their feelings were on consumers' use of or involvement in the following sexuality issues: social media, erotica, dating, sexual relationships, contraception, masturbation, and LGBTQ+. Specifically, DSPs were asked about their thoughts on their role in educating, facilitating, and supporting their consumers in these sexual issues. Three themes emerged from the transcriptions of the in-depth interviews with the DSPs as they relate to their attitudes and beliefs: *sexuality is a life experience and for everyone*, *consumers' sexuality is cute*, and *sex is their right but not my role*. The three identified themes are discussed below and direct quotations from the interview transcriptions are offered to support the findings.

**Sexuality is a life experience and for everyone.** The first theme to emerge from the interviews with the DSPs was the DSPs' universal belief that sexuality is a life experience and something that is part of everyone's being. Most DSPs went so far as to state without any limitation or hesitation that their consumers have a right to their sexual expression. They

Table 4.2 Themes for Attitudes and Beliefs, Experiences in Sexuality, Influencing Factors, Gender, and Suggestions for Working with Sexuality-Related Issues

### Suggestions for Sexually Related Issues

#### **Attitudes and Beliefs**

- Sexuality is a life experience and for everyone
- Consumers' sexuality is cute
- Sex is their right but not my role

#### **Experiences in Sexuality**

- Sex is part of the job
- My job is to keep them safe and appropriate
- We're left to figure it out on our own

#### **Influencing Factors**

- Parents and guardians dictate what happens
- It depends on the person and the place
- My own personal values and experiences play a role

#### **Gender**

- Everybody is equal
- The sexual double standard is alive and well
- Working with the other gender makes it harder to relate

#### **Suggestions for Working with Sexuality-Related Issues**

- More sexuality training and education is needed for DSPs
- Consumers need more skills training on sexuality issues
- Parents and guardians need sexuality acceptance training
- Clearer policies are needed on sexuality issues

expressed that individuals with ID are just as deserving as anyone else and felt strongly that sexuality was a human right and is acceptable for individuals with ID.

One female DSP described her support for her consumers' sexuality and reflects this attitude that sexuality is part of being human.

Oh, absolutely positive. When you take a DSP course, they teach you that sex is a need.

It's a human nature need, whether you have intellectual disabilities or not. Sex is a need, whether you're masturbating, or using sex toys, or just looking at magazines. I feel very positive about that because everybody needs that part of their life... (Mary)

Mary describes that sex is a human need and feels very positively towards her consumers engaging in sexual activities.

One male DSP described his support for consumers' sexual lives and his belief in respecting their personal lives.

Oh, that's completely fine. And it's their personal life. They have their own life. We have our own life. And I kind of just am cool. I'm cool with anybody dating and finding someone that makes them happy. Regardless of what they have or any of that (Lewis).

Lewis expressed support for his consumer's right to have sexual autonomy acknowledged that they have this right regardless of their ID.

One female DSP discussed the job duties of a DSP and reflected on her belief in supporting the sexual needs of the consumers.

The agency that I work with is pretty positive towards it as well. My feelings are that it's normal and it should be accommodated. Adults with disabilities have the right to access erotica the same as any adult. And our job as DSPs is to support patient learners in accessing and using erotica safely. That can involve training on how to use and clean sex

toys in order to minimize injury or infection, and assisting with a purchase of erotic literature and films, or helping to set up subscription access to something like Playboy Channel. I think it's pretty normal and we should accommodate it. (Elouise)

Elouise normalized consumers wishing to access erotica and discussed how educating and supporting consumers in the safety and function of the erotica should be accommodated for.

**Consumers' sexuality is cute.** A second theme to emerge from the interviews with the DSPs about their consumers' interest or activities related to sexuality was their perception of them as adolescent or child-like, no matter their consumers' age. Some DSPs believed their consumers to be naïve and innocent in their sexual lives. When asked about various aspects of sexuality, statements describing their adult consumers with ID as “cute” and “sweet” reflected this attitude. One female DSP described her consumer in a childlike way.

So he met this girl at Program, and they were talking on the phone almost every day, and they actually had set up a time to go bowling. And I took him to bowl with her, and it was the cutest little thing ever. Like, they were holding hands. They were pecking on the cheeks. They were acting like they were in high school all over again. And it was the coolest thing to watch them interact with one another. Because when you become a DSP, they tell you, "Oh, well, these guys are two or three years old in their head." And then you go there, and you're like, "What are these people talking about? These guys act like they're in high school." (Kristin)

Kristin was supportive of her consumer's sexuality and when she stated the relationship is “the cutest little thing ever” she revealed that her perception of her consumer's relationship is juvenile.

In another experience, one female DSP discussed her consumer's relationship and her role in dropping the consumer off at a girlfriend's house.

My person served, he was 59. He was 59 years old and he very definitely had a girlfriend. He had a girlfriend and they were pretty cute. He was so high functioning that he didn't have staff at nighttime, so sometimes I would leave there on a Sunday when he had pay per view and she'd be at his house and she wouldn't be there in the morning. I feel like he was no different than any other person dating. (Patricia)

Patricia felt that the consumer has the same sexual rights as others but described the consumer's relationship using terms that are usually reserved for children. One male DSP shared similar attitudes when describing his experiences with his consumer dating.

Yes. I worked in a house, all females. Two were 23 to 28. And both, actually, in fact, were dating someone at the time. It was a matter of going out with other staff because the other person would have a staff with them, taking them out on ice cream dates or going to the movies, it was sweet to see them in these relationships. We didn't have to do many reminders. They seemed to have a good sense about physical parameters and not going overboard with PDA, I guess. There was some hand-holding and maybe they would give each other a hug and a smooch after they left. But that about sums up my experience with that. (Carl)

Carl used the term "sweet" to describe the dating of his consumers. He then went on to share that he did not have to remind them of appropriate parameters for displays of affection in public.

Kristin, Patricia, and Carl supported the sexuality of their consumers and care for their wellbeing. Yet, there was an underlying current within these responses that, due to their

consumers' ID, they are knowingly or unknowingly categorized as innocent and described with words such as "sweet" and "cute."

**Sex is their right but not my role.** The third and final theme to emerge related to attitudes and beliefs is that DSPs discussed how they felt they should support the right of their consumers to engage in various sexuality-related issues, but did not feel responsible to be directly involved in the consumer's education, support, or facilitation. Some DSPs held the attitude that someone else was responsible to provide sexuality support. Parents, guardians, nurses, or an agency's management were named as possible supports for the consumers. Furthermore, some DSPs felt that sex education should be provided by a more knowledgeable professional or when the individual was in a school setting as a student. One male DSP believed he should not be the person to educate his consumers.

I think as a worker, the primary role is to, again, provide privacy and educate about being private and saying it's got to be in your bedroom. That's the place to do it. Just so that they're safe and everybody else in the house is not seeing what they're doing. But I don't think it's something that we should be teaching and I think it's better if there is a sex-ed class, or maybe we could help with potential videos to help them learn. But I think that would have to go through the administrator to see if that's something they could implement. But I think sex ed classes are great. It certainly helps give some information on all those pieces. (Carl)

Carl discussed a sexuality education class or informational videos as alternatives to a DSP being responsible for the sexual support in consumers' lives.

A female DSP discussed another alternative, reflecting an attitude that the DSP is not responsible for educating consumers on sexual issues.

I think education would be huge. I mean, in my experience, our clients know that they have the right to do what they want and especially with mild to moderate ID, they will tell you, and they know. So, I think sex ed training during a counseling session would be good, where they can go in with their girlfriend or boyfriend or partner and ask specific questions to the counselor. To them, that would be a huge help. I don't know if training for everybody at once would be effective, but if hospitals or doctors' offices offered counseling with them and their partner to talk about sex ed, I think it would be hugely helpful. (Olivia)

Olivia shared her belief that medical personnel or a clinician needs to be the primary educator for consumers' sexuality education and these professionals could be responsible to answer questions about sexual relationships.

One female DSP believed other options, beyond her directly being responsible, should be used to educate consumers about sexual issues.

It would be nice to maybe have everyone together to talk about what's appropriate to do or not. As well as if people had some access to a couple of books or even a video of some sort, so there's something that we can go over together. Maybe not full porn, but something more educational. Like references maybe or maybe some other reading materials. (Uri)

Uri suggested that providing access to literature and informational movies is an acceptable option in place of DSPs providing direct sexuality education or direction. Carl, Olivia, and Uri each reflect an attitude that education, support, and facilitation of sexuality issues is not their responsibility, and offer alternative solutions to a DSP being tasked with handling consumers' sexual issues, particularly education.

**Attitudes and beliefs summary.** There were three themes that emerged that reflect DSPs' attitudes and beliefs when it comes to their consumers' sexuality. The first theme that emerged was a belief shared by DSPs that sex is a life experience for everyone. Most of the DSPs declared, without hesitation or limitation, that sexuality was a human right for anyone. The DSPs shared a belief that sexuality was an absolute right for consumers and that everyone is equal; consumers have the same sexual desires and needs as anyone else.

A second theme that emerged related to DSPs' attitudes and beliefs was that they view consumers' sexuality as "cute." Some DSPs described their consumers' sexual lives using the terms "sweet" and "cute." Through their comments, DSPs knowingly or unknowingly revealed an attitude toward their consumers' sexual behavior as innocent, naïve, and infantilized. While DSPs were clearly supportive of their consumers' rights to sexuality, their attitudes can be seen as patronizing as they describe their adult consumers in adolescent or childlike ways.

A third and final theme to emerge related to DSPs' attitudes and beliefs was that they see sex as a right for their consumer, but not necessarily their responsibility. The DSPs felt that the role of educating, facilitating, and supporting sexuality was not part of their job duties. For example, DSPs felt that a parent, guardian, nurse, therapist, doctor, or the program staff should be responsible for providing sexuality education. The DSPs also recommended films and literature as an alternative to DSPs having these educational discussions directly with their consumers.

### **Experiences in Sexuality**

In this section, I describe DSPs' experiences with various sexuality issues when working with consumers who have mild to moderate ID. I will answer the second sub-research question: *What are the experiences for DSPs in relation to the sexuality of individuals with ID and the*

*DSPs' employment position?* The participants were again asked to reflect on seven sexuality topics: social media, erotica, dating, sexual relationships, contraception, masturbation, and LGBTQ+ issues. However, instead of being asked about their attitudes on their role as DSPs in educating, facilitating, and supporting their consumers, they were asked to describe their experiences with consumers in these areas. The research participants shared stories of how they educated, facilitated, and/or supported their consumers with these sexual issues. Three distinct themes emerged: *sex is part of the job*, *my job is to keep them safe*, and *we're left to figure it out on our own*. Each of these themes is discussed below and direct quotes from DSPs are included.

**Sex is part of the job.** The first theme to emerge under experiences was the recognition that DSPs deal with the sexual needs and issues of their consumers with ID. While the DSPs shared experiences in all seven areas they were asked about, participants most frequently had experiences with facilitating and supporting their consumers' use of erotica as part of masturbation, as well as their use of social media and dating. Some DSPs also recounted experiences with their consumers who identify as part of the LGBTQ+ community. Examples of the experiences shared by DSPs are described below. One male DSP described his experiences with erotic literature and masturbation and his consumers.

Yes, quite a few times. A lot of the times I would, if that was the case, if that was happening, I would just make sure that their door was closed and make sure to not announce it to the room, but maybe just say he's busy right now, or she, and let that be. Then maybe check up a little later to make sure that everything is all set. The magazine was a monthly subscription, it was basically set on his bed, and we let him know it was there, and then gently remind him that the door needs to be kept closed if he's viewing it.

(Ian)

Ian recognized that consumers will have subscriptions to erotic magazines and subscribe to erotic films. His response to a consumer engaging with the erotica was to offer them privacy by closing the door and ensuring privacy.

One female DSP described the range of experiences she has had assisting her consumers with erotica and masturbation.

I had a 30-year-old client ask me to go on porn sites and print him out pictures, which is their right. Not that I was obligated to do it. I could have refused and said, "No, I'm not comfortable doing that." But like I said, I agree with the whole meaning of sex. I've helped them set up their DVD players to get movies going. I've helped them use pornographic sites, like Pornhub or something like that. Things that they need. I've put batteries in vibrators. I've cleaned up semen. I've done it all. I'm more in touch with sexuality. When they talk to me about these things, I don't say, "That's inappropriate." I say, "Okay, well, if we want to talk about these things, we can go in your room and talk about it if you like." But I don't disagree with the things that they say, because it's their right to talk about things like that. And like I said before, we are all they have. Because again, some of them don't have family. (Jennifer)

Jennifer expected to be involved in the education, facilitation, and support of erotica and masturbation. She felt as though these duties are normal parts of the job.

Another common experience identified by DSPs is their involvement in dating and the use of social media. Their experiences ranged from consumers talking about wanting to date or dating advice, to having a steady relationship for years. One female DSP described her experience with assisting consumers with dating and the use of social media to find a date.

Sure. It's funny. When we get a younger consumer with mild or moderate ID, the top two things they want to do is have sex and drive a car. We know that nine times out of ten the option of driving a car is not going to happen. So, if they start expressing their wants or desires, we start setting up the tools for them to understand everything, and we set up match.com profiles and we educate them as best as we can with trying to set up a profile and help them read their messages if they're unable to, or yeah. It's been a learning experience. I think the most common one that we use is Plenty of Fish. (Olivia)

Olivia discussed an understanding that consumers want to date. She supported her consumers' requests to meet people online by helping them to develop online consumer profiles for dating.

Some DSPs also shared their experiences of supporting consumers who identify as LGBTQ+. They described being in a unique position as a DSP, in which they have seen the greater challenges for some of their consumers due to having both an ID and being part of the LGBTQ+ community.

One female DSP discussed her experience with a consumer who identified as a gay man and his challenges.

Yes, I have. I had a young gentleman who was roughly in his twenties I believe. He identified as a gay male and he was using technology to find boyfriends and various hookups. And it wasn't due to our agency, but his legal guardians, his parents believed it wasn't safe for him and that he was making unsafe choices and it was pretty upsetting for him because eventually they took away his phone and he lived in a group home where there was no internet access and he felt very, I'd almost say, excluded or isolated. That was his word, is that he felt isolated and that kids his age were able to have phones and

go out on dates and he felt very constricted and isolated. I thought that was really sad.

(Finley)

Finley felt that the greatest challenges in supporting LGBTQ+ consumers are the parents and guardians. Research participants reported consumers were willing to disclose their sexual orientation to the DSPs but not their parents or guardians. DSPs shared that, in their experience, they are sometimes more supportive than the consumers' parents and guardians.

**My job is to keep them safe and appropriate.** A second theme that emerged from the interviews with DSPs about their experiences in sexuality was a concern for consumer's safety and their role ensuring their consumers are being sexually appropriate. All of the interview respondents discussed the safety and appropriateness of the consumers' sexual lives.

Specifically, DSPs talked about their experiences with consumer safety in terms of concern with sexual exploitation in sexual relationships (both in-person and online), and in some cases, financial exploitation. One female DSP shared her experiences with consumers who were being sexually exploited.

One young lady who lives in a group home who I've known for eight years, she told me last week that she was approached by a person on her friend's list on Facebook. "If you show me yours, I'll show you mine." She didn't know how to handle that. So we talked about education and boundaries, appropriate boundaries around social media, is this person really your friend or what could be their motive or is that something we should, that maybe you should, think about. Do you have a relationship with this person? What you put on social media and online stays on social media and online. So my opinion on that is I might encourage it. But there I am cautious of people trying to exploit others.

Another example that I have is we have a different young lady who sent her boyfriend

nude type pictures and he shared them with his friends. She has been sexually exploited by him and she feels that that's okay because it was her boyfriend. So trying to educate her around the safety around social media is important. (Natalie)

Natalie shared two instances where two females were asked to send explicit sexual photos.

One male DSP described his experience with a male consumer who has developed a relationship with a woman online. The DSP discovered he was being financially exploited.

I had a client who began a relationship with a woman online. From what I remember she was not living in the US and asked him to send money after talking with him for a few months. He knowingly or willingly, however you want to put it, gave the money in the first case. The police are like, "Well, there's not much we can do." Consumers have to understand that yeah, that's their choice, but then there's nothing that can happen to defend them when the person disappears and with their money. (Weston)

Natalie and Weston show DSPs are compassionate towards the situations where consumers are taken advantage of and exploited in their relationships. Participants described encouraging their consumers to develop relationships and to have sexual experiences, but also discussed how safety and appropriateness are a concern.

DSPs also shared experiences with helping consumers understand appropriate locations and times for sexual relationships to occur. One female DSP discussed her experience with a male consumer who was caught in an unsafe sexual relationship and setting.

I'm one of a few people on my team that can have those uncomfortable conversations with the clients. So example, I learned this summer that one of our clients was having sexual intercourse behind a dumpster at his employment. So he and I talked about safe sex practices. Like, if you want to have your intimate relationship with this person, I

highly encourage you to do that if that's what you want to do but let's talk about condoms.

Let's talk about safe sex not in public and not while you're at work. (Gabby)

Gabby wanted to make sure she supported the sexual relationship of her consumer but had greater concerns about the safety and appropriateness of her consumer. A leading responsibility of DSPs is to keep their consumer safe and appropriate and this includes in their sexual lives.

**We're left to figure it out on our own.** The third and final theme to emerge from the interviews about their experiences in sexuality was that DSPs felt they have been left to figure out situations on their own. The majority of the DSPs discussed that their role in the sexuality of their consumers was ambiguous and each DSP needed to respond according to their "best guess" due to their unclear expectations, as well as the uniqueness of each situation.

One female DSP provided a description of the ambiguity surrounding sexual issues and DSPs' responsibilities and role in the matter.

The first experience that I have that kind of made me nervous, I would bring him to her house on, wrestling night, Friday night. I'd bring him over to her house and I would leave them there and he would take a taxi home. I brought him there and her parents were gone for the weekend. He just decided that he was going to stay the night. I leave because he doesn't have overnight staff, so I called the guardian immediately because immediately I was worried about like, okay, he's a guy, she's a girl. What am I letting happen here? I don't know. I don't know what the background was. I don't know. I called his guardian and she seemed more worried about the food intake that he was going to consume while he was there because he was diabetic than she was about him staying there with her. I left as I was supposed to. When I saw my boss, I, of course, like immediately cornered him

and was like, "What's going on?" Seriously. I left him there with her to stay the night and I was a little bit nervous I got to say. (Patricia)

In Patricia's experience, she was not prepared and was left to figure it out on her own. This is similar to another female DSP who shared how she had to make decisions without much guidance.

...and then sometimes she'll go to his house and we have to bring her and they usually have a couple of hours together. And then a couple of times we were kind of shocked but she was like, "When he gets here, we're going to take a shower together." And then we all didn't really know how to feel about that because it's not just her house, it's so many other people in the house. But I mean, it's her right so they did. The day that he came over and she said, "We're going to take shower when he gets here," my manager was here and she just kind of looked at me like she didn't know what to do either. So she's like, "I guess, it's her right." So I think it's really like an area people don't really know what to do sometimes. (Harriett)

Harriett described how she felt unprepared to handle this experience when her consumer advocated for the right to shower with her boyfriend. The DSP explained that she was unsure how to respond for several reasons including the other members of the household and their reaction to the couple showering, and not knowing if the consumer was allowed to according to her plan or the agency's policy.

Another female DSP shared a lack of training in her role as a DSP when it comes to handling sexuality-related issues with consumers.

I think it'd be good to have a class about it or clearer expectations and to know what policies are. Like, for the example of that one consumer having sex with her boyfriend,

yeah. I think that there could be a lot more training on things like this before we get thrown in there like, "Well, that's what you're dealing with today, kind of thing. Pass it on to the others." And then it's like, "What?" Then I have to tell the others and I'm like, "What?" So, now it's my responsibility to share initiatives or to like, share new procedures. Like either putting in shift notes for the oncoming staff, saying this is what's happening now. Now they have condoms... But that's what... Like nobody really said why or how or who, it just was like... And then it's your job to then share with other people that this is what's going to happen. It's a lot of pressure on you. (Violet)

Violet felt pressured to know new expectations for her consumers and to then train or educate others as new sexually related issues developed for her consumer. Patricia, Harriett, and Violet shared that they felt a lack of clarity in their duties when assisting consumers with their sexual lives and sexual relationships. Unclear expectations and a lack of communication led to the DSPs feeling like they were not prepared to navigate the changes or challenges that accompanied the sexual lives of their consumers.

**Experiences in sexuality summary.** DSPs were able to recount many experiences related to sexuality when working with consumers with mild to moderate ID. Three themes emerged from the interviews with DSPs. The first theme was an acknowledgment by all the DSPs that sexuality is part of the job. The participants stated that consumers commonly rely on their DSPs to support them with their sexual needs. The most common sexuality-related experiences shared by DSPs centered on facilitating or assisting their consumers with erotica and masturbation, as well as social media and dating. Some DSPs also shared experiences assisting consumers who identify with the LGBTQ+ community. Overall, the DSPs were supportive and

recognized their employment in such a position meant they would be dealing with consumers' sexual lives.

The second theme that emerged under experiences in sexuality was DSPs recognition that their job is to keep their consumers safe and appropriate. DSPs recounted experiences with intervening with consumers' who were being sexually exploited, as well as helping their consumers understand appropriate times and places to engaging in sexual relationships. Although DSPs described wanting to promote independence and sexual rights for their consumers, they also described fears of their consumers being taken advantage of.

A third and final theme that arose under experiences in sexuality was that DSPs felt they are left to figure out on their own how to handle various sexuality-related situations with their consumers. DSPs felt that the guidance they received was ambiguous and they were occasionally frustrated or overwhelmed at the lack of communication from administration. DSPs described being nervous about experiences they encountered and wondered if they made the best decision or did the right thing. Participants discussed the challenges to handling situations being due to having an unclear policy, minimal guidelines, unclear expectations, and little training related to their role with sexuality.

### **Influencing Factors**

This section will examine how participants describe the influences on their work as a DSP when it comes to handling sexuality issues with their consumers. I will answer the third sub-research question: *What factors influence DSPs' responses to the sexuality of individuals with ID?* The interview questions associated with this research question inquired about the DSPs' knowledge of agency policy, training received, and how parents' expectations influenced their work. There were three distinct themes that emerged: *parents and guardians dictate what*

*happens, it depends on the person and the place, and my own personal values and experiences play a role.* These identified themes and direct quotes from DSPs' interviews are discussed below.

**Parents and guardians dictate what happens.** The first theme related to factors that influence how DSPs respond to or support a consumer's sexuality concerns parents and guardians. All participants described parents and guardians as the greatest influence on DSPs' responses. They described a variety of ways that a parent has influenced what happens in their adult child's life. All DSPs reiterated this theme: they are required to follow the wishes of parents and guardians even if it conflicts with their own desires or beliefs regarding how a situation may be handled or what they might think is best for the consumer. Many of the stories they shared about parents were not positive or supportive of the consumer's sexuality.

One female DSP discussed her experience with a consumer who wanted to date and the parents' control over this adult consumer's life.

This is a really tough one. We have actually had multiple meetings regarding this. We've had issues before with her expressing to us, "I really want to date somebody. I want to explore this. My parents won't let me." And it was decided upon that her guardians were the ones that were going to make that choice. So, I don't think it's right, but my boss said that we have to respect her parents' wishes at this time. (Tiffany)

Tiffany is frustrated with the parents not allowing the consumer to date. The decision that was made for the consumer is what Tiffany had to follow.

A female DSP who had a consumer removed from the program by the father offered another example of the control parents have over the consumer's life.

Well, I know in the past there were a couple of gentlemen who started hanging out together before they came to this program. Who started hanging out together and I'm not exactly sure about what happened or if ... I don't think there was any sexual anything. I just think that there were signs they were attracted to one another. And once the father found out he pulled him right out of the program and put him in another one. (Sarah)

Sarah discussed that a father removed his adult child from the program because the consumer was expressing sexual interest in someone of the same gender. The parent did not approve of the relationship. In this situation, the parent's influence was so impactful that the DSP was no longer able to work with the consumer.

Another female DSP shared her frustrations with guardians and their decisions over the consumer.

Parents' and guardians' expectations affect a lot. Unfortunately, with one of my clients that does come in a lot where her guardian isn't so for her dating and isn't so for her developing relationships, so it's a little bit frustrating because we do see the room for her to do that, but nobody will really let her take that step. (Jennifer)

Jennifer saw room for the consumer to experience dating and to develop potentially romantic relationships, but due to the guardian, the consumer was unable to. Tiffany, Sarah, and Jennifer shared experiences in which they were to defer to parents, and where parents and guardians were unsupportive of consumers' sexual lives. DSPs felt that the guardians and parents have the greatest impact on influencing their role in supporting consumers' sexuality.

**It depends on the individual and the situation.** Another theme that emerged from the in-depth interviews with participants concerned their response to the sexual needs of their consumers depending on the individual and the situation. The situation was often dealt with on a

case-by-case basis. Participants reported they felt they had no clear policy or directives and were expected to respond to each sexual incident as they saw fit. DSPs reported they had to consider each instance as it occurred and consider the consumer, or the home environment independently each time and determine how to respond. Unlike other situations (such as administering first aid), dealing with such personal situations related to sexuality across all consumers was not possible to put in a policy manual.

One female DSP discussed her experiences in which different rules were developed as the need arose.

If I were to support a sexual relationship or consumers dating it would depend on the relationship and which consumers you're asking about, I guess, if it was making them susceptible to exploitation or being taken advantage of, no. But we don't have anything set in stone as to what we're supposed to do. So it's basically a case-by-case situation.

Yep, and there would be no consistency because, I mean, one staff's going to handle it one way, and another staff's going to handle it another way. (Olivia)

Olivia stated that much of her support or approval of a consumers' relationship depended on a variety of factors. A consumer's safety and ability to consent, and understand a relationship, was noted by a majority of the DSPs in the interviews.

Another female DSP discussed an experience with her agency in which they made a decision based on the individual situation.

I also had one gentleman that, he was roughly in his forties and he dated a few different individuals that were in the day program that he went to. And one of the concerns we had is he... I'm not sure if he was unable to comprehend certain boundaries or if they were intentionally crossed or what. But there was a lot of worry because he had a history of

stalking, and he had various restraining orders against him and we had to figure it out as we went. And this particular agency allowed us to give a hug to our clients, one per shift. But this client was not allowed to receive hugs because he would touch staff in inappropriate places if they were to give him a hug. So he lost that privilege. (Finley)

Finley described how one policy does not fit all situations. The decision was made that the consumer was no longer allowed to hug the DSPs due to his history and current actions.

A male DSP shared how he responded to consumers' displays of affection based on the situation.

So if somebody were holding hands too much as far as like maybe too much PDA, so it advanced beyond just hand-holding, that would definitely be case-by-case. I know here at the program we have an older couple, and they talk about getting married. They sit on the couch together, drink their coffee together, and hold hands together. If it were to escalate, which it has as far as like hands under a blanket, again we're around other people, not appropriate. Definitely a hug or a kiss on the cheek is acceptable here. Certainly, it's case-by-case. If it was advancing to anything more, we would just remind it's not appropriate here. (Ian)

Ian felt that handholding or other minor displays of affection are reasonable, but would offer reminders to a couple to be appropriate if he felt they needed it. Olivia, Finley, and Ian reported needing to determine what the appropriate action is each time a situation arises related to a consumer's circumstance. DSPs found it difficult to know how to respond to the sexual lives and issues of their consumers. They reported that this ambiguity was stressful. There are few clear-cut policies about such individual sexual situations.

**My own personal values and experiences play a role.** The third and final theme identified by DSPs as a major influencing factor was their own personal values and experiences. This theme emerged from the interviews with DSPs in two very different ways. The first was DSPs who said their religious values (and specifically their negative opinions on the LGBTQ+ community) influenced how they responded to their consumers' needs. The second was found by those DSPs who identified as part of the LGBTQ+ community who felt their own experience influenced how they responded to their consumers' sexual needs and desires.

One female DSP described an example of how her own personal views have influenced her work with consumers.

I just think people being transgender is ridiculous, honestly. People can do whatever they want or think whatever they want about themselves. And I don't really... But, I'm a female and males are males. (Dianne)

Dianne stated identifying as transgender is “ridiculous” for anyone who identifies as such. She identified as a Christian and stated that the idea of people changing genders goes against her religious beliefs. She would not support such a consumer.

A female DSP discussed how her own personal beliefs may impact her work with some of her consumers.

I personally do not believe in same-sex marriage. I don't support it as a Christian. I also don't believe in being transgender. So if I had a client who participated in that, I may have a hard time relating to them. I would probably feel uncomfortable because I disagree with it. (Harriet)

Harriett felt strongly that same-sex marriages and transgender individuals are not supported by her religious values and described how this would influence her work with consumers.

In another example, a female DSP explained how her own religious views play a role in her work with consumers.

A client wanted to have posters on their walls that had nude women. I said, "We don't allow that, and I personally did not. I'm a Christian." I'm more the mother type that'd be like, "No-no-no. That doesn't need to be on your wall. We can tone it down some," so, yeah, they want to have a pretty girl on their wall on a poster, fine, but not a naked girl on their wall. (Quinn)

Quinn was conservative in her views of sexuality and tolerates consumers' requests for erotica only to the extent that she is comfortable with. Dianne, Harriet, and Quinn felt that, as Christians, they had the right to impose their own values if they were opposed to something about their consumer or their behavior.

In the same way that some DSPs discussed using their own personal values to oppose their consumers' sexual rights, other DSPs discussed using their personal values and experiences to support their consumers. Specifically, four DSPs who identified as lesbian women each shared how this part of their identity played a role in supporting the sexuality of their consumers.

A female DSP discussed her experiences as a member of the LGBTQ+ community in terms of believing her consumers who said they might be gay or lesbian.

Well, as a woman that has a girlfriend, I don't have any issues with any of that. Even for individuals with intellectual disabilities, I feel like they should have the same opportunities as we do. I don't feel like they should be... Sure. There are options in life. I mean, it's their body and it's their personality. Do you know what I mean? I mean, we can say that we've been attracted to the same sex for our whole life. Well, what if they have been too? I mean, who are we to say? (Patricia)

Patricia talked about believing a consumer when they state they are gay or lesbian and supporting that consumer. She described how she feels this has influenced her response. She discussed how she has been more responsive to consumers who identify as being a part of the LGBTQ+ community due to her own experiences being discriminated against.

Another female DSP felt she had greater sensitivity to other minority groups, such as her consumers with mild to moderate ID.

Yep. I think one that's really important is providing the opportunity to go to support groups. I myself identify as gay. So I know firsthand the different things that... barriers we face every day in life, and different looks and different stereotypes and discrimination. And I think providing a safe place to talk about what you're feeling and connecting to other people with similar mindsets, and who have been through what you've been through, provides really a foundation of support that goes beyond just what a worker can do. And I think that's extremely important because if you identify as LGBTQ, you are significantly higher, or the risk of suicide or attempted suicide goes up by a certain amount of percent. I can't remember, but I remember reading it in one of the papers I had to do for school. So providing additional support I think would be one of the biggest and most important things, as workers, that we could do. (Finley)

Finley stated that consumers who identify as part of the LGBTQ+ community have a greater risk of suicide and discussed the barriers and stereotypes faced by this community. All four of the DSPs who identified as lesbian women were supportive and were able to relate their own experiences to that of their consumers.

**Influencing factors summary.** Many things influence how DSPs handle sexuality issues with their consumers. Three major themes emerged from the interviews. The first theme was a clear understanding by DSPs that parents and guardians dictate what happens. Throughout the interviews, it was evident that the DSPs were unable to make alternative decisions based on what they felt was best or most appropriate for the consumer. If parents disagreed the DSPs were to follow the requests of the parents and guardians. If a DSP were to go against the parents' or guardians' expressed wishes, there was a chance that parents would pull their consumer from the program and go to another agency that would uphold their demands. DSPs talked about how some parents and guardians were not present in the consumer's daily life, but they had complete control over what happened in the consumers' sexual life. For example, parents decided whether a consumer could read *Playboy*, access pornography, listen to music with sexual content in the lyrics, go on dates, or if the consumer could have a romantic relationship with a member of the same or opposite sex. DSPs had a number of examples where they had had to respect and obey the parents' wishes when they themselves disagreed.

The second theme that emerged under influencing factors was how their actions depended on the person and the place. The participants stated their jobs were challenging enough, and in the area of sexuality, even more so because there was no clear policy. The DSPs were expected to respond on a case-by-case basis depending on the consumer and the situation. For example, how a DSP responds might depend on such things as if a consumer were seen as having a lower understanding due to their IQ, or if a situation arose while the consumer was at work, in the home, or in public. DSPs described a range of situations that were entirely unique to the individual, such as a consumer's request to view erotica, how to handle masturbation, meeting romantic partners online, use of contraception, and having a guest overnight. DSPs

described learning on the job from their colleagues and how they made the best decisions they could in the moment. Responding in a case-by-case manner suggests there is little consistency for consumers and it is likely that each DSP may respond to the same situation in a different way due to their experiences and attitude.

The third and final theme that emerged under influencing factors was the DSPs' acknowledgment that their own personal values and experiences with sexual issues played a role in how they handled certain situations with their consumers. In some cases, DSPs described how their faith and morality led to their hesitation or unwillingness to support the sexuality of their consumers. For some of the DSPs, they saw the LGBTQ+ community as inappropriate and reported they had a hard time understanding or supporting someone who identified as part of that community. On the other hand, other DSPs who identified as part of the LGBTQ+ community shared how this influenced their response to consumers. Those DSPs discussed how their own sexual orientation and personal knowledge of what it is to be discriminated against or to be stigmatized influenced them to support their consumers' sexual rights. Those DSPs, felt their experience being treated as a minority gave them a greater sense of empathy when working with their consumers.

## **Gender**

In this section, I describe how a DSPs gender influences their work with consumers' sexuality, as well as how the gender of the consumer might influence the way DSPs handle issues. I will answer the fourth sub-research question: *How does gender (of the DSP and consumer) influence the role, approach, and ideas for ways to assist adults with ID related to sexual issues?* Specifically, the DSPs were asked if they thought their role in assisting their consumers' sexuality needs and desires differed if they were working with a male or female

consumer. In addition, they were asked if they thought their own gender identity affected their response to consumers in areas of sexuality including the use of social media, erotica, dating, sexual relationships, contraception, masturbation, and LGBTQ+ issues. There were three distinct themes that emerged: *everybody is equal*, *the double standard is alive and well*, and *working with the other gender makes it harder to relate*. These identified themes and DSPs statements are discussed below.

**Everybody is equal.** The first gender theme that emerged from the interviews was that the majority of the participants downplayed gender and insisted that everybody was equal. When DSPs were asked about their gender and the gender of their consumers influencing and affecting their opinions and responses, most made statements similar to “I treat everyone the same,” “they are a person first,” or “I do not see the gender or disability, just the person I work with.”

One male DSP shared that he does not see a difference in his actions according to gender -his own or that of his consumer.

No, I don't think there's a separation there. I think mainly, again, it comes back to the education of safety and privacy and making sure that those are upheld. I don't think it really changes between male or female. I think maybe it's more education for females, I think, because of the contraception and things like that. (Xander)

Xander is more concerned with a consumer’s privacy and safety rather than what gender the person is. A minor difference in dealing with consumers was highlighted by Xander when he noted the need to educate female consumers on contraception due to their ability to get pregnant.

A female DSP commented on the importance of knowing the consumer as an individual rather than identifying them by their gender.

I differ depending on the client, not the gender. I've been doing this for so long that I don't look at clients as male and female. I look at them as individuals, and I get to know the individual and what he or she can tolerate or what his or her needs and desires are, and I base it on one's cognitive level. I don't feel that I categorize them as male and female first. (Brittany)

Brittany described putting the focus on the consumer first, rather than on their gender. She pointed out that what is important is the consumers' needs and cognitive level.

Another female DSP stated that while there are anatomical differences, the sexuality-related issues their consumers' experience are similar regardless of gender.

I don't think in any major way, outside of how we might train in anatomical differences. Because I know that both males and females, or however an individual might identify, they all encounter similar issues regarding safety, regarding emotional and physical readiness and the capacity to experience a diverse spectrum of preferences, in regards to sexuality and dating. So I think, as far as the basic approach, then no, not really. I guess with erotica and stuff, there are different medias and stuff, and there are different products that are targeted to males or females but I personally don't treat them differently though. (Elouise)

Elouise acknowledged that there are anatomical differences and that erotic materials or devices would be different. However, she said beyond their anatomy, consumers are the same regarding safety and preferences with sexuality and dating.

Xander, Brittney, and Elouise shared that a consumer's gender is not an influencing factor beyond acknowledging an anatomical difference. The majority of DSPs felt that a consumer's gender was not a contributing factor in their behaviors and opinions of a consumer's

sexuality. The DSPs felt “everybody was equal” regardless of their gender; they considered their consumers’ individuality more than their gender when assisting with sexual issues.

**The sexual double standard is alive and well.** The second theme that emerged from the interviews with the DSPs was that a double standard exists in how the DSPs responded to male and female consumers on particular sexuality issues. Despite the majority of DSPs stating that they are not influenced by the gender of their consumers and that all consumers are treated the same (as described above in the first theme), a closer look at the responses by DSPs revealed that the consumers’ gender does play a role in how the DSPs think about and respond to their consumers. There is a clear juxtaposition between what the DSPs’ stated about their response to gender verses what their expectations and assumptions were for their male versus female consumers. When asked about their attitudes and beliefs, as well as their experiences with specific sexuality topics (i.e., social media, erotica, dating, sexual relationships, contraception, masturbation, and LGBTQ+ issues), differences were found in how DSPs responded to a consumer based on their gender.

The sexual double standard emerged from the transcripts when examining how DSPs described their expectations of and assumptions about their male versus female consumers. DSPs described the expectations they had for their male consumers as being more sexual and having a greater interest in sex than their female consumers (whether this was true or not). On the other hand, when describing female consumers, DSPs stated that they expected female consumers to be easier to deal with on a day-to-day basis since it was assumed they had less interest in sex (whether this was true not). For example, male consumers were perceived as more interested in masturbation than females. Both male and female DSPs assumed that male consumers were more sexually aggressive, while their assumptions of female consumers were more focused on the

need to protect them and keep them safe in and/or from a sexual encounter as compared to males. Some examples of these differences in their attitudes and assumptions of male and female consumers are described below.

A male DSP discussed his attitudes and expectations with masturbation and consumers. For the most part, I just assume these guys get an erection and they go take care of it. I don't know about the ladies I work with; I don't think they ever need to. (Weston)

Weston revealed that he was of the belief that women do not need to masturbate compared to men. He assumed the men under his care were the most likely to get an erection and to masturbate, and his expectation was that this is just how all men respond.

One female DSP discussed male consumers she has worked with.

If a male client saw a pretty woman, I think they would just pull down their pants and start masturbating pretty much. With males I think, you just have to put your foot down a little harder than it would be for a female. You're not going to see a woman doing that stuff like one of the guys might. (Dianne)

Dianne discussed that she expected the male consumers to be more easily aroused and more likely to want to masturbate. She emphasized that she felt she had to be more assertive around male consumers compared to females based on her assumption that males were more interested in masturbating whereas women were not.

Another female DSP discussed her assumptions of female consumers versus male consumers' and their interest in sex.

Some of my female clients' have been raped or molested as children, so I imagine they aren't interested in sex in any way, shape, or form. I think it's mostly my male clients who would be into stuff like pornography and the use of rubber vaginas. (Kristin)

Kristin discussed that female consumers were assumed to be less or not at all interested in sex due to having experienced sexual abuse. On the other hand, her male consumers were assumed to be much more interested in sex whether they had a history of abuse or not.

The interviews revealed a greater concern towards female consumers' sexual safety compared to the concern for the male consumers' sexual safety. Despite both male and female consumers having mild to moderate ID, the DSPs viewed their female consumers as more vulnerable. DSPs reported they expected male consumers to engage in a sexual relationship and were much less likely to envision females wanting to engage in a sexual relationship. Also, DSPs were less supportive of females due to their fears of unwanted pregnancies or a concern that a female consumer would be taken advantage of. The DSPs were more likely to anticipate dangers for a female expressing her sexuality rather than a male. Here is an example of a female DSP's concerns reflecting this difference.

And then, there's always the question of what is his intentions? For my male clients, I think it's more about their intentions. For my females, I worry about pregnancy, STDS, and absolutely all that they have to be concerned with. (Mary)

Mary questioned her male consumer's intentions and worries about her female consumers' safety.

One male DSP shared his expectations of his consumers.

I think it's normal for the guys. I don't want them to masturbate in front of other people and I sometimes worry that will happen. I think my guys are a lot more likely to masturbate than any of the females I've worked with, that's just how guys are. It's a client's rights, but the women aren't really interested. I don't expect that I would ever see a woman doing what the guys might do. (Ian)

Ian felt that consumer's rights and sexuality are important for his male consumers, yet safety for others in the home is paramount. Like Mary, Ian also questioned his male consumer's intentions and was worried about the female consumer's safety.

**Working with the other gender makes it harder to relate.** A final theme to emerge related to gender was DSPs' acknowledgment that working with the other gender can be more difficult. When DSPs described their work with consumers, female DSPs found it easier to work with and relate to their female consumers as compared to male consumers, and male DSPs found it easier to work and relate to male consumers. Here is an example of a female DSP talking about how she feels about female consumers:

My women consumers, they are just as women as I am. They like to do their makeup.

They like to talk about boys. Not that we go around saying, "Ho, ho, look at how big his penis is." Those aren't really things that we bring up in conversation, but when it comes to, let's say a firefighter on the TV, and my consumer goes, "Oh, look how sexy he is."

You're not going to say, "No, that's inappropriate, we don't talk like that." You're going to say, "Wow, he is pretty cute, isn't he?" They are just as human as anybody else. And they need that. (Uri)

Uri identified with her female consumers and promoted a shared sisterhood where the female DSPs can talk with her female consumers.

A male DSP discussed his relationships with male consumers.

My biggest thing is that anytime that it came to the idea of relationships, most of the clients that I had those conversations with were male. I don't recall a female ever wanting to talk with me about sex actually. I think maybe on the guy side, it's camaraderie or patting each other on the back. Like, "Oh, hey. You're flirting with this girl. Good job."

Maybe that's the difference there. So being a male myself, I would explain consequences that I would have if I didn't practice safe sex or give consent or get consent and just make sure that they understood. (Ian)

Ian could not remember a time when he talked to a female consumer about sex, whereas he was able to share accounts of when he talked with male consumers about sexuality issues.

A female DSP discussed her professional relationship and obligations in working with male consumers.

I have a consumer that comes to day program who is almost obsessed with masturbating. So at those times, we direct him to the bathroom, and as a female, I would not go into the bathroom to help clean up after him. That's something the males would do. (Rachel)

Rachel also described that she would not be comfortable helping a male consumer clean up after masturbating and as a female DSP she would not be required to do so.

A male DSP described his experiences with female consumers.

In the house that I was primarily in, it was mostly males. We did have a couple of females though and well, one girl was really funny because she would go to the bathroom for a while, and then she would walk back out and she would tell me that her vagina was wet. Just like, all right, I don't know what to do with this information. I think she told me to get a reaction out of me because I was a male. That was always a touchy area for me just because as a male in a mostly female-dominated industry I watch myself very carefully just to make sure that like I'm not accused of anything heinous or stuff like that. So it was just like, "Okay, female staff's going to be here in a couple of minutes and I'm going to ask them to help you out." (Weston)

Weston showed concern for himself as a male DSP in a female-dominated professional industry. He safeguarded himself by asking for a female DSP to support the female consumers in their sexual situations like the one he described. In general, DSPs were assigned to work primarily with consumers of their own gender when it came to sexuality issues. This was discussed as being more comfortable for both the DSPs and the consumers they served, as well as a way to reduce liability (i.e., a male DSP abusing or being accused of abusing a female consumer).

**Gender summary.** Three themes emerged from gender. The first theme was that everybody was equal. Overall, the DSPs felt their treatment of female and male consumers was not influenced by their consumers' gender, but more a reflection of the consumer's needs, interests, and personality. The DSPs stated that they treated their consumers according to what sexual interests were expressed and what sexually-related educational needs they had.

The second theme that emerged under gender was that a sexual double standard exists. Both male and female DSPs described expectations that their male consumers would be more sexual and have a greater interest in sex than their female consumers. Female consumers were described as easier to deal with since DSPs assumed they were less interested in sex compared to males. Both male and female DSPs discussed their different assumptions of the sexual issues of male consumers (i.e., male consumers' use of erotica and engagement with masturbation) as compared to female consumers (i.e., female consumers' vulnerability and risks in pregnancy and STDs). DSPs assumed male consumers were more sexually aggressive, while their assumptions of female consumers were focused on having to protect and keep the females safe in or from a sexual encounter.

A third and final theme to emerge was that DSPs working with consumers of the other gender reported it harder to relate. The majority of participants said they preferred to work with

consumers of their own gender when sexuality issues were being discussed or dealt with. They described seeking out other DSPs of the same gender as the consumer to support the consumer in their sexual issues.

### **Suggestions for Working with Sexuality-Related Issues**

In this final section of the findings, I will describe the DSPs' suggestions for working with their consumers on sexuality issues. In this section, I will answer the fifth and final sub-research question: *What suggestions do DSPs have for working with sexuality-related issues of individuals with ID?* The DSPs were asked what they would need to deal more effectively with their consumer's sexuality when considering various issues: social media, erotica, dating, sexual relationships, contraception, masturbation, and LGBTQ+. More specifically, interview questions asked DSPs what they would need or want to support the sexual lives of their consumers. They were also asked what, if anything, stands in the way of consumers expressing their sexuality.

Four distinct themes emerged, including *more sexuality training and education is needed for DSPs, consumers need more skills training on sexuality issues, parents and guardians need sexuality acceptance training, and clearer policies are needed on sexuality issues*. Each of these identified themes and examples of DSPs statements is reported below.

**More sexuality training and education is needed for DSPs.** The first theme that emerged under suggestions was that more sexuality training and education is needed for DSPs. The DSPs responded that they were minimally trained and would like more education and training around a variety of sexual issues. A majority of the respondents felt ill-equipped and specified they would like more education. One female DSP discussed the specific knowledge she would like training on with social media and dating.

I guess what I would like to see, personally, is more education for DSPs around what is available for consumers for social media, dating sites, and things that might be safe for them to use. I've seen that there are some dating sites that are just for people with disabilities, but we aren't trained on stuff like that as DSPs unless we research it ourselves. Then we can help our consumers better. (Addi)

Addi would like to have more education on how to better support her consumers' online dating and the use of social media. If she wanted education, she would have to conduct her own research.

Another female DSP discussed her lack of experience with some issues, which in turn, makes her less likely to be able to educate her consumers.

I mean, we don't have training for staff on how to put a condom on, and we have a lot of people who don't know how to do that. How are we supposed to help our clients if we don't know how to do it ourselves and then no option to train people on how to do something? Even like that female contraceptive that you insert before you have sex — like we don't have any training in it. If we as females have never used it before, then we're not going to know. (Brittney)

Brittney was intimidated by some of the sexual knowledge she is expected to have, and perhaps does not know, due to her possibly being inexperienced or uneducated on sexual issues herself.

One female DSP discussed a lack of training for DSPs and needing to rely on the sexuality education class that was offered in high school as her only source of sexual training.

As Direct Support Professionals, we do not get training around sexual education or safety. Usually going through high school there is some level of sexual education and that is pretty much all of us have. People in higher roles in the company, like house managers

and/or case managers, may have more experience with training on sexual education or conversations surrounding this topic because they have likely had a situation in which it is needed. (Sarah)

Sarah has little education and relies on a house manager for support with sexuality issues she may have with her consumers. If a house manager is unavailable, then Sarah relies on her own high school sexuality education to support consumers' sexual lives. Addi, Brittney, and Sarah felt that the brief training on sexuality they received during orientation was not enough.

Furthermore, many DSP could not specifically remember what was covered on sexuality in their training to become a DSP or they reported they had received the training years ago.

**Consumers need more skills training on sexuality issues.** The second theme that emerged under suggestions was that consumers need more basic education and skills training on sexuality. DSPs further suggested training be developed for the consumers' needs and intellectual abilities and could be provided through the use of educational videos or by creating a sexuality education class for the consumers. DSPs were concerned that many consumers had missed out on a sexuality education class in high school or that they never received the "birds and the bees" talk from family because they were perceived as non-sexual or that sexuality education was not necessary for them.

One male DSP suggested various topics to offer as part of education and skills training to his consumers.

We offer so many different activities that these guys could learn information about so many things. And I find it funny that we really only spend time on nutrition when it comes to health stuff. If we were to introduce different areas of an individual's health and make sure that they understand what is healthy and safe, I think that could be beneficial

to people. So not just sexuality, but sexual health too with doctor's visits and taking care of, even, your genitalia area and like how to be safe there and how to have good hygiene or those things too. (Weston)

Weston was commented that many services and educational opportunities are presented to consumers, but with all of the activities, sexuality education and skills training is not one of them.

One DSP female discussed suggestions or areas of education and training.

We also have a policy where some of our younger clients have been to, like, birth control meetings, or talked about what happens when you have sex. They talk about all the bad things that happen, but they don't say any of the good things. So it's really hard for them to decide whether they would or wouldn't have sex, you know what I mean? (Natalie)

Natalie was concerned that consumers were only receiving negative information as part of their sexuality education and that they were not receiving any positive information.

A female DSP shared her ideas for areas where a consumer could improve their social skills to prepare them for dating.

I know that there are some people that are interested in dating, and they have no idea where to start. Or they are interested in social media, but they may only know of Facebook or something. So, if there are ways for them to meet or to connect with other people with disabilities and maybe socialize, I think it would be really helpful for them to be introduced to that material and to get some training on that. (Elouise)

Elouise was interested in providing her consumers with social networking skills to meet and develop relationships online. Weston, Natalie, and Elouise discussed suggestions for consumers' sexuality education and skills training. They described how, as DSPs, they are in a unique

position because they spend so much time with their consumers and can see firsthand what needs to be offered in terms of skills training.

**Parents and guardians need sexuality acceptance training.** The third theme that emerged under suggestions for sexuality-related issues was that parents and guardians need training to help them accept their adult children with ID as adults. DSPs described parents and guardians as the primary reason the consumers were unable to experience sexuality. The DSPs understood that parents and guardians have the final say and the greatest power in the sexual lives of the consumers. One male DSP discussed how parents see their adult children as children and not adults when sexuality is considered.

Parents, you really didn't have a whole lot of issues with, unless we'd go into our yearly meeting about how this individual is progressing and we would talk about their social issues, skills, and the fact that they've shown interest in a person. And some parents would be like, "Oh, it's okay if they've gone on a date to McDonald's or something, that's perfectly fine." But you would have another parent that would be like, "I don't want my child in any sexual relationship. They won't understand what's happening." And then there were some that still treated them like children even though they're 35. (Weston)

Weston felt frustrated that his consumers were not able to engage in potentially sexual ways or develop relationships.

A female DSP added her perspective of witnessing parents not treating their adult child as an adult.

So that made it very difficult, especially when it was more parents because I found a lot of parents still viewed my consumers, who were well into their 30s or 40s, as children. So

they didn't want to discuss it. It almost was like it was just easier for them to pretend their kids didn't have these sexual needs or thoughts. (Gabby)

Gabby experienced parents or guardians outright refusing to discuss their adult child's sexuality.

Another male DSP discussed how parents can be intrusive in their child's life when it comes to sexuality.

I think educating clients on the fact that, yes, you can, in fact, have sexual relationships and relationships with others, and that you shouldn't let disability stand in your way. But then I think outward about parents, even if they're not guardians, they are very intrusive into their children's lives and treat them as if they were younger, which is not great. I think that also stands in the way. I think if they had ultimate freedom from all of that, that would be great. (Carl)

Carl shared his frustrations towards the parent's involvement, even as non-guardians. Parents were still very influential in the lives of consumers. Weston, Gabby, and Carl described how, if sexuality were discussed, the majority of the parents would not be willing to acknowledge the topic as an option or discuss sexual matters. Participants shared that they felt that, as DSPs who spent considerable time with their consumers, they were more aware of what would be appropriate for the consumer compared to the consumers' parents and guardians. However, the majority of DSPs said parents were not willing to consider another perspective about their children—even though they were adults—when it came to sexuality. Parents were not accepting of their adult child's sexuality.

**Clearer policies are needed on sexuality issues.** The fourth and final theme that emerged under suggestions for being able to deal more effectively with consumers was that clearer policies are needed regarding sexuality issues. DSPs discussed needing clearer

expectations and guidance on what role DSPs have in educating, facilitating, and supporting consumers when it comes to sexuality issues.

One female DSP discussed not having a policy or not knowing what the policy was around sexuality issues and their role as a DSP.

I think every agency should have a policy that clearly defines what is expected. So I feel like when you're dealing with these topics you've never discussed in any trainings or any meetings, right? The gray area of it all is very intimidating, and not knowing what is appropriate and what is not. And I think if agencies had clear boundaries and clear expectations, I think it would make us better able to support our clients in the sexual kind of aspect of their life. (Finley)

Finley struggled with not having clear guidance or knowing what the expectations are when she is working with her consumers' sexuality issues.

A female DSP shared that some education does occur, but it is not sufficient.

There is no policy for the agency. I know that in the DSP training [College of Direct Support] we were taught about personal boundaries and space with our clients. But there was nothing specific about yes or no or the length of time or where to have that space. So it is up to the DSP to make that decision. A lot of that is influenced by family. (Natalie)

Natalie described a program called Circles; this training is about personal space and is not specific enough to be related to a dating scenario or a sexual relationship.

Another female DSP discussed a lack of clear policy.

Well, yeah probably policy. Because I don't think we really have one other than having the annual meeting. So, if it's unclear, I think policies need to be made. I do think we

should have policies and have it more of an open book and people just need to be much more educated. (Sarah)

Sarah would like more guidance on her role and how to accomplish her work as a DSP in relation to her consumer's sexuality. She believes DSPs need more education and clearer information coming from the administration. Finley, Natalie, and Sarah were unaware of policies and felt they were left to respond to the consumers' sexual issues according to what they felt was appropriate. DSPs described a need for agencies to have clearer policies and to offer pieces of training on those policies. They wished for consistency and clarity in order to better provide support for the sexual needs of their consumers.

**Suggestions for working with sexuality-related issues summary.** Four themes emerged from suggestions that would improve their work with their consumers on sexuality-related issues. The first theme was the need for more sexuality training and education for the DSPs. The participants shared that, in many cases, they have minimal training. Their training often amounted to their own sexuality education class in high school, or in the original DSP training where sexuality was one of the many, many topics covered in their employment training. DSPs described feeling inexperienced and untrained and reported they do not have the skills unless they themselves seek further education on their own time to better assist their consumers' sexual needs.

The second theme that emerged was that DSPs felt consumers need more education on sexuality issues. The DSPs had suggestions for pieces of training in many areas, including sexual health, sexual safety, dating skills (in person and through social media), safe masturbation practices, understanding flirting and courtship, sexual hygiene, and contraception. The

participants described how such education and training in sexuality would improve consumers' skills, and in turn, would provide more opportunities in their sexual lives.

The third theme under suggestions to improve their work with consumers on sexuality issues was the need for some sort of training for parents and guardians to see their adult children with ID as the adults they are. DSPs described how many parents did not see their adult children as capable of sexual experiences. Parents and guardians were described as a barrier for consumers and for DSPs. They understood that the sexuality topics they could or could not educate a consumer on depended on the parents.

The fourth and final theme that emerged under suggestions for being able to deal more effectively with the range of sexual issues of consumers was that DSPs felt they needed clearer policies. DSPs discussed needing clear guidance from the agency they worked for on what role DSPs have in educating, facilitating, and supporting consumers when it comes to sexuality.

### **Three Broad Categories**

As described earlier, the first level of analysis for findings related to each of the sub-research questions focusing on the topics of *attitudes and beliefs*, *experiences in sexuality*, *influencing factors*, *gender*, and *suggestions* when working with sexuality-related issues. The second level of analysis allowed this primary researcher to collapse these particular themes into fewer even broader concepts (see Table 4.3). The following findings will highlight the conceptual categories (as referred to by Corbin and Strauss, 2015) that emerged when the themes were examined. The resulting broad categories include *My Hands are Tied*, *Isolation*, and *Champions for Sex*. The three broad categories will be described below, including which of the various themes share these broad substantive categories. Sample quotes from DSPs will be included to clarify how these particular themes fit within the three broad categories.

Table 4.3 Three broad Categories to Emerge Across the Themes: *My Hands are Tied*, *Isolation*, and *Champions for Sex*

### **MY HANDS ARE TIED**

- Sexuality is a life experience and for everyone (Attitudes and Beliefs)
- My job is to keep them safe and appropriate (Experiences with Sexuality)
- Parents and guardians dictate what happens (Influencing Factors)
- It depends on the person and the place (Influencing Factors)
- Working with the other gender makes it harder to relate (Gender)
- More sexuality training and education is needed for DSPs (Suggestions)
- Parents and guardians need sexuality acceptance training (Suggestions)
- Clearer policies are needed on sexuality issues (Suggestions)

### **ISOLATION**

#### **For the DSP:**

- We're left to figure it out on our own (Experiences with Sexuality)
- Parents and guardians dictate what happens (Influencing Factors)
- It depends on the person and the place (Influencing Factors)
- Working with the other gender makes it harder to relate (Gender)
- Clearer policies are needed on sexuality issues (Suggestions)

#### **For the Consumer:**

- Consumers' sexuality is cute (Attitudes and Beliefs)
- Sex is their right but not my role (Attitudes and Beliefs)
- My own personal values and experiences play a role (Influencing Factors)
- The sexual double standard is alive and well (Gender)
- Consumers need more skills training on sexuality issues (Suggestions)
- Parents and guardians need sexuality acceptance training (Suggestions)

### **CHAMPIONS FOR SEX**

- Sexuality is a life experience and for everyone (Attitudes and Beliefs)
- Sex is part of the job (Experiences with Sexuality)
- My job is to keep them safe and appropriate (Experiences with Sexuality)
- My own personal values and experiences play a role (Influencing Factors)
- Everybody is equal (Gender)
- More sexuality training and education is needed for DSPs (Suggestions)
- Consumers need more skills training on sexuality issues (Suggestions)
- Parents and guardians need sexuality acceptance training (Suggestions)

## **My Hands are Tied**

When examining the themes, the participants described a sense of having their hands tied, meaning they felt limited, constrained, or unable to act freely because something prevented this. When DSPs described their work related to sexuality with individuals with ID, this sense of having their hands tied emerged across all of the topic areas of focus for this study (see Table 4.3), including *attitudes and beliefs, experiences in sexuality, influencing factors, gender, and suggestions for sexually related issues*.

More specifically, when describing their beliefs, the DSPs talked about how “Sexuality is a life experience and for everyone” yet often qualified this statement by adding that they recognized the limits to their beliefs and how that may not be a reality for the consumers they work with. The DSPs’ shared that their hands were tied when it came to their actual experiences and was apparent in the theme, “My job is to keep them safe and appropriate.” While many of the DSPs talked about working to keep the consumers safe and appropriate in their sexual experiences, they often qualified this by adding their frustration with parents or the agency protocol. For example, Eloise described how her job is to keep her consumers safe but her hands are sometimes tied, “I guess our primary role would be to advocate for them, to connect them with the types of [sexuality] services that they need, or products or whatever it is, and also train them how to use those things so that they can do so safely. But we can’t do that sometimes because we aren’t allowed to.”

This sense of feeling their hands were tied was also evident when describing the factors that influenced their response to sexuality issues in the themes, “Parents and guardians dictate what happens” and “It depends on the person and the place.” These themes capture the essence of how many DSPs feel when trying to address sexuality issues. Likewise, this sense of

constraint or limits when working with consumers was also apparent when examining gender issues and was found in the theme, “Working with the other gender makes it harder to relate.” In this theme, in particular, DSPs described their frustration with being expected to assist a consumer of the opposing gender with an issue they felt they were not trained or capable of helping with (e.g., a male DSP feeling ill-equipped to explain to a female consumer about tampon use or female DSP feeling unqualified to explain condom use to a male consumer).

Finally, this sense of having their hands tied was also present when they described suggestions for improving their work around sexuality, as in the themes, “More sexuality training and education is needed for DSPs,” “Parents and guardians need sexuality acceptance training,” and “Clear policies are needed on sexuality issues.” Many DSPs felt they were limited or unable to help their consumer due to their own lack of training, and most pointed to parents as the biggest obstacle when working with their consumers around sexuality. They also felt their hands were tied when describing the need for clearer policies around a number of issues. For example, Sarah described her frustration with the lack of clarity in her agency, “We don’t really have guidance on what to do other than having the annual meeting for a consumer. So, if it’s unclear, we have to guess or ask someone else working in the house. I think policies need to be made.”

Clearly, DSPs perceived constraints, limitations, and an inability to act freely as being a frustrating aspect of their job. Feelings of frustration were described by DSPs who felt they were the ones who worked closely with their consumers and understood their needs and desires sometimes better than parents or the agency. They felt powerless to advocate for their consumers since decision-making was often made at the parent/guardian or agency level. The feeling that their hands were tied and with it, that they were powerless, is conveyed in this example from Ian,

“I have one consumer who's a 28-year-old-man and cannot listen to music with curse words and has never been allowed to talk about dating or meeting someone because his guardian says no. Again, it's his choice. He should be able to, but because his guardian says, ‘Nope, not going to happen,’ I have to also respect her wishes and try to enforce her wishes upon him even if I disagree.”

Some further described this as a fearful feature of their job, in terms of the fear of losing their consumers to another agency or losing their job if they did not comply with what the parents or agency required, even though they felt their consumer’s sexual needs or desires were being denied.

### **Isolation**

When examining the themes, a sense of isolation emerged as a second broad category, cutting across all the topics of focus for this study, including: *attitudes and beliefs, experiences in sexuality, influencing factors, gender, and suggestions for sexually related issues*. The DSPs shared their own feelings with isolation, and at the same time also revealed the isolation experienced by the consumers they have worked with (see Table 4.3).

The DSPs’ shared this sense of isolation when describing their experiences working with consumers around sexuality, and this was reflected in the theme, “We’re left to figure it out on our own.” The DSPs discussed how they were often left alone to support their consumers’ sexual needs without much training or support from their agency. As Gabby shared, “I really don’t know what to do sometimes. Once my consumer said she and her boyfriend were using jelly from the fridge, like for sex. I was shocked, and I didn’t know what to do, and I was all alone.”

This sense of isolation was also evident when DSPs described the factors that influenced how they handled certain sexuality issues for their consumers, as was found in the theme,

“Parents and guardians dictate what happens.” Here the DSPs described being left out of team meetings where the parents, case manager, and agency representatives typically meet to decide on sexuality issues for their consumers. As Weston described, “I am someone who sees their son or grandson every single day and they could be three to four hours away and the family is still dictating the choices. It's not fair really, I think if anyone has a say it should be someone like me at those meetings instead, or at least I should be there too speaking up for the client.”

Likewise, the sense of isolation was also apparent when looking at gender in the theme, “Working with the other gender makes it harder to relate.” DSPs shared examples of working with opposite gender consumers and not feeling supported or not having the help needed to assist them. For example, Violet shared her experience, “I have this client, you can tell he's sexually frustrated, I'm not sure if we could get him some magazines or a movie or something and have him go in his room because obviously he needs to masturbate. But I don't know, it's hard because I'm alone with him and I'm female and he follows me around the house, so, I feel it should be a guy taking him shopping for those things.”

DSPs' sense of isolation was also present in their suggestions working with consumers on sexuality issues, and was most prominent within the theme, “Clearer policies are needed on sexuality issues.” The DSPs described finding themselves in the homes alone with consumers and having very little guidance from the agency on how to handle particular situations that arose related to sexuality. For example, Carl shared, “I once had a younger female consumer in her 20's who had a boyfriend that nobody knew. They would talk over the phone and they had a typical relationship, flirting, all that. But then she started talking about the other people in the house and was giving out the address and I was like woah, woah, stop and I had to figure out what to do.”

This sense of isolation was not just limited to the DSPs. The isolation experienced by their consumers in regard to sexuality also emerged from the interviews. Specifically, when considering DSPs' attitudes and beliefs, isolation for consumers was apparent in the theme, "Consumers' sexuality is cute." DSPs' comments about their consumers' dating suggest consumers are perceived as children when they do date or want to have a love relationship. It was also apparent with the theme "Sex is their right but not my role." While DSPs acknowledged and supported the consumers' sexuality, they did not always feel they should be the ones to have the conversation about contraception or help a consumer clean their sex toy, therefore leaving the consumer isolated or alone to figure it out or get help elsewhere.

This sense of consumer isolation was also evident when DSPs described influencing factors, especially when considering the theme, "Parents and guardians dictate what happens." DSPs gave multiple examples of how parents and guardians deny their adult children's sexuality and therefore isolate the consumer from such things as dating, viewing erotica, using social media, or having a sexual relationship.

Likewise, consumers' isolation was also apparent within the topic of gender in the theme, "The double standard is alive and well," especially when DSPs talked about the assumption that females needed to be protected more so than the males, and therefore limited in their activities. Finally, isolation for consumers emerged when discussing the suggestions for sexuality-related issues, the theme, "Consumers need more skills training on sexuality issues." DSPs described how most of their consumers were not included in sexuality education programs in school and that the consumers' parents did not talk to them about sexuality. They were left in the dark on most issues. In addition, isolation of consumers was found in the theme, "Parents and guardians

need sexuality acceptance training” in order to see their adult children as adults. As stated above, DSPs saw how parents isolated their consumers from many sexuality-related activities.

### **Champions for Sex**

The third broad category to emerge from the examination of the themes was that the participants played an important role for their consumers by being champions for their consumers’ sexuality issues. By this, it means that they recognized that their role as a DSP was not just limited to assisting consumers in daily living skills (e.g., cooking, hygiene, community involvement), but the DSPs interviewed for this study acknowledged that an important role they played was to support and advocate for their consumers’ sexuality issues. As DSPs, this role of being a champion for sex cut across all the topics of focus for this study (see Table 4.3), including *attitudes and beliefs, experiences in sexuality, influencing factors, gender, and suggestions for sexually related issues*.

In terms of DSPs’ discussion of their own attitudes and beliefs about working with consumers on sexuality, this notion that they are *Champions for Sex* is most clearly seen in the theme “Sexuality is a life experience and for everyone.” For example, Addi shared, “I totally support consumers in any sexual orientation. People are just people and they love who they love. It doesn’t matter if they have a disability or not, everyone should have a chance at any kind of relationship if that's what they want.”

This sense of being a champion for sex, by advocating and supporting their consumers’ sexual needs and desires, was also evident in the DSPs’ experiences as found in the themes, “Sex is part of the job” and “My job is to keep them safe and appropriate.” As Jennifer described in her interview, “When a consumer tells me they want to date, I know I need to support them, but I

also need to make sure they are being safe and know everything they need to know to make an informed decision.”

This sense of being *Champions for Sex* was also apparent when DSPs described the factors that influenced their work with consumers on sexuality, as in the theme, “My own personal values and experiences play a role.” For example, a DSP who identified as a lesbian woman described, “I have insight into what it’s like to be a minority and that’s why I am so supportive. It’s hard enough to have a disability but to have a disability and be gay or lesbian, it’s tough for them.”

DSPs as *Champions for Sex* for their consumers was also present when looking at the role of gender, and was apparent in the theme, “Everybody is equal.” As Weston said, “Everyone should have the same opportunity to access social media and try out new ways of meeting people, they are the same as you or I, it doesn't matter if they are male or female or have a disability or not. I see my consumers as being just like everyone else.”

Finally, this sense of being *Champions for Sex* was evident when DSPs talked about suggestions for working with their consumers on sexually related issues, and can be seen in all the themes that emerged: “More sexuality training and education is needed for DSPs,” “Consumers need more skills training on sexuality issues,” “Parents and guardians need sexuality acceptance training,” and “Clearer policies are needed on sexuality issues.” In their interviews, DSPs offered many suggestions for this overall message that improvements can be made in order for them to support the sexual lives of their consumers.

### **Summary of the Themes and Three Broad Categories**

Following open coding, a total of 16 themes emerged from the secondary or axial level of analysis. These themes were then organized under the topics of focus for this study: *attitudes and*

*beliefs, experiences in sexuality, influencing factors, gender, and suggestions for sexually related issues.* The third and final level of analysis or selective coding allowed this primary researcher to collapse these particular themes into fewer even broader concepts. Each level of analysis will be described below. In terms of the 16 themes, three themes emerged from the interviews with the DSPs for each of the first four sub-research questions focusing on DSPs: *attitudes and beliefs, experiences in sexuality, influencing factors, and gender*; and four themes emerged from the last sub-research question focusing on DSPs *suggestions for working with sexuality-related issues.* An examination of the 16 themes revealed three broad categories: *My Hands are Tied, Isolation, and Champions for Sex.* A summary of the themes and broad categories are presented below.

There were three themes that emerged from the interviews with the DSPs concerning their *attitudes and beliefs.* All participants expressed that sexuality is a human right and for everyone. The majority of the DSPs shared that despite having an ID, the consumers they worked with had the right to their sexual expression. DSPs believed it is acceptable for consumers to use or be involved with a range of sexual issues including social media, erotica, dating, sexual relationships, contraception, and masturbation, as well as to be supported as a person who identifies as LGBTQ+. The DSPs were compassionate about the limited sexual lives some consumers have, despite consumers wishing for more. Many DSPs used endearing terms such as “cute” and “sweet” to describe their consumers’ sexual activities. The use of such descriptors reflects a perception of their adult consumers as adolescent or child-like. The participants also believed that sex was a right for the consumer but it was not their responsibility to provide education or support. Most participants described a need for sexual opportunities, education, and social engagement for their consumers. However, the DSPs did not feel equipped or educated enough to provide the services.

There were three themes that emerged from the participant's *experiences in sexuality*. Most of the participants recognized that sex is part of the job. DSPs are often inside their consumers' homes and involved with their personal lives. Consumers are isolated socially and may only be able to rely on the DSP for support with their sexual lives. The majority of the participants had experiences helping to educate, facilitate, and support consumers in a wide range of sexuality-related issues. The most frequent experiences centered on the use of erotica as part of masturbation, and consumers' use of social media and dating. DSPs also shared experiences with consumers who identified as part of the LGBTQ+ community. When considering sexuality issues, the participants felt that they were responsible for making sure their consumers were safe and appropriate in their sexual lives. A majority of the DSPs showed support for the sexual lives of their consumers. However, there were certain areas of sexuality where DSPs were especially cautious when working with their consumers. Online exploitation and sexual relationships were the common concern for the DSPs. Furthermore, when considering the sexual experiences, they were encountering with their consumers, DSPs reported that they were often left to make decisions and respond on their own. Ambiguous policies and minimal guidelines led DSPs to report feeling frustrated and nervous that they be making the wrong decisions for their consumer.

There were three themes that emerged from the DSPs discussion of *influencing factors*. Parents and guardians were reported as the greatest influence on what the DSPs feel they are permitted to do or how DSPs respond to the sexual needs of their consumers. A majority of the participants felt the parents and guardians have the greatest power in consumer-related decisions. Consumers and DSPs would need to defer to parents' expectations and wishes despite what the consumer wanted and regardless of how a DSP might perceive the situation. Furthermore, a

majority of DSPs were left to figure out how to deal with each consumer's sexual issues on a case-by-case basis. Without clear policies or directives from their agencies, there was very little consistency for how to handle a situation from one consumer to another, even inside the same group home. The DSPs shared that there are many considerations and people to communicate with prior to a decision being made. Finally, DSPs were influenced by their personal values and experiences. On the one hand, some DSPs reported that their religious values influenced how they responded to some sexual issues of their consumers (such as holding a negative opinion of the use of erotica or LGBTQ+ issues). On the other hand, DSPs who identified as part of the LGBTQ+ community felt this served as a major influence for supporting the sexuality issues of their consumers; they reported being more supportive due to their own experienced discrimination and their ability to relate to minority status.

There were three themes that emerged related to DSPs and *gender*. The majority of DSPs stated there is no difference in how they treat their male and female consumers when it came to sexuality issues. DSPs were quick to state such things as "I treat everyone the same" or "do not see the gender." DSPs reported that they did not feel gender was a significant factor in their response to the range of sexuality issues they might encounter with their consumers with ID. Despite this sentiment, a closer look at the responses by DSPs to various sexuality issues revealed that gender played a role in their attitudes and experiences. The data from the transcript narratives revealed a sexual double standard. For example, both male and female DSPs assumed that male consumers were more sexual and had a greater interest in sex, while female consumers were assumed to be less sexual and to have less interest in sex. DSPs assumed their male consumers had a greater interest in erotica and masturbation, and that their female consumers had little interest in sex and needed to be protected. DSPs also acknowledged that working with

the other gender was more difficult. Female DSPs reported it was easier to work with female consumers on sexuality issues, while male DSPs reported it was easier and more comfortable to work with male consumers.

Finally, there were four themes that emerged from the interviews with DSPs for *suggestions for working with sexuality-related issues*. DSPs reported they would appreciate and need more training and education on sexuality in general, more specifically, how to handle certain sexuality issues with their consumers. They described their DSP training on sexuality as absent, unmemorable, insufficient, or too long ago to remember. Since the original orientation and training they received through the State's College of Direct Support, the majority of the DSP said they had not received any further training on sexuality issues. DSPs reported that sexuality education and skills training is also needed for their consumers. DSPs felt a number of modalities might be suitable for educating their consumers to be more safe, appropriate, and skillful in their sexual lives. Furthermore, DSPs were clear that parents and guardians need training to help them accept their adult child as an adult with sexual feelings and desires. In the interviews, parents were discussed as a major obstacle in their adult children's sexual lives. Finally, DSPs felt that clearer policies are needed on how to address sexuality issues. Responding to the sexuality needs of consumers is seen as ambiguous and DSPs are uncertain on how to respond. The current policies are described as vague and many of the DSPs were unaware of what the policies even are. DSPs had a set of focused suggestions and felt that these suggestions would make responding to the sexual lives of their consumers much easier and more consistent. Finally, a call for new policies and clearer guidelines on the current policies was requested by DSPs. They felt that training and education on what the policies are would be helpful, especially when paired with instruction on implementing them correctly and consistently. While the DSPs wished for

clarity, they also acknowledged that in some cases the nature of working with consumers is very individualized. Overall, the majority of the DSPs desired to support their consumers' sexual lives, but they were often unsure about agency policies and procedures or parents' and guardians' expectations or wishes when handling the range of sexual experiences.

After the 16 themes were identified, they were then integrated into a broader and more abstract level. This third level of analysis, referred to as selective coding, examined the connections between the 16 themes and revealed three broad categories: *My Hands are Tied*, *Isolation*, and *Champions for sex*. These three broad categories will be summarized below.

Within the broad category, *Hands are tied*, there was a sense that participants felt limited, constrained, or unable to act freely because something prevented them from acting or responding to their consumers' sexuality issues. The broad category, *Isolation*, was found in both DSPs and consumers, where DSPs were left to make decisions with limited training and guidance from their employment agencies and were often left out of meetings where decisions were made that impacted their job duties. DSPs sense of isolation extended to their consumers in the sense that the consumers are very limited in their socialization and they are often not permitted to be sexual or express their sexuality. Finally, in the third broad category, *Champions for sex*, there was a sense that most participants wanted to support the sexual lives of their consumers, the DSPs saw themselves as the person most likely to be open to the consumers' sexual issues and wished to have more training to be better able to support their consumers.

The three broad categories, *My Hands are Tied*, *Isolation*, and *Champions for Sex* were connected to each other in several ways. For example, DSPs expressed that they felt limited, constrained, or unable to support their consumers in the area of sexuality. The majority of the DSPs wanted to be supportive of the sexuality of their consumers and acknowledged that sex is a

life experience. However, DSP's reported they were not trained or knowledgeable enough to respond to some of the situations they found themselves in. DSPs described that they were left alone and were not invited to participate in meetings where decisions were made and therefore, often felt unsure of how to respond to consumers' unique sexuality issues. Overall, DSPs had a positive attitude and had the consumers best interest in mind when they responded to the consumers' sexuality needs. The DSPs saw sexuality as part of their job. They felt they were confidants and resources for their consumers, but they were also isolated and had to rely on their knowledge of sexuality or use "best guesses" when trying to be supportive. They were the champions for their consumers' sexual lives when no one else seemed to be. However, they also knew they risked consequences from parents and guardians if they supported their consumers' sexuality if this went against the parents' wishes. Despite these challenges, the DSPs interviewed for this study acknowledged that an important role they play is to support and advocate for their consumers' sexuality issues. These findings will be discussed in terms of their contributions to the literature and theories in Chapter 5: Discussion.

## **CHAPTER FIVE**

### **DISCUSSION**

The purpose of this qualitative study, using grounded theory, was to explore how DSPs working in Maine describe their perceptions of and experiences with sexuality issues when working with individuals with ID. There have been several studies that have addressed staff attitudes and experiences with sexuality for this population. Some have used qualitative research methods (e.g., Abbott & Howarth, 2007; Allen, 2008; Ćwirynkalo et al., 2017; Feely, 2016; Schaafsma et al., 2014; Senne, 2016; Young, et al., 2012), while others have used quantitative methods (e.g., Evans et al., 2009; Gilmore & Chambers, 2010; Meaney-Tavares & Gavida-Payne, 2012; Murray & Minnes, 1994; Murray et al., 1999; Oliver et al., 2002; Pebdani, 2016; Saxe & Flanagan, 2014).

This study is important because it adds to the understanding of how DSPs view and support the sexuality of individuals with ID. In addition, previous researchers have suggested that DSPs' attitudes and experiences with the sexuality issues of adults with ID is consistently overlooked and understudied (McDonald et al., 2018; Pebdani, 2016). This study specifically focused on DSPs' attitudes and beliefs, experiences, influencing factors, gender issues, and suggestions they have related to sexuality when working with individuals with ID.

The study sample consisted of 24 DSPs who provided support in residential or community settings in the State of Maine. The participants, of which five were male and 19 were female, comprised the population sampled (See Table 4.1). Participants were required to meet the following selection criteria:

- Employed by an agency in the State of Maine
- Employed for at least six months in a residential or day program setting

- Support adults with mild or moderate intellectual disabilities

The participant interviews were analyzed and have illuminated the collective insights, the common challenges, and the nuances of DSPs working with individuals with ID and their consumers' sexual lives. In detail, this study provides new information to the field of research on DSPs employed in rural locations such as Maine, by extending what is known about the collective professional experiences related to sexuality. The State of Maine is not represented in any studies reviewed. By filling research gaps that have emerged from literature, this study has been successful in regards to reaching the primary intention of answering the research question and sub-questions.

This chapter will provide a thorough narrative to answer the overarching research question: *How do Direct Support Professionals (DSPs) view and support the sexuality of those with ID?* The five sub-questions that were answered are:

- Sub-Research Question 1. *What attitudes and beliefs are held by DSPs regarding the sexuality of individuals with intellectual disabilities?*
- Sub-Research Question 2. *What are the experiences for DSPs in relation to the sexuality of individuals with ID and the DSPs' employment position?*
- Sub-Research Question 3. *What factors influence DSPs' responses to the sexuality of individuals with ID?*
- Sub-Research Question 4. *How does gender (of the DSP and consumer) influence the role, approach, and ideas for ways to assist adults with ID related to sexual issues?*

- Sub-Research Question 5. *What suggestions do DSPs have for working with sexually related issues of individuals with ID?*

This study reveals how these DSPs view and support the sexuality of their consumers. In the following pages, I will discuss literature and theory contributions this study has made. This will be followed by a discussion of the limitations of this research. In addition, the implications for policymakers, DSPs, individuals with ID, parents, and guardians, and educational institutions will be described. Finally, suggestions for future research and overall conclusions will be discussed.

### **Contributions to the Literature**

The following section discusses how this study contributes to the body of literature available on the attitudes of support professionals as it relates to the sexuality of individuals with ID. I will expand the reference point offered within this subsection, by illustrating how my study is grounded in literature and compares to current literature. The three broad categories, *My Hands are Tied*, *Isolation*, and *Champions for Sex*, that resulted from the analysis as described in the previous chapter will specifically be discussed.

#### **My Hands are Tied**

This broad category, *My Hands are Tied*, is one that is found in only a handful of studies (Allen, 2008; Evans et al., 2009; Feely, 2016; Senne, 2016). This gap in the research is due to the fact that few studies examined the attitudes and experiences related to sexuality issues of the staff who worked directly with consumers with ID, and even fewer studies used a qualitative method that would allow for an in-depth examination of staff experiences. While not explicitly stated as “my hands are tied,” the findings from those few studies revealed that staff feel limited, constrained, or unable to act freely in their work around sexuality issues with their consumers. These studies are discussed below.

Allen (2008) conducted a qualitative study with 31 direct care staff working with consumers with ID at four different agency sites in Connecticut. He conducted in-depth interviews to understand the typical practices by direct care staff and the barriers they encounter in facilitating the sexual expression of individuals with ID. His study found that staff regularly encounter and deal with sexuality issues and desire to have more training. Specific to the broad category *My Hands are Tied*, he found there is a lack of official conversation on consumer sexuality, which leads to fear and confusion among staff (Allen, 2008). Staff in his study reported such things as being discouraged from engaging in any sexual discussion between staff and consumers, and being told to defer to a consumer's guardian for sexual decisions. Parents and guardians were identified by staff as having a significant influence over their consumers' sexuality. Similar to this study's findings, the staff in Allen's study (2008) identified unsupportive parents and family as an obstacle, as well as the interdisciplinary team that made decisions about consumers' sexuality without input from the direct staff. Staff shared their concern for losing their job if they provided encouragement to their consumer when it came to sexual issues.

In addition, this broad category, *My Hands are Tied*, can be seen in Allen's (2008) finding that staff receive limited and incomplete sexuality training, which in turn leads to their limited ability to handle consumer's sexuality issues. In his interviews with staff, they described situations where they felt unprepared to handle a range of sexuality-related situations. Any training they did receive was limited to sexual abuse issues. Most staff described receiving no training on general sexuality issues, and therefore not knowing how to talk to their consumers or how to help them, reflecting a feeling of having their hands tied.

In another study of DSPs, Senne (2016), used semi-structured interviews in a qualitative study to gain a better understanding of how sexuality is viewed and supported by those who work directly with individuals with developmental disabilities. This study took place in Minnesota and included eight participants who worked for one agency. In line with the broad category *My Hands are Tied*, her findings identified a number of ways that staff felt limited or constrained in their response to their consumers' sexuality issues. Staff described frustration with parents and interdisciplinary teams, leading to a limitation of their work around sexuality with consumers. According to the participants, families held more conservative views and saw their consumers' as perpetual children, thus limiting the sexual expressions and opportunities for their consumers. Her interviews also highlighted staff fears if they did not comply with parents' or agency expectations. For example, staff understood that if they provided support to their consumer around sexuality that conflicted with what the parents wanted, they could be written up or fired. Further support for this category can be seen in Senne's (2016) findings that staff expressed concern that if they supported their consumers' sexual relationships or expressions it may result in a parent or guardian becoming angry with the DSP or with the agency as a whole (Senne, 2016).

In a third study involving in-depth interviews with staff who work with consumers with ID, Feely (2016) also found staff experienced constraints, limitations, and an inability to act freely. Interviews were conducted with five staff in Ireland, as well as five consumers. In terms of the feeling that their hands are tied, some staff reported they did not have permission to provide sexual support, and to do so was described as potentially dangerous. Staff described that if they attempted to facilitate rather than suppress the sexuality of consumers, they could be subject to discipline. In one example, a staff member described how they aided a consumer in

learning about lubricant online and were flagged by the administration and disciplined. Feely (2016) concludes that this singling out of staff for aiding their consumers' sexual interests and desires is a deterrent and offers further support for the broad category found in my research that staff often feel their hands are tied when trying to work with consumers around sexuality.

Finally, one additional study was conducted by Evans et al. (2009) that did not rely on in-depth interviews, but whose conclusions suggest staff felt their hands are tied. This study used a questionnaire to investigate the attitudes of 155 staff in Ireland. The authors compared the staff attitudes to those of 153 family members. Their questionnaire used both a Likert-type scale and yes/no responses to examine staff discussion of sexuality with consumers, education and training, the sexual rights of consumers, and views about relationships of consumers. The final section of the questionnaire contained three hypothetical case scenarios (pregnancy, privacy for sexual expression, and intimacy between consumers) for participants to fill in their response to "How should this situation be dealt with?" While their findings revealed that most of the staff were open and comfortable discussing sexuality with their consumers with ID, those who were not confident in working with sexuality issues identified a lack of support by the agency, a lack of training, and a lack of clear guidelines as contributing to their lack of confidence and ability to discuss sexuality with their consumers. Furthermore, this study supported the broad category of *My Hands are Tied* when it concluded that participants felt frustration with the organizational policies, and staff reported they felt constrained and limited in their ability to serve their consumers in the area of their sexuality.

### **Isolation**

This broad category, *Isolation*, is one that is found in previous studies of DSPs. The findings from three qualitative studies describe staff experiences of isolation when handling sexuality issues of their consumers with ID (Abbott & Howarth, 2007; Allen, 2008; Senne,

2016), and several quantitative studies imply staff isolation (e.g., Evans et al., 2009; Meaney-Tavares & Gávida-Payne, 2012; Murray et al., 1999; Pebdani, 2016). Other studies of staff describe the isolation experienced by consumers and are described below (e.g., Allen, 2008; Ćwirynkalo et al., 2017; Esmail et al., 2010; Evans et al., 2009; Senne, 2016).

In a qualitative study by Abbott & Howarth (2007), 71 staff working with consumers with ID were interviewed in locations across the UK, including England, Scotland, Wales, and Northern Ireland. The study spanned three years and explored staff perceptions of and experiences with consumers with ID who identified as lesbian, gay or bisexual. The majority of staff did not feel confident working with those consumers and identified a number of barriers that prevented them from having the confidence to work with such consumers. In terms of the broad category *Isolation*, the interviews revealed that it was quite common for staff to feel alone in their work with consumers, and to state that they lacked the training to know what to do. Interviewees were typically young support staff, working alone in small residential homes. This isolation led many staff members to report that they chose to ignore the sexual needs of the consumers they were hired to support. Furthermore, this study supported the broad category of *Isolation* when it concluded that participants reported a lack of policy guidance or training to equip them to work with their consumers, and they felt alone to make decisions when confronted with sexuality issues by their consumers. As one interviewee stated, “But where’s the backup for us in the workplace? You know, can we allow this? Should we stop that? What can we do about whatever? (Abbott & Howarth, 2007, p.122)” which reflects how alone staff members felt when they would return to the consumers’ homes to work. Abbott and Howarth (2007) concluded that staff training and clearer policies are needed, which will help staff feel less isolated.

A second qualitative study discussed in the previous section on *My Hands are Tied*, also identified isolation as an issue for the 31 direct care staff who were interviewed about staff practices (Allen, 2008). While not specifically labeled as isolation, Allen's findings revealed that staff felt they were alone and left to figure things out themselves when it came to working with consumers' sexual intimacy concerns. Specifically, staff described feeling uncomfortable handling sexual intimacy issues alone with consumers of the opposite gender. They also were unsure when and with whom conversations around sexuality should be discussed, and they described being left to figure it out themselves. The need for clear policies and better training on general sexuality issues (not just sexual abuse) was emphasized by staff in order to help them not feel like they are alone in figuring out what to do or how to handle sexuality-related situations.

In the third qualitative study, Senne (2016) also identified isolation as an issue in her research with staff in Minnesota. As described in the previous section on *My Hands are Tied*, this study aimed to gain a better understanding of how sexuality is viewed and supported by staff who work with individuals with ID. The eight participants did not feel they had training in policies for how to support individuals with ID in sexuality, and many participants did not know if such policies existed. In addition to lacking knowledge about policy, the DSPs expressed their lack of knowledge about what role they were to play in order to assist consumers with ID around sexuality issues. Their interviews reflected a sense of isolation by staff on how to respond. They were alone to figure out what to do or to figure out the best way to respond (Senne, 2016).

One could infer that the staff experienced isolation when examining the findings of other studies that used surveys to assess staff attitudes and experiences (e.g., Evans et al., 2009; Meaney-Tavares & Gavida-Payne, 2012; Murray et al., 1999; Pebdani, 2016). While staff did not

describe in detail their experience as they would in a qualitative study and were not asked directly on a survey if they felt isolated, their responses to specific items on surveys can be examined for clues to this broad category of *Isolation* (i.e., when staff indicated they have little training or guidance for working with sexuality issues yet this is an expectation of the job). For example, a survey of 332 staff in England (Murray et al., 1999) found 63% were unsure or did not know their organization's policies regarding how to deal with consumers' sexuality issues. In a study of 155 staff in Ireland, Evans et al. (2009) used a survey and responses to case studies and found that very few staff (12%) reported they had received any training in how to discuss sexuality with consumers; they were expected to figure out how to respond to sexuality issues without any training or guidance. In another survey of 66 staff in Australia using the ASQ-ID (Meaney-Tavares & Gavida-Payne, 2012), it was found that less than half (41%) of the staff had received any kind of training in sexuality for working with individuals with ID. In a final example of a quantitative study, a survey of 71 staff in New York using the ASQ-ID (Pebdani, 2016), found that a little over half (52%) of the sample reported that their employer did not have a policy related to sexuality and therefore were alone to figure out what to do.

The broad category, *Isolation*, was not limited to the isolation felt by DSPs which is also reflected in a comparison of my study to the literature. It is noteworthy to point out that a number of previous studies examining staff attitudes and experiences around sexuality included a discussion of the isolation experienced by their consumers. Consumers' isolation was found in several studies where parents denied the consumers' ability to engage in dating relationships or sexual behaviors (Ćwirynkalo et al., 2017; Evans et al., 2009; Senne, 2016). For example, staff shared stories such as consumers not being able to use social media to meet others, being denied access to pornography, or not being allowed to date someone of the same sex if the parents were

opposed to their adult child's sexual orientation. Other studies described the isolation of consumers when describing that they were denied access to sexuality information (Allen, 2008; Esmail et al., 2010). Staff recognized that consumers had not received sexuality education previously in school, and were not receiving it now as adults in these community-based programs or living situations. Finally, the isolation of consumers was described as a lack of opportunities to meet new people outside of their living arrangement. For example, Senne (2016) described a lack of community integration, and that consumers are constantly chaperoned and watched and therefore have no freedom to do as they choose or meet others to have a relationship.

### **Champions for Sex**

This third broad category, *Champions for Sex*, is one that was not consistently found in previous studies of DSPs. Some studies reviewed from the literature revealed that DSPs saw their role as supporting the sexual issues their consumers faced, including two qualitative studies (Allen, 2008; Ćwirynkalo et al., 2017). Several quantitative studies found staff who scored high on positive views of consumers' sexuality and that those who were more willing to be an advocate were more likely to be younger, have less conservative religious values, and to have previous experience with a family member with a disability (Evans et al., 2009; Gilmore & Chambers, 2010; Meaney-Tavares & Gavidia-Payne, 2012; Murray & Minnes, 1994; Oliver et al., 2002; Pebdani, 2016; Saxe & Flanagan, 2014). On the other hand, other studies suggested DSPs did not see themselves in this role as a "Champion for sex;" they did not see their role as an advocate or as someone who should be a supporter of their consumers' sexuality (Abbott & Howarth, 2007; Schaafsma et al., 2014; Young, et al., 2012).

In terms of seeing their role as an advocate and supporter of their consumers' sexuality, two qualitative studies described DSPs in a way that falls in this category, *Champions for Sex* (Allen, 2008; Ćwirynkalo et al., 2017). In the first qualitative study, findings from in-depth interviews with 31 staff from Connecticut who worked with consumers with ID (Allen, 2008), found that most of the DSPs were supportive of the sexuality of their consumers. Findings showed that DSPs were clear in stating that individuals with ID were entitled to their sexuality and they were supportive as long as safety considerations were in place. As one DSP is quoted, "It is their right to have as much as they want, within some confines, they have to be safe (Allen, 2008, p.67)." Allen (2008) reported that staff viewed sexuality as a human right and they acknowledged that all people with ID have sexual needs and desires. Participants' responses that demonstrated that they fit the category of *Champions for Sex*, can be found when staff described being more comfortable having sexual conversations with their consumers as compared to parents or others. Furthermore, the participants of the study identified themselves as the initial contact for their consumers seeking guidance and support for sexual information; the consumers were comfortable talking to the staff about their sexuality (Allen, 2008).

In a second qualitative study interviewing 16 staff at day programs and residential centers in Poland, Ćwirynkalo et al. (2017) found staff were supportive and advocates for their consumers with ID. Staff reported that they recognized that intimate relationships were a right of individuals with ID and that such relationships could enhance the quality of life for their consumers. Another finding in their study was an acknowledgment by the staff that all people have sexual needs, including consumers. Ćwirynkalo et al. (2017) found that DSPs pay attention to the sexual rights of their consumers, including the right to express their sexuality and their right to enter into a relationship with someone, including to marry and to have children.

Other quantitative studies found that staff with more positive views of consumers' sexuality, and those more willing to be an advocate, were more likely to be younger, have less conservative religious values, and to have previous experience with a family member with a disability (Evans et al., 2009, Gilmore & Chambers, 2010; Meaney-Tavares & Gavidia-Payne, 2012; Murray & Minnes, 1994; Oliver et al., 2002; Pebdani, 2016; Saxe & Flanagan, 2014). While not describing themselves with the label of *Champions for Sex* per se, the results of these surveys provide information on who is most likely to be an advocate and supporter of their consumers' sexuality. Five studies of staff attitudes using surveys found that age was an indicator of support and advocacy (Evans et al., 2009; Gilmore & Chambers, 2010; Meaney-Tavares & Gavidia-Payne, 2012; Murray & Minnes, 1994; Oliver et al., 2002). Specifically, these studies found that attitudes of younger staff were much more positive in terms of acceptance and advocacy for their consumers' sexuality. An additional survey study found religion played a role in staff attitudes toward their consumers' sexual interests and needs. Saxe and Flanagan (2014) found that those participants who self-identified as having no religious affiliation were more supportive and greater advocates for consumers' sexuality as compared to those staff who identified as conservative Christian. Finally, one study found a strong positive association between staff who were more willing to be an advocate and supporter for their consumers with ID and their prior experience with knowing someone with a disability. Pebdani's (2016) survey of 71 staff found that those who had a family member with an ID had more positive attitudes toward and support for the sexuality of the consumers they worked with.

Not all studies found that DSPs viewed themselves as fitting the category of *Champions for Sex*. In fact, three studies found that staff did not see this as part of their job or as a role they were willing to engage in with their consumers (Abbott & Howarth, 2007; Schaafsma et al.,

2014; Young, et al., 2012). For example, a qualitative study of 71 staff across the UK (Abbott & Howarth, 2007) examined comfort with sexual orientation issues with their consumers and found that the staff did not feel they were in a role to be advocates for their consumers' sexuality. Their interviews revealed that DSPs believed that it was intrusive and inappropriate to bring up issues around relationships and sexuality unless it came from the individuals with ID themselves. Furthermore, because of a lack of confidence, experience, or willingness to engage with sexuality issues, DSPs had a fear of doing work in this area. According to Abbott and Howarth (2007), many staff chose to ignore the sexual needs of the people they supported.

Young et al. (2009) conducted a qualitative study to interview 10 staff who worked directly with individuals with ID. Their interviews revealed that staff experienced considerable anxiety when considering the sexuality of individuals with ID and indicated little awareness or commitment to proactively support such sexual relationships. Staff described both men and women with ID by using negative gender stereotypes and that denied their consumers' positive expression as sexual beings.

One other study found staff held negative attitudes toward educating their consumers with ID on sexuality issues. Schaafsma et al. (2014) surveyed 163 staff responsible for the well-being and sexual health of their consumers. Even though it was supposed to be part of their job, they found that less than half of the staff (39%) saw themselves as responsible for the sexuality education of their consumers. For those staff that saw themselves as responsible for teaching sexual health, they reported that it was typically in response to problematic sexual behavior or only if the consumers had a question (Schaafsma et al., 2014). The findings of these three studies are contrary to what most of the other studies reviewed previously suggest.

## **Contributions to Theory**

This section will present information in a narrative format on the three theoretical influences. The three theoretical influences are The Theory of Planned Behavior, Feminist Disability Theory, and Gender Theory. This integrative view of the three broad categories, *My Hands are Tied*, *Isolation*, and *Champions for Sex*. The following is a discussion of where my study fits into bigger theoretical bodies of work according to the three theoretical influences.

### **Theory of Planned Behavior**

This theory posits that someone with a positive attitude towards a belief or action would be more likely to perform the behaviors that are required to support the belief or obtain the action (Swango-Wilson, 2007). Additionally, the Theory of Planned Behavior looks at subjective norms and behavioral control and the theory includes things like liability, policy, and law. This theory suggests that attitude is not the only thing that influences an individual's behavior. One of the three broad categories within this study is *My Hands are Tied*. According to the participants the DSPs attitudes are generally positive towards their consumers' sexuality but their behaviors were not always positive. This theory considers the mitigating factors between attitude and behavior.

The findings of the study align with the Theory of Planned Behavior. The participants spoke of the issues that prevent them from supporting the sexuality of individuals with ID. The DSPs were at times isolated in the residential homes and reported they did not feel supported or properly trained by their agencies and therefore were hesitant to offer support to their consumers. The DSPs had generally positive attitudes towards the consumers' sexual lives, but a number of issues influenced DSPs' behaviors, including parents and guardians wishes, unclear agency policy, and a fear of losing the financial gains a consumer provides if the family decides to switch to a different (more cooperative) agency. According to the Theory of Planned Behavior, if

staff had a positive attitude and there were fewer barriers and they felt their employers supported their behavior, staff would be more supportive in their behaviors.

### **Feminist Disability Theory**

This theory challenges the cultural meanings attributed to bodies that societies deem disabled and views disability as a system of exclusions that stigmatize human differences. When comparing this study to Feminist Disability Theory, similarities and differences exist. The information analyzed for this study were from professionals that worked as DSPs for individuals with ID. The information was not from individuals who experience disabilities themselves. However, the findings of this study confirmed that there are challenges for individuals with disabilities in terms of having control over their own bodies, accessing privacy, and being allowed to experience sexual pleasure. Both broad categories, *My Hands are Tied* and *Isolation*, revealed that there is marginalization of these individuals and that consumers are not always treated with equality and are often not in control of their own sexuality. The DSPs stated that on the basis of the consumers having an ID, they often deferred to parents or guardians as the decision makers for the consumer. It is apparent that if a parent or guardian wishes, they can take away the rights of the consumer, and the civil and human rights of the individual with ID are not upheld. Regardless of current civil rights laws and policies, parents appear to exercise the ultimate authority, and are even able to withhold basic human rights such as sexuality.

Disability rights have been promoted through legislation, such as the ADA of 1990 and ADAAA of 2008, and the disability rights movement from the 1960's to today. However, in daily practice, the sexual rights of individuals with ID are still limited. The legislation and advocacy movements implemented have supported the rights and equality of individuals with ID and staff are more positive now towards the sexual lives of individuals compared to attitudes

historically. As described in Chapter 1, disability rights laws are working to make things more transformative and feminist disability scholars have fought for, and to some extent achieved, success in viewing a disabled body as equal and for women with disabilities to be seen as a “pleasurable being.” As this study indicates, there is still much work to be done. The study revealed a tension between what staff want to do in terms of being advocates and champions for their clients’ sexual issues and what they can realistically do when their hands are tied. Furthermore, there appears to be a corporatization of individuals with ID noted within some of the participants’ narratives. Feminist Disability Theory recognizes individuals with a disability being viewed and treated as a commodity. Agencies supporting parents' wishes about their adult child’s sexuality due to the fear that the family might select a different agency is such an example where the financial consequences outweigh the human rights of the individual.

### **Gender Theory**

The premise of Gender theory suggests that masculinity and femininity are sets of mutually created characteristics shaping the lives of men and women. It challenges the idea that there are fixed biological determinants. The theory focuses on what is understood as masculine and/or feminine in any given context and it refers to the inequality and power struggle of genders. The broad category, *Champions for Sex*, relates to Gender Theory in that the majority of DSPs were found to be supportive and believed that sexuality is a right for both males and females with ID. Furthermore, some DSPs identified themselves as advocates for their consumers, and the majority of DSPs stated that they do not see or respond differently to their consumers based on gender. However, a closer look at the participant responses reveals that there is a double standard based on gender.

Another aspect of this study that falls under the consideration of Gender Theory is the comparison of attitudes of DSPs in relation to an individual's act of masturbation or engaging with erotica. DSPs reported it was common and supported that an individual masturbate in their own space and privately. However, when that same individual crosses a gender divide and wishes to mutually masturbate, have an intimate relationship or engage in erotica as a couple, this become less supported and is stated to be an issue for some DSPs. The broad categories of *My Hands are Tied* and *Isolation* could serve as reasoning for this lack of support. The DSP may be unprepared for how to best respond to the request of mutual intimate sexual activities or may not feel a mutual relationship would be supported by the parents or guardians and therefore be fearful of retaliation. This same example links the broad category of *Isolation* for the consumer to Gender Theory. When a person's sexuality involves just that individual masturbating, the activity is supported. However, when that same individual wishes for human contact or human engagement in their sexuality the DSP is likely to be less supportive. Gender concerns becomes an attitudinal issue and DSPs are less supportive, leaving the consumer isolated from human engagement and intimate physical touch.

Further consideration of Gender Theory can be seen when male consumers had more access to and support for masturbation than females, suggesting female consumers are more likely to have their sexuality ignored. In addition, most DSPs are women, so if cross-gender DSP-consumer relations matter, according to Gender Theory, it is possible that male consumers might not be getting support for their sexuality issues.

### **Limitations**

There were several limitations to this study. First, the findings of this study cannot be generalized nor transferable to other populations. Second, the sample was restricted to those who

volunteered to be interviewed. Volunteering for this study may mean the participants were more willing to talk about sexuality as compared to those who did not volunteer to participate in the study. It also involved snowball sampling. Since snowball sampling does not select units for inclusion in the sample based on random selection, it is impossible to make generalizations from the sample to the population. As such, snowball samples should not be considered to be representative of the population being studied. Third, with the limited number of male participants (5 out of 24 participants), it was not possible to examine unique themes between male and female DSPs. Fourth, the interviews relied on the participants' ability to recall, as well as on their perceptions of events, and this could not be verified. Fifth, is the site selection strategy. This study only included DSPs from the State of Maine and the majority of the participant sample was Caucasian. A final limitation is that individuals with ID themselves were not included in this study, nor their parents and guardians. While individuals with ID and their parents and guardians were discussed frequently and were part of the focus for this study, information was only gathered from DSPs working in this field.

### **Implications**

There are a number of implications based on the findings of this study and the three broad categories *My Hands are Tied*, *Isolation*, and *Champions for Sex*. This study revealed that DSPs perceive constraints, limitations, and an inability to act freely when it comes to addressing their consumers' sexuality issues and needs. They often find themselves alone to support their consumers' sexual needs without much training or guidance from their agency. Despite these challenges and frustrations, the DSPs see themselves as the people on the front lines to support and advocate for their consumers' sexuality issues. These broad categories provide a framework for thinking about what needs to happen. Below are specific ideas for agency policy, DSPs/professional staff, individuals with ID, parents and guardians, and educational programs

including, secondary schools and academic institutions. The DSPs who participated in this research also made specific recommendations that have been incorporated into the recommendations below.

### **Agency Policy**

It was clear from the interviews with DSPs that their work with consumers would be better served if the agency had a clear policy around sexuality. That policy should acknowledge sexuality as a human right for their consumers, and emphasize that their agency supports this right. The agency should further explain how they will implement the policy, in terms of such things as consumer privacy, access to sexuality information and education, rights to use of social media, access to erotica, development of dating and sexual relationships (including same-sex relationships), and contraception and safer sex practices. The role, or the lack of a role, for parents and even legal guardians should be included in the agency explanation of policy. Clear guidance on whether legal guardians can deny a human right to adults without proving potential harm or danger needs to be implemented.

One would think that such a policy would be easy to establish knowing that there is a long-standing precedent for the rights of people with ID. Beyond the Americans with Disabilities Act of 1990, are rulings like the 9th United States Circuit Court of Appeals ruling where it was ruled that the ability to engage in sexual relations is a major life activity under the definition of the ADA (ADAAA, 2014). Focusing specifically on the State of Maine, DHHS regulations state that relationships are a part of the “overall quality of a person’s life” (Maine DHHS, 2018b, p.35). The Maine Revised Statutes, under Title 34-B: Section 5606, explains that a person with ID is entitled to private communications, reasonable opportunities for phone and internet communication, unrestricted rights to visitors during reasonable hours, the right to their own personal property, and may not be sterilized (State of Maine Revised Statutes, 2019). For example, the agency could adopt and publicize the joint position statement of AAIDD and The

Arc which asserts “People with intellectual disabilities and/or developmental disabilities, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected” (AAIDD, 2019b; The Arc, 2018b).

Such a policy is important, not only to assist the DSP in their work with consumers, but it is also important to parents and guardians who are choosing to place their adult children with ID in these day programs and residential settings. In addition, it provides the consumer with consistency. Without such a policy, decisions about a consumers’ sexual needs and desires may be left to the individual DSP, which can create confusion for the consumer. While this study found that most DSPs felt comfortable and positive about sexuality and wanted to be supportive and serve as an advocate, there were a few DSPs who did not feel this way and were ambivalent or even negative. A policy would require such staff to put their own personal values aside or retain a minimal level of freedom that follows the policy in place which supports the sexual rights of the consumers it serves.

### **Team Approach**

There is a need for a unified team approach. Currently, agency representatives, parents and/or guardians, and the consumer meet at a minimum once a year to review the goals and plans for the consumer. Meetings are also scheduled to deal with specific concerns as they arise. According to the DSPs, sexuality may be a reason for such a meeting. However, DSPs are not always invited into these meetings and this was raised as a concern by those participants who were interviewed for this study. Parents, case managers, and a house manager might be invited into the team meeting, but the people who are engaging with the consumer every day (i.e., the DSPs) are not always invited into the meeting. Knowing from this study that the DSPs are the ones championing for the consumer, it would be important to have them there to advocate and

support their consumer's sexuality interests. This is also a time where the agency can reiterate their policy that states that they support the consumers' sexual rights so that a parent and/or guardian who is hesitant can understand why and how the agency will assist the consumer. The parents do not have a right to know everything.

### **Professional Staff**

The implications of this research for the DSPs (or other professionals who provide direct care) point to the need for more support and training. Through the interviews, the DSPs identified that, while they see themselves as the advocates for their consumers, they also experience frustrations to support and advocate for their consumers' sexuality issues due to having their hands tied and feeling isolated. With such a high turnover and burnout rate among DSPs (Alvey, 2018), it is important to consider what can be done to improve their work situation so they do not feel so frustrated and alone. Some specific examples include having clear guidelines (discussed above) so the DSP knows how to respond, and also recognizing and respecting that DSPs are often the ones who are most intimately involved with the consumers. Unlike others who only visit or interact on a weekly or monthly basis, the DSPs are able to see and understand things others may not observe directly.

In addition, these findings suggest that providing DSPs with ongoing training and discussion focused on sexuality is important. Also, it would be useful for DSPs to have a supervisor who is open, affirming and comfortable to turn to for guidance, as well as a support network of other DSPs to discuss the sexuality issues they are seeing and dealing with on a regular basis. This would alleviate some of the feelings of not knowing how to respond, as well as feelings of isolation.

## **Individuals with ID**

While this study investigated how DSPs view and support the sexuality of those with ID, the findings have implications for the consumers they work with. The study revealed that DSPs identify their consumers as isolated when it comes to their sexuality. DSPs reported that consumers often lack sexuality education and access to sexual health services. Furthermore, laws should require sexuality education for students with disabilities and include the typical curriculum with adaptations and accommodations as necessary. Due to this lack of education and gap in knowledge, there is a need for DSPs to be given guidance on how to educate the consumers they work with on these issues. Other opportunities to learn about sexuality should be provided to consumers by offering classes or group discussions. These classes should not have a singular focus of abuse prevention, but should be more broadly focused on such things as developing friendships, stages of dating, and other sex-positive topics. In terms of health, DSPs noted that some consumers had never accessed basic sexual health services (e.g., gynecological exams, access to contraception).

DSPs also identified isolation for their consumers when they discussed their lack of social life. They shared that their consumers' existence may consist of living in a group home with three others of the same sex and being supervised 24/7 by a staff member and never having access to other peers. Without opportunities to work or volunteer outside the home or to have activities with others that would naturally lead to social connections, the consumers' lives were often reduced to isolation and a set schedule with limited access to others. The DSPs described the lack of spontaneity that comes with consumers being dependent on others (e.g., a lack of transportation), and everything having to be arranged and coordinated in order to have a social

engagement, let alone a date. Opportunities to be alone are limited, as well as opportunities to practice social skills and meeting others (e.g., going to a bar or party).

In addition, DSPs described how the parents further limited the consumers' ability to have a social (sexual) life. DSPs shared stories of parents limiting their adult child's access to the internet or to social events, or denying their adult child's desire to date or be sexually involved with someone else.

Ultimately, consumers with mild to moderate ID can find themselves frustrated, confused, and even in a situation where their sexual rights are withheld. Without a clear policy and guidelines, the consumer faces inconsistency in how their sexual needs and interests are addressed. Instead of policy it will be the DSPs' level of training, comfort, or even their best guess and personal beliefs may be depended upon, or left to the parents and/or guardians who may not have a positive perspective on their adult child's sexuality informing decisions.

### **Parents and Guardians**

The interviews with the DSPs provided several suggestions for what needs to happen with parents in order for them to support the consumers' sexuality. It became evident that it is the parents and/or guardians who dictate what happens in the lives of the consumers. DSPs described some parents and/or guardians as supportive and positive in their approach to their adult children, however, these parents were the exception. Most DSPs identified parents and/or guardians as the greatest barrier to their work in supporting the consumers' sexuality. DSPs shared many examples of wanting to educate, facilitate, and support their consumers with mild or moderate ID, but were unable to do so because the parent and/or guardian said no. Universally, DSPs identified the need to educate parents to see their adult child as an adult.

DSPs further identified the importance of having *all* parents on board when it came to accepting their adult child's sexuality. For example, DSPs described situations where a supportive parent was open to their adult children dating, but this was not possible because the parent of the other adult child who they wanted to date denied such a request. Clarification needs to be made for parents as to when an adult with ID becomes an adult with rights.

Another recommendation is to help parents and/or guardians see DSPs as an important resource and an important part of the team. The DSPs work closely, day in and day out, with their adult child. Helping parents to trust and feel confident in the DSPs' work is important in order for the consumer to be able to have the sexual rights outlined by Federal laws and State statutes. To say, "People with intellectual disabilities and/or developmental disabilities, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected" (AAIDD, 2019b; The Arc, 2018b) is meaningless if the parents are the ultimate authority and have the right to say no. There needs to be clarification that parents are not the ultimate authority, that their adult children have rights as individuals. The need for a team approach, as mentioned above, can play an important role in moving parents in a positive direction, with the help of the agency who has a policy and the DSPs who are advocates of the consumer's sexuality.

### **Educational Programs**

The educational training that DSPs participate in is important for setting the groundwork for their work with consumers. In the area of sexuality, it is important that DSPs are educated on sexuality as part of their training. If DSPs are to educate, facilitate, and support their consumers, it is important they possess accurate sexuality information and have a sex-positive attitude.

In the State of Maine, in order for someone to be certified as a DSP, they must complete the training through the Maine College of Direct Support provided through the Office of Aging and Disability Services and Maine Department of Health and Human Services. This training has both an online and a live component. The online training includes 52 lesson modules. Only one of those modules is specifically focused on sexuality. It is also included in the one live classroom session that DSPs attend prior to being certified. Once certified, all DSPs have to participate in continuing education as part of professional development, but sexuality is not required. The findings from this study suggest that there is a need for a greater focus on sexuality in both their initial training and ongoing educational seminars in order for DSPs to effectively work to advocate and support their consumers' sexuality issues.

Beyond the DSP's required training for certification, many of the DSPs involved in this study said they had pursued additional education (i.e., attended a community college or university). They identified studying in programs such as Psychology, Rehabilitation Services, Social Work, and Special Education. These programs provide another opportunity to emphasize sexuality as an important aspect of working with consumers with ID.

### **Future Research**

There is a need for more qualitative studies in this area. Much of the research to date has been quantitative, using a quick survey to assess attitudes. These do not allow for an in-depth understanding of the lived experiences of DSPs and their role as an advocate and supporter of their consumers' sexuality. This depth of understanding would not have been possible without the in-depth interviews. Clearly, there is much more to learn about the role of DSPs.

This study focused on DSPs working with consumers with mild to moderate ID. Future research could include the work of DSPs with individuals who are classified as having severe ID.

Furthermore, this study was conducted in the rural State of Maine; a larger study could include several geographical areas in both urban and rural locations in order to compare their findings.

Future research could include not only the DSPs but also their consumers. The issue of consumer isolation was raised as a concern. More research on this particular issue will be important. Furthermore, more research on those consumers who identify as lesbian, gay, bisexual or transgender would be useful. This appears to be underrepresented within the literature and an important area for further research.

### **Conclusion**

This research was significant because it adds to our understanding of how DSPs view and support the sexuality of individuals with mild to moderate ID. It has been an understudied area of research. This study was able to identify numerous themes around DSPs' attitudes, experiences, influences, gender, and recommendations for improving their work with consumers. It was able to paint a clearer picture of DSPs as the true champions for their consumers' sexual issues, yet who often find their hands are tied and their work isolating. DSPs reported barriers due to the negative attitudes of both agencies and parents and/or guardians. Due to the over-control reported by DSPs, consumers are denied opportunities to establish relationships and experience their sexual desires and interests.

There are Federal laws and State statutes that profess that individuals with ID have sexual rights, yet a closer look has not been taken at how this is played out on a day-to-day basis between persons with ID and the people and programs they are involved with. Ultimately, this study was important because it shows that there are DSPs who work on the front lines, who are there because they want to help these individuals with mild to moderate ID. DSPs need support so they do not feel frustrated or so alone in their efforts to be champions for their consumers'

sexuality. Finally, based on these findings, there is a call for agencies to have a clear policy, to use a team approach which includes the DSPs, and better training for DSPs as well as parents. This will ensure consumers have the sexual rights they are supposed to be guaranteed under the laws.

## REFERENCES

- Abbott, D., & Howarth, J. (2007). Still off-limits? Staff views on supporting gay, lesbian and bisexual people with intellectual disabilities to develop sexual and intimate relationships? *Journal of Applied Research in Intellectual Disabilities*, 20, 116-126.
- ADAAA. (2014). Americans with Disabilities Act Amendments Act of 2008. Retrieved from [https://search.ada.gov/search?query=major+life+activity&search=go&sort=date:D:L:d1&output=xml\\_no\\_dtd&ie=iso-8859-1&oe=UTF-8&client=default\\_frontend&proxystylesheet=default\\_frontend&affiliate=justice-ada](https://search.ada.gov/search?query=major+life+activity&search=go&sort=date:D:L:d1&output=xml_no_dtd&ie=iso-8859-1&oe=UTF-8&client=default_frontend&proxystylesheet=default_frontend&affiliate=justice-ada)
- Addlakha, R., Price, J., & Heidari, S. (2017). Disability and sexuality: Claiming sexual and reproductive rights. *Reproductive Health Matters*, 25(50), 4–9.
- Ajzen, I. (1985). From intentions to actions: A theory of planned behavior. In *Action control* (pp. 11-39). Springer, Berlin, Heidelberg.
- Alford, S. (2020). Sex education programs: Definitions & point-by-point comparison. Retrieved from <https://advocatesforyouth.org/resources/fact-sheets/sex-education-programs-definitions-and-point-by-point-comparison/>
- Allen, J. D. (2008). *Sexual expression and intellectual disability in Connecticut: A qualitative description of staff practices* (Doctoral Dissertation, Southern Connecticut State University). Retrieved from ProQuest Dissertations and Thesis Database. (UMI No. 3327025).
- Alvey, H.L. (2018). *Evaluating burnout in direct support professionals in America: An exploratory factors analysis of the Copenhagen burnout inventory* (Doctoral Dissertation, Spalding University) Retrieved from ProQuest Dissertations & Theses Database. (UMI No. 13861855).
- American Association on Intellectual and Developmental Disabilities (AAIDD). (2019a). *Definition of intellectual disability*. Retrieved from <https://aidd.org/intellectual-disability/definition>. Silver Spring, MD.
- American Association on Intellectual and Developmental Disabilities (AAIDD). (2019b). *Position statements*. Retrieved from <https://aidd.org/news-policy/policy/position-statements> Silver Spring, MD.
- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders*. Washington DC: American Psychiatric Publishing.
- Andersen, J. P., & Zou, C. (2015). Exclusion of sexual minority couples from research. Retrieved from <https://www.hsj.gr/medicine/exclusion-of-sexual-minority-couples-from-research.php?aid=7377>

- Andrews, A. & Veronon, L. J. (1993). Sexual assault and peoples with disabilities. Special issue: Sexuality and disabilities: A guide for human service practitioners. *Journal of Social Work and Human Sexuality*, 8 (2), 137-159.
- Anti-Defamation League. (2020). A brief history of the disability rights movement. Retrieved from <https://www.adl.org/education/resources/backgrounders/disability-rights-movement>
- The Arc. (2018a). *What is people first language?* Retrieved from <https://www.thearc.org/who-we-are/media-center/people-first-language>
- The Arc. (2018b). *Autonomy, decision-making supports, and guardianship*. Retrieved from <https://www.thearc.org/who-we-are/position-statements/rights/Autonomy-Decision-Making-Supports-and-Guardianship>
- Arias, B., Ovejero, A., & Morentin, R. (2009). Love and emotional well-being in people with intellectual disabilities. *The Spanish Journal of Psychology*, 12, 204-216.
- Armitage, C. J., Conner, M., & Norman, P. (1999). Differential effects of mood on information processing: Evidence from theories of reasoned action and planned behavior. *European Journal of Social Psychology*, 29, 419-433.
- Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15 (4), 285-296.
- Baladerian, N. (2013). *Disability and abuse project*. Retrieved from <http://disabilityandabuse.org/wordpress/?p=205>
- Balius, A. (2018). *"I want to be who I am:" Stories of rejecting binary gender* (Master's thesis, University of South Florida, Tampa, Florida). Retrieved from <https://scholarcommons.usf.edu/etd/7262>
- Bazelon, D. L., & Boggs, E. M. (1963). *Report of the Task Force on Law* (pp. 1–49).
- Bazzo, G., Nota, L., Soresi, S., Ferrari, L., & Minnes, P. (2007). Attitudes of social service providers towards the sexuality of individuals with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 20 (2), 110-115.
- Biennial Plan (2018). *Office Of Aging And Disability Services Biennial Plan for Services to Adults with Intellectual Disabilities Or Autism 2017-2018*. (2018).
- Birks M, Mills J. *Grounded theory: A practical guide*. 2nd ed. London: SAGE, 2015.
- Blatt, B., & Kaplan, F. (1974). *Christmas in purgatory: A photographic essay on mental retardation*. Syracuse, NY: Human Policy Press.

- Bogdan, R., & Biklen, S. K. (2003). *Qualitative research for education: An introduction to theories and methods* (4th ed.). London, England: Pearson.
- Brantlinger, E. (1983). Measuring variation and change in attitudes of residential care staff toward the sexuality of mentally retarded persons. *Mental Retardation*, 21, 17-22.
- Brown, H. (1994). An ordinary sexual life? A review of the normalization principle as it applies to sexual options of people with learning disabilities. *Disability & Society*, 9, 123-145.
- Brown, M., & McCann, E. (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities*, 74, 124-138.
- Butler, J. (2015). *Gender trouble: Feminism and the subversion of identity*. NY: Routledge, Taylor & Francis Group.
- Carey, A. C. (2003). Beyond the medical model: A reconsideration of feeblemindedness, citizenship, and eugenic restrictions. *Disability & Society*, 18(4), 411–430.
- Carey, A. C. (2009). *On the margins of citizenship: Intellectual disability and civil rights in twentieth-century America*. Philadelphia, PA: Temple University Press.
- Center for Community Inclusion and Disability Studies (CCIDS) University of Maine. (2019). *Waitlist statistics* [Data File]. Retrieved from <https://ccids.umaine.edu/>
- Centers for Disease Control and Prevention (CDC). (n.d.). Statistics of adults in Maine with disabilities. Retrieved from <https://www.cdc.gov/>
- Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. London: Sage.
- Cheeseman, N.A. (2015). *Understanding the history of institutionalization: Making connections to de-institutionalization and the Olmstead Act for Persons with Intellectual Disabilities in the State of Illinois*. Dissertations. 127. <https://digitalcommons.nl.edu/diss/127>
- Chou, Y. C., Lu, Z.-Y. J., & Pu, C.Y. (2015). Attitudes toward male and female sexuality among men and women with intellectual disabilities. *Women & Health*, 55(6), 663–678.
- Chrastina, J., & Večeřová, H. (2018). Supporting sexuality in adults with intellectual disability: A short review. *Sexuality and Disability*. 1-14. <https://doi.org/10.1007/s11195-018-9546-8>
- Cohen, N., & Arieli, T. (2011). Field research in conflict environments: Methodological challenges and snowball sampling. *Journal of Peace Research*, 48(4), 423–435.

- Corbin, J., & Strauss, A. L. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. (4th ed.). Los Angeles: SAGE.
- Creswell, J. W. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). Thousand Oaks, CA: Sage Publications.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches*. Los Angeles, CA: SAGE Publications.
- Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample. *Journal of Intellectual & Developmental Disability, 29*, 255-264.
- Cuskelly, M., & Gilmore, L. (2007). Attitudes to sexuality questionnaire (individuals with an intellectual disability): Scale development and community norms. *Journal of Intellectual & Developmental Disability, 32*(3), 214-221.
- Ćwirynkalo, K., Byra, S., & Żyta, A. (2017). Sexuality of adults with intellectual disabilities as described by support staff workers. *Hrvatska Revija Za Rehabilitacijska Istraživanja, 53*, 77-87.
- Department of Health, Education, and Welfare. (1973). *Rehabilitation Act of 1973*, 29 U.S.C. Åò 701 et seq. (1973) (amended 1992). Washington, DC.
- Department of Health and Human Services (DHHS). (2018a). *Disability statistics* [Data File]. Retrieved from <https://www.maine.gov/dhhs/>
- Department of Health and Human Services (DHHS). (2018b). *DHHS regulations* [Data File]. Retrieved from <https://www.maine.gov/dhhs/>
- Desjardins, M. (2012). *The sexualized body of the child: Parents and the politics of “voluntary” sterilization of people labeled intellectually disabled*. Durham, NH: Duke University Press.
- DiGiulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *Canadian Journal of Human Sexuality, 12*, 53-68.
- Direct Support Professional Training. (2019, July). Curriculum for Licensed Facilities. Retrieved from <https://www.cde.ca.gov/ci/ct/rp/dspt.asp>
- Disability Justice. (2019). *The right to self-determination: Freedom from involuntary sterilization*. Retrieved from <https://disabilityjustice.org/right-to-self-determination-freedom-from-involuntary-sterilization/>
- Doerr, A. (2009). *Three generations of imbeciles are enough*. Retrieved from <https://theprivacyreport.com/2009/06/25/three-generations-of-imbeciles-are-enough/>.

- Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264.
- Esmail, S., Darry, K., Walter, A., & Knupp, H. (2010). Attitudes and perceptions towards disability and sexuality. *Disability and Rehabilitation*, 32, 1148-1155.
- Evans, D.S., McGuire, B.E., Healy, E., Carley, S.N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family career perspectives. *Journal of Intellectual Disability Research*, 53, 913-921.
- Federal Register. (2013, August). *Change in terminology: "Mental retardation" to "intellectual disability."* Washington, DC. Retrieved from <https://www.federalregister.gov/documents/2013/08/01/2013-18552/change-in-terminology-mental-retardation-to-intellectual-disability>
- Feely, M. (2016). Sexual surveillance and control in a community-based intellectual disability service. *Sexualities*, 19(5-6), 725–750.
- Finger, A. (1992). Forbidden fruit. *New Internationalist*, 233, para 6.
- Fitzgerald C. & Withers P. (2013) 'I don't know what a proper woman means:' What women with intellectual disabilities think about sex, sexuality and themselves. *British Journal of Learning Disabilities* 41, 5–12.
- Frawley, P., & Wilson, N. J. (2016) Transition staff discuss sex education and support for young men and women with intellectual and developmental disability. *Journal of Intellectual & Developmental Disability*, 41(3), 209-221.
- Galea, J., Butler, J., Iacono, T., & Leighton, D. (2004). The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 29, (4) 350-366.
- Galton, F. (1883). *Inquiries into human faculty and its development*. Bristol, U.K.: Thoemmes Press.
- Garland-Thomson, R. (1997). *Extraordinary bodies: figuring physical disability in American culture and literature*. New York, NY: Columbia University Press.
- Garland-Thomson, R. (2005). Feminist disability studies. *Journal of Women in Cultural and Society*, 30(2), 1557–1587.
- Gerschick, T. J. (2000). Toward a theory of disability and gender. *Journal of Women in Cultural and Society* 25(4), 1263–1268.

- Gill, M. C. (2015). *Already doing it: Intellectual disability and sexual agency*. Minneapolis, MN: University of Minnesota Press.
- Gil-Llario, M. D., Morell-Mengual, V., Ballester-Arnal, R., & Díaz-Rodríguez, I. (2018). The experience of sexuality in adults with intellectual disability. *Journal of Intellectual Disability Research*, 62(1), 72–80.
- Gilmore, L., & Chambers, B. (2010). Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *Journal of Intellectual & Developmental Disability*, 35(1), 22-28.
- Glaser, B. G. & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Piscataway, NJ: Transaction Publishing.
- Gosney, E. S., & Popenoe, P. (1929). *Sterilization for human betterment: A summary of results of 6,000 operations in California, 1909-1929*. New York, NY: Macmillian Publishers.
- Grenon, I., & Merrick, J. (2014, October 20). Intellectual and developmental disabilities: Eugenics. *Frontiers of Public Health*. 2, 201.
- Grieve, A., McLaren, S., Lindsay, W., & Culling, E. (2009). Staff attitudes towards the sexuality of people with learning disabilities: A comparison of different professional groups and residential facilities. *British Journal of Learning Disabilities*, 37, 76-84.
- Halstead, S. (2002). Service-user and professional issues. *Journal of Intellectual Disability Research*, 46, 31-46.
- Haynes, A. (2016). *An investigation into parental attitudes about sexuality and children with intellectual disabilities*. (Unpublished Master's thesis) City University of Seattle, Seattle, WA.
- Healy, E., McGuire, B. E., Evans, D. S., Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability (Part I: Service-user perspectives). *Journal of Intellectual Disability Research*, 53, 905-912.
- Hellemans, H., Roeyers, H., Leplae, W., Dewaele, T., Deboutte, D. (2010). Sexual behavior in male adolescents and young adults with autism spectrum disorder and borderline/mild mental retardation. *Sexuality and Disability*, 28, 93-101.
- Hingsburger, D., & Tough, S. (2002). Healthy sexuality: Attitudes, systems, and policies. *Research and Practice for Persons with Severe Disabilities*, 27(1), 8–17.
- Hock, R. R. (2016). *Human sexuality* (4th ed.). Boston, MA: Pearson.
- Holstein, J. A., & Gubrium, J. F. (1995). *The active interview*. Thousand Oaks, CA: SAGE Publications.

- Hsieh, H., & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*, 1277-1288.
- Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, L., ... & Officer, A. (2012). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *The Lancet, 379*(9826), 1621-1629.
- Human Rights Watch. (2011). *Sterilization of women and girls with disabilities*. Retrieved from <https://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities>
- IDEA. (2004). *Individuals with Disabilities Education Improvement Act of 2004*, Pub. L. No 108-446, 118 Stat. 2647. Washington, DC.
- Inclusion BC. (2019). *Institutions and people with intellectual disabilities*. Retrieved from <https://inclusionbc.org/our-resources/institutions/>
- Kafer, A. (2005). *Accessible futures? Disability, feminist and queer theory, and progressive politics* (Doctoral Dissertation, Claremont Graduate University) Retrieved from ProQuest Dissertations & Theses Database. (UMI No. 305006871).
- Kelly, G., Crowley, H., Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted.' *British Journal of Learning Disabilities, 37*(4), 308-315.
- Kelly, J., Murphy, D., Sikkema, K., & Kalichman, S. (1993). Psychological interventions to prevent HIV infection are urgently needed: New priorities for behavioral research in the second decade of AIDS. *American Psychologist, 48*, 1023-1034.
- Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability, 9*(2), 93-111.
- Ladd-Taylor, M. (2017). *Fixing the poor*. Baltimore, MD. Hopkins University Press.
- Leedy, P. D., & Ormrod, J. E. (2005). *Practical research: Planning and design* (8th ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (1st ed.). Newbury Park, CA: SAGE Publications.
- Lofgren-Martenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. *Sexuality and Disability, 22*, 197-207.
- Lofgren-Martenson, L. (2009). The invisibility of young homosexual women and men with intellectual disabilities. *Sexuality and Disability, 27*, 21-25.

- Longhi, S. (2017). *The disability pay gap*. Washington DC: Equality and Human Rights Commission. Retrieved from <https://www.equalityhumanrights.com/sites/default/files/research-report-107-the-disability-pay-gap.pdf>
- MacMurchy, H. (1920). *The alms: A study of the feeble-minded*. Boston, MA. Houghton Mifflin.
- Maine Association for Community Service Providers (MACSP). (2019). *Supporting Maine citizens with developmental disabilities to live, work, and play in the community*. Retrieved from <http://meacsp.org/>. Augusta, ME.
- Maine Coalition for Housing and Quality Services. (2019). *Section 21 & 29*. Portland, ME. Retrieved from <https://www.maineparentcoalition.org/section-21--29.html>
- Maine College of Direct Support. (2018). *Required Modules*. Retrieved from <https://www.maine.gov/dhhs/oads/provider/developmental-services/college-of-direct-support.html>
- Maine Department of Education (Maine DOE). (2020). Students with ID in public schools in Maine. Retrieved from <https://www.maine.gov/doe/home>
- Maine Department of Health and Human Services. (2018). *Required modules for certification as a Maine direct support professional* [Pamphlet]. Augusta, ME.
- Malony, H. N. (2001). *Pastoral care and counseling in sexual diversity*. New York, NY: Routledge.
- Martino, A. S., & Perreault-Laird, J. (2019). "I don't know if I can talk about that:" An exploratory study on the experiences of care workers regarding the sexuality of people with intellectual disabilities. *Disability Studies Quarterly*, 39(3). Retrieved from <https://dsq-sds.org/article/view/6383/5407> <https://doi.org/10.18061/dsq.v39i3.6383>
- McCabe, M. P., & Cummings, R. A. (1996). The sexual knowledge, experience, feelings and needs of people with mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 31, 13-21.
- McCabe, M. P., & Cummins, R. A. (1998). Sexuality and quality of life among young people. *Adolescence*, 33, 761-773.
- McCabe, M. P., Cummins, R. A., & Deeks, A. A. (2000). Sexuality and quality of life among people with physical disability. *Sexuality and Disability*, 18, 115-123.
- McCarthy, M., & Thompson, D. (1994). HIV/AIDS and safer sex work with people with learning disabilities. In A. Craft (Ed.), *Practice issues in sexuality and learning disabilities*, (pp. 186-201). London: Routledge.

- McConkey, R., & Ryan, D. (2001). Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability. *Journal of Intellectual Disability Research, 45*, 83-87.
- McDonald, K. E., Conroy, N. E., Olick, R. S., Carroll, A., Cuddy, M., Feldman, M. F., ... Worrall, P. (2018). A quantitative study of attitudes toward the research participation of adults with intellectual disability: Do stakeholders agree? *Disability and Health Journal, 11*(3), 345–350.
- McKenzie, K., Shewan, L., & Wilson, S. (2016). The rights of individuals with disability to parenthood. *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan* (pp. 85-101). Springer Publishing, Cham.
- McMillan, J. H., & Schumacher, S. (2014). *Research in education: Evidence-based inquiry*. Harlow, Essex: Pearson.
- Meaney-Tavares, R., & Gavidia-Payne, S. (2012). Staff characteristics and attitudes towards the sexuality of people with intellectual disability. *Journal of Intellectual & Developmental Disability, 37*(3), 269-273.
- Menon, P., & Sivakami, M. (2019). Exploring parental perceptions and concerns about sexuality and reproductive health of their child with intellectual and developmental disability (IDD) in Mumbai. *Frontiers in Sociology, 4*.
- Moustakas, C. (2010). *Phenomenological research methods*. Thousand Oaks, CA: Sage Publications.
- Murphy, G. H., & Ocallaghan, A. (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine, 34*(7), 1347–1357.
- Murray, J.L., & Minnes, P.M. (1994). Staff attitudes towards the sexuality of persons with intellectual disability. *Australian and New Zealand Journal of Developmental Disabilities, 19*, 45-52.
- Murray, J. L., MacDonald, R. A. R., Brown, G., & Levenson, V. L. (1999). Staff attitudes towards the sexuality of individuals with learning disabilities: A services-related study of organizational policies. *British Journal of Learning Disabilities, 27*, 141-145.
- Mutcherson, K. (2017). Disability, procreation, and justice in the United States. *Laws, 6*, 27.
- NADSP Competency Areas. (2020). DSP training competency areas. Retrieved from <https://nadsp.org/competency-areas-text/>
- Naples, N. A., Mauldin, L., & Dillaway, H. (2018). From the guest editors: Gender, disability, and intersectionality. *Gender & Society, 33*(1), 5–18.

- National Academies of Sciences, Engineering, and Medicine. (2015). *Mental disorders and disabilities among low-income children*. Washington, DC: The National Academies Press.
- National Center for Learning Disabilities (NCLD). (2019). *IDEA Funding Statistics* [Data File]. Retrieved from <https://www.nclld.org/>
- National Information Center for Children and Youth with Disabilities (NICHCY). (2019). *Parents and Sexuality Education*. Retrieved 2019, from <https://www.washington.edu/doit/national-information-center-children-and-youth-disabilities-nichcy-0>
- Niekerk, J. C. V., & Roode, J. D. (2009). Glaserian and Straussian grounded theory. *Proceedings of the 2009 Annual Research Conference of the South African Institute of Computer Scientists and Information Technologists on SAICSIT 09*.
- Office of Aging and Disability Services (OADS). (2019). *Provider Directory* [Data File]. Retrieved from <https://www.maine.gov/dhhs/oads/provider/developmental-services/directory/index.html>.
- Office of Aging and Disability Services (OADS). (2020). *State of Maine Aging and Disability Services Goal* [Data File]. Retrieved from <https://www.maine.gov/dhhs/oads/>
- Oliver, M. N., Anthony, A., Leimkuhl, T. T., & Skillman, G. D. (2002). Attitudes toward acceptable socio-sexual behaviors for persons with mental retardation: Implications for normalization and community integration. *Education and Training in Mental Retardation and Developmental Disabilities, 37*(2), 193-201.
- Olmstead, S. B., Koon, J. T., Puhlman, D. J., Pasley, K., & Fincham, F. D. (2013). College men, unplanned pregnancy, and marriage: What do they expect? *Journal of Sex Research, 50*(8), 808–819.
- Patton, M. Q. (2014). *Qualitative Research & Evaluation Methods: Integrating Theory and Practice* (4th ed.). Thousand Oaks, CA: SAGE Publications, Inc.
- Pebdani, R. N. (2016). Attitudes of group home employees towards the sexuality of individuals with intellectual disabilities. *Sexuality and Disability, 34*(3), 329–339.
- Plummer, K. (2003). *Intimate citizenship: private decisions and public dialogues*. Montreal: McGill.
- Positive Choices. (n.d.). *Positive choices*. Hartford, CT.

- Presidential Report. (2017). *Report to the President 2017 America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy*. Retrieved from <https://www.citationmachine.net/apa/cite-a-report/manual>
- Reiter, J. & Walsh, R. (2018). *Involuntary sterilization of disabled Americans: An historical overview*. Retrieved from: <https://www.abclawcenters.com/blog/2018/11/06/involuntary-sterilization-of-disabled-americans-an-historical-overview/>.
- Rushbrooke E., Murray C. & Townsend S. (2014) The experiences of intimate relationships by people with intellectual disabilities: a qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 27, 531–41.
- Ryan, D., & McConkey, R. (2000). Staff attitudes to sexuality and people with intellectual disabilities. *The Irish Journal of Psychology*, 21(1-2), 88-97.
- Saxe, A., & Flanagan, T. (2014). Factors that impact supports workers' perceptions of the sexuality of adults with developmental disabilities: A quantitative analysis. *Sexuality and Disability*, 32(1), 45-63.
- Schaafsma, D., Kok, G., Stoffelen, J. M., Doorn, P. V., & Curfs, L. M. (2014). Identifying the important factors associated with teaching sex education to people with intellectual disability: A cross-sectional survey among paid care staff. *Journal of Intellectual & Developmental Disability*, 39(2), 157-166.
- Schaafsma, D., Kok, G., Stoffelen, J. M., & Curfs, L. M. (2017). People with intellectual disabilities talk about sexuality: Implications for the development of sex education. *Sexuality and Disability*, 35(1), 21-38.
- Schalock, R. L., Yeager, M. H., Wehmeyer, M. L., Verdugo-Alonso, M. A., Thompson, J. R., Tasse, M. J., ... Borthwick-Duffy, S. A. (2010). *Intellectual disability: Definition, classification, and systems of supports*. (11th ed.). American Association on Intellectual and Developmental Disabilities. Silver Spring, MD.
- Schuengel, C., Kef, S., Hodes, M. W., & Meppelder, M. (2017). Parents with intellectual disability. *Current Opinion in Psychology*, 15, 50-54.
- Senne, E. (2016). *Experiences of direct support professionals supporting sexuality for individuals with developmental disabilities*. (Unpublished Master's thesis) St. Catherine University, Saint Paul, MN.
- Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 48-56.
- Siebelink, E. M., de Jong, M. D. T., Taal, E. & Roelvink, L. (2006). Sexuality and people with intellectual disabilities: Assessment of knowledge, attitudes, experiences, and needs. *Mental Retardation*, 44, 283-294.

- Sieber J. (1992). Planning ethically responsible research: A guide for students and internal review boards. *American Psychological Association*. Newbury Park: Sage Publications.
- Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015): Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities Journal*, 50(1), 3-16.
- Snow, K. et al. (2014). *Chartbook: Adults with intellectual disability or autism spectrum disorder*. Portland, ME: Muskie School of Public Service.
- Sobsey, D., & Varnhagen, C. (1988). *Sexual abuse and exploitation of people with disabilities*. Ottawa: Health and Welfare Canada.
- State of Maine Revised Statutes (2019). Title 34-B: Behavioral and developmental services chapter 5: Intellectual disabilities and autism subchapter 4: Rights of persons with intellectual disabilities or autism. Maine Legislature, Maine Revised Statutes. Retrieved from <http://legislature.maine.gov/statutes/34-B/title34-Bch5sec0.html>
- Stephenson, A. C. (2017). *"We're Human": An Analysis of Formal and Informal Training Methods for Direct Care Staff Working with Dual-Diagnosis Populations* (Master's thesis, Marshall University) Retrieved from ProQuest Dissertations & Theses Database.
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge Univ. Press.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. London: SAGE publications.
- Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2015). The close relationships of people with intellectual disabilities: A Qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 29(2), 172-184.
- Sunstein, B. S., & Chiseri-Strater, E. (2016). *Fieldworking: reading and writing research*. Boston: Bedford/St. Martins.
- Swango-Wilson, A. (2007). *Caregiver Attitude of Sexuality of the Intellectually Disabled Population and Implications for Sex Education* (Doctoral dissertation, Walden University). Retrieved from ProQuest Dissertations and Thesis Database. (UMI No. 3277951).
- Swango-Wilson, A. (2009). Perception of sex education for individuals with developmental and cognitive disability: A four cohort study. *Sexuality and Disability*, 27, 223-228.

- Tamas, D., Jovanovic, N.B., Rajic, M. Ignjatovic V.B., & Prkosovacki B.P. (2019). Professionals, parents and the general public: Attitudes towards the sexuality of persons with intellectual disability. *Sexuality and Disability*, 37(2), 245-258.
- Trent, J. W. (1994). *Inventing the feeble mind: A history of mental retardation in the United States*. Berkeley, CA: University of California Press.
- Trudel, G., & Desjardins, G. (1992). Staff reactions towards the sexual behaviours of people living in institutional settings. *Sexuality and Disability*, 10, 173-188.
- Tugut, N., Golbasi, Z., Erenel, A. S., Koc, G., Ucar, T. (2016). A multicenter study of nursing students' perspectives on the sexuality of people with disabilities. *Sexuality and Disability*, 34, 433–442.
- U.S. Bureau of Labor Statistics. *Employed persons by detailed occupation, sex, race, and Hispanic or Latino ethnicity* [Data File]. (2020, January 22). Retrieved from <https://www.bls.gov/cps/cpsaat11.htm>
- U.S. Census Bureau. (2018). *QuickFacts: Maine*. Retrieved from <https://www.census.gov/quickfacts/fact/table/ME/PST045218>. Washington, DC.
- United Nations (UN) (1948). UN: The Universal Declaration of Human Rights, *International Documents on Corporate Responsibility*.
- Wade, H. (2002). Discrimination, sexuality and people with significant disabilities: Issues of access and the right to sexual expression in the United States. *Disability Studies Quarterly*, 22(4).
- Walcott, D. (1997). Family life education for persons with developmental disabilities. *Sexuality and Disability*, 15, 91-97.
- Walker-Hirsch, L. (2007). *The facts of life—and more: Sexuality and intimacy for people with intellectual disabilities*. Baltimore, MD: Paul H. Brookes.
- West, B. A. (2015). Gender theory. In J. M. Bennett, *Sage reference publication: The Sage encyclopedia of intercultural competence*. (p. 340). Thousand Oaks, CA: Sage Publications.
- Wheeler, P. (2007). 'I count myself as normal, well, not normal, but normal enough:' Men with learning disabilities tell their stories about sexuality and sexual identity. *Tizard Learning Disability Review*, 12(1), 16-27.
- Wilkenfeld, B., & Balian, M. (2011). Educators' attitudes and beliefs towards the sexuality of individuals with developmental disabilities. *Sexuality and Disability*, 29, 351-361.
- Wolfe, P. (1997). The influence of personal values on issues of sexuality and disability. *Sexuality and Disability*, 15, 69-90.

- Wolfensberger, W. (1969). The origin and nature of our institutional models. *President's Committee on Mental Retardation*. Washington, DC.
- World Health Organization (WHO). (2010). *Sexual and reproductive health*. Retrieved from [http://www.who.int/reproductivehealth/topics/sexual\\_health/sh\\_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/)
- Wright, P. W. D., & Wright, P. D. (2006). *Wrightslaw: Special education law*. Hartfield, VA: Harbor House Law Press.
- Yool, L., Langdon, P. E., & Garner, K. (2003). The attitudes of medium-secure unit staff toward the sexuality of adults with learning disabilities. *Sexuality and Disability*, 21, 137-150.
- Young, R., Gore, N., & McCarthy, M. (2012). Staff attitudes towards sexuality in relation to gender of people with intellectual disability: A qualitative study. *Journal of Intellectual & Developmental Disability*, 37(4), 343-347.

## APPENDICES

## Appendix A

### Letter to Agency Directors for Recruiting Participants

Dear (name of Director of Agency):

My name is Nicole Achey and I am a doctoral candidate in Human Development at the University of Maine. I am writing to ask for your help in finding participants for the study I am conducting. I would appreciate if you could forward my letter of invitation (attached) and the informed consent form (attached) to Direct Support Professionals (DSPs) at your agency. I am interested in interviewing DSPs who are employed to provide support to adults with mild or moderate intellectual disabilities. I would like to interview those who have worked at least 6 months in such a position.

The purpose of my research is to explore how DSPs view and support the sexuality of those with ID. I am interested in learning about DSPs' experiences with and attitudes toward a variety of sexuality issues involving their consumers (e.g., use of social media and erotica, dating and sexual relationships, use of contraception, masturbation, LGBTQ+ issues), as well as how they see their role. I am also interested in understanding what factors shape the way DSPs respond to the sexuality of individuals with intellectual disabilities, how gender influences their perceptions, and any changes DSPs might suggest when working with sexuality-related issues of individuals with ID.

If you have questions, I can be reached at 970-324-6503 or my email is [nicole.achey@maine.edu](mailto:nicole.achey@maine.edu). You can also contact my dissertation advisor, Dr. Sandra Caron, at the University of Maine in the Family Relations programs. Dr. Caron's phone number is 207-581-3138 and her email is [scaron@maine.edu](mailto:scaron@maine.edu). For questions about rights as a research participant,

please contact the Office of Research Compliance, University of Maine, 207/581-2657 (or e-mail [umric@maine.edu](mailto:umric@maine.edu)). Thank you for your assistance with my research.

Sincerely,

Nicole Achey

PhD Candidate

## **Appendix B**

### **Letter of Invitation to DSPs**

My name is Nicole Achey, and I am a doctoral candidate in Human Development at the University of Maine. I asked the Director of your agency to forward this letter to you as a DSP. I am seeking volunteers for my research study entitled: *Direct Support Professionals' Perspectives on Sexuality Issues of Adults with Intellectual Disabilities: A Qualitative Analysis of Interviews with Providers in Maine*

I would like to interview those who have worked at least six months in such a position. I am interested in interviewing DSPs who are employed to provide support to adults with mild or moderate intellectual disabilities. The purpose of my research is to explore how DSPs view and support the sexuality of those with ID. I am interested in learning about DSPs' experiences with and attitudes toward a variety of sexuality issues involving their consumers (e.g., use of social media and erotica, dating and sexual relationships, use of contraception, masturbation, LGBTQ+ issues), as well as how they see their role. I am also interested in understanding what factors shape the way DSPs respond to the sexuality of individuals with intellectual disabilities, how gender influences their perceptions, and any changes DSPs might suggest when working with sexuality-related issues of individuals with ID.

You will be asked to take part in an interview that will be digitally recorded for audio. The interview may take up to 90 minutes at a location convenient for you. Your participation is completely voluntary and you can withdraw at any time. There are no known risks to participation in this study beyond possible discomfort in discussing some sexuality-related issues. Please know you do not have to answer any questions that you are not comfortable with.

Attached is an Informed Consent document that provides further details about this study, guidelines for confidentiality and pertinent contact information.

If you are interested in participating in this study or if you have further questions, I can be reached at my personal cell phone: 970-324-6503 or my email [nicole.achey@maine.edu](mailto:nicole.achey@maine.edu). You can also contact my dissertation advisor, Dr. Sandra Caron, at the University of Maine in the Family Relations program. Her phone number is 207-581-3138 and Dr. Caron's email is [scaron@maine.edu](mailto:scaron@maine.edu). Thank you for considering this invitation.

Sincerely,

Nicole Achey

IPhD Candidate

University of Maine

## Appendix C

### Informed Consent

*Direct Support Professionals' Perspectives on Sexuality Issues of Adults with Intellectual Disabilities: A Qualitative Analysis of Interviews with Providers in Maine*

Nicole Achey, Doctoral Candidate in Human Development

University of Maine, Orono, ME 04469

Nicole.achey@maine.edu

970-324-6503

You are invited to participate in a research project being conducted by Nicole Achey, a doctoral student in Human Development at the University of Maine. My advisor is Dr. Sandra Caron. I am interested in interviewing DSPs who have experience working with adults with mild to moderate intellectual disabilities. I would like to interview those who have worked at least 6 months in such a position.

The purpose of my research is to explore how DSPs view and support the sexuality of those with ID. I am interested in learning about DSPs' experiences with and attitudes toward a variety of sexuality issues involving their consumers (e.g., use of social media and erotica, dating and sexual relationships, use of contraception, masturbation, LGBTQ+ issues), as well as how they see their role. I am also interested in understanding what factors shape the way DSPs respond to the sexuality of individuals with intellectual disabilities, how gender influences their perceptions, and any changes DSP's might suggest when working with sexuality-related issues of individuals with ID.

**What Will You Be Asked To Do?** If you decide to participate, you will be asked to participate in a single interview that will be audio recorded and later transcribed without any

identifying information. The interview will take approximately 90 minutes at a location convenient for you. As stated above, the purpose of my research is to explore how DSPs view and support the sexuality of those with ID. I am interested in learning about your experiences with and attitudes toward a variety of sexuality issues involving your consumers. I will be asking you questions about their use of social media and erotica, dating and sexual relationships, use of contraception, masturbation, LGBTQ+ issues, as well as how you see your role. I am also interested in understanding what factors shape the way you respond to the sexuality of individuals with intellectual disabilities, how gender might influence your perceptions, and any changes you might suggest when working with sexuality-related issues of individuals with ID.

Sample questions are as follows:

- Do you respond to the sexual health needs of Individuals with ID (i.e., doctor's visits, safer sex practices)? What or who prevents or encourages you?
- Do you assist consumers with their sexual rights (i.e. privacy, relationships?) What or who prevents or encourages you?
- Are there any risks in supporting an individual's sexual desires?

**Risks.** There are minimal risks to you from participating in this study. A risk associated with this study may be discomfort in speaking about sexuality topics. These risks will be minimized by allowing the interview to progress at a comfortable pace for you and by allowing you to decline to answer any question or to discontinue the interview at any point.

**Benefits.** You may benefit from sharing your thoughts and experiences. This research will help us learn more about the types of challenges related to sexuality that DSPs may encounter when working with adults with mild to moderate intellectual disabilities. This research may be used to inform DSP training programs, and agencies providing DSP services in Maine.

**Confidentiality.** All information supplied in the context of this study will be used to contribute

to this research. While excerpts from the interviews will be utilized in the final results and conclusions, you will be assigned a code name to protect your identity. Your name and any identifying information will be kept confidential and not appear in any publications. All data will be kept in a locked file cabinet in my home office and I am the only person with access. Data on my computer will be password protected. My dissertation committee will have access to coded data to ensure the analysis is true to your original words. Coded data will be kept at my home office in a locked file cabinet. Email may be used for communication. Although the University's email has many protections, I cannot guarantee that email correspondence is completely secure. Any email correspondence with participants will be deleted after the completion of the interview.

**Voluntary.** Participation is voluntary. If you choose to take part in this study, you may stop at any time. You may skip questions you do not wish to answer.

**Contact Information.** If you have further questions about this study, please contact me at:

Nicole Achey

970-324-6503

[nicole.achey@maine.edu](mailto:nicole.achey@maine.edu)

You may also reach my dissertation advisor at:

Dr. Sandra Caron

Professor - Family Relations & Human Sexuality

5749 Merrill Hall, Room 220

University of Maine

Orono, ME 04469-5749

(207)581-3138

[scaron@maine.edu](mailto:scaron@maine.edu)

If you have any questions about your rights as a research participant, please contact the Office of Research Compliance, University of Maine, 207-581-2657 (or e-mail [umric@maine.edu](mailto:umric@maine.edu)).

## **Appendix D**

### **Interview Questions**

Introduction: Thank you for agreeing to be interviewed for my study. As you know from the Informed Consent, I am interested in hearing about your work with adults with mild to moderate Intellectual Disability. I am specifically interested in issues related to sexuality. The purpose of my research is to explore how DSPs view and support the sexuality of those with ID

In addition to gathering some demographic information about you, I have a series of questions related to your experiences with and attitudes toward a variety of sexuality issues involving your consumers (e.g., their use of social media and erotica, dating and sexual relationships, use of contraception, masturbation, LGBTQ+ issues), as well as how you see your role. I am also interested in understanding what factors shape the way you respond to the sexuality of individuals with intellectual disabilities, how gender might influence your perceptions, and any changes you might suggest when working with sexuality-related issues of individuals with ID.

I'd like to record the interview. Is this okay with you?

Please know that I will transcribe the taped conversation, deleting any identifying information about you or a consumer. I will delete our taped conversation as soon as it is transcribed.

Demographic Questions:

What is your age?

What gender do you identify with?

What is your ethnicity?

What is your education level?

What is your job title/professional role?

How many years have you worked for this agency?

How many years have you worked with individuals with Intellectual Disability?

How many clients have you worked with who had mild to moderate Intellectual Disability?

**Research Question 1: What attitudes and beliefs are held by DSPs regarding the sexuality of individuals with intellectual disabilities?**

What are your feelings about consumers use of or involvement in the following sexuality issues, and your thoughts on your role (e.g., educating, facilitating, supporting):

- Social Media (e.g., to meet or develop relationships online)
- Erotica (e.g., use of sex toys/vibrators, literature, viewing films)?
- Dating
- Sexual relationships (e.g., requests for overnight guests)
- Contraception (e.g., condoms, the pill or IUD)
- Masturbation
- LGBTQ+ (e.g., consumers who identify as lesbian, gay, bisexual or transgender)
- Other sexuality-related issues

**Research Question 2: What are the experiences for DSPs in relation to the sexuality of individuals with ID and the DSPs' employment position?**

Tell me about your experiences with consumers in the following areas and describe how you dealt with such issues as the staff person (e.g., educating, facilitating, supporting):

- Social Media (e.g., to meet or develop relationships online)
- Erotica (e.g., use of sex toys/vibrators, literature, viewing films)
- Dating
- Sexual relationships (e.g. requests for overnight guests)
- Contraception (e.g., condoms, the pill or IUD)
- Masturbation
- LGBTQ+ (e.g., consumers who identify as lesbian, gay, bisexual or transgender)
- Other sexuality-related issues
- In terms of the experiences have shared, do you see these as typical experiences with consumers?

**Research Question 3: What factors influence DSPs responses to the sexuality of individuals with ID?**

What contributes to the way you respond to the sexuality of individuals with ID?

- Policies: Does your organization have a policy on sexual issues? Are you aware of it? Do you think it is enforced or encouraged?
- Training Opportunities: Have you received trainings on the sexual issues of individuals with ID? Have these trainings informed your work as a staff person?

- Parent: How do Parents' expectations influence how you respond to the sexual issues of individuals with ID?
- Other: Is there anything else that influences the way you respond to the various sexual issues of individuals with ID?

**Research Question 4.** How does gender (of the DSP and consumer) influence the role, approach, and ideas for ways to assist adults with ID related to sexual issues?

Do you think your approach to these issues differs for male vs. female consumers (i.e., use of social media, erotica, dating, sexual relationships, contraception, masturbation, LGBTQ+ issues)?

- Assisting: Do you feel your role in relation to sexuality has differed depending on if it is a male or female consumer (if you have experience working with both men and women)?
- Do you think there are different ways to assist male vs. female consumers when it comes to sexuality issues (i.e. use of social media and erotica, dating and sexual relationships, contraception, masturbation, LGBTQ+ issues)?
- Do you think your gender identity affects your opinions and behaviors?

**Research Question 5: What suggestions do DSP's have for working with sexuality-related issues of individuals with ID?**

What is needed if staff workers are to deal effectively with various sexuality issues of their consumers (i.e. use of social media and erotica, dating and sexual relationship issues, contraception, masturbation, LGBTQ+ issues)?

- Do you have any recommendations for the policies and education around sexuality (for yourself and for your consumers)?

- If you wanted to support the sexual aspects of your consumers' lives what would you need or want?
- Do you think anything stands in the way of individuals with ID being able to express their sexuality? What?
- Do you have any remaining thoughts?

## **BIOGRAPHY OF THE AUTHOR**

Nicole Achey was born in Lewiston, Maine on August 27th, 1983, and was raised in Winthrop, Maine. She attended the University of Maine at Farmington for her undergraduate degree in Rehabilitation Services. She then went on to the University of Northern Colorado and earned a Master's Degree in Rehabilitation Counseling. Nicole worked as a Rehabilitation Counselor for the State of Colorado before relocating back to Maine to join the Rehabilitation Services Department at the University of Maine at Farmington. Nicole has held a faculty position there since 2012. Nicole and her family currently live in Sidney, Maine.

Nicole began her interdisciplinary doctoral studies at the University of Maine in 2013. Nicole is a candidate for the Doctor of Philosophy degree in Interdisciplinary Studies in Human Development from the University of Maine in August 2020.