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Desirable Conversations: Sexuality and Women with Intellectual Disabilities

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Desirable Conversations: Sexuality and Women With Intellectual Disabilities

by

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A dissertation submitted in partial fulfillment of the
requirements for the degree of

Doctor of Education
in
Educational Leadership: Special and Counselor Education

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Abstract

The American Association on Intellectual and Developmental Disabilities (AAIDD, 2011) asserted that individuals with intellectual disabilities, irrespective of gender, have an equal right to learn about and experience their own sexuality. A review of the extant literature indicated that the voices of women with intellectual disabilities on the topic of familial culture, as it relates to sexuality, are rarely included (McCarthy, 1993; Shakespeare, 2000; Siebers, 2012).

The purpose of this qualitative study was to examine the role of familial culture and lived experiences of women with intellectual disabilities, ages 21-35, in understanding their own sexuality. Eight women participated in individual and three repeated focus group interviews. The questions that guided this study included: (a) What is the role of familial culture in addressing sexuality for young women with intellectual disabilities and (b) How do young women with intellectual disabilities describe their understanding of sexuality?

The findings of this study suggested that familial culture played a significant role in the women's decisions regarding accessing their own sexuality. In addition, data collected indicated that women's lived experiences highly influenced in their understanding of sexuality and as women with intellectual disabilities. Data from a thematic analysis were used to develop a person-centered theoretical model for understanding sexuality. In addition, these data were used to create a research-based

theatrical script, known as an Ethnodrama (Saldaña, 2005a) to bring forward the voices of these women affirming their understanding of sexuality.

Dedication

This work is dedicated to the pure inner light that will facilitate more work in the area of sexuality, women, and varied intellectual abilities!

Acknowledgments

"Stopping and seeing"

Nothing in this world, including our coming into it and leaving it, can be facilitated alone. So, here I *stop to see* clearly and acknowledge every minute I grew up as a human being through this dissertation. I am in deep, humble gratitude, and thankful for each and every one who facilitated this journey.

I first *stop* to honor my ancestors for this life and for their guidance in my sustaining heart; the voice of my grandparents, Shri. Baij Nath Sobti and Smt. Krishna Sobti that continue to resonate in my heart and mind, they said, ". . . just keep learning, keep growing, and don't think about the results . . ."

I am in deep gratitude for receiving unconditional love, support, and wisdom from my mother Smt. Neeta Malhotra, my sister Neeti Malhotra, and my husband Ryan Gregory. My mother sacrificed all her life to ensure that both her daughters get the best education and life as a whole. Ma, this dissertation work was possible only because of all your hard work to ensure that we live our dreams. My sister, Aapi,[1] you made sure that you were available to talk to me at any time of the day and you helped me be a better person. You are my think tank! While I was on this dissertation journey, I found my husband in my friend, I am very grateful to have you in my life, Ryan. Thank you for holding my hands and walking next to me without judging me one bit; you are a precious and the best gift my life could give me!

---

[1] Aapi means sister in Urdu language.

Without this unwavering support from my family, I would not have ever pursued and then finished this tertiary degree. I never saw my father, as he left his body[2] when I was 14 days old, but I know that if he was alive, he would have been the happiest father today. He wanted to raise both his daughters as humble, strong, educated, and determined women.

I am extremely indebted to my kind and knowledgeable adviser, Dr. Randall De Pry for his consistent advice to me, to trust my own process and ways of doing things, while I learn to compartmentalize my to-do list and be a professional. Thank you Randy for spending your precious time in reading this work several times and guiding me at every step and pushing me to go beyond my perceived capabilities. At the same time, I owe a lot to my wonderful dissertation committee for supporting me at every step to make sure that this work takes *her* shape as it should. Thank you, Dr. Mary Oschwald, for all your listening, guidance, and trust in me for doing this work. Thank you, Dr. Ben Anderson-Nathe for showing me the light of critical thinking and broadening my lens to see my work from a holistic preview. This is a lifelong gift! Dr. Ann Fullerton, thank you for accepting my request to be on my committee and always being kind and immensely supportive of my work. Dr. Sheldon Loman, I am thankful to receive your perspectives. Thank you for being part of this team.

I am grateful to all of the women who participated in this project and cared enough to share their experiences. I am grateful that they spent their time and trusted me

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[2] In Hindu religion, the phrase "he left his body" connotes "death"; this phrase is used with a belief that the soul is immortal and the body experiences reincarnation until Moksha or emancipation. Even though, I am not a religious person, I used this phrase as it reminds me that my father is still alive and is around me, though he is not in his physical body.

to share their intimate truths of life. Thank you for being you, for being strong, and being a future mentor for the people who will learn from you.

I am grateful for all the financial support I received from my family, the graduate assistantship with Dr. Brown, and the University Studies program. I am also grateful for all the job opportunities that facilitated my life's need in this country. I also want to acknowledge that the financial hardships I experienced opened new doors of compassion and more love for this dissertation work.

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I am grateful for all my lovely colleagues at the University Studies department; Joseph Whitman, Luke Maurer, Lisa Durden, Jason Damron, Scott Parson, and Johnnie Mozzacco and many more kind souls at Portland State University who have been quite supportive of my academic and learning journey. I am also thankful to those who were with me at the start of this dissertation journey. Thank you, Drs. Leslie Munson, Christine Chaille, Randy Hitz, Karen Noordhoff, and Julie Esparza Brown. I sincerely thank you for providing me with this opportunity to be courageous, to learn to trust myself, and to gradually find my grit as I continue on this journey. Julie, thank you for giving me love, support, and a home in your heart.

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---

[3] Behen: Sister

acknowledgement section by writing that my dissertation taught me three core values of

life: acceptance, trust, and compassion. And thank YOU for reading.

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Preface

I begin this dissertation with a narration[4] of my experience with sexuality and

women with intellectual disabilities in the early stages of my career as a special educator.

My first job as a special educator was in the urban slums of northern India. My job as an

itinerant special educator was to provide services within the seven identified slums during

a one-year contract period. My primary job was to provide awareness about special

education facilities run by the state government for individuals with disabilities within the

community. Under the supervision of my senior colleague, the job also included

community mobilization, identifying children with intellectual disabilities[5] within the

community and training paraeducators,[6] parents, and caregivers about various issues

concerning girls and women with intellectual disabilities. Sexuality related concerns were

always on the checklist but were never properly addressed.

On the last day of my job contract, while stepping out of those sordid, straggling

and bustling narrow streets of one of the slums I worked in, I saw a young girl, chained,

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[4] My intent here is to present how the word sexuality gets percolated through the filters of culture derived from one's values, ethnicity, gender, and spirituality as a whole; which ends up regulating sexuality education for women with intellectual disabilities. The narration also marks an avenue to examine the debates around the issues concerning sexuality and intellectual disabilities within this dissertation proposal. If I didn't have the experience in this narrative, I wouldn't have been seen the importance of this work and its contribution to the field of special education as a whole.

[5] The term intellectual disability is a diagnosis used to describe individuals who experience significant limitation in adaptive skills required for daily living. It impacts individuals from all racial, ethnic, educational, social, and economic backgrounds. However, the focus on "substantial functional limitations" creates a setup to understand that an individual diagnosed with an intellectual disability or some other developmental disability are usually dependent upon the assistance of others and rely on "special" support including educational, vocational, recreational, and residential services. Intellectual disability (ID) is the current term for what was formerly called mental retardation. The designation "mental retardation" still frequently appears in print, but there is an international consensus in the use of "intellectual disability," although it, too, may be replaced in the future.

[6] Paraeducators are an integral part of the learning and teaching team who assist with multiple levels of support within the community school.

sitting in a corner of a squalid wall with a petrified facial expressions and her clasped

body reflected the markings of harsh lashings she had experienced. I tried communicating

with her, but she kept silent. I assumed that anxiety muddled with pain kept her silent.

After looking at her condition closely, out of rage, I tried to uncage her bruised body. I

inquired about her family of the people who were walking in that area as she lacked the

ability to speak due to her visible profound disabilities and the harsh treatment she had

endured. Out of the hustle-bustle a crowd gathered of many local people to watch my

activity.

After hours of struggle to find her family members, an obviously outraged woman

appeared and approached me aggressively. She said, "The girl was tied by her father

because she was making obscene and sexually provocative gestures in public." She added

that, "She is *hyper-sexed and filthy.*" The woman vehemently told me to leave the girl

alone and mind my own business.

A 15-year-old girl with profound intellectual disabilities was almost lynched

because she lacked skills to express her sexuality in a socially appropriate manner.

Within the contours of my own ethical, cultural, and spiritual[7] understanding of sexuality,

this dramatic interaction began whizzing thorough my mind. I was stunned and

spellbound by this interaction with this angry woman. In spite of our shared ethnicity, I

understood in that moment that I had a different spiritual understanding of the importance

of sexuality and a persons' body-image from that of this woman and perhaps many other

people as well. I account for these differences in two ways. First, because of my

educational background; I realized that I am from a different culture. Secondly, I am from

a different economic class from that of the people who lived in the neighborhood where I

was only a temporary visitor.

An elderly couple standing within the crowd advised me to step-out, leave, and go

home since it was not safe for me to stay there due to the large crowd of angry of people.

While I wanted to emphasize the multivalent and often contradicted discourses that

guided my actions, I respected their words and left the community. On my way home, my

mind was racing non-stop with questions. What could I have done differently? What went

wrong? What was the lens those people were using to see young woman and her means

of expressing her own sexuality? Was it her physical appearance? Was it their

perspectives or the dominant surroundings, or their own spiritual[8] values that informed

their thinking about this girl's behaviors?

My mind was also boggled by an existential question: What kind of special

educator was I? I left this girl with intellectual disabilities alone and never protested for

her individuality. My understanding of the word *sexuality* was clearly different from the

perceptions of those I had just encountered. My own understanding had certainly evolved

as a result of my own cultural underpinning, which was different from those living in that

community I had just left. Also, my quintessential concern about who I am as a woman

and who I am as a special educator and the ideas that inspired to teach sexuality

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[8] Spiritual/ spirituality is the most personal experience an individual possesses and uses as a lens to explore the world around them. It includes the knowledge, values and rationality derived from one's ethnicity, culture, religious values and even gender. Also, the word *spirituality* includes one's moral and ethical stand points around sexuality and lies beyond the boundaries of religion and faith.

education were far different than the paradigms that informed the thinking of those whom I had interacted in that neighborhood.

The next day, I shared my concerns with my supervisor. However, with the completion of my term of employment with the organization, the concerns were slapped down by the bureaucratic practices and I was asked to move on. As a special educator who passionately believes in bringing forward the voice of my students, I found myself caged within my own thought processes. This girl and her situation left a deep scar on my psyche.

Within a month, I started a new position in a small special school designed for children with intellectual disabilities from elite families. Despite the socio-economic contrast between this school and my former working environment, I found myself in a similar situation. Once again, I was placed in situations, wherein I fielded questions from my colleagues and the mothers of the students, related to the sexuality of my students with different levels of intellectual abilities. The trepidations I and others experienced as we negotiated how to best address sexuality related issues, again proved to be a significant barrier along my path as a special educator. I found that few of my colleagues never addressed sexuality education as it was against their individual value system to talk about it with these *kids*.

A key reason that most of the teachers I worked with said that they chose not to address topics related to human sexuality in class was that, parents of their students believed that to do so would be inappropriate; discussing such topics openly was against many parents' religious views. Allegorically, the role of culture, religious values, spiritual

understanding, and ethnical connotations of sexuality as a whole was used to percolate the pedagogy of sexuality for students with intellectual disabilities.

Interestingly, in an instance when the topic of sexuality was discussed openly in the school, the dialogue began after it came to light that a young girl had been sexually abused. However even in this situation, perplexities found within the parents and special educators communities continued to influence the nature of what was discussed and what was withheld during conversations between teachers and their students.

Even though there were differences in terms of social class and facilities available to those people I interacted with, while in this professional setting in comparison with the former setting, culture played a huge role in the exploration of sexuality for young women with intellectual disabilities in both situations. My work experiences as a female special educator and my experience of observing choices made by a friend's[9] mother during this period prompted me to dig deeper into issues of related sexuality. I reflected on the ideas that the physical, social, and psychological realms of sexuality are rooted deep within the cultural connotation and constructions of an individual. My dissertation is an outgrowth of this period of exploration and an attempt to bring forward the voice of women who are have intellectual disabilities. This work is part of my ongoing effort to

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[9] My friend had hydrocephalus, a condition that resulted in profound intellectual disabilities. She lacked verbal abilities to communicate in the typical way, however she did develop her own ways to communicate her needs which we all understood. Her mother received no assistance or services from the state and she used to lift and carry her daughter everywhere. My friend was sterilized at the age of 10 soon after she started her menarche. Her mother explained that she agreed to this procedure because she felt that she was unable to manage any additional responsibilities related to caring for her daughter. Also, in her opinion, she felt that my friend was incapable of handling her own body. My friend had profound intellectual disabilities.

understand how familial culture affects their learning and how they experience their own sexuality.

As a researcher I want to explore these concepts and provide avenues for women with intellectual disabilities to give voice to their perspectives on issues related to sexuality. This work is part of my professional journey as someone dedicated to the goal of creating a platform for further research on culturally appropriate sexuality education for this particular population.

CHAPTER ONE

INTRODUCTION

Women with intellectual disabilities have the same sexual desires and develop at almost the same rate as those not labeled with an intellectual disability (Bernert, 2011; Bernert & Ogletree, 2012; Wolfe, 1997). Notwithstanding, the topic of sexuality and intellectual disabilities has mainly been discussed tangentially within the academic research. The literature read for the purpose of this study emphasizes the idea that families play a central role in addressing sexuality in the life of individuals with intellectual disabilities (Alcorn, 1974). Additionally, past research also indicates that most women with intellectual disabilities face several barriers to expressing their sexuality (Pownall, Jahoda, Hastings, & Kerr, 2011; Swango-Wilson, 2010), such as access to privacy, lack of accurate information, access to sexual relationships, vulnerability, credibility to make decision related to sexuality, lack of self-determination, and lack of acceptance (Gougeon, 2009, 2010; Grieve, McLaren, & Lindsay, 2007; Smith & Routel, 2010; Ward, Atkinson, Smith, & Windsor, 2013; A. Turnbull, & Turnbull, 2001; A. Turnbull, Turnbull, Erwin, & Soodak, 2006).

The purpose of this dissertation was to explore the role of familial culture in understanding sexuality by young women[1] with intellectual disabilities. Additionally, the

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[1] While I acknowledge that one appropriate term I could have used is *female identified bodies* (those who identify themselves as women), I employed the vernacular of the special education domain and used the term *young women with intellectual disabilities* in this manuscript.

purpose of this study was to examine the understanding of sexuality by young women

with intellectual disabilities through their current life experiences. Using the

transformative research paradigm as a research framework, critical disability theory as a

theoretical framework, and Ethnodrama/Performance ethnography[2] as a methodological

framework, I incorporated one individual and three repeated focus group interviews as

data collection methods to conduct this research.

     Using thematic data analysis (Braun & Clarke, 2006), the thematic outcome of the

study adds to the body of literature on this topic. Implications for future research and

practice, along with recommendations are also provided. The current chapter will present

the background of the study, the statement of the problem, the purpose and significance

of the study along with the research questions. Additionally, in this chapter I will also

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[2] Performance Ethnography is also termed as *Ethnodrama* (Saldaña, 2005a, 2009). The concept of presenting qualitative research as theatre was first explored by V. Turner (1982). Denzin (2003a) wrote that performative ethnography as a method has its roots in critical race theory and the transformative research paradigm. There are several terms used by different scholars (Denzin, 2002; Goldstein, 2010, 2012; Saldaña, 2005a) to express the approach including names such as "Performative Ethnography." Saldaña has described Ethnodrama as a dramatic script that is crafted out of significant selections of qualitative data such as interview narratives, observation, field notes, journal articles, diaries, media articles, and even court proceeding. Since there are many names that are used in the academic literature, for the convenience of the reader and simplicity of the word, I have used the term *Ethnodrama* in the rest of this chapter and ahead in this dissertation.

The purpose of using Ethnodrama for this study was to go beyond the esoteric process of academic research and disseminate the study findings in the manner that it's reachable to everyone. The foundation of performance ethnography/Ethno-theater/Ethnodrama is to embed the craft of artistic theater techniques to present the research participants' voice/experiences and/or the researcher's interpretations of data. Ethno-theater is different from Ethnodrama. Ethno-theatre employs "the traditional craft and artistic techniques of theatre production to mount for an audience a live performance event of research participants' experiences and/or the researcher's interpretations of data" (Saldaña, 2005b, p. 2).

In contrast, Ethnodrama is the construction of the script out of the qualitative data gathered from the research. The goal of using Ethnodrama in this *dissertation* is to present the written script that consists of dramatized, significant selections of narrative collected through interviews, participant observation field notes, and researcher journal entries. "Simply put, this is dramatizing the data" (Saldaña, 2005b, p. 3).

provide an overview of the methodology, limitations and delimitations, and a list of key terms used throughout the study, along with their operational definitions.

Background of the Problem

Sexuality and Women With Intellectual Disabilities

The Sexuality Information and Education Council of the United States (SIECUS), with their purpose of promoting comprehensive sexuality education[3] in the United States (SIECUS, 2011), explains that human sexuality is an amalgamation of one's beliefs, values, behaviors, and biological understanding of the self that is influenced by their ethical[4,] spiritual, and cultural[5] concerns. SIECUS promotes sexuality education that includes a list of topics such as self-care, peer interaction, friendships, romantic relationships, self-defense from sexual abuse, and appropriate social-sexual behavior. Generally, sexuality is defined as an integration of physical, emotional, intellectual, and sociological aspects of one's personality (Cornelius, Chipouras, Makas, & Daniels, 1979). Additionally, Hawkins (1980) explained that sexuality includes every element of human existence that is about and beyond the two genders that evolves across the lifetime. Greenberg, Bruess, and Oswalt (2014) presented different dimensions of

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[3] Comprehensive sexuality education is an educational program that focuses on a wide range of topics for developing interpersonal and relationship skills. It includes topics such as self-care, peer interaction, friendships, romantic relationships, self-defense from sexual abuse, and appropriate social-sexual behavior. It promotes an inclusive, inter-disciplinary, student-centered, and multi-modal approach to teaching sexuality.

[4] Ethical dimension includes the dichotomy of rights and wrongs pertaining to sexuality, which includes one's values, spiritual beliefs, religious views, morality, rationality and ideals.

[5] Cultural dimension of sexuality includes the totality of one's traditional and contemporary influences of one's race and ethnicity, individual or familial values, spirituality or religion, sexuality (Greenberg et al., 2014) and disability as a culture (Tepper, 2005).

sexuality. They wrote that sexuality as a whole is filtered through the role of one's culture, psychological,[6] social, and biological[7] dimensions. All these dimensions are separate from each other at the same time they overlap each other, "the interrelationship of these dimensions results in individual's sexuality in totality" (Greenberg et al., 2014, p. 5). Notwithstanding, most of the research on sexuality related to women with intellectual disabilities is focused on either the biological, psychological, or social domains, and the role of familial culture and their own understanding of sexuality is almost entirely absent.

The World Health Organization (WHO, 2002b) has stated that sexuality is influenced by class, age, education, marital status, religion/spirituality, race, and ethnicity, as well as bodily abilities. Although sexuality is an innate aspect of one's well-being, on the practical level, sexuality-related issues for women with intellectual disabilities are mostly suppressed under the guise of protection and care (Gill, 2005, 2012; Gougeon, 2009, 2010; Griffiths, 2004; Tepper, 2000). Sexuality for women with intellectual disabilities gets woven through the traditional constructs of femininity (Bernert & Ogletree, 2012; Teuben, & Davey, 2000), and is bound by the rules of intimate engagement that include barriers to express sexuality, with regard to their socialization and intimate partner selection (Abbott & Howarth, 2007; Bernert, 2011;

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[6] Psychological dimensions include one's acquired attitudes and feelings toward oneself and others' sexuality. It includes the perspectives of sexuality that one begins to learn right from the time one is born.

[7] Biological dimension includes the physicality of sexuality, physical appearance, masturbation, physiology and anatomy of human body.

Dotson, Stinson, & Christian, 2002; Evans, McGuire, Healy, & Carley, 2009, Griffiths, 2004; Healy, McGuire, Evans, & Carley, 2009).

The expression of sexuality is culturally constructed, which is different for different people (Bruess & Schroeder, 2014). Differences exist in part, because of the cultural diversity experienced by individuals contributes to individuals' understanding of sexuality as a whole (Schroeder, 2009). Besides the cultural lens, sexuality for most women with intellectual disabilities is often seen through the medical lens of disabilities, focusing only on the corporeal nature. Furthermore, bigotry related to gendered sexual scripts in general, along with the addition of intellectual disabilities, creates a double restriction for women with intellectual disabilities and their rights to explore their sexual self (Bernert, 2011; Bernert & Ogletree, 2012).

In the past, McCarthy's (1999, 2010) study on women with intellectual disabilities and their perspectives on sexual expression revealed that most women with intellectual disabilities grew up with negative beliefs about sexual pleasures. Consistent with McCarthy, Bernert, and Ogletree (2012) more recently conducted a two-year piece of ethnographic research on the perspectives of women with intellectual disabilities wherein they found that most of the women they studied had limited and negative experiences of sexual expression; nevertheless, they understood the meaning of sex without any explanation. Bernett and Ogletree's study showed that even today, most women with intellectual disabilities still experience a lack of sexual self-determination (Gill, 2012)[8] and possess negative perceptions of sexual experiences. This aligns with

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[8] Self-determination includes sexual choices (Bernert & Ogletree, 2012). *Sexual self-determination* is a term used to describe self-determination skills to assert oneself sexually. This term is given by Gill (2012).

other studies conducted to explore the attitudes toward the sexuality of individuals with intellectual disabilities (Aunos & Feldman, 2002; Bernert, 2011; Hingsburger & Tough 2002; Lesseliers & Van Hove, 2002). These perceptions appear to be largely due to messages that individuals with intellectual disabilities receive from their caregivers or parents who perceive individuals with intellectual disabilities as being asexual or hypersexual (Murphy & Young, 2005; Noonan & Gomez 2010) or as only heterosexual (Abbott & Howarth, 2007; Burns & Davies, 2011; Löfgren-Mårtenson, 2009; McCarthy, 1991, 1996, 1998a, 1998b, 1999, 2010; Noonan & Gomez, 2010; Teuben, & Davey, 2000).

Sexuality and Self-Determination

According to the American Association on Intellectual and Developmental Disabilities (AAIDD, 2008), irrespective of gender, every individual with intellectual disabilities has a right to sexual expression, and that understanding their perceptions of sex and their actual experiences with regard to the conditions and contexts can have important implications for assisting them with their sexual health. However, Palmer (2010) wrote that individuals with intellectual disabilities experience higher degrees of social isolation, a reduced quality of life, and are more likely to live with their family (rather than independently) than are their peers without disabilities.

In the similar vein, Wehmeyer (2014) conveyed that families play a significant role in the life of individuals with intellectual disabilities, to nurture their self-

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Self-determination skills related to sexuality of women with intellectual disabilities can be improved by enhancing self-efficacy that can increase an individual's sexual esteem (Taleporos & McCabe, 2001), enabling them to manage their "sexuality in ways that are sensual, satisfying, and safe" (Bernertt & Ogletree, 2012, p. 247).

determination, and stand to promote inclusion and successful transition in the social

world. Shogren (2011) wrote that family highly influences self-determination. Shogren

further added that familial culture plays an important role in nurturing self-determination,

autonomy, and personal perspectives of individuals with intellectual disabilities.

However, there is a dearth of research on understanding the influence of families in

nurturing the self-determination of individuals with intellectual disabilities (Shogren,

2011; Smith & Routel, 2010; Walmsley, 1996), and the role of families in understanding

of sexuality by women with intellectual disabilities (A. Turnbull et al., 2006; A. Turnbull,

Turnbull, Erwin, & Soodak & Shogren, 2010; Smith & Routel, 2010; T. Turnbull,

Schaik, & Wersch, 2011; Wade 2002).

The AAIDD (2011) has asserted that 'many adults with intellectual disabilities

can develop meaningful, mutual relationships that may include a range of sexual activity

and/or marriage" (para. 8). However, the cultural construction of sexuality often creates a

dichotomous representation when teaching sexuality education in a manner that is

considered to be culturally appropriate (AAIDD, 2011; Noonan & Gomez 2010). Despite

advocacy statements from the WHO and AAIDD related to sexuality education, the

divide between pedagogical curriculum and the reality of family influence remains

unbridged. On the one hand, it is the mothers who are typically the first sexuality

educators for their daughters, and that education is rooted in the familial culture as well

as the set of believes on sexuality by mothers or parents (Pownall, Jahoda, & Kerr, 2011).

On the other hand, the typical curriculum used for individuals with intellectual

disabilities to teach sexuality education in the school may not include the role of individual's culture (Boehning, 2006).

Shakespeare (2000) emphasized that most research does a remarkable job of emphasizing the issues of physical access and discriminating factors experienced by individuals with disabilities as a whole. However, the issues of sexuality get intertwined within the familial cultural spheres. Consequently, education and support around sexuality, sexual health, and personal relationships has tended to be avoided or ignored (Lafferty, McConkey, & Simpson, 2012). Critical disability theories provide social models[9] that serve as useful tools to examine sexuality and disabilities as a whole. This social model of disability focuses on constructing change within the social and economic spheres of society rather than expecting individuals to change (Barnes & Sheldon, 2010; Corker & Shakespeare, 2002; Goodley, 1998; Tepper, 2000, 2005; Tremain, 2002).

Social Models of Disability, Sexuality and Intellectual Disabilities

Society's views toward intellectual disability, in general, affect the sexual experiences of women with intellectual disabilities within the social sphere. The four models of disability, as proposed by disability studies scholars summarize these views and their associated implications for individuals with disabilities. These include: the

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[9] Social Models of Disability: The *social model* of disability sees the issue of disability as a socially created problem and a matter of the full integration of individuals into society. In this model, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence, the management of the problem requires social action, and is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is both cultural and ideological, requiring individual, community, and large-scale social change. From this perspective, equal access for someone with an impairment/disability is a human rights issue of major concern (Goodley, 2013).

Biomedical Model, the Functional Model, the Environmental Model, and the

Sociopolitical Model (Smart & Smart, 2007).

The Biomedical Model of disability generally presents the view that disability is a

medical concern that exists within the individual (Smart & Smart, 2007). This model has

roots in medieval traditions where people with disabilities were regarded as mentally or

physically defective, in need of treatments or cures to restore "biological wholeness"

(Smart & Smart, 2007, p. 78). This view led to increased levels of stigma and

discrimination against individuals with disabilities. Although some components of the

Biomedical Model are now viewed as problematic (e.g., blaming the individual instead of

society), certain aspects of the model (e.g., clinical diagnostic categories for classification

of mental or physical ailments) persist within the medical profession, to this day (Smart

& Smart, 2007).

While the Biomedical Model of disability emphasizes mental or physical

limitations at the individual level of impact, the Functional and Environmental Models

(Dembo, 1982; Thomason, Burton, & Hyatt, 1998) of disability consider the impact of

environmental barriers (Smart & Smart, 2007). The Americans with Disabilities Act of

1990 is an example of legislation implemented with the goal of decreasing physical

barriers and increasing access to public facilities and services. These models begin to

acknowledge the role of external barriers in exacerbating the difficulties associated with

mental or physical limitations (Smart & Smart, 2007).

The Sociopolitical Model, also referred to as the Minority Model of disability

(Hahn, 1985; Kleinfield, 1979) marks a radical shift from the assumptions held by the

previous three models described herein (Smart & Smart, 2007). This model challenges

the notion of *disability* as a social construct that has no roots in the actual physical or

mental limitation, but rather redefines disability as a result of society's negative views

toward the impairment and the individual experiencing it (Smart & Smart, 2007).

According to this view, individuals with disabilities ought to serve as the experts and take

active roles in coordination of services (Smart & Smart, 2007). This view is in keeping

with the Americans with Disabilities Act of 1990, which states that individuals with

disabilities have protected status similar to other diverse groups in the United States who

have pursued equal treatment under the law.

These four models of disability allow researchers and practitioners to

conceptualize society's views toward individuals with disabilities through four broad

categories, ranging from internal causes of disability to consideration of functional and

environmental factors to pursuit of equal protection under the law. Over time, these views

have served to justify actions that have directly impacted the lives of individuals with

disabilities.

For example, today, agencies such as Planned Parenthood (2009) provide

sexuality education for individuals with intellectual disabilities using teaching methods

that would have been considered highly controversial just a few decades ago, such as

anatomically correct dolls and pictures and explicit videos. However, within the school

setting, individuals with intellectual disabilities are most often treated as anomalies when

addressing sexuality education; their sexuality remains a neglected issue within the

special education curriculum (Duguay, 2011; Gordon, 1971; Ward et al., 2013).

More than three decades ago, Gordon (1971) discussed the issue in "Missing in Special Education: Sex." He emphasized that special educators have a responsibility to acknowledge sexuality education within the curriculum. He also pointed out that special educators must take steps to oppose the idiosyncratic notions about sexuality and students with intellectual disabilities. He called for special educators to radically take control and teach the topic in their classrooms (Gordon, 1971).

Despite this call to action, special educators today continue to lack pedagogical support to teach sexuality-related issues, which are for the most part avoided and hidden under a thick veil of protection (Simpson, Lafferty, & McConkey, 2006; Ward et al., 2013). Compounding the lack of available instruction, according to National Standards of Sexuality Education (2012), parents have the right to withdraw their child from sexuality education if they do not think such instruction is appropriate for their child. This resurfaces the role of familial culture and the influence of family on sexuality and understanding of sexuality by individuals with intellectual disabilities.

However, societal attitudes toward sexuality of individuals with intellectual disabilities have begun to change for the positive (Ballan, 2008; Boehning, 2006; Cuskelly & Bryde, 2004; Evans et al., 2009; Whitehouse & McCabe, 1997; Wilkerson, 20002; Wolfe, 1997). Such as, there are more attempts in bringing forward the possibility and endeavors of marriage and romantic relationships experienced by individuals with intellectual disabilities through popular culture. Nevertheless, there is still reluctance to address the sexuality of women with intellectual disabilities on the part of many parents, caregivers, educators and curricula designers. This is because women with intellectual

disabilities are often either considered child-like by some or overly sexed by others (Bowman, Scotti, & Morris, 2010; Cuskelly & Bryde, 2004; Dukes & McGuire, 2009; Evans et al., 2009; Howard-Barr, Rienzo, Pigg, & James, 2005; Ward et al., 2013; Whitehouse & McCabe, 1997) and therefore many continue to consider that women with intellectual disabilities are in need of protection from particular topics that are consider to be inappropriate.

Sexual Abuse and Women With Intellectual Disabilities

Most individuals with intellectual disabilities are at a greater risk of abuse and victimization when compared to individuals with other types of disabilities and when compared to individuals without disabilities (Petersilia, 2001; Sobsey, 1994a). In 2008, approximately 12.9 per 1,000 individuals with cognitive disabilities were estimated to be victims of serious violent crimes compared to rates of 4.8 per 1,000 for individuals with hearing impairments, 7.2 per 1,000 for individuals with visual impairments, and 4.2 per 1,000 for individuals with ambulatory impairments (Harrell & Rand, 2010; McCarthy & Thompson, 1997).

Recently, the Bureau of Justice Statistics released a report on Crime Against Persons with Disabilities, 2009-2012 by Harrell (2014). The report shows that individuals with intellectual disabilities experience the highest rate of violent victimization (63 per 1,000). It also reports that violent crime- rape or sexual abuse and other crimes such as robbery had been nearly three times higher than the rate for persons without disabilities in 2012.

In the past 20 years there has been an increase in reported cases of sexual abuse of individuals with intellectual disabilities (Conway, 1994; Goldman, 1994; McCormack, Kavanagh, Caffrey, & Power, 2005). The percentage of sexual abuse experienced by women with intellectual disabilities is higher in comparison to the male gender (Lumley & Scotti, 2001; McCormack, Kavanagh, Caffrey, & Power, 2005). According to a survey of service providers, 87% of adults with intellectual disabilities had been sexually abused (Brown & Turk, 1992). In addition, individuals with intellectual disabilities have also been incarcerated for committing sexual offenses (Murrey, Briggs, & Davis, 1992). Day (1994) showed that individuals with intellectual disabilities who committed sexual offences reported that they had high levels of sexual naiveté, lack of knowledge about typical sexual relationships, lack of relationship skills, and difficulties interacting with the opposite sex.

Most of the studies focusing on sexual offences conducted to date are focused on males with intellectual disabilities. As explained by Allen (1991) and Kaplan and Green (1995), this is presumably related to the fact that sexual abuse by females is more often hidden in child caring practices, such as bathing, dressing, and changing diapers. Furthermore, a recent study in the Netherlands by Wijkman, Bijleveld, and Hendriks (2014) explored that almost 60% of juvenile female sex offenders committed sexual abuse with other juvenile females. The researchers discussed that since the sexual abuse rate is higher than the rate of offenses committed by females with intellectual disabilities, this population is not given much attention in the empirical literature.

Notwithstanding this situation, the sexual rights and needs of women with intellectual disabilities have in fact received increased attention in the past several decades. Indeed, the importance of the health and safety of individuals with intellectual disabilities has been highlighted in a number of international policy documents (United Nations, 1993, 2006). For instance, Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (2011) underpins a framework to promote equal rights to health, which includes sexual and reproductive health.

Safety and sexuality training and education are strategies researchers and practitioners propose to reduce vulnerability to victimization for members of this population (Champagne & Walker-Hirsh, 1993; Planned Parenthood, 2009). However, despite such recommendations, the sexual expression and exploration of one's sexuality is still given low priority and remains enigmatic within the academic literature (Gill, 2009; Jarman, 2012).

Statement of the Problem

The literature that I read emphasizes the important role of mothers in the lives of young women with intellectual disabilities, along with other stakeholders such as special educators, siblings, school administrators, and ideologues. Mothers advocate for the rights of their growing daughters to attain equal opportunities within the school setting, and to prepare them to live independently in society (Brantlinger, 1992; Fitz-Gerald, 1978; R. M. Foley, 1995; Nolley, Muccigrosso, & Zigman, 1996a, 1996b; T. Turnbull et al., 2011; Wilkerson, 20002; Wolfe, 1997).

It is important to note that, in collaboration with special educators, many parents (mostly mothers) teach sexuality-related issues at home, and promote such instruction within the school setting (T. Turnbull et al., 2011). This emerging change is important because of the fact that familial culture plays an influential role on fostering self-determination of individuals with intellectual disabilities irrespective of their gender (Shogren, 2011; T. Turnbull et al., 2011; Wolf, & Zarfas, 1982). Furthermore, familial culture also plays an important role in teaching of sexuality education to individuals with intellectual disabilities irrespective of gender (T. Turnbull et al., 2011; Wade 2002; Walmsley, 1996).

Scholars argue that new research is needed across multiple systems that affect sexuality, autonomy, and self-determination of individuals with intellectual disabilities (Wade, 2002). Also, there is a need for research on the diverse cultural factors that influence sexuality, self-determination, and working with families. My dissertation begins precisely at these fault lines to explore the role of familial culture that is influenced by the historical, societal, and political contexts of intellectual disabilities within which the understanding of sexuality for women with intellectual disabilities is constructed.

I conducted a qualitative study that explored the role of familial culture in understanding sexuality by women with intellectual disabilities. Additionally, the purpose of this study was to examine the understanding of sexuality by young women with intellectual disabilities through their current life experiences. The research questions posed for this study are: what is the role of familial culture in addressing sexuality for

young women (21-35 years) with intellectual disabilities and how do young women

(21-35 years) with intellectual disabilities describe their understanding of sexuality?

Definition of Key Terms

Intellectual disabilities: Intellectual Disability formerly referred to as mental

retardation or MR). The AAIDD (2012) has defined intellectual disability as "a disability

characterized by significant limitations both in functioning and in adaptive behavior,

which covers many everyday social and practical skills. This disability originates before

the age of 18" (AAIDD, 2012, para.2).

Intellectual disability is usually diagnosed in childhood, prior to age 18, most

often using an assessment of intellectual functioning such as an IQ (intellectual quotient)

test (AAIDD, 2012). Four general categories are used to describe the severity of an

intellectual disability diagnosis, including borderline, mild, moderate, and severe, based

on the actual IQ score and the severity of limitations in adaptive behaviors. An IQ of 70

and below is one criterion used in a comprehensive assessment resulting in a diagnosis of

ID (AAIDD, 2012).

Familial culture: Familial culture is the tradition a family creates that is then

augmented throughout the person' lifetime, either slightly or significantly, depending on

social interdictions and norms a person experiences over time. This may or may not be

influenced by one's religious and spiritual practices and racial and ethnical background.

Sexuality: For the purpose of this study, sexuality is defined as an interaction

between one's physical, social, psychological, and cultural dimension of existence

(Greensberg et al., 2014).

Sexuality education: SIECUS (2011) has defined comprehensive sexuality education as "a lifelong process of acquiring information and forming beliefs about identity, attitudes, and values about identity, relationships, and intimacy" (para. 1). According to this definition, a comprehensive sexuality education program will address topics such as sexual development, reproductive health, interpersonal relationships, affection, intimacy, body image, and gender roles. From this perspective, sexuality is addressed in terms of biological, sociocultural, psychological, and spiritual dimensions in the cognitive domain, affective domain, and behavioral domain.

In chapter 2, I build upon many of the ideas described in chapter 1 with presentation of the literature that informed this study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter presents a review of published literature related to sexuality and women with intellectual disabilities. The purpose of this study was to examine the role of familial culture in understanding sexuality by women with intellectual disabilities. Additionally, this study also explored women with intellectual disabilities' understanding of sexuality. Specifically, this chapter will present a review of literature relevant that is highly relevant to this particular piece of research to provide context for this study.

This chapter is organized to address the four questions that were identified to conduct the literature review for this study. First, what is the historical representation of sexuality and intellectual disabilities? Second, how does society depict women with intellectual disabilities and their sexuality? Third, what does the literature inform us about the influence of familial culture on sexuality for women with intellectual disabilities? Fourth, what does the literature tell us about the dimensions of sexuality for women with intellectual disabilities? In the end of the chapter I provide methodological literature to justify the selection of research methods based upon a review of the literature.

Sexuality and Women With Intellectual Disabilities

In the literature I reviewed, the juxtaposition of sexuality and women with intellectual disabilities primarily explored the experience of sexual abuse and sexual

offence committed by individuals with intellectual disabilities. In addition, the primary

focus of research on sexuality and individuals with intellectual disabilities included the

attitudes of parents toward sexuality (Fischer & Krajicek, 1974; J. E. Hall, Morris, &

Barker, 1973; Jahoda & Pownall, 2013), attitudes of staff in institutional settings

(Brantlinger, 1983; Franco, Cardoso, & Neto, 2012; L. Mitchell, Doctor, & Butler, 1978),

and the attitudes of individuals who experience intellectual disabilities themselves (J. E.

Hall & Morris, 1976; Edmonson, McCombs, & Wish, 1979; Ward et al., 2013). For the

most part, I found that the voices of women with intellectual disabilities on topics such as

romantic relationships, sexual activity, and homosexuality are rarely included in the

professional literature base (McCarthy, 1991, 1996, 1998a, 1998b, 1999; D. T. Mitchell,

2002; Shakespeare, 1997, 2000; Siebers, 2012; D. Thompson, 1994; S. A. Thompson,

2007). The role of social differences such as race and ethnicity, spirituality and religion,

and how these influence perspectives related to the sexuality of women with intellectual

disabilities are also missing within the empirical research.

Notwithstanding, the rare instances of where discussions of sexuality and women

with intellectual disabilities is found within the professional literature is within the

literary works of critical disability studies, sexuality studies, cultural studies, and the

literature focusing on feminist theories and sexuality. Indeed, the case of this particular

study, the philosophical framework of feminist critical disability theory underpins my

research, which I will describe in the following section.

2.2 Theoretical Framework for This Study

This study uses critical disability theory as a theoretical framework. Critical disability theory provides a lens to unravel the inherent complexities associated with disablement and issues related to equality (Rioux & Valentine, 2006). It provides a foundation for understanding the connection between the existing social, legal, cultural, economic, political, structural, and educational rationale for complete and holistic inclusion of individuals with disabilities in society. This perspective is based on *social models* of disabilities (Wendell, 1989). Unlike the rehabilitation model and the special education model, the *social model* of disability positions disability as a socially constructed element. The social model provides a lens to see people with disabilities, including those with intellectual disabilities, as part of the social world by emphasizing that the concept of disability itself is socially constructed. This theoretical framework prompts reflective analysis related to issues to do with oppression and subjectivities experienced by individuals with disabilities. These oppression and subjectivities are associated with the conjunction of severity of disability and acceptance in the social world (Smart & Smart, 2007).

Critical disability theory provides a politicized view of the meaning of disablement in contemporary society. As a theoretical construct, critical disability theory is a lens used to envision equitable opportunity for every individual in the society. For example, D. T. Mitchell and Snyder (2006) asserted that acknowledgement of a cultural stance within the field of disability research will buttress and reveal the effects of violence, restriction, confinement, and the absence of liberty experienced by people with disabilities. This perspective aligns with the research recommendation forwarded by

Shogren (2011) related to examining the construct of self-determination[10] itself and the role of culture by on individuals' ability self-realize.

S. R. Smith (2010) wrote that critical disability theory provides a lens through which to conduct exploration to develop an understanding of the complexity of social and cultural power structures related to individuals with intellectual disabilities. Based on the foundational principles of social feminist theories, critical disability theory is believed to be an activist critique, seeking ". . . to empower the powerless and transform existing social inequalities and injustices" (McLaren, 2007, p. 186). Based upon this perspective, I employed the use of the transformative research paradigm to develop my research methodologies for this study.

Garland-Thompson (2013) posited that the location of disability within the community is a cultural trope that situates bodies with physical and cognitive differences as invisible. Goodley (2014) strengthened Garland-Thompson's assertion by stating that for the most part, disability is viewed through the interwoven lenses of biology and culture. In contrast to this perspective, critical disability studies relocates the mental construct of disabilities, including constructs related to intellectual disabilities, to the social, cultural, and political indices by pulling it out from medical mental constructs.

My dissertation work is based on Campbell's (2009) intersectional analysis, a framework found within critical disability theory. Campbell wrote that the exploration and understanding of the crisscross of race, ethnicity, sexuality, class, and gender

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[10] Self-determination: Field, Martin, Miller, Ward, and Wehmeyer (1998) defined self-determination as "a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations, together with a belief of oneself as capable and effective, are essential to self-determination" (p. 2).

identities is the way to explore the reasoning for the oppression that negates the existence

of the *other* as a sexual being. Consequently, within framework of critical disability

theory, the intersectional analysis presented by Campbell provided an appropriate

theoretical framework to understand the solidarity of the contemporary lives of women

with intellectual disabilities.

This theory provides a foundation from which to further create a theory grounded

within the framework of culturally appropriate conversations around and about women

with intellectual disabilities and their sexuality. To understand the value of Campbell's

(2009) approach it is important to understand the historical perspectives connected with

sexuality and intellectual disabilities. In the next section I will explore how sexuality and

intellectual disabilities are projected within history.

2.3 Histories Unreeled

Question 1

What is the historical representation of sexuality and intellectual disabilities?

To understand current representations of sexuality and intellectual disabilities, it

is important to consider the historical representations of sexuality and individuals with

intellectual disabilities within history from a cartographical perspective. The disability

rights movement that emerged from the civil rights movement of the 1960s and 1970s in

the United States promoted the idea of disability as identity. This movement provided the

impetus for action against historical oppression of individuals with disabilities and their

sexuality which flourished during the eugenics movement (Jarman, 2012).

Eugenics Movement

The British scientist Sir Francis Galton coined the term *eugenics* in 1883. The term was adapted from the Greek word Eugenes meaning "wellborn" (Brantlinger, 199). Within the same year, Sir Francis Galton published *Inquiries into the Human Faculty and its Development*. This book propelled the scientific community to consider eradicating intellectual disabilities through genetic engineering (Rowe & Savage, 1987). The foundational concept of the eugenics movement was to control the factors in reproduction to *beautify* mankind (Ballan, 2001, 2008).

Simultaneously Charles Darwin theorized the evolutionary advantage of the fittest, further supporting the foundation for eugenics with the goal of eventually attaining a perfectible body by undergoing progressive genetic improvements over multiple generations of humans (Davis, 1959). The aim of eugenics was to eliminate deviations from what they consider to be the so-called norm by encouraging the *normal* population to reproduce at a pace that decreases reproduction of *abnormal* beings (Cole & Cole, 1993; Davis, 2012).

The eugenics movement was bolstered by the rediscovery of the laws of inheritance as formulated by Gregor Mendel. He theorized that defective genes responsible for intellectual disabilities, mental illness, epilepsy, criminality, and pauperism, could be eliminated and therefore improve human genetic stock; providing eugenicists with a scientific basis for controlling the reproduction of inferior humans (Davis, 2013).

From the stance of the critical disability theory, the representation of individuals with intellectual disabilities during that era presented an ideological consolidation of power of the *other* over the life of individuals with intellectual disabilities; termed biopower[11] by Foucault (1990). Based upon this concept of biopower, those who believed in the theory of eugenics rationalized the practice involuntary sterilization of individuals with intellectual disabilities to stop the procreation of genes that they considered to be defective.

Ironically, during this period of history in the 1880s, approximately 75% of people with intellectual disabilities residing in the United States were married. However, sterilization was indiscriminately forced upon many individuals with intellectual disabilities despite that fact that many were in committed, monogamous relationships (Haavik & Menninger, 1981; Pardini, 2002). Individuals with intellectual disabilities were seen in terms of a medical gaze[12] that dismissed individuality and failed to objectively evaluate their bodily abilities.

Between 1945 and 1955, 75,000 involuntary sterilizations were conducted annually in the United States (Bass, 1963, 1972, 1978). In fact, America outrivaled countries worldwide in terms of the number of involuntary sterilizations performed (Kempton & Kahn, 1991). Along with sterilization, birth control methods were strongly promoted in an effort to discourage individuals with intellectual disabilities from

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[11] Biopower: Foucault described biopower as a technology of power that is used by people to manage people in group. Biopower is literally having power over bodies; "an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (Foucault, 1990, p. 48).

[12] Medical gaze: Foucault (1990) used the term "medical gaze" to put forward the dehumanizing separation of human body and the identity by providing rationale to focus on the medical needs over the human identity.

procreating (Cheng, & Udry, 2003; Rowe & Savage, 1987). From the limited perspective

of the medical gaze, parents of children with intellectual disabilities were strongly

advised as to how they should frame sexuality education related to personality

development and self-determination process from a deficit perspective (Frank, 1951).

Lessons related to how to instruct children about their autonomy and self-determination

skills related to the choice regarding sterilization still needed to be unreeled (Rowe &

Savage, 1987; Reynolds, 2003; Smith & Routel, 2010). However it is important to note

that the scarcity of opportunities to receive sexuality education was not limited to those

with intellectual disabilities during this era. Rather than fact-based sexuality instruction

intended to promote informed decision-making, even people without any labeled

disabilities experienced coercion to regulate their sexuality such as the use of punitive

measures such as shame and guilt (Rowe & Savage, 1987).

During this time in history, a number of research studies operating within the

eugenics framework were conducted to explore various aspects of sexuality and

intellectual disability. For instance, a study by Gamble (1952) on the role of sterilization

as a method for prevention of mental deficiency concluded that, depending upon the

severity of the disability, individuals with intellectual disabilities have a 50% chance of

procreating children with intellectual disability. Gamble claimed that he looked at

disabling conditions from a medical standpoint and explained that recessive genes cause

intellectual disabilities and hence, sterilization of individuals with intellectual disabilities

is a medically justifiable course of action. This study impacted further medical research

aimed at strengthening policies that supported involuntary sterilization of individuals with intellectual disabilities.

On the other hand, a quantitative study by Mosier, Grossman, and Dingman, (1962) was conducted to find the relationship of the severity of disability and the onset of sexual development of adolescents with intellectual disabilities. The results showed that there was no significant difference between the onset of sexual development and the severity of disability. The research also documented that females with intellectual disability are equally capable of getting married and enjoying sexual relationships as their non-disabled counterparts (Mosier et al., 1962; Reynolds, 2003).

In a similar vein, Goodenough (1956), one of the few advocates for individuals with intellectual disabilities, asserted that individuals with intellectual disabilities possess the potential to enjoy a full life including intimate relationships and marriage. He claimed that this potential is equal to that of individuals who do not experience intellectual disabilities.

Paradoxically, despite the advancement of disability rights activism, the number of people who were institutionalized due to intellectual disabilities increased from 128,145 in 1950 to a peak of 193,188 in 1967 (Stroman, 1989). However, by the beginning of the 1970s, the activism of parents' groups, specifically mothers, strengthened the role of the deinstitutionalization movement in the United States of America (Rhodes, 1993). The deinstitutionalization movement resulted in the mandated transition of individuals with intellectual disabilities from institutions and hospitals to

group homes, halfway houses, and independent living arrangements (Kempton & Kahn, 1991; Rhodes, 1993).

However, the medical model of disability[13] paradigm (S. R. Smith, 2010), related to individuals with intellectual disabilities challenged the deinstitutionalization movement toward true independence of this population (Stroman, 1989). For example, despite progress, individuals with intellectual disabilities were still viewed as weak, sinful, and in need of strict control including external regulation of their sexual behaviors. This topography of individuals with intellectual disabilities, which was inherited by the medical model of disability (Reynolds, 2003; S. R. Smith, 2010), challenged the deinstitutionalization movement toward true independence of this population (Stroman, 1989). In an opinion poll conducted in 1970, 54% of the sample objected to marriage of individuals with intellectual disabilities. In another survey conducted in the same year, 80% of people objected to dating or any other sexuality related involvement by individuals with intellectual disabilities irrespective of gender (Scheerenberger, 1987).

Notwithstanding widespread liberal allegiances to the academe of human rights, the advocacy movement that brought about residential facilities was confronted by the prevailing viewpoint that rationalized inequitable access to sexual freedom. Research on sexuality education for individuals with intellectual disabilities within school settings and the research surrounding sexuality and intellectual disabilities as a whole were deemed a

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[13] Medical model of disabilities: The medical model of disability view disability as a problem of the person, directly caused by disease, trauma, or other health condition, which therefore requires sustained medical care provided in the form of individual treatment by professionals. In the medical model, management of the disability is aimed at a "cure," or the individual's adjustment and behavioral change that would lead to an "almost-cure" or effective cure (Shakespeare, 2000).

low priority (Abramson, Parker, & Weisberg, 1988). Thus, research-based approaches to improve sexuality education for this population were slow to develop and individuals with intellectual disabilities continued to lack sound guidance as to how to communicate their sexuality in a socially appropriate manner (Ballan, 2002, 2008). Without instruction and knowledge, sexual curiosity and expression often resulted in inappropriate sexual behavior that compounded negative public reaction (Abramson et.al., 1988).

Nevertheless, despite the cyclical nature of these challenges, the deinstitutionalization movement propelled normalization principles within the social realms of individuals with intellectual disabilities. According to critical disability theory, the deinstitutionalization movement paved the way to social inclusion. However, the stigmatization related to sexual expressions are continued even today (Chappel, 1997; Corker & Shakespeare, 2002; Rembis, 2010). Additionally, a growing body of literature has indicated that, compared to the general population, still individuals specially women with intellectual disabilities experience social exclusion including involuntarily sterilization of women (Stefánsdóttir & Traustadóttir, 2015).

Generally, the principles of autonomy or individualism, personal choice, and equal opportunity in decision-making are rooted within the *normalization principles*, which seek to prepare individuals with disabilities to live in ways perceived to be so-called *normal* (Nirje, 1969; S. J. Taylor, 2006; Wolfensberger, 1972a, 1972b). On the contrary, Rice (2006) wrote that normalization is one of several "techniques of subjugation" that operates by "ordering and classifying people hierarchically" (p. 19). In Rice's view, *normalization* referred to the goal of subjugating individuals to fit within the

boundaries of behavior determined by those who are members of dominating groups of people−and not necessarily the goals of groups who are viewed by the dominant culture as people who are living outside the social boundaries of normative cultural maps. As a result of this perspective (Rice, 2006), the decision-making power among the various stakeholders regarding sexuality in the lives of individuals with intellectual disabilities was restricted to those within the dominant groups under the guise of providing protection and care to those who were incapable of making sound choices (Shakespeare, 1996, 1997, 2000).

In contrast, Wehmeyer (2007) wrote that emerging views related to individualism and self-determination are culturally constructed constructs derived from the deinstitutionalization movement. The purpose of promoting self-reliance and self-determination through the deinstitutionalization movement was to accept the disabling condition and provide social support to individuals with intellectual disabilities living within society rather than on the fringes of society.

Notably, despite the fact that parent groups have historically led advocacy moments, the generic history articulated in the reviewed literature failed to bring forward some of the transgressive roles played by parents within the conjunctional topic of sexuality and intellectual disability.

History locates individuals with intellectual disabilities perilously at the intersections of race, class, and gender, constituting them as non-existent by the very social institutions that are constructed to nurture, protect, and empowered (Erevelles & Minear, 2010). As Klingner, Blanchett, and Harry (2007) noted, the educational system

in the U.S. largely places race, color, class, and ethnicity at the peripheral spheres of any

services focusing on individuals with disabilities, including those with intellectual

disabilities. Even though the advocacy movement that underpinned special education and

rehabilitation related research and the design of services intended for individuals with

intellectual disabilities, marginalized racial groups such as Latinas, Native Americans,

African-Americans and others historically underrepresented populations appear to receive

little attention in the research (Klingner, et.al., 2007; Erevelles, 2002; Erevelles & Minar,

2010; Ferri & Connor, 2005; Harry, 1992; Klingner et al., 2007). Within the field of

research on sexuality and intellectual disabilities, the intersection of race, culture,

language, and disability in connection with sexuality are largely unexplored, missing

components in the collective body of literature.

2.4. Societal Attitudes

Question 2

How does society depict women with intellectual disabilities and their sexuality?

In this section I discuss the literature reviewed to explore the societal perspectives

on the constructions of sexuality and individuals with intellectual disabilities irrespective

of gender. First, I will explore the attitudes of women with intellectual disabilities on

sexuality. I then present literature on the attitudes of the professionals. Finally, I discuss

studies that focus related to the attitudes of parents.

Attitudes of Women With Intellectual Disabilities

Bernert and Ogletree (2012) conducted a study about the perceptions of sex by

women with intellectual disabilities. The results showed that most of the women in this

study generally had negative attitudes of sex, regardless of the quality of their

relationships with men. They also tended to focus on negative consequences when

discussing sex. Negative perceptions of sex were held among both women who had

engaged in intercourse and women who anticipated engaging in intercourse for the first

time. Their negative perceptions of sex were attributed to fear of the act, fear of

experiencing negative consequences, physiological concerns about the sex act itself, and

perceived or actual lack of pleasure during the act. These findings were consistent with

Butler, Galea, Iacono, and Leighton (2004) who noted discomfort, confusion, and

ambivalence among persons with intellectual disabilities in their perceptions of sex, and

with Lesseliers and Van Hove (2002), and McCarthy (1999) who also documented the

lack of sexual pleasure women with intellectual disabilities tend to experience.

     McCarthy (1999) conducted a research study with 70 women with intellectual

disabilities to understand their perspectives on sexuality. The study attempted to tease out

the various elements of culture such as religion, race, and ethnicity, and the role of gender

on issues related to sexuality that impacted women's perceptions related to sexuality.

McCarthy's study revealed that most of women with intellectual disabilities who

participated in the study considered sexual activities as bad. The researcher emphasized

that sexuality is positioned within a cultural framework and that examining the influences

of an individual's cultural framework provides a deeper understanding of the perspectives

held by populations of women.

     The spectacles of critical disability studies perspective provides a framework for

understand how women with intellectual disabilities think about sexuality and sexual

pleasures and the associated subjectivities that influence their perceptions, especially

focusing on female bodies. However, my review of literature found that the intersection

of sexuality, intellectual disabilities, and women serve as a unruly framework for

interpreting the influence of social categories such as race, ethnicity, religion/spirituality,

gender, and disabilities generally on societies perceptions as a whole (Shakespeare,

Gillepsie, Sell, & Davies,1996; Shildrick, 2009). In the section I present the literature that

speaks to the attitudes of professionals toward sexuality and intellectual disabilities.

Attitudes of Professionals

Most studies from the late 1970s and early 1980s suggest that experiencing the

expression of sexuality by individuals with intellectual disabilities was an abjectly

frustrating experience for professional care providers (Haavik & Menninger, 1981;

L. Mitchell et al., 1978; Saunders, 1979). For example, research conducted by Haavik

and Menninger (1981) found that although staff would *tolerate* kissing or holding hands

amongst residents with intellectual disabilities, the expression of other sexual behavior

was actively discouraged.

In a similar vein, Coleman and Murphy (1980) conducted survey research to find

the status of sex education and attitudes toward sexuality in facilities for the individuals

with intellectual disabilities. Questionnaires from the authors were sent to institutions

selected from the1979 Directory of *Inpatient Facilities for the Mentally Retarded*. Out of

350 surveys 131 completed surveys were returned. The survey results suggested that

professional care providers favored sterilization. While many respondents said that they

allowed residents to masturbate, the expression of sexuality, or sexual behavior beyond

self-pleasure was actively discouraged. Despite this prevailing attitude, this study also

showed that only 38% of the institutions surveyed provided residents with informal

sexuality education.

Similarly, Chapman, and Pitceathly (1984) conducted quantitative research with

care staff from residential and sheltered workshops ($N = 20$) to understand their attitudes

toward sexuality, marriage, and parenthood on the part of individuals with intellectual

disabilities. These results showed that most staff members were ambivalent and obscurant

toward the notion of sexuality related to the population they serve. Studies such as this

one are important because studies it demonstrated that the success of sex education

programs are directly dependent on whether care staff endorse the expression of sexuality

by those with intellectual disabilities with positive attitudes (Chapman & Pitceathly,

1984; Delp, 1971; Dickman, 1985; Donovan, 1998).

The studies from the late 1980s and 1990s suggest that attitudes of caregivers

toward sexuality related issues changed from highly conservative to a more liberal

perspective (Murray & Minnes, 1994). In contrast to the earlier era, as a result of

changing attitudes, many facilities offered sex education programs and some provided

treatment services to individuals with intellectual disabilities who committed a sexual

offence. Craft, Stewart, Mallett, Martin, & Tomlinson, (1996) write the school students

with intellectual disabilities are not given adequate information through the sex education

curriculum.

Most of the research studies I read discussed the impact of the

deinstitutionalization and normalization movement on the need for programs to teach

appropriate socio-sexual skills to women with intellectual disabilities. Rather than finding wholesale discrimination, the studies indicated that caregivers were forming distinctions of attitudes toward sexuality that varied according to the perceived level of severity of individual's intellectual disabilities. The studies indicated that the level of disability classified an individual's ability to participate in the sexual relationships, marriage, and parenthood (Dotson, Stinson, & Christian, 2003; Shakespeare, Gillepsie, Sell, & Davies, 1996)

The majority of studies conducted during the 1980s and 1990s used the Sexuality and Mental Retardation Assessment and Inventory to assess staff attitudes toward the expression of sexuality by people with intellectual disabilities (Brantlinger, 1983; Murray & Minnes, 1994). While such quantitative metrics proved useful for understanding emerging trends in attitudes among care providers, Holmes (1998) suggested that to explore such issues in more depth, qualitative methodologies would be useful. He suggested that one reason for this is that the cultural framework of the people working with individuals with intellectual disabilities and their families highly influenced the exploration of sexuality and sexuality education. However, despite this call to action, during the 1980s and 1990s most of the published studies were quantitative in nature and in fact I was unable to locate studies that attempted to explore the qualitative component focusing especially on women with intellectual disabilities.

Yool, Langdon, and Garner (2003) conducted a qualitative study with four full-time staff members, a psychiatrist, a senior care-worker, an advocacy worker, and a domestic employee who directly worked with individuals with intellectual disabilities.

The general aim of the study was to explore staff attitudes toward the sexuality of people with intellectual disabilities. The results suggested that staff held liberal attitudes with respect to sexuality and masturbation. However, with respect to sexual intercourse, homosexual relationships, and the involvement of adults in decisions regarding their own sexuality, the study participants shared that they believed that individuals with disabilities were completely dependent upon their caregivers. Female staff members also raised concern about having to work with sex offenders. Based on the studies reviewed regarding attitudes of the caregivers, the main concerns that governed the attitudes of the female caregivers in regards to the sexuality of people with intellectual disabilities were related to topics such as sexual offense, masturbation, and other sexual behavior such as sexual deviance. Burns and Davies (2011), in their study shared that most women with intellectual disabilities do not openly talk about same-sex relationships. Also, even if they are attracted towards the same sex person, they do not consider their relationship as a romantic or sexual relationship.

A quantitative study on parents and caregiver's perspectives on sexuality and intellectual disabilities by Evans et al. (2009) shows that family and caregivers of individuals with intellectual disabilities recognize the rights of their charges to express aspects of their sexuality. In practice however, the conservative attitudes of many family caregivers were found to directly influence the sexual attitudes and behaviors of individuals with intellectual disabilities (Cuskelly & Bryde, 2004; Shakespeare et.al., 1996; Sheldrick, 2007).

Most studies in the area of sexual abuse and individuals with an intellectual disability reveal that venerability associated with the naivety concerning what is and is not appropriate sexual behavior is a significant problem connected to the sexual abuse or possibly behaving in an abusive manner toward others (Evans et al., 2009; McGee, Garavan, de Barra, Byrne, & Conroy, 2002). Studies in the past have focused on the attitudes of professionals, parents, and caregivers and found that the training of professionals and caregivers is essential to reduce idiosyncratic responses to the sexuality of those with an intellectual disability (Cuskelly & Bryde 2004; Sheldrick, 2007; Yool et al., 2003).

Attitudes Toward Women With Intellectual Disabilities

The deconstruction of the reviewed literature using a critical disability theory lens showed that the voices of women with intellectual disabilities and their parents are almost absent from the discourse. Further, despite the prevailing *social model* of disability, women with intellectual disabilities are represented as only part of corporeal segments hidden under the social spheres (Block, 2000).

Interesting, for the most part the sexual desires of women with intellectual disabilities were described by the various stakeholders in their lives rather than by the women themselves. Reviews on societal attitudes toward individual with intellectual disabilities were for the most part negative (Altman, 1981; Roper, 1990; Wright, 1987). Such prevailing attitudes tend to reinforce one another and also influence familial attitudes toward sexuality (Atkinson & Walmsley, 1999; Snyder & Mitchell, 2003).

Attitudes of Parents on Sexuality and Intellectual Disabilities

While research literature has demonstrated parents' reluctance to address sexual matters pertaining to negative societal attitudes toward the sexuality of women with intellectual disabilities such societal attitudes are not static. As recently as the 1980s Passer, Rauh, Chamberlain, McGrath, and Burket (1984) reported that 85% of parents surveyed favored sterilization of their adolescent daughter with intellectual disabilities. Their study also showed parents' ambivalence to balance the rights of their growing child with intellectual disabilities and safety in terms of exploration of their sexuality. However, more recent studies have provided evidence from cross-sectional studies that contemporary younger mothers of individuals with intellectual disabilities are more accepting of their offspring's sexuality and that parents want to understand how to deal with their growing child's sexuality related issues (Cuskelly & Bryde, 2004; Karellou, 2007b; Swango-Wilson, 2008; Zetlin, & Turner, 1985).

For example, a quantitative study that examined parents in Turkey conducted by Isler, Tas, Beytut, and Conk, (2009) affirmed that parents expressed their concerns and keenness to acquire knowledge regarding sexuality for their growing adolescents with intellectual disability. At the same time, the lack of communication between parents and their children is related to embarrassment (Dukes & McGuire, 2009; Dupras & Tremblay, 1976; Fitz-Gerald & Fitz-Gerald, 1987), lack of information about sexuality (Welshimer & Harris, 1994), and communication issues (Bundy & White, 1990) continue to serve as barriers to change.

Studies conducted since the 1980s demonstrate that such barriers to open communication between parents and children with intellectual disabilities are gradually

shifting. In 1982, Parsons reported that 38% of parents of an adult with an intellectual

disability responded positively to a statement suggesting that consensual sex between

adults with an intellectual disability should be permitted. Encouragingly, by 1991, this

number increased to 85% of parents agreeing with the statement (Fisher, 1991). Using

factorial analysis to analyze data pertaining to understanding the attitude of parents and

other caregivers regarding sexuality of adults with intellectual disabilities, Cuskelly and

Bryde (2004) determined that parents have conservative attitudes toward addressing

sexuality in comparison to other caregivers from the community. The study concludes

that there is a need to examine what aspects of a sexuality education program parents find

difficult to relate with, and address those areas.

Similarly, in Greece, Karellou (2007_) conducted a study to understand the

attitude of lay people around sexuality of adults with learning disabilities. The study

concluded that society is becoming more positive toward sexuality related views. This is

important because societal attitudes are one of many factors which impact parental as

well as special educators' role in teaching sexuality education to individuals with

intellectual disabilities in the school setting (Abramson, Moriuchi, & Waite, & Perry,

1983; Ballan, 2008; Edwards, 1988a, 1988b; Harold & Benson, 1979; Isler et al., 2009;

Lamb, 2010; Malfetti & Rubin, 1968; Picker, 1984; Rienzo, 1981). However, despite

observations of changing attitudes, I noticed that none of the studies I reviewed

elucidated the needs to address sexuality education programs within the school setting.

Parents, specifically mothers, and special educators who are the key stakeholders

in the lives of individuals' with intellectual disabilities also build on their perspectives

based on cultural factors that influence them, as well as their family as a whole. A dissertation study by Ballan (2008) elucidated the factors that influence parents' attitudes about their child with intellectual disabilities. These factors include: socioeconomic status, race and ethnicity, support services, physician attitudes, presence of other children in the home, presence of a spouse in the home, availability of social networks in the community, single versus two parent homes, previous births of children without disabilities, and the physical appearance of the child with intellectual disabilities. Most of the studies I read that addressed parental attitudes showed that, for the most part, many parents have conservative views regarding sexuality and their child/ren with intellectual disabilities. Mothers have expressed that if sexuality is to be taught it should be taught at home; however, there is little evidence that home instruction is actually happening (Cheng & Udry, 2005).

Contrary to what is actually occurring in the home, S. Foley (2013) wrote that parents need to pave ways to create an open dialogue on facilitated sex as a mechanism to meet the sexual needs of adults with Down syndrome. S. Foley furthered the dialogue by writing that to foster facilitated sex and related activities, first there is a need to *uncage* adults with intellectual disabilities from the constant surveillance by caregivers and parents. However, there is still a dearth of qualitative research about how culture impacts what parents think about what they want their growing offspring with intellectual disabilities to learn about sexuality and how culture impacts parental attitudes about how to teach their children about such topics (Abramson, et.al. 1983).

Other studies show that parents of individuals with intellectual disabilities lack confidence, information and professional support that would help them to negotiate how to approach addressing the subject of sexuality with their sons and daughters (Clegg, Sheard, Cahill, & Osbeck, 2001; Garbutt, 2008). Parents are aware of the competing discourses about risk and vulnerability on the one hand, and the importance of autonomy on the other (Couwenhoven, 2007). As a result of conflicting goal, parents report that while they feel that they are encouraged to maintain a protective stance, while at the same time, self-determination and autonomy are promoted as essential to wellbeing (Almack, Clegg, & Murphy, 2009).

Importantly, gender is an important factor to consider when examining parents' views about their offspring's sexuality. The issue of protection of children with intellectual disabilities remains linked to more general gender stereotypes, with particular concerns expressed by some parents about their daughter's sexual vulnerability. For example, Pownall et al. (2011) conducted focus group interviews with eight mothers of children with intellectual disabilities. Four had daughters, and four had sons. Most mothers discussed how they found talking about sexual matters uncomfortable. The researchers claimed that the mothers' views about the developing sexuality of their offspring with intellectual disabilities needed to be understood in the broader context of their sons' and daughters' socially marginalized position within the greater community.

While more recently conducted research suggests that parents and caregivers do recognize the importance of providing their adolescents with information about sexuality (Pownall, Jahoda, & Hastings, 2012; Swango-Wilson, 2008), the limited research

available suggests that both young people and their families find it difficult to discuss sexual matters together (Pownall et al., 2011). Similarly, cross-sectional studies have suggested that younger parents of children with intellectual disabilities are more accepting of their children's sexuality (Cuskelly & Bryde, 2004; Karellou, 2007a, 2007b). However, such acceptance does not guarantee that attitudes are translated into action, and oftentimes young people with intellectual disabilities are not given the opportunities required to adequately develop their sexual identities (Shepherdson, 1995; Swango-Wilson, 2008).

The study by Pownall et al. (2012) conducted a comparative study between mothers who had children with intellectual disabilities and mothers who had able-bodied children. The study shows that most mothers who have children with intellectual disabilities expressed the need to protect their child from detrimental experiences. Most mothers in the study added that it was imperative to choose not to talk about sexual matters with their child and keep their child/ren away from such pleasures. Their responses also indicated that their offspring have limited opportunities to develop social experiences and explore their sexual identities. The researchers involved in this study suggested that mothers may have felt that providing such information would be meaningless and potentially anxiety provoking for their child and therefore ought to be avoided.

Additionally, mothers involved in the Pownall et al. (2012) study revealed that they were uncertain about what information their child could understand or cope with in regards to sexuality. This is also reflected in mothers' attitudes toward their offspring's

sexuality, believing that their child did not have the same sexual feelings as other young people their age and that they were less interested in developing intimate relationships. Although researchers have found that parents of adolescents without disabilities also report uncertainty over when to start talking to their child about sex, their offspring's increasing independence from the family may act as an indicator that their child is ready (Pownall et al., 2011).

Despite the potential significance of parents' roles, there remains limited understanding of family perspectives and support needed in relation to the exploration of sexuality and education (Fraser & Sim, 2007; Morris, 2002). The limited research available suggests that both young people and their families find it difficult to discuss sexual matters (Pownall et al., 2012). Although the body of research literature exists to document parents' attitudes, concerns, and belief systems about their growing child's sexuality, issues that were raised before in the 1970s, 1980s and 1990s such as sterilization do not appear to have been adequately explored. Issues that have been given consideration in research are related to sexual abuse, sexual offense, and appropriate sexuality expression.

Looking through the critical disability lens, concerns related to the needs of women with intellectual disabilities regarding sexuality education appears to be limited by the influences of the power dynamics inherent in culture, society, and familial relationships. Therefore, the pioneering work of Edgerton (1967) in listening to the views of people with intellectual disabilities and that of Bogdan and Taylor (1989) in giving

validity to their stories influenced the way this study was carried out as well as making an important contribution to disability studies.

2.5. Familial Culture and Women With Intellectual Disabilities

Question 3

How is familial culture and women with intellectual disabilities represented within the academic literature?

The term *culture* is considered to be a highly complex word that challenges one to think about the meso and macro levels of cultural connotations available within various schools of thoughts such as the fields of Anthropology, Sociology and Developmental Psychology. However, what does this word suggest when the term is used as a lens to see families who have children with intellectual disabilities?

The praxis of familial culture as a culture in-of-itself may be contested by cultural studies scholars. However, the familial culture plays an important role in enrooting the self-determination and self-concept of the growing child with intellectual disabilities (Shogren, 2011). Also, familial culture plays an important role in proliferating the concept of sexuality (Bernert, 2011). Despite the fact that many studies acknowledge the idea that familial culture plays a critical role in terms of informing and guiding women with intellectual disabilities sexuality, the scholarly work in the field conducted to date does not necessarily provide a deeper understanding of this critical role. Thus, I begin this section with a description of the construct of culture itself.

Understanding the Role of Culture

The word culture is articulated at many levels and often by using several
ostensive definitions and theories. The most basic level is reflected in the language
people use (Parekh, 2000), related to race, ethnicity, and also nationality. From an
anthropological stand point, Lewis (1970) wrote that understanding of familial culture
involves what people believe in and how they adapt their beliefs as collectives and as
individual members of a family.

Sociologists place attention on attitudes, beliefs, and dogma created and held by
the group of people who are part of the larger culture and subcultures. Sociology suggest
that every individual is part of a larger culture that comprises the nationality and race and
ethnicity and the subcultures that they create with individual experiences such as
spirituality and religion, sexuality, and disabilities.

Based on the literature I read pertaining to understanding of sexuality and
individuals with intellectual disabilities, the word culture is not just connected to the race
and ethnicity, but it's also connected to the culture of abilities (Tepper, 2000). S. Hall
(1990), who is considered to be a pioneer in the field of intercultural work, wrote that
culture is the way one communicates. S. Hall wrote from the perspective of being an
Anthropologist that any cultural meaning is constructed through various stories,
processing information hidden within those stories and creating meaning out of them to
make meaning in the present life of an individual and the community as a whole.

Notwithstanding these helpful insights that attempt to define the meaning of the
term culture, important question amidst all the definitions and theories of culture remain
unanswered. Questions such as how do individuals with intellectual disabilities create

their understanding of sexuality using culture as a lens? And, how do those understandings affect their sexual behaviors and sexual self-determination (Bernett & Ogletree, 2013).

Again, I have found that much of the research that focuses on sexuality and intellectual disabilities primarily describes the role of parents in the lives of their children. Most of the studies I read that examine the role of family in nurturing self-determination explain that the familial contribution directly impacts levels of self-determination of individuals with intellectual disabilities (Wehmeyer, 2014). The studies emphasize that culture plays a critical role in determining what works best for particular families when focusing on the life of their growing child with disabilities, particularly children who experience intellectual disabilities.

Familial values themselves create subcultures. For instance, the culture that is created by different parent groups who collectively create their own understanding of working with their child for and toward self-determination and an independent living. This culture becomes intertwined within the various practices and belief systems other cultural subgroups that these families are part of such as spiritual or religious practices, their own understanding of sexuality and also their own disabling conditions.

Scholars in the field of self-determination and sexuality for individuals with intellectual disabilities recommend that studies be conducted that explore the cultural construction of sexuality. In the literature I reviewed on the role of culture in the U.S., I have found that when exploring various aspects of the lives of individuals with intellectual disabilities (such as special education services, education related to self-

determination skills and parental influences on children with disabilities), greater emphasis is given to the influence of ethnic identity groups such as African American, Hispanics and other groups such as Asians (East and South) forming larger cultural group rather than emphasizing subcultures such as sexuality (Rubin, 2011), spirituality or religion, or examining disabilities as a culture (Sieber, 2000). Hence, based on my review of literature and the purpose of this study, I define familial culture as the tradition a family creates that is then augmented throughout the person' lifetime, either slightly or significantly, depending on social interdictions and norms a person experiences over time. This may or may not be influenced by one's religious and spiritual practices and racial and ethnical background.

For the purpose of this dissertation study, I argue that it is difficult to extract out an individual's various layers of culture that underpin one's existence in the world. However, exploring what one learns from family as a culture constructs a distinct understanding about sexuality.

Goodley (1998, 2013), McRuer, (2013), and Sieber (2000) each individually asserted that disability in-of-itself is a cultural identity of people who experience disabling condition, which is also known as Crip culture (McRuer, 2013). However, Löfgren-Mårtenson (2013) wrote that for the most part, intellectual disability is often times diminished in favor of emphasizing other disabling conditions, some of which may be considered by some to be so-called culturally disabling conditions. Sexuality itself as a cultural identity (Rubin, 2011), for example identifying as member of Queer culture, may be viewed as a disabling factor in the lives of people with intellectual disabilities.

Although this distinction is clearly relevant to this study, only a few articles explore the spectrum of sexuality (Queer culture) as a culture and women with intellectual disabilities (Bernert, 2011; Bernert & Ogletree, 2012; Löfgren-Mårtenson, 2009, 2013).

Self-Determination and Familial Culture

Overall, the topic of familial culture and sexuality sits uncomfortably within the literature focusing on individuals with intellectual disabilities (Erevelles, 2011). However, there has been an attempt to explore the importance of the role of culture in nurturing self-determination of individuals with intellectual disabilities (Shogren, 2011; Wehmeyer, 2014).

The construct of *self-determination* is primarily described as a human rights concept instead of a skill-set to be taught (S. R. Smith, 2010). However, in the body of literature I read, the concept of self-determination gets embedded within the cultural understanding of intellectual disabilities. At the personal level, the concept of self-determination (having choice, control, and power in one's life) is explicitly taught as part of the transition training for adults with intellectual disabilities irrespective of gender. The rationale for this is that individuals with intellectual disabilities need explicit guidance to acquire comprehensive knowledge of how to have choice and control to explore one's sexuality in order to access this basic human right.

Löfgren-Mårtenson (2009) conducted a study in Sweden, to explore the invisibility of homosexual individuals with intellectual disabilities by interviewing caregivers, parents, and individuals with intellectual disabilities. None of the parents involved in this study believed that their children were having homosexual relationships.

Additionally, few staff members shared information that individuals with intellectual disabilities may have such relationships. In fact, Löfgren-Mårtenson found that 90% of women with intellectual disabilities involved in this study said that they disapproved of homosexuality due to ethical dilemmas. Despite this view, the care givers for these women reported that their female clients were in fact involved in homosexual relationships (S. A. Thompson, 2007).

This findings reported in the study conducted by Löfgren-Mårtenson were similar to that of McCarthy's (2010) study where she revealed that most women with intellectual disabilities considered same-sex relationships as a "bad" thing. Moreover, Bernert and Ogletree (2012) conducted an ethnographic study with 14 women with intellectual disabilities to explore their perception of sex. The study included ethnographic interviews as well as two focus group interviews. The results of this study demonstrated that most women had negative perceptions of sex, however, they were involved in a heterosexual relationship. They researchers wrote that such negative perceptions were due to fear of the act of sex itself. These findings are consistent with Butler et al. (2004) who noted discomfort, confusion, and ambivalence about the perception of sex by individuals with intellectual disabilities. These findings also align with Lesseliers and Van Hove (2002) and McCarthy (1999), who documented that women with intellectual disabilities tend to experience less pleasure from engagement sexual activities in comparison to women who do not experience intellectual disabilities.

Several studies cited by Leutar and Mihoković (2007) reported that individuals with intellectual disabilities experience shame, fear, and insecurities about their abilities

to explore themselves fully as a sexual being, which affects their keenness to have sexual relationships. Consistent with these findings, the results of Bernert and Ogletree's (2012) study showed that women's negative perception of sex limited their sexual behaviors, particularly decisions related to abstinence. These findings were also consistent with the results of Bernert's (2011) focus group study on women with intellectual disabilities. Bernert's results showed that most women with intellectual disabilities experience limited social exposure to explore opportunities to find a partner, or sexual experience (Bernert, 2011). This situation may be a result of the *medical gaze* women are subjected to which was presented earlier in this chapter. Bernert discussed that within the contexts of constant surveillance around women with intellectual disabilities, in most caregiving facilities, staff and caregivers suppress women's sexuality as a means of protection (Bernert, 2011; Cheng & Udry, 2003, 2005; Hingsburger & Tough, 2002; Lesseliers & Van Hove, 2002; Stinson, Christian, & Dotson, 2002).

For women with intellectual disabilities, rules of intimate relationships get complicated when woven together with their perceptions of the traditional rules of femininity (Bernert & Ogletree, 2012). In addition, cultural perceptions of parents and caregivers create a bias toward the sexuality of women with intellectual disabilities (Hingsburger & Tough, 2002).

Another layer is the role of disability as a cultural identity experienced by individuals with disabilities. Rules for intimate relationships include suppressed sexual expressions, intimate partner selection, and sexual expression are dependent upon the cultural understanding of sexuality of parents and professionals who are directly

connected to this population (Abbott & Howarth, 2007; Bernert, 2011; Evans et al., 2009; Stinson et al., 2002; Wolfe & Blanchett, 2003). Notwithstanding studies that have shone a light on topics related to sexuality and people with intellectual disabilities, there remains a minimum of research on sexuality related studies specifically focused on women with intellectual disabilities.

Several authors have affirmed that the lack of sexuality education and experience to explore one's sexuality directly affects the negative perception of sex by women with intellectual disabilities (Bernert, 2011; Bernert & Ogletree, 2012; Cheng & Udry, 2003, 2005; Hingsburger & Tough, 2002; Lesseliers & Van Hove, 2002; Stinson et al., 2002). The opinions of parents and caregivers who consider women with intellectual disabilities as being asexual/hypersexual (Murphy & Young, 2005; Noonan & Gomez, 2010), or being heterosexual (Abbott & Howarth, 2007; Löfgren-Mårtenson, 2009; McCarthy, 1999; Noonan & Gomez, 2010), are primarily governed by cultural understandings of sexuality (Lindsey, Robins, & Terrell, 2003). Limited information and misinformation from parents and professionals on sexuality negatively influence the sexuality of women with intellectual disabilities (Hingsburger & Tough, 2002; Löfgren-Mårtenson, 2009; Swango-Wilson, 2008).

The emphasis on disability, instead of the person, diminishes the dialogue on sexuality and sexual experience (Bernert, 2011; Murphy & Young, 2005; Tepper, 2000). The strands of the empirical research on sexuality and intellectual disabilities position women with intellectual disability as a commodity appear to be intertwined within the role of familial culture and sexuality as a whole (Shildrick, 2009; Sweeney, 2007). The

research cited in this chapter overwhelmingly suggests that there is a need to examine how women with intellectual disabilities perceive themselves as sexual beings, and how they are perceived by other.

2.6. Women With Intellectual Disabilities and the Dimensions of Sexuality Question 4

What does literature tell us about the dimensions of sexuality and women with intellectual disabilities?

In this section I will discuss how the three dimensions of sexuality (physical, social, psychological) and women with intellectual disabilities are explored in the literature.

Physical

Conflicting data related to women with intellectual disabilities sexual experiences is often apparent in the literature I read. For example, Dotson et al. (2003) interviewed eight women with developmental disabilities with an average age of 35 years. Out of eight participants, seven were Euro-Americans and one was Latina. Even though the study did not focus on ethnic diversity, the study acknowledged that five of the eight women in their study were sexually active, and four stated that they had knowledge about masturbation. Similarly, Siebelink, de Jong, Taal, and Roelvink's (2006) study stated that most respondents with intellectual disabilities had experience with many facets of romantic relationships and sexuality. Their findings indicate that 75% of participants had kissing experience, and 51% had experienced sexual intercourse. Similarly, a study conducted by McCabe and Cummins (1996) found that 80% of participants with

intellectual disabilities had kissing experience, and 48% had had sexual intercourse. In a later study, McCabe (1993, 1999) found that 78% had experience with kissing, and 58% with intercourse.

Conversely, in a study by Yacoub and Hall (2008), most of their research participants had not experienced any sexual relationships. Likewise, the study by Löfgren-Mårtenson (2004) reported that sexual intercourse is "quite uncommon among intellectually disabled youths" (p. 202). Löfgren-Mårtenson attributed this to extreme restrictions placed on privacy and independence.

The reasons for the disparities in research participants' experiences with sexuality appear to be attributable to levels of education. Siebelink et al. (2006) found that more knowledge led to more positive attitudes about sexuality. In their study, they developed a questionnaire to investigate 76 respondents' sexual knowledge, attitudes, experiences, and needs. Results showed that both sexuality and romantic relationships were important aspects in the lives of many of the participants. Males reported more sexual needs and experiences than females, specifically with regard to masturbation, adult movies, and prostitution. Males' attitudes toward these activities were also more positive than that of women with intellectual disabilities.

Using SEX-Ken ID scale developed by McCabe (1993, 1999), Yacoub and Hall (2008) conducted semi-structured interviews to explore the sexual lives of men with mild learning disabilities. Key areas of questioning pertained to friendship, sex education, sexual interactions, contraception, sexually transmitted infections, sexual orientation, and perception of the sexual lives of others. The researchers found that knowledge in itself

does not lead to implementation of safer sex practices and that sexual coercion was commonly reported.

A topics related to the issue of facilitated sex[14] was unexpectedly raised by a study participant in the study conducted by Yacoub and Hall (2008). Even though this study did not include women participants and all of the participants were unmarried males, the findings in this study aligned with other studies that show that most adults with intellectual disabilities are deprived of opportunities to develop and express their autonomy related to their sexuality. Most of the studies reviewed show that despite the fact that the participants had knowledge about the physical aspects of sexuality, that did not lead to safer sex (Yacoub & Hall, 2008), and sexual activity did not mean they had more knowledge of what it means to practice safe sex (Siebelink et al., 2006; Sweeney, 2007; Tepper, 2000, 2005).

Sobsey (1994a) has determined that individuals with intellectual disabilities are 4 to 10 times more likely to be sexually assaulted than non-disabled individuals. Furthermore, Champagne (2007) has contended that individuals with intellectual disabilities are particular vulnerable because perpetrators often choose victims who will not report the abuse. Essentially, having an intellectual disability creates an assumption that people are unable to adequately advocate for themselves and need constant supervision and support (Gill, 2010). Fegan, Rauch, and McCarthy (1991, 1996, 1998a,

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[14] Facilitated Sex: "Facilitated sex refers to access to sexual and reproductive health services, as well as access to adult shops and 'top shelf' pornography. It also refers to the right to sexual expression, friendship and intimacy and to the places and spaces where relationships are formed" (Earle, 2001, p. 438).

1998b, 1999) wrote that individuals with intellectual disabilities are particularly

vulnerable to sexual assault and abuse, because they are likely not to resist unwanted

sexual advances and, by extension, not report experiences of abuse. The research that I

read reported that most women with intellectual disabilities who are sexually abused

experience sexual abuse by a person they know. Most often their abusers are family

members or support staff in their home settings (Champagne, 2007). However, given that

the authority that a victim of sexual abuse would report to is most likely the caregiver or

support staff, this situation serves to further disenfranchise individuals who experience

abuse (Fegan et al., 1993).

Compounding this situation is the fact that the way in which care services are

designed and delivered contributes to the high numbers of incidences of sexual abuse. An

individual's ability to consent to sexual activity is important to consider but so is an

examination of various residential settings that place individuals in situations that

facilitate abuse (Niederbuhl, & Morris, 1993). For example, despite efforts to support

individuals autonomy in other ways, individuals with intellectual disabilities are often

told what to do, where to live, and in some cases, whom to love.

Social and Psychological

The literature I read placed a strong emphasized on the importance of romantic

relationships in the lives of adults with intellectual disabilities (Siebelink et al., 2006;

Ward, Bosek, & Trimble, 2010). However, my review of the literature also revealed the

interconnection of romantic relationships with the high rates of interpersonal violence

(Copel, 2006; D. Smith, 2008; Tepper, 2000, 2005; Ward et al., 2010). The studies also

reveal that most individuals with intellectual disabilities, irrespective of gender, have

unswervingly conveyed the desire for opportunities to make friends and spend time with

them (e.g., Knox & Hickson, 2001; Ward et al., 2013). However, the rate of victimization

experienced by individuals with intellectual disabilities is 1.5 to 10 times higher than

people without disabilities (Mansell, Sobsey, & Moskal, 1998; Petersila, 2001; Rand &

Harrell, 2009; Sobsey & Doe, 1991; Sobsey, Lucardie, & Mansell, 1995; Tepper, 2000,

2005). Furthermore, research suggests that, these individuals receive almost no sex

education or any type of education or training in assertiveness, healthy relationships, or

how to avoid sexual abuse (Barger, Wacker, Macy, & Parish, 2009).

Research has repeatedly shown that interpersonal violence negatively impacts the

abilities of individuals with intellectual disabilities to live independently and to maintain

their health (Hughes, 2009). The literature I read also stressed that the lack of appropriate

socio-sexual interactions also adds vulnerability to experience exploitation and

inappropriate sexual relationships (Bruder & Kroese, 2005; Sobsey & Varnhagen, 1989).

Studies have consistently documented that women with intellectual disabilities tend to

have small social networks comprised primarily of family members and staff (Emerson &

McVilly, 2004; Robertson et al., 2001). In addition to having a small network, some

individuals experience little or no social connectedness to others. In a qualitative study

about romantic relationships, Ward et al. (2013) found that of 24 individuals with

disabilities who experienced interpersonal violence, 38% had no one they felt they could turn to for help.

Despite the well-known increased risk, little research attention has been given to preventing interpersonal violence and/or promoting healthy relationships for this exceptionally vulnerable population (Barger et al., 2009). To make matters worse, there is a paucity of empirical research documenting the effectiveness of approaches to teach sexual abuse prevention skills to people with intellectual and developmental disabilities. Also, a dearth of evaluation studies that examine the behavioral impact of teaching healthy relationship skills, or combining these skills with sexual abuse protection and making appropriate judgments continues to serve as a significant barrier to improving approaches to preventing abuse and supporting the healthy sex lives of women with intellectual disabilities.

For the purpose of this study, the reviewed literature provided an opportunity to understand the representation of issues related to sexuality in connection to women with intellectual disabilities. The literature informs that most studies focusing on sexuality are conducted in the physical dimension of sexuality. There are only few studies that attempt to examine the understanding of sexuality by women with intellectual disabilities. More so, there are almost no studies that examine the role of familial culture in understanding of sexuality by women with intellectual disabilities. This dissertation study provided an important data to fill the gap in the literature. Figure 2.1 illustrates the review of literature conducted for the purpose of this study.
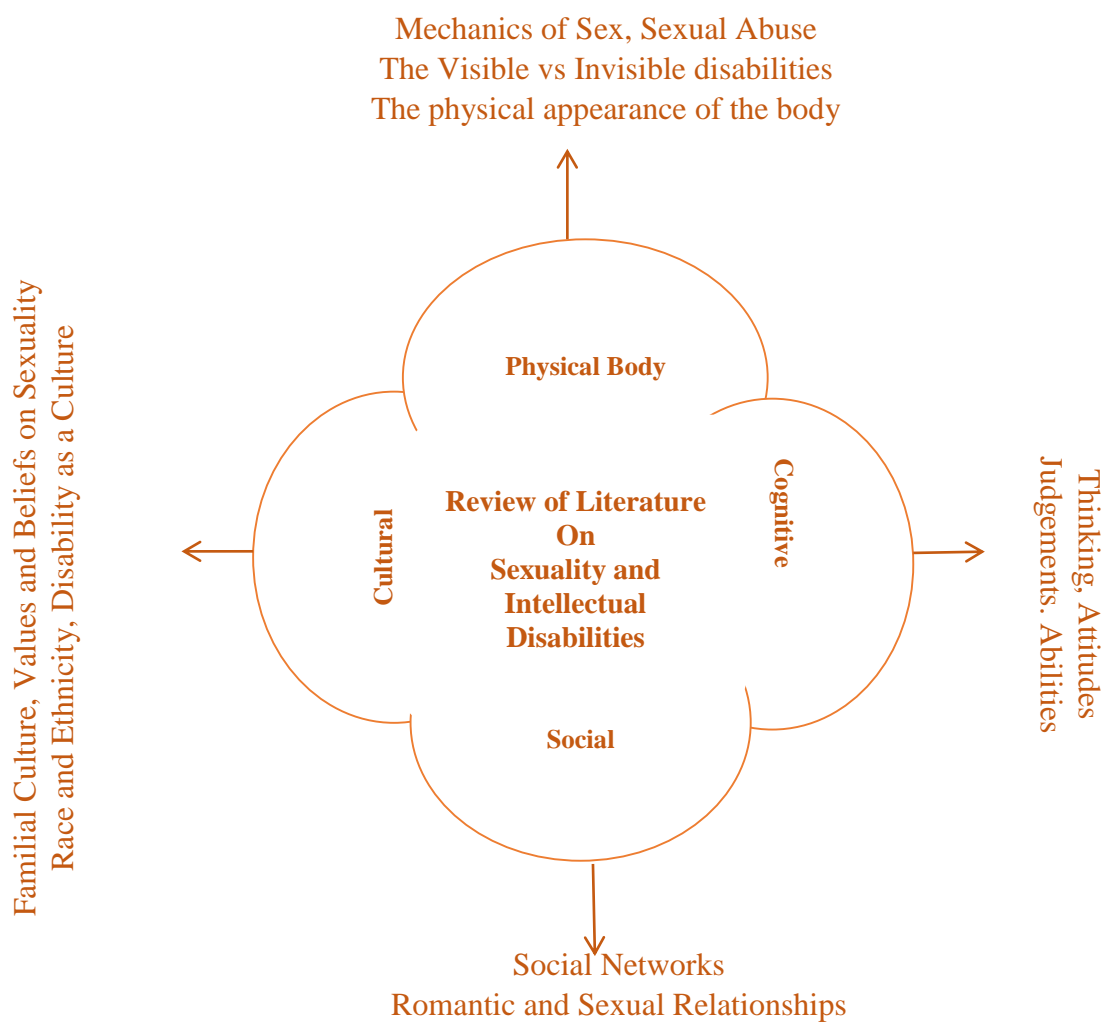
Figure 2.1. Review of literature on sexuality and intellectual disabilities.

2.7 Review of Methodological Literature

Research Paradigm

Building on the frameworks provided by Guba and Lincoln (2005), a research

paradigm is defined by four fundamental questions: (a) axiological questions, what is the

nature of ethics? (b) ontological questions, what is the form and nature of reality ? (c)

Epistemological questions, what is the basic belief about knowledge? and (d)

methodological questions, how can the researcher go about finding out whatever they

seek to know? I have employed the transformative research paradigm (Mertens, 2010) as

a reflective worldview for my study. Here, the transformative research paradigm is used

as a lens to explore research questions to emancipate the voice of women with intellectual

disability and to further the research in sexuality and disability.

According to the National Commission for the Protection of Human Subjects of

Biomedical and Behavioral Research (1979), the transformative research paradigm and a

qualitative methods approach are culturally sensitive approaches for a study of this

nature. The basis of the transformative research paradigm is to directly engage culturally

diverse members of society with an aim of promoting social justice. Mertens (2010)

asserted that the transformative research paradigm provides a framework for

understanding issues related to social justice in the research process. Moreover, the

transformative paradigm with its axiology, ontology, epistemology, and methodological

assumptions provides a logical framework for different types of issues connected with

disability research (Mertens, 2010). The transformative framework underpins the

research design that seeks to realize change and social justice by addressing injustices

that are due to an imbalance in the power roles found within communities (Creswell &

Plano Clark, 2011). Hence, the transformative research paradigm fit best with the purpose

of this study that aims to bring forward the voice of women with intellectual disabilities.

Transformative research seeks to challenge the status quo of oppressive

hegemonic systems, aiming toward the creation of equitable societies (Mertens, Sullivan,

& Stance, 2011). Importantly, a key of this work is to stimulate the recognition of diversity within the community of people with disabilities (Asch & Fine, 1992; Fine & Asch, 1988; Mertens, Harris, Holmes, & Mertens, 2009; Wilson & Mounty, 2007).

The axiological assumptions of the transformative paradigm involve ethical considerations including respect, beneficence, and social justice to ensure that the research procedures will be fairly administered (Mertens, 2010). The transformative *axiological* assumptions set the stage for the other belief systems associated with this paradigm (see Table 2.1).

Table 2.1

Basic Beliefs of the Transformative Paradigm[15]

Assumption	Explanation
Axiology/Nature of ethics	Underpinned by the principles of ethics in research: respect, beneficence, and justice. Respect: within the cultural norms of interaction within a community and across communities. Beneficence: the promotion of human rights and social justice. Justice: outcomes of research and furtherance of a social justice agenda.
Ontology/Reality	Multiple realities are shaped by social, political, cultural, economic, ethnic, gender, disability, and other values.
Epistemology/Nature of Knowledge	The study is an interactive link between the researcher and participants: relationship between the researcher and the participants facilitates to understand their experiences. The issues of understanding the culture and building trust are paramount. Power and privilege are explicitly addressed. Development of a trusting relationship is critical.
Methodology/systematic Inquiry	Interactive link between the researcher/evaluator and participants. Methods adjusted to accommodate cultural complexity. Power issues explicitly addressed. Contextual and historic factors are acknowledged.

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[15] Adapted from Mertens (2010)

The *ontological* assumption of the transformative research paradigm asserts that socially constructed realities are influenced by power and privilege. This paradigm enhances the "voices of those who are disenfranchised on the basis of gender, race/ethnicity, disability or other characteristics" (Mertens, 2007, p. 214). Within this research paradigm, qualitative methods are preferred to highlight issues of need and to give voice to these issues (Creswell & Plano Clark, 2011). This research aims to uncover the various versions of reality and align with a version that will uphold social justice and human rights. The ontological assumption leads to an epistemological assumption to conduct research in ways that are credible for the members of the diverse communities.

The *epistemological* assumption of the transformative research paradigm is that the power and privilege experienced by the individuals in relationship with the community builds knowledge (Symonette, 2009). This knowledge is attained through self-reflection and self-awareness of the historical, social, and the political experiences of individual with disabilities within the context of their community (Barnes, 2009; Sullivan, 2009).

The transformative research paradigm according to Mertens (2010) provides a framework for the researcher to be cognizant of power relations associated with gender, disability, sexual orientation, ethnicity, race, nationality, and other forms of diversity associated with less power. The transformative research paradigm also provides a lens to understand systems of oppression (e.g., ableism, racism, sexism, and audism) (Dillard,

2000). The *methodological* assumption of the transformative research paradigm focuses on the appropriate methodology for conducting research.

Research Methods

In fall 2013, I attended a theatrical performance presented by a theater-based organization that works with various nonprofit organizations focusing on marginalized population. The performance I attended was a collection of stories written by mothers who have children with Down syndrome. Professional actors enacted the stories depicted; mothers who have children with Down syndrome developed the scripts. All the mothers involved in the project were individually interviewed using an oral history[16] interview format; they were asked to meet in groups and record their interactions. These interviews were conducted informally by a group of volunteer instead of by a researcher.

As a lover of theater and a burgeoning researcher, I was very impressed with the methods used to bring forward the voice of these mothers without having their names said in front of the audience. I thought that an *objectively* developed research study that has *subjective* collaboration with theatre arts will not only help in bringing forward the voices of women with intellectual disabilities but also will provide a creative platform to conduct a scholarly piece of work. I decided to use theatrical exercises as part of the data collection method and a theatrical performance as a data dissemination process.

Under the methodological framework of Ethnodrama, I have used individual as well as focus group interviews as methods to collect data for this study. I selected

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[16] Oral history is a qualitative data collection method that focuses on the idea of the interviewee as an active participant in the research process. Oral history draws on memory and testimony to gain a more complete or different understanding of a past experienced both individually and collectively (Thompson, 2000).

Ethnodrama as a research method as it aligns with the transformative research paradigm that aims to enlighten the inquiry and describe the perceptions of certain groups found within a population (Goldstein, 2008, 2012; T. C. Turner, 2008).

Ethnodrama is a process of crafting a script from a variety of source materials. This may involve data such as individual as well as focus group interviews, field notes, journal entries, observation notes and other forms of qualitative data collection methods that can become the primary source material for performance adaptation or dramatization by a playwright (Saldaña, 2005b, 2011).

Saldaña (2005a, 2011) provided a clarification on the difference between Ethno*drama* and Ethno*theatre*. He wrote that Ethnodrama is a script created out of qualitative data whereas Ethnotheatre is the theatrical production created out of an Ethnodrama. Saldaña developed the concept of Ethnodrama based on the work on T. C. Turner (2008). For T. C. Turner, theater is a paradigm of process wherein the lived experiences of people serves as qualitative data that is a liminal resource that enriches the ritual of performance to reach the audience. This aligns with Butler-Kisber's (2010) arts-informed perspectives of qualitative research.

The basic content of Ethnodrama is the reduction of the qualitative data to present it in a manner that communicates through dramatic impact (Saldaña, 1998), from *a* significant epiphany to *the* significant epiphany. In the case of this study, I found that this method helped me meditate and reflect on the participants' voice and share their key perspectives through a theatrical script to reach the community. The script was then created based on the stage play concept by Chong (2004).

Ethnodrama (Saldaña, 1998, 2011) is ideal when exploring a sensitive topic such as sexuality and the role of familial culture. The transformative research paradigm aligns well with the underpinning principles of Ethnodrama. In alignments with the concepts of transformative research paradigm, Goldstein (2008) wrote that the Ethnodrama methodology is useful to bring forward the voice of people who are not heard otherwise and create transformative change in the social world. Ethnodrama has the power to reach larger audience and encourage public reflexive insight into different experiences of the participants belonging to different communities such as multilingual and multiracial communities.

As ethnographic playwright Mienczakowski (1997) wrote, when we are *very lucky*, the audiences and performers of performative ethnography leave the room or the auditorium *changed in some way*. In the similar vein, Denzin (1997) connected the experience of Ethnodrama as a logical way to *concretize* the research experience. He adds that the qualitative research based on the cultural elements gets a wider platform to essentialize and articulate the research findings. Denzin has clearly recognized that many forms of research performance work are bound to aesthetic conventions that need to be set aside for audiences of ethnographic performances.

Besides that, Denzin (2003a, 2003b) further described performative ethnography as using multiple lenses involving various areas of studies that involve various cultural differences. For example, one lens is derived out from the American race theory that builds on the works of bell hooks is Du Bois work in black theater that captured black life and culture. A second lens draws on the pragmatist interactionism of the work of George

Herbert Mead; Mead's work focused on the underpinning principles of engagement

(symbolic interactionism) with the social inquiry to bring out the required change within

the social behavior. A third example is the work of Giroux (1992) that aimed to

recuperate the required meaning of the life of people who are deemed to be incapable.

Fourth, are examples that emerge from critical race theory that works to bring forward

the voice of Chicana by providing witness to social discrimination and exclusion through

enactment of their stories.

Denzin (2010) has interwoven these examples as four strong pillars that he used

to explain the goal of performative ethnography/Ethnodrama. He wrote that this

methodology as a whole gives distinction to the lived experiences of people to provide

opportunities for others to conceptualize the realities of the participants involved in the

drama.

Additionally, Mienczakowski (1997) wrote that performance ethnography has a

potential to create more open and accessible comprehension of the research findings than

the traditional written report. Similarly, Goldstein (2008) stated that script writing out of

data could help a researcher reflect deeply about the participants' placement within the

script. As a playwright it is important to reflect on the nature of the character, how the

dialogue between the multiple characters is presented, how does the silence presented by

a character speak to the given situation and what is the point of departure for the whole

transformative journey.

Goldstein, Gray, Salisbury and Snell (2014) provided conceptual questions to

connect theater and qualitative research design. They wrote that incorporating theater

exercises while interviewing participants for the research, provides participants an avenue

to connect with other participants and share. Besides that, the presentation of the stories

provides audience an opportunity for community participation. I believe that the crucial

aspect of the use of the theatrical exercises within my research was incorporating the

point of view of the audience member. Following the conceptual questions given by

Goldstein et al. (2014), Appendix O presents the reflective process incorporated in this

study before creating the interview protocol.

Focus Group Interviews as Methods of Data Collection

According to Morgan (personal conversation, Winter, 2012), a typical number of

focus groups is three to five when different sets of participants are present in each focus

group interview. However, Morgan also wrote that when there are not enough

participants or it is too expensive and time consuming to assemble multiple groups, using

one or two groups may be a solution. Besides that Morgan also suggested that creating a

research setting where participants meet two to three times to talk about the topic may

facilitate secure and effective focus group communication. This is helpful when the

research focus is on the sensitive topic and involves a vulnerable population. For this

reason, in this study, I used repeated focus-group interviews with a same set of

participants.

When writing the script some researchers use the precise language used by the

research participants, thus maintaining a *verbatim* approach. Some adapt the participant

interviews to create a more aesthetically shaped adaptation. And still other playwrights

may develop an original dramatic composition based on or inspired by raw interview

materials. Also, playwrights may create one or more composite characters based on the

themes emerging from several interviews with different participants (Saldaña, 2011).

Thus, the composite character is a fictional creation that nevertheless represents and

speaks to the collective realities of its original sources.

To ensure that the participants' words are intact and presented as they were shared

with me, I have used verbatim approach in this study. Nagy, Hesse-Biber, and Leavy

(2006) wrote that the verbatim style performances are often about cultural reification.

Additionally, the primary purpose is to present the voice of the participants of the study

instead of the dramatization of the act.

In summary, in addition to contributing to the body of research that directly

relates to this dissertation study, this research makes an important contribution in terms of

providing an innovative example of how one may employ the use of Ethnodrama

qualitative research methods to decipher the perspectives of particular groups and provide

access to these perspectives for a wider range of audiences. The use of transformative

performance ethnography is connected with the concept of creating a platform for the

participants, especially individuals with disabilities, to bring forward their voices. These

qualitative methods emphasize the individual's subjective experience.

As observers of their own stories about understanding of sexuality that may or

may not involve oppressive situations in which they find their stories out in the world,

participants may envision a positive future or the stories may add vulnerability within the

participants. Expanding on the transformative research paradigm, my work addresses the

use of theater for Social Change, in interest of exploring the role of familial culture in

understanding sexuality. In the next section, in order to provide a greater understanding of how this dissertation will contribute to the field, I provide a review of the methodological literature that informed this dissertation research.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

The purpose of this study was to examine how familial culture influences the understanding of sexuality in women with intellectual disabilities. Additionally, this dissertation also examined the understanding of sexuality by young women with intellectual disabilities through their current life experiences. I used the transformative research paradigm and Ethnodrama (Saldaña, 2003, 2005a, 2005b) as a methodological framework and individual and three repeated focus group as methods of collecting data.

In the previous chapters, I presented a review of literature that primarily focused on the physical, social, and psychological/cognitive dimensions of sexuality. Besides exploring the meaning of sexuality, I also reviewed the literature to explore the association of sexuality and women with intellectual disabilities. I also reviewed literature to examine the role of families in the lives of individuals with intellectual disabilities, especially in the lives of women with intellectual disabilities. However, the role of familial culture is largely missing from the current body of academic literature focused on sexuality and intellectual disabilities.

This study drew upon data generated from individual as well as focus group interviews and theatrical exercises to address the following two research questions: What is the role of familial culture in addressing sexuality for young women (21-35 years) with intellectual disabilities and How do young women (21-35 years) with intellectual

disabilities (describe their understanding of sexuality? This chapter presents the various steps involved in conducting this study. First I will provide justification for the methods used to conduct this study. After that I will emphasis on the various steps involved in conducting this study and a description of my role as a researcher.

3.2 Research Methods: Justification for the Chosen Method

For this dissertation, I have used a qualitative approach to this study that involved individual interviews and three repeated focus-group interviews using Ethnodrama as a methodological framework. Most prior research on sexuality and intellectual disabilities primarily focused on the use of quantitative methods (such as survey design) to explore the attitudes of the subjects' parents and professionals toward sexuality (Fischer & Krajicek, 1974; J. E. Hall et al., 1973; Pownall & Jahoda, 2011; Swango-Wilson, 2008). However, the actual voices of women with intellectual disabilities and their understanding of sexuality were rarely included (Capando & Kempron, 1981; Fitzgerald & Withers, 2013; McCarthy, 1991, 1996, 1998a, 1998b, 1999); D. T. Mitchell, 2002; Shakespeare, 1996, 2000; Siebers, 2012; D. Thompson, 1994).

Quantitative research may provide a broader understanding of sexuality in women with intellectual disabilities, but it neglects to explore the minutia of the lived experiences of women who personally experience intellectual disabilities. In contrast, most of the research studies I reviewed suggested that qualitative methods provide a deeper understanding of the topic at hand. Taken together, these are the reasons why I chose to use qualitative methods instead of quantitative methods for this dissertation research.

In this study, I integrated innovative Ethnodrama research methods to illuminate the nuanced dynamics of the experiences of young women with intellectual disabilities. Ethnodrama involved research-based script writing which is a particularly promising, action-oriented research method that invites continued inquiry and critical reflection with a goal of reaching out to an audience beyond academia.

My decision to pursue this hybrid methodology follows the work of many qualitative arts-based researchers, for example. Saldaña (2011) posited that an Ethnodrama is both a genre and "art form" (p. 15) that has "the ability to heighten the presentation and representation of social life" (p. 15). Using the Ethnodrama methodological approach not only gave me an artistic vision of the data through the process of creating a script out of the data, but also aided in the "data analytic process" (Saldaña, 1998, p. 184).

Additionally, during the focus group interviews, I used theatrical activities as an icebreaker at the start of every focus group interview. This gave participants an opportunity to connect with one another and create a safe place to talk. The use of theatrical exercises elicited more thoughtful and forthright sharing of their perceptions and experiences as women with intellectual disabilities.

Qualitative data gathered included both individual interviews and repeated focus groups, observation notes, and my own journal entries. I interviewed eight young women with intellectual disabilities individually, out of which, seven agreed to participate in the focus group discussions. The details of each focus group interview are given in the following sections of this chapter.

Through the interviews, I aimed to better comprehend the role of familial culture in the understanding of sexuality by young women with intellectual disabilities while also exploring how these women understand sexuality. The data analysis and interpretation, helped in understanding and describing participants' experiences, which further helped to transform the data into an Ethnodrama (Denzin, 2003; Saldaña, 2005b). This Ethnodrama is included in the appendices of this dissertation.

3.3 Participants: Recruitment and Sampling

Women with intellectual disabilities who participated in this study were able to communicate using speech, respond verbally to verbal questioning, and give verbal consent to participate in this research. Access to participants was gained through other professionals who worked in the study's locality. Active consent was gained from each of the eight participants. Any participants who were limited in their ability to read had the information sheet presented to them verbally and in the presence of a professional who witnessed their consent. In compliance with requirements for conducting research involving humans plus requirements specifically designed for this study, every participant met the following criteria. (see Appendix E):

1. Consent: Participants demonstrated their willingness to participate in this study by signing the informed consent form after reading it or having it read to them.

2. Age: All participants were between 21-35 years of age. Initially, the participant age range was from 25-35. However, during the recruitment process I was contacted by a mother who wanted her daughter, a 21-year-old with Down syndrome, to take part in the study. I decided to expand the age range of participants from 25-35 to 21-35. I resubmitted my proposal to my institutional review board (IRB) to obtain their approval to include her in the study and thus expanded the age range to 21-35.

3. Spoken Language: One of the criteria for selection of participants was that participants should be able to speak in English. For this reason, I had to reject two Swahili speaking participants since they couldn't speak in English and they needed their caregivers to translate.

4. Written Language: Able to write at least at the fourth grade level. This was useful, especially during the focus group discussions wherein every participant was asked to do a free-write before verbally responding to a question posed by the researcher. The free-write activity provided participants with time to reflect and then share thoughts that were directly connected to each question.

5. Language Comprehension: Every participant needed verbalization skills sufficient to express herself. The expense and logistics of securing interpreters, language-assistive devices, and other related resources were beyond the resources of this study.

6. Time Commitment: Willing to spend 45 minutes for the individual interview and 3 hours for every focus group meeting. This time during the focus group interviews involved two 15-minute breaks and one 30-minute break.

7. Locality: For the convenience of facilitating the focus group interviews, another criteria for participation was the locale where participants lived; all participants needed to live in the greater metropolitan area of Portland, Oregon. However, I had a participant who received the flyer through the Mt. Hood Kiwanis Camp[17] newsletter. Even though she lived in Salem, Oregon— which is an hour drive from Portland—she wanted to participate in the study. Because I was having difficulty finding participants, I agreed to allow her into my study.

Recruitment

To recruit participants, I approached more than 97 individuals from various organizations that provide support services for individuals with intellectual disabilities; this process took approximately three months. I found their contact information through the Multnomah County's Development Disabilities Services database. I also contacted regional officers who were in charge of providing training for foster-care service

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[17] Mt. Hood Kiwanis Camp is a 2-week supervised, adapted, and supportive summer experience that serves campers with a variety of abilities and disabilities. A small team of professionals and fellow students help those with disabilities have fun fishing, hiking, rock-climbing, canoeing, horseback riding and camping.

providers, as well as officers who manage group homes in Multnomah County. I met staff

and organization leaders in person and even in groups during professional staff meetings.

Ultimately, I interviewed eight women with intellectual disabilities. Initially all of

these women voluntarily agreed to participate in the study both for individual interviews

as well as three repeated focus group meetings. However, of the eight participants, as the

days of the focus group meetings approached, only seven women agreed to meet for all

three of the focus group meetings due to scheduling conflicts. In the end, only three

participants were able to participate in all the focus group meetings.

Each participant made a distinct contribution to the study based on differences in

their living situations and current relationship status. Table 3.1 provides tabular details of

the women who participated in the study. A detailed, narrative participant description is

provided in chapter 4 of this dissertation.

Sample Design

Sampling design is the key component of a research study (Creswell, 2007).

Although I initially proposed to recruit participants using purposive and convenience

sampling methods, I also incorporated snowball sampling methods. I wanted to ensure

that participants were diverse in terms of ethnicity and disability, yet the participants I

recruited primarily demonstrated class differences.

As proposed, participants were selected with the assumption that they would

substantially contribute to the topic being explored (Creswell, 2007; Polkinghorne, 2005).

In the beginning, it was proposed that at least 12 participants would participate in the

study. Due to several reasons such as the topic of the study, a lack of willingness to

Table 3.1

Participant Description

Participant	Race	Religion	Living Situation	Individual Interview	FG1	FG2	FG3
P001	Caucasian	Not specified	Lives with parents	X	X	X	X
P002	Caucasian	Raised Catholic but now calls herself pagan	Lives alone but near her parents' house	X	X	X	X
P003	Caucasian	Raised Catholic but does not currently follow any religious tradition	Lives with foster parent (group home)	X	X	X	X
P004	Caucasian	Not specified	Lives with mother and stepfather	X	X	X	_
P005	Mixed race (Caucasian and Hawaiian)	Raised Catholic but now follows Judaism (her boyfriend's religion)	Lives with father and boyfriend	X	X	_	_
P006	African American	Christian	Lives with foster parent	X	X	_	_
P007	African American	Believes in God but does not practice a religion.	Lives with foster parent	X	X	_	_
P008	Mixed race (African American and Caucasian)	Not specified	Lives with mother	X	--	-	-

participate, lack of permission from the parents to participate in the study, and language barriers, I was unable to find the desired number of participants. Hence, I decided to compromise and accept the first eight participants from the individual interviews as the final set of participants for the focus group as well.

Sampling Methods

Flyers were sent to various Portland-based organizations that work directly with adults with intellectual disabilities, including but not limited to The Northwest Down Syndrome Association, Disability, Disability Art and Culture Project, Family and Community Together, Multnomah Developmental Disabilities Services, Oregon Council of Developmental Disabilities, Self-Determination Resources Inc. and Inclusion Inc. These local service organizations received a letter (CES H) endorsed by me, along with several sample recruitment flyers (CES J) describing the study and asking for help recruiting participants.

In the letter, I described the criteria for participant selection, highlighting concepts such as client rights, self-determination, and voluntary consent, and stressed the importance of these ideals so prospective participants would not feel coerced. I also explained that interviews would be filmed and the stories used to create a script for a stage performance. I also indicated that counselors would be present during the focus group sessions.

After describing the participant selection process, I outlined the logistics of the study, including the total number of meetings, recording of individual interviews and theater workshops, contact information, the presence of a female assistant moderator, and

time commitment. I also indicated that participation was voluntary and that participants could opt to skip questions or withdraw completely from the study at any time. I thoroughly explained that the purpose of the study was to learn about the role familial culture played in the understanding of sexuality in young women with disabilities,

After I conducted several follow-up phone calls and meeting professionals in person, I was told by one of the caregivers that no one had time to read the whole letter. So I drafted a new letter with only a few of the study's main points that I wanted professionals to convey to their clients and their families. This letter was again sent to the same organizations I had contacted earlier. I also used this new letter to reach out to the organizations I had not contacted earlier.

3.4. Procedures

Data Collection

Data collection consisted of short individual interviews (45-60 minutes) followed by three repeated focus group interviews. Because I wanted to encourage the participants to fully and freely express their own perspectives on sexuality, the interviews were first conducted individually; once they agreed to participate further, they were interviewed in three, theme-based groups.

Besides the individual and focus group interviews, the data collection methods (Figure 3.1) also included my written journal entries and observational notes by the co-moderator; the counselors' notes provided secondary data. Two rehabilitation counseling students and one co-moderator aided the data collection process by taking observational notes during the focus group interviews, with one counseling student present for one

focus group interview and the other student present for the remaining two. The help of these additional people was essential and allowed the group to run more smoothly while increasing the overall quality of the data. The next section provides step-by-step details of the interview protocols and data collection process.

Secondary Data:	• Researcher's Journal Entries • Observation Notes by the co-moderator, counselor and the researcher.
Repeated Focus Group Interviews	• Focus Group I • Focus Group 2 • Focus Group 3
Individual Interviews	• 8 individual interviews
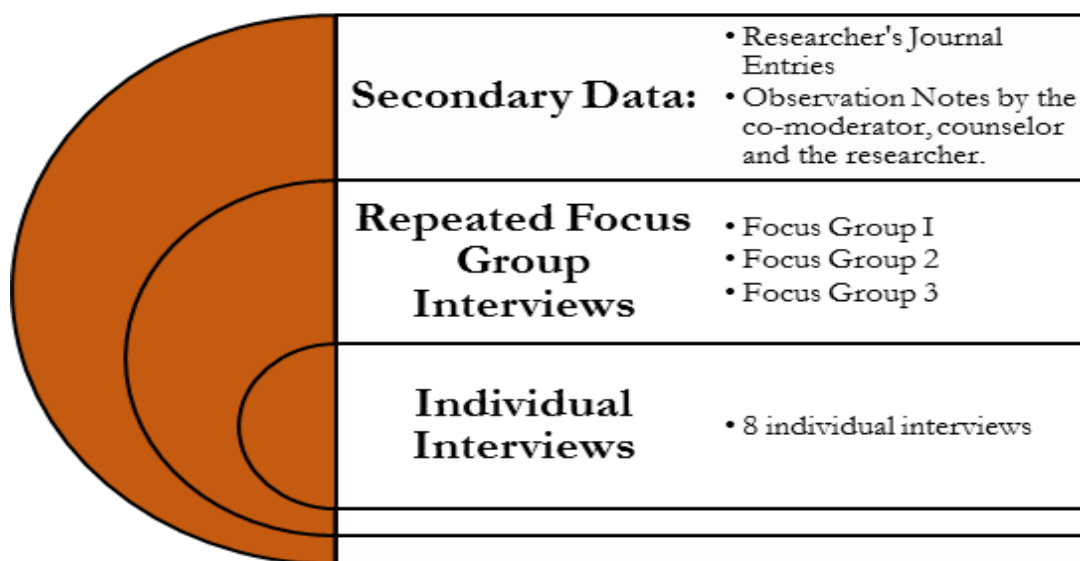
Figure 3.1. Data collection methods.

3.5 Instruments and Measures

Individual Interviews

D. Thompson (1994) asserted that communicating directly with adults with intellectual disabilities is the best approach to understand how they experience their sexuality and relationships. I used a casual, conversational approach and adjusted according to the participants' comfort while maintaining the structure of the interview

process. I found that this method did allow the women[18] to take the lead and voice their opinions and stories. However, I also felt that this strategy was more successful during the group interview than during the individual interviews.

A semi-structured interview schedule was used to guide participant interviews; audio and video were recorded, with the audio later transcribed and analyzed. Interview questions were based on existing literature, particularly McCarthy's (1999) interview schedule relating to the sexual experiences of women with intellectual disabilities. The interviews were conducted in a flexible manner, with specific topics covered determined by the direction initiated by the women during the conversations. Each interview took place in a venue of the participant's choice. The total time taken for each participant varied between 45 minutes and 1 hour.

When participants struggled to express themselves or to understand me, I rephrased the questions and provided clarifications. Also, participants were encouraged to use their own words to confirm that they understood. For example, when I asked about their understanding of masturbation, one of participants said, "You mean my fantasy?" After I asked what she meant, she explained, "Oh, I touch myself and fantasize about… [Silence with awkward facial expressions]." Placards with basic answers—for example, "I don't know," "Pass"—were also provided to address any apparent hesitancy. However, since all of the participants were comfortable verbally communicating their hesitancy, none of them chose to use the placards.

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[18] Transformative paradigm works to humanize people involved in research by avoiding the overuse of terms such as "participants" and completely avoids terms such as "subjects." Hence, the participants in this study are addressed as *women*.

The individual interview questions were more general in nature; more intimate questions were asked in the focus group interviews. This gave participants some time to adjust to the interview situations. Participants were also encouraged to ask questions of their own. Changes were made to the interview schedule as the research progressed, with previous interviews being used to inform subsequent stages of data gathering and theorizing (Bannister, Burman, Parker, Taylor, & Tindall, 1994). The aim of making such changes was to address gaps in the previous schedule and to facilitate a fuller exploration of the topic.

The interview guide (x A) was based on the guidelines given by Sigelman, Budd, Spanhel, and Schoenrock (1981) and was adapted from questions used by Timmers, DuCharme, and Jacob's (1981) research on sexuality and relationships with a unique focus on culture. I did not strictly adhere to the predetermined order of questions–I found that three of the participants had been sexually abused in the past, therefore it was necessary to adjust my line of questions to suit their respective levels of comfort. I also frequently modified the questions in attempt to elicit a response, particularly in situations when a participant seemed embarrassed, reluctant, or unable to respond (Brantlinger, 1997).

Besides being a screening tool, individual interviews served as a friendly meeting to gain trust and assure participants that they were safe when they met in groups. As a gesture of gratitude, each participant was given a $5 Starbucks gift card, pamphlets from Planned Parenthood and Portland Women's Crisis Line, and a small notepad with a pen along with snacks and lunch during the focus group interviews.

Figure 3.2 presents the organization of the individual interview. Every interview was divided into three sections- introduction, family, and sexuality. During the first section, participants were given opportunity to introduce themselves. During this time I made extensive notes to understanding her. During the second session, women spoke about their families and what they learned from them about sexuality while growing up. During the third section of the individual interview, women who participated in the study were requested to directly talk about sexuality.

Introduction
- Description of protocol
- Researcher's introduction
- Participants' introduction

Tell me about your family
- What your is family like.
- Tell me about the celebrations and festivals you celebrate as a family.
- Religious or spiritual experiences with family?
- Siblings?
- Tell me more.

What is Sexuality?
- What did you learn about sexuality while growing up?
- What do you think about sexuality now?
- Tell me about your experiences.

Figure 3.2. Organization of the individual interview.

Focus Group Interviews

Following each individual interview, all participants were invited to participate in a focus group. A total of seven participants chose to participate in the first focus group. I established and followed several guidelines to ensure confidentiality, comfort, and physical accessibility during the focus groups:

- Confidentiality

    - Other than first names, I did not mention any other identifying information concerning the participants during the focus group, leaving the participants to share as much personal information as they wished.

    - Similar to the individual interview procedures, I kept focus group information confidential. Participants were asked not to disclose their peers' stories or personal information outside of or following the group.

- Comfort: The goal of providing comfort and safety during the interaction was kept as a priority. This was done by incorporating timely breaks, providing the availability of counselor if they needed, and involving the use of theatrical ice-breaker exercises that would help participants interact with one another more comfortably. As a result, for each participant in the focus group, the experience of sharing their story with understanding peers was affirming and therapeutic. The women expressed how important it was to feel fully acknowledged, listened to, and heard. Following the discussion, several of the young women continued talking about the activities they were involved with, exchanged contact information with one another, and expressed interest in staying in touch with each other.

- Considering the topic of the study and knowing that three participants were sexually abused, I made arrangements to have a counselor present in the room in case any participants needed to talk to someone other than me. To facilitate this resource, I wrote the rehabilitation counseling department at Portland State University to help recruit counselors for the study. I invited myself to speak to students who were in

their last term of the rehabilitation counseling program and needed practicum credit

hours to complete their degrees. Out of 20 cohort members, 4 contacted me to be part

of the study. In the end, I had two student counselors sit in on the first focus group

meeting, and one student counselor sit in on the remaining two focus group meetings.

However, none of the participants expressed any desire to talk to the student

counselors in private.

- Access
- Sitting arrangements granted participants easy access to food and drinks provided

  during every focus group meeting. The focus group meeting room was also right

  next to the bathrooms.

Figures 3.3, 3.4, and 3.5 show the focus group interview settings. Figure 3.3

shows the view from the front side of the room and figure 3.4 shows the back view of the

room. Figure 3.5 shows the separate information table set up. The information table

shown in figure 3.5 had flyers and condoms from Planned Parenthood,[19] flyers from

Portland Women's Crisis Line, flyers and office supplies (pens, sticky notes, and

notepads) from the Women's Resource Center, and miscellaneous flyers on contraception

methods along with some self-care related pictures. These self-care pictures were

downloaded and printed as an additional gift for the participants.

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[19] Planned Parenthood is a local nonprofit organization

Figure 3.3. Focus group interview setting one.

Figure 3.4. Focus group interview setting two.

Figure 3.5. Information table.
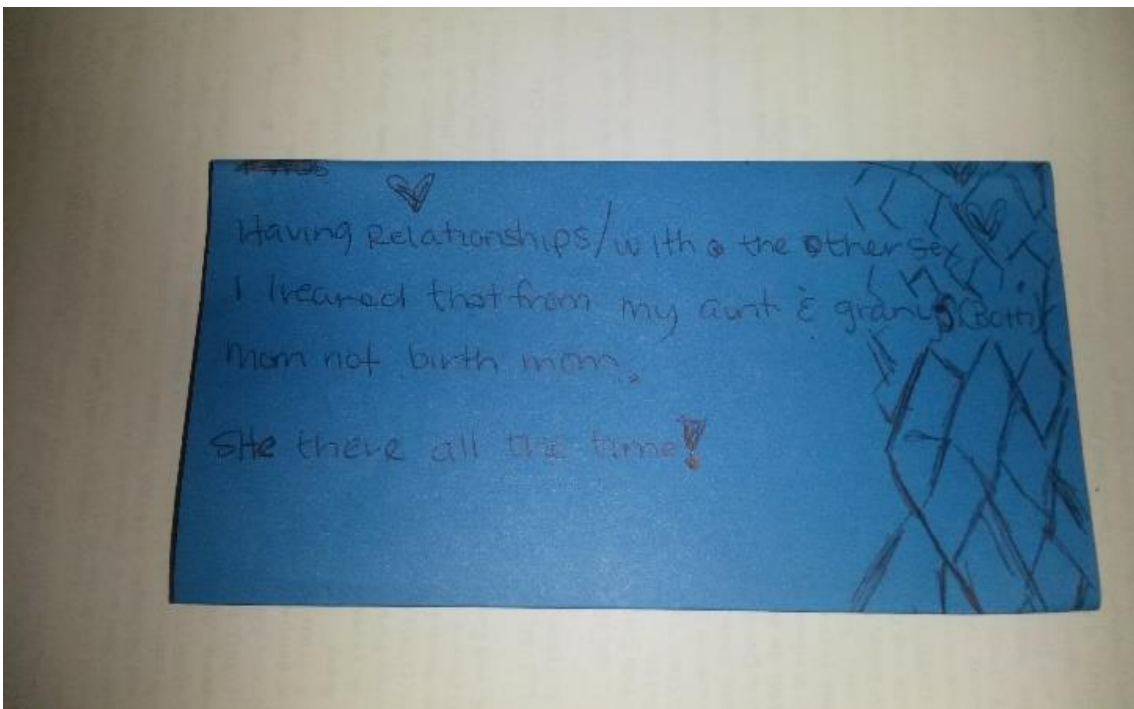
Figure 3.6. First example of free writing during the focus group interview.
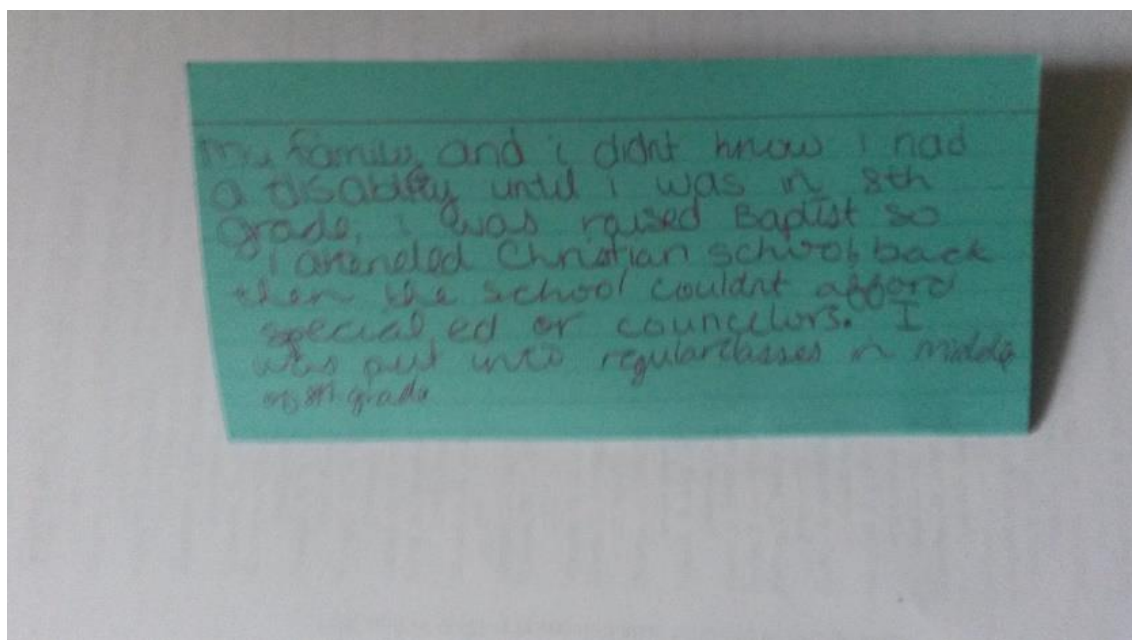
Figure 3.7. Second example of free writing time during focus group interview.

These figures depict the participants' favorite flowers, pictures of dancers dancing happily, and even their own dance performances. (Two of the participants were performing dancers—one was a belly dancer, and the other was a fusion dancer. Both of them perform on stage on regular basis.). In all, three repeated focus group sessions were conducted with the same women participants. Each session covered a theme relevant to sexuality as taken from the literature. Theme-based focus group interviews were planned primarily to make it easier for participants to talk about sexuality. The first focus group session focused on cognitive aspects of sexuality; the second session focused on physical aspects of sexuality; and the final session focused on social aspects of sexuality. It was assumed that participants would be able talk more comfortably as they built on the comfort within the group.

I mostly talk to my mom about sex and anything. Also same with my sister. I can talk about anything as well. As for my dad not much really. But there are some things that I do talk about.
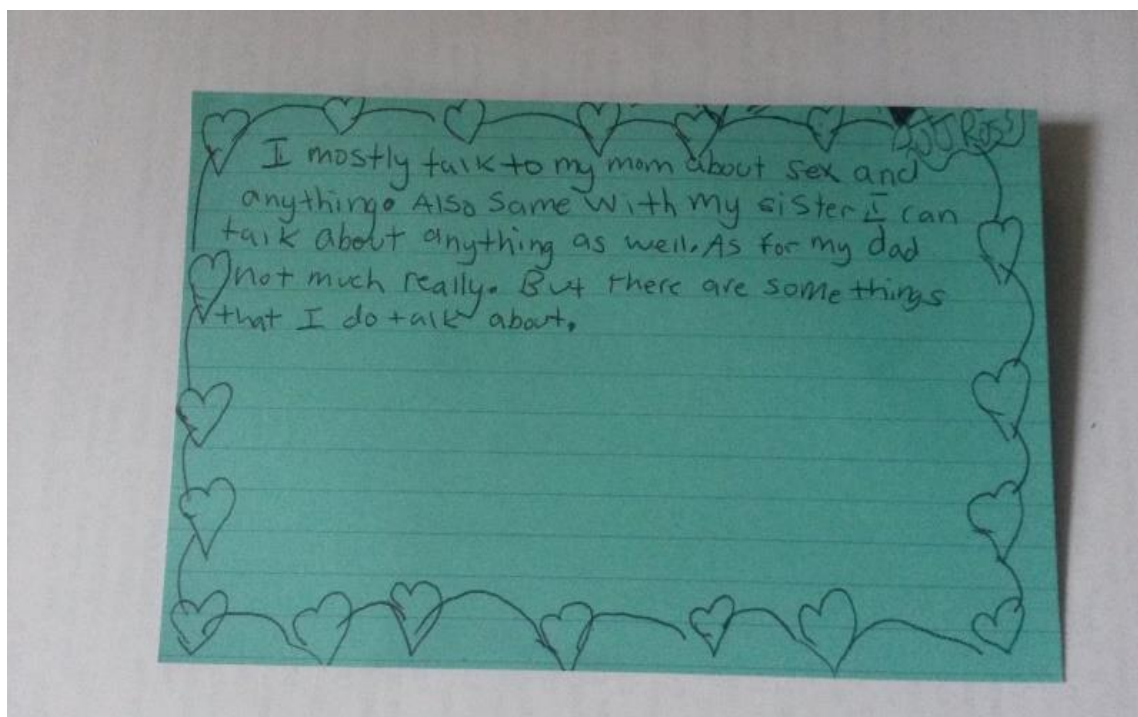
Figure 3.8. Third example of free writing during the focus group interview.

Even though the focus group interviews were theme-based, each theme intersected in some manner during every interview session. This phenomenon is similar to that observed during the Bernert's (2011) focus group study on women with intellectual disabilities and their understanding of sexuality. Bernert explained that her study participants openly spoke about their experiences with the physical, social, and cognitive dimensions of sexuality. Bernert explained that this is due to the lack of communication around the topic and lack of concrete information about the meaning of sexuality. All the focus group interviews were conducted on three consecutive Saturdays for 3 hours each. Theatrical exercises were used as icebreakers to create a more comfortable environment for the participants to communicate.

Focus Group Interview Activities

Knowing that focused writing activities (Bloor, 2001; Colucci, 2000; Krueger, 1998) facilitate reflection and discussion, I used writing exercises that gave participants extra time to think and list the ideas they wanted to share. Figures 3.6, 3.7, and 3.8 provide few examples showing the use of the writing activities. These activity-oriented questions provided a framework to talk about sensitive topics in a less threatening manner. This process gave participants a sense of self-affirmation and confidence. After the first interview one of the participant's mother emailed me and said that her daughter "felt like a responsible adult doing those activities in the group interviews," adding that her daughter looked forward to attending all the focus group interviews. She said "It was more like an important work meeting for her." From my journal entries, memos, and reflections, I found that when participants were given note cards to write on, they took the task seriously and had a sense of pride in writing and sharing. I also found that few of the participants preferred to sketch out their ideas rather than using words to describe their perceptions.

After the focus group interviews concluded, one participant shared that these activities made her feel important that she felt like "someone who has something important to contribute in the community."

The following procedures were followed during all three focus group interviews: Each focus group interview session was divided into four sections, with breaks between each section (see Appendix J).

- Section 1 (Introduction): Theatrical activity (see Appendix K) as an icebreaker.

- Sections 2 and 3 (Pre-lunch and post-lunch sections): Each section had two main questions. After each question was posed, the participants were given 5-8 minutes to free write and reflect. Figures 3.6, 3.7, and 3.8 give examples of responses during the free write.

- Section 4 (Closing meditation): Each focus group interview ended with a short meditation session 2-3 minutes long. I suggested participants opt out of meditation if it made them uncomfortable, yet everyone participated. These brief meditation periods intended to bring closure to any emotions built up during the interview session. After the meditation period concluded, participants were reminded that they were safe in the room.

- Note cards: During the free write time, participants were given note cards to reflect and write to organize their thoughts before sharing them with the group.

- Recording: Each focus group interview was videotaped as well as audio recorded.

- Accommodated personal needs: The participants were told that they could step out anytime they wanted. While we were talking during the second group interview, one of the participants gave me a note card that said "break." To accommodate her specific needs, the small smoking breaks were included as well, which included an opportunity to stretch and rest too. Even though the interview schedule was structured to make sure all questions were covered, breaks were allowed whenever participants needed to step out of the conversation.

Based on the experiences of using free writing and theatrical activities, Table 3.2 presents the creative method used during the focus group meetings to elicit individuals' thinking and support communication among the women.

Table 3.2

Use of Creative Methodology in the Focus Group Interviews

Free writing
1.   Helped to collect thoughts before sharing with the larger group
2.   Provided women with a sense of authority and confidence
Theatrical activities
1.   Acted as an icebreaker and helped participants interact with one another
2.   Provided a sense of connection and belonging
3.   Participants who were shy considered this a challenging activity
Interconnection of the activities (Free listing, free writing, sharing)
1.   Primarily used to provide comfort zone to the participants (Krueger & Casey, 2000)
2.   All writing activity was done in silence, which facilitated opportunities for the quietest participant to contribute and share (Colucci, 2007)

The Roles of Moderator, Co-Moderator and Counselors

Since I was the moderator of the focus group interviews, I made sure that I used both low moderator involvement as well as high moderator involvement as determined by the stages of questions. As a moderator, I ensured that I was facilitating the discussion while I took notes. The co-moderator's role was to conduct the theatrical exercises (described in Appendix P) and take extensive notes during the focus group discussions. The co-moderator also ensured that the cameras and audio recorders were working, assisted participants if they needed help finding their way to the restrooms, and aided with debriefing. The counselors' primary roles were to be present with the participants and conversation and take extensive notes. In every focus group interview, I introduced the counselor and reminded the group that the counselors were there to support them.

Secondary Level Observational Data

The assistant moderator, counselors and I took extensive notes during the three focus group meetings using a note taking format as suggested by Krueger and Casey (2000); as shown in Appendix H). Additionally, after the focus group interviews concluded, I recorded each participant's degree of discomfort or embarrassment with different interview topics, questions, and responses. These were recorded on a response-style summary sheet (see Appendix E). I adopted Thomas and Stenfert-Kroese's (2005) behavioral definition of embarrassment to include "blushing, sweating, avoidance of using sexual terminology, avoidance of eye contact, and excessive fidgeting while talking with the interviewer" (p. 115). This helped in understanding the participants' comfort level with each topic.

Recordings

Audio and video were recorded during every interview. No identifying participant information appeared on any of the data collection forms, the transcribed interviews, or the transcribed focus group interviews; in the transcripts, each participant's actual name was replaced by a series of letters. The audio tapes, transcribed interviews, and focus group material were stored in a locked cabinet separate from hard copies of participant-identifying information. After the interview tapes had been transcribed, I listened to the tapes while following along with the transcripts to check for accuracy. I watched the videos to observe participants' body language, tacit expressions, and subtexts. I also made notes about their affective behaviors during the interviews, which later helped me with the data analysis process.

After the transcription and note-taking processes were complete, the interview tapes were destroyed. Password-encrypted electronic versions of the interview transcripts were kept on Google Drive (password protected), on an external hard drive, and saved on a password-protected electronic network on my own personal computer. The transcriptions were coded with a study identification number, and this code list was kept in an additional separate locked file. Thus, the information given by study participants was not attached to their names in any way.

Only those people with specific permission and a legitimate role in the study such as the researcher and the rehabilitation counselor who helped with the data validation process were allowed access to the transcripts and de-identified data. Participant confidentiality was and will be strictly adhered to throughout the duration and beyond the extent of this project.

3.6 Data Validity

Lincoln and Guba (1985) suggested two main threats to the internal validity of a qualitative study are researcher bias and reactivity. My own biases were minimized by consistent and thorough reflection processes and self-critiques of my own assumptions (Maxwell, 2012).

For the purpose of validating data, I invited three colleagues to go through the interview transcripts and watch the individual interview videos. I requested that my colleagues use a checklist I created for the participant selection for the focus group interviews (see Appendix G); I also requested they give me their feedback if the transcripts were missing any information. For the focus group interviews, I invited the

co-moderator and the rehabilitation counselor to watch the videos and look for the gaps in the data.

3.7 Role of the Researcher

In this study, I played numerous roles, including that of researcher, focus group moderator, Ethnodrama playwright, and doctoral student. Because of my wide range of roles, all of my field notes, journal reflections, and careful examinations of my presence as researcher proved critical in guiding and evaluating my role as the researcher. I titled my dissertation "Desirable Conversations" because I wanted to create an acceptable phrase for the conversations about sexuality that are often concealed. From the moment of entering the field for the recruitment of participants up to the last day with my interview participants, I experienced quite a journey.

Desirable conversation—I used this operative metaphor intentionally to release the caged voices of desire, need, and passion, and to provide opportunities for the women involved in my study to move beyond restrictive presentations of the conjunction of sexuality, gender, and intellectual dis/abilities. *Desirable Conversations* is unlike like anything I have ever done in my life. As a woman who was raised in a middle-class conservative family, conversations about sex and sexuality were not seen as desirable. Hence, it was imperative for me to identify my work as *desired* because it is my understanding that everyone is a sexual being and it is important to recognize and honor our sexual identities.

As a qualitative researcher, I write about my experience as one that was heartfelt; this experience reminded me of the value of love, care, acceptance, and simply trust. To

provide greater clarity, this section, role of the researcher, is divided into several

subsections. In the first subsection, I present my role in *selecting a methodology*. After

that, I present my role as researcher looking for participants in the recruitment stage of

the research. In the third subsection, I present my roles as *interviewer and moderator* of

the focus group discussions, and in the final subsection, I present my role as *data analyst*.

I realized that at every step of this research, a piece of me was involved at both a very

subtle level and at the same time, in an overtly concrete manner.

Selection of the Methodology

Being a qualitative researcher is being an instrument of research (Janesick, 2009)

it requires being qualitatively involved at every step of the study while keeping personal

biases and preconceptions in check (Maxwell, 2008). I intentionally used Ethnodrama

because theater is my passion, and I believe theater is a very strong tool to connect with

people while conveying a social message (Boal, 1995). It can create an unspoken bond

among group members and facilitate conversation about topics that may be considered

taboo. Also, Ethnodrama as a methodology compelled me to stay connected with my

feelings, unbiased objectives, and tacit experiences; it also helped me maintain the ethical

stance necessary for a qualitative study.

Besides my personal connotations of the power of theatre, interdisciplinary

research scholars see Ethnodrama as an important methodology that has an artistic

purpose. The core obligation for the playwright—to create a unique, insightful, engaging

text about the human experience—is similar to the core obligation of a qualitative

researcher writing a research report (Saldaña, 1999).

Recruiting Process

The recruiting process was challenging yet full of positive affirmations that kept me moving ahead in my study. Although recruiting participants was a difficult journey, I felt supported by those who believed in my work. I was told that I was on the right path both in terms of the study as well as the methodology I used for this research. I was reminded that this work is important—that it needs to be brought to larger audience and should not be limited to the academic world. Positive affirmations kept me going, but overcoming the intimidation of the recruitment process was difficult.

I was told by one of the caregivers that "no one wants to talk about sex in this country—and especially [not] for this population." She then wished me luck on my research, adding that I was "really courageous." I found that I was seen as a bold Indian woman who was trying to talk about sex with people who are either seen as nonsexual, seen as not needing to be sexual, or are viewed as being overtly sexual.

Although people were giving me their best wishes for my study, after 3 months of constant recruiting, I had yet to secure one participant for my study. Whether through serendipity or perseverance, I was finally able to meet with organizations who believed in sexuality rights as human rights for individuals with intellectual disabilities. I did so by putting myself and my research on center stage. After spending 3 months and failing to recruit any participants, I started inviting myself to the staff meetings of various organizations like Self-Determination Resources Inc., Independence Northwest, and Community Vision. I decided to share my personal story and present myself in front of strangers who work with individuals with intellectual and developmental disabilities. It

was extremely difficult to share parts of me that I do not like to reveal openly; I felt

naked and very, very vulnerable. But I did it. I revealed a very personal part of myself to

show that any potential participants could trust me. My personal story and a commitment

as a researcher connected with these organizations. They were genuinely interested in my

work, and they wanted to do their best to help me reach those who would be interested in

participating in my study.

Even though I understand that I didn't have to share my life's journey and

connection with sexual abuse, vulnerability, and intimidation that is what I chose to do. I

am not sure if it was the right thing to do as a researcher, but I felt it was the right thing to

do at that time. I wanted people to trust me instead of potentially seeing me as someone

selfishly trying to hear others' personal stories and thoughts simply to complete an

academic report.

I also decided to host several informal coffee dates with caregivers, mothers of

young women with intellectual disabilities, and with anyone whom I thought would help

me. Eventually, I started getting responses, and people wanted to help me connect with

potential participants. Most of the time, I had positive experiences, but there were rough

patches as well. At one point, one of the mothers said that it seemed like I was "doing

good work," but that this study was "not for [her] daughter. No, thank you!" There were

also mothers who wanted their daughters to talk to me, but their daughters were not

ready. One of the mothers said, "I am glad I met you in person . . . After getting your

flyer, I was not sure if I [could] trust some researcher to talk to my daughter on such a

sensitive topic." I was not trusted as a researcher, however my identity as a woman was

trusted. This made me think that one possible reason for the dearth of research into sexuality, women, and intellectual disabilities is the means of gaining access to participants, with access hindered by mothers, caregivers, and issues such as social environment, living situation, understanding about sexuality as mediated by the severity of intellectual disability, and the role of familial culture.

Interviewer and Focus Group Moderator

I kept a researcher's journal to reflect on my own ideas that resulted from interacting with and listening to participants during interviews. As a researcher, I did my best to keep my personal biases and responses in check when talking to participants. Yet I still found myself becoming cautious, concerned, terrified, emotional, and even petrified when the term *sexual abuse* would emerge during individual interviews. However, I didn't let those feelings show in front of my interviewees. Instead, I would return home and journal until I could find clarity with regard to my feelings. I felt that this journey through the dissertation process was not just an academic requirement or a chance to talk to many fascinating women, but an opportunity to examine and break free from my own fears.

Playwright

To ensure that I was taking the right steps and correctly employing my chosen methodology, I took courses in scriptwriting with Karen Magaldi at PSU's[20] theater department. I took a yearlong series of courses to ensure that I learned both the art of playwriting and how to read and perform a finished script. I also took classes on the

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[20] In an effort to protect the identity of participants, I have used the abbreviated name of the university.

Theater of Oppressed (Boal, 1995) and began exploring how I could use the skills I

learned in these courses. I also connected with Dr. Johnny Saldaña, who teaches

Ethnodrama at Arizona State University. Dr. Saldaña generously shared resources I could

use to learn the art of scriptwriting as a qualitative researcher. I used these skills to curate

the script and as a data analysis process as well.

3.8 Data Analysis

Figures 3.9 and 3.10 present the step-by-step data analysis process. Figure 3.9

presents the initial analysis of the data that includes transcription, data validation, and

data organization. After completing the interviews and reviewing the transcripts with

Colleagues to validate the data, I began the initial analysis by completing a close read of

each transcript. After the data was organized and uploaded to Atlas.ti for analysis, I

looked for clues into possible codes and themes. Figure 3.10 is adapted from Saldaña's

(2011) coding manual. Saldaña wrote that data coding is cyclic in nature and that it

involves numerous steps to familiarized oneself with the data to form a connection and

look for pattern that emerge from the themes.
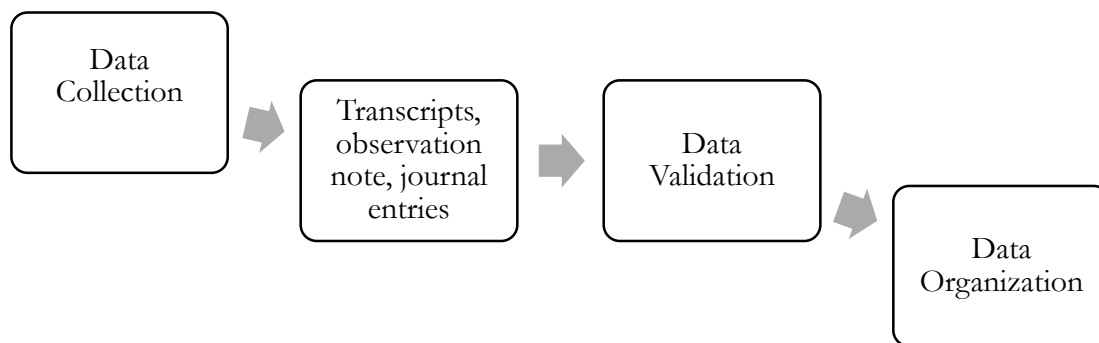
Figure 3.9. Initial steps in data analysis.
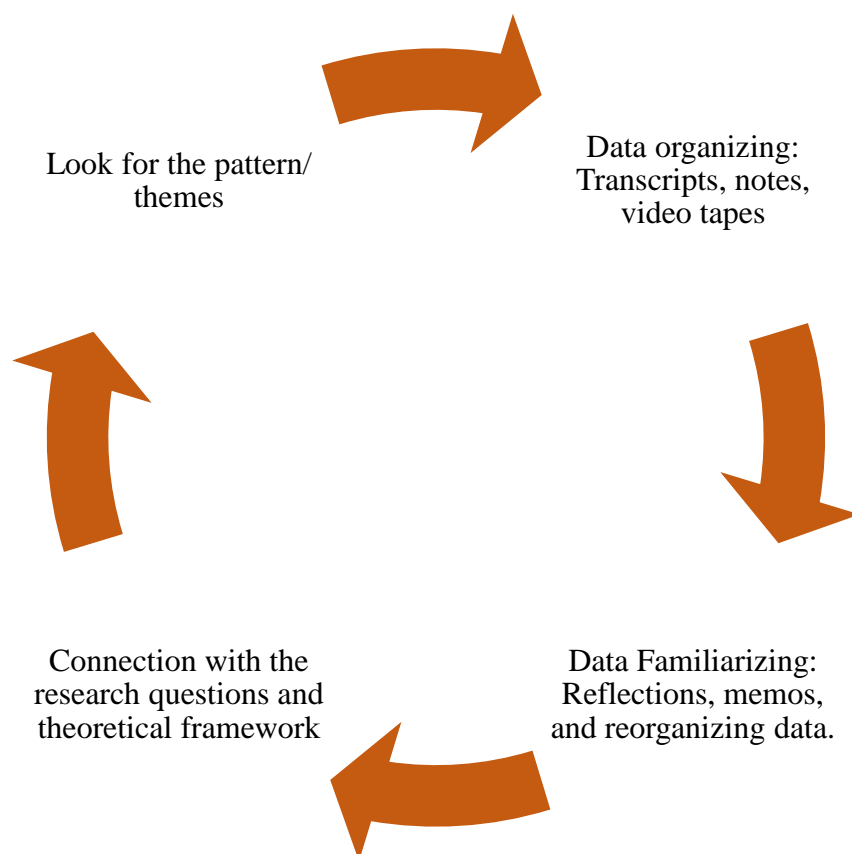
Figure 3.10. Data coding process.

The process of data analysis involves not just labeling the data but finding the links between the data points. The data for this study was analyzed for two purposes. One, to get a deeper conceptual understanding of the influence of the familial culture in understanding sexuality by young women with intellectual disabilities. The second purpose was to create an Ethnodrama. To create a conceptual framework, the entire data set was coded using an open coding method known as in vivo coding[21] (Charmaz, 2006b; Corbin & Strauss, 2008; Glaser & Strauss, 1967).

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[21] In vivo coding is also known as verbatim coding or literal coding. *In vivo* means "in that which is alive," a term used by participants themselves (Strauss, 1987, p. 33).

Conceptual Understanding of Data

Charmaz (2006a) suggested that a researcher must perform several rounds of reading and paying close attention to participants' words to find an emerging pattern. I wrote extensive memos and selected quotations from the transcripts that were associated with my research questions. In the qualitative data analysis method, this process is referred to as coding.[22]

Saldaña (2009) emphasized that after initial analysis (Figure 3.9) and reading the transcripts several times, the researcher must follow up with at least two rounds of data coding in order to thoroughly analyze the data. As part of the first round of coding, I employed the use of the open[23] coding method while using Atlas.ti to create memos in the transcripts. I also looked for quotations and verbatim narratives to create in vivo code. All of the resulting codes were then compared with other codes throughout all of the transcripts of individual interviews. Likewise, I followed the same procedure for analyzing the focus group interviews. Atlas.ti helped me to create links between memos and codes to identify patterns. Memos were compared across transcripts to identify themes (Figure 3.11). Those themes became the basis for my findings and conclusions.

First, the data as a whole was analyzed as a whole that gave an understanding participants' perspective as a whole. Figure 3.11 presents the process of creating themes

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[22] "Coding is the process of assigning codes to the data. A code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data. The data can consist of interview transcripts, participant observation field notes, journals, documents, literature, artifacts, photographs, video, websites, email correspondence, and so on" (Saldaña, 2009, p. 193).

[23] Also known as initial coding, open coding is breaking down qualitative data into discrete parts to do a close examination of similarities and differences found in data (Strauss & Corbin, 1998). It provides a starting point for deep and thorough analysis of data (Saldaña, 2009).

out of the entire data set. Table 3.3 explains the process of coding in data analysis stage one.
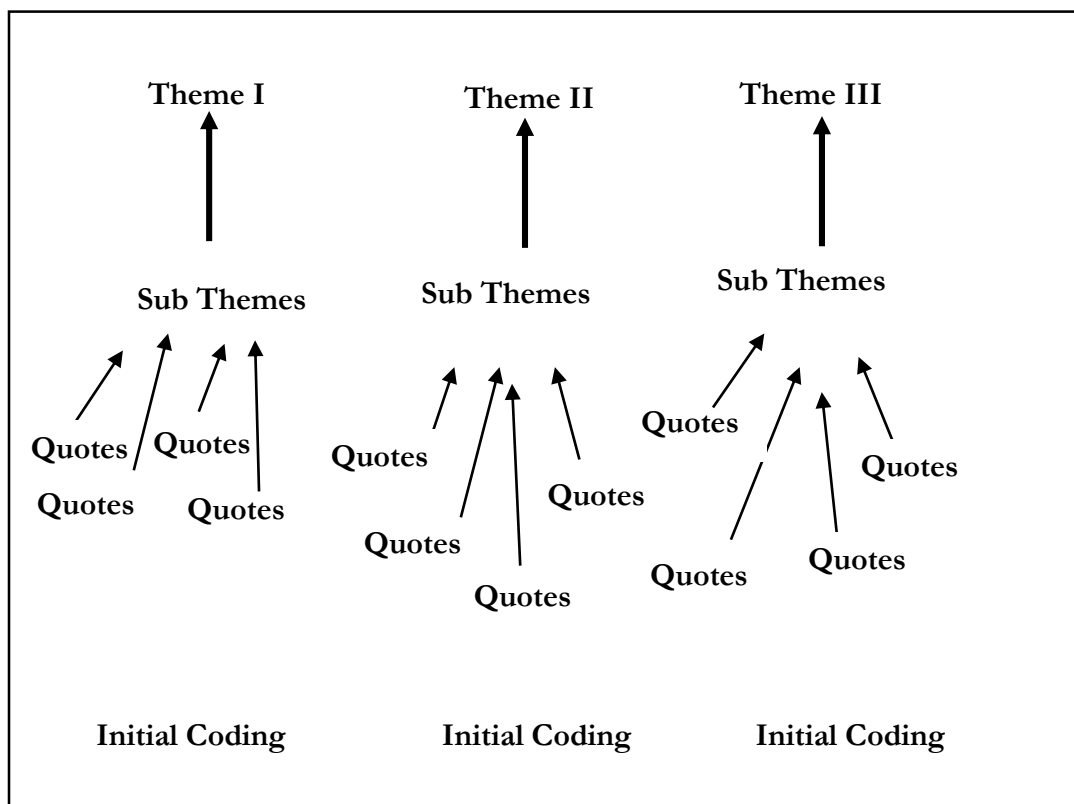
Figure 3.11. Thematic outcome.

Open Coding Methods Using In Vivo Coding

Open coding is also known as initial coding (Charmaz, 2006a). This method gave me the opportunity to examine the data line-by-line, simultaneously reflecting and processing the information (Glaser, 1978). Clarke (2005) also suggested that this method helps in looking at the non-human material elements of the social world. I used this aspect to analyze the memos, observation notes and my journal entries. Open coding methods using in vivo coding was selected for the following reasons:

- To honor the young women's voices and ground the analysis from their perspectives (Saldaña, 2005b);

- To provide a microanalysis method (Strauss & Corbin, 1998);

- To support the work of examining the "antecedents, causes, consequences, and the sense of temporality" (Saldaña, 2009, p. 103);

- To purposively serve the needs of the study and its data-analysis process;

- To align with a methodological framework.

Table 3.3

Data Analysis, Step One: Open Coding Using In Vivo Coding

Description of Process	Main tools	Input	Output	Method
Emergent themes (Saldaña, 2009)	Open coding using in vivo coding (Charmaz, 2006a, 2006b; Strauss & Corbin, 1998)	Transcripts coded to understand the data set to create a contextual understanding of the data	Themes based data organization	Step 1: Individual participant's coding Step II: Group Level Data: research Questions explored using participants' interaction
Discrete part analysis	Open coding (Charmaz, 2006a, 2006b; Strauss & Corbin, 1998)	Data divided into smaller chucks and assigned with themes	Data sorted by themes within each group	Coded charts are compiled and explored to see which code is the dominating code within the data. Grouping the data with similar codes
Close examination: Identifying themes and their causal relationships (within all the transcripts)	Open coding (Charmaz, 2006a, 2006b; Strauss & Corbin, 1998)	Data segment: Themes + supporting rationales	Drafts of Charts	Coded all the individual + 3 focus groups transcripts + observation notes
Transforming texts into themes and diagrams (Saldaña, 2009)	Causal maps (for understanding the construction of themes)	Themes to understand the data text as a whole	Drafts of Charts	Describe the meaning of the themes
Generalizing structural representation	The five themes emerged referred as the contextual framework of this study. The purpose of analyzing the entire data set was to get a deeper understating of the participants' perspectives on their understanding of sexuality.			

The iterative process helped me break down the data into discrete parts (steps two and three from Table 3.3) to closely examine each component (Strauss & Corbin, 1998). As a researcher, this method helped me to systematically structure my mind to take an analytical lead for further exploration and "to see the direction in which to take [my] study" (Glaser, 1978, p. 58).

Using Braun and Clarke's (2006) thematic analysis process, all the codes were organized within the five themes: (a) vulnerable/vulnerability, (b) credible/credibility, (c) access/accessibility, (d) self-determination, and (e) self-compassion. These five themes that emerged out of the first step of data analysis are presented as the contextual framework that describes the participants' understanding of sexuality. The Table 3.4 provides a summary of the major findings that emerged out of this stage of the data analysis. It also provides a brief synthesis of the findings, and the connection with the relevant literature or theory reviewed in chapter 2.

The purpose of step one of analyzing data was to have a conceptual understanding of the data as a whole. However, since the methodological framework of this study was Ethnodrama, these themes are not seen as the final results of the study.

Table 3.4

Summary of the Conceptual Themes: Data Analysis Step One

Major Findings	Brief Synthesis of the Findings	Connection to the Reviewed Literature for This Study
Theme 1: Self-compassion This theme described Participants': • Self-affirmation, • Kindness toward oneself, • Acceptance and kindness toward past life experiences, sexual abuse, and experiences of being a woman with intellectual disabilities.	Findings from this study suggest that self-compassion is the core context that helped most of the participants to cope with their Post-Traumatic Stress related to sexual abuse and the fear of sexual abuse. Findings indicated that self-compassion helped them to move on with their life. Findings also indicate that participants were compelled to remind each other about self-care and to voice their fear. For example, Oprah said, "At one point of my life, I was not what I saw in the mirror, I didn't like myself. but now, I am happy with who I am…I am, I have this disability and it's like God has helped me to accept it and he gave me this boyfriend, who is like me, he has disability as well. I always wanted someone who is educated, and this and that, you know the one who doesn't have disability, but I have accepted him for who he is and myself as who I am . . ."	Neff (2009) explained that self-compassion is relevant when considering personal inadequacies, mistakes, and failures, as well as when struggling with more general life situations that cause us mental, emotional, or physical pain. She further adds that self-compassion is a way of being which helps people be less self-critical and more self-accepting, particularly during difficult times.

Table 3.4 (continued)

Major Findings	Brief Synthesis of the Findings	Connection to the Reviewed Literature for This Study
Theme 2: Self-determination This theme described participants': • Expression of making choice, creating boundaries, • Expression of identifying their own disability as a different way of living instead of taking it as their weakness.	This finding indicated that participants were well informed about their own difference in understanding and skills to approach daily life's needs. This finding is directly connected with the influence of their families. However, participants also indicated that they learned from their own life's experiences informing. Participants informed that their disability is a way of living with different abilities. For example, Berne said, "My friend says you're just so kind to everybody that you just don't know that there are those out there that would hurt you. I told her that I'm not stupid I know that there are some weirdos out there . . ."	Wehmeyer (2002), Lee and Wehmeyer (2004) and R. L. Taylor, Richards, and Brady (2005) mentioned that the definition of self-determination is the act of person as the primary causal agent in life and their choices, and making decision, which achieve better quality of life, without any external impact or intervention.
Theme 3: Vulnerable/ vulnerability This theme described Participants': • Narration of helplessness and the *fear* of being raped, • Expressions of fear of approaching somebody, for romantic relationship. • Expressions of fear of approaching sex.	The findings of this study point to the participants' experience of vulnerability associated with sexual abuse, besides being vulnerable in reaching out to find a partner and a romantic relationship; however they reminded each other for being kind to oneself. For example, Ross said, "I think that every girl . . . I mean and how you how you present and how you . . . I mean how you say things that may not come out at . . . for example . . . it's kind of like saying, think about it's just don't say it."	Women with intellectual disability are disproportionately vulnerable to victimization, abuse, exploitation and harm. Statistics suggest that the majority of women with intellectual disability experience sexual assault and exploitation by age 18 (McDonald & Richmond, 2008) Women with intellectual disability are particularly vulnerable to multiple forms of violence, abuse and exploitation in the home, community, institutions and workplaces (Frohmader & Meekosha, 2012).

Table 3.4 (continued)

Major Findings	Brief Synthesis of the Findings	Connection to the Reviewed Literature for This Study
Theme 3: Credible/credibility This theme described Participants': • Description of being denied or rejected for their decisions regarding sexuality, • Expressions of distrust regarding their choice and experience, • Dependence upon mother or caregiver.	The study also informed about the dependence on caregivers or mothers to make choice and future decisions. For example, Anna said, "I can make my own decisions, I want to live with my boyfriend . . . I don't need my mom's help to make my own decision, but she does . . . [make decisions for me on daily basis[24]]."	McCarthy (2010) found that women with intellectual disability are routinely denied choice and autonomy over decisions regarding sexuality and fertility, and are not provided with accessible information to make informed choices.
Theme 4: Access/accessibility: This theme described Participants': • Expressions of dependence on their mother and caregivers to access potential dating partners and sexual relationship.	This finding point out that participants needed permission, and even assistance to access an opportunity to date, indulge in friendships, and even have sex because of their need for assistance from their caregiver, which are the signs of a corporeal dependency. For example Berne said, "I want my prospective partners to meet my mom . . . My provider is a little cooler than my mom . . . and don't do . . . and spending all the time with your parents is not cool."	Goodley (2014), Tepper (2000, 2005) and other disability studies scholar indicate this as the root cause of the lack of freedom for individuals with intellectual disabilities to enjoy a holistic life that include sexuality, romance and relationships.

Data Analysis for Ethnodrama (Step Two)

The second purpose of the analysis was to analyze the data to address the research

questions of this study and create Ethnodrama. I reread the interview transcripts and used

Saldaña's (2009) dramaturgical coding in the second cycle of the analysis. In

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[24] This extension of the sentence was added based on Anna's words that her mother make most of her decisions every day. She tells her what to do and where to go and Anna follows what her mother tells her to do.

dramaturgical coding, coding is done line-by-line using a combination of in vivo and gerund codes. Each line that was already coded was assigned a secondary code to reveal the perspectives, motives, and conflicts of the participants. Saldaña (2009) wrote that dramaturgical coding is based on a system of exploring the interpersonal and intrapersonal interactions between the participants in the group setting. Saldaña further wrote that this coding method provides a deeper understanding of how participants interact and manage themselves within the social setting, present their conflicts (CON) with each other, and convey their objectives (OBJ), subtexts (SUB), attitudes (ATT), emotions (EMO), and tactics (TAC). Table 3.5 presents the ways dramaturgical coding is used in the data analysis process.

Table 3.5

Data Analysis, Step 2: Coding Process Using Dramaturgical Coding

Codes	Description	Example From Interview	Methods of Analysis
Objectives (OBJ)	Motives in the form of action words (verbs)	"It's difficult to find a date."	OBJ EMO and SUB associated with OBJ Sorted the ATT and connected with the OBJ, EMO, and SUB Looked for CON and connected with TAC
Conflicts (CON)	Confrontation of conflicts that prevents her to achieve her objects	""It's not easy as it sounds."	
Tactics (TAC)	Strategies to deal with the conflicts	"I met someone with my mom . . . but, you know . . ."	
Attitudes (ATT)	Attitudes toward the setting, others participants or other and the conflict	"It's frustrating."	
Emotions (EMO)	Emotions experienced by the participant	"They see my wheelchair first."	
Subtexts (SUB)	Unspoken thoughts or impressions in the form of gerunds	"I am going to the singles' social organized by my religious group (I am a pagan)."	

Dramaturgical Coding

Saldaña's (2009) dramaturgical coding is based on the perspective that life is a

performance—that every individual is playing a character who communicates with other

characters, and that these characters must achieve objectives, engage in conflicts, and

devise tactics to deal with conflicts, all while displaying a variety of attitudes and

emotions toward their situation; in particular, their attitudes and emotions are expressed

through unspoken thoughts or impressions in the form of gerunds. This form of coding

helped me dig deeper into an individual participant's character and their interactions

within the group. The process of comparing and finding the contrast within the

individual's objectives, conflicts, tactics, subtexts, and attitudes as actions and reactions,

helped provide a deeper understanding of "power relationships and the process of human

agency" (Saldaña, 2009, p. 124). This process helped in organizing the data to address the

research questions for this study. Here are additional reasons why I incorporated this

coding method into the second-stage data analysis process:

- The data set can be transformed into a theatrical script, deliberately presenting participants' objectives, conflicts, and other pre-determined codes (Saldaña, 2011). The research can be recrafted into verbatim monologues or an on-stage group conversation (Chang, 2005).

- Stories culled from interviews are used to present as a project for transforming a community's paradigms about oppressive concepts into a social drama (Denzin, 2003). Since I am using a transformative research paradigm, I found that this coding method helped me craft the script from both individual and focus group interviews alike.

Throughout the process, I used constant comparative methods (Glaser & Strauss,

1967). At first, I compared different sets of data to find similarities and differences. For

example, interview statements were compared with other interview statements or experiences that were mentioned; experiences were also compared with other experiences. After coding the interviews, I examined the data to explore commonalities and generate categories based on pattern-shared characteristics (Saldaña, 2009). To get a holistic understanding of the data, I organized data around themes that were generated from the literature review, research questions, interview content, and overall purpose of the study. When coding line-by-line, I also watched the interview videos to look for meaningful silence, elusive elements of emotions or subtexts, and changes of voice that signaled a change in emotion or less obvious subtext. I reread transcripts several times to see if there was any note of the emotions present during the conversation.

Carspecken (1996) wrote that the meaning of the action is not always presented in the language—it is mostly presented in the action itself and in the person's bodily states. Carspecken adds that as a critical ethnographer, it is important to take careful note of the subject's body language. In keeping with this observation, the video recordings played an important role in understanding participants holistically. I relied heavily on the videos because my process involved coding for embodied signs of emotions and subtexts. In fact, I had to watch the videos several times to make sense of each participant's manner of speaking during both individual interviews and in the focus group conversations.

Delineation of Dramaturgical Coding

After doing the data coding for the conceptual understanding, I documented, transformed, and dramatized the qualitative data that described the participants'

experiences (Denzin, 2010; Saldaña, 2005a 2005b, 2009). I conducted data analysis to create an Ethnodramausing Saldaña's (2011) dramaturgical coding method.

First, significant statements were identified from all data sources: verbatim interview transcriptions, personal journals, participant observation field notes, and audio recorded sessions. Then, after reviewing significant statements several times, possible themes were noted, identified using in vivo coding, and compiled; meanings were also formulated. Statements that supported themes were then prioritized, and statements that were too weak to support themes were eliminated. Finally, dramaturgical coding was applied to the themes denoting participant objectives, conflicts, tactics, attitudes, emotions, and subtexts (Saldaña, 2011).

Participants' verbatim narratives were used to present the final themes emerged from the data analysis process: (a) "I am comfortable with who I am," (b) "I love my mom," (c) "I feel kind of sexual," and (d) "He raped me." These themes are presented in the results section (chapter 4) to address the two research questions of this study.

The Table 3.5 is a summary of the themes that emerged out of this stage of the data analysis and its connection with the Ethnodrama. The table also provides a brief synthesis of the findings, and connection with the contextual framework of the study created out of data analysis stage one.

Table 3.6

Summary of Ethnodrama Themes: Data Analysis Step Two

Major Finding	Brief Synthesis of the Findings	Connection With Ethnodrama
Research Question 1: What is the role of familial culture in addressing sexuality for young women (21-35 years) with intellectual disabilities?		
Theme 1:I am comfortable with who I am This theme represented participants' understanding of themselves and their bodies: • Choice and boundaries • My body feels good • Rejections are part of the game: There are more fishes in the sea • I love myself just way I am.	This finding reports to the participants' understanding of themselves as women with intellectual disabilities in connection to their understanding of sexuality. This finding also points out the connection of their living situation with what they learned from their mothers regarding what it is to be a woman.	This theme helped in created two acts as part of the Ethnodrama (see Appendix Q). The reader's theater based script emphasized the women's understanding of choice and boundaries, one's body, and concept of rejection.
Theme 2: I love my mom This theme represented participants' relationship with their mothers and what they learned from them: • I learned from her . . . • She said, welcome to adult world! • My mom and my sister are my friends	The findings inform about the participants relationship with their mother and the role she played in their current understanding of sexuality as an adult. Also, three participants shared their experience of the absence of their birth mother while growing up and the influence of foster mother on their own understanding of sexuality.	This theme helped in creating interactive dialogues where the narrators talk about their mothers and what they learned from her. The narratives from the participants are used to create a dialogic interaction on this theme.
Research Question 2: How do young women (21-35 years) with intellectual disabilities describe their understanding of sexuality?		
Theme 1: I feel kind of sexual This theme represented participants' understanding of sexuality, gender, sex, and masturbation: • Sexual Pleasure • Masturbation: I feel comfortable • You always have to act like a woman	The findings inform that participants felt comfortable talking about their sexual desires, fantasies and experiences. The findings also inform about participants' understanding of being a woman who has sexual desires and how it interweaves with their understanding of sexuality. Participants also shared what they learned about being sexual while growing up.	This theme is used as monologues as well as an interactive dialogue by using women's verbatim script as part of the Ethnodrama.

Table 3.6 (continued)

Major Finding	Brief Synthesis of the Findings	Connection With Ethnodrama
Theme 2: He raped me This theme represented participants' experience and fear of sexual abuse: - I think I was raped - I am scared of being raped . . . - Safety and prevention	The findings inform that participants felt vulnerable to sexual abuse. Three out of eight women experienced sexual abuse in their life. However, the other participants shared that they have a fear of being raped and sexually abused. This aligns with the past studies on sexual abuse experienced by adults with intellectual disabilities that 87% of adults with intellectual disabilities are sexual abused.	Like above, this theme is also used as monologues as well as an interactive dialogue by using women's verbatim script as part of the Ethnodrama.

Ethnodrama

As part of the data-analysis process, I have created an Ethnodrama (see Appendix N). This process helped me create a verbatim theatrical script aimed at answering my research questions. Participants' narratives were organized into themes to address the two research questions posed for this study. The themes developed using the thematic analysis process adopted from Braun and Clarke's (2006) in data analysis stage two process are: (a) "I am comfortable with who I am," (b) "I love my mom," (c) "I feel kind of sexual," and (d) "He raped me." These four themes are used to present the data analysis of the study. A detailed description is given in chapters 4 and 5.

3.9 Focus Group Attrition and Management

The first focus group was attended by seven participants, the second group was attended by four participants, and the third group was attended by three participants. Most of the literature analyzing focus group data (e.g., Krueger, 1994; Merton et al.,

1990; Morgan, 1996, 1997; Stewart, Shamdasani, & Rook, 2007; Strauss & Corbin, 1994) talks primarily about the ways of seeing data in different sets (individual as well as group sets) instead of simply missing or excluding data. This applies to the data that result when some group participants choose not to answer any one question out of a given set of questions. That person is still included in the data set.

Also, this section presents the methods used to look for apparent agreement, coercion, and self-censoring ways that participants used who had alternative viewpoints (Carey & Smith, 1994; Sim, 1998). However, I used the group conversation as the "focus of analysis" as described by Kidd and Parshall (2000, p. 299). Kidd and Parshall suggested that by considering group conversation as a "focus" of analysis instead of a "unit" of analysis, the researcher facilitates an unbiased conclusion when looking at the individual or group data before the making their final analysis. This process helped me look at the groups' perspective, meaningful discourses, and conflicting viewpoints (Morgan, 1995).

The conversational style used by the women in all three focus group discussions was synchronized. In other words, all of the group participants were engaged in back-and-forth conversation among themselves, showing agreement and disagreement with one another's perspectives and opinions. The free write activity before each discussion facilitated this level of engagement. Free writing allowed participants to prepare to share their own voice and then integrate their voices into the group's shared perspectives. The synchronous data allowed me to code the raw data in its original form as a reflection of the group's perspective.

One Group Versus Many Groups

Even though the themes of every focus group interview were independent from one another, there were intersections between these themes, and each discussion ended up as a subgroup of a bigger group.

Theatrical Script/Ethnodrama

An Ethnodrama is a performance script created out of qualitative research data. The process of creating the script (see Appendix N) provided an opportunity to not only craft a script that can be performed by professional actors but also helped me, after numerous memos and vignettes, to understand the participants on a deeper level (Erickson, 1986). Table 3.5 presents a comparative chart of the similarities and differences in the methodologies used to present study results.

Table 3.7

Similarities and Differences in the Method of Result Presentation

Data Analysis: Emergent Themes as Verbatim	Data Analysis: Theatrical Script
Similarities	
• Themes categorized and presented as verbatim present participants' voices as they shared during the interviews. • Data results are presented ethically with an aim to present the understanding of the context (research questions) of the study. • The data is presented and published in peer-reviewed journals.	• Research-based theater that aims to "remain true to the informants who contribute to our research" (Mienczakowski et al., 2002, p. 34). • Ethnodrama aims to communicate research findings, remain faithful to primary research subjects, and present questions that maintain the veracity of the data. • The performance is presented as an interactive performance with the audience. This interaction serves pedagogical and research purposes. Also, the script is published in peer-reviewed journals focusing on qualitative research and art-based research.
Differences	

Table 3.7 (continued)

• Results are limited to academia. • Result presentation is within academic journals.	• Can reach larger audiences through interactions with and performances in community theaters. • Results are presented within academic journals as well as theatrical presentations.

3.10. Credibility

I increased the credibility of the study by triangulating the data collection methods and analytic techniques (Lincoln & Guba, 1985). Using individual interviews, focus groups, observations, and journal entries, I ensured that I mitigated personal biases to increase the credibility of my study (Maxwell, 2005). Since I had a co-moderator and student counselors present during the focus group meetings, I was able to enlist their help in validating data by having them watch all the interview videos and provide me with their observations of the data. This assistance also provided transparency in the analytic process (Lincoln & Guba, 1985). Additionally, the small sample size of the group allowed for deep, rich, data-gathering opportunities.

3.11 Summary

The purpose of data collection, transcription, data analysis and creating an Ethnodrama was primarily to explore the role of familial culture in the understanding of sexuality by young women with intellectual disabilities. The secondary focus of this study was to explore the understanding of sexuality by young women with intellectual disabilities.

Thorough consideration of the researcher's positionality was given to reduce personal biases at every stage of this study (Patton, 2002). Ethical considerations with oversight from the IRB took into account the potential risks participants might have experienced. An informed consent procedure was used and steps were taken to secure confidential data and participant privacy. The data collection process consisted of open-

ended individual interviews with eight participants and three repeated focus group

interviews with seven participants. Each interview was videotaped, audio recorded and

transcribed. After the interviews were transcribed, data validation for the individual

interviews and focus group interviews was performed by me with the help of student

counselors and the co-moderator of the focus group interviews. The data analysis used

two stages of data coding and was presented as themes and a verbatim theatrical script

(Saldaña, 2009, 2011).

CHAPTER FOUR

ANALYSIS OF RESULTS

4.1 Introduction

The purpose of this dissertation research was to explore the role of familial

culture in the understanding of sexuality by young women with intellectual disabilities.

Additionally, the purpose of this study was to examine the understanding of sexuality by

young women with intellectual disabilities through their current life experiences. Using

performative ethnography, also known as Ethnodrama,[25] the study involved individual as

well as three repeated focus group interviews. Interviews were mainly conducted in a

university classroom, however, a few individual interviews were conducted at the

participants' convenience off-campus.

This study drew upon data to address two research questions. Those questions

were: What is the role of familial culture in addressing sexuality for young women (21-35

years) with intellectual disabilities and How do young women (21-35 years) with

intellectual disabilities (describe their understanding of sexuality?

4.2 Analysis of Data

I analyzed and interpreted the data using a social model of disabilities created out

of critical disability theory informed by the work of disability studies scholars such as

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[25] Saldaña (2005b) described Ethnodrama as a dramatic script that is crafted out of significant selections of interview narratives, observation, field notes, journal articles, diaries, media articles, and even court proceeding. The purpose of using Ethnodrama for this study is to expand the research and disseminate in the manner that it's reachable to everyone. Also, this playwriting process of Ethnodrama also served as a framework to organize the themes of this study.

Shakespeare (1999a, 1999b, 2002) and McRuer (1993). Additionally, I used strategy for analyzing qualitative data described by (Charmaz, 2006a; Corbin & Strauss, 2008; Glaser & Strauss, 1967).

First, I transcribed both individual interviews and focus group discussions and initially sorted the data. Through repeatedly reading the transcripts, I became immersed in the data. I then coded transcripts line-by-line and generated themes, offered interpretations, searched for alternate explanations, and finally, I drafted the final report. In the following sections, I will describe these steps in great detail.

Data Analysis

As discussed in chapter 3, this study involved two distinct steps in data analysis. I employed the use of a coding software program, Atlas.ti ™, and I manually coded the interview and focus group data using Excel spreadsheets. Using the Altlas.ti ™ software in tandem with the Excel spreadsheets allowed me to apply constant comparative analysis to all of the coded transcripts data and to collapse the sets of initial codes across the entire data set into a set of final themes.

Thematic Analysis

The first step of data analysis was done to create a conceptual understanding of the data. For this purpose, the entire data text was first coded to obtain a deeper understanding of the data as a whole. The coded data was organized into the following themes: (a) vulnerable/vulnerability, (b) credible/credibility, (c) access/accessibility, (d) self-determination, and (e) self-compassion. The series of steps involved in creating the

conceptual framework of the study helped me to acquire a deeper understanding of the data. It also provided me with a broader perspective of participants' narratives.

In step two of the data analysis, coded data were organized into themes to inform the research questions. To do this, I created links between memos and codes to identify patterns and collapse the set of initial codes into final codes (refer Table 3.4). Findings from the individual interviews, focus group interviews, observation notes, and the journal memos entries are incorporated throughout this chapter to substantiate the themes that emerged from this set of final codes.

After employing the second step of data coding using the dramaturgical coding approach, I used participants' verbatim narratives to represent the final themes emerged from the data analysis process: (a) "I am comfortable with who I am," (b) "I love my mom," (c) "I feel kind of sexual," and (d) "He raped me." This was done to honor the voice of the participants. In the next section, I further explain how this analysis was employed which aligns with dramaturgical dialogic analysis.

Dramaturgical Dialogic Analysis

I employed in vivo coding and then dramaturgical coding to look for themes that emerged out of the data gathered from the participants' lived experiences and how they make meaning of those situations.

As a researcher, this process of exploring the participants' dialogues using the two-step process of data analysis assisted me in the process of analyzing the data closely. This iterative approach also helped me to maintain the authenticity of the participants' perspectives as I interpreted their narratives. In addition to presenting the data

thematically, the data is also presented as an Ethnodrama as a means to maintain the speakers' authentic voices and expressions and further create a dramaturgical script (see Appendix Q). This Ethnodrama served as a framework to explore the interactions between the study participants as well their interaction with me as a researcher. I used this methodology to buttress justification for the themes that emerged out of the data based on the works of Goldstein (2008), T. C. Turner (2008), and Saldaña (2003, 2011).

To create the Ethnodrama, I selected excerpts from the raw transcripts to include as part of the script to showcase of the research participants' life stories as possible within the confines of this dissertation study. Furthermore, I have selected excerpts to showcase themes that unfolded throughout the study and informed the two research questions.

Riessman (2008) claimed that interaction such as the one just described reflects the identity of the participants and provides them with opportunities to demonstrate who they are, how they speak, how they interact with others and react to the experiences of relating their own stories and their reactions to the other participants' stories. In chapter 5, both set of themes are used to explain the synthesis of the study.

Before discussing the interview findings, I offer background information about the participants in this study by providing a brief biographical sketch of each participant. I have assigned pseudonyms to each of the participants in order to protect the confidentiality of the eight young women who were involved in this study.

4.3 Participants' Description

Anna

Anna is a Biracial (African-American and white) American who is 24 years of age who currently lives with her mother, a single parent. Anna often spends time with her father during the weekends. Anna is currently involved in an intimate romantic relationship and has experienced three prior romantic relationships. Anna's mother shared that Anna has a moderate to severe level of intellectual disability and that she experiences seizures on a regular basis, for which she is on medication.

Although Anna does not hold a fulltime job, Anna walks her neighbor's dog and receives a financial stipend for her work. This is not a job she performs on a regular basis, nor does she hold any other form of employment. However, she walks dogs whenever she gets an opportunity.

Anna experiences recurrent dreams of being kidnapped and raped in a white van, but she understands that this is only a dream. She said, "Oh, I know it's just a dream, but it's a recurrent one, I get scared to an extent that whenever I see a white van, I get scared."

Anna described herself as someone who has demons that will go away if she is baptized again. In her words, "I will be able to drive my own car and have my own house to live with my boyfriend, after I am baptized."

She thinks that there is something wrong with her, but she claims that she loves herself just the way she is, irrespective of the fact that she is dependent upon her mother

for most of the activities of her day. On asking about what is sexuality, Anna said, "Sex is like having fireworks inside me."

As a researcher, I observed that she behaved differently in front of her mother and when she was alone in the room for the interview. When she was alone she presented herself as a young woman talking about an important topic. However, when she stepped out of the room where the interview took place and saw her mother waiting for her, her behavior was more childlike than it was during the interview.

At the time of the recruitment process, I met Anna's mother and spoke with her about Anna's participation in the study. Her mother said, "are you sure you want to talk to her? She may not give you the information you are looking for, she lives in her own fantasy most of the time . . ." and then she laughed. Anna participated only in the individual interview.

Ross

Ross is a Caucasian young woman with Down syndrome who is 22 years of age and currently lives with her parents. Ross shared that she is very close to her mother and sister and that she feels comfortable talking with them about sex and sexuality. She added, "I am close to my father too."

Ross stutters while she talks most of the time. She is very cautious of her word choices and often pauses to reflect before saying anything. She finds an outlet for communication through dance and refers to herself a dancer. She related that she thinks of herself as a passionate person who performs with her dance group whenever she gets an opportunity.

Ross is currently involved in a romantic relationship and claims that she loves her boyfriend. She said, "With my disabilities, it's better to be with a man than a woman." "Sex is fine, I am happy even if I am single, I have my mother and my father."

At the time of the interview, she was looking for jobs at a grocery store. On the last day of the interview she said, "Someday I want to get married but first I need a job, then get my own apartment, and then I will get married. Got to take it slow. I have made many mistakes in the past, now I want to take it slow."

Ross was one of three participants who attended all the interviews. She attended one individual and three focus group meetings.

Lilith

Lilith is a Caucasian woman with Down syndrome. She was 29 years of age at the time of the interview. She lives with her mother and her mother's boyfriend, whom she addressed as her stepfather. Lilith seems like she is someone who was raised in an elite family based on the clothing she wears and her sentence, "my father owns a shoe store and that store is in my name. I am famous. If you want discount, give my name when you visit *my* store." She is very well versed with the socially appropriate manner of greeting someone. She is extremely polite and wants to ensure that she is following what you are saying.

Lilith describes her disability as, "my body had Down syndrome." Her speech is not very clear, however, she does communicate with confidence. She is learning to be a belly dancer and is part of a group that performs adaptive belly dance.

She shared that she has a deep desire to get married, have kids and have a happy life. Lilith is in a relationship with a man who also has Down syndrome and lives in California. However, Lilith disclosed that she has a fear that she was sexually abused by her boyfriend. She said that she has shared this fear with her mother, but does not want to share this fear with anyone else as she doesn't want to hurt her boyfriend.

Lilith attended most of the interviews. She participated in one individual interview and two focus group meetings.

Oprah

Oprah is an African American woman who was 28 years old at the time of the interview. Her mother is currently incarcerated and so her grandmother has adopted Oprah as a foster daughter.

She thinks that her "mother" [grandmother] and her aunt teach her to live by example and faith. Oprah has a strong faith in her religion and she is dedicated to following her family's traditional faith. She refers to herself as a practicing Christian. In addition to pursuing religious experiences, she has also attended community college for few classes.

Oprah is in a relationship with a man with a disability. She said, "He is like me, I think it's the best." She works at the same place where her boyfriend works.

Oprah was brutally sexually abused by her mother's boyfriend when she was nine years[26] old. As reported, she was also involved in making sexual advances to other children in her family and to her friends, of which she said, "I lack understanding, but I

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[26] This information was given by her foster mother.

was wrong, but now I don't do that [force siblings to participant in unwanted sexual acts]."

During the conversation about relationships, Oprah stated that, "we all need love, want someone to give love and get love. Everyone can see that I have [a] disability, even though it's visible, but I still have my own unique way of doing things. It's like you know the limitations may be there with my thinking process, but I still have the unique way of doing things."

Oprah participated in two discussions. She engaged in one individual interview and the first focus group meeting.

Maya

Maya is a 30-year-old African American woman. Maya and Oprah live together and are related in that Maya is Oprah's aunt's foster daughter. Both of Maya's parents were in jail at the time she was interviewed. Before she was adopted by her aunt, Maya lived with her grandmother.

Maya conveyed that she was not happy living with her foster mother. However, she said, "I guess, it's ok, but I find my ways to visit my grandmother, she is the best."

Maya's foster mother informed me that Maya was recently kidnapped for 48 hours and that during this time, she was assaulted and raped. However, it appeared that Maya was still processing what happened (a typically sexual assault survivor sign[27]) and she was reluctant to talk about her experience.

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[27] According to the National Sexual Assault Collation, the sexual assault survivor may not be able to comprehend the sexual abuse and may say nothing happened. Also, it is observed that that it is not uncommon for the sexual abuse survivors to postpone of ignore reporting sexual abuse or to deny that they were abused when they are initially questioned. Possible reasons could include fear of the stigma associated

Maya is one of the two higher functioning women among the eight study participants. She currently works at a coffee shop and takes pride in what she does.

When asked about her sexual orientation, Maya said, "I like both men and women, they are the same. It doesn't matter." When asked if she knew about the term "bisexual," she said, "Oh, I have heard that word, I don't know that."

Sarah

Sarah is a 31-year-old Caucasian single woman. She lives in a foster home with other adult women who also have some form of intellectual disability. Sarah describes herself in this way, "I have a sweet face, blue eyes, and I am a good person."

She loves to talk about politics and takes pride in talking from her general knowledge. She presents herself as a soft spoken, friendly tomboyish woman who frequently smokes cigarettes. She related that she loves skateboarding and making cartoons.

Sarah shared that, "I am not sure why guys don't want to be with me." She further added, "my job coach says, there are plenty of fishes in the sea, I am sure I will find my guy." In all the interviews she emphasized that "you gotta take it slow in relationships, I have made mistakes in the past."

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with the abuse, embarrassment and retaliation. Research also reports that sexual assault survivors may deny the abuse they've suffered, or misrepresent parts of their story. Additionally, the research also informs that many survivors even try to hide their experiences by outright denying it when others ask (including classmates who may make jokes, tease or bully them based on the irregular relationship they see or sense), and by making statements with false bravado. The literature also informs that sometimes survivors fear getting in trouble for their own "bad" or illegal behavior (underage drinking, using drugs, lying to parents about where they are or who they are with) and will make false statements to friends, family and even investigators about those acts.

Sarah shared that she was raped 10 years ago. When asked about her abuse, she said, "I was very angry, when he raped me, felt helpless, but it's been 10 years."

Sarah also shared that she was incarcerated for an act of domestic violence in the past. She was not very comfortable to talk about what happened and why she was incarcerated and later under the supervision of an officer. She said, "It's past, I am different now, learning to manage my anger, I must, I am 30 now."

Sarah was one of three participants who attended all the interviews. She participated in one individual and three focus group discussions.

Berne

Berne is a Caucasian, 30-year-old single woman. She is a higher functioning young woman with intellectual disability who has Spina Bifida. Berne uses wheel chair for mobility. She lives in an apartment near her parents' house and refers to her three cats as her "daughter."

Berne is an outspoken woman with a strong opinion about sexuality, relationships, her gender, disability, and sex. She said, "All I want is to be in love and yes have sex, is that too much to ask?" She also added, "I am not sure why they break off with me?"

While sharing her experiences with online dating and strip club experiences she said, "Speaking as a physically disabled woman, I have to say, I guess, I have had boyfriends but, all men don't see you. They see you as a friend, they see you as the buddy, but they don't see you as the woman they want to spend rest of their life with."

Berne also recalled her experiences of paying a man to have sex, which she said, "didn't work well." She said, "I asked my mother if I can do this, she said, 'Oh, you are an adult. But don't tell me about all this . . .'" She said, "My mother has always supported me, but it's frustrating that I can't find anyone." She said, "This evening I am going to the single's club, I might find someone there."

Berne considers her religion to be paganism. She said, "Hey, you know, I'm pagan . . . I kind of became desensitized, angry, I guess you could say, at the Christian religion because when I was born, I was told if you believe in God you'll walk. Not by my parents or anybody I knew, just, just, you know, weird outside people. And I just was thinking I was made wrong, and I didn't understand why there were, why people didn't see me whole as God sees. God is supposed to see everybody whole . . . I can't walk . . ."

Berne was one of three participants who attended all the interviews. She participated in one individual interview and three focus group meetings.

Jane

Jane said that she is a half Caucasian and half Hawaiian woman who was 27 years of age at the time of the interview, but she was not sure about this as she was adopted by her current parents. She said, "As a woman with disability, who didn't grew up with mom, I learned many things [about sexuality] on my own, so, disability, it's frightening, it's tough sometimes, [this is] all I know."

Jane is in an intimate relationship with a boyfriend whom she has been with for the past 10 years. She currently lives with her father and her boyfriend. Her mother and her siblings moved to Hawaii after her parents separated a few years ago.

She said, "I don't know about my disability as I was adopted when I was 3 years old. But I struggled understanding things in school." She added, "I go to college though, just like you, and I have a dream to start my own magazine." Jane attends regular community college and works as a volunteer at a local theater group for individuals with intellectual disabilities, so that she can take a class. Jane participated in two of the meetings. She engaged in an individual interview and the first focus group discussion.

Prior to the initiation of this study, all participants provided written informed consent acknowledging their willingness to participate in this study.

4.4 Presentation of Results

In this section, I report the findings of this study pertaining to the research questions posed for the study. The themes that emerged out of the second stage of the data analysis describe how participants spoke about their families and how their families influence their current understanding of sexuality. In addition, this section will report on the influence that their personal life experiences have had on their understanding of sexuality.

I will present each theme separately along with the description of the sub-themes that emerged from the data analysis process. Table 4.1 provides a list of questions that were asked during the individual as well as focus group interviews to address the two research questions posed for this study.

Table 4.1

Summary of the Interview Questions

Research Question 1: What is the role of familial culture in addressing sexuality for young women (21-35 years) with intellectual disabilities?
Individual Interviews
• What did you learn about sexuality when you were growing up? • What did you learn about being a woman with intellectual disabilities and sexuality?
Focus Group I
• What did you learn about sexuality when you were growing up? • What did you learn about being a woman with intellectual disabilities and sexuality?
Focus Group II
• Have you heard about the term, masturbation? • Did anyone speak to you about it [masturbation] while growing up? • Have you heard about what sexual abuse is? • Do you remember talking about sexual abuse at home while growing up? If yes, would you like to share what did you learn about it?
Focus Group III
• What did you learn about relationships while growing up and from whom? • What did you learn about going out and meeting new people while growing up? • Can you please talk about what you learned about correct sexual behaviors?
Research Question 2: How do young women (21-35 years) with intellectual disabilities describe their understanding of sexuality?
Individual Interview
• What is it like to be a woman with intellectual disabilities and sexuality? • What do you think about yourself as a romantic/sexual person? • What do you know about sexual relationships? • Have you heard about the term, masturbation? • Can you please share what you think masturbation is? • Tell me, what do you understand by the word "sexuality"?
Focus Group I
• What is it like to be a woman with intellectual disabilities • What do you think about sexuality? • What do you think about yourself as a romantic/sexual person?

Table 4.1 (continued)

Focus Group II
• What do you know about sexual relationships? • Tell me what do you understand by the word "sex"? • Have you heard about the term, masturbation? • Can you please share what you think masturbation is? • Have you heard about what sexual abuse is?
Focus Group III
• What is it to be in a romantic relationship? • Can you please share about your experiences of friendships, dating and/or romance? • Talk about the feeling of love, your wants or desires, and hanging out with others as part of your experience. • Also other feelings such as anger, fear, angst, disgust, and any emotions that are the fallout from sexual experiences that were disappointing, controlling, scary, painful, violent, abusive, or just plain boring. What would you like to share about it?

Research Question 1

What is the role of familial culture in addressing sexuality for young women (21-

35 years) with intellectual disabilities?

To examine the role of familial culture in their understanding of sexuality, I asked

above stated questions (Table 4.1) throughout the individual and three focus group

discussions to address research question one. Two themes were identified which were

further elucidated by three sub-themes that emerged from the analysis.

Theme 1, "I am Comfortable With Who I Am"

The most salient theme that emerged from the interviews and focus groups was

the core belief about being comfortable as a woman with intellectual disabilities who has

sexual desires. Although the participants shared their sense of vulnerability surrounding

the topic of sexuality, as well as their concerns related to their limited access to sexual

and romantic relationships, participants agreed that they are comfortable with their

disability and gender. The women repeatedly confirmed that they take pride in what they do, which represented a sense of *self-determination* and *self-compassion*. This theme "I am comfortable with who I am" is further divided into three sub-themes explicated below.

"I love myself, just the way I am." Participants shared that their families played a pivotal role in terms of supporting their sense of acceptance of being women with intellectual disabilities. Participants in this study unanimously repeated that they accept themselves as they are and that they are happy despite of their struggles living as women with intellectual disabilities.

A key finding in this study is that the women involved in this study emphasized that they learned about sexuality through their own individual life experiences in addition to learning from their respective family members. This finding is important because the women acknowledged that they pursued knowledge and reflected on what they learned beyond the information provided by their families and that their understanding grew as a result of this pursuit.

For example, upon asking about socially appropriate and more specifically, sexual appropriate behaviors, Sarah replied,

> [I learned about sexual behaviors] not just from my mom; my older sister too, and my younger sister like, and she is like, she is fully awesome like that, and she never got told till she got older, because she was young. [Learning from my sister] didn't affect me at all because it was something I wanted to learn and something I wanted to understand a whole lot better than my mom.

The following excerpt of the conversation presents the essence of the discussion on the topic of intellectual disabilities and being a woman. This excerpt is extracted from all the three focus group interviews:

Ross: Disability is, someone that has also special needs, and different abilities, different abilities can be . . . For example for my own abilities is being more independent and there are things I can do. For my abilities, it's being more independent and there might be some disability . . . I think that it [disability] does affect you. Like, I am like other people and their disability it's just that way. It just feel kind of normal. We have that disability and we have that strong impact.

Berne: Well, growing up, I never, I was not allowed to say the word "disability" my mom doesn't like that word. So, she always just called it *different.* And, I was always told that, being different is not wrong . . . it does not mean that you are less than . . . it does not mean that you are not as good . . . It does not mean anything but that, like society, sometimes makes it look you are not meant to be pitied. You know . . . people don't need to feel sorry for you . . . blah, blah, blah. It comes with its challenges but it also comes with its rewards and its, its battles and that can be won and sometimes that can are like . . . ok, I didn't exactly win that battle, but it doesn't mean I'm not . . . I'm going to give up on it.

Oprah: Well, I was like, born, I was . . . I have a disability because my mother did drugs and alcohol, while I was in her stomach, that lead to me being . . . when I was born drug affected may be and then I was labeled as being mental [mentally] retarded and so I have a disability, so, yes . . . I have disability from that . . . I remember her, I have seen her . . . I could have grown with hate and everything towards my biological mother, but I don't, because God gave me my biological mother, and she didn't raise me like that, I love my biological mother, just like I love my mother, yes, I have issues with her, but I love her . . . I have forgiven her. I am fine, just way I am.

Maya: I am a visual learner . . . that's what I put . . . so I have to see somebody do it so that I learn.

Lilith: [We can] teach them to use sign language, when they are very young, they're always smart and they socialize, they socialize with other kids, during the other pre-schools and be really active in society and other school districts. They are really smart, if you teach them how to be active in the all different school districts.

Sarah: The way I think of disabilities is like being good at stuff. Well, my mom thinks I have disability. But I don't see it. My mom thinks that, but I don't see it.

She added,

I am not affected by what my disabilities are, you know I'm a grown woman. And you know, I used to, when I was younger, in middle school I used to be sensitive

about it but ever since I got in my adulthood I stopped being sensitive and just not taking it seriously.

To that, Jane said,

> We don't know my disability, since I was adopted. I was adopted since I was 3-years old. Since we are not sure what it is . . . we are still trying to figure out what it is. But, with my disability it is very tough to understand things sometimes. But, I have a dream. I go to Community College and I am a student just like you . . . I love my school, it's hard though . . . I love myself.

While some of the women continued to speak of the role of disability in their life as women, a few of them were unable to articulate the role that their disability played as they did not think they had any form of disability. For example, during each of the individual interviews, every participant was asked if they had any form of disability. To that, Anna said, "I don't have any disability, I may lack in understanding sometimes. Also, I can't see from far." During the individual interview, Anna said, "I love myself, just the way I am" Later during the focus group, Anna also added, "I want to get baptized again, I can get rid all the bad spirits out, I think I have inside me."

Participants shared that although they have difficulty in understanding, they have learned to navigate through finding different ways to learn. Most of the participants shared that what they learned while growing up helped them in terms of gaining knowledge and learning how to learn, but that they also gained many if not most of their skills from their own life experiences as adult women.

Despite the ways participants described their disabilities, everyone shared a common believe that they are happy just the way they are. Participants shared that they learned about making appropriate choices and learned things about boundaries while

growing up *and* that this process of learning continues into their adulthood as they continue to gain experience.

      "Choice and boundaries." On talking about sexuality, participants spoke about the role of choice, boundaries, and rejection, and how these concepts affect the way that they feel about themselves. For example, in the context of discussing these ideas, participants spoke about their understanding of "making choice[s] and learning about boundaries." The women said "my body feels good;" they talked about gaining "access to sexuality;" and they described "rejections as part of the game."

      While talking about sexuality and disability, Sarah said,

> Because start out slow with what you're doing. Like start out slow with going on a date and then if this boyfriend works out, then there's always a second date. And then there's nothing they could take a sworn getting a promise ring. And then if that works out with them and then they will go from there and takin' it slows with an engagement ring. You have to keep your promise . . . by staying with that person like for a long time . . . if that persons good to you . . . and not being like verbally abusive . . . and all that kind of stuff and make sure that they are treating you right . . . because if they don't because we women like you know . . . we as women . . . we have boundaries . . .

Elsewhere she said,

> I was in a jail a lot. Well, there was a lot of stuff I did in the past, vandalizing. Well, because the reason why I was on probation was because I was not supposed to be in St. Johns because if I go near the St Johns area it's because I would use drugs and party and that's the main reason why I was on probation for that. I was raped because I snuck back to St. Johns. I was going a little too fast at that time. You know, you know since I got older it was hard for me to slow it down. Because, I needed some boundaries, I told myself; it's a self-talk. I've learned it; I learned it from Clackamas Community College. I grew up in Clackamas Community College, I learned, learned the self-talk before, what to do. If it becomes a relationship, I decided, like you know I was getting, I was like almost in, you know, I was getting close to my 30s. It's like, you know what, I was like, you know, I was like telling myself it's important for me to slow down on the relationship and time to put some boundaries on that. That's how I did it that way. I was going too fast.

She further added,

> Because my mom always says, don't go too fast on the guy and my older sister says that you got to always set boundaries. My older sister is right, she's my protector, that's what she is. I've done that on Facebook. I have, so that's when I stopped doing that. I let the guys ask me first on Facebook because Facebook for relationships status I keep it as single.

In response to this comment Berne added, "Don't go too fast, also known as don't scare them off which I have a habit of doing."

Even though everyone spoke about the concept of boundaries and choice, not everyone could explain exactly what they meant by this term. On talking about sexuality, Lilith frequently spoke about prevention of sexual abuse, by making choice, and how can one prevent oneself from being sexually abused. Likewise, Ross, spoke about few strategies, such as not talking to the strangers or screaming at the top of one's voice if one is approached by a stranger in an abusive manner. She said, "I think, you have to keep boundaries, as a woman."

> Ross further added,

> I think that . . . that is the way . . . secretive . . . and it's about like . . . I don't know . . . like . . . about who you really are . . . and [I don't want to] not to talk about anything . . . .anything silly, because it concerns people . . . and it might be the friendship or how you . . . aaaa, how you feel like . . . and it's about . . . and what I mean by that is like . . . it's like . . . and a way that can also be . . . In a way that can also be . . . boundary . . . that whom do you want to talk about yourself . . . my mom and dad always tell me that and to my sister.

The following excerpt taken from the women's dialogue pertains to their understanding of choice and boundaries in relation to Lesbian, Gay, Bisexual, Transsexual, Queer and Intersexed (LGBTQI)[28] relationships,

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[28] LGBTQI: Lesbian Gay Bisexual Transgender Queer and Intersex

Jane said,

> I was raised Baptist . . . and when maybe I was in high school, my sister came out . . . you know what love is love, she is gay or not . . . and she is happy and I am happy for her . . . and you wouldn't think she is . . . [Gay]. It's the choice that she made.

Sarah stated,

> I was with my one of my [boyfriends] . . . I was with my . . . one of my . . . one of I was with my one of my best thing . . . like Harry Potter like midnight showing . . . at midnight . . . there was a Mayor Silverton, who was a transgender . . . and you know . . . you know . . . and I support it, and you know, I . . . follow . . . at this place . . . follow gay and lesbian . . . on the twitter . . . and you know the former Mayor is gay you know.

In response to Jane and Sarah's comments, Oprah replied,

> There are boundaries . . . we have talked about different . . . sexuality like too, they . . . the beginner . . . or . . . my, my, my . . . my believe is . . . that . . . you can . . . love the person . . . without . . . what I like is that . . . with that sort . . . am mm . . . not like what . . . I can . . . it's not my believe am mm . . . to grow and . . . to judge somebody because . . . they are . . . they or when they know . . . or whatever they choose to be . . . that . . . am mm . . . that is not my place . . . I am not the judge . . . there are plenty of things where you will find fault in me . . . so . . . I love the person . . . like . . . I can love the person . . . but I don't have to . . . I mean I can love the person without passing a judgement . . . I know, I can be still kind, without judging you, I can still be kind . . . I can see you and say hi how are you doing, without confrontation without judgment . . . what do you or whatever life that you choose . . . for me that's what it's all about . . . your sexuality . . . your choice . . . I choose to be straight . . . I . . . you know . . . that that that . . . that is what . . . that's for you . . . that's your choice . . . and that's what we know . . . and is what you . . . like . . . when you read in the paper . . . a certain so called Christian group am mm . . . they print they print am mm . . . gay and lesbian funeral . . . or for some that is like a picnic . . . I think . . . that's what had been told that . . . who you are. I had been that's what . . . who are you to judge . . . I am fine . . . but what you go by example . . . he didn't judge . . . the people for doing it right or . . . doing it wrong . . . he shall . . . love the person who they and, and, and where they are at . . . he didn't like . . . he tell me that . . . as a Christian that I am not supposed to judge . . .

Maya promptly said,

I want to say that, it means that, like our [my] job . . . it says that like we have . . . like gay, transgender . . . it's part of the job . . . this is what we learned . . . and some people are more [open] about, about their sexuality and people are more open about it . . . they are more open . . . where I work . . . they are more open about the sexuality and they are more, yeah, they are more open, or may be closed off . . . yeah . . . they know that . . . who is straight who is not . . . like I know my customers . . . who you know . . . so I know . . . they are more open about their sexuality . . . and at F* they are open about their sexuality . . .

To this, Berne promptly said,

I remembered the Catholic . . . like you don't have sex before marriage . . . you know . . . In my opinion, like . . . are you like, but . . . in my opinion . . . there is nothing wrong or right . . . you know…your body has you know . . . like . . . it's a vulnerable position . . . that's what I tell people that . . . like this is me . . . who I am . . . like you know . . . like kind of lusted . . . [Laughs].

Upon speaking of role of their disability in understanding sexuality, romantic relationships, dating, and prevention of sexual abuse, participants spoke about making *right* choice and creating and maintaining boundaries. A few of the participants also shared that being women with intellectual disabilities, it is important to learn about creating boundaries. Most of them shared that they learned about the concept of choice and boundaries from their mothers and also from their siblings.

Maya: I wrote being a woman with disabilities won't or don't have anything to do with . . . just because we have a disability it doesn't . . . it doesn't change the fact that we have a disability . . . or we look different . . . but you can't really tell unless we tell you if we have a disability or not. And another thing about sexuality, I think everybody has one in their own. Somebody has something wrong with them but you just can't tell inside. I just don't think anything is wrong with us having the same thoughts as everybody else.

Sarah: About, sexuality, let's see, when you have a boyfriend there's boundaries because a young boyfriend, you don't want to go too fast. You want to take it slow. That's the way, and that's the way I like it. Because start out slow with what you're doing. Like start out slow with going on a date and then if this boyfriend works out then there's always a second date.

Lilith: If you have a boyfriend and if you don't want to be touched in a physical sexual way just prepare yourself and, ammm, use self-control and you gotta be positive and be control and be prepared to take in control and including around safe sex too . . .

Ross: I think disability and sexuality as a woman is having a relationship with a partner . . . and also to thinking of having a partner. And thinking about your future and how you feel being sexual. I think as you are becoming a woman . . . it's something you kind of have to think about when you do have a relationship with someone. And I think the first thing that would come into mind is do I want a relationship and how will umm and how it will go well.

Jane: As a woman with a disability . . . I believe like . . . your sexuality in a disability, it works together because umm like you can have . . . it brings like about like a self- confidence . . . like in who . . . like me as a woman, I feel comfortable as who I am . . . It brings like self-confidence . . . like I, I agree with Ross, when about choice . . . you know it's a choice if you wanna have a boyfriend or a girlfriend you know or whoever . . . it's like it's, it's whatever you feel comfortable in is your choice that you have that self-confidence.

Oprah: Yeah, it's [sexuality] to me it's like an expression.

Participants shared that while growing up, family played an important role. This role was different for each of the participants as each woman had their own individual experiences. Oprah was adopted by her grandmother as her mother was incarcerated. During the individual interview, Oprah said,

My foster mom, she encourages to set our own comfort zone, in which, what we want, we can achieve. She raised me to be like, if you have a disability, that doesn't matter, if you want something, work hard and you can achieve anything. For my biological family, I don't really have closeness because my mother was not ready to take care of me. I experienced hurt. Being a woman who I am today is because of my adopted family and sister and mother. I have other foster brother and sister. We don't see them as foster. We like, we all are family. I don't know who my father is, I kinda look at the priest at my church as male role model.

During the focus group interview, Oprah added, "My mother and sister teach me to live by example."

Sarah did not talk much about her experiences of living within the foster care system. She shared that she had lived with her mother and her stepfather while growing up and then she started living at the foster care system which she considers to be like a family to her. She said, "I am very close to my family. My aunt was the closest, but she died when she was just 45. My older sister and my brother, they are my protector." Later in the interview, she briefly mentioned, "My new living situation that I'm at now; I do like it a lot because I'm close to my family."

All of the participants shared ideas related to sexuality that they learned from their families in addition to knowledge gained through their individual experiences that they had while they were growing up. However, only one participant shared about the role of religion in her family and its influence on her learning about sexuality.

Participants shared their core beliefs about who they are, based on what they learned about while growing up and what they experienced as an adult. Even though all of the participants shared that they are happy the way they are, on the second of the three focus group meetings, Berne said,

> I like myself, looking at myself with clothes on . . . but not comfortable looking at myself with clothes off . . . because . . . I don't really like my body . . . the way it's shaped and the way it is, and I just . . . like . . . it has spina bifida and paralysis . . . I have been through with my life. [Gasp] But, I still . . . I used to go through self-harming . . . because I was angry at my body for not working the way it should and I have hurt my legs not . . . not cutting . . . just, just scratching . . . making scares and stuff because I was not feeling anything . . . but I would bring self to bleed . . . but just that . . . I am no longer angry at my body.

In response to this comment, Sarah added,

> I feel . . . I do love my body . . . the way it is . . . and . . . you know . . . the body is so nice . . . and you know . . . it doesn't bother to me. I know . . . it's like . . . my feelings . . . like, like when I look . . . I look into the mirror and see and I see that

beautiful face . . . and just want you know . . . I think that it doesn't to me from outside . . . always this smile . . . and these beautiful hair . . . I was angry before, but not anymore. I learned from my counselor to let go of my anger.

Berne then added,

I have always taken pride of my parents . . . I always wanted to look and I always believed that the impression you make on people is very important . . . even though we always say that, it's always the inside that counts but people always do still look people on the outside . . . I always like saying that . . . but it makes me feel good too.

In addition to sharing their journeys on the road to acceptance, the participants also spoke about their experiences of rejection, abandonment and isolation. The next sub-theme presents the participants' narratives related to the topic of rejection.

"Rejections are part of the game; there are more fishes in the sea." Every participant spoke about the feeling of alienation. However, during one of the focus group discussions, Sarah promptly said, "rejections are part of the game; there are more fishes in the sea." She further shared that she experienced rejection several times. And she said, "I don't know why they leave me . . ."

To that Berne said,

I know if I will date again, I am little scared because the guys I have dated before are, they [have] all left. So, it's gonna be really hard to put myself out there again. Sometimes, they say that it's better to be alone than being in the wrong relationship. But, then again being alone really sucks! My church is having a new single's group starting up, so I going to join that. Hopefully I'm going to find somebody who's, not anybody old but not really, really young. Because a lot of people who go to my church are old hippies. Keep my fingers crossed.

Oprah replied,

If we . . . if you think that date and everything . . . rejection is common. Well, I view, like . . . the guy has a choice of . . . who he want to go out with . . . you have the choice too…rejection is common, and you have the choice . . . you like and . . . I am sorry . . . I lost my train of thoughts . . . it goes . . . it goes both ways . . .

you can choose who you like and . . . and know that the person may not like you back . . . and . . . you . . . to me like your boyfriend and whoever it is…you choose . . . passes some types of way reflect who you are . . . as a, an . . . individual . . . I mean . . . you have to see some time, aaaa, common ground . . . also . . .

To Oprah's comment, Jane replied,

Yeah, I will share . . . as a woman with a disability . . . if men . . . I wasn't told about how to shave my legs . . . because my mom wasn't around . . . so I had to learn all my own . . . you know . . . when my cycle came . . . I didn't have that . . . you know . . . I learned on my own . . . so . . . disability . . . it's frightening you know… what's going on you know . . . it's tough sometimes . . . you know . . . all I know is . . . I know . . . then rejection . . .

With the exception of Jane, everyone shared that their mother played a very important role in making them who they are in their current life. Jane, who lives with her father, shared that she had "to learn everything on her own." However, it was clear that other adults played an important role in the development of her awareness of how to deal with rejection and sexuality in general when she shared that her teachers in school played a very important role while she was growing up.

Thus, the women made it clear that multiple adult role models influenced their perspectives and that their role models assisted their ability to reconcile with experiences of rejection to varying degrees. Speaking of adult role models, the next theme provides details related to how the women perceived their relationships with their mothers and the influence of their mothers of their development as sexual beings.

Theme 2, "I Love My Mom"

Participants described their relationships with their mothers and the role they played in their current understanding of sexuality. This theme emerged in every discussion. This theme is further divided into three sub-themes that further describe their relationship with their mother.

"I learned from her." This sub-theme reflects participants' connotations of what they learned about sex and sexuality being a woman with intellectual disabilities. Participants spoke about various topics like sex, relationships and masturbation. The following excerpt presents dialogue from these conversations related to what the women learned about sexuality from their mother:

> Berne: I learned about . . . learned from my mom, about sex. I learned about sex, from my mom and I learned about, sex through health classes, about babies, and I had a relationship class. I have grown up, it's not the marriage I want, we just learned that from my mom that, treating myself with dignity is more important than finding someone to be with, I can find anybody, if I wanted but I must treat myself with respect . . .

But later in the third focus group interview, Berne said, "I want to be with a man and get married."

> Ross: I always talked to my mom about sex and also some with my sister. Because, I feel more comfort . . . that is within my comfort zone, it won't be tough with my mom and my sister, as per my dad goes, I haven't talked to him much, as it's not within my comfort zone, but there is something I talked to him about . . .

Ross further added,

> I said that for my mom and my sister because they are kinda common as a skill, more and kinda I can't talk to my dad. It's obvious . . . he is a man, so . . . I can, talk about things about my other stuff. I am like, as even I am a woman like them . . .

> Oprah: I grew up in a Christian home . . . my mother my sister, they tell me . . . by . . . they tell me by example. I . . . my first . . . my first, from what I can remember . . . my first what was I going to talk about . . . well . . . my first knowledge . . . yeah, knowledge about the puberty, menstrual cycle and everything. I learned at school like . . . and . . . I also . . . learned by example of my own . . . and my mom . . . and my cousin . . . and they tell me by example like . . . if you choose to be with somebody . . . stick with that person . . . don't you just have . . . and I learn by like . . . you know . . . going to church like . . . like . . . like . . . no . . . no sex…before marriage . . . if you do that then no problem . . . ask for forgiveness for that and practice celibate . . . its normal to have like . . . like . . . it's normal to have those feelings or urges or whatever you want to call them . . . but . . . how

you deal with it . . . you know what I mean . . . it's how you handle the . . . handle . . . how you handle . . . the feeling . . . its normal and everyone has those feelings and then urges . . . you know . . . it's how you handle that . . . and as long as you handle that . . .

Anna added, "I love my mother, and I like to be under her skin; she tells me to ask my sister about toys and sexuality" In contrast, Ross shared "I learned about masturbation from my mom."

Jane then shared,

My mom never taught me anything about it [sex], you know, she told me to ask my teachers . . . My physical education teacher helped me learned about it, and gave me books to read…maybe my mom was shy . . .

Sarah then said,

My mom told me all about it like what sex is like and I . . . its . . . we were . . . like more of woman . . . guy and woman falls in love and then get married and then after that . . . then they have that sex thing . . . I went through that awkward stage . . . I . . . you know . . . I knew I was going become a woman and I know . . . exactly . . . you know . . . it was happening to me as a childhood and into the adult zone . . .

Thus with one exception, the participants shared that as children, much of what they learned about sex and being a woman was learned from their mothers. However, all of the women said that they also gained knowledge from others in the lives, such as teachers and sisters. In the case of Jane, she shared that her father played the role she believed that her mother would have played in her life had she lived with her mother when she was growing up.

In the next section, the participants' narratives are presented under a sub-theme- "Welcome to the adult world . . ." While the current theme relates most closely to the role

mothers played while the women were growing up, the following theme relates to the

women's transition into adulthood.

    "Welcome to the world of adults." The narratives presented here are extracted

out of both individual interviews as well as focus group discussions. The following are

the participants' voice presented in a dialogue format:

> Sarah: I went through that awkward stage . . . I . . . you know . . . I knew I was going become a woman and I know . . . exactly . . . you know . . . it was happening to me as a childhood and into the adult zone . . . I have . . . when I was older . . . when I got my adulthood . . . I was older . . . yeah . . . I was getting attracted . . . you know . . . there were lot of guys . . . I used to get asked out a lot by lots of guys . . . My mother told me, welcome to the world of adults . . .
>
> Ross: My mom told me . . . when I think of masturbation, I think for all woman . . . I think we always . . . always do it, because somehow it feels comfortable to our . . . own body . . . somehow this is what we do and . . . as an adult woman's life that . . . it does depend on how you do it and where . . . you do it . . . and what's it is like . . . because it's kind of growing up . . . I still do it and I do . . . well . . . it kind of depends on age as well . . . somehow it got started and somehow it is kind of natural . . .
>
> Sarah: I know the horniness . . . yeah, I know . . . I felt like that . . . my mother told me about that . . . She said that the sensation of horniness is ticklish in a way . . . you know . . .
>
> Berne: I was dating a senior . . . he liked to be kissy, kissy, grabby, grabby, and yeah, and somebody caught us making out in the elevator . . . yeah . . . yup yup . . . My mother said ". . . you had been riding . . . you have been wanting for guys since when you were 3 yrs. old." Oh, yah, she said, "she is my daughter" . . . My mom said, "I was always sexual, welcome to the world of adults . . ."
>
> Ross: I had a similar thing when I was still at school with ex . . . that's how . . . I was . . . I was kind of making out . . . you know . . . as soon as my mom came to know . . . shhhhhup . . . it was all over . . . it was so [ooooo] weird . . . it was so [ooo] uncomfortable . . . I still remember I had a long talk with my mother . . . it's being an adult thing . . . [long gasp . . .].

Participants also shared about the role of their sister in their lives. In the next sub-theme, participants' narratives describe the friendship they share with their mother and sister.

"My mom and my sister are my best friends." Participants related that they share friendly relationships with their sisters as well as being friends with their mothers. However as the following excerpts demonstrate, the women also shared that as adults, they felt that they could not share everything with their mothers or sisters:

> Berne: Well . . . I used to talk to my older sister . . . I . . . . she said that you can talk to about sex and all that . . . and I get to translate that all the time . . . she said it's all normal and I got the magazines . . . that . . . with lot of . . . like my ex-boyfriend had . . . you know . . . and it's all . . . you know . . . and do like that and I watched lot of romantic movies . . . and like . . . you know . . . I see all the couples doing it . . . . it's normal . . .

> Lilith: My sister is expecting her first baby very soon . . . and she will have it any moment right now . . . she told me about the baby and how . . . I talk to my mom too . . .

> Ross: I think . . . I think for me . . . it's kind of hard to understand at first . . . that if we go to . . . mothers or sisters . . . they can kind of teach you to understand it in a way and you can ask . . . they would know more than us . . . because for us it's kind of hard . . . because as per me . . . it's kind of my disability . . . is the understanding part . . . for me, it's kind of hard to understand that . . . concepts . . . so kind of I ask my sister and my dad at some kind of point but not too much because he is my dad . . . but I ask my mom and my sister . . . I can reach kind of . . . talk about it . . .

> Oprah: I want to be like anybody else, my relationship with like my foster mom, my sister, they helped me understand that you are beautiful, just how God made you, and you should be happy for who you are and you know my relationship with my boyfriend has helped me to grasp that too . . .

> Sarah: I am very close to my mom . . . you know . . . I do miss her a lot . . . and I got a stepdad. My stepdad is like a father figure to me . . . since I was a year old, he took care of me . . . My older sister and my brother . . . they are my protector . . .

Jane: I am close to my boyfriend's sister . . . my sister moved out and they are all older than me, I am the baby of the house . . .

Ross: I am too . . .

Berne: I also learned that . . . take self-defense classes or keep pepper spray or just stay alert or something . . .

Ross: I learned from my mom . . . she says that you have to be alert . . . when it comes to such stuff . . . you need to be on tough of it and just try not to turn out to you and then you need to find someone and take some help and that's what I think about it . . .

Participants shared that they learned about self-compassion and skills to be self-determinant from their families, especially from their mothers. They also shared that this learning had a strong influence on their understanding of sexuality, and how to access sexual relationships and other forms of friendship.

The women also shared that they learned to accept their disability with the strong support from their familial environment, while they acknowledged they are often not trusted with their decision, which influence on their access to relationships. The next section address the second research question posed for this study.

Research Question 2

How do young women (21-35 years) with intellectual disabilities describe their understanding of sexuality?

To address this question, I present the results in two predominant themes: "*I feel kinda sexual*" and *"he raped me*." These themes represent the collective presentation of what participants shared about their understanding of sexuality. Each theme is presented with three sub-themes. Narratives presented by participants are organized and presented according to the following themes:

Theme 1, "I Feel Kind of Sexual"

This was the most prevalent theme that demonstrates participants' understanding and desires on being a sexual being. This theme is further presented with the three sub-themes. The three sub-themes are: (a) "Sexual pleasure," (b) "Masturbation: I feel comfortable," and (c) "You always have to act like a woman." Each theme is explicated below.

"Sexual pleasure/s." Most participants in the study shared their desire of sexual pleasure by being with a partner and experiencing a sexual relationship. At the same time, there were participants who expressed that they overcame their fear and negative perceptions related to sex by practicing abstinence.

For example, when asked about her perceptions about her own sexuality, Lilith constantly spoke about sexual abuse and rape. She shared that she gets really scared when her boyfriend gets closer to her physically. She shared that she had to undergo regular therapy to overcome her fear of being raped by her boyfriend.

On talking about sexual pleasure, Lilith said,

I love people to hug me . . . I love people like . . . hug me . . . like kiss me on my little cheeks . . . I loooovvvvveeee that moment . . . But I don't like doing bottom rubbing . . . I don't want that . . . I love people when they hug me . . . comfort me . . . people like spoil me, hold me . . . that's like my favorite thing to do . . . that's like my favorite moment.

The women also spoke about going slowly in a relationship. They also emphasized their decisions to refrain from intercourse and intentionally choosing abstinence.

Participants were suggested to write and share about what comes to mind when they think about the word *sex*. Participants not only shared their understanding of the word but also shared about their understanding of sex being a woman with intellectual disability. In response to this prompt, Ross shared,

> I think, what sex is to me is if you have a, a, a guy . . . you love somebody . . . and some with romantic and love and you kind of fill all you get into in and do get into it and that's how it starts .kind of . . . sex . . . and in other way about sex is when you are with someone your true love and you know you always want to . . . live with that person all your life and you . . . feel this way . . . your life and your . . .

In response to this comment, Sarah said,

> The word sex is . . . it's to give more than to get . . . then do the sex part . . . when I think that [sex] there is a love thing that turns me on, and that is separate and then have a dark chocolate…I am happy when I am in a relationship.

Berne's perspective on the matter was,

> I wrote that sex is sharing your body with someone . . . sometimes its love and sometimes it's not love . . . sometimes its lust . . . it's between the two people . . . sometimes you meet at a bar . . . You feel lonely . . . You are drunk . . . and you just want to go, go, go. Has to be safe for your body and for the partner too . . . there is sexual attraction . . . when I had sex it's been with people I had loved . . . I was nineteen years old and we were both virgins . . . I remember and . . . . it was a nice . . . Last time when I was in a relationship I felt wonderful, felt desired, felt flirty, umm, I was sexually attracted, I was in love. And when I was with him, I felt safe. No, not sex per se, just being with someone.

During this conversation, Sarah spoke of regret with regard to past sexual experiences that encouraged her present decision to practice abstinence. As previously noted, two participants chose abstinence for fear of experiencing negative sexual consequences. Thus, abstinence not only served as a strategy to avoid negative consequences, but also insulated them from coping with fears connected with sex or confronting the idea of engaging in sex.

However those who were not practicing abstinence shared a common notion of having a sexual partner. For example, Jane shared, "I love my boyfriend, and we use protection and its fine. We are too young to have babies" In the similar vein, Oprah shared, "loving him makes me love myself." She shared that even though they try to *control* but if mistake happen, she sits in long prayer to repent for her act. She added, "God forgives."

Ross explained that she must go slowly in her physical association with her boyfriend, however she also shared that she had been sexually active with her past boyfriends. She said, "I made mistakes, I don't want them anymore . . ." Almost all of the participants knew about condoms and some forms of contraception. However, negative perceptions of sex for three of the participants specifically related to their concerns about being raped and the possibility of unintended pregnancy. Thus, knowledge of prevention and use of contraception did not appear to significantly contribute to their sense of efficacy in preventing unintended pregnancy or sexually transmitted infection or diseases.

"Masturbation: I feel comfortable." Four out of eight participants shared that they practice masturbation. Jane was uncomfortable talking about masturbation, whereas Ross initiated the conversation when the topic of masturbation was discussed during day two of the focus group meetings. Ross also shared that she was taught about masturbation by her mother. Ross said,

> It's comfortable. I think masturbation . . . mastu . . . masturbation . . . it just feels natural for woman who also has a disability . . . because for some it is different . . . than for people . . . and how it in a way that it just feels comfortable . . . when you do masturbation . . . it's just kind of obvious . . . like its more about your private parts and that it becomes . . . kind of comfort . . . they kind of have and that you share . . . out in public . . . when you are out in there in public . . . in my

mind it's kind of weird if you . . . it might feel uncomfortable . . . that it should be like . . . private . . . and I also think of like your room of bathroom of any kind of place you can think of . . . Also, when I think of masturbation, I think for all woman . . . I think we always, always, always do it, because somehow it feels comfortable to our . . . our body . . . somehow this is what we do and . . . as an adult woman's life that . . . it does depend on how you do it and where . . . you do it . . . and what's it is like . . . because of kind of growing up . . . I still do it and I do . . . well…it kind of depends on age as well . . . somehow it got started and somehow it is kind of natural.

Both, Ross and Lilith described that they have Down syndrome. On day two, Lilith invited Ross to sit next to her and she told me that Ross "is like me, I want to be friends with her." Upon listening to Ross, Lilith had surprised expressions. When I asked her to share her views, Lilith said,

Ok . . . I have never done it . . . so . . . I have not done it . . . before it was kind of disgusting to me . . . kind of degrading . . . kind of gross to me . . . some men do it all the time when they have sex without the woman . . .

After listening to Lilith, I said, "Ross, just shared her experience, what do you think about that?" To that Lilith said, "I know that part . . . it's kind of interesting . . . but I am just not into that kind of subject . . ." She further added, "It's kind of disgusting for me when I see that in movies."[29]

Sarah was uncomfortable using the word masturbation. Instead, she referred to this act of self-pleasure as *fantasizing* adding,

Berne added to Sarah's ideas by saying,

Me, personally . . . I don't do it. But I know that . . . I don't have any feeling below my waist . . . so . . . I prefer doing it with a person . . . I have actually seen it done many times . . . sometimes . . . it's part of foreplay . . . sometimes a woman does and shows it to the man and then she . . . you know I watch porn sometimes . . .

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[29] Lilith did not speak with Ross after the interview. She was not present during the last focus group meeting as well. Perhaps Lilith was offended by the conversation regarding masturbations and that this was the reason that she did not return to the last focus group meeting.

not all the time . . . But sometimes . . . alone . . . of course . . . so . . . yeah . . . But . . . I also don't think that masturbation is wrong . . . I think it is part of who you are and your body and it makes you feel good and it's like treasuring yourself as a sexual being . . . I don't think there is anything wrong with this . . .

Five out of eight participants shared that they have intimate pleasure devices that they use regularly. Most of the participants shared that either they got the devices from their sister or that their personal care-worker bought the devices for them. During her individual interview, Anna shared that her sister got it for her, but her mother is not letting her replace the battery and she was advised to wait for her sister to visit to replace the battery.

"You always have to act like a woman." Participants also spoke about their understanding of how they must act like a woman when in public. Participants gave several examples of what they meant when they said that one must act like a woman when on a date and when in a relationship and also at the time of sex.

The following collection of excerpts from all the focus group and individual interviews presents participants' understanding of socially appropriate behavior as women.

> Sarah: I am not affected by what my disabilities are, you know I'm a grown woman. And you know, I used to, when I was younger, in middle school, I used to be sensitive about it. But ever since I got in my adulthood I stopped being sensitive and just not taking it seriously.

> Ross: I think that every girl. For example, because you, aamm, go to a church or a concert, or anything you're at you always have to act appropriately, [you] have to be, aaa, and have, aamm, to . . . how you present yourself publically, depending where you are at, and for me for example, if I am out with my friend's, I need to be appropriate around my friends because I don't want to harm them by any way and then I think that my head is a locker and that's how I do it is if you have the urge to, just put it in my locker that is my head, I put in there (my head) and turn the lock (uses gestures to show she has turned the key on the side of her head) and

then that's how the two do it . . . and another example of being appropriate . . . ammm . . . if you are going to a church, there are some ways you have to act in a different kind of way at when it comes to the church and if you are religious and as for that it's kind of risky of how you say things I mean and how you, amm, how you present and how you . . . I mean how you say things that may not come out at . . . for example . . . it's kind of like saying, think about it's just don't say it.

Berne: I am trying to remember, the way I'm going to be acting the way I say something, is it going to harm or it is going to help? Are my actions going to make me good or make me look bad or make someone else look bad and I don't want to be a part of that. Like I said, I don't want to bring bad attention to myself.

Sarah: I was thinking about the restaurant. Because if you are at a fancy restaurant, you're supposed to be like polite. And you're supposed to appropriate. Because that's what I've been taught. I have this girlfriend, she's my step grandma. She is the one who taught not just me, but all us grandkids about how to be polite and everything and she used to say, thank you.

Berne: Yeah, saying please and thank you, taking your turn when you're speaking . . . That's the hardest thing for me. I have the tendency to interrupt people and I feel so bad when I do it. I have like I am so, so, sorry, so sorry. But I get so excited about talking about things like right now personally I think I'm doing better, aam, I am sorry, I apologize for interrupting you. But it's like using eye contact, using soft using nice words and you don't bring up topics on the dinner table or at restaurants things like religion or politics unless the person you are with brings that up. Because that's not going to end well . . . . You don't want to sound too eager! Don't go too fast, also known as don't scare them off which I have a habit of doing.

All the participants shared that it is important to act in a *lady-like* manner which

they learned from their individual families as well as from various experiences as women

in their life's journey.

Theme 2, "He Raped Me"

While participants shared their positive experiences as a sexual being, participants

also shared about their experiences of sexual assault and sexual abuse. This theme is

further presented with the three sub-themes. The three sub-themes are: (a) "I was raped,"

(b) "I am scared of being raped," and (c) "safety and prevention." Each theme is explicated below.

"I was raped." Three out of eight participants had been sexually abused at some point in their lives. Out of those three, one of them experienced sexual abuse at the age of nine and the other two experienced sexual abuse as young adult.

All three of the women who had experienced sexual abuse were reluctant to share about their experience. However Sarah explicitly shared in each discussion she participated in that she has overcome the pain and her post-traumatic stress related to her abuse. She said, "it was almost 10 years ago . . . it's hard at times, but I am over with it . . ."

During the individual interview, Sarah chose not to share about the incident she had experiences until near the end of the interview. Right before I was about to wrap up the interview, she said,

> There was something bad happened to me long time ago . . . you know . . . this cocky guy . . . he used to pull out my . . . and I was raped long time ago . . . they never caught him . . . Police hadn't caught him . . . he didn't give them his name either . . . it was long time ago . . . it was long time ago . . .

She further added,

> I don't have those fears anymore . . . I used to . . . you know . . . I used to have that ange . . . I don't have that now . . . like I used . . . because I have seen counselors and psychiatrist . . . I was in . . . that time . . . I wasn't supposed to be . . . I violated my probation . . . I was on probation . . . I was at the grassy part of the park when that happened . . . I was drunk . . . I tried to stop him . . . he pushed back . . . my friend took me to the police station . . . I did tell my cousin that I was raped . . . I shouldn't . . . my friend took me to OHSU and everything . . . I could have screamed . . . for help. I can't remember anything else . . .

On the third day of the focus group interview, Sarah shared that,

Oh yeah, when I was raped. I had a lot of anger out of me. I took that out on my housemates for no reason, there was certain stuff like one was chewing on gum and I got irritated at that. It was because the anger was coming out. This was when I was in my adult, second adult foster parent home. And she acted nerved, they're from Hawaii, and she called my grandma up and to calm me down so my grandma actually didn't want me taking my anger out on anybody. I've been pretty good about not getting angry. I've been thinking like, because I've been told to close my eyes and go somewhere, you know like think . . . . so I do close my eyes a lot and go to the beach, me on a surfboard that's my happy place. What you gotta do before you get angry either close your eyes or use your stress ball. That'll help reduce the stress.

Berne added,

You know, for me it's not just having sex. Due to my physical paralysis it's how you pay attention to, how my boyfriend pays attention to my body, and what ummm pleasures me and I pay attention to what pleasures him and umm how he makes me feel and how I make him feel. It's the whole idea of just being with someone is what I miss the most. It's just having that, being able to call or text and just say hey honey how's your day going, do you want to come over and see me or that kind of thing. I miss talking to somebody about how my day went . . . I know if I will date again, I am little scared because the guys I have dated before are, they all left. So, it's gonna be really hard to put myself out there again . . .

Ross ended the exchange on this topic by saying,

I think as far as my relationship goes, I am thinking about it and I am kind of set and I going kind of slow, and it's in the future. But now it's kind of odd but I am focused on my job and hopefully, it's something that something like baby steps on the road like having my own house, having a marriage and when kids come by, I don't think I want to have kids, because my mom says that as per my body goes, it's really big stress, I think. I just can't do it and I know I kind of don't have to but I am kind of same way with my mom, because the truth is that you don't have to go through that . . .

Participants also spoke about the fears associated with sexual abuse.

"I am scared of being rape." In every interview[30] when talking about sex and

understanding of sexuality, Lilith surfaced the topics of rape and other forms of sexual

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[30] Lilith attended individual interview and the first two focus group interviews.

abuse. On the second day of the focus group meetings, participants were asked to talk

about their understanding of sexuality. Lilith started the dialogue by saying,

> When a man touches woman's private parts . . . if they are uncomfortable in that
> sort of areas . . . but now . . . It's like degrading to other woman . . . to be upset
> . . . that cause a date rape relationship . . .

She further added,

> It's like sexuality with other women too, [boyfriend take] advantage of their
> private parts and touching their private parts and stuff like that . . . sometimes I
> see that in myself . . . something that my boyfriend did to me . . . I am and I can
> talk about it more, I . . . I was at the Mt. Kiwanis camp hall . . . prom night . . . he
> was . . . I didn't know that but I did notice, you know . . . the "p" word into my
> underpants and I had my lady problem . . . with . . . I had my little pad in . . . and I
> felt that . . . it felt very hard . . . and I just know that I was not very comfortable
> . . . I said . . . that I didn't want to tell this to our parents . . . I kept it a secret.

On asking about her feelings about this event, Lilith added,

> I just don't want to say anything to him . . . to his mother or his stepdad or to my
> mom and my dad, and so . . . I spoke to my grief counselor. And spoke to her
> about it . . . and . . . I cried . . . cried . . . and I had my grief thing and I cried my
> eyes out and my mom said that its ok . . . and deal with it . . . get over it . . .

> Lilith concluded her thoughts on this topic by saying that "It [the experience]

affected . . . to myself confident . . . to my self-esteem . . ." During the focus group

interview, everyone in the group approached her and gave her advice that she must speak

to somebody and not keep a secret. For example, upon hearing Lilith's story Berne

immediately urged,

> You must tell something to him though . . . you need to tell someone about it . . .
> because when you are in a relationship you talk to people . . . like if he does
> something . . . or said something that you don't like . . . you really need to talk to
> him . . . It is like if you don't . . . it will keep going keep going . . . not until it's
> like exposed.

Sarah whispered, "Yeah . . . you don't that [let] him to hurt you." To which Berne added,

"correct . . . and not like I love . . . it's not only men who take advantage there are some

women out there that I know of and I know that I might be one of them . . ."

For the most part, Sarah chose to play the role of being a listener during this

portion of the conversation. It was observed that observed that while listening to the

conversation she drew doodles, stepped away from the group to several times to get

refreshments and requested several short smoking breaks. However, after checking with

her two to three times throughout this portion of the conversation, toward the end of this

particular focus group conversation, she finally chose to share her experience. She said,

> I would say . . . at first . . . well . . . you get raped . . . when you don't see it
> coming . . . I would say that you need to be careful of your surrounding when
> someone is trying to attack you from behind . . . I know as I was being raped . . . it
> happened at Cathedral Park . . . and I tried . . . I tried to scream . . . you know . . . I
> tried to push him off . . . I was scared . . . to death. When he did that . . . and
> because when that happened . . . I just told him . . . I, I, I, I had a, I luckily had a
> cop right there when it happened. I told him what happened and but they never
> caught him. Because sometimes, they get away . . . aaa . . . most of the time they
> will get away . . . but sometimes but sometimes . . . they do get caught . . . aaa . . .
> they arrested the wrong man too . . .

She further added,

> Right now you know it's ok . . . But, you know . . . something like that happened
> to me again I have the tendency to spit on the person in his face and I have fake
> thing, that fake blood that I plan to put it on his face . . . I have the trick that I can
> use . . . with that fake stuff that every year at around October . . . you know with
> that fake blood thing . . . You know . . . that was my idea is to do that . . . Oh,
> when someone tries to rape you, or whatever and when it happens . . . you know
> when something like that happens . . . I can spit on the person's face . . . and I do
> have whistle that my care staff bought me . . . I can always blow that on his face.
> Other ways I can do too…

Following these words, there was a deep silence for 10 to 15 seconds. However, I observed that when Sarah was talking about her avoidance strategies, she had a confident smile on her face. After the silence, Berne said,

> I wonder why women go to the bathroom in group . . . it's safety . . . if you go to the bathroom by yourself . . . and if you find someone you don't know . . . there is a chance of rape . . . and you prevent yourself . . . if someone is tapping you or following you then you can go for help . . .

Lilith promptly said, "The buddy system . . . yeah . . . like the buddy system . . . you got to play down and prevent yourself from being kidnapped using buddy system . . ."

Berne replied, "Yeah. Exactly yeah, exactly . . ."

On asking about the influence of rape on her current relationship, Sarah added, "Like it happens a lot . . . like you can't feel love like before . . ."

"Safety and prevention." I also observed that before Sarah shared her experience, Ross shared ideas pertaining to what she had learned about how to prevent sexual abuse.

> "I think there is abuse of sex . . . it is called a sexual harassment and that it happens to lots of men and also telling about it . . . and that's how I l get my input about . . . it's interesting that so many . . . there is a situation kind . . . let's just pretend a situation that can happen . . . probably you are on the TriMet . . . which is kind of, of awkward to face . . . and if you see somebody doing it and this is how I learned . . . taking them up to the TriMet staff thinking of you or its just getting alert too much on that and then I will have to stop the bus and then get off the bus or may be call somebody to pick me up and say that there is somebody who is kind of weird . . . and then ask them to take you home . . ."

She further added,

> I just have been learning about it lately . . . and it kind of depend where you are at . . . there are kind of weird people who can come up to you in a sexual way and in its . . . that they come in your zone and it's kinda hard to get out of it . . . sometimes it can be hard . . . but . . . if you find somebody whom you can trust and the get some help . . . if you know somebody who can help . . . or if you see some people say cops for example and not too much to the cops as it can get kind

of uncomfortable in a way . . . and, I just think it just has to be depending where you are at…my mom says that . . . you got to be careful of what you do . . . like, like you always have to be careful of what you do and be aware of your surroundings . . . which is . . . my mom says you have to be alert, like if you have music in your ears, you kind of have to put them out so that you can hear what is around you…which is what I learned from my mom . . . she says that you have to be alert . . . when it comes to such stuff . . . you need to be on tough of it and just try not to turn out to you and then you need to find someone and take some help and that's what I think about it . . .

Sarah promptly added,

Right now you know its ok . . . But, you know . . . something like that happened to me again I have the tendency to spit on the person in his face and I have fake thing that fake blood that I plan to put it on his face . . . I have the trick that I can use . . . with that fake stuff that every year at around October . . . you know with that fake blood thing . . . You know . . . that was my idea is to do that . . . Oh, when someone tries to rape you or whatever and when it happens . . . you know when something like that happens . . . I can spit on the person's face . . . and I do have whistle that my care staff bought me . . .I can always blow that on his face. Other ways I can do too . . .

Lilith, "and you can whistle too . . ."

Berne added, "scream and let everyone know . . . I would say."

After hearing Sarah's words, Ross silently observed the conversation that followed. From this point on, she chose to not actively participate in this discussion.

At the end of all the focus group interviews, participants along with the co-moderator, counselor, and I as a researcher and facilitator, sat in for five minutes of meditation to give a closer to all the emotions that emerged during the focus group interview.

4.5 Limitations of the Study

The following section describes some key limitations of the study. The primary limitation of this study was the participants' limited communication skills. Each participant had a different level of communication skills used to express themselves.

Also, each of the participants had different cognitive ability levels that were reflected in their mannerisms, expressions, and their abilities to clearly articulate their ideas in conversations.

A second critical limitation had to do with the limits of the research methods used in this study. I conducted three repeated focus groups and individual interviews. While I did find that sharing their story with me was perhaps a therapeutic and empowering experience for participants as they received an opportunity to process through the multiple perspectives from the group, I now realize that conducting multiple in-depth interviews would have provided an opportunity for the participants to develop a higher level of trust with me and perhaps with their peers involved in the research. By having had a limited time to build a trusting relationship, it is probable that the participants disclosed only a small part of their perceptions with me and with each other during the group interviews and focus group discussions. That said, despite limited contact, the young women who participated in this study made impromptu connections with other women in the group during the focus group conversations. Interestingly, two of the participants had known each other in high school and were able to revive this connection with one another, which enhanced their feelings of safety and trust.

Another important limitation related to the interpersonal relationships between the members of the focus groups was that when the participants met in the focus groups, what they chose to share or not share over the course of the conversations was influenced by others in the group. It is notable that the perceptions that were shared during the individual interviews depicted insights about the experiences while growing up and their

current understanding of sexuality. The conversational topics appeared to trigger certain responses in individuals. Few of the participants chose to be silent and when ideas prompted others to be brave and share their experiences too.

Another limitation of this study relates to the research methodology that informed the decision to not gain the perspective of the women's mothers or foster mothers or to purposely involve them in some manner during the initial stage of the study.

Given the sensitivity of the topic and the vulnerabilities of women with intellectual disabilities, participant recruitment was a bit of a struggle in this study. During the participant recruitment period, I was constantly reminded to connect with mothers first and then communicate with the prospective participants. I feel that this could be because of the socially constructed mindset of seeing individuals with intellectual disabilities as being less-than-competent to make their own decisions. This observation aligns with the past research on the role of parents as lifelong guardians and protectors in the lives of individuals with intellectual disabilities. If I had planned to incorporate this power differential element within the study, it seems likely that gaining access to the participants would have been easier.

Theater activities used during the focus group interviews were designed to function as ice-breakers to assist the participants to feel comfortable enough to share their perceptions. However, I found that those activities also informed about the ways participants interact with their own perceptions as well as with the group.

For example, during one of the focus group sessions, two of the four participants were asked to look at themselves (306 degrees) in the mirror, reflect on what they

observed in the mirror, and then talk about their experience. Each woman took her own innovative way to approach this activity. For example, they each looked at different part of their bodies to *see* themselves, to reflect on their observations and then took unique approaches to share their perceptions. The woman who uses a wheel chair gazed at the top part of the body which was still while the two dancers in the group used variations of dance movements while they looked at themselves in the mirror.

Following this reflective experience, participants were asked to share their perceptions. The woman who used a wheel chair said, "I don't see myself at the bottom, I can never see myself naked in the mirror as I hate my body. I can see the upper part of my body, this is me, I like myself this way."

One of dancers said, "I do this often, I like to see myself in the mirror. I am awesome." Likewise the other dancer also gave the positive affirmation.

However, the fourth participant who had experienced sexual abuse in the past refused to look into the mirror. In fact she had her head down throughout the entire time that she was asked to gaze in the mirror. At the time of discussion, she said, "I am ok."

I noted that Sarah chose not to participate in the activity. Sarah was sexually abused. I wonder if this activity brought up her past imagery related to the abuse. Upon reflection, I realized that an important limitation of this research method was that the exercises were not planned based on the trauma-informed approach. I further discuss this concept of trauma-informed approach in chapter 5. For example, I realized that given that there were no alternatives provided to the participants, this limited their ability to participate in self-reflection beyond simply gazing in a mirror.

Another limitation of this particular exercise was that I found that the resulting data was difficult to analyze. The activities were designed for the participants to become more comfortable with one another before discussing potentially sensitive topics. While I did record a number of memos and journal entries to aid my own reflection on the experience, I felt that having a rubric designed in advance of the activity would have been a more useful and reliable way to analyze each women's responses during the activity.

Another limitation to this study was also related to the recruitment methods I selected for this dissertation research and the topic of generalizability. Because qualitative inquiry is concerned with locating participants who can share their experiences and who are most appropriate for giving information about the topic at hand, I took the time to locate participants who wanted to speak about their understanding of sexuality. While qualitative inquiry does not strive for generalizability to the larger population, it does provide thick descriptions and rich information to interpret stories and experiences of a few participants rather than many. Although this study did not strive for generalizability, the study did surface important data that challenges some of the accepted wisdom in the field and is therefore useful for those who work with woman with intellectual disabilities to draw from and apply as they see fit in their own situations.

A third limitation related participant recruitment are the methods I initially selected verses the methods that I was eventually forced to employ. At the time of recruitment, I began using convenience sampling methods and the added snowball sampling methods in order to involved at least eight women in the study. I was dependent upon the brokerages working for and with people with intellectual disabilities and other

organizations in order to connect with the participants. Using the snowball sampling method, I recruited new participants based on the recommendations of those who had already been interviewed. I asked the participants if they knew of peers who might be interested in taking part in this study, and who might be willing to be interviewed. However, due to the sensitive nature of the topic, it was difficult to acquire recommendations.

Using the snowball sampling method may have limited the pool of potential participants and created a self-selection bias. One of the participants' mother said, "I tried to talk to other parents, but they were reluctant to let their daughters be part of this study." One of the participants said, "I want my friend to be part of the study, but her mother will not allow her to attend."

Another limitation that arose as a result of using the snowball sampling method was that although I successfully recruited two participants who lived in the same house, this ended up creating attrition within the group. In this case, one of the two women threatened the other to disclose all the intimate information she knew about her from her past. As a result, both women felt unsafe and chose to withdraw from the focus group.

A related limitation of the study was the small sample size. Due to attrition within the group, only three participants attended all three of the focus group meetings. On the first day there were seven participants involved in the focus group. On day two, there were four participants, and on the third day, the group had been reduced to only three participants.

Chapter 4 presents the results emerged out of data analysis stage two. In chapter

5, I discuss the results using the themes merged out of data analysis presented in chapter

3 and use as an overarching lens to discuss the finding of this study.

CHAPTER FIVE

DISCUSSION, CONCLUSION, AND IMPLICATIONS

5.1 Introduction

The purpose of this dissertation research was to explore the role of familial

culture in the understanding of sexuality by young women with intellectual disabilities.

Additionally, the purpose of this study was to examine the understanding of sexuality by

young women with intellectual disabilities through their current life experiences. The

data collected were used to address the following research questions: (a) what is the role

of familial culture in addressing sexuality for young women (21-35 years), with

intellectual disabilities, and (b) how do young women (21-35 years), with intellectual

disabilities describe their understanding of sexuality? The findings of this study suggest

that familial culture creates a basic foundation for the study participants' understanding

of sexuality. However, participants also shared that their individual life experiences

helped them develop an understanding of sexuality as adult women with intellectual

disabilities. In this chapter, I present a synthesis of the study findings discussed in chapter

4. Additionally, I present an emergent model of a person-centered approach to

understanding sexuality derived from of the findings of the study. As an epilogue, I

present the connection of the study to the Ethnodrama and the implications that could be

useful for policy and practice. The chapter closes with final conclusion and

recommendations for future research. In the next section, I present the synthesis of the

findings conferring the research questions. The synthesis is presented to address the two research questions framed for this study:

5.2 Synthesis of the Findings

Research Question 1

What is the role of familial culture in addressing sexuality for young women (21-35 years) with intellectual disabilities?

The synthesis of the core findings augment the review of the literature presented in the second chapter of this dissertation. Six out of eight participants shared that their mother played a huge role in their understanding of sexuality. Out of those six, four participants shared that their sister also played an important role in learning about sexuality. This finding aligns with the body of research in the area of the role of mothers to prepare their daughter with intellectual disabilities about bodily changes and sexual development to live independently as a member of society (Brantlinger, 1992; Fitz-Gerald, 1978; R. M. Foley, 1995; Gingiss & Hamilton, 1989; Nolley, Muccigrosso, & Zigman, 1996a, 1996b; T. Turnbull et al., 2011).

However, participants also shared that due to their disability, their access to sexual relationships is frequently compromised. This experience is either because they are required to obtain permission from their family (mainly her mother and father in one case) or because of their need for assistance from their caregiver. Both situations are signs of a corporeal dependency that in fact, create a lack of accessibility to sexuality or sexual relationships. At the same time, this also determines a constant need of corporeal assistance to main a quality of life.

In keeping with this observation, I found that mothers and sisters maintain a high degree of influence on the participants in this study. Mothers and sisters perspectives strongly influence their decisions pertaining to sexuality. However, at the same time, mothers and sister/s also play an important role in nurturing the development of the participants' self-determination skills, irrespective of their intellectual disabilities, and support the participants' perceptions of feeling *credible* enough to voice their desires as women. For example, Berne said, "I, me and my sister, we just learned that from my mom that, treating myself with dignity is more important than finding someone to be with, I can find anybody, if I wanted, but I must treat myself with respect . . ."

As a group, participants stated that they received support from their family, especially mothers and sisters, to understand sexuality. For example, Ross shared that, "I can talk to my mother about sexuality; it kinda makes sense, as she is a woman, I am a woman, and she is like me, so . . ." Three out of eight participants shared that their respective sisters provided them with adult intimacy products such as sex toys and taught them how to pleasure themselves.

Specifically, Ross shared that her mother guided her how to masturbate. She shared that, "it feels comfortable. I do it in my own room, though." In contrast, Lilith shared that any kind of sexual activity makes her feel disgusting and she gets scared that it represents rape. She said, "I like to keep out of it." However, she did not specify if this was her own experience or whether or not her mother influenced her to think in this way.

Every family maintains distinct beliefs and assumptions around the various realms of sexuality, which may be guided by one's religion, nationality, class, race, gender roles

in the family, and disabilities (Cuskelly & Bryde, 2004; Karellou, 2007a, 2007b; Swango-Wilson, 2008; Zetlin, & Turner, 1985). In turn, parental belief systems related to sexuality directly influence their approach toward sexuality for their growing child with intellectual disabilities (Abramson, Moriuchi, & Waite, & Perry, 1983; Ballan, 2008; Edwards, 1988; Edwards & Elkins, 1988; Harold & Benson, 1979; Isler et al., 2009; Lamb, 2010; Lamorey, 2010; Malfetti & Rubin, 1968; Picker, 1984; Rienzo, 1981). The participant's voice also demonstrates familial culture as their gatekeeper to approach sexuality and sexual relationships.

In a study conducted by Evans et al. (2009), researchers found that parents' perceptions, attitudes, and beliefs about sexuality directly influence what they talk about and teach to their growing child with intellectual disabilities. Importantly, if the child is a female, the concerns that parents have for their child with intellectual disabilities tends to be doubled (Esteev, personal communication, 2015). For example, Ross shared the influence of her mother's role in her decision making regarding pregnancy. Ross said, "My mother told me that it [being pregnant] may not good for my body, and I may not be able to handle that stress." Upon asking how she feels about her mother's suggestion, she said, "I am fine, kinda, my mother knows best for me." This remark aligns with the past studies that examined the attitudes and perceptions of parents and professional about sexuality for individuals with intellectual disabilities (Cuskelly & Bryde, 2004; Evans et al., 2009; Yool et al., 2003).

These studies also revealed that most parents and professionals experience *vulnerability* in addressing sexuality as a topic of conversation for individuals with

intellectual disabilities (S. Foley, 2013). Koller (2000) wrote that as a result of deep-seated concerns and feelings of vulnerability related to how to properly address topics related to sexuality, parents and professionals create safety nets and attempt to cultivate healthy sexual development for people with intellectual disabilities.

In the similar vein, Hingsburger and Tough (2002) wrote that even well-meaning parents build "prisons of protection" (p. 25) that tend to hinder their children's self-determination in this area of their lives. This phrase *prisons of protection* aligns with Anna's comment during her individual interview: "I can make my own decisions, I want to live with my boyfriend . . . I don't need my mom's help to make my own decision, but she does . . . [make decisions for me on daily basis[31]]."

The familial beliefs and assumptions about sexuality are key contributing factors to the sense of vulnerability parents feel regarding how to address sexuality with their growing child with intellectual disabilities (Fraser & Sim, 2007; Morris, 2002). This vulnerability associated with sexuality often influences what parents decide to teach or not to teach their growing child with intellectual disabilities about sexuality (S. Foley, 2013). Notwithstanding, whether this experience of sexuality is embraced, hidden, or is considered confusing, the literature read emphasizes the idea that families play a central role in addressing sexuality in the life of individuals with intellectual disabilities (Alcorn, 1974). Such decisions have implication on how children develop their self-determination skills and embrace their sexuality (Gill, 2005, 2010, 2012).

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[31] This extension of the sentence was added based on Anna's words that her mother makes most of her decisions every day on her behalf. She tells her what to do and where to go and Anna follows what her mother tells her to do.

In growing individuals with intellectual disabilities, a heightened perception of vulnerability may impress a sense of fear surrounding how to navigate sexual relationships including the fear of being abused sexually. In turn, this may result in causing the development of fear-based self-defense skills strategies. For example, in this study one of the participants was constantly talking[32] about rape and sexual abuse to address all the interview questions related to sexuality. Upon speaking with her mother, I found that since there was a history[33] of sexual abuse in their family, she and her daughter were engaged in frequent dialogue about rape and sexual abuse and what her daughter needs to do to prevent this form of abuse from happening to her. In this case, the participant's family's beliefs and assumptions directly influenced their teaching about sexuality and prevention of sexual abuse to their daughter from a fear-based perspective.

Out of eight, four women involved in this study lived in foster care facilities. Out of those four, two of them lived in the same house. The women living in foster homes shared that they were not comfortable to connect with their foster care mothers and speak of anything related to sexuality. Since they had a strict faith-based environment at home, they were taught to value celibacy and abstinence from sex. Oprah, who has lived with her foster mother since she was 9 years of age added, "my [foster] mother and cousin teach me to live by example." She qualified this statement by sharing that she has learned

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[32] As an answer to the question, *what is sexuality,* the participant only spoke about rape and her fear of being raped. After the individual interview I contacted the participant's mother to ask if her daughter was raped or experienced/ experiencing any sexual abuse.

[33] The mother told me that her sister in-law is a woman in her 50s who has Down syndrome and was sexually abused three times when she was in her twenties. The mother also shared that as parents, they were scared that their daughter might experience the same thing, so they wanted to make sure that their daughter is well aware about what rape is and how she can prevent it.

from her familial environment to acknowledge that, "I am a human, mistakes happen, so when I do something bad, I sit in prayer and ask for forgiveness." These statements allude to the influence of her familial environment on her perception of sex before marriage as a sin, which may be repented through prayers.

Foster care experiences. Maya, who lived in the same house as Oprah, shared that she is closer to her grandmother than her foster mother. Maya shared that she was 16 when she moved to her foster care home. She also shared that her biological mother is in jail. She said, "I don't know who my father is . . . she did drugs . . . it's ok . . . I am fine . . . I love my grandmother very much."

Maya shared that when she was very young (age not specified), her grandmother had adopted her after her mother went to jail. Maya further added that, "it was difficult for my grandmother . . . so I have come here to live at my foster care home…but I visit her [grandmother] regularly . . . my foster mother is fine too."

In connection to sexuality, Maya said, "I like to talk to my friends, I feel more comfortable . . . it's too awkward to talk about sex, I am not comfortable . . . something happened too . . . it was difficult, but its fine, I am over with it now, I have a job" After sharing this, Maya abruptly ended the conversation.

On talking to her foster mother, it was revealed that she was kidnapped and was sexually abused approximately a month before this interview. The foster mother also shared that she has often caught Maya sending sexually explicit pictures to strangers. Additionally, she added that she wanted Maya to participate in the study so that the

conversation on sexuality will help Maya understand sexuality from a more moral perspective. She said, "she needs help, I want her to be safe . . ."

After the first focus group interview, Maya's foster mother shared that she has asked Maya to deposit her phone with her and that she has limited Maya's access to her friends as a punishment for watching and sending sexually explicit information. She also shared that Maya needs to see a behavioral specialist because of her behavior problems pertaining to sexuality. Maya was allowed to participate in only one focus group discussion after meeting for the individual interview.

Due to the fact that I was unable to collect detailed information on Maya's experiences, there was a great deal of ambiguity in Maya's living situation around topics pertaining to sexual abuse, incarceration of her mother, drugs, kidnapping, living in a faith-based foster home, the role of her grandmother and attempts of protection made by her foster mother. However, Maya's situation reflects that under the guise of protection and care, Maya's foster mother barred her access to social relationships, and perhaps her credibility as a woman who has reached the age of consent to make decisions about how she wanted to behave on her own. That said, I want to add that no final conclusions can be made due to the ambiguity and incomplete nature of the data that was collected. Notwithstanding, it is important to note that during the interviews, Maya presented herself as a strong woman who accepts her disability and sexuality.

Sarah shared that life in her foster home involved a mix of different emotions and experiences. She shared that she had been living in foster care since she was an adolescent and that she had lived in total of four foster care homes. Sarah related that she

had changed foster homes because she was uncomfortable and did not like the way her foster parents lived in the past. She indicated that drug and alcohol use that took place in the households influenced her decisions to leave foster homes.

Despite that she lived in foster homes for most of her life, Sarah spoke only about her birth parents and siblings. She shared that after her father went to jail, she and her remaining family members experienced difficult living situations which prompted her move into a foster home. She did not share much about the living situation before she was moved to her first foster care home although she did mention that she had also experimented with drugs and alcohol in the past and had spent time in juvenile detention for her aggressive behavior. She also shared that she had experienced sexual abuse in the past.

Both Sarah and Maya provided limited information about their experiences at the foster home. However, in connection to her current living situation, Sarah shared that, "I like living here as this one is close to where my mom lives . . ."Although Sarah possess limited communication skills, I inferred that Sarah experienced a challenging and uncertain living situation in foster care. However, despite the many challenges that she related, she consistently spoke of herself as being a strong, beautiful and attractive woman.

In contrast, Jane who also lived in a foster care home, chose not to focus on talking about her birth parents. While she did say that her father played an important role in her life, she emphasized that she primarily relied on her teachers at school and her

fiancé's sister to learn about sexuality. In addition, she shared that her boyfriend has helped her to navigate through experiences related to sexuality.

Overall, the participants' narratives point to the fact that familial culture plays a highly influential role in the participant's understanding of sexuality and that this sense of understanding varies for different families. Based on the narratives provided by the participants in this study, it can be interpreted that family's belief systems and assumptions held by the women's families created a foundation for most women's understanding of sexuality. Both the women and their care provider's sense of vulnerability associated with sexuality is highly influential on the participants' access to sexual relationships, self-determination related to sexuality, self-compassion, and learning about credibility as women with intellectual disabilities.

Research Question 2

How do young women (21-35 years) with intellectual disabilities describe their understanding of sexuality?

In addition to finding that familial culture influences participants' understanding of sexuality, participants also shared that they learned about sexuality from their individual life experiences as well. Participants spoke about their learning some conventional paradigms related to gender, access to sexual relationships, and sexual abuse. Additionally, a few of the participants shared their experiences with online dating, visits to strip clubs, and experiences of rejection. For example, participants shared about experiences of being ridiculed because of their inability to comprehend ideas and

correctly interpret situations. However, they also shared their perceptions related to embracing moments of approaching sex.

No one in the group shared that they are homosexual, at the same time Ross's remark, "with my disability, it's better that way [to be with a man than with a woman]" aligns with the perceptions listed in the literature that most individuals with intellectual disabilities are either asexual or heterosexual (Murphy &Young 2005; Noonan & Gomez 2010) or as heterosexual only (Abbott & Howarth, 2007; Löfgren-Mårtenson, 2009; McCarthy, 1999; Noonan & Gomez, 2010).

When participants were asked directly about their understanding of homosexuality, they shared that even though they do not identify as being homosexual, they did acknowledge homosexuality as a legitimate sexual orientation. When asked about their own sexual orientations, Lilith promptly said, "I am not . . . I am not a lesbian." Lilith said this with a sense of pride, and later in the interview, she expressed that she thinks "it's disgusting" for her. While the participants did not say that it was a bad thing for other people to be homosexual, their remarks make it obvious that they were told that it would be better if they engage only in heterosexual relationships. This pattern is similar to patterns found in McCarthy's (1993) study wherein she claimed that most women with intellectual disabilities considered same-sex relationships as a "bad" thing for themselves.

Participants' comments indicated that the concept of homosexual relationship is influenced by the cultural climate of the region they live currently live in (Löfgren-Mårtenson, 2009). During a focus group discussion, Sarah promptly said, "Oh, and our

mayor was gay, too." In response to that observation, Jane shared that, "my sister is gay but I am not; we were both raised as Christian." Maya promptly responded by saying, "how does that matter who is loving whom, at least they have someone to love." This statement indicates nuanced attitudes toward sexual orientation among the participants.

Such attitudinal nuances challenges the findings reported in a study conducted by Löfgren-Mårtenson (2009) who found that 90% of women with intellectual disabilities disapproved of homosexuality. This was due to ethical dilemmas they inherited from the families around sexuality and sexual relationships. In fact, in the course of this study, despite the claim that she is not homosexual, Maya (who only participated in one focus group and an individual interview) stated that she is interested in both men and women. She added, "It doesn't matter [if it's a man or a woman]. My [foster] mother doesn't know that." In response to the question asking what does she know about being bisexual, she said, "maybe, I don't know . . ." After this discussion, Maya indicated that she was reluctant to continue the conversation along this line of thought.

Guzman and Platero (2014) wrote that the conjunction of intellectual disability and sexuality is intrinsically deeply rooted in the notion of having a so-called *normal body* and *normal understanding*. Additionally, McRuer (2013) wrote that individuals with disabilities and people who identify themselves as LGBTQI have been historically seen as "sinners," "evil" or "defective" (p. 93) and deviant from the normative stance. McRuer wrote that as a result of this perception, individuals with or without disabilities, who do publically identify as LGBTQI experience daily discrimination that affects relevant areas of their development and socialization such as family acceptance, access to

education, housing, employment or leisure, among others. As a result, they experience

isolation even within their own families, neighborhoods, or the most immediate

surroundings in which they live (Sandahl, 2003). Statements made by Maya and Ross

speak to this subjectivity associated with sexuality found within the cultural sphere that

they experience.

Data from the study indicates that, three out of eight participants had been

sexually abused. Among the three women, one had been kidnapped and sexually abused

for a period of 48 hours.[34] In the case of the second woman, her mother's boyfriend

sexually abused her at nine years of age. The third woman was sexually abused in a

public park in the dark of night. These statistics within the small sample involved in this

study align with findings reported in the literature that claim that women with intellectual

disabilities are at an even higher risk of sexual abuse than woman without disabilities.

For example, Petersilia (2001) claimed that she found that women with intellectual

disabilities are 4 to 10 times more likely to be abused than women without disabilities.

Disturbingly, more than 87% of women with intellectual disabilities are sexually abused

(Brown, 1996; Khemka & Hickson, 2000; Turk & Brown, 1992).

All three women who experienced sexual abuse shared a common belief in their

abilities to go beyond the painful experience. Oprah reflected that her approach to coping

with abuse and her post traumatic stress disorder was rooted in her strong faith. She

shared that "God wants us to learn, I pray all the time. I don't know why it happened, but

I am learning to live by example . . ."

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[34] This information was given by the foster mother. This participant only participated in the individual interview and first focus group interview.

However, it is unclear as to how this coping mechanism impacts her understanding of sexuality as was evidenced by the follow up comment, "being a woman, it [understanding] gets difficult." Upon asking about what she meant by this difficulty, she was unable to explain her own words and she ended up repeating what she shared. The experiences these women related regarding their work to move on from their experiences of sexual abuse align with the literature that states that women with intellectual disabilities can be much more vulnerable to sexual abuse and victimization and that the strategies used to cope with the emotions that result from such experiences are directly influenced by their intellectual disabilities (Begum, 1992).

Notwithstanding this research was limited to very few interactions with the participants, the participants in this study shared that they did receive counseling services but that they lack any form of peer support groups that assist them in figuring out how to interpret and cope with their experiences of sexual abuse. However, the three participants who shared their experience of sexual abuse demonstrated their zeal to attain sexual self-determination and to go past their abusive experiences and challenge the status quo.

Furthermore, participants who shared that they had experienced sexual abuse, also expressed that they were too naïve to file charges against their attacker. Sarah shared that, at the time when she was raped, she did not know how to navigate through the situation, as patrolling officers did not make an arrest. Sarah said, "I told them what happened, but they never caught him, because sometimes they get away . . ." She did contact a friend that took her to the hospital after the attack.

Sarah shared that she had been receiving counseling to assist her process in dealing with the post-traumatic stress associated with her experience of sexual abuse. She also shared that, "Right now you know its ok. But, you know . . . something like that happened to me again I have the tendency to spit on the person in his face . . ." As Lorde (1980) said, "it is not difference which immobilizes us, but silence. And there are many silences to be broken" (p. 15).

Out of eight participants, two of them who had not experienced sexual abuse shared that they have a fear of being raped. One of these two women shared that she does not want to engage in a sexual relationship in order to prevent negative sexual consequences. This fear-based position is similar to those of participants in a study conducted by Bernert and Ogletree (2012). However, despite their fears of being raped, Anna shared she wants to experience sex and that a motivation for this desire is that "sex is like having fireworks inside of me." Upon asking where she learned about the sensation of fireworks inside of her, she said, "I created it! I feel good with that thing [intimate sexual product], I want to do that with my man."

Both of these women shared that they were dating although they did not engage in sexual relationships. These two women lived with their mothers whom they were nearly completely dependent upon for assistance. According to their mothers, both women spend most of their time watching movies and television alone. Indeed, this observation is consistent with studies that have shown that most women with intellectual disabilities spend much of their time watching television that does not provide complete information nor assist the viewer in interpreting what they see and that such experiences negatively

influence their perceptions of sexuality (Harader, Fullwood, & Hawthorne, 2009; Hingsburger & Tough, 2002; Löfgren-Mårtenson, 2009; Servais, 2006; Stinson et al., 2002; Swango-Wilson, 2008).

Research conducted by McCarthy (1999) and Blanchett and Wolfe (2002) supported the suggestion forwarded by Bernert and Ogletree (2012) that the information consumed through movies and other public broadcasting programs are typically rife with fear-based messages which often emphasize negative outcomes related to sexual activity. Bernert and Ogletree (2012), Lesseliers and Van Hove (2002) and McCarthy (1999) documented that frequent exposure to media with negative associations related to sexual experiences contributes to women with intellectual disabilities becoming often fearful, full of confusions, and lacking in sexual pleasure due to inadequate knowledge of sexuality from a more rounded perspective.

In keeping with these observations, most of the participants shared that over the years they have developed a strong fear of being raped, fear of tarnishing an image of being "lady-like," experience deep physiological concerns about the sex act itself, and perceived or actual lack pleasure during the sex act. These findings were consistent with Butler et al. (2004) who noted discomfort, confusion and ambivalence among individuals with intellectual disabilities related to their understanding of sexuality due to incomplete, unclear and distorted information on sexuality.

Begum (1992) brings forward the point that if women with intellectual disabilities do not conform to conventional gender roles, then the fight to gain access to institutions such as the family becomes extremely difficult, if not impossible. Participants also shared

that being a woman, it is important to abide by the social expectations. Literature

suggested that most women living with intellectual disabilities fight very hard to conform

to their perceived ascriptions as women (Stefánsdóttir & Traustadóttir, 2015).They

possibly settle with or accept abuse in their lives in order to gain a sense of social value

that has often been missing throughout their life course (Hassouneh-Phillips & McNeff,

2005). This situation together with gendered power imbalances increase the possibility of

associated confusion related to acceptance of sexuality and as a result of their confusion,

women with intellectual disabilities are often prone to be more likely to experience abuse

(Powers et al., 2002).

Altogether, the group of women who participated in this study shared that as

adults with intellectual disabilities, their understanding of sexuality is beyond the

concepts of sexual functioning or mechanics of sex. They don't see any connection of

sexuality with their disability, as seen through the lens of a biomedical approach of

disabilities (Smart & Smart, 2007). They shared that for the most part, they learned about

sexuality from their individual life experiences. The experiences gave them an

affirmation that they want to live a full life that includes dating, romance, caring for

family, marriage and experience of motherhood (Di Giulio, 2003).

In addition, the group of women also shared their understanding of being a

woman with intellectual disability (and in case, along with a physical disability) and their

awareness of their vulnerabilities related to (a) access to relationships, (b) body-image

(Hassouneh-Phillips & McNeff, 2005; Ide, 2004; Moin, Duvdevany, & Mazor, 2009;

Parker & Yau, 2012; Rousso, 1981), (d) self-esteem and self-confidence (Esmail et al.,

2010), (e) lifelong living within a care giving environment such as living with family, and (f) dealing with trauma (Hassouneh-Phillips & McNeff, 2005).

Besides the awareness of their vulnerabilities, the study revealed that the participants saw themselves as being complex women who accepted and reflected on the core elements of their own identity as a human being by being compassionate toward themselves. Additionally, few women also shared that they experienced a sense of a lack of credibility in their ability to make their own decisions related to their sexuality. Notwithstanding this perception, participants unanimously agreed that having disability does not describe a person in their entirety, however it is a way of being that influences ones approach decision making differently than the way decision making is approached by those who do not experience intellectual disabilities.

5.5 Outcome of the Findings

As a whole, this study facilitated the process of designing an emergent model that is informed by a person-centered approach. I will first illustrate (Figure 5.1) the connection between the study findings and the literature I reviewed of study. After that I provide a brief literature review to situate person-centered approach within this dissertation.

For the purpose of this study, sexuality was defined as an interaction between one's physical, social, psychological (cognitive), and cultural dimensions of existence (Greenberg, Bruess, & Oswalte, 2014). In Figure 5.1 the inner most Venn diagram (orange color) points to the definition of sexuality and the reviewed literature for this study. Additionally, the outer most circle (orange color) represents the brief review of the

literature presented in chapter 2 in connection to the understanding of the four

dimensions of human sexuality.
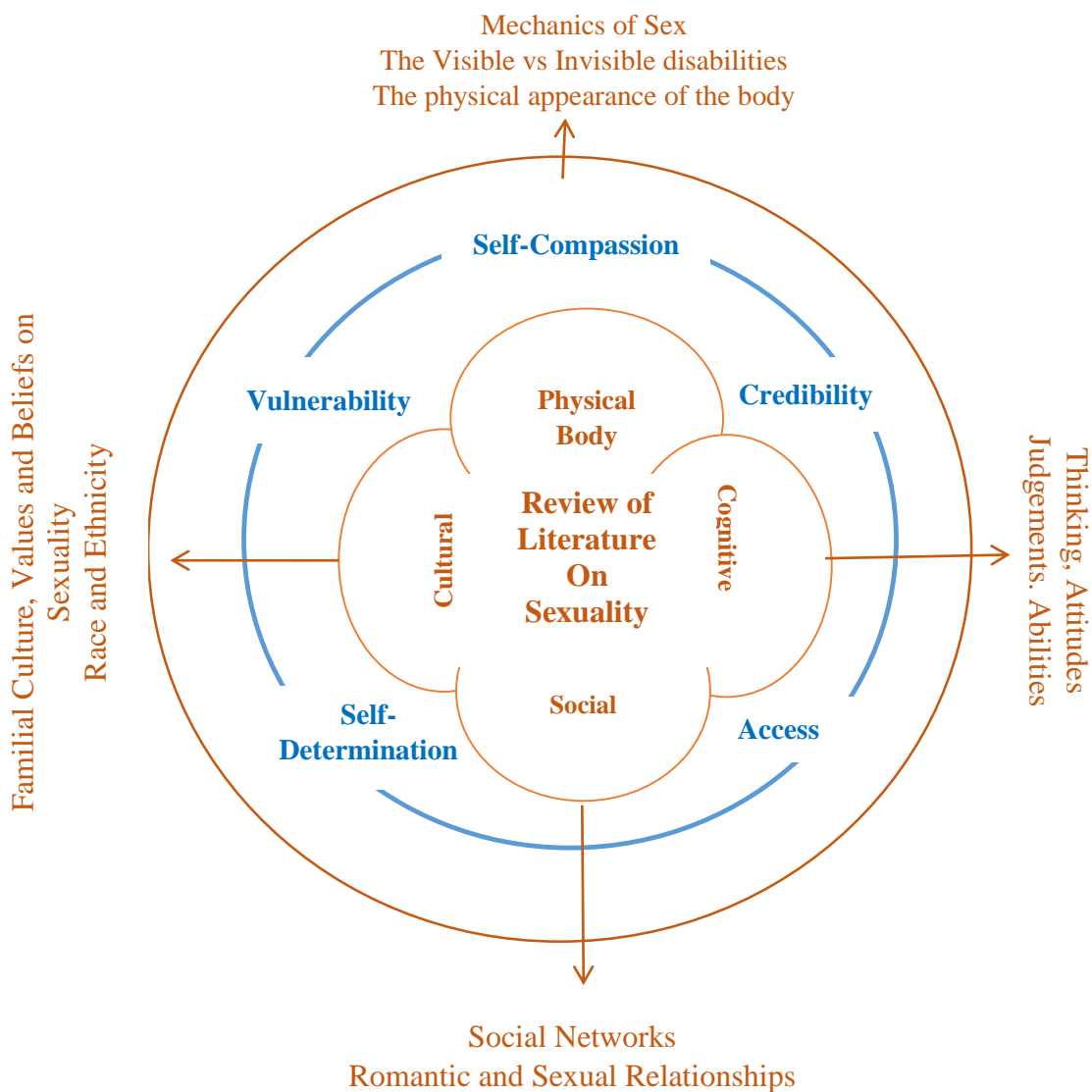
Figure 5.1. The connection of the literature review and the outcome of this study.

Figure 5.1 presents the understanding of sexuality by the participants in this study.

The women in this study, described their understanding of sexuality (Physical, Social,

Cognitive and Familial Culture), as a filtration through the experiences of self-

compassion, self- determination, credibility, accessibility, and vulnerability. However, the findings of this study also suggest that the women each had their individual understanding based on their individual life experiences and the role of their individual familial culture. This individual experience of all the women who participated in this study directly speaks to person-centeredness to understand sexuality. Here, I present literature to support the emergent model with reference to gender neutral information related to intellectual disabilities to situate this dissertation within a larger context.

Person-Centered Approach

Most literature focusing on a person-centered approach for working with individual with intellectual disabilities generally relates to the development of *person-centered planning* approaches to facilitate independent living programs for individuals with intellectual disabilities. Another setting where one may also find person-centered approach in action would be within school transition programs (Garner & Dietz, 1996; Mount, 1992; C. L. O'Brien & O'Brien, 2000; J. O'Brien & Mount 1989).

The person-centered approaches build on a framework that focuses primarily on the quality of the life of an individual (J. R. Thompson, Schalock, Agosta, Teninty, & Fortune, 2014). Kim and Turnbull (2004) described a person-centered approach as a method that maintains focus on the person first by listening to and meaningfully supporting the person with intellectual disabilities based on their needs, abilities, aspiration and preferences.

J. O'Brien and Lovett (1992) wrote that person-centered approach is "a family of approaches to organizing and guiding community change in alliance with people with

disabilities and their families and friends" (p. 5). The definition provided by J. O'Brien and Lovett aligns with the concept of the transformative paradigm used in this dissertation study. This description also speaks to the connection of multiple approaches to bring forward the voice of the individual with disabilities. Although I was able to find a great deal of literature on person-centered planning for group programs and the person-centered approach for working one-on-one with individuals with intellectual disabilities in connection with transitioning programs, I found that there is almost no literature that specifically proposes how to employ the person-centered approach to address sexuality.

Recognition of this important gap in the literature and the outcomes of this study presents an opportunity to create a person-centered approach to sexuality. In the following section, I will describe a person-centered model that would seek to address this gap. Importantly, I acknowledge that this model ought to be considered an *emergent* model with a scope to be further refined based on future study using this model.

The Person-Centered Approach to Understanding of Sexuality

The model is developed out of the findings of this study and the literature reviewed for the purpose of this study. The findings of the study revealed that an understanding of sexuality gets percolated through each individual person's experiences of vulnerability, credibility, accessibility, self-determination, and self-compassion which are highly influenced by one's living situation either with the immediate family or with foster family. This foundation of understanding impacts how people interpret their life experiences, develop a rationale as to how to interpret information and strategically form their own stance toward sexuality.

Figure 5.2 presents a model that demonstrates a person-centered approach to understanding of sexuality. In this figure the emphasis on conceptualizing sexuality as person-centered draws ones focus to considering quality of life as an appropriate outcome of policies and supports (Park et al., 2003; Schalock et al., 2002), but also confirms the connection to critical disability studies which emphasizes the value of embracing and honoring the embodied human existence. The model alludes to breaking away from the medical gaze and envisions the potential of a person to self-determine in all aspects of their being, including their sexual self since this is an essential component of what it means to be fully human.
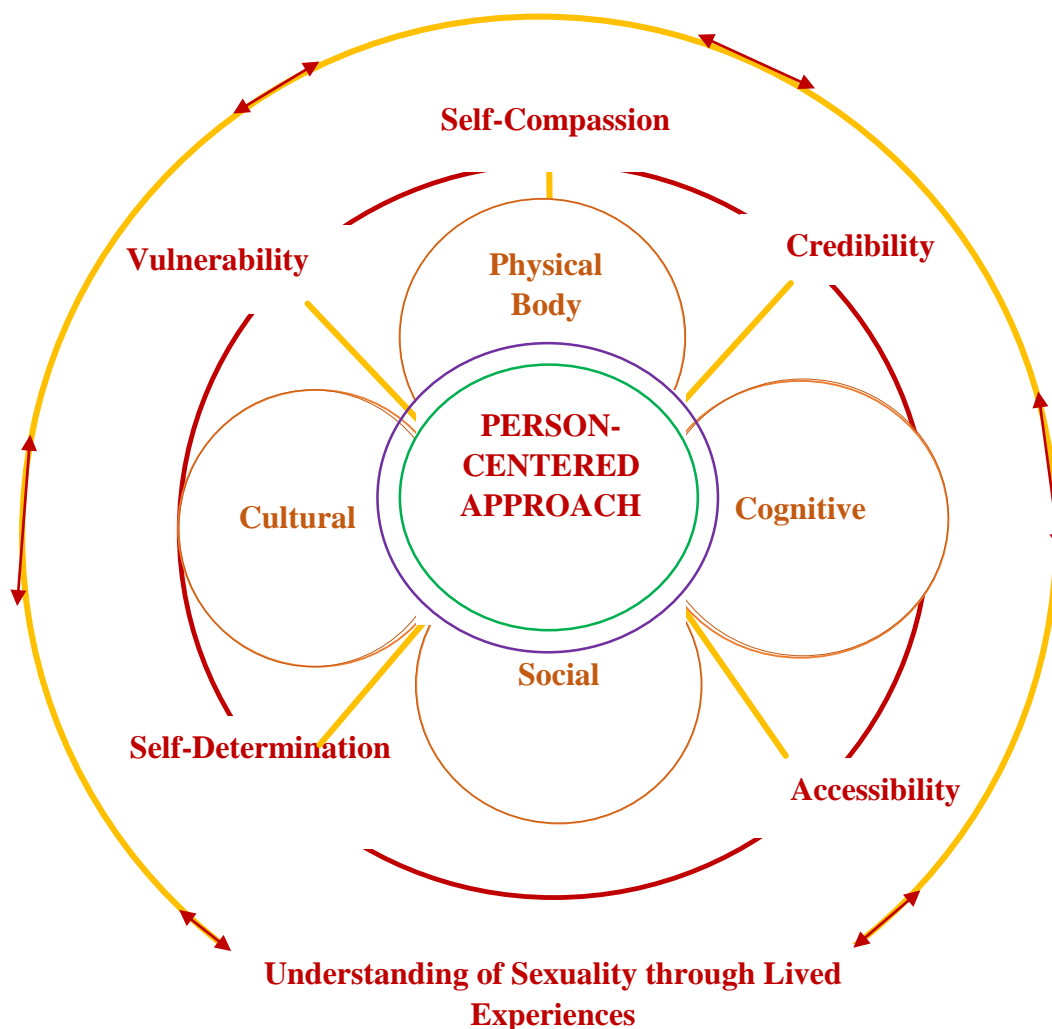
Figure 5.2. An emergent model of person-centered approach to understanding of sexuality.

The proposed model also provides an opportunity to see sexuality as a human rights issue. Positioning sexuality within the realm of person-centeredness, creates a prospect of providing accessibility to one's sexuality based on a human rights perspective as a substitute of goals related to protection that are fear-based in nature.

Moreover, this model draws attention to the myriad of inputs that are the key to the people supporting an individual with intellectual disabilities for example care providers, families and friends. By acknowledging the fact that every individual

continues to grow and change over time, thus part of the work of the care provider is to help women to negotiate this process of growth. This model creates a platform to situate the individual's understanding of sexuality percolated through their individual experiences of self-compassion, self-determination, credibility, accessibility, and vulnerabilities associated with sexuality.

While person-centered planning is unlikely to be a panacea for understanding sexuality, this model may open up opportunities to users for weaving in topics related to human sexuality within programs that employ a person-centered approach that includes consideration such as self-compassion, self-determination, credibility, accessibility, and vulnerabilities associated with sexuality. Furthermore, adding the element of sexuality to the existing model of a person-centered approach may improve the involvement of some stakeholders, most notably the young women themselves and their families. Involving them in planning their future represents significant progress on the decisions related to sexuality, choice, rights and inclusion (Individuals with Disabilities Education Improvement Act of 2004).Yet, the exact impact of person-centered approach to sexuality on developing options and service delivery may depend upon the collaborative efforts of various stakeholders.

With that said, I also acknowledge the concern raised by Claes, Van Hove, Vendevelde, van Loon, and Schalock, 2010) regarding the suspicion that even the best person-centered process may lack substance. Given the discomforts many people have surrounding topics related to human sexuality, even with a well-described model for including sexuality in a person-based approach, it may be the case that care providers and

educators will provide inadequate guidance in this area in order to simply check a box that says that they did provide this service. Unless those who provide such services perceive the person-centered approach as a mechanism to develop a genuinely personalized and individual service to individuals with intellectual disabilities and their families that address the needs of the whole person irrespective of gender, discomforts with topics related to sexuality may win the day. In order to avoid this situation, given that people with intellectual disabilities are often cared for through more than one program, those involved in coordinating and training care providers themselves will need to embrace sexuality as part of the person-centered agenda and as an integral part of service planning across professional boundaries.

5.5 Implications

5.5 a Implications for Policy

Topics related to sexuality from multiple perspectives is crucial because of the implied connotations of sexuality within the social environment and the variety of perceptions people have concerning the word sexuality. The literature that I reviewed emphasised that most individuals with intellectual disabilities experience familial or caregiver's protection for most of their lifetime, which affects their access to their sexual self and exploring sexuality.

Based on the functional and environmental models of diabilities, it is the responsibility of the people in and around the lives of individuals with disabilities to provide a barrier free environment. These barriers are not just limited to physical barriers,

but also include assistance in negotiating emotional and social barriers to feel safe yet

desired so as to further nurture self-determination (Smart & Smart, 2007).

For example, Berne was a 30-year-old woman who experiences both an

intellectual disability and Spina Bifida, which confines her to a wheelchair. Berne shared

that she always brings her mother along with her when she goes on a date. She confided

that she does so because, " my mother feels secured that I am safe." She added, " I feel

fine as I don't want to meet weird people all by myself " and, "I am happy that I get to fix

the date online and then we go to meet the person." Thus, from Berne's perspective, her

mother is enabling Berne's access to her sexuality.

Societally, an important form of support necessary to enable equitable access to

human rights stems from policy. If seen from critical disability studies perspective, the

privilege to embrace one's sexual self is currrently not accesseble to most women with

intellectual disabilities. One way to encourage such change is through advocacy efforts

and policy expansion.The Developmental Disability Act of 2000 outlines the rights of

individuals to live a safe life free of abuse, neglect, and exploitation. In addition, the

WHO (2002a, 2002b) has stated that sexuality is a human right and the sexuality

education must be facilitated for everyone. However, federal legislation related to

sexuality education for individuals with disabilities is lacking a policy that focus on the

person-centered approach to sexuality for individuals with intellectual disabilities. The

Developmental Disability Act of 2000, the Individuals with Disabilities Education

Improvement Act of 2004, and the Americans with Disability Act of 1990 are all void of

any references to sexuality education or safety training for individuals with disabilities, specifically in regard to people with intellectual disabilities.

Many public laws related to individuals with intellectual disabilities (e.g., Developmental Disabilities Act of 2000; Individuals with Disabilities Education Act of 2004) already require individual support plans that can be developed within conceptual and measurement framework. Adding verbage to the existing policies that align support needs related to sexuality and include the assessment of sexuality related personal outcomes, is one way that this critical gap may be addressed.

For instance, Medicare and Medicaid, the primary funding sources for community services and supports for individuals with intellecual disabilities in the U.S., have recently implemented a quality framework that focuses on participant outcomes and the use of that information for quality assurance and improvement (U.S. Department of Health and Human Services, 2005). Each of these public policies offer an opportunity to integrate a person-centered approach to sexuality as a conceptual and measurement framework into current public policies and programmatic practices.

Considering the sexual abuse rates of women with intellectual disabilities (Harrell & Rand, 2010), and even of people without disabilities (Petersilia, 2001; Sobsey, 1994a, 1994b), I recommend that stakeholders engage in broad-based advocacy efforts, resulting in the creation of policies and connected strategies that support the development of comprehensive sexuality education and safety training for individuals with intellectual disabilities. In the following section, I will describe some implications for practice that arise out of this study.

5.5 b Implications for Practice

Even though every participant in the study received sexuality education in school or adult transition programs, participants shared that the education they received did not focus on their identity as a woman and did not involve any information on the trauma associated with sexual abuse and sexual assault. Parents, staff, and caregivers of individuals with intellectual disabilities often have multiple opportunities to communicate safety and sexuality information as a result of ongoing, if not daily contact and interactions. However, as stated by one of the participant of the study, "I prefer to connect and talk to someone like me [rather] than talking to my mother." This comment highlights the importance of research that examines the role of peer-to-peer mentoring on the dimensions of sexuality such as physical, social, and cognitive to further address the contexual framwork derived out of this study.

The role of peer-mentoring has been widely studied in the area of higher education, jobs, and even student retention. I highly recommend that research be conducted that explores the impact of a peer-mentoring programs that address sexuality related issues specific to those experienced by women with intellectual disabilities and that this work be approached from a person-centered perspective to gain greater understanding.

Four participants in this study shared their personal goals related to meeting new people and making new friends. One of the participants also shared that she wants to be connected to the women's group where she can communicate her challenges related to sexuality. Thus, an important implication of this study relates directly to staff and

directors of agencies that provide educational and social programming for individuals with intellectual disabilities. Agencies are encouraged to create opportunities for safety and sexuality training that draw upon a person-centered approach as part of the regular meet-up group sessions held within their institutions.

Additionally, the participants of the study enjoyed the opportunity to meet new people through the focus group meetings. However, from my perspective, these limited encounters did not provide opportuities for the participants to develop meaningful friendships with those within the group. Agencies have the opportunity to organize social events such as informal mixers held before the training or alternatively, sharing lunch or dinner immediately following workshop or training. Additional time for informal conversation could potentially provide meaningful experiences for all individuals engaged in the workshop/training. This will further build trust to address sexuality with a focus on self-compassion, self-determination, vulnerability, accessebility, and credibility as an individual. By providing such opportunities within such contexts, care providers will be afforded with the possibility to facilitate effective communication among the women and simulteneously increase opportunities for women with intellectual diabilities to expand their social networks with each other, peer mentors, and with agency staff members.

Mental health implications of abuse and victimization have been documented in the literature (e.g., Champagne, 2007; Matich-Maroney, 2003; Peckham, Howlett, & Corbett, 2007). For example, certain topics covered in the curriculum could serve as triggers for bad memories. With sensitivity to these concerns, in addition to resources and

referral information, I recommend that curriculum be designed to weave in a *trauma-informed* approach to address sensitive content that involves person-centered programing for every individual. For example, Family life and sexual health (FLASH, 2006) is the primary sexuality education curriculum used by special education in both King County (Washington) and Multnomah County (Oregon). FLASH is often promoted as an exemplar of comprehensive sexuality education for special education and does approach issues directly related to people who experience intellectual disabilities. Although FLASH provides a comparatively more comprehensive notion of sexuality education than many other curricula such as CIRCLES (see chapter 2). However, FLASH as a curriculum is designed to teach the sexuality from more of a medical stance, this curriculum fails to adequately address concepts of sexuality related to possible trauma connected with sexuality and other concepts such as gender identity, sexual orientation, or healthy relationships.

Trauma-Informed Approach

A growing body of scientific literature from the field of social work, health care, and women studies indicates the success of trauma-informed training programs focusing on vulnerable population. Trauma-informed systems are structured with an understanding of the causes and effects of traumatic experiences, along with practices intended to support recovery rather than exacerbate vulnerabilities. Trauma-informed practices include educating all stakeholders engaged with the individuals and their families. This involves conducting a systematic assessment of individual needs and dedicating resources to the provision of trauma-specific interventions (Ford & Hawke, 2012).

For example, in this dissertation study, a certified counselor was made available to be present with the women involved in the focus group discussions. Plus, every participant was provided a list of resources they could connect with if they needed assistance processing their experiences as participants in the discussions.

There are several books (e.g., A. Craft & Craft, 1983; Hingsbuger & Tough, 2002) and articles (e.g., Bernert, 2011; Bernert & Ogletree, 2012; Hingsburger & Tough, 2002; Lesseliers & Van Hove, 2002, 2009; Stinson et al., 2002) that focus on the pedagogy of sexuality for individuals with intellectual disabilities. In addition, there are several curricula (e.g., CIRCLES curriculum, Champagne & Walker-Hirsch, 1982) that are being implemented in the classroom. Most of these curricula are based on the teaching of the mechanics of sex. However, these books, articles and curricula provide a generic understanding of sexuality, and they are not based on person-centered approach that address the multidimentional aspects of sexuality that included trauma, vulnerability, and pleausre to list a few. Nor do these curricula appear to consider the role of one's living situation as a major social determinants of health in relation to sexuality. I strongly recommend that curricula be developed that intentionally weaves in the person-centered approach to address the understanding of sexuality. Furthermore, I recommend that this curricula involve peer-mentoring as part of the implementation strategy.

The emergent model that I developed as a framework that was derived out of this study can be further researched and developed for enhacing the practices asociated with the understanding of sexuality. Besides the role of peer-mentoring, I also recommend the use of this emergent model as a powerful contexual framwork that may be used to

research the role of self-compassion, self-determination, vulnerability, accessebility, and credebility in addressing sexuality by mothers or families to further the person-centered approach to facilitate the development of understanding sexuality on the part of women with intellectual disabilities.

5.6 Conclusion

The participants in this study shared their understanding about the interconnections between constructs of difference or alienation, emancipation and identity, sexuality-related discourses such as sexual pleasure, fear of sexual abuse and experiences of sexual abuse. By and large, the participants experiences could be characterized as finding ominous silence within their social spheres regarding issues related to sexuality, women, and intellectual disabilities (Champagne, 2007; Sobsey, 2010).

Participants' understanding of sexual abuse, their relationships with their mothers and in some case, their sisters, and the hidden affirmation of accepting themselves as they were, created a deeper understanding of their identity as women who embrace their sexual-selves. The first five themes that emerged out of this study as a whole were that of self-compassion, self-determination, vulnerability, accessebility, and credibility. These themes along with the other four, "I am comfortable with who I am, I love my mom, I feel kind of sexual, and he raped me" provide a new framework to address sexuality using the person-centered approach. I believe using this framework will create opportunities to reflect upon and rethink what is known about intellectual disability through the lens of sexuality. This will not only provide opportunities to understand the

conjunction of the words sexuality and intellectual disability from a theoretical

perspective, but will also provide opportunities for deeper reflection upon one's own

understanding of what is it to be human. Such reflections may facilitate a deeper

understand of the core of human sexuality that is embedded within the realms of

vulnerability, self-determination, self-compassion, access and being credible as a human

being.

EPILOGUE

This dissertation study has provided numerous conceptual as well as practical insights related to sexuality, women with intellectual disabilities and the use of Ethnodrama as a research method. As a critical thinker, feminist, and a strong advocate of disability rights as human rights, I feel that the context of sexuality often gets intertwined between the medical domains of disability and the societal norms associated with sexuality. However, the core meaning of sexuality, which is an essence of human existence, often gets lost within the norms of rights and wrongs associated with the term sexuality.

I have resisted the temptation to code certain images as "rights" and as "wrongs." Within the literature I have read thus far, most of the people involved in the disability rights movement challenge the stereotypical and paternalistic representations of women with intellectual disabilities within the society which is often a static trajectory. Insomuch that these proliferate prescribed notions of women with intellectual disabilities and serve to limit the possibilities of taking a more person-center approach in viewing these women and their potential. Additionally, the effect conveys an understanding of intellectual disability and sexuality that refutes the individual within the family unification.

I found within my review of scholarly literature frequent representations of the sexuality of individuals with intellectual disabilities that were colored by an overall sense of protectionism. The voices raised by the women in this study contest the typical representation of women with intellectual disabilities. They took pride in being who they

were and wanted to embrace themselves sexually, with a radical idea of self-compassion.

I saw this perspective as a revolutionary evolution in the area of sexuality and individuals

with intellectual disabilities on their own accord.

As a feminist researcher, I think including a model of person-centered approach to

sexuality within curricula in a reflective manner and that doing so will create useful tools

for caregivers to more fully attend to the needs of women with intellectual disabilities.

Revising curricula from this perspective may provide practical supports that focus on the

meaning of sexuality for that particular individual and with a core focus on celebrating

one's life.

I do acknowledge the associated challenges associated with any attempts to

change curricula in this manner, as such work with involve working to change powerful

dominant paradigms. At the same time I strongly think that this calibration is possible

with the guidance of the individuals with intellectual disabilities themselves. For this to

occur, it is important that supports be provided that allow for their voices to be clearly

heard. I have attempted to provide just such a vehicle for clear communication around

this potentially murky topic through the use of Ethnodrama. The concept of using

Ethnodrama goes beyond the esoteric world of academia and reaches out to the broader,

communal world.

The Ethnodrama

I wrote an Ethnodrama, entitled "Desirable Conversations," as a presentation of

raw data gathered from observations, field notes, informal conversations, and formal

interviews with the participants. After qualitative data was compiled, synthesized, and

analyzed, common themes and sub-themes were extracted to give shape and dramatic structure to the script.

Because I was intrigued by what the data did not reveal, the Ethnodrama utilized metaphors found in the participants' narratives as the framework for the story. What did the participants talk about individually before meeting in the focus groups? Did they know each other prior to meeting in the focus groups and did familiarity with one another (or the lack thereof), influence their conversation during the focus group interviews? What were their experiences and how did they talk about their interactions with family regarding sexuality? As a result of these questions, I framed the Ethnodrama as a data analysis strategy based on an emerging view of understanding of sexuality by young women with intellectual disabilities.

I used Ethnodrama as a methodological framework, which involved employing a data analysis process using Saldaña (2009)'s dramaturgical coding approach to create a theatrical script (see Appendix Q) that will be performed on stage by professional artists in the winter of 2016. I chose this approach to disseminate these women's narratives in order to avoid limiting dissemination to the academy through venues such as academic literature and to reach and engage a wider audience.

This dissertation study looked into two questions: the role of familial culture in the understanding of sexuality by young women with intellectual disabilities, and how women who participated in the study actually described their current understanding of sexuality. I see this study as a response to the call by Shakespeare, for "more stories of

individual disabled people" because "generating narratives is particularly important for reversing the invisibility of the sexualities of disabled people" (Shakespeare, 1996, p. 95).

I have used a transformative research paradigm because I wanted to bring to light the particular perspectives of woman with intellectual disabilities in a systematic manner on topics that have been infrequently explored in previous studies. I chose this approach because a key purpose of this study was to elicit and document how young women with intellectual disabilities understand sexuality by providing readers access to women's authentic voices and narratives.

The most important finding in this study was that the participants did indeed possess independent sexual voice. Perhaps their abilities to comprehend and communicate their ideas was less-than-sophisticated, yet their voices were clearly evident. Some were faint, some were graphic, but they each had a sexual voice that was all their own. Additionally, participants experienced a full and meaningful social-sexual landscape that was focused on areas such as sensuality and intimacy. This study provides knowledge that can be useful in making needed changes in that it specifically explored the lived social-sexual lives of participants from their point of view.

Walker (2004) has reminded us all that our voices matter, eloquently declaring, "No person is your friend (or kin) who demands your silence, or denies your right to grow and be perceived as fully blossomed as you were intended" (p. 36). It is my hope that the readers were able to hear each participant's voice–their self-compassion, sexual desires, self-determination, vulnerability, and voices that desire access and credibility as a woman in this large society.

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APPENDIX A

TELEPHONE INTERVIEW: SCRIPT

Telephone Script to invite participants as part of the Individual Interviews

"Hello. My name is Neera Malhotra. I'm calling from the Graduate School of Education, Portland State University. Few days ago (or few weeks ago, depending) you had shown your interest in participating in an interview. . I am calling to invite you to participate in a face-to face interview to talk about the influence of your culture on your experiences of sexuality education. Would you be interested in talking about your experiences with me?"

Telephone conversation: If yes, and the woman wants to participate, then:

"Thank you. Then if it is OK with you, can we select a date and a time to sit face-to-face and talk. Would this be OK? Thank you. It was good talking with you. I look forward to talking with you within the week."

Telephone conversation: If no, and the woman does not want to participate, then:

"I appreciate your time; if you change your mind and do want to talk about your experiences, you can always call me at (my telephone number)."

***

APPENDIX B

INITIAL SCRIPT FOR ONE-ON-ONE INTERVIEW

Initial Script for One-on-One Interview

"Hello. My name is Neera Malhotra. I am a student at the Portland State University. I have a big project due for which I need to talk to you. Few days ago (or few weeks ago, depending) you had shown your interest in participating in an interview. Thank you. Is this an OK place for you to talk, one in which you feel comfortable, and one in which you have between 30-45 minutes to talk with me? OK, great; before I ask you some questions, I'd like to go over a Participant Consent form."

Proceed to read the Participant Consent form out loud and obtain the woman's consent to participate.

APPENDIX C

PARTICIPANT CONSENT

Participant Consent–Individual Participant Interviews

(I read out loud to each participant before starting the interview)

Hi,

I am going to read this form to you so I remember to say everything. I request you to pay close attention to what I say because I want you to know what we will do if you decide to participate. My name is Neera Malhotra; I am a student at Portland State University. You are invited to help me with my work. I want to learn from you if you agree to participate in this interview. I also plan to conduct a group interview after I finish interviewing other women individually. This group interview schedule will depend upon the information I will get from the individual interview. You are welcome to step out anytime and stop participating from this discussion. If you agree to talk with me, you will help me learn about you and the influence of your culture on learning about your sexuality. . I am hoping that with your input we can help young children and adolescents who are still in school to learn about sexuality education that is culturally appropriate who are still in school.

What Will I Have To Do?
If you decide to participate in this interview, you will talk with me 1:1 for about 30-45 minutes. I would like to hear what you think about your own values, family, your ethnic background, and if you attend any spiritual practice and their influence on your understanding about sexuality. This interview will be recorded with a digital audio recorder. The audio interview will be immediately transcribed and then destroyed. The transcription will NOT include your name or any personally identifying information about you.

Are There Any Risks?
Some of the questions may make you feel upset, sad, or frustrated. You may remember times when you felt scared or hurt. Some questions may be very personal and you might feel embarrassed. If you hear a question that makes you feel that way you can answer the question or ask to skip that question. You can stop the interview at any time. I have a list of telephone numbers of agencies in your area that you could call to get additional help and support.

What Will I Get In Return?
1. You will be invited for a get together and an opportunity to meet new friends at the end of the study. I will send you an invite after the interview, whether or not you have completed it.
2. You will have direct input on ways to improve sexuality education for other young woman.

What Are You Doing To My Privacy?

Your privacy is very important to me. I will do the following things to your privacy:
- ➢ Your name and all other unique personal identifying information about you will be removed from the transcript;
- ➢ I will not tell anyone if you participate in this interview;
- ➢ When I write about your interview in articles or for presentations in the future, I will not include your name.

Any Questions?

If you have questions about this interview or this consent form, you can talk to me at any time during the interview. You can also talk to my adviser, Dr. Randall L. De Pry; his email is: rdepry@pdx.edu and his telephone number is: 503.725.4493. You can also contact the Chair of the Human Subjects Committee of Portland State University about your rights as a research participant. Hours of the PSU Human Subjects Committee Office are: Monday–Friday, 9:00am to 5:00pm, Pacific Standard Time. The office is located at Portland State University, Market Center Building, 1600 SW 4th Avenue (corner of SW 4th and Market), Room 620, Portland, Oregon 97201. Telephone numbers are: 503.725.4288, 1.877.480.4400 (toll free); the email is: hsrrc@lists.pdx.edu

If My Name is On This Form, What Does It Mean?

This is a consent form. Your name below means that:
- ➢ You have listened to and understand what this form says about the study;
- ➢ You are willing to take part in the study by talking to me on the phone;
- ➢ You know that you do not have to take part in this study. Even if you agree to start, you know you can change your mind and stop at any time during the 1:1 interview discussion; and,
- ➢ A copy of this form will be mailed to you by the research staff, if you request it, so that you have a copy of it to keep for yourself.

Signatures:

Your printed name and my signature below indicate that you understand the information on this form and that you agree to be in this study.

_____   _____

Participant name printed (Done by researcher)   **D**ate

_____

Researcher signature

APPENDIX D

INDIVIDUAL INTERVIEW QUESTIONNAIRE

Individual Participant One-on-One Interview Questions

Introduction: Hello, My name is Neera Malhotra, I am a student at Portland State University. How are you? [Ice-breaker]. Thank you for giving me time to talk to you today. I am here to talk to you about the influence of your culture on your understanding about sexuality. I will ask you series of questions about you, your culture and sexuality. I appreciate your time and respect your privacy; your answers will be kept in total secret. More importantly your name will not be used whenever I will write about this interview. I am here to learn from your experience, knowledge and believe. This interview will further help in informing people who are responsible to teach within the school setting.
I WILL GIVE THE CONSENT FORM (CES B) HERE!
Assign ID #, ID should consist of the first three letters of their LAST NAME and number of the participant. Example: Participant # 1: Dannie Esparza (ID= ESP01)

ID………

Interviewer Name	Date	Location
Coder:	Gender:	Consent Signed
ID:	Ethnicity	Age
Religious/Spiritual	Employed/Unemployed	Disability

I: Opening Questions/warm Up: So, tell me about you.
Probes:
- Your name:
- Your age:
- What is your ethnical background?
  - Caucasian
  - African American
  - Latino
  - Asian
  - Pacific Islander
  - Mixed
  - Other
- Do you currently go to school? Y/N
- Have you attended school in the past?
  - Less than high school
  - High School
  - Associate's Degree
  - Bachelor's Degree
  - Master's Degree
  - Other
- Who do you live with?
- Do you experience any disability?
  - Can you talk about it little bit?

- Do you go to Church or participate in any other religious or spiritual practice?
  - If yes, how frequently in a month?
  - If No, thank you lets go to the next question?
- Can you tell me what do you understand about culture?
  Probes:
  - How do you identify yourself as? As Black, Asian (Chinese, Japanese, Korean, or Vietnamese), Filipino, Hawaiian, Hispanic, Pacific Islander, or White.
  - Do you celebrate different holidays other than what others celebrate?
  - Do you think your family has different values than your friends' family? If yes, what difference do you find?
  - If no. tell me about your family. Do/did you have/had a nuclear family which means you live only with your parents and siblings (if she had answered that she lives with her family in the earlier question on living situation) or it's a large family where you have your grandparents and other cousins live together in the same house hold?
  - What is it to be a woman with intellectual disabilities?
- Can you tell me what do you understand about sexuality?
  Probes:
  - What was your major sources of information? (parents, church/place of worship/peers, self-taught)
  - Growing up, was it OK to ask questions about sex? How did people respond if you did ask?
- Wrap Up
  Probes:
  - Before we end, is there anything else you would like to share?

Thank you for taking out time to talk to me. Like I met you, I will be meeting other women too, to discuss the questions I discussed with you. After I finish interviewing all the women, I will contact you again to ask if you will be willing to participate in the group interview or not. For the purpose of this study, the group interview is based on few selection criteria related to the questions we discussed. I will also send you an invite for the get together in the month of June. I greatly appreciate your time today.

Thank you.

APPENDIX E

RUBRIC FOR PARTICIPANTS' SELECTION

Checklist for the Participant Selection for the focus group interview

Participant Code:			
Criteria	**Present**	**Absent**	**Comment/Feedback**
Participate in some kind of spiritual and/or religious			
Identify herself as a women with intellectual disability			
Is in a relationship			
Speak and understand English.			
Willing to spend 30-45 minutes for an individual interview.			
Willing to participant in three focus group interviews and spend 80-90 minutes			
Lives in Greater Portland, Oregon metropolitan area.			

APPENDIX F

OBSERVATION FORM

Observation Form- Individual Interview

Participant Code:
Time of interview:

Topic Area	Behavioral Description
Familial Values	
Individual Values	
Intellectual disability	
Race & Ethnicity	
Religion & Spirituality	
Same Sex	
Sex	
Sex Education	
Wrap Up	
Misc	

APPENDIX G

PARTICIPANT'S CONSENT: GROUP INTERVIEW

Participant Consent–Focus Group Discussion

(read out loud to the group participants before the focus group)

   I Neera Malhotra, and Nichole (co-moderator) doctoral students would like to invite you to talk about the influence of your culture on your understanding of sexuality. I am going to read this form to you so I remember to say everything because I want you to know what we will do if you decide to participate. My name is Neera Malhotra; I am a student at Portland State University and doing a study. Nichole is helping me with this study by being here in this group interview. She is here to help us if you need to talk to someone in person. Or, if you need any assistance. You are invited to help in this project to understand how culture plays a role in understanding sexuality. From you, I want to learn about how you feel about your culture and its influence on learning about your sexuality. You are welcome to step out anytime from this discussion. I am hoping that with your input we can help young children and adolescents to learn about sexuality education who are still in school.

What Will I Have To Do?

   If you decide to participate, you will be asked to participate in a 60-minute focus group discussion. The discussion will be recorded. We have two people (women) who will be recording this discussion using a closed-captioning, hence two member will be present in the room who will be recording this interview discussions. We will get the transcript immediate and it will NOT include your name or any other personally identifying information. If you have any concerns with their presence, please let me know or let Nichole know.

Are There Any Risks?

   Some of the focus group questions may make you feel upset, sad, or frustrated. You may remember times when you felt scared or hurt. You can stop the interview at any time or ask me to call you again to complete the interview during a second call. I have a list of telephone numbers of agencies in your area that you could call to get additional help and support. During our conversation, someone may come in your room who do not want; if this happen, you may stop our conversation by saying "No, I'm not interested." If this happens, we can reschedule this interview if you are still willing to finish the interview.

What Will I Get In Return?

3. You will be invited for a free workshop on sexuality and relationships once this study is completed. Plus you will be invited to be part of "women's only" get together. I will send you an invite after the interview, whether or not you have completed it.
4. You will have direct input on ways to improve sexuality education for other females who experience similar life patterns like you do.

What Are You Doing To Protect Me?
Your privacy is very important to me. I will do the following things to protect you:
➢ Your name and all other unique personal identifying information about you will be removed from the transcript;
➢ I will not tell anyone if you participate in this focus group discussion;
➢ When I write about your interview in articles or for presentations in the future, I will not include your name.

Any Questions?
If you have questions about this interview or this consent form, or focus group interview you can talk to me at any time during the interview. You can also talk to my adviser, Dr. Randall De Pry; his email is: rdepry@pdx.edu and his telephone number is: 503.725.4493. You can also contact the Chair of the Human Subjects Committee of Portland State University about your rights as a research participant. Hours of the PSU Human Subjects Committee Office are: Monday–Friday, 9:00am to 5:00pm, Pacific Standard Time. The office is located at Portland State University, Market Center Building, 1600 SW 4th Avenue (corner of SW 4th and Market), Room 620, Portland, Oregon 97201. Telephone numbers are: 503.725.4288, 1.877.480.4400 (toll free); the email is: hsrrc@lists.pdx.edu

If My Name is On This Form, What Does It Mean?
This is a consent form. Your name below means that:
➢ You have listened to and understand what this form says about the study;
➢ You are willing to take part in the study by talking to me on the phone;
➢ You know that you do not have to take part in this study. Even if you agree to start, you know you can change your mind and stop at any time during the 1:1 interview discussion; and,
➢ A copy of this form will be mailed to you by the research staff, if you request it, so that you have a copy of it to keep for yourself.

Signatures:
Your printed name and my signature below indicate that you understand the information on this form and that you agree to be in this study.

_____   _____
Participant name printed (Done by university researcher)   Date

_____
Researcher signature

APPENDIX H

FOCUS GROUP SCRIPT

Focus Group Script

Welcome
Thanks for agreeing to be part of the focus group. We appreciate your willingness to participate and the time you have taken join us.

Introduction
My name is Neera Malhotra, I am a student at Portland State University. Thank you for giving me time to talk to you today. I am here to talk to you about the influence of your culture on your sexuality education. I will ask you series of questions about culture, you, and sexuality education. I appreciate your time and respect your privacy; your answers will be kept in total secret. More importantly your name will not be used whenever I will write about this interview. It was important to have an objective moderator run the group and a co-moderator: Nichole. Also, we need to record this interview, so we will have two women who will be responsible for the closed captioning.
How are you? [Ice-breaker].

Purpose of Focus Group
I appreciate your time and respect your privacy; your answers will be used for the study however your personal information will be kept will be kept in total secret. This interview will further help in informing people who are responsible to teach within the school setting.

Structure of the Group
We will have a time-limited open discussion. We will be together about an hour.

Ground Rules
- WE WANT <u>YOU</u> TO DO THE TALKING.
  We would like everyone to participate.
  I may call on you if I haven't heard from you in a while. Is that okay?
- THERE ARE NO RIGHT OR WRONG ANSWERS
  Every person's experiences, suggestions, and opinions are valid.
  Speak up whether you agree or disagree.
  Be kind and share the floor with others.
- THE GROUP IS NOT EXPECTED TO SOLVE ANY PROBLEMS HERE
  It is not our intention to problem solve or come to conclusions. Instead, our goal is to capture a wide range of responses and comments.
- Any other ground rule you would like to add?

Captioning
We will be typing up everything that is said in the group for the purpose of writing up a report afterward. You will be identified by number in the transcript, not name.

Attention
You have the right to withdraw from the group session at any time and for any reason.

Confidentiality
No names will be included in the report.
You information will be shared within the group in this room and sharing about another person's experience outside of the group would be inappropriate--especially given the highly personal nature of the topics covered. So, we request that what is said in the room stays in the room.

Any questions before we start?

APPENDIX I

FOCUS GROUP I

Stories of my understanding of sexuality

Focus Group Meeting I: What I think about sexuality: Stories of my understanding of sexuality in my social world.

Introduction

We will be meeting three times on THREE Saturdays. I really appreciate your time and energy. Thank you. Today, we will talk primarily about your feelings, thinking, and what you know about sexuality. Also, share how you make decisions regarding sexuality and why. You can think about what you learned, heard from the people in your life, like your family, friends, and neighbors. Also, think about the places you visit like, dance class, dance performances, coffee shops, your work place, Church etc and talk about your experiences.

Once again, please know that because of the nature of the group, confidentiality is reduced, and you are requested to not share what is said during the interview, outside of the group. Sure? Great, let's start!

Research Questions

Research Question 1: What is the role of familial culture in addressing sexuality for young women with intellectual disabilities (21-35 years)?

Research Question 2: How do young women with intellectual disabilities (21-35 years) describe their understanding of sexuality?

Objectives:

1.1 Participants will recall and share about what they think about sexuality.
1.2 Participants will share their thoughts, feelings, desires, and actions about themselves as a sexual being.
1.3 Participants will share about their thinking, judgments, and attitudes about sexuality and talk about similarities and differences from what they learned from their families.
1.4 Participants will share their stories of experience about being a woman with intellectual disabilities and sexuality and talk about how their learning from families affected their experience.
1.5 Participants will participate with the other group members

Materials

- Drawing boards
- Index cards
- Markers, flip charts; crayons or paints, markers, scissors and white card
- Visual Supports—sign cards (NO, STOP, BREAK, PASS)

Anticipated Time for the focus group interview: 10:00am- 12:30 pm

- 9:30-10:00: Meet and Greet
- 10:00-10:30: Theatrical Activity
- 10:30- 10:35: Break
- 10:30-11:30: Focus group Interview
- 11:30- 11:35: Break
- 11:35-12:00: Focus group Interview continued
- 12:00- 12:20: Lunch break
- 12:20- 1:00: Continue and then wrap up

Note: Focus group interview questions are designed to elicit responses to answer the research questions. The questions written in this column are for the reference for the researcher and the co-facilitator. The statements written in the probes column will be used to talk to the participants.

Focus Group Outline and Questions

Time	Obj/ RQ	Ques	Activity	Probe
9:30-10:00	Meet and Greet 1.5		Meet and Greet Introduction Consent signature	*"Thank you for participating and being part of this group." We can stop any time if you are not feeling comfortable and want to talk or sit alone.*
10:00-10:30	Obj: 1.1; 103		Name Game Free write/Index Card Activity Steps: Participants are suggested to move around in the room, meet one another, and ask each other's name and ask ONE thing that they are comfortable sharing. Sit back. Using the index cards write the thing they learned about the other that they are comfortable sharing.	*There are these sign cards you can use if you want.* *Ok, let's start with our first activity.*

			Put the card in the open basket (center of the table) Then, write THREE things that they want to share with us only. After writing, put the card in the envelop and put it in the black box. Get back as a group. Let everyone pick a card, open and read and guess who wrote that.	*Pick the card from the basket and read aloud and guess the name of the person.* *Share if you want to share anything besides just her name, you can add anything you want besides your name . . .* *Thank you! Let's take a short bathroom break and get back as a group. Looking forward to talk more.*
Break: 10:30- 10:35				
10:35-11:30	Obj: 1.1, 1.2, 1.3	What were the three emotions/ thoughts/ feelings you shared and why?	Using the index cards and envelop Write/think at least three emotions/ feelings/ thoughts around disability that they want to share. *We will use this exercise, only if need.*	*Wonderful! How are you feeling? Let us know if you need to speak to the counselor or you need anything. Snacks, coffee is here on the table, feel free to help yourself.* *Let's continue our conversation from where we left. Let's talk about what we just shared and observed in the group. What did you share and why?* *Some of you shared that you experience disabilities. What do you think about disability? Do you think you have one?*

	Obj: 1.1 1.3 1.4	What are your thoughts, judgments, and attitudes about sexuality? How are they similar and different from what they learned from their families?	Using the index cards and envelop Write/think at least three emotions/ feelings thoughts around sexuality that they want to share.	*Now, take a moment to think about the word sexuality.* *What do YOU think & feel about sexuality?* *Thank you. We will continue to talk about this in our time today and next three Saturdays.*
				Can you please talk about your family and how you see them?
			Using the index cards and envelop write/think at least three emotions/ feelings/ thoughts about the family that they want to share.	
				Please talk about yourself as a women, is it same as your drawing?
			Activity 2 Give each young person a piece of white card. Ask them to draw shape of a face. It can be a stick figure. One side represents what they think people see/know/believe about them i.e., on the outside. The other side represents what they feel about themselves i.e., things going on the inside, what people do not necessarily know or see. Free write Talk about what you just created.	
Break: 11:30-11:35				
11:35-12:00	Obj: 1.1, 1.2, 1.3, 1.4	What did young women with intellectual disabilities learn	Activity Put the drawing in front Free write:	*Welcome back!* *Thank you for sharing your views, thoughts, stories, emotions around this*

		about being a woman with intellectual disabilities and sexuality? How is it similar or different from what they learned from their family?	Using index card, write three things that comes to your mind about sexuality and your mask. Write three or more things that come to your mind when you think about your childhood/ your growing up phase with your family after looking at your drawing.	*difficult topic. I am highly impressed and thankful for your contribution thus far.* *Let's continue our conversation. Thank you. You are doing a great job, so far!* *If you are comfortable, please share what you wrote on the card.* *Tell me what did you learn about relationships while growing up and from whom?* *Tell me how you feel about same sex/ homosexual relationships?* *What do you know about sexual relationships?* *What do you think about yourself as a romantic/sexual person?* *How is it different from or similar to what you learned while growing up?*
Lunch break 12:00-12:20				
12:20-12:45		What is the role of familial religious/ spiritual practices in addressing sexuality? Wrap Up		*Welcome back! Let's talk more about sexuality. Thank you for sharing your valuable insights. I am highly impressed and thankful for your contribution thus far. Let's talk about you, your faith, and your process of making decision about sexuality.* *Few of you shared that you believe in God and follow a certain practice that helps you make decisions around sexuality. Also, I heard some of you making decisions with the help of your friend and family. Please share how do you*

12:45-1:00				*find your right choice/decision/thinking/feeling around sexuality and why?*
		Silent Meditation		*Thank you very much for your time. Now we will spend some time in reviewing what all we discussed and answer if you there is any question or concern.*
				Let's sit in silence for two minutes.
				Close your eyes
				Think about the good memories of your childhood
				And one good thing about being a woman.
		Session closed		*Now, let's take a deep breath.*
				Sit in silence for a minute and observe your breath.
				Feel your breath going in and out. Feel your breath touching your nostrils, your upper lips.
				Silence
				Open your eyes
				Pause
				Is there anything you would like you say/share/comment?
				Let's wrap and I look forward to meet you next time.

Note to self:
The group will discuss various emotions, feelings, thinking and ideas about sexuality. I will take notes on:

- What nuance did I observe?
- Look for what emotion is being conveyed?
- How do the participants show differences between annoyed, angry and furious

- How do gestures, facial expressions, and inflection help in understanding what the person is feeling?

APPENDIX J

FOCUS GROUP II

Focus Group Meeting II: The story of my physical body

Introduction
We will be meeting one more time on next Saturday. I really appreciate your time and energy. Thank you. Today, we will focus on a full range of physical aspects of sexuality which includes body parts, body image, bodily pleasure, bodily abuse, physiology, and bodily abilities. We will also talk about body image, private vs public, physical pleasure, expression of pain, masturbation, and the mechanics of sex. We will talk about the influence of familial culture in their understanding of their physical body.
Once again, please know that because of the nature of the group, confidentiality is reduced, and you are requested to not share what is said during the interview, outside of the group. Sure? Great, let's start!

Research Questions
Research Question 1: What is the role of familial culture in addressing sexuality for young women with intellectual disabilities (21-35 years)?

Research Question 2: How do young women with intellectual disabilities (21-35 years) describe their understanding of sexuality?

Sub-Questions
1. What did participants learn about body while growing up? (body image/ parts/ private vs. public)
2. What do participants understand about masturbation/ self-pleasure?
3. What is sex? How is masturbation different from sex?
4. What is sexual abuse?

Objectives:
1.1 Participants will recall and share about what they think about sexuality.
1.2 Participants will share their thoughts, feelings, desires, and actions about themselves as a sexual being.
1.3 Participants will share about their thinking, judgments, and attitudes about sexuality and talk about similarities and differences from what they learned from their families.
1.4 Participants will share their stories of experience about being a woman with intellectual disabilities and sexuality and talk about how their learning from families affected their experience.
1.5 Participants will participate with the other group members

Materials
- Drawing boards
- Index cards
- Markers, flip charts; crayons or paints, markers, scissors and white card
- Visual Supports—sign cards (NO, STOP, BREAK, PASS)

Anticipated Time for the focus group interview: 10:00am- 12:30 pm
- 9:30-10:00: Meet and Greet/Activity 1
- 10:00-10:30: Activity 2 and Discussion
- 10:30- 10:35: Break
- 10:30-11:30: Focus group Interview
- 11:30- 11:35: Break
- 11:35-12:00: Focus group Interview continued
- 12:00- 12:20: Lunch break
- 12:20- 1:00: Continue and then wrap up

Note: Focus group interview questions are designed to elicit responses to answer the research questions. The questions written in this column are for the reference for the researcher and the co-facilitator. The statements written in the probes column will be used to talk to the participants.

Focus Group Outline and Questions

Time	Obj	Sub Q's	Activity	Probe
9:30-10:00	Meet and Greet 1.5		Meet and Greet Introduction	*"Thank you for participating in this group work."* We are happy that you are part of this project and have decided to be here and the next Saturday. *Please feel free to take breaks in between and help yourself with food and drinks available here on the table. Also, know that we can stop any time if you are not feeling comfortable and want to talk or sit alone. Once again, please know that because of the nature of the group, confidentiality is reduced, and you are requested to not share what is said during the interview, outside of the group. Sure? Great, let's start!*
			Activity 1: Name Game Find the name card other than yours and give to the person it belongs.	*There are these sign cards you can use if you want.*
10:00-10:30	Obj: 1.1; 103	1	Activity 2: Steps: Stand in front of the mirror. Look at every part of your body, your head, hair, face, facial features: eyes, eye brows, nose, nostrils, gap between nose and lips, lips, cheeks, chin, see if there are any moles/freckles/acne, or anything that you see on your face.	*Ok, let's start with our first activity. We have this mirror, One at a time, come closer to the mirror, look into it, and see yourself. If you are uncomfortable doing it, you can choose to opt out.* *First look at your head and face. What do you notice about yourself?* *Spend a minute here, look deeper and get back to your seat.* *Please use index card/s to write about your body and your sexuality and seal in the given envelop and put it in the black box.*
			Go down to your neck, shoulders, breasts, arms, stomach, legs, knees, feet, toes, and go back and look at your whole body, once again. Go beyond your clothes, close your eyes and think about your body. How it looks under clothes. Open your eyes, look again, spend a minute and go	*Let's talk about your experience of this activity.* *How do you feel?* *Do you have any story to share with the group? I remember that my grandmother used to sing songs to*

			back to your seat. Now, look at yourself top to bottom, and move your body to get a 360 degree view of your body. Sit back and write what come to your mind using index card. Write that want to share ONLY with the researcher. Seal it in envelop. Write what you want to share with the group.	*help me learn about my body. Do you have any such story to share?* *Let's talk about our bodily changes that happened when we were kids, then adolescents, and then being a woman. Can you see any differences and similarities?* *Thank you! Let's take a short bathroom break and get back as a group. Looking forward to talk more.*
Break: 10:30- 10:35				
10:35-11:10	Obj: 1.1, 1.2, 1.3	2		*Let us know if you need to speak to the counselor or you need anything. Snacks, coffee is here on the table, feel free to help yourself.* *Let's continue our conversation from where we left.* *Let's talk about what we just shared and observed in the group.* *How are you feeling?* *What did you notice about yourself in the mirror?* *Let's talk about you thoughts about your body and your sexuality?*
Bathroom break: 11:10- 11:15				
11:15-12:00				*Welcome back!* *Thank you for sharing your views, thoughts, stories, emotions around this difficult topic. I am highly impressed and thankful for your contribution thus far.*

	Obj: 1.1, 1.2, 1.3, 1.4	2	Activity 3 Using index Card, write three words that come to your mind when you think about the word masturbation.	*Let's continue our conversation. Thank you. You are doing a great job, so far!* *So far we have discussed about our body parts, what we understand, and what we learned about it while growing up. We also spoke about our individual experiences, and learning about our bodies, and what we learned at home while growing up.* *Let's take a step further. Let's talk more about bodies.* *Let's talk about self-pleasuring. Have you heard about the term, masturbation?*
		3		*Can you please share what you think masturbation is?* *Did anyone speak to you about it while growing up?*
			Activity 4 Using index Card, write three words that come to your mind when you think about the word sex.	*Tell me what do you understand by the word "sex"?* *Let's talk about what you understand about it, if you feel comfortable, please feel free to share about your own experience.* *Tell me about your learning at home about sex while growing up.*
Lunch break 12:00-12:20				
12:20-12:45	4			*Welcome back! Let's talk more about sexuality.* *Thank you for sharing your valuable insights. I am highly impressed and thankful for your contribution thus far. Thank you. I would now request that we discuss some sensitive issues. Have you heard about what sexual abuse is? Do you remember talking about sexual abuse at home while growing up? If yes, would you like to share what did you learn about it?*
		Wrap Up		*Thank you very much for your time. Now we will spend some time in reviewing what all we discussed and answer if you there is any question or concern.*
		Silent Meditation		

12:45-1:00				*Let's sit in silence for two minutes.* *Close your eyes* *Think about the good memories of your childhood* *And one good thing about being a woman.* *Now, let's take a deep breath.* *Sit in silence for a minute and observe your breath.* *Feel your breath going in and out.* *Feel your breath touching your nostrils, your upper lips.* *Silence* *Open your eyes* *Pause* *Is there anything you would like you say/share/comment?* *Let's wrap and we will meet next week.*

Note to self:
The group will discuss various emotions, feelings, thinking and ideas about the physical aspects of sexuality. I will take notes on:

- What nuance did I observe?
- Look for what emotion is being conveyed?
- How do the participants show differences between annoyed, angry and furious?
- How do gestures, facial expressions, and inflection help in understanding what the person is feeling?

APPENDIX K

FOCUS GROUP III

Stories of my social life and sexuality

Focus Group Meeting III: What I learned from my family and social life: Stories of my social life and sexuality.

This session focuses on the social representation of the body. In this meeting we will talk about your understanding that you adopted from your social world. We will discuss your association with your family and what you learned from them about friendships, dating, attraction, romance and sexual relationships. In this meeting we will talk about the feeling of love, your wants or desires, and hanging out with others as part of your experience. We will also talk about dark feelings: anger, fear, angst, disgust, and any emotions that are the fallout from sexual experiences that were disappointing, controlling, scary, painful, violent, abusive, or just plain boring. We will primarily focus on your own experiences as women and what you learned from your families about how to be in the social world. Also, please know that because of the nature of the group, confidentiality is reduced, and you are requested to not share what is said outside of the group.

Objectives:

1.1 Participants will recall and share about what they learned about social spaces/areas from their families.
1.2 Participants will recall and share their stories about growing up, which includes what they learned about themselves as sexual beings.
1.3 Participants will share about their understanding of friendship, romance, attraction, dating and sexual relationships.
1.4 Participants will talk about their experience of love, desires, socialization, anger, pain, abuse, disappointment, fear, disgust, violence, boredom.
1.5 Participants will participate with the other group members

Materials

- Visual Supports–sign cards (NO, STOP, BREAK, PASS)
- Markers/colors and blank drawing sheets
- Magnet poetry kit

Anticipated Time: 09:30am- 12:30 pm

- 9:30- 9:45: Meet and Greet
- 9:45-10:30: Art Activity + Discussion
- 10:30-10:45: Break
- 10:45-11:30: Focus group Interview
- 11:30- 11:40: Break
- 11:30-12:15: Focus group Interview continued
- 12:15-12:30: Wrap up

Time	Obj/ RQ	Questions	Activity	Probe
9:30 9:45	1.5		Meet and Greet: Stand in a circle. Recall name of the person sitting/standing on your right. The person standing on the right introduce the next person, and so forth.	*"Thank you for coming again and being part of this group." We are happy that you are part of this project. Please know that you can withdraw anytime you want.* *We can stop any time if you are not feeling comfortable and want to talk or sit alone. We have flash cards you can use whenever you need.* *On the table, all your name cards are placed. We will now stand in a circle. The person on your right will try to remember the name of the person next to her on the right side.*
9:45-10:30	1.1; 1.5		Pick a few colors and some paper Follow as prompted by the researcher Draw/scribble/write. Reflect and Share with group	*Recall the name of the person on your right and bring her/point at/or ask me to get her name tag. Share if you want to share anything besides just the name.* *Thank you!* *Now, let's start with our first activity. In this activity, we will play with colors, colored pencils, and a magnet poetry kit that has words written on the magnet.* *Let's start:* *You are now divided in two groups. Each group will have three participants.* *Now, pick a few colored pencils/crayons and a sheet of paper.* *In your small group, talk to each other about one relationship that you cherish the most. Also, share why you think that this relationship is important for you.* *Each one of you must get at least five minutes to share.* *Now, Either.* *Using colored pencils/crayons, create a picture/draw/scribble about what you learned about relationships from each other. As a group create an art piece or picture reflecting your discussion.* *OR* *As a group, using the magnet poetry kit, create a haiku (short poetry using only few words) to describe*

				what you learned about relationships from each other. *Let me know if you have any question.* *Let's talk about the images/art pieces/pictures/haiku you just created in your small groups. Talk about what you learned about relationships from your group.*
Break				
10:45 - 11:30		What does it meant to be in a relationship? What do participants talk about social conducts? What did they learn while growing up? What did participants learn about dating/romance / friendship while growing up?		*Welcome back!* *Let's continue our discussion.* *In the previous section we discussed about different relationships.* *Now, let's talk about your relations in those relationships. Can you talk about what does it mean to be related to someone?* *Please tell me what was it to be in a relationship with someone while growing up.* *What did you learn about going out and meeting new people while growing up?* *For example, when I was growing up, my mother would teach me how to talk to others when I am talking to my uncles, cousins, strangers, when we would go out or visit family gatherings, friends, etc. I remember I was told how to behave like a "good girl" when in public. Do you remember anything like this? Can you please share how it was for you? Were you told to do things in a certain way because you were a girl, etc.?* *Thank you! Let's talk some more.* *As we grow older we learn skills to make new friends, meet people, and form new relationships on our own. What did you learn about dating, romance, etc., while growing up in your family? What was it like?* *Can you please share about your experiences of friendships, dating and/or romance?* *Do you think these associations are similar as your other relationships*

				you mentioned before? What is similar and different?
Break				
11:40 - 12:15	Obj: 1.3 1.4 RQ: 1,2	What do participants talk about sexuality? What did they learn about it while growing up?		*Welcome back! Thank you for this time and your efforts, let's talk about sexuality and relationships. Before break we spoke about different relationships, friendships, dating and romance.* *Let's talk about what is it to be sexual and how to express that when you are hanging out with others? Why do you think what you think? What did you learn about it while growing up?* *What is it to be in a romantic relationship?* *Talk about the feeling of love, your wants or desires, and hanging out with others as part of your experience.*
12:15 - 12:25		Wrap up		*Also other feelings such as anger, fear, angst, disgust, and any emotions that are the fallout from sexual experiences that were disappointing, controlling, scary, painful, violent, abusive, or just plain boring. Would you like to share about it?* *Thank you very much for your time. It's time to wrap up and end this session. We shared some happy and difficult moments.*
12:25 - 12:30		Silent meditation		*Let's sit in silence for two minutes. Close your eyes Think about the good memories of your childhood And one good thing about being a woman. Now, let's take a deep breath. Sit in silence for a minute and observe your breath.*

				Feel your breath going in and out. Feel your breath touching your nostrils, your upper lips. *Silence* *Open your eyes* *Pause* *Is there anything you would like you say/share/comment?* *This was our last meeting. I will contact you if you are interested in being part of the rehearsals. We will also inform you about the final dates of stage performance. If there is any question or concern, feel free to contact me anytime. Thank you very much for being part of this precious project.*

APPENDIX L

FOCUS GROUP OBSERVATION FORM

Observation Feedback by the Counselor and the Co-Moderator

Taking Points for every question

- Write down big ideas, hunches, or thoughts.

- Note other factors such as passionate comments, body language, non-verbal activity, head nods, physical excitement, eye contact, or other clues

- Remember the purpose of the focus group interview

- For every question for this table:

Research Question	
Key points/ Summary	Notable Quotes
Observation/ comments	

APPENDIX M

RESEARCHER'S REFLECTIVE QUESTIONS

How did the interview go?

What I did?

1. Did I ask what meanings she makes of her experiences and understanding of sexuality? Was I receptive to learn than to prove preexisting ideas that were brought into the interview?: What could have been different?

   A. Listen to her:

If the participant is requested to tell her understanding of sexuality, what are the follow up questions besides the open ended question. For example, when I asked her "what do you understand about sexuality?" If she didn't understand, ask her,

- What do you understand about the word sexuality/ sex?
- What comes to your mind when you hear me ask you this question?
- What are your feelings about this word?
- What are the feelings about the events, facts, childhood memories, current life's circumstances when you hear the word sexuality/sex?

Is she says "I have a fear of the word "rape"":

Ask:

- How do you understand what happened to you?
- What meaning do you make about the event that happened in your life?
- What do you think about it?
- Do you think about it in more than one way?
- How do you value your experience that you are describing about your experience?

   B. Listen to my own self:
- Trust my own hunches, feelings, responses that arise through listening to the participants.
- Trust that you can take this work forward.
- Notice my own areas of confusion, personal discomfort, confidence level, and alertness.

APPENDIX N

ENGLISH AND SPANISH FLYERS

Let's Talk about sex!

Looking for Women who identify themselves as women with intellectual disabilities (21-35 yrs) to talk about their understanding of sexuality.

Eager to talk about the role of your family in understanding sexuality?

Interested in sharing your stories within community as a theatrical performance?

Are you a woman who identify yourself as a woman with intellectual disabilities? OR do you know someone who would be interested?

ROLE OF FAMILIAL CULTURE IN UNDERSTANDING SEXUALITY

(IRB approval #143189)

Research study on the role of familial culture in understanding sexuality by young women with intellectual disabilities.

We will meet individually and in groups.

Stories will be presented as a theatrical performance by professional artists in Fall 2015 by School of Theater, PSU

Make new friends and form a girl's group!

TALK. LISTEN. VOICE. And GET HEARD!

Safe environment. Help needed for a research study!

THANK YOU!

Portland State
UNIVERSITY

CONTACT

Neera Malhotra

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Come join us, YOUR VOICE IS IMPORTANT!

¡Hablemos de sexo!

Estoy en busca de mujeres que se identifican como mujeres con discapacidades intelectuales (de 21 a 35 años) para hablar de su conocimiento respecto a la sexualidad.

¿Ansiosa por platicar acerca del papel que toma tu familia en comprender la sexualidad?

¿Estarías interesada en compartir tus historias con la comunidad en una representación teatral?

¿Eres una mujer que se identifica con alguna discapacidad intelectual? O conoces a alguien que estaría interesada?

PAPEL DE LA CULTURA FAMILIAR PARA ENTENDER LA SEXUALIDAD

(IRB approval #143189)

Es un estudio de investigación sobre el papel de la cultura familiar en comprender la sexualidad de las mujeres jóvenes con discapacidades intelectuales.

Nos reuniremos individualmente y en grupos.

Tus historias se presentarán en una obra de teatro por artistas profesionales en el otoño del 2015 por la Escuela de Teatro de PSU.

¡Harás nuevas amigas y serás parte del grupo!

PLATICA. ESCUCHA. ALZA LA VOZ. ¡Y SERAS ESCUCHADA!

Ambiente seguro. ¡Tu ayuda es necesaria para este estudio de investigación!

¡GRACIAS!

CONTACTA A:

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únete a nosotros, ¡TU OPINION ES IMPORTANTE!

Portland State
UNIVERSITY

APPENDIX O

ETHNODRAMA: PROJECT REFLECTION

Questions for Performed Ethnography and Research-Informed Theater Project Design: Sexuality and Women with Intellectual Disabilities

Goals and Assessment

1. What is/are the goal(s) of this project?

To explore the role of familial culture in understanding how women with intellectual disabilities acquire understanding of sexuality. The goal is to explore how women describe their understanding of sexuality that they learned from their family.

Research Question 1: What is the influence of familial culture in addressing sexuality for women with intellectual disabilities?
Research Question 2: How does familial culture influence the understanding of sexuality by young women with intellectual disabilities (25-35 years)?

2. Who are the research participants?

- 9-12 Women with Intellectual Disabilities
- Consent: Demonstrate their willingness to participate in this study by signing the informed consent form after listening/reading it. Participants must give consent. Informed consent includes understanding: relevant facts, having the ability to consider risks and benefits, and being able to make a voluntary decision (Grisso, 1986). Age: Participants must be between 25-35 years of age.
- Spoken Language: Participants must be able to speak and understand English.
- Written Language: Able to write at at least grade level 4.
- Language Comprehension: Each participant must have verbalization skills sufficient to express herself, since the expense and logistics of securing interpreters, language assistive devices and other related resources are beyond the scope of this study.
- Must be willing to participate in theatrical workshops at part of the focus group interviews
- Must be willing to participant in one focus group interviews and spend 6 hours workshop. This time include two 15 minutes break and one 45 minutes long break.
- Is in a relationship (at least 4 out of 12 participants to form a group)
- Lives in Greater Portland, Oregon metropolitan area.

3. What do we hope to achieve?
   a. Explore and understanding the meaning of sexuality by women with intellectual disabilities.
   b. Information on the role families played in their understanding of sexuality.

     c. Stories related to sexuality
     d. Emancipate voices of women with intellectual disabilities
     e. Awareness about sexuality connected to women with intellectual disabilities within the community.
     f. Explore if the results align/overlap with the critical disability theory. The three elements of CDT include (a) the social model of disability, (b) multidimensionality and valuing diversity, and (c) language will guide the discussion section of this dissertation.

          i. Social model of disability: Social models focus on concept of disability within the sociological framework which is sufficiently inclusive to encompass the population with which it is concerned. I am curious to see how will data gathered then analyzed and stories performed will bolster the social model of disabilities.

          ii. Multidimensionality and valuing diversity: Multidimensionality describes the presence of the multiple interconnected dimensions of an individual that influence one's daily lives such as culture, race, gender, religion and spirituality. I am curious to know what does multidimensionality of the participants identity will inform about the understanding of sexuality.

          iii. Language: The analysis of how participants talk about sexuality in connection to intellectual disabilities. Also, how will the presentation of the

4. How will we assess this project?
The interviews will be analyzed using Thematic Data Analysis. The stories will be presented as a theatrical performance. An evaluation process will be developed to evaluate the project.

5. How will we know the extent to which we achieved what we hoped to achieve?
I am working on creating rubric that focuses on all the 6 points/goals mentioned above in question number 2. It should be ready by July 15th.

6. How will we demonstrate to those who are assessing the project (funders/peers/the research participants) that the work is ethical/legitimate/credible/trustworthy/rigorous?

Audience(s)

- Given the goal(s) of this project, who is/are our primary audience(s)?

Primarily for the performance of these stories, I want to aim at the academic and community service staff. Also, I want to focus at the following members of the society:

- The members of the organizations serving women like Women Resource Centers at the different organization in the state. Multnomah Women Services.
- Community organization serving people with intellectual disabilities
- Parent run organizations like Northwest Down Syndrome Association
- Academic Departments at PSU: Graduate School of Education, Liberal Arts, Social Work, Sociology, Anthropology, Psychology and University Studies (possible Capstone project/ teaching a cross listed course/interdisciplinary course)
- The research participants: If willing.
-

- People who work with the research participants? A public audience? All of these?

- Researcher: Neera Malhotra
- Artists: 1:1 (9-12 artists)
- In what ways does knowing who our primary audience(s) is/are impact on the way we:
  - Write the script? : No it will not. The primary purpose of this performance is to bring forward the voice of women with intellectual disabilities in front of community members.

  - Make aesthetic choices in direction, dramaturgy, and performance? Irrespective of who is the audience, the choices in direction? Dramaturgy and performance would be done in the most professional manner as possible.

Responsibilities to the Research Participants

- What are our responsibilities to the research participants? Have we been transparent and clear about what we plan to do with the information/stories they have shared with us?
  - As a researcher it is my responsibility to look into the safety of the participants and make sure that the information gathered is kept confidential.
  - The participants will be informed during the informed consent that the information they will share with me (the researcher) will be used to create stories and their stories will be recorded and will be performance by professional actors. The participants will have the key role to select what will be presented as a theatrical story.
  - Participants will be told that besides the researcher, they will be in contact with the theatrical workshop facilitator/co-moderator, professional artists and might be the volunteers- who will be transcribing the interview.
  - Every participant will be provided detailed information about the research process in advance. This will include description of focus group interviews as

well as the individual interviews. They will be told that they have to sign a consent form if they agree to participate in the study. The consent form will include research logistics related to the total time required, number of meetings, audio and video taping of the interviews and the details of the location, where participants will be meeting.

- While conducting the focus group interviews that involves theatrical workshops, the participants will be reminded that their stories will be enacted by professional artists. Also, they will be reminded to let the researcher know what all information they will be reluctant to share in public.

- Participants will be told that once they share their stories with me, the director and I will be select parts of the stories to be shared with the audiences as a performance. After the parts are selected, participants will be consulted to get their approval for live performance. The participant will be ensured that they can consents or withdraws consent for the stories selected, either at the time of notification, or at any point during the rehearsal or performance process. If consent is withdrawn, the story will be immediately pulled and will not be rehearsed and certainly not performed.

- Participants are encouraged to come to each rehearsal and are required to come to at least one rehearsal. Each participant, as the playwright, has the opportunity to talk with the director and actors throughout rehearsal about the performance of their story. They can ask actors questions, actors can ask the participants questions that clarify the stories, participants can make changes to the stories at any point during the process and participants are able to watch everything the director and actors do to get the rehearse and prepare the story for performance. Participants give feedback and notes throughout the process.

- Participants will be ensured that they can choose to either change their name, add a pseudo name, or can choose make sure that their name is added if they want their name to be added in the performance. They will be told that they can do that at any point during the focus group interviews, individual interview, and even right before the performance.

- The participants will be ensured that she will be the creator of these narratives and has all control over the conversation. She can change the information she shared at any point of time.

- Participants will be reminded at every step of the research that after the interview are recorded, transcribed, uploaded in a software and analyzed, the transcripts will be converted into stories that will be performed by professional actors. It will be made sure that if the participants desire acknowledgement, they receive applause from the audience at the end of the show (in addition to having their name listed with their pieces in the printed performance program...if the participant has selected a penname that name is used in place of their given name). Otherwise, they may attend the performance in private, or not at all, depending on their needs and desires.

- In general during an interview, I will restate or summarize information and then question the participant to determine accuracy. The participants can

either agree or disagree. These summaries will reflect their views, feelings, and experiences, and if accuracy and completeness are affirmed, then the study is said to have credibility (Creswell 2007; Lincoln & Guba, 1985).

- "Have we created a space in our planning for member checking?

  Yes. I have planned to involve member checking (Member checking is a method used in the qualitative research to ensure quality control and to seek the accuracy, credibility and validity of what has been recorded during a research interview (Barbour, 2001; Byrne, 2001; Coffey & Atkinson, 1996; Doyle, 2007; Lincoln & Guba, 1985). Also, member checking is known as participant verification (Rager, 2005), informant feedback, respondent validation, applicability, external validity, and fittingness (Morse, Barrett, Mayan, Olson, & Spiers, 2002) in three different Ways:
  1. While conducting the individual interview: I will reaffirm or recapitulate what I have heard from the participants and request the participant to determine its accuracy. The participants will either agree or disagree that the summaries reflect their views, feelings, and experiences. If the accuracy and completeness are affirmed by the participants, then that information will be recorded, this is also known as assuring the credibility of the study (Creswell 2007; Lincoln & Guba, 1985).
  2. After the individual interviews are conducted: Lincoln and Guba present one more kind of member checking. They write that participants are sent back the transcript at the end of the research, after analysis, to review for truthfulness of the work. The participants check to see whether a "true" or authentic representation was made of what she conveyed during the interview. (Member checks may involve sharing all of the findings with the participants, and allowing them to critically analyze the findings and comment on them (Creswell, 2007).
  3. Before the Focus group Interview: Colbourne (2005) highlighted that "through research interviews participants gain reflection, self-awareness, finding a voice, obtaining information, and venting repressed emotions" (p. 551). Hence, it is important to check

Is it necessary/desirable for us to ask the research participants about when in the process *they* want to be involved in member checking?

Yes. The consent letter will include the member checking strategies that will be involved for the research process.

At what moment(s) in the process is member checking important? After the transcripts are completed to see what information in the transcript can be used and what can't be used? After the script is completed? Before the first workshopping of the script with actors? During the first workshopping of the script with actors? After the first

workshopping of the script with the actors? Several of these? All of these? During member checking what we looking for? To see what we got it right/right enough? To see what we got it wrong? Both of these? If during member checking, we find out that our participants have concerns about how their words/stories have been represented, how will we proceed?

Responsibilities to the Audience(s)

- What are responsibilities to our audience(s)?

  The literature reviewed for this dissertation informs that the society as a whole has very little acceptance of the topic of sexuality in connection with disability, especially women with intellectual disabilities. The purpose of incorporating performed ethnography is to bring forward the voice of women with intellectual disabilities on their very personal topic on sexuality in front of the audience/community to bring in transformation in the thinking process related to sexuality and abilities.
- How much background knowledge about the project needs to be provided?
  It is important to brief the audience about the research process, the purpose of the study and the
- How will we draw the audience into the performance?
  Stage: student lead organization and I will do the marketing for the stage performance.
- How will we engage them?
- How will we work in alliance with our audience's needs?

Responsibilities to the Research-Artistic Team

- What are the responsibilities to the research-artistic team?
  The key responsibility is to conduct focus group interviews and the interviews
- During the first workshopping of the script with actors, to what extent do we see the actors' work as part of the analysis process?
  The actors are not responsible for the analysis process. The actors will come in contact with the scripts after the data has been analyzed by me.
- What are the implications of considering the actors as part of our analysis team?
  In terms of authorship/acknowledgement on the project? In terms of obtaining their formal consent to participate in the project (which is especially important in projects that are subject to an institutional ethical review)?
  They are not part of the analysis team.
- Is it important that the actors who are workshopping the script come from the same (ethnic/cultural/racialized/class) communities as the research participants? Why? Why not?

Actors who will be presenting the story of the participants will be acting as a catalyst to bring in required connection with the audience and transformation. The face of the actors belonging to the similar ethnic/cultural/class and racial as participants can be the protagonists that present the stories just beneath the surface of the participants.

- Is it important that we provide the audience with information about the research project? Why? Why not? What needs to be shared?
  Yes, the purpose of presenting these stories out is to
- How will it be shared (with a display in the lobby, a live introduction, through a program, within the script itself, within the performance itself)?

Research Design

- What research paradigm (Creswell, 2013) underlies the research study?
  Transformative research paradigm
- Is the paradigm compatible with a methodology of performed ethnography/research-informed theater?
  Yes. Transformative research paradigm has a basis of the critical research paradigm that
- Howe and Eisenhart (1990) propose a number of questions that a research-artistic team might answer in building their research design. Do the research questions drive the data collection and analysis?
- Are collection and analysis techniques completely applied in a technical sense?
  Yes, I am planning to use Thematic data analysis- explain.

- Are the research/artistic team's assumptions and subjectivities made explicit?
  o Researcher is collaborating with the theatrical workshop facilitator (co moderator)
- Does the project have significance within one or more (academic) conversations about social life?

  This dissertation research focus on the role of familial culture in understanding of sexuality by women with intellectual disabilities. The secondary purpose of this dissertation is to create a platform for the women to put forward their voice in the community.
- Does the study have "value" in informing and improving (some kind of) practice?"
  The study aims at exploring the understanding, hence informing about what these women understanding about sexuality. While doing so, it may or may not affect the

- What kinds of identity, institutional and systemic politics will arise in implementing this project?

- How will the team respond to these politics?

Aesthetic and Theatrical Design

Drawing from Patrice Pavis's (1985) work on theater analysis, Jenny Salisbury has created a number of questions that a research-artistic team might answer in building their aesthetic design.

- Given the goals and research of the project, what are the narrative and textual foundations that will hold the production together?
  Dani Snyder-Young (2010) suggests that performed ethnographers might look to playwrights and/or performance artists whose work shares themes with their data and use the forms they choose as aesthetic models. Similarly, in one of our course discussions, Pamela Snell suggested that the goal in research-informed theater is to tell a story that is emerging from the data collected for the project. Decisions about how researchers might tell that story arise from the data itself. Possibilities include the following: An imagined story and characters, which is supported by the research; A series of direct address speeches, directly quoting research participants (through the use of verbatim transcripts or found materials); Montage; Collections of words and images which create thematic links, without a linear structure; A linear/climatic structure; a circular/serial structure; a combination.

  Given the structure and goals of the project, how will the elements of the production inform/present the work?

  Performance space (classroom, conference, black box theater, outside, etc)?

Pedagogical Design

- Do we want to push, provoke, and disturb the audience? If so, how will we do so? I want the audience to be present with the stories and provoke to think about what can be done to address sexuality related issues for women with intellectual disabilities. While conducting the marketing of the performances, I will add in a blurb about the research purpose and the audience will be briefed about the research and research findings (it's a hope that the data analysis and dissertation writing would have completed by then).
- If so, what opportunities will be provided for the audience to talk about their responses to our provocation?
  First, it is a hope that the data analysis and an academic publication (research article) would be out before the performance. Besides an academic performance, I will start an online blog focusing on the performances right after the data analysis has been. This blog will be made public after considering the ethical stance of the

research findings. The blog will be updated with the updates on the rehearsals, and everything connected with the performance. Within the blog, there will be any given comment format for the audience to talk about their responses. Is it important that we provide the audience opportunities for post-performance discussion after each performance? Why? Why not?

Depending upon the available funding, we can conduct workshops and seminars after the performance. This will disseminate the purpose of the research.

- Who might facilitate these discussions?
    - Researcher/I will facilitate these discussions
- Is it important that we create discussion guides to accompany the scripts/performance? Why? Why not?
- Who might write the discussion guides?

Researcher/I and if PI (Dr. Randall De Pry) is available, it will be a collaborative endeavor.

Honoring and negotiating multiple commitments to research, aesthetics, and pedagogy

After analyzing the data, writing and workshopping the script/devising the performance, have we privileged one set of (research, aesthetic, pedagogical) commitments over another (e.g., a research commitment to thick ethnographic description and social and cultural analysis over an aesthetic commitment to drama and theatricality or an aesthetic commitment to drama and theatricality over a research commitment to thick ethnographic description and social and cultural analysis)? If so, have we found a way to be transparent about the commitments we've privileged?

APPENDIX P

ROLES AND RESPONSIBILITIES: MODERATOR AND CO-MODERATOR

Introduction
Considering the topic and the methodology selected for the study(Performative Ethnography), we need to follow a protocol for the roles and responsibilities as moderators of the group interviews. In the qualitative research (the kind selected for this research study), the two people involved in the study are required to sit together for the reliability and *confirming* of the data, This is done to validate the information gathered from the participants. Also, this data analysis process and the process of data confirmation will help in crafting the scripts for the theatrical performance. Both the moderators (you and I) will meet, one time before and after the focus group interviews (this will be audio recorded) to discuss the observations, views, feedback and/or concerns that was noted during the interview. This meeting will also be used to check in for the next focus group interview. Hence, I created this documents that provides a framework for the project on sexuality and women with intellectual disabilities to help us have clarity in our roles and responsibilities, following the research standards. This framework will demonstrate the roles and responsibilities that are usually assigned to the moderators of the focus group interview.

Roles and Responsibilities: Neera (Moderator) and Francesca (Co-Moderator)

Before the focus group meetings
Will meet before the day of focus group meeting (Dates needed to be changed from 2/28;3/1;3/14 to 3/28; 4/4; 4/11) to revisit planned activities and discuss if there is any question/concern or feedback. This will bring in clarity and will help in organizing the whole the meeting.

During the meeting
When conducting the focus group meeting, there is a possibility that the participant need to step out, either moderator or the co-moderator will take this opportunity to connect with the person and talk with her. This could happen because of the triggering conversation (sexual abuse/sexual intimacy/domestic violence). In this situation,
- Either moderator (Neera) or the co-moderator (You: Francesca) will step out with the participant and help her reach the rehabilitation counselor (available outside the focus group meeting room).
- Help the participant connect and be with her until she feels safe with the counselor.
- Sit with her, if she wants otherwise return to the room if participant want to talk to the counselor alone.
- Counselor will be requested to take detailed notes and she will help the participant take required steps.

- Moderator/Co-Moderator will check with the participant will she is willing to get back in the group. If yes, bring the participant inside without interrupting the discussion. If no, thank the participant for the visit and ask her if needs any support in going back home. If participant has come with another adult, contact them and be with the participant until she feels safe and comfortable.

After the meeting, we will discuss what happened during the individual meeting and will take notes.

Roles Based on the Agenda
9:15-9:30am
Neera adjusts the recorder, Francesca gives the final check if the recorders both video as well as the audio recorders are working.

9:30-10:00: Meet and Greet + sign consent forms: Neera: Introduces herself and Francesca. Greets the participants and read consent letters. Francesca will provide support (if needed) in getting the letters signed and also help participants who need additional support while Neera reads the letter. While doing so, Francesca takes notes on the process.

Neera re-adjusts the recorder, Francesca gives the final check if the recorders both video as well as the audio recorders are working.

10:00-10:30: Theatrical Activity
Francesca leads the activities and Neera support participants in understanding the activities and help when needed. While doing so, Neera takes notes on the process.

Neera adjusts the recorder, Francesca gives the final check if the recorders both video as well as the audio recorders are working.

10:30-11:20: Focus group Interview
- Francesca and Neera bring the group back to the sitting area. Neera ask, how is the group feeling as a whole while Francesca check on participants and adjusts the cameras and the recorders.
  - Neera leads the questions (1&2).
  - Francesca takes notes and keep checking the recorders.
  - Francesca leads (last two questions)
  - Neera take detailed notes and check on participants and recorders

11:20- 11:30: Break

Neera adjusts the recorder, Francesca gives the final check if the recorders both video as well as the audio recorders are working.

11:30-12:30: Focus group Interview continued

Neera leads the questions (1 & 2) (listed after the break)

Francesca take detailed notes

Francesca supports in clarity if needed by the participants.

Participants can reach either Neera or Francesca when they need to step out/talk/or even take a break. In that situation, if Neera is leading the questions, Francesca support/s the participant/s and vice-versa.

Francesca leads the last two questions

Neera take details notes

Neera supports in clarity if needed by the participants.

Wrap Up:

Neera leads the meditation

Francesca take detailed notes

In any situation, both Neera and Francesca are responsible to scan through events, conversations, and actions that would require mandatory reporting. Also, if the counselor is available, the moderator and the co-moderator (whoever available) will make sure that the participants are safe.

Disclaimer: during the meetings, the roles may get adjusted based on the need of the moment.

After the Focus group meetings (April Week of 6th and 20th: Schedule meeting in advance)

1. After all the focus group meetings, Francesca and I (Neera) will sit together and discuss if there is any specific observation. This is part of the research methods. The purpose of this activity is to check the reliability of the information collected. This will also help in validating the information gathered and will confirm the methodology used. This meeting will be done after EVERY focus group interview.

    a. Check in
    b. Discuss past group interview
    c. Share notes/observation/feedback based on the rubric

       d. Discuss transcript and video (if applicable)

       e. Discuss if there is any need to change/add or point at anything for the benefit of the participants and the study as a whole.

2. **Script writing:**

       a. Both Neera and Francesca will write scripts

       b. Meet in the Week of June 1st or June 8th (fix meeting in advance)

    i. Share drafts of scripts and give feedback and discuss the final version

   ii. Discuss transcript and video (if needed) to further refine the scripts

  iii. Discuss if there is any need to change/add or point at anything to ensure that we are hooking the audience.

  iv. This process will further validate the interviews (data collection process) and help in data analysis.

   v. Final draft of the script by June 30th.

Neera will revisit the final script after the first draft of data analysis. This may bring in changes in the script. She will have the final draft of the script by July 15th.

April- June-August
Neera will work with Francesca, Patrick (Artistic Director), Karin Magali (PSU), and the team for the production while she will finish data analysis and writing.

APPENDIX Q

ETHNODRAMA

School of Theater

Graduate School of Education

PORTLAND STATE UNIVERSITY

**THIS IS A ROUGH DRAFT: COLLECTION OF THE ETHNODRAMA
CAN NOT BE USED AS IT IS FOR THE PERFORMANCE PURPOSES.**

Desirable Conversations:

Sexuality and Women with Intellectual Disabilities

Neera Malhotra

Abstract: "Desirable conversations" is an Ethnodrama (script writing as a qualitative research methods) developed as part of the data analysis process of a qualitative study that involved three repeated focus group and eight individual interviews. Women with intellectual disabilities were interviewed to explore their understanding of sexuality which may or may not be influenced by their familial culture. We met on three Saturdays and spoke about the three dimensions of sexuality- physical (mechanics of the bodies), social (relationships and friendships) and psychological (intellectual abilities, judgements, and attitudes). The study revealed that participants perceive sexuality beyond the few dimensions of human existence. Participants of this study explained sexuality as an expression that gets percolated through the skills to be self-compassionate, self-determinant, the facilitated access to the sexual relationships, and feeling credible as women, besides the associated vulnerability to the word- sexuality within this social world. This Ethnodrama is an attempt to bring forward their voice to this universe!

Introduction

Prologue

Desirable Conversations is a series of interview-based theater work exploring the understanding of sexuality by young women with intellectual disabilities. This series of dialogues weave in the issues of sexuality with their familial culture, society, relationships and identity of women who are seen through the lens of the label "intellectual disabilities." It's not a traditional play or documentary-theater project performed by actors. Instead, Desirable Conversations is presented as an opportunity to plant a seed of knowing, understanding, and loving the art of "making love." When I write the art of "making love," I refer to the element of eternal desire of love unbound by the boundaries of labels, I refer to the process of "making" as a path of acceptance, trust, and fearless abilities with a thick foundation of "love." These interviews form the basis of a script that intertwines participants' individual experiences together in a chronological narrative touching on both social and personal experiences.

Stage Directions

Act 1: Act 1, all the actors come on stage individually. Only one music stand and a chair (with an option to remove) stand upstage.

Act 2: Six music stands and five chairs stand upstage arranged in "V" shape, the pointed edge of "V" toward the back of the stage. Each music stand holds

a copy of the script, which the performers read from throughout the performance.

Act 3: Four music stand and three chairs upstage.

Act 4: Three music stands and two chairs upstage.

In the end everyone gets back on stage.

Spot light comes up

Description of the Women

Ross. Ross is a Caucasian young woman with Down syndrome who is 22 years of age and currently lives with her parents. Ross shared that she is very close to her mother and sister and that she feels comfortable talking with them about sex and sexuality. She added, "I am close to my father too." She stutters while she talks most of the time. She is very cautious of her word choices and often pauses to reflect before saying anything. Ross is currently involved in a romantic relationship and claims that she loves her boyfriend. She said, "with my disabilities, it's better to be with a man than a woman." "Sex is fine, I am happy even if I am single, I have my mother and my father." She calls herself a dancer and related that she thinks of herself as a passionate person. She performs with her dance group whenever she gets an opportunity.

At the time of the interview, she was looking for jobs at a grocery store. On the last day of the interview she said, "Someday I want to get married but, first I need a job, then get my own apartment, and then I will get married. Got to take it slow. I have made many mistakes in the past, now I want to take it slow." Ross was one of three participants who attended all the interviews (one individual and three focus group interviews.)

Lilith. Lilith is a Caucasian young woman with Down syndrome was 29 years of age at the time of the interview. She lives with her mother and her mother's boyfriend. She addresses him as her step-father. Lilith seems like she is someone who was raised in an elite family.

Lilith describes her disability as, "my body had Down syndrome." She is very well versed with the socially appropriate manner of greeting someone. She is extremely polite and wants to ensure that she is following what you are saying. Her speech not very clear, however, she does communicate with confidence.

She shared that she has a deep desire to get married, have kids and have a happy life. Lilith is in a relationship with a man who also have Down syndrome, however he lives in California. However, Lilith disclosed that she has a fear that she was sexually abused by her boyfriend. She said that she has shared this fear with her mother, but does not want to share this fear with anyone else as she doesn't want to hurt her boyfriend. She is getting training to be a belly dancer. She is part of a group that performs adaptive belly dance. Lilith attended individual and two focus group interviews.

Oprah. Oprah is an African American woman who was 28 years old at the time of the interview. Her mother is currently incarcerated and so her grandmother has adopted her as a foster daughter. She thinks that her "mother" [grandmother] and her aunt teach her to live by example and faith. Oprah has a strong faith in her religion and she is dedicated to following her family's traditional faith. She refers to herself as a practicing Christian.

Oprah is in a relationship with a man with a disability. She said, "he is like me, I think it's the best." She works at the same place where her boyfriend works. Oprah was brutally sexually abused by her mother's boyfriend when she was nine years old. As reported, she was also involved in making sexual advances to other children in her family and to her friends, of which she said, "I lack understanding, but I was wrong, but now I don't do that [force siblings for sexual acts]."

During the conversation about relationships, Oprah stated that, "we all need love, want someone to give love and get love. Everyone can see that I have disability, even though it's visible, but I still have my own unique way of doing things. It's like you know the limitations may be there with my thinking process, but I still have the unique way of doing things." Oprah's participation in this study was limited to the individual interview and the first focus group interview.

Maya. Maya is a 30-year-old African American woman. Maya and Oprah live together and are related in that Maya is Oprah's aunt's foster daughter. Before she was adopted by her aunt, Maya lived with her grandmother. She conveyed that she was not happy living with her foster mother. However, she said, "I guess, it's ok, but I find my ways to visit my grandmother, she is the best." Both of Maya's parents were in jail at the time she was interviewed.

Maya's foster mother informed me that Maya was recently kidnapped for 48 hours and that during this time, she was assaulted and raped. However, it appeared that Maya was still processing what happened (a typically sexual assault survivor sign) and she was reluctant to talk about her experience.

Maya one of the two higher functioning women among all the women present in the group. She currently works at a coffee shop and takes pride in what she does.

When asked about her sexual orientation, Maya said, "I like both men and women, they are the same. It doesn't matter." When asked if she knew about the term "bisexual," she said, "Oh, I have heard that word, I don't know that."

Sarah. Sarah is a 31-year-old Caucasian single woman who smokes frequently. She lives in a foster home with other adult women who also have some form of intellectual disability. Sarah describes herself as, "I have a sweet face, blue eyes, and I am a good person." She loves to talk about politics and takes pride in talking in her general knowledge.

Sarah is a soft spoken, friendly tomboyish woman who loves skateboarding and making cartoons. She added, "I am not sure why guys don't want to be with me." She further added, "my job coach says, there are plenty of fishes in the sea, I am sure I will find my guy." In all the interviews she emphasized that "you gotta take it slow in relationships, I have made mistakes in the past."

Sarah shared that she was raped 10 years ago. When asked about her abuse, she said, "I was very angry, when he raped me, felt helpless, but it's been 10 years."

Sarah also shared that she was incarcerated for an act of domestic violence in the past. She was not very comfortable to talk about what happened and why she was incarcerated and later under the supervision of an officer. She said, "It's past, I am different now, learning to manage my anger, I must, I am 30 now." Sarah was one of three participants who attended all the interviews (one individual and three focus group interviews.)

**Berne`.** Berne` is a Caucasian, 30-year-old single woman. She is a higher functioning young woman with intellectual disability who has Spina Bifida. Berne` uses wheel chair for mobility. She lives in an apartment near her parents' house and calls her three cats as her daughters.

Berne` is an outspoken woman with a strong opinion about sexuality, relationships, her gender, disability, and sex. She says, "all I want is to be in love and yes have sex, is that too much to ask?" She also added, "I am not sure why they break off with me?"

While sharing her experience with online dating and strip club experience she said, "Speaking as a physically disabled woman, I have to say, I guess, I have had boyfriends but, all men don't see you. They see you as a friend, they see you as the buddy, but they don't see you as the woman they want to spend rest of their life with."

Berne` also shared her desire of paying a man to have sex, which she said, didn't work well. She said, "I asked my mother if I can do this, she said, 'oh, you are an adult. But don't tell me about all this…'" She said, "my mother has always supported me, but it's frustrating that I can't find anyone." She said, "this evening I am going to the single's club, I might find someone there..."

Berne` follows Paganism as a religion. She said, "Hey, you know, I'm pagan… I kind of became desensitized, angry, I guess you could say, at the Christian religion because when I was born, I was told if you believe in God you'll walk. Not by my parents or anybody I knew, just, just, you know, weird outside people. And I just was thinking I was made wrong, and I didn't understand why there were, why people didn't see me whole as God

sees. God is supposed to see everybody whole…I can't walk…" Berne was one of three participants who attended all the interviews (one individual and three focus group interviews.)

Jane. Jane said that she is a half Caucasian and half Hawaiian woman who was 27 years of age at the time of the interview, but she was not sure about this as she was adopted by her current parents. She is in an intimate relationship with a boyfriend who she has been with for the past 10 years. . She said, "as a woman with disability, who didn't grew up with mom, I learned many things [about sexuality] on my own, so, disability, it's frightening, it's tough sometimes, [this is] all I know." Jane currently lives with her father and her boyfriend. Her mother and her siblings moved to Hawaii after her parents separated a few years ago.

She said, "I don't know about my disability as I was adopted when I was 3 years old. But I struggled understanding things in school." She added, "I go to college though, just like you, and I have a dream to start my own magazine." Jane attends regular community college and works as a volunteer at a local theater group for individuals with intellectual disabilities, to be part of the theater class. Jane participated in the individual interview and the first focus group interview.

<center>

Dialogues on Disability

"I am, what I am, I am happy with my being"

Disability is…

Ross

</center>

"Disability is, someone that has also special needs, and different abilities,

different abilities can be...For example for my own abilities is being more

independent and there are things I can do. For my abilities, it's being

more independent and there might be some disability…I have Down's

syndrome…I know something that it's the understanding of things…So, I have Down syndrome…it's my body as it's strong kind of feel [feeling]."

Berne`

"Well, growing up, I never, I was not allowed to say the word 'disability' my mom doesn't like that word. So, she always just called it different. And, I was always told that, being different is not wrong… it does not mean that you are less than…it does not mean that you are not as good. It does not mean anything but that like society sometimes makes it look you are not meant to be pitied. You know...people don't need to feel sorry for you...blah blah blah. It comes with its challenges but it also comes with its rewards and it's, it's battles and that can be won and sometimes that can are like, ok, I didn't exactly win that battle, but it doesn't mean I'm not...I'm not going to give up on it."

Oprah

"Well, I was like, born, I was...I have a disability because my mother did drugs and alcohol, while I was in her stomach, that lead to me being, when I was born drug affected may be and then I was labeled as being mental [mentally] retarded and so I have a disability, so, yes…I have disability from that...I remember her, I have seen her…I could have grown with hate and everything towards my biological mother, but I don't, because, God gave me my biological mother, and she didn't raise me like that, I love my

biological mother, just like I love my mother, yes, I have issues with her,

but I love her. I have forgiven her. I am fine, just way I am"

Maya

"I am a visual learner...that's what I put…so I have [to] see somebody do it

so that I learn."

Anna

"I have freckles…I was born second…I can't read from far away…I use

glasses, I got a new one recently… I can't read far away…I use glasses or

sit up front…I am very close to my mom, and I like to be under her skin…

I think I have it inside me…the bad spirits…I don't understand sometimes.

I think, that if they were not there I won't have any these dreams, dreams

of being raped…I really want to be baptized again…because I don't

remember being baptized as a child…[being Baptized]. It means that I can

get all the bad spirits out….I think the spirits are bad, angry and they don't

want me around…"

Lilith

"[We can] teach them to use sign language, when they are very young,

they're always smart and they socialize, they socialize with other kids,

during the other pre-schools and be really active in society and other

school districts. They are really smart, if you teach them how to be active

in the all different school districts….My body, my body has Down syndrome and when you have Down syndrome, on your feet, you always have wide feet with bunions on your feet when you were born. I have couple of surgeries on my feet…as you're walking. I [have] got wide feet it's kinda hard to get, buy shoes for it. So I have couple of surgeries on this left foot so it's hard to buy for. So I got couple of surgeries on my feet it's kinda hard to buy shoes for...but, my dad gets me special shoes. They are designed only for me…he also has a store in my name…everyone knows me there…Exactly. So that's how I got my disability from."

[silence]

"Oh, but, [my body] it feels natural…it feels great [smiles]."

Sarah

"The way I think of disabilities is like being good at stuff. Well, my mom thinks I have disability, but I don't see it. My mom thinks that, but I don't see it. I am not affected by what my disabilities are, you know I'm a grown woman. And you know, I used to, when I was younger, in middle school I used to be sensitive about it but ever since I got in my adulthood I stopped being sensitive and just not taking it seriously."

Oprah

"When I think about disability, I think about like...we, I may have

limitations...and ammm…you know...I may look differently than others

but I umm am my own unique way of doing things. My disability…it's

visible but I still have my own...I have limitation in my thinking

process...but you know…I still have…"

Jane

"We don't know my disability, since I was adopted. I was adopted since I

was 3 years…since we are not sure what it is…we are still trying to figure

out what it is, but with my disability it is very tough to understand things

sometimes."

And the Body is…

Berne`

"I like myself, looking at myself with clothes on…but not comfortable

looking at myself with clothes off…because…I don't really like my

body…the way it's shaped and the way it is, and I just…like…it has spina

bifida and paralysis… I have been through with my life. [Gasp] But, I

still…I used to go through self-harming…because I was angry at my body

for not working the way it should and I have hurt my legs not…not

cutting…just just scratching…making scares and stuff because I was not feeling anything…but I would bring self to bleed…but just that...I am no longer angry at my body.”

Ross

“It's my body as it's strong kind of feel…when it comes to sexuality….like...when there is...it's some kind…I feel some kind of touch in my skin, that it makes sense. Specially (stammers)...sometimes…I feel like sexual in a way that and I want to have sex and sometimes I don't… it's kind of depend on what I want…I mean that…aammm… that...when it feels like sexual in my skin…it does feel sexual in a way that kind of way...in my touch...I kind feel the way that I feel sexual…I do touch myself…but I do it in my own room…because it's more private (stammers) that way…so…I learned about this from my mom and I think it is to masturbate I think it's called...and that's what I do it as it's kind of feels comfortable...”

Sarah

“I feel...I do love my body…the way it is...and…you know…the body is so nice...and you know…It doesn't bother to me…I know...it's like...my feelings...like like when I look… I look into the mirror and see and I see that beautiful face…and just want, you know…I think that it doesn't to me from outside…always this smile...and these beautiful hair...”

Jane

"I thought it was very interesting you know…the body. The women's

body…God made us this way. I believe to produce babies you

know…that's not what we are doing...you know…we are too young to

think about that..."

Ross

"I told my dad that somehow I wanted to grow up fast…why…but now I

just feel week…especially when you are disabled you need to know how

to take care of yourself…ammm independently if possible...because you

don't want to… you cannot be…aammm you can be needy…I am learning

that it can be ok thing to do...and I am trying to learn to be independent as

possible…"

Lilith

"[My body] it feels natural…it feels great…If I get raped, I will be

miserable...and I will go to Police and for investigation..."

Anna

My body is …

Dialogues on the Family
"I love my mom…"
My Mom and my sister…

Oprah

"My foster mom, she encourages to set our own comfort zone, in which, what we want, we can achieve. She raised me to be like, if you have a disability, that doesn't matter, if you want something, work hard and you can achieve anything. For my biological family, I don't really have closeness because my mother was not ready to take care of me. I experienced hurt. Being a woman who I am today is because of my adopted family and sister and mother. I have other foster brother and sister. We don't see them as foster. We like, we all are family. I don't know who my father is. I kinda look at the priest at my church as male role model."

Sarah

"My mom always says, don't go too fast on the guy and my older sister says that you got to always set boundaries. My older sister is right she's my protector, that's what she is."

Lilith

"I love my mom very much…and my sister."

Sarah

"I am very close to my mom...you know…I do miss her a lot...and I got a stepdad...my stepdad is like a father figure to me…since I was a year old,

he took care of me…My older sister and my brother…they are my protector...At present I live with my foster mom…"

Berne`

"I learned about…learned from my mom, about sex. I learned about sex, from my mom and I learned about, sex through health classes, about babies, and I had a relationship class. I have grown up, it's not the marriage I want, we just learned that from my mom that, treating myself with dignity is more important than finding someone to be with, I can find anybody, if I wanted but I must treat myself with respect…" But later in the third focus group interview, Berne` said, "I want to be with a man and get married."

Ross

"I always talked to my mom about sex and also some with my sister. Because, I feel more comfort...that is within my comfort zone, it won't be tough with my mom and my sister, as per my dad goes, I haven't talked to him much, as it's not within my comfort zone, but there is something I talked to him about…" She further added, "I said that for my mom and my sister because they are kinda common as a skill, more and kinda I can't talk to my dad. It's obvious…he is a man, so...I can, talk about things about my other stuff. I am like, as even I am a woman like them…"

Oprah

"I grew up in a Christian home…my mother my sister, they tell me…by...they tell me by example. I my first…my first from what I can remember…my first what was I going to talk about…well...my first knowledge…yaa knowledge about the puberty, menstrual cycle and everything…I learned at school like…and…I also...learned by example of my own…and my mom…and my cousin…and they tell me by example like…if you choose to be with somebody...stick with that person...don't you just have...and I learn by like…you know…going to church like...like...like...no...no sex…before marriage…if you do that then no problem…ask for forgiveness for that and practice celibate...it's normal to have like...like…it's normal to have those feelings or urges or whatever you want to call them…but… how you deal with it...you know what I mean...it's how you handle the...handle...how you handle...the feeling… it's normal and everyone has those feelings and then urges…you know...it's how you handle that...and as long as you handle that…"

Anna

"I love my mother, and I like to be under her skin; she tells me to ask my sister about toys and sexuality."

Ross

"I learned about masturbation from my mom."

Jane

"My mom never taught me anything about it [sex], you know, she told me to ask my teachers…My physical education teacher helped me learned about it, and gave me books to read…may be my mom was shy…"

Sarah

"My mom told me all about it like what sex is like and I...it's…we were...like more of woman…guy and woman falls in love and then get married and then after that…then they have that sex thing. "I went through that awkward stage…I...you know...I knew I was going become a woman and I know… exactly...you know...it was happening to me as a childhood and into the adult zone..."

"Welcome to the world of adults"

Sarah

"I went through that awkward stage...I...you know…I knew I was going become a woman and I know...exactly…you know...it was happening to me as a childhood and into the adult zone…I have...when I was older… when I got my adulthood…I was older…ya…I was getting attracted…

you know...there were lot of guys...I used to get asked out a lot by lots of

guys...My mother told me, welcome to the world of adults…"

Ross

"My mom told me…when I think of masturbation, I think for all

woman…I think we always… always do it, because somehow it feels

comfortable to our...own body...somehow this is what we do and…as an

adult woman's life that...it does depend on how you do it and where...you

do it...and what's it is like…because it's kind of growing up…I still do it

and I do…well...it kind of depends on age as well…somehow it got started

and somehow it is kind of natural…"

Sarah

"I know the horniness…yaa. I know...I felt like that...my mother told me

about that…She said that the sensation of horniness is ticklish in a

way...you know..."

Berne`

"I was dating a senior...he liked to be kissy kissy grabby grabby and

yaaa...and somebody caught us making out in the elevator...yaaa...yup

yup...my mother said…you had been riding…you have been wanting for

guys since when you were 3 yrs. old…Oh, yah, she said, 'she is my

daughter'…my mom said, I was always sexual, welcome to the world of adults…"

Ross

"I had a similar thing when I was still at school with ex…that's how...I was...I was kind of making out...you know...as soon as my mom came to know…shhhhhup…it was all over...it was so [ooooo] weird…it was so [oo] uncomfortable…"

"I still remember I had a long talk with my mother…it's being an adult thing…[long gasp…]."

"My mom and my sister are my best friends."

Berne`

"Well...I used to talk to my older sister...I...she said that you can talk to about sex and all that...and I get to translate that all the time…she said it's all normal and I got the magazines…that...with lot of...like my ex-boyfriend had…you know…and it's all…you know...and do like that and I watched lot of romantic movies...and like…you know...I see all the couples doing it...its normal...

Lilith

"My sister is expecting her first baby very soon...and she will have it any moment right now…she told me about the baby and how…I talk to my mom too…"

Ross

"I think...I think for me…it's kind of hard to understand at first...that if we go to...mothers or sisters...they can kind of teach you to understand it in a way and you can ask...they would know more than us...because for us it's kind of hard…because as per me…it's kind of my disability...is the understanding part...for me, it's kind of hard to understand that… concepts...so kind of I ask my sister and my dad at some kind of point but not too much because he is my dad…but I ask my mom and my sister…I can reach kind of…talk about it...

Oprah

"I want to be like anybody else, my relationship with like my foster mom, my sister, they helped me understand that you are beautiful, just how God made you, and you should be happy for who you are and you know my relationship with my boyfriend has helped me to grasp that too…"

Sarah

"I am very close to my mom…you know...I do miss her a lot… and I got a

stepdad. My stepdad is like a father figure to me...since I was a year old,

he took care of me…My older sister and my brother…they are my

protector…"

Jane

"I am close to my boyfriend's sister…my sister moved out and they are all

older than me, I am the baby of the house…"

Ross

"I am too…"

Berne`

"I also learned that…take self-defense classes or keep pepper spray or just

stay alert or something…"

Ross

"I learned from my mom...she says that you have to be alert…when it

comes to such stuff…you need to be on tough of it and just try not to turn

out to you and then you need to find someone and take some help and that's what I think about it…"

Ross

"I always talked to my mom about sex and also some with my sister...because...I feel more comfort...that is within my comfort zone…it won't be tough with my mom and my sister...as per my dad goes...I haven't talked to him much...as it's not within my comfort zone...but there is something I talked to him about...I said that for my mom and my sister because they are kind a...common as a skill...more and kind a I can't talk to my dad...it's obvious...he is a man...so...I can...talk about things about my other stuff...I am like...as even I am a woman like them..."

Dialogues on Sexuality
"I am, what I am, I am sexy."
"I feel kind of sexual."

Sarah

"I know the horniness...yaa. I know the word...I felt like that…my mother told me about that...She said that the sensation of horniness is ticklish in a way...you know…"

Ross

"When it comes to sexuality…like…when there is...It's some kind...I feel

some kind of touch in my skin that it makes sense. Specially,

sometimes...I feel like sexual in a way that and I want to have sex and

sometimes I don't…it's kind of depend on what I want…what sex is to me

is if you have a a a guy…you love somebody…and someone with

romantic and love and you kind of fill all you get into in and do get into it

and that's how it starts .kind of…sex…and in other way about sex is when

you are with someone your true love and you know you always want

to…live with that person all your life and you …feel this way…your life

and your…My boyfriend has a disability. He has Down syndrome. I don't

think [disability has any connection with sexuality]. It's kind of an adult

kind of thing"

Sarah

"The word sex is to give more than to get…it's and and...and another thing

about sex is turn on a woman with...like you know...get on the bed and

then you start making out and then...then do the sex part...when I think

that there is a love thing that turns me on and that is separate and then

have a dark chocolate…I am happy when I am in a relationship."

Berne`

"Sex is sharing your body with someone…sometimes it's love and sometimes it's not love…sometimes it's lust…it's between the two people… sometimes you meet at a bar...you feel lonely...you are drunk...and you just want to go go go…has to be safe for your body and for the partner too…there is sexual attraction…when I had sex it's been with people I had loved...I was 19 years old and we were both virgins…I remember and...it was a nice… Last time when I was in a relationship I felt wonderful, felt desired, felt flirty umm I was sexually attracted, I was in love, and when I was with him I felt safe. No not sex per say, just being with someone."

Ross

"I think disability and sexuality as a woman is having a relationship with a partner…and also to thinking of having a partner. And thinking about your future and how you feel being sexual. I think as you are becoming a woman…it's something you kind of have to think about when you do have a relationship with someone. And I think the first thing that would come into mind is do I want a relationship and how will umm and how it will go well."

Oprah

"Yaa, it's [sexuality] a to me it's like an expression. Loving him, makes me love myself…"

Lilith

"If you have a boyfriend and if you don't want to be touched in a physical sexual way just prepare yourself and ammm use self-control and you gotta be positive and be control and be prepared to take in control and including around safe sex too.."

Choice and Boundaries…

Ross

"I think, you have to keep boundaries, as a woman."

Sarah

"About, sexuality, let's see, when you have a boyfriend there's boundaries because a young boyfriend, you don't want to go too fast. You want to take it slow. That's the way, and that's the way I like it. Because start out slow with what you're doing. Like start out slow with going on a date and then if this boyfriend works out then there's always a second date."

Jane

"As a woman with a disability…I believe like…your sexuality in a

disability, it works together because umm like you can have...it brings like

about like a self- confidence...like in who… like me as a woman, I feel

comfortable as who I am… It brings like self-confidence...like I, I agree

with Ross, when about choice...you know it's a choice if you wanna have

a boyfriend or a girlfriend you know or whoever...it's like it's, it's

whatever you feel comfortable in is your choice that you have that self-

confidence."

Berne`

"I remembered the catholic…like you don't have sex before

marriage…you know…In my opinion, like…are you like, but…in my

opinion…there is nothing wrong or right…you know…your body has you

know…like…it's a vulnerable position…that's what I tell people

that…like this is me…who I am…like you know…like kind of

lusted…[laughs]."

Sarah

"I feel…I do love my body…the way it is...and…you know…the body is

so nice…and you know…it doesn't bother to me...I know…it's like…my

feelings…like like when I look...I look into the mirror and see and I see

that beautiful face…and just want you know…I think that it doesn't to me from outside…always this smile…and these beautiful hair...I was angry before, but not anymore. I learned from my counselor to let go of my anger."

Ross

"I think so yaa. I do think that I'm happy because I was having sex when I was still at school with ex...I was, I was kind of making out…that's how…you know...as soon as my mom came to know…shhhhhup…It's all over now…it was so weird…It was so uncomfortable. I think I moved way to fast. So, now I go slow, I like it this way. My boyfriend and I don't do anything…What you like and being passionate you believe and it might because when you have sex, it is because you are lovable and you have a guy that you really love and you do feel really loveable because he kind of attracts you to it. The attraction is setting off the vibes, attraction and that's how you get into it and it's kind of go two way."

Conversations on LGBTQI[1]…

Lilith

"I am not…I am not a Lesbian…"

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[1] LGBTQI: Lesbian Gay Bisexual Transgender Queer and Intersex

Jane

"Personally I know lot of gay people, if they are happy they are happy...I

personally don't believe in it…I was raised Baptist…and when maybe I

was in high school, my sister came out…you know what love is love, she

is gay or not…and she is happy and I am happy for her…and you wouldn't

think she is…[Gay]. It's the choice that she made."

Sarah

"I was with my one of my [boyfriend]…I was with my…one of my…one

of I was with my one of my best thing…like Harry Potter like midnight

showing… at midnight…there was a Mayor Silverton, who was a

transgender… and you know…you know…and I support it, and you

know, I...follow…at this place…follow gay and lesbian…on the

twitter…and you know the former Mayor is gay you know."

Oprah

"There are boundaries…we have talked about different...sexuality like too,

they…the beginner...or…my my my…my believe is...that...you can...love

the person...without...what I like is that…with that sort...am mm...not like

what...I can…it's not my believe am mm…to grow and…to judge

somebody because...they are…they or when they know…or whatever they

choose to be…that…am mm…that is not my place...I am not the judge…

there are plenty of things where you will find fault in me…so…I love the

person…like…I can love the person…but I don't have to...I mean I can

love the person without passing a judgement...I know, I can be still kind,

without judging you, I can still be kind...I can see you and say hi how are

you doing, without confrontation without judgment…what do you or

whatever life that you choose… for me that's what it's all about...your

sexuality...your choice…I choose to be straight...I...you know...that that

that…that is what…that's for you…that's your choice…and that's what we

know…and is what you…like...when you read in the paper…a certain so

called Christian group am mm…they print they print am mm…gay and

lesbian funeral…or for some that is like a picnic...I think… that's what had

been told that… who you are. I had been that's what...who are you to

judge...I am fine…but what you go by example…he didn't judge…the

people for doing it right or…doing it wrong…he shall…love the person

who they and and and where they are at…he didn't like…he tell me

that…as a Christian that I am not supposed to judge…"

Maya

"I want to say that, it means that, like our [my] job…it says that like we

have…like gay, transgender…it's part of the job…this is what we

learned…and some people are more [open] about, about their sexuality

and people are more open about it…they are more open…where I

work...they are more open about the sexuality and they are more, yaa they are more open, or may be closed off…yaaa...they know that…who is straight who is not…like I know my customers…who you know…so I know…they are more open about their sexuality…and at first they are open about their sexuality…"

Berne`

"I remembered the catholic…like you don't have sex before marriage…you know…In my opinion, like…are you like, but…in my opinion…there is nothing wrong or right…you know…your body has you know…like…it's a vulnerable position…that's what I tell people that…like this is me…who I am…like you know…like kind of lusted… [Laughs]."

Ross

"It just happened that I lacked in understanding because of my disability of understanding…because there was just one time that she told me that she was uncomfortable...so I stopped…I just touched her...not kissed her…I wanted it...but it was her that she didn't like it… so I had to stop...aaaaa...I wanted it but she didn't want… since she is my friend...I stopped it as I don't want to make her uncomfortable…with my disabilities…it's better to be with a man…"

Anna

"I have not tried girls and girls...but I am interested in boys but I was

interested in high school in my high school and I told my teacher that I

was a gay...but that was a long time ago…"

On Masturbation…

Sarah

"I touch and then you know...I start doing that…I try not to do the

moaning sound...you know…it just feel horny...I just...I got to move it

in...I don't touch myself that often. I have that thing that my staff bought

me."

Lilith

"I love people to hug me…I love people like…hug me…like kiss me on

my little cheeks…I loooovvvvveeee that moment…But I don't like doing

bottom rubbing…I don't want that…I love people when they hug

me…comfort me…people like spoil me, hold me...that's like my favorite

thing to do…that's like my favorite moment."

Ross

"It's comfortable. I think masturbation...mastu…masturbation...it just feels natural for woman who also has a disability...because for some it is different...than for people...and how it in a way that it just feels comfortable…when you do masturbation…it's just kind of obvious…like it's more about your private parts and that it becomes…kind of comfort…they kind of have and that you share...out in public…when you are out in there in public…in my mind it's kind of weird if you...it might feel uncomfortable…that it should be like…private…and I also think of like your room of bathroom of any kind of place you can think of...Also, when I think of masturbation, I think for all woman…I think we always always always do it, because somehow it feels comfortable to our…our body…somehow this is what we do and...as an adult woman's life that...it does depend on how you do it and where...you do it...and what's it is like…because of kind of growing up...I still do it and I do…well…it kind of depends on age as well…somehow it got started and somehow it is kind of natural."

Lilith

"Ok...I have never done it…so...I have not done it…before it was kind of disgusting to me…kind of degrading…kind of gross to me…some men do it all the time when they have sex without the woman..."

Sarah

"I have sex toys and because I shut my bedroom door and I....I...take the stuff like that...I use that…in my…because when I think about that kind of stuff that's what I do…that…you know…I start like practicing it… I don't use that all the time…but I use like…not very much...not that often…you know…like very much...when I see something…like stuff like that...It turns me on…in a way…"

Berne`

"Me, personally...I don't do it. But I know that…I don't have any feeling below my waist…so…I prefer doing it with a person…I have actually seen it done many times…sometimes…it's part of foreplay…sometimes a woman does and shows it to the man and then she...you know I watch porn sometimes…not all the time...but sometimes…alone…of course… so...yaa..But...I also don't think that masturbation is wrong…I think it is part of who you are and your body and it makes you feel good and it's like treasuring yourself as a sexual being…I don't think there is anything wrong with this…"

Anna

"I think the toy is the guy and I think I want to do that with a real guy…"

On sex…

Berne`

"I wrote that sex is sharing your body with someone…sometimes it's love and sometimes it's not love…sometimes it's lust…it's between the two people...sometimes you meet at a bar...You feel lonely...You are drunk...and you just want to go go go. Has to be safe for your body and for the partner too...there is sexual attraction...when I had sex it's been with people I had loved...I was 19 years old and we were both virgins…I remember and...it was a nice… Last time when I was in a relationship I felt wonderful, felt desired, felt flirty umm I was sexually attracted, I was in love, and when I was with him I felt safe. No not sex per say, just being with someone."

Ross

"I think, what sex is to me is if you have a a a guy…you love somebody…and some with romantic and love and you kind of fill all you get into in and do get into it and that's how it starts .kind of…sex…and in other way about sex is when you are with someone your true love and you know you always want to…live with that person all your life and you…feel this way…your life and your…"

Lilith

"Sex is intercourse, with a wife and husband together…Intercourse means sexual intention with your wife and husband together...that's what I know about it..."

Sarah

"The word sex is…it's to give more than to get…then do the sex part...when I think that [sex] there is a love thing that turns me on, and that is separate and then have a dark chocolate…I am happy when I am in a relationship."

Jane

"I love my boyfriend, and we use protection and it's fine. We are too young to have babies. In the similar vein..."

Ross

"[I learned about sex] from classes and from my mom too….I have a thing of a fear about sex...on a bad zone…because I don't want to get pregnant...I don't think I am ever gonna be the one with kids...I don't want to have a baby right now...just that part of having kids is what I don't want...but I do want to get married…"

Oprah

"Loving him makes me love myself."

Anna

"I go to the library and get books on it [Sex]...because I want to figure that

out, so I get books on it…"

"I know that that sex is for boys and girls and and and and boys does girls

and girls and and and…or you can just do yourself...play with your

toys...that's all I know...I do it every night…it feels comfortable…it's a

like a vibrator…that I do every night, it's really comfortable and I use and

the handle is pink...and I really like using it on myself...I know it

does…emotions and and I know that one a guy puts his penis inside a

girl…it feels like a fireworks…"

[Silence]

He raped me…

Sarah

"There was something bad happened to me long time ago...you know...this

cocky guy...he used to pull out my...and I was raped long time ago...they

never caught him...Police hadn't caught him… he didn't give them his

name either...it was long time ago...it was long time ago..."

Lilith

"When a man touches woman's private parts…if they are uncomfortable in that sort of areas…but now...It's like degrading to other woman…to be upset…that cause a date rape relationship…"

"It's like sexuality with other women too, [boyfriend take] advantage of their private parts and touching their private parts and stuff like that…sometimes I see that in myself…something that my boyfriend did to me...I am and I can talk about it more, I...I was at the Mt. Kiwanis camp hall…prom night…he was…I didn't know that but I did notice. you know…the 'p' word into my underpants and I had my lady problem…with…I had my little pad in…and I felt that…it felt very hard…and I just know that I was not very comfortable...I said…that I didn't want to tell this to our parents...I don't know if that was rape…I was under pressure, but I still love my boyfriend as usual. He is kind, he is sweet and I love his personality."

"I kept it a secret."

"I just don't want to say anything to him…to his mother or his step dad or to my mom and my dad, and so...I spoke to my grief counselor. And spoke to her about it...and...I cried…cried…and I had my grief thing and I cried my eyes out and my mom said that it's ok…and deal with it…get over it…"

"It affected…to myself confident…to my self-esteem..."

Berne`

"You must tell something to him though…you need to tell someone about it…because when you are in a relationship you talk to people…like if he does something…or said something that you don't like…you really need to talk to him...it is like if you don't...it will keep going keep going...not until it's like exposed."

Sarah

"Ya…you don't that [let] him to hurt you."

Berne`

"Correct…and not like I love…it's not only men who take advantage there are some women out there that I know of and I know that I might be one of them…"

Lilith

"I felt his thing on my underwear then my my ladies thing then I had my periods...then I felt his thing right underneath it...it feels really hard...very uncomfortable...I just know that was kind of rapish..."

Sarah

"I would say…at first…well…you get raped… when you don't see it coming...I would say that you need to be careful of your surrounding when someone is trying to attack you from behind…I know as I was being raped...it happened at Cathedral Park…and I tried...I tried to scream…you know...I tried to push him off…I was scared…to death. When he did that…and because when that happened…I just told him...I I I I had a I luckily had a cop right there when it happened. I told him what happened and but they never caught him. Because sometimes, they get away...aaa...most of the time they will get away…but sometimes but sometimes…they do get caught...aaa…they arrested the wrong man too..."

"Right now you know it's ok…But, you know…something like that happened to me again I have the tendency to spit on the person in his face and I have fake thing that fake blood that I plan to put it on his face…I have the trick that I can use…with that fake stuff that every year at around October…you know with that fake blood thing...You know…that was my idea is to do that…Oh, when someone tries to rape you or whatever and when it happens…you know when something like that happens…I can spit on the person's face…and I do have whistle that my care staff bought me...I can always blow that on his face. Other ways I can do too…"

Berne`

"I wonder why women go to the bathroom in group…it's safety…if you go to the bathroom by yourself…and if you find someone you don't know…there is a chance of rape…and you prevent yourself…if someone is tapping you or following you then you can go for help…"

Lilith promptly said,

"The buddy system…yaa...like the buddy system…you got to play down and prevent yourself from being kidnapped using buddy system…"

Berne`

"Yaa...Exactly yaa exactly…"

Sarah

"Like it happens a lot...like you can't feel love like before…"

Ross

"I think there is abuse of sex…it is called a sexual harassment and that it happens to lots of men and also telling about it…and that's how I l get my input about…it's interesting that so many...there is a situation kind…let's just pretend a situation that can happen...probably you are on the

TriMet…which is kind of of awkward to face...and if you see somebody

doing it and this is how I learned...taking them up to the TriMet staff

thinking of you or it's just getting alert too much on that and then I will

have to stop the bus and then get off the bus or may be call somebody to

pick me up and say that there is somebody who is kind of weird...and then

ask them to take you home…"

She further added,

"I just have been learning about it lately...and it kind of depend where you

are at…there are kind of weird people who can come up to you in a sexual

way and in its…that they come in your zone and it' kinda hard to get out

of it…sometimes it can be hard...but…if you find somebody whom you

can trust and the get some help...if you know somebody who can help…or

if you see some people say cops for example and not too much to the cops

as it can get kind of uncomfortable in a way…and, I just think it just has to

be depending where you are at…my mom says that…you got to be careful

of what you do…like like you always have to be careful of what you do

and be aware of your surroundings…which is…my mom says you have to

be alert, like if you have music in your ears, you kind of have to put them

out so that you can hear what is around you…which is what I learned from

my mom…she says that you have to be alert…when it comes to such

stuff…you need to be on tough of it and just try not to turn out to you and then you need to find someone and take some help and that's what I think about it…"

Sarah

"Oh yeah, when I was raped. I had a lot of anger out of me. I took that out on my housemates for no reason, there was certain stuff like one was chewing on gum and I got irritated at that. It was because the anger was coming out. This was when I was in my adult, second adult foster parent home. And she acted nerved, they're from Hawaii, and she called my grandma up and to calm me down so my grandma actually didn't want me taking my anger out on anybody. I've been pretty good about not getting angry. I've been thinking like, cuz I've been told to close my eyes and go somewhere, you know like think…so I do close my eyes a lot and go to the beach, me on a surfboard that's my happy place. What you gotta do before you get angry either close your eyes or use your stress ball. That'll help reduce the stress."

Berne`

"You know, for me it's not just having sex. Due to my physical paralysis it's how you pay attention to, how my boyfriend pays attention to my body, and what ummm pleasures me and I pay attention to what pleasures him and umm how he makes me feel and how I make him feel. It's the

whole idea of just being with someone is what I miss the most. It's just having that, being able to call or text and just say hey honey how's your day going, do you want to come over and see me or that kind of thing. I miss talking to somebody about how my day went."

Berne` further added,

"I know if I will date again, I am little scared because the guys I have dated before are, they all left. So, it's gonna be really hard to put myself out there again…"

Ross

"I think as far as my relationship goes, I am thinking about it and I am kind of set and I going kind of slow, and it's in the future. But now it's kind of odd but I am focused on my job and hopefully, it's something that something like baby steps on the road like having my own house, having a marriage and when kids come by, I don't think I want to have kids, because my mom says that as per my body goes, it's really big stress, I think. I just can't do it and I know I kind of don't have to but I am kind of

same way with my mom, because the truth is that you don't have to go

through that…"

Sarah

"I was in...that time...I wasn't supposed to be...I violated my probation...I

was on probation… I was at the grassy part of the park when that

happened...I was drunk…I tried to stop him… he pushed back…my friend

took me to the police station...I did tell my cousin that I was raped...I

shouldn't...my friend took me to OHSU and everything...I could have

screamed...for help…I can't remember anything else…"

Dialogues on Being a Woman

"You always have to act like a woman…"

Being a woman, disabilities, and expectations…

Sarah

"I am not affected by what my disabilities are, you know I'm a grown

woman. And you know, I used to, when I was younger, in middle school I

used to be sensitive about it but ever since I got in my adulthood I stopped

being sensitive and just not taking it seriously."

Ross

"I think that every girl. For example, because you aamm go to a church or

a concert, or anything you're at you always have to act appropriately,

[you] have to be aaa and have aamm to...how you present yourself

publically, depending where you are at, and for me for example, if I am

out with my friend's, I need to be appropriate around my friends because I

don't want to harm them by any way and then I think that my head is a

locker and that's how I do it is if you have the urge to, just put it in my

locker that is my head, I put in there (my head) and turn the lock (uses

gestures to show she has turned the key on the side of her head) and then

that's how the two do it...and another example of being

appropriate...ammm...if you are going to a church, there are some ways

you have to act in a different kind of way at when it comes to the church

and if you are religious and as for that it's kind of risky of how you say

things I mean and how you amm how you present and how you...I mean

how you say things that may not come out at...for example…it's kind of

like saying, think about it's just don't say it."

Berne`

"I am trying to remember, the way I'm going to be acting the way I say

something, is it going to harm or it is going to help. Are my actions going

to make me good or make me look bad or make someone else look bad

and I don't want to be a part of that. Like I said, I don't want to bring bad

attention to myself."

Sarah

"I was thinking about the restaurant. Because if you are at a fancy restaurant, you're supposed to be like polite. And you're supposed to appropriate. Because that's what I've been taught. I have this girlfriend, she's my step grandma. She is the one who taught not just me but all us grandkids about how to be polite and everything and she used to say, thank you."

Berne`

"Yaa, saying please and thank you, taking your turn when you're speaking...That's the hardest thing for me. I have the tendency to interrupt people and I feel so bad when I do it. I have like I am so so sorry, so sorry. But I get so excited about talking about things like right now personally I think I'm doing better aam I am sorry, I apologize for interrupting you. But it's like using eye contact, using soft using nice words and you don't bring up topics on the dinner table or at restaurants things like religion or politics unless the person you are with brings that up. Because that's not going to end well………..You don't want to sound too eager!"

[silence]

"Don't go too fast, also known as don't scare them off which I have a habit of doing."

"Rejections are part of the game; there are more fishes in the sea."

Berne`

"I know if I will date again, I am little scared because the guys I have

dated before are, they [have] all left. So, it's gonna be really hard to put

myself out there again. Sometimes, they say that it's better to be alone

than being in the wrong relationship. But, then again being alone really

sucks! My church is having a new single's group starting up, so I going to

join that. Hopefully I'm going to find somebody who's, not anybody old

but not really, really young. Because a lot of people who go to my church

are old hippies. Keep my fingers crossed."

Oprah

"If we...if you think that date and everything…rejection is common...Well,

I view, like...the guy has a choice of…who he want to go out with...you

have the choice too…rejection is common, and you have the choice...you

like and...I am sorry...I lost my train of thoughts… it goes… it goes both

ways...you can choose who you like and… and know that the person may

not like you back…and...you…to me like your boyfriend and whoever it

is…you choose...passes some types of way reflect who you are… as a

an… individual…I mean...you have to see sometime aaaa common

ground… also..."

Jane

"Yaa I will share...as a woman with a disability...if men…I wasn't told about how to shave my legs…because my mom wasn't around…so I had to learn all my own…you know…when my cycle came…I didn't have that…you know...I learned on my own...so…disability…its frightening you know…what's going on you know...its' tough sometimes…you know...all I know is…I know...then rejection…"

Sarah

"I you know I had been rejected before...and it was like...you know...and...I tried to, to have a friend hook me up with this guy… one guy I wanted to go out with… and I would always get rejected...this guy was like...and I hated that...I tried to you know...tried to dress out...you know...wanted to dress out...you know...dress in whatever it will work...you know...but...it still didn't work…you know...the job coach...my job coach...my old job coach...how much we have in common…we had been talking about that…that how much she had been rejected...rejected by guys…There are plenty fish in the sea…you know…you will get a boyfriend someday...and I took his advice...see ammm...you know...I was 17 when I first got my boyfriend..."

On Relationships and Marriage…

Sarah

"I get happy when I am in the relationship…I want to get married…but it would be in the future… they say that if you pick the right guy, who is like open minded…then...when you pick the right guy and if you go out on a date and if we stick being girlfriend and boyfriend for a long time… like…usually like…for long time...and then if you ever get engaged…there will be like a long road...but...dating...you know...you got start dating…then you want to go to hotel then…"

Berne`

"I want my prospective partners to meet my mom. My mother has loved all the guys that she's met that I've been with. She's met all my friends, boyfriends, she's pretty much adopted all my friends. She's never said I don't like that person you're being with she's never been that kind of parent that like tries to get into my life so much. We're mother and daughter but we're like best friends. My provider is a little cooler than my mom, she's a little younger than my mom so she knows a little bit more about what things you do and don't do like you don't say hey girlfriend to your daughter. Sometimes she he tries to be cool like texting hey girlfriend. I'm just like really? So spending time with your parents is not cool."

Anna

"My two boyfriends...I broke up with him…he said, I am too picky…my second boyfriend…I broke up with him…as I didn't want to kiss him...he wanted to kiss…he talks about sexuality and ask if we wanted to get together and if he wants to get his own place and I can come over and we can do it…we went out once to a movie...it was at a movie theater...and the movie was playing and we kissed in the theater…it felt great...it was just a kissed and some touch…felt great…the kiss felt great…he wants to get his own place and to do the sexuality…he wants me to come to his place and do the sexuality...he told me to keep a secret from his parents."

Ross

"Yes I do…I do want to get married…it's just that part of having kids is what I don't want…it's just about what I learned...oooo it's so hard...oo no...I just can't do it…and there is whole idea of being pregnant… especially for my body as well…when I was talking to my mom about it...and she said that it's too much stress for my body…I don't want any stress and NO...that would be too hard…I do want to live with my boyfriend it's too early now...I need to first have a job…"

Berne`

"Speaking as a physically disabled woman, I have to say I guess I have had boyfriends but all in all men don't see you. They see you a friend, they see you as the buddy, but they don't see you as the woman they want to

spend rest of their life with. I was with a man for four years and that was the longest relationship I've ever had. I thought that he ended up, we were going to be together forever but he ended up cheating. I struggle sometimes to see myself in society as a woman because growing up they're really weren't women in wheelchairs that were role models for me. It's hard to see myself as a sexual being…sometimes because, a lot of people, when it comes to physical and mental disabilities ammm they want to cuddle people. They don't want them to know about that kind of stuff. I was lucky my mother wasn't like that but I mean still, so part of my life is like yaa I am adult but I have people who think that I am innocent. I don't really believe that's right but with my body it's very hard for me to accept that I am a woman the way I am treated. The way a woman should be treated with a marriage, a long relationship, kids…I think about that stuff a lot. With me physically, pregnancy would be difficult, really difficult. When sometimes people talk to me about that I say I don't know, I don't think so. I also worry that if ever I got married will he want to stay with me when he knows what all spinal bifida entails. I have incontinence problems, I have a shunt here, I have depression…I have this and that. I've never found anybody who wants to stick around…it's a lot of...lot of aaammm I won't say bad stuff...but it's hard...they say that I just don't see you that way...I like you just as a friend. I've heard that so many times...in my high school years…what's the point...they will go out with a stuck up

cheerleader…but they won't go out with me...I have got very

discouraged...I have had relationships...I had sexual relations. Guys

always ask, they say what's the point in having sex if you can't feel

sex?...well…it's called being with somebody...it's called having that

companionship. If you don't have that companionship you feel like you're

half a person."

Ross

"As far as my future goes. When I go upstairs and kind of cleaning my

room. Then, in my closet, I think I found my mom's old wedding dress. I

thought I must put it on as this is so cute. It was so pretty. It had a shawl,

pink dress and I thought it is so cool...it was so cute. It was long and I

thought this is really cool. I had put that on me and looked in the mirror,

and put my head over it and said, wow, this is so cool. Like, I totally want

it in my future, I want to have a very pretty a big wedding and then I

thought about myself that when it comes to marriage, it's not about what

you do or what you wear, and about the wedding, it's about the guy you

are with and the love and that's how I thought about it and kind of going in

both ways. Because I do want to spend time with the guy forever as well

and I do want a fancy wedding as well. I want this and I want that because

this is kind of fun and I have never been married, this is my first time, I

kinda want it like a in a special kind of way. I also thought that it's not all

about being fancy and it can go simply. I don't care. Instead of big and

fancy one like I said before, I kind of go go both ways. I might have to

wait until my, until I am ready. I was talking to my mom also about dad

because I really want to do like as for now, I have a job coach named

Amanda and she is training me for the hiring process, and one of a good

news is that that I have got an interview from the Whole Foods so I have

been waiting for that. I am trained for the interview skills and hope that I

will get I will get my first job. I am hoping that is one thing in my mind

right now."

Sarah

"My new living situation that I'm at now; I do like it a lot. Cuz I'm close

to my family. Five minutes away from my grandpa, from 10 minutes from

my mom, and my older my sister and brother. It's fun being close. And

it's why I'm glad to be back in Portland, it's better than Oregon City yaa.

The adult foster home that's in NE Portland; that's my fourth. And I do

hang out there with them a lot because I do watch a lot of movies. But like

when it gets to the weekdays, Monday- Friday. Monday is my free day. I

go with my job couch on TriMet, which is awesome, we go together and

we travel in Portland a lot, there is a Target and they're at the third floor

and. she is awesome. I hired her right after that because after my other job

coach was offered a job in Thailand. She is supposed to come visit me in

June and she's supposed to bring back some souvenirs, which will be awesome. She also, she told me she has a cat and she also has a dog. It's a family dog, I met her dog; I met her dog…you know when I was living in, this was my second, well after Gresham this is my second adult foster home. I was in a Jail a lot…probation violation. I wasn't supposed to be in St. Johns, but I snuck there anyways, just to get revenge on the judge, payback on her for what she did for taking that away from me. And she keeping me away from my family for no reason. And I did like self-harm to myself because of that, like lighting matches and putting them out on my hands, and I reused a razor with self-harm. And umm I only did that for little bit, because you know in the past I used and more drugs and partied and you know when I went to Oregon city, I did screw up like twice, when it was like the twelfth and last time being in the jail and the judge, she said that if I'm in her courtroom one more time, she said she next time I see and ever since then I didn't screw up."

Berne`

"It's the whole idea of just being with someone is what I miss the most. It's just having that, being able to call or text and just say hey honey how's your day going, do you want to come over and see me or that kind of thing. I miss talking to somebody about how my day went."

Ross

"My boyfriend has a disability. He has Down syndrome...I think as far as my relationship goes...I am thinking about it and I am kind of set and I going kind of slow, and it's in the future. It's kind of an adult kind of thing. But now it's kind of odd but I am focused on my job and hopefully, it's something that something like baby steps on the road like having my own house, having a marriage and when kids come by, I don't think I want to have kids, because my mom says that as per my body goes, it's really big stress, I think. I just can't do it…and I know I kind of don't have to but I am kind of same way with my mom, because the truth is that you don't have to go through that…the whole thing is that I am not comfortable about the whole idea [of sex]...like for my sister it's very simple...but, for me...not really…"

Anna

"I want to make a life together and they want often find their own place and and and find their own house and yes...and have a great honeymoon ammm like on a beach with dolphins and or, or go to something outside home...lay in bed and and and have sex ammm...My fantasy is our aammm...my having sex or...I I wish I could have it...sex...because makes me have fireworks…and inside...and I never had it before and and I see my and I see other people do it…I want to have sex too…"

Dialogues of Self-Compassion

"Compassion is the way to be…"

Sarah

"And I have been doing SO GOOD. And I've been away from jail for 10 years. Well, there was a lot of stuff I did in the past vandalizing. Well, cuz the reason why I was on probation was because I was not supposed to be in St. Johns cuz if I go near the St Johns area it's because I would use drugs and party and that's the main reason why I was on probation for that. I was raped because I snuck back to St. Johns. But, you know what…I am over it now…I have a job at a coffee shop…I told myself; it's a self-talk. I've learned it, I learned it from Clackamas Community College. I grew up in Clackamas Community College I learned, learned the self talk before, what to do. If it becomes a relationship I decided like you know I was getting, I was like almost in you know I was getting close to my 30s. It's like you know what, I was like, you know I was like telling myself it's (?) important for me to slow down on the relationship and time to put some boundaries on that. That's how I did it that way. I was going too fast. I am always happy. I am shy, first time I am shy like when I go to a dance when being around guys, I have that shyness, I just want to get to know that person first. And I'm a nice person. And I like you know, making friends with new people and ya I'm very friendly because I get along with certain people that don't never say anything negative. And I get, I get angry sometimes."

Oprah

"At one point of my life, I was not what I saw in the mirror, I didn't like

myself. but now, I am happy with who I am…I am, I have this disability

and it's like God has helped me to accept it and he gave me this boyfriend,

who is like me, he has disability as well. I always wanted someone who is

educated, and this and that, you know the one who doesn't have disability,

but I have accepted him for who he is and myself as who I am…"

Maya

"I am fine…I love my grandma, sex is a wonderful thing…but I faced

that…I am thankful for all my friends, they love me…"

Lilith

"I am sooooo lovable…"

Berne`

"My friend says you're just so kind to everybody that you just don't know

that there are those out there that would hurt you. I told her that I'm not

stupid I know that there are some weirdos out there…"

Sarah

"Oh yeah, when I was raped. I had a lot of anger out of me. I took that out

on my housemates for no reason. There was certain stuff like one was

chomping on gum and I got irritated at that. It was because the anger was coming out. This was when I was in my adult, second adult foster parent home. Umm and she acted nerved, they're from Hawaii, and she called my grandma up and to calm me down so my grandma actually didn't want me taking my anger out on anybody. "

Berne`

"My church is having a new single's group starting up, so I going to join that. Hopefully I'm going to find somebody who's, not anybody old but not really, really young. Cuz a lot of people who go to my church are old hippies. Keep my fingers crossed."

Ross

"I am helpful, happy, silly, ethnic, awesome, loveable, and twenty-two. I really don't know how I feel…but I am awesome…"

Jane

"I think...I think…compassion is the way to be…"

Anna

"I want to say one thing…once my mom had it…my mom had sex before with one of her old boyfriends and I get to have a chance to have it so...her old boyfriend…it was guy that had two kids...we used to go play…and visited his kids and he came over to our house and he had sex with my mom and then I…saw them…I was very mad so I was outside the door...I stopped and I ripped off my bed covers…I was so mad...I destroyed everything off my bed….the covers and kicking stuff and that's all I did...I felt good...It did…I am not sorry for that…all I wanted was to have sex…next day my mom took me to her…I have a new medication now...the grey color pill…"

[light off]