SEXUALITY WORKPLACE ISSUES AMONG DIRECT SERVICE PERSONNEL

WORKING WITH INTELLECTUALLY DISABLED POPULATIONS IN COMMUNITY

INTEGRATED LIVING ARRANGEMENTS: A CASE STUDY

By

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Sexuality Workplace Issues Among Direct Service Personnel Working with Intellectually Disabled Populations in Community Integrated Living Arrangements: A Case Study

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A prospectus submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Health Education

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Abstract

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CHAPTER 1

INTRODUCTION

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a
disability -- to try to help people who have not shared the unique experience to
understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation
trip -- to Italy. You buy a bunch of guidebooks and make your wonderful plans.
The Coliseum. Michelangelo's "David." The gondolas in Venice. You may learn
some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your
bags and off you go. Several hours later, the plane lands. The flight attendant
comes and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean, Holland? I signed up for Italy!
I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland
and there you must stay.

The important thing is that they haven't taken you to a horrible,
disgusting, filthy place full of pestilence, famine and disease. It's just a different
place.

So you must go out and buy new guidebooks. You must learn a whole new
language. And you will meet a whole new group of people you would never have
met.
It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

As the parent of a son with a disability and multiple health-related issues, I read this essay in Dear Abby over twenty years ago. Dear Abby reprints “Welcome to Holland” to emphasize National Down Syndrome Awareness Month every October. It has been reprinted in Chicken Soup for a Mother’s Soul, been used as the theme for disability conferences, made into a quilt, and used for series of oil paintings (http://www.journeyofhearts.org/kirstimd/holland.htm).

In the disability community, it has become an iconic symbol. In my opinion, it still best expresses what it feels like to be the parent of a child with special needs of any type or condition. Its longevity in print, and on the Internet, indicates that many other parents of the disabled believe the same. It is not only the feeling the parents of those with disabilities experience at birth, but also with each new phase of life. Watching their children experience the “normal” milestones of first kisses, first dates, and first loves is the expectation of any parent. Having
those experiences is the expectation of human beings in general. It is expected in our world that
one will grow up, experience a first kiss, fall in love, get married (if desired), have a family (if
desired), have someone to love, and to have someone to love them back.

Along the way, it is expected that a healthy sex life will also be part of the experience of
growing into a healthy, mature adult. Our hope for our children is that they will be sexually
healthy; that they will accept, appreciate and take care of their bodies; that they will have
relationships that are enriching and not exploitative; and that they will express themselves in safe
and pleasurable ways. Further, we wish that they will avoid unintended pregnancies, sexually
transmitted infections and abuse; that they will feel good about being male or female; and most
importantly, they will be accepted as who they really are as a person.

All human beings have a need to care and be cared for. Humans are sexual beings.
Sexual activity is the source of our most intense physical pleasures and a central ingredient in
many of our intimate emotional relationships (Insel & Roth, 2010). Ongoing communication and
contact with other people is essential to our physical and psychological health. Our sexuality is
the way we define ourselves as men and women. That definition is a critical part of our self-
image and can influence our interactions with others. The quality of our interpersonal
relationships is determined by how good we feel about ourselves as people worthy of receiving
and capable of giving affection. Sexual activity is our most intimate way of expressing and
receiving affection. Sexuality is more than just sexual behavior. According to Insel and Roth (p.
124, 2010), it is a complex, interacting group of inborn, biological characteristics and acquitted
behaviors people learn in the course of growing up in a particular family, community, and
society. They further define it as including “biological sex (being biologically male or female),
gender (masculine and feminine behaviors) sexual anatomy and physiology, sexual functioning
and practices, and social and sexual interactions with others (p. 124). Through the so-called “sexual revolution,” we have become more aware of ourselves as sexual beings and a bit more objective in accepting sex as a part of life rather than a topic “for whispers or plain brown wrappers” (Neistadt & Freda, 1987, p. 8). However, we have not yet reached the point where society as a whole has a healthy outlook toward sex. We have religious, political, traditional, and cultural values all pulling in different directions (Neistadt & Freda, 1987, p. ix).

Sexuality is a core characteristic and formative factor for human beings. It is a state of mind, representing our feelings about ourselves, what it is like to be male or female, how we relate to people of our own gender and those of the opposite gender, how we establish relationships, and how we express ourselves. Our individual sense of identity is powerfully influenced by our sexuality (Insel & Roth, 2010). It is basic to our sense of self. As such, it is an important part of human development and growth. It is the ability to be intimate with another in mutually satisfying ways. Sexual feelings and actions can cover a gamut of expressions. Holding hands, flirting, touching, kissing, masturbating, and having sexual intercourse are just some of the ways in which sexuality can be expressed (Macrae, 2010). Normal growth during adolescence includes sexual maturation and an increase in body size; these changes are affected both by heredity and environment (Merck, 2003, p. 1552). During puberty, sexual development usually occurs in a set sequence, resulting in an increased interest in sexual anatomy and behaviors (Merck, 2003, p. 1554). Masturbation amongst boys is nearly universal, but is somewhat less common among girls (Merck, 2003, p. 1552). By late adolescence, sexuality has shifted from exploratory to being an expression of intimacy and sharing (Merck, p. 1554). The same developmental milestones for sexuality occur in people with intellectual disabilities (ID).
Religion, culture, ethnicity, and education can also affect how sexuality develops and is expressed (e.g. how sexuality was handled within one’s family can affect how one’s own sexuality develops). Sexuality can be addressed by practitioners in any setting (Macrae, 2010). Intervention can occur in homes, group homes, nursing homes, rehabilitation centers, community mental health centers, pain centers, senior centers, hospitals, retirement communities, and other venues. Enhancing an individual’s ability to participate in affectionate and sexual activities can have a profound effect on that person’s life (Macrae, 2010).

Researchers are revealing hidden complexities behind the simple act of kissing, which relays powerful messages to the brain, body, and kissing partner (Walter, 2008). According to Walters (2008), a kiss “triggers a cascade of neural messages and chemicals that transmit tactile sensations, sexual excitement, feelings of closeness, motivation, and even euphoria” (p. 26).

Sexuality and the need for closeness with another person are basic human drives like the needs for food, water, air, or shelter (Mitchell, 1985, p. 4). The majority of people with ID are in the mild and moderate range, and most of these develop normal reproductive capacities (Craft & Craft, 1983, p. 9). No one has ever questioned that ID populations have the same needs as other people for food, water, and shelter, but sex education and opportunities for social interaction with members of the opposite sex are often denied (Mitchell, 1985, p. 5).

**Background**

**Defining Sexuality & Affectionate Behaviors**

Sex is a word that conjures up different images in each person’s mind. Sex is everywhere in our society. Sexual images and information can be found in movies, books, magazines, television shows, on the Internet, in the lyrics of popular music, and even on billboards (Alters & Schiff, 2009). The common thoughts people have when they hear the word sex usually relate to
love, romance, satisfaction, reproduction, and morality. The term sex can also refer to one’s
gender (male or female), sexual intercourse, or other intimate physical activities (Alters & Schiff, 2009). Defining and understanding sexuality is different experience for everyone.

Sexuality is the aspect of personality that encompasses an individual’s sexual thoughts, feelings, attitudes, and action. All people need affection, love and intimacy, acceptance, and companionship. Each person has a unique collection of private and public sexual experiences that shapes his or her sexuality (Alters & Schiff, 2009). Through different kinds of experiences during our lifetimes, people have learned to consider sexuality in certain ways. Liking, fondness, affection, attractiveness, infatuation, and lust are feelings related to love. Sexuality is woven into every aspect of human life; sex influences a person’s identity, self-esteem, emotions, personality relationships, lifestyle, and overall health (Alters & Schiff, 2009). Because it can arouse intense feelings, sexuality can be an emotionally charged topic. In many communities, sexual expression is regulated with restrictions and taboos, specifying which functions and behaviors are acceptable and normal and which are unacceptable and abnormal (Insel & Roth, 2010).

There are few issues in our society that polarize communities, professional caregivers, families, and individuals as dramatically as the topic of human sexuality, especially in regards to people with disabilities. Even more polarizing is the sexuality of persons with ID. All people are sexual beings, regardless of their disabilities. Acknowledgment that people with ID are sexual is a relatively new development in the human service field (Allen, 2003). Many people refuse to acknowledge that all people have sexual feelings, needs, and desires, regardless of their mental abilities. People with ID often find themselves in a very different position where training in sexuality and social-sexual behavior is concerned. If he or she is raised in an environment where ID persons are thought to be essentially sexually impartial, and disinterested in contact
with the opposite sex, very little socialization may occur with regard to appropriate social-sexual behavior (Mitchell, p. 7, 1985). As a result, many young people with disabilities do not receive sex education, either in school, at home, or in their group home or “Community Integrated Living Arrangement”, or CILA. At the same time those with developmental disabilities may learn at a slower rate than do their non-disabled peers, yet their physical maturation usually occurs at the same rate (Allen, 2003). As a result of normal physical maturation and slowed emotional and cognitive development, they may need sex education that builds skills for appropriate language and behavior in public. There is a general consensus in the healthcare community concerning the need for defined policies and services aimed specifically at reproductive health for individuals with ID (Lin et al., 2011).

Physical development of the ID population is comparable to the same rate as the non-handicapped, resulting in the same interest in the opposite sex. The physiological aspects of sexual functioning are generally intact but social judgment about how, when, and where to use that physical ability may be impaired (Neistadt & Freda, 1987, p. 32). Unfortunately, because parents and caretakers have frequently assumed that physical sexual development does not occur, ID populations have often arbitrarily experienced restricted social-sexual development (Mitchell, 1985, p. 5). A typical behavior management plan in residential settings may include the reduction of developmentally handicapped people’s needs to simply addressing the mere biological urges (Hingsburger, 1990, p. 21). By taking sexuality out of the context of human interaction and human interchange, sex becomes simple behavior; and simple behaviors can be programmed away (Hingsburger, 1990, p. 21). According to Hingsburger (1990), “the fires of passion are dealt with by the fire extinguisher of programming and since behaviors can be programmed, loving need never be discussed.” He further states, “Every one of use would feel
offended if our own personal loving relationships were seen from only a genital perspective” (1990, p. 21).

Allen states that “as antiquated institutions are closed and residents are moved into more mainstream settings, some human rights issues have been inadequately addressed because of an enduring paternalistic attitude that people with ID are childlike and require protection from adult experiences” (p. ix). Personal biases of support staff and guardian family members also serve to further restrict individual freedoms (Allen, 2003, p. ix). Agencies that provide support to people with ID are conservative by their very nature because they are typically working with people unable to advocate on their own behalf (Allen, 2003, p. 21). Previous studies have shown that the sexuality of people with ID has often been stereotypes, with this group typically characterized as being “childlike and asexual, invariably leading to a denial of their social-sexual maturity and needs” (Lin, et al., 2011, p. 1). Advocates for people with disabilities are concerned with the well-being of the whole person, and sexuality is part of the human experience (Monat-Haller, 1992). According to Munster, “the undeniable fact is that our ability to meet the many needs of the developmentally disabled has not kept pace with their growing numbers (2005, p. 10). Further, she states, “a ‘normal’ family is one in which each member is equally important and everyone works together for the benefit of all; but how is it possible to have a normal family life when one member of the family is not normal (2005, p. 51)? An important part of meeting the needs of the developmentally disabled is to recognize the need for change and to respond to it in the best way one knows how (2005, p. 51). The ID population is commonly overlooked in relation to health concerns involving sexuality, sexually transmitted diseases, and end-of-life decisions (Prater & Zylstra, 2006).
One of the most difficult decisions a parent must make is to place their child, of any age, into an institution (Munster, 2005, p. 62). All people need to feel acknowledged, important, and loved (Munster, 2005, p. 92). If those needs are not met, residents typically pick up the behaviors around them and practice them to the extreme to get the attention they crave (Munster, 2005, p. 92). Anyone living in an institution develops behaviors to cope with the living conditions (Munster, 2005, p. 92). “By now I had toured all the state hospitals and had seen firsthand the bizarre behavior that accompanies deprivation. When patients do not receive adequate touching or other stimulation such as talking and appropriate activities to help them connect with the world, they often rock as a form of self-care; starved for touch, some patients hit and bite themselves” (Munster, 2005, p. 91). “As a parent, you never stop trying to locate a loving and caring environment that could adequately provide adult supervision for your developmentally disabled family member (Munster, 2005, p. 102).

Sexual Attitudes of Direct Service Professionals (DSPs)

Direct service professionals are people who work directly with people with physical and/or intellectual disabilities with the aim of assisting the individual to become integrated into his/her community or the least restrictive environment (NADSP, 2014). A DSP is a person who assists an individual with a disability to lead a self-directed life and contribute to the community, assists with activities of daily living if needed, and encourages attitudes and behaviors that enhance community inclusion (NADSP, 2014). A DSP may provide supports to a person with a disability at home, work, school, church, and other community places. In addition, a DSP acts as an advocate for the disabled individual by communicating their needs, self-expression and goals.

According to Alreck & Settle (2004), society strongly influences the sexual attitudes and behaviors of a population by identifying acceptable sexual activities and placing restrictions on
Attitudes predispose people to act in a certain way toward the object of the attitude. The attitude comes before the behavior and affects the way the person will act. Different values, religions, morality viewpoints, sexual experiences, and communication styles may impede the ability of DSP to deal with the sexuality needs and issues of those with ID. Attitudes have three parts: what the person knows or believes about the topic; how the person feels about the topic, or how it is valued; and the likelihood that the individual will take action based on the attitude (Alters & Schiff, 2009).

Studies indicate that institutional staff accept masturbation as a normal aspect of sexual development and agree that many staff are in need of sex education (Davies & Johnson, 1989). Parents and staff agreed that mandatory premarital counseling should be required as a prerequisite to the marriage of mentally handicapped person but should not be required for the rest of the population (Davies & Johnson, 1989). Parents favored sex education programs for their handicapped children far more often than they favored sex education programs for non-handicapped people. Staff felt that abortions should be more readily available to pregnant mentally handicapped women, leading to debates about the freedom of choice and the ability for informed consent for the ID population. Subsequently, the topics of abortion and sterilization were the most controversially debated. Staff seemed to have little difficulty imposing their values on handicapped people (Davies & Johnson, 1989).

According to Davies and Johnson (1989), the respondents in the study represented a typical cross-section of front-line workers in the field of intellectually disabled. They were mostly females, had an average age of 34.5 years, and a maximum of two years of college-level career preparation. The study concluded that the most important need identified was that many staff needed further intensive training so they feel adequate in providing sex education and
counseling to the mentally handicapped people with whom they work. This training needs to be not only factual but also to provide the staff with the opportunity to explore their own feelings about sexual topics as well as to learn some practical and non-directive counseling skills (Davies & Johnson, 1989).

Partnerships between researchers and practitioners have become more appealing in recent years because many types of educational research have left the laboratory and moved into real life settings within the community (Scientific Research in Education, 2002). These collaborations with practitioners can bring intellectual resources to the research that would not be possible if working in the isolation of a lab (Scientific Research in Education, 2002). DSP (and by implication their supervisors) are in the best position to know what kind of real “honest-to-goodness human needs exist for the client” (Hingsburger, 1990, p. 28). This places the responsibility on DSP to act in ways that model and teach appropriate relationship-building skills (Hingsburger, 1990, p. 86). People with ID may receive no training at all about proper behavior around the same or opposite sex, or about appropriate public behavior that is considered sexual in nature (Mitchell, 1985, p. 7). Another factor that may contribute to the lack of sexuality knowledge in ID populations is that many ID individuals are placed in institutions where they are sexually segregated and are exposed only to adults (DSP) who are emotionally neutral to each other (Mitchell, 1985, p. 7). This can result in ID residents behaving inappropriately. Failure to acknowledge sexual attraction may result in tension or social awkwardness (McKinney & Sprecher, 1991, p. 95). Sexual tension complicates an already difficult type of relationship (McKinney & Sprecher, 1991, p. 94). The five main reasons for helping ID residents to understand human sexuality are: 1) their difficulties in learning; 2) to ease the constraints of their physical and social overprotection as well as that of their segregated living situations; 3) the
recognition of their legal rights; and 4) to address public health concerns (Garner & Chapman, 1993, p. 199).

A frequently voiced complaint among staff members at many facilities is that some residents will constantly cling to or try to touch staff members (Mitchell, 1985, p. 66). Residents raised in an environment where persons believe sexuality and/or affectionate behaviors in ID populations are inappropriate, may be punished or discouraged from expressing those behaviors (Mitchell, 1985, p. 9). Like any other behavior, sexual responses are learned, shaped, and reinforced by environments (Craft & Craft, 1983, p. 10). Helping people to understand sexual roles and norms, family relations, and sexual feelings about themselves and others is an important staff responsibility (Gardner & Chapman, 1993, p. 199). The degree of discomfort DSP have in discussing human sexuality needs to be explored because it is probably one of the strongest reasons people have difficulty with the idea of people with disabilities and sexuality (Hingsburger, 1990, p. 100). No one wants to have to explain sexuality in the kind of concrete detail necessary for an individual with developmental disabilities to understand (Hingsburger, 1990, p. 100). Therefore, sex education for ID populations tends to be basically biology—sperm, egg, and the virtue of chastity (Hingsburger, 1990, p. 101). Institutions may not be good at training people as to what constitutes acceptable and unacceptable sexual behaviors (Craft & Craft, 1983, p. 10). The concept of sex education prompts complex reactions and contradictory attitudes, even when the recipients of the education are of normal ability (Craft & Craft, 1983, p. xiii). Adding the term developmentally disabled to sex education stirs even more conflicting emotions (Craft & Craft, 1983, p. xiii). Any discussion of sexuality and affectionate behaviors in CILA settings must include the sensitive issues which are frequently confronting those who
come in contact with the ID population. Sexuality can present management problems is any residential setting.

Mitchell (1985) observed in her work as a consultant to residential facilities that problems involving sexual behavior were often ignored or poorly managed. She felt that this mismanagement was not deliberate but rather the result of parents and caretakers not having the knowledge about what kind of behaviors those with ID should and could be taught in the area of sexuality (Mitchell, 1985, p. 86). Sex education should be approached much like other forms of functional education for ID populations. The sexuality education process should address what the residents reasonably need to know in order to perform sexually without endangering themselves or others or engaging in either coercive or public acts (Hingsburger, 1990, p. 112).

The expression of sexuality on the part of ID populations is not a special privilege to be granted only to a select few, but a basic human need and a right (Mitchell, 1985, p. 10).

**Social Learning Theory**

An explanation for the development of sexual attitudes and behaviors may be found in the Social Learning Theory (SLT). SLT is a theory which includes the premise that as children, and even as adults, we learn by modeling our behavior on that of other people. Behavior is influenced by the environment, personal factors, and aspects of the behavior itself. The concepts included in this theory affirm reinforcements that occur in society shape attitudes and behaviors (Bandura, 1986). Through thinking, perceiving, and believing, people anticipate certain consequences of a behavior or event. It is these beliefs and perceptions that determine various courses of actions (Bandura, 1986). Self-efficacy, as defined by Bandura (1997), refers to an individual’s concept of their ability to complete a task and attain a specific goal or objective.

Self-efficacy can be built by confidence building that is achieved in steps; persuasion that can be
in the form of literature, conversations with peers or family; through a combination of motivation and information; and by learning through emotional and physiological responses to behavior (Bandura, 1997).

SLT helps in the understanding of complex relationships (such as sex) between the individual and his or her environment; how actions and conditions reinforce or discourage change; and the importance of believing in and knowing how to change (Bandura, 1986).

Reinforcements occur in society to shape attitudes and behaviors. If a person behaves in a loving way and receives love in return, he/she will continue to behave lovingly towards others. However, if a person “behaves lovingly but receives ridicule from key influentials, it is less likely they will behave that way again” (Bruess & Greenberg, 2004 p 98). People show appreciation and affection, revulsion and indifference with expressions and gestures. Unfortunately, the nonverbal expression of feelings and thoughts is easy to misinterpret (Bruess & Greenberg, 2004). Cognitive approaches such as the SLT are based on the premise that negative thoughts, images, feelings, and beliefs produce undesired behaviors (Needs citation).

This is relevant to this study because how human sexuality and affectionate behaviors are addressed in the training of DSPs and how DSPs themselves act in response to human sexuality and affectionate behaviors experienced in the workplace may be unduly influencing the quality of life of the residents in regards to sexuality growth and development.

Statement of the Problem

The basic premise underlying all sexuality education and counseling for people with ID is that these individuals have the right to develop and express their inherent sexuality in a socially appropriate manner (Monat-Hallerer, 1992). The concept of the right to sexuality is accepted for people without disabilities. Among persons of average intelligence, much of their concept of
sexuality is derived from peers, the media, and school (Monat-Hallerer, 1992). Schepp (1986) stated: “the ideal sexual learning is positive and informative about sexuality and is appropriately timed for the developing individual” (p. 21). It stands to reason that the concepts of sexuality among persons with ID are also derived by their peers, the media, and the staff surrounding them. The increasing number of people with intellectual disabilities living within the community setting rather in institutions has amplified public awareness that these individuals have sexual expectancies, desires and needs (Servais, 2006). The contact residents in CILA facilities have with the outside world are limited by requiring approval from the DSPs. DSPs serve as the gatekeepers to the world for the residents. DSPs often serve a parental role, including for the areas of human sexuality and affectionate behaviors, or as a health educator for their residents. If DSPs are not trained adequately on topics such as human development and sexuality, they may be uncomfortable serving in those roles. Further, while mandated DSPs training includes sexual abuse prevention (DHS.gov), training materials need to be examined to see what message is being sent and interpreted by DSPs in regards to healthy sexuality for the residents of CILA homes. How human sexuality and affectionate behaviors are addressed in the training of DSPs and how DSPs themselves act in response to human sexuality and affectionate behaviors experienced in the workplace needs to be examined to improve the quality of life of the residents in regards to sexuality growth and development.

**Purpose of the Study**

The purpose of this study is to explore the workplace experiences and training of DSPs, with types of sexual and affectionate behaviors exhibited by intellectually disabled adults in their care in the CILA setting. How well DSPs feel prepared to handle those occurrences and how current training materials assist DSPs in dealing with the human sexuality issues they experience
in the workplace will be explored. The experiences, perceptions, emotions, preparation and
employee training of DSPs will be investigated. The study will focus on analyzing DSPs
thoughts, feelings, and experiences in relation to health and sexuality/affectionate behaviors
experienced in the CILA workplace through interviews. This analysis will provide an
understanding of what ideas and values DSPs bring to their roles of guiding the sexuality and
affectionate behaviors of those residents in their care. If the basic level of sexuality experiences
for working with ID populations by DSP can be identified, training programs can be developed
to build skills in regards to sexuality workplace issues to enhance the CILA experience for both
DSP and their residents.

A review of the literature indicates that barriers to achieving sexual knowledge and
autonomy by current ideologies of care for ID populations have resulted in the ideological shifts
that have outpaced industry practice (Healy, McGuire, Evans & Carley, 2009). Further
evaluation of the social, cultural, and environmental levels of influence on sexuality is necessary
(Healy et al., 2009). This study will examine the perceived sexuality training needs of DSP and
the perceived relevance of such needs as they relate to Qualified Developmental Disability
Professional (QDDP) responsibilities, competencies, and mandated training from regulatory
agencies.

**Need for the Study**

Intellectually disabled populations are growing within the community setting for several
reasons. Special needs students leave the traditional school setting after the age of 21. In the past
many of these students became residents of state institutions after leaving school. However,
state-funded institutions have been replaced by group homes or CILAs as the preferred method
of assisting those with ID who cannot live without assistance and supervision. With the support
of trained staff, residents of these types of programs work on personal goals for independent living and community integration, which include their social and sexuality requirements. Little research has been conducted pertaining to their sex education needs or to the sexuality training needs of DSP working in CILA settings. Even less research has been conducted focusing on the responsibilities of the CILA DSP training programs to meet those needs. More research to document the need for additional employee training to assist DSP in dealing with sexuality issues within ID populations in CILA settings should be conducted to better meet the needs of ID adults and the staff that work with them. Better trained DSPs will result in better experiences for ID adults as well as a reduction in the number sexuality incidents within the CILA setting due to DSPs not understanding the various sexuality needs of their residents.

This study should be conducted in the field of health education because sexuality is a health topic and one that those trained in the field of health education are more comfortable exploring. Health educators are used to the terminology, the anatomy, and the complexities of dealing with this emotional topic that may be viewed as controversial or uncomfortable by those from other fields of study. This study is important to the world of health education because collaboration between fields is important, especially as it pertains to human behavior. Too often topics viewed as special education are left to be handled only by special education professionals, who are not trained as educators or in specific topics such as human sexuality. This study is better suited to be conducted in the world of health education because health educators are trained to create, develop, implement, and evaluate sexuality curriculum for diverse populations, a specific skill not always provided to professionals from other fields of study. Finally, this study should be conducted in the field of health education because the researcher is exploring
whether the topic of human sexuality education is being overshadowed in the CILA setting by the need for sexual abuse prevention training when working with people with ID.

If all individuals have the right to develop and express their inherent sexuality in a socially appropriate manner, an environment that supports negative thoughts, images, feelings, and beliefs that produce undesired behaviors should be avoided. Additionally, if DSPs can unwittingly influence the behavior and thoughts of people with ID through the social environments they create more information needs to be known about those environments within the CILA setting. The results of the National Survey of Adolescents and Young Adults Sexual Health Knowledge, Attitudes, and Experiences (2003) revealed young people are more concerned about sex and sexual health than any other health issues in their lives. The study further revealed that nearly one in four sexually active young people contract a sexually transmitted disease (STD) every year. Between three and four million adolescents in the U.S. contract a sexually transmitted disease each year, and an estimated one-half of all newly contracted HIV infections occur among young people under 25, most through sexual practices (Shafer & Boyer, 2000). It would seem logical that “young” people, either by chronological age, level of intelligence, or both, would also be concerned about sex and sexual health. Although there are multitudes of studies on children with disabilities, the lives of these children as they grow up are less examined, leaving a gap in the knowledge among professionals (Kirschbaum & Olkin, 2002). Previous studies have focused on staff attitudes towards their own sexuality rather than their attitudes and experiences dealing with sexuality workplace issues working with ID populations in the workplace. Most existing studies were conducted in hospital or nursing home settings located in foreign countries such as Belgium, Canada, Ireland, Italy, Japan, and the United Kingdom. If the basic level of sexuality experiences for working with ID populations
by DSP can be identified, training programs can be developed to build skills in regards to sexuality workplace issues to enhance the CILA experience for DSP and residents. This study may increase awareness of potential biases, add additional literature on the importance of further collaboration between fields of study, and encourage the inclusion of more practical applications within sexuality training curriculum for employees. Results could lead to broader changes in sexuality training materials to reflect more health-centered, holistic approach to sexual health for CILA residents. This study may encourage health educators to critically examine their current beliefs, assumptions, and approaches to human sexuality when working with special populations.

Research Questions

The following research questions direct this study:

1. How do DSPs in CILA settings experience sexuality and affectionate behaviors?
2. How prepared do DSPs feel to deal with work issues regarding sexuality and affectionate behaviors?
3. How do employee training materials help guide staff behavior in regards to sexuality and affectionate behaviors of residents?
4. How do DSPs perceive their influence on the sexual expression of ID residents in the CILA setting?

Research Design

An exploratory, descriptive research design employing a case study method will be used to generate qualitative data and examine the phenomena of sexuality and affectionate behaviors in the CILA setting. Yin (p. xiii, 2003) stated: “…case studies continue to be used extensively in social science research—including the traditional disciplines (psychology, sociology, political science, anthropology, history, and economics) as well as practice-oriented fields such as urban-
The case study approach allows an intensive study of the background, current status, and environmental interactions of a given social unit on the level of the individual, group, institution, and/or community (Isaac & Michael, 1997). The study will consist of in-depth interviews of DSP staff, which will be video-taped; DSP observations through the review of the video-taped interview; and document analysis of agency web pages, newsletters, employee training materials, employee handbooks, employee job descriptions, policies from various departments within the agency and agency resource library materials. In-depth interviews will be used to explore and gather descriptions about how DSP experience sexuality workplace issues when working with ID populations. The way DSP experience and interpret the overall occurrence of sexual and affectionate behaviors by ID populations affects job stress and employee retention. By using this approach one can better understand the essence of sexuality workplace issues with ID populations through the social and personal aspects. According to Innovative Learning.com (n.d.), modern behaviorists believe human behaviors are influenced by the everyday social environment. The opinions, thoughts behavior, advice and support of the people surrounding an individual influence his or her feelings and behavior.

**Study Setting**

The study will take place in a community in the rural Midwest which has been the location of programs for the ID since 1969. There currently are four different organizations located there providing services such as residential, developmental, vocational, and adult daycare services for ID clients, as well as supportive services to residents with mild ID who live independently within the community. All of the agencies include a system of housing for their residents known as a CILA. CILA is a residential program for adults with developmental
disabilities. Groups of four to six individuals live in a structured environment that is supervised 24 hours per day. Another term commonly used in place of the term CILA is group home. With the support of trained staff, residents work on personal goals for independent living and community integration. Three CILA homes from one agency which serve moderate to high functioning residents will serve as the case under study. The agency chosen is the one from within the target area that the researcher has had the least amount of experience working with in the past.

The community selected for this study is a rural college town of approximately 25,000 people. The agency selected has other Midwest locations that will not be included in this study. Only agency CILA homes exclusively serving moderate to high functioning residents located within the city limits will be included. There are three CILA homes from the chosen organization that meet those criteria. All CILA homes are in neighborhood settings and are designed to have a home-like atmosphere instead of an institutional environment.

The agency has granted access to potential study participants and use of their facilities for the study. One-on-one interviews of participants will be conducted at a location chosen by the participant. Potential sites are the office of the researcher, a private conference room located on a nearby university campus, a private conference room located at the agency worksite, the agency training room, or an alternate location chosen by the participant. Access has been granted by the agency to the group home locations; however, these locations will not be utilized in order to minimize the effects of the study on the ID residents.

**Sampling**

Each CILA home has a staff of six to eight employees, and one supervisor, who work in shifts to cover program services 24 hours per day. The agency has three moderate to high
functioning CILA homes, which are staffed with three DSPs who work the second shift each day. DSPs who work directly with the residents between the hours of 3 pm and 9 pm, when the residents are actually awake and in the CILA homes, will be targeted because those are the hours the residents are in the home and awake. Residents spend the day at therapy or at the adult daycare facility. Residents are put to bed in the evening at 9:00 p.m. Staffing is reduced during the evening hours while the residents are asleep. In-depth semi-structured interviews will be conducted with three to six DSPs per home (for a total of nine to eighteen interviews) to examine the experiences and training of DSPs in regards to sexuality and affectionate behaviors in the CILA setting.

Qualitative research typically includes a small number of individuals to preserve the individuality of each in the analysis process (Maxwell, 2005, p. 22). This is used to better understand how events, actions, and meanings are shaped by the unique circumstances in which these occur rather than to collect data from large samples and aggregate the data across situations or larger populations (Maxwell, 2005, p. 22). Staff will be identified through a staff list provided by the agency. Each participant will be asked to participate through an introductory letter, followed by a personal visit with the researcher. A total of 18 DSPs are employed in at these three homes. However, DSPs who work directly with the residents between the hours of 3 pm and 9 pm, when the residents are actually in the group homes setting will be considered a priority for this study. DSPs who work at least 30 hours per week will be recruited for participation first, followed by part-time DSPs or those who only work on the weekend. Ideally, at least three of the six DSPs per group home will agree to participate in the interview process. Each DSP will be given the opportunity to participate in the study and will be included in the study if they
choose to participate. This study will examine the experiences and training of nine to eighteen DSPs with sexuality and affectionate behaviors in the CILA home setting.

If adequate participation cannot be obtained from the DSPs working in CILA homes serving solely moderate and high functioning residents, participants will be solicited from the staff of other CILA homes within the organization that serves a mixture of low and moderate functioning residents. The organization currently employs 54 DSPs—six in each of the nine CILA homes serving low, moderate, and high functioning residents within city limits.

Participants will be recruited until at least two DSPs from at least three different CILA homes are interviewed and at least nine different DSPs have participated in the study overall. If all eighteen DSPs working in the three CILA homes serving moderate to high functioning residents agree to participate, the recruitment process will also end.

**Data Collection**

Upon approval from the Institutional Review Boards of Southern Illinois University-Carbondale and Eastern Illinois University, qualitative data collection will begin and include four sources of data—semi-structured interviews, observation of behaviors on interview video tapes, document analysis, and field notes. Reviewing documents can add important information to a case study. Participants will be solicited in person by the researcher, via mail, phone, and by visiting targeted workplaces. Interviews will take place in a location most-convenient to the participants. Potential sites include an on-campus conference room and a conference room located at the workplace.

**Data Analysis**

Because this study employs the case study method, data will be analyzed using content analysis. Content analysis is a process which allows for examination and interpretation of data
through reduction, analysis of specific statements, and searching for meanings (Maxwell, 2005, p. 93). A qualitative study seeks to gain an in-depth and thorough understanding of a particular phenomenon or issue. The interviews will be audio and video-taped and transcribed by a professional court reporter within four weeks of each interview. Transcripts will be reviewed by the interviewee for accuracy (member-checking). Triangulation of data is collecting information using a variety of sources or methods (Maxwell, 2005, p. 93). This strategy reduces the risk that conclusions will reflect only the systematic biases or limitations of a specific source or method, and allows for a broader and more secure understanding of the issues under investigation.

Triangulation of data will occur through member-checking, review by an expert panel, documents analysis, field notes by the researcher, reflective summaries by the researcher, and transcribed data. Two raters, working independently, will be used establish inter-rater reliability. The raters will be the researcher and one tenured-faculty from a state university. Thematic coding and inductive reasoning will be employed in the evaluation of the data to generate themes or categories. Themes will allow the researcher to gain an overall perspective about the phenomena of how DSP experience sexuality and affectionate behaviors in the workplace.

Assumptions

The following assumptions are made for this study:

1. DSPs behavior directly influences resident sexuality and affectionate behaviors. Such behaviors directly influence the quality of life for ID residents.

2. All individuals who participate in the in-depth interviews will respond honestly and to be the best of their abilities.

3. Access to program staff will be granted.

4. Access will be granted to program documents.
5. DSPs employed by the agency working in the CILA setting will volunteer to participate.

6. Participants in this study may or may not be representative of staff at other CILA homes.

7. Results may not be generalized to other ID CILA/group home programs in similar settings.

8. It can be assumed individual experiences will vary, and some of those experiences may lead to external influence on attitudes.

**Delimitations**

Restrictions to the study may include the following:

1. This study is limited to direct service personnel who work directly with ID residents who live in CILA homes.

2. All participants in this study reside in a small city located in a politically conservative region of the Midwest.

3. The case study will focus on DSPs of one agency within one city of an agency serving ID populations in the Midwest.

4. Participants for the interviews will be recruited from CILA homes serving high-functioning or moderate-functioning residents.

5. This qualitative study consists of a purposeful sample of direct service personnel agreeing to participate in the interview process.

**Limitations**

Qualitative research relies on the skill of human perception and is, therefore, influenced by that human “lens” and human bias. Qualitative research is not generalizable in most cases.
(Isaac & Michael, 1997). Data reduction is difficult and qualitative research is very time-consuming. It is very difficult to replicate a qualitative study and the procedures are typically not standardized. This study has several limitations that may affect its potential to be generalized to all CILA staff. They are:

1. The interviews will be conducted in English, which may or may not be the primary language of the DSP involved in the study.

2. The study may be limited by a lack of willingness to participate by the CILA staff. Since this study is dealing with the personal issue of sexuality, participant recruitment may be difficult due to embarrassment or hesitation of the participants to discuss the topic.

3. Those who choose to participate in the interview process may have experienced the program differently than those who choose not to participate.

4. Research participants may distort aspects of their reports of sexuality and affectionate behaviors experiences because of memory issues (such as recall of specific details) or from embarrassment about discussing sexuality issues.

5. Research participants may distort aspects of their report in order to try to present themselves in a certain light to the investigator.

6. Some research participants may not interpret an interview question in the way intended by the researcher.

Definitions of Terms

**AAIDD** – American Association on Intellectual and Developmental Disabilities. An interdisciplinary association of professionals, parents, individuals with disabilities and others
interested in ID, which publishes guidelines for the diagnosis of ID (Accordo & Whitman, 2011).

**Accommodation** – An adaptation made to an environment, facility, or task to enhance the performance of an individual with a disability (Accordo & Whitman, 2011).

**Acting Out** – A psychoanalytic term that refers to expressing feelings, unconscious drives, or impulses through external behavior rather than verbally articulating them. This acting out of feelings is usually expressed in annoying, disruptive, or antisocial ways. Typical acting out behaviors includes fighting, stealing, crying, pouting, hyperactivity, temper tantrums, and verbal threats (Accordo & Whitman, 2011).

**Activities of Daily Living (ADLs)** – Self-help activities such as bathing, toileting, eating, cooking, being mobile, performing simple health care procedures, and keeping house (Accordo & Whitman, 2011).

**Activity-Based Intervention** – An early intervention approach that capitalizes on daily caregiver-child transactions. It relies on child-initiated transactions, embeds goals in daily activities, uses logically and naturally occurring antecedents and consequences to develop functional skills that transfer readily to other contexts (Accordo & Whitman, 2011).

**Adult Protective Services** – Social, medical, legal, residential, or custodial services provided to adults who are unable to gain access to such services for themselves. In the event that there is no guardian or significant other, or in cases of a guardian or significant other being abusive to the adult with the disability, a public or private agency may provide adult protective and service coordination services (Accordo & Whitman, 2011).

**Affectionate Behavior(s)** – Hugging, holding hands, sitting side-by-side, and/or kissing

**Behavioral Capability** – Knowledge and skills necessary to perform behavior
Behavior Coach – A one-to-one caregiver for an individual with ID or developmental disabilities (Accordo & Whitman, 2011).

Behavior Modeling – A training intervention popularized by social learning theory. A practitioner demonstrates (models) the appropriate behavior or uses a visual representation, and the learner is reinforced for accurate replication of the behavior (Accordo & Whitman, 2011).

Borderline Intellectual Functioning - An IQ score between 70 and 85 in the absence of functional or adaptive impairment. Educationally speaking, someone with borderline intellectual functioning is a slow learner (Accordo & Whitman, 2011).

Caregiver – Any person with physical or legal responsibility for the care of a child, an older adult, or an adult with developmental disabilities (Accordo & Whitman, 2011).

Community Integrated Living Arrangement (CILA) - a living arrangement for adults (age 18 and older) in a group home, family home or apartment where 8 or fewer unrelated adults with developmental disabilities live under supervision of the community developmental services agency. Residents receive complete and individualized residential habilitation, personal support services and supports under the direction of a community support team within the local agency (DHS.gov).

Deinstitutionalization – The relocation of people with developmental disabilities and psychiatric illnesses from institutional settings to community placements; one component of normalization (Accordo & Whitman, 2011).

Dependency – Behavior characterized by overreliance on another person or system. The reliance can be emotional, physical, or financial. The dependent person fails to use his or her own skills and abilities, passively leaning on another person or system to care for his or her needs (Accordo & Whitman, 2011).
Developmental Age (DA) – The age (in years and months) that best describes a child’s level of performance by equating it to the performance of a typically developing child of that chronological age (CA) (Accordo & Whitman, 2011).

Developmental Approach – The theory that people with mild intellectual disability without evidence of physical brain damage behave and learn exactly the same as their typically developing peers except for the impact of personality variables (Accordo & Whitman, 2011).

Direct Service Personnel – are people who work directly with people with physical disabilities and/or intellectual disabilities with the aim of assisting the individual to become integrated into his/her community or the least restrictive environment.

Disability – a physical or mental impairment (Meeks & Heit, 2003, p. 250 & p. 570).

Disabled – A person whose level of impairment interferes with his or her functioning in adult roles, creating difficulties living independently, maintaining employment, completing or advancing their educations, and relating interpersonally with others (Cook, 2000).

Group Home – A supported living residence licensed by the state for people with ID, developmental disabilities, and certain mental illnesses. The group home environment tries to be like that of a typical home, encouraging shared responsibility and cooperative social interaction. To qualify for federal assistance, group homes must adhere to guidelines established by the Developmental Disabilities Administration of the U.S. Department of Health and Human Services (Accordo & Whitman, 2011).

Habilitation – The provision of medical, psychological, educational, and family services to people with disabilities in order to maximize their vocational, mental, physical, and social abilities and to facilitate their functioning as independently as possible (Accordo & Whitman, 2011).
Handicap – A disadvantage for a given individual that results from an impairment or disability that limits or prevents the fulfillment of a role that would otherwise be typical for that individual. Except when citing laws or regulations, one should not use the term handicap to describe a disability (Accordo & Whitman, 2011).

Identity – A sense of being male or female, an acknowledgement of the different sexual roles, a preference for heterosexual or homosexual relationships, a molding of different male and female role characteristics (Gardner & Chapman, 1993, p. 199).

Intellectual Disability (ID) – Cognitive impairment. To meet the criteria for having ID under the Individuals with Disabilities Education Act (IDEA) of 1990 (PL 101-476) a student must have an intellectual ability score (IQ) of 70 or below with adaptive and academic skills commensurate with ability. ID replaces the term “mental retardation” in the United States (Accordo & Whitman, 2011).

Intelligence Quotient (IQ) – A quantitative score that is accepted as reflecting an individual’s cognitive abilities (Accordo & Whitman, 2011).

Maladaptive Behavior - Recurrent behaviors and behavior patterns that prevent an individual or family from obtaining a desired goal or meeting the demands of the environment (Accordo & Whitman, 2011).

Mental Age (MA) – An age-equivalent score; a measure of mental development as determined by intelligence and achievement tests; expressed as the age for which that level of performance is the average. MA is a “commonsense” concept for helping parents understand the approximate age at which their child functions so that appropriate achievement and behavioral expectations can be used (Accordo & Whitman, 2011).
Modeling – The enacting of a specific behavior or set of behaviors with the intention of having an observer imitate that behavior (Accordo & Whitman, 2011).

Multiple Disabilities – The coexistence of more than one disability in a single individual. The more severe a single disability, the more likely it is that a second disability will be present (Accordo & Whitman, 2011).

Normalization – the belief that ID populations have the right to progress through the normal developmental stages of life and that their decisions must be respected whenever possible (Mitchell, 1985).

Observational Learning – Learning that takes place by observing and remembering how others succeeded or failed (Accordo & Whitman, 2011).

QDDP – Qualified Developmental Disability Professional; formerly known as Qualified Mental Retardation Professional or QMRP (qddp.org).

Reciprocal Determinism - Behavior changes resulting from an interaction between the person and the environment.

Self-Concept – a person’s picture of self and the self-evaluation of this picture (Brammer, Shostrom & Abrego, 1989, p. 29).

Self-Efficacy – confidence in ability to perform a certain task

Self-Esteem – An individual’s perception and valuation of his or her worth, especially when compared with a particular reference group, and the feelings that emerge from those judgments (Accordo & Whitman, 2011).

Sexuality – sexual behaviors, arousal, and responses, as well as sexual attitudes, desires, and communication (McKinney & Sprecher, 1991, p. 2).
Social Intelligence (SI) – The ability to understand and deal effectively with social and interpersonal events (Accordo & Whitman, 2011).

Social Learning Theory – A theory of development and learning that emphasizes both the principles of behaviorism and the individual’s internal attributions and thoughts in determining behavior. Social learning theory includes the concepts of modeling, imitation, and self-efficacy. Social learning is more likely to occur when the model is attractive, is powerful, or possesses other desirable qualities (Accordo & Whitman, 2011).

Temperament – Individual differences in emotional, motor and attentional reactivity and self-regulation consistently displayed in all kinds of settings and situations (Rothbart & Bates).

Vicarious Reinforcement – Observing others reinforced for behaving appropriately

Value System – A collection of beliefs that helps a person identify and classify things as being good or bad, or neither good nor bad (Alters & Schiff, 2009).

SUMMARY

This study will explore the workplace experiences of DSPs with types of sexual and affectionate behaviors of intellectually disabled adults in their care in CILA settings and how prepared DSPs felt to deal with those experiences. The experiences, perceptions, emotions, preparation and employee training of DSPs will be investigated. The study will focus on analyzing DSPs thoughts, feelings, and experiences in relation to health and sexuality/affectionate behaviors experienced in the CILA workplace through interviews. Document analysis of their training materials, employee materials, and policies and procedures will be conducted to determine how their training prepares them to deal with those experiences.
CHAPTER 2
LITERATURE REVIEW

Purpose

The purpose of this study is to explore the workplace experiences and training of DSPs, with types of sexual and affectionate behaviors exhibited by intellectually disabled adults in their care in the CILA setting. How well DSPs feel prepared to handle those occurrences and how current training materials assist DSPs in dealing with the human sexuality issues they experience in the workplace will be explored. The experiences, perceptions, emotions, preparation and employee training of DSPs will be investigated. The study will focus on analyzing DSPs thoughts, feelings, and experiences in relation to health and sexuality/affectionate behaviors experienced in the CILA workplace through interviews. Many scholars from a wide array of disciplines in behavioral sciences (e.g., sociology, psychology, communication, anthropology, family studies) have studied the topic of sexuality (McKinney & Sprecher, 1991, p. 10).

Anytime a phenomenon is studied by scholars trained in diverse disciplines, the knowledge gained has both advantages and disadvantages (McKinney & Sprecher, 1991, p. 11). A major benefit of an interdisciplinary approach to human sexuality is approaching the topic from different angles from different areas of expertise, as well as the application of an “array of theoretical and methodological approaches” (McKinney & Sprecher, 1991, p. 11). However, the many different interpretations of the phenomenon can create obstacles when researchers try to learn from each other or apply those interpretations to a new study (McKinney & Sprecher, 1991, p. 11). Researching the topic of sexuality for ID populations required looking for existing research in the fields of special education, psychology, sociology, counseling, nursing, education, workforce development, human resources, politics, and healthcare.
Research Questions

The following research questions direct this study:

1. How do DSPs in CILA settings experience residents’ sexuality and affectionate behaviors?

2. How prepared do DSPs feel to deal with work issues regarding sexuality and affectionate behaviors?

3. How do employee training materials help guide staff behavior in regards to sexuality and affectionate behaviors of residents?

4. How do DSPs perceive their influence on the sexual expression of ID residents in the CILA setting?

Historical Review

Sexuality and Intelligence Level

The purpose of a literature review, according to Yin (2003, p. 9), is to review previous research to develop sharper and more insightful questions about the topic under consideration. For a long time it was believed that individuals with ID were not capable of falling in love, of seeking emotional satisfaction, or being interested in marriage or having children (Karellou, 2003b, p. 66). The concept of Intelligence Quotient (IQ) is problematic when dealing with sexual issues—even more so in CILA settings where multiple people who are not related interact on a regular basis. Most human beings seek loving relationships with other individuals to meet their emotional needs. The motivation to pursue sexual activity (sex drive) is an instinctual behavior motivated by the sex hormones (Alters & Schiff, 2009). These sex hormones direct sexual behavior along with certain thoughts, sensations, and emotions (Alters & Schiff, 2009).
The IQ concept derives from around 1916 when a Stanford University psychologist, Lewis Terman, translated and revised the intelligence scale created by Alfred Binet and Theodore Simon, resulting in the *Stanford-Binet Intelligence Scale*. In this instrument, Terman used the ratio of mental age to chronological age. This ratio concept led to the use of the term IQ. For example, a six year old child with a mental age of six would have an IQ of 100 (the “average” IQ score); a six year old child with a mental age of nine would have an IQ of 150 (Sgroi, 1989, p. 211). This mental age-chronological age concept works well for children, but is more challenging when working with adults. Conceptualizing the difference between a mental age of 18 and a mental age of 28 is difficult at best. It was such a problem to quantify that currently intelligence is measured according to individual deviation from standardized norms, with 100 being the average.

Adaptive behavioral deficits were added as one of two diagnostic criteria for ID in 1963 (Accordo & Whitman, 2011). A person is considered to be disabled when their level of impairment interferes with their functioning in adult roles, creating difficulties living independently, maintaining employment, completing or advancing their educations, and relating interpersonally with others (Cook, 2000). Subsequent modifications of the diagnostic criteria have continued to emphasize both IQ score and adaptive behavioral deficit as dual criteria to make a diagnosis of ID (Accordo & Whitman, 2011). ID is usually diagnosed when a person has a cognitive delay or deficit that is more than two standard deviations off the expected average, or, a score on the standard IQ test of 75 or below (Greenspan and Wieder, 1998, p. 8). An individual with this type of developmental delay and/or disability may lack the ability to make age-appropriate decisions in regards to sexuality because their mental age does not match their
chronological age. However, their physical and psychological needs in regards to their sexuality remain.

Between 1910 and 1930, 29 states enacted and put into practice laws that permitted the involuntary sterilization of the feebleminded, as well as the mentally ill, the epileptic, and the criminal (Castles, 2002, p. 1). The sterilization process was referred to as “Eugenics”, and was increasing dramatically in the 1950s in the southern states. North Carolina authorized approximately 200 sterilizations per year through the late 1950s (Castles, 2002, p. 3). The underlying premise for the sterilizations was the judgment of the patients’ unfitness for parenthood. The heightening of the civil rights consciousness of the 1960s led to a greater appreciation by mental health workers of their clients’ individual rights which led to a sharp decrease in the use of sterilization (Castles, 2002, p. 5). The guiding premise of the 1960s and 1970s for ID populations was their right to live as normal of a life as possible and the reciprocal obligations of being responsible for their own actions (Robinault, 1978, p. 238). At that point in history, it was still felt that an individual who did not know the relationship between having sex and having a baby could not be responsible for his or her sexual behavior.

During the 1960s there was a growing concern around the world over civil rights. These concerns aided in the development of the philosophy of normalization, which was first proposed in Scandinavia and then introduced in North America by Wolfensberger in the 1970s. Normalization advocates the ‘reintegration of those stigmatized due to a disability back into society and emphasizes the importance of facilitating the disabled to live ordinary lives (Karellou, 2003, p. 66). Normalization refers to the use of a variety methods in order to establish and maintain personal behaviors and characteristics that are also as culturally normal as possible.
acknowledgement of the sexual needs and rights of the ID (Karellou, 2003, p. 66). This philosophical shift occurred in how people with ID were viewed and treated; the “rights” of people with disabilities became formally “enshrined” by the United Nations (Wilson, Parmenter, Stancliffe & Shuttleworth, 2011, p. 276).

In 1971 the United Nations instituted a “declaration of rights of retarded persons” that stated every member of a given society should enjoy the same rights regardless of disability (Wilson, et al., 2011, p. 276, Karrellou, 2003, p. 66). In the United States, the Sexuality Information Education Center of the United States (SIECUS) reports of the early 1970s were among the first materials available to the general public which included many references to writings, audiovisual materials, and book reviews that related to the sexual activity of disabled populations (Robinault, 1978, p. 197). The first curriculum guides for sex education for disabled populations also appeared during that timeframe. However, such consideration of the sexuality of people with disabilities was limited by the availability of knowledgeable staff and funding (Robinault, 1978, p. 199). Reflecting the changing philosophies, three significant gatherings took place around the world where the sexuality of people with ID was formally debated as a concept beyond segregation, sterilization, and eugenics (Wilson, et al., 2011, p. 276). The first, held in Hot Springs, Arkansas in 1971, was titled Human Sexuality and the Mentally Retarded. The second was held in 1974 in Washington D.C. and was called Symposiums on Reproductive Rights of the Mentally Retarded. The third conference took place in 1975 in West Germany and was called Mental Handicap, Human Relationships, Sexuality (Wilson, et al., 2011, p. 276). While most research and resources were geared towards specific physical disabilities, such as spinal cord injuries, professionals working with ID populations developed a list of basic rights,
sex information, expression, and birth control services for the population they served. According to Robinault (1978), these basic rights were:

1) “People with special needs should have free access to information on sexuality and birth control;

2) Masturbation is a normal expression of sex, no matter how frequently it is done and at what age;

3) All direct sexual behavior involving the genitals should be in privacy;

4) Any time a physically mature girl and boy have sexual relations, they risk pregnancy;

5) Unless they are clear about wanting to have a baby, and the responsibility that goes with child rearing, both the male and the female should use birth control;

6) Unless the participants are 18, they should not have intercourse;

7) Adults should not be permitted to use children sexually; and

8) In the final analysis, sexual behavior between consenting adults (regardless of mental age) and whether it is homo or hetero should be no one else’s business provided there is little risk of bringing an unwanted child into this world (p. 239).”

In addition, two additional factors were recommended for consideration during this point in history. These were the need for greater acceptance of abortion as a safe, legal alternative to bringing an unwanted child into the world and the concept that voluntary sterilization could be a desirable protection for some individuals who could function perfectly well in a marriage if there
were no children (Robinault, 1978, p. 239). In 1985, Craft identified six main rights related to
the sexuality of people with ID (p. 172). There included the right to grow up, which meant the
right to be treated with respect and dignity appropriate to their adult status; the right to know or
have access to as much information as they could understand; the right to their sexuality; the
right to be protected from sexual abuse; the right to express their sexuality; and the right to live
in a humane environment that would allow them to use socially appropriate behaviors.

While the field of sexuality education for ID populations was still at the formative stages,
questions about the influence of staff on the psychosexual development of those with mental or
physical disabilities was already a concern. The concern was not with the ID population itself
but rather “the competence of their contact care personnel be they parents, teachers, helping
professionals, aides, camp counselors, or anyone else” (Robinault, 1978, p. 39). Robinault
further questioned if these potential guides were acquainted with developmental facts of this
stage of growth and with the peculiar needs of their disabled clients. Moreover, he asked, can
the adult caregivers handle their own feelings sufficiently to handle daily incidents with proper
emotional weight? Most importantly, he asked, can they recognize when they do not know how
to handle a situation regarding sexual curiosity or behavior and did they know to whom to go to
or to whom to refer the client, parent or colleague in order to handle the situation (Robinault,
1978, p. 39)?

The enactment in 1975 of Public Law 94-142, the Education of All Handicapped
Children’s Act, expanded appropriate educational opportunities for ID children (Sgroi, 1989, p.
203). This law mandated the inclusion of parents in the decision making process about their
children’s special education and vocational needs and increased collaboration efforts between
home and school. It resulted in fewer children being institutionalized and began the movement
to place those with special needs within the community. This integration enabled society to become more fully aware of the developmental potential of persons with ID (Neistadt & Freda, 1987, p. 32). This integration into the community setting also created a paradox in that the individuals whom society had the most ambivalence about regarding sex education were the persons who needed it the most because ID individuals had less opportunity to acquire a realistic understanding of their sexual selves than did their non-ID peers (Sgroi, 1989, p. 204).

**Physical Abuse**

The access to information and education, particularly in regards to sexuality and sexuality exploitation or abuse, was viewed as being of critical importance. Curriculum development and instructional methodology was created to respond to a need for training of persons with ID to protect them from sexual abuse (Sgroi, 1989, p. 205). This became the focus of sexuality research and program development by ID professionals during the mid to late 1980s (Sgroi, 1989, p. 205). The results were a set of standardized guidelines for conducting sexual abuse avoidance training with ID adults. Sexual abuse evokes strong responses. The potential for sexual abuse is used as a reason for protecting the ID population through harm reduction policies and protectionism (Gill, 2010). In many cases, this concept assumes that people with ID are unable to adequately advocate for themselves and need constant supervision and support. It is assumed that their sexual rights should be protected while their sexual expression should be “shunned or silenced” (Gill, 2010, p. 204). Gill argues that the very way in which services are delivered to ID populations “feeds into a high experience of sexual abuse and assault because the individuals are told what to do, where to live, and whom to love” (Gill, 2010, p. 204).

The most common type of abuse is physical abuse. Sexual abuse is more prevalent in the ID sample than in the other client groups. People with ID are more likely to have experienced
follow-up action, usually through more monitoring (Beadle-Brown, Mansell, Cambridge, Milne & Whelton, 2010). Much of the literature on the issue of abuse or adult protection in the field of ID has focused on sexual abuse with variation in prevalence ranging from 10 to over 80%, depending on the research study and sample group (Turk & Brown, 1993; McCabe et al., 1994; Brown et al., 1995; McCabe & Cummins 1996; McCarthy & Thompson, 1996, 1997). A retrospective study completed in England found physical and psychological abuse was the most prevalent in ID populations; followed by institutional abuse and neglect with psychological abuse; then institutional abuse with neglect; and finally, discrimination, institutional abuse, and psychological abuse (Beadle-Brown, et al., 2010, p. 579). The Beadle-Brown study further found that there had been a dramatic increase in the number of referrals to treatment centers for abuse from the late 1990s to 2005 due to the increased detection of existing levels of abuse practices because of improved procedures, policies, and management oversight (Beadle-Brown, et al., 2010, p. 581).

The Valenti-Hein study conducted in Australia discovered that individuals with developmental disabilities were sexually assaulted at a rate 10.7 times higher than that for nondisabled individuals. However, only three percent of sexual abuse cases involving people with developmental disabilities will ever be reported (Valenti-Hein & Schwartz, 1995). The risk of sexual abuse in an institutional setting, such as residential and group homes, is two to four times as high as the risk when the individual is in the community (Sobsey & Mansell, 1990). Unequal power dynamics that might favor professionals, family members, and staff instead of a genuine willingness to participate by all partakers becomes one of the determinants of abuse (Gill, 2010). McCarthy and Thompson (1996) define the distinctions of the different types of potential sexual abuse. Sexual abuse happens “where sexual acts are performed on or with
someone who is unwilling or unable to consent to those acts” where “any sexual contact which is unwanted and/or unenjoyed by one partner and is for the sexual gratification of another” and where that person’s apparent willingness is unacceptably exploited” (McCarthy & Thompson, 1996, p. 120). These definitions of abuse rely on the lack of consent or willingness to engage in sexual activity, but also focus on the presence of exploitation (Gill, 2010).

Safety is also an important consideration in discussions of consent. Having individual choices respected and feeling safe in the expression of those choices is an important consideration in the determination of consent. The relatively high frequency of sexual abuse found among ID populations has influenced researchers to focus a significant amount of their time and efforts on those who experience and participate in the abuse (Gill, 2010).

**Professional Preparation Programs**

The first Disability Studies programs in the United States were established in the mid-1990s. The passage of the Americans with Disabilities Act of 1990 guaranteed equal opportunity to individuals with disabilities in many areas one of which was state and local services (Retzleff, 1999). Disability has historically been treated as a condition to be “cured or ameliorated or a characteristic that can interfere with the social order and social interaction” (Taylor, 2011, p. 94). Disability is a social, cultural, and political phenomenon; consequently the expansion of educational opportunities and professional preparation programs had to be developed to help develop professionals to better work with those with disabilities of all types. From this “new” perspective, disability is not a characteristic that exists exclusively in the person so defined, but is a construct that finds its meaning in social and cultural contexts. Scholars even use different language to refer to the people at the center of inquiry in disability. Taylor, (2011), states: “A disabled person is used to draw attention to the centrality of disability in individual identity;
person with a disability or “people first” language conveys the idea that having a disability is second to people’s identities as human beings; person labeled disabled (intellectually disabled, mentally ill, and so on) focuses on how disability is a socially constructed definition imposed on people” (p. 95).

According to a 2004 SIECUS Report, the accessibility of information related to sexuality and disability for all—including students, professionals, disabled, non-disabled, universities, hospitals, institutions, public libraries, and the general public, needs to be improved and efforts should be increased to develop new educational opportunities and programming (Boyle, 2004). This effort should specifically include efforts to ensure that professionals in all disciplines working with disabled people have appropriate training to increase their level of comfort about sexuality. According to Boyle (2004), they must become “permission-givers who may not have all the answers but who know when to refer a client to a professional with well-developed skills and knowledge in sexual counseling, education, and/or therapy; thereby helping people with disabilities to benefit more than is imaginable” (p. 1).

Approaches used to study sexuality have almost exclusively been those of self-report or subjective experiences and self-report of behavior; few studies exist which examine sexuality through the reports of outsiders (observers) (McKinney & Sprecher, 1991, p. 12). Even fewer studies exist which explore the experiences of those who observe sexual behaviors through their positions in the workplace. Self-administered questionnaires, interviews, and behavioral records or diaries are typical modes of administration in these self-report approaches (McKinney & Sprecher, 1991, p. 12). Lyon, (1992), found most surveys: “confined themselves to narrow groups such as college students or women of childbearing years, or to sexual attitudes rather than
practices” (p.15). This was still true for many of the studies frequently cited today (add citations).

Review of Existing Staff Research

Foundational research and literature review for this project was conducted over a three-year period. The initial plan was to conduct a quantitative study of the attitudes, behaviors, and knowledge of sexuality and affectionate behaviors experienced in the workplace by DSP in group homes that work with ID populations. An extensive literature review was conducted using standard databases for the field of health education in the libraries of two state universities located in the Midwest. Databases used were EBSCOHost, JSTOR, and databases specifically for health science and medical fields. Search parameters included sexuality, mentally retardation, group homes, staff attitudes, developmental disabilities, disability, sex education, intellectual disability, staff, and workplace issues. No articles were found and it seemed a viable research topic had been identified. However, the researcher conducted the same search using Google, and found numerous pre-existing studies, although most of the studies occurred in other countries or were extremely dated. It appeared the topic had already been thoroughly researched and investigated. The next step was to review the articles found in the Google search more closely.
## Table 1

**Existing Research Summary**

<table>
<thead>
<tr>
<th>Study</th>
<th>Type of Disability</th>
<th>Method</th>
<th>Participants</th>
<th>Instrument</th>
<th>Country</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>“A Right to Know” – Facilitating a relationship and sexuality program for adults with intellectual disabilities in Donegal</td>
<td>Intellectual Disability</td>
<td>Pilot Study for New Sexuality &amp; Relationship Program</td>
<td>Health Service Executive Centers Staff &amp; ID Clients</td>
<td>Ireland</td>
<td>2009</td>
<td></td>
</tr>
<tr>
<td>Attitudes Towards ID Sexuality</td>
<td>Intellectual Disability</td>
<td>Quantitative</td>
<td>Caregivers &amp; Parents</td>
<td>SAQ-ID</td>
<td>Ireland</td>
<td>2001; 2006</td>
</tr>
<tr>
<td>Defining “Sexualized Challenging Behavior” in Adults with ID</td>
<td>Intellectual Disability</td>
<td>Qualitative</td>
<td>Staff</td>
<td>Recorded Interviews</td>
<td>Ireland</td>
<td>2009</td>
</tr>
<tr>
<td>Effectiveness of a sex education program facilitating social skills for people with intellectual disability in Japan</td>
<td>Intellectual Disability</td>
<td>Quantitative – Controlled Experiment</td>
<td>ID clients living in a Welfare Facility</td>
<td>Kikuchi’s Scale of Social Skills, 2007 (KiSS-18)</td>
<td>Japan</td>
<td>2011</td>
</tr>
<tr>
<td>Interviewing Victims of Sexual Abuse with an Intellectual Disability</td>
<td>Intellectual Disability</td>
<td>Single Case Study - Qualitative</td>
<td>Single health professional working with a single client</td>
<td>Interviews</td>
<td>Netherlands</td>
<td>2010</td>
</tr>
<tr>
<td>Judging the Acceptability of Sexual Intercourse Among People with Learning Disabilities</td>
<td>Learning Disability</td>
<td>Mixed Methods</td>
<td>Volunteers</td>
<td>Testing with use of situational vignettes</td>
<td>France</td>
<td>2008</td>
</tr>
<tr>
<td>Laypeople’s Attitudes Towards the Sexuality of People with Learning Disabilities in Greece</td>
<td>Learning Disability</td>
<td>Quantitative</td>
<td>General Public</td>
<td>GSAQ-LD</td>
<td>Greece</td>
<td>2003</td>
</tr>
<tr>
<td>Rights, sexuality and relationships in Ireland: ‘It’d be nice to be kind of trusted’</td>
<td>Intellectual Disability</td>
<td>Focus Groups &amp; Interviews - Qualitative</td>
<td>Clients of National Disabilities Services</td>
<td>Ireland</td>
<td>2009</td>
<td></td>
</tr>
</tbody>
</table>
McConkey and Ryan (2008) developed a questionnaire to measure what types of sexual incidents staff experienced when dealing with resident sexuality in services for teenagers and adults with intellectual disability. The literature review for this study also found that existing studies in this area focused mainly on staff attitudes towards sexuality in general, rather than on actual staff experiences with dealing with sexuality incidents in the workplace (McConkey & Ryan, 2008). Over 67% of the staff who completed the questionnaire had experienced some type of sexuality incident with the residents in their care (McConkey & Ryan, 2008). The study indicated that over 50% of the staff felt that more training and clear policies would help increase their confidence in dealing with resident expression of sexuality in the workplace (McConkey & Ryan, 2008). Unfortunately, the study took place in Ireland and this researcher was unable to obtain a copy of the questionnaire after six months of effort.

The most cited research for identifying how DSP experience sexuality in the workplace was conducted by McCabe. McCabe (1999) developed the Sexual Knowledge, Experience, and Needs Scale (SexKen) and adapted it for use with the general population (SexKen); for people with mild intellectual disability (Sex-Ken-ID); for people with physical disability (SexKen-PD), and for DSP of people with disabilities (SexKen-C). However, again finding the actual instrument proved to be elusive. Extensive research indicated a copy of the instrument could be found in the book *Handbook of Sexuality-Related Measures*, edited by Fisher, Davis, Yarber, and Davis, 2011. However, after purchasing the book it was found to only include a description of the instruments. After further research, contact information was found for Dr. McCabe and she generously shared her materials for use in this study. The SexKen-C is a 56-page, self-administered questionnaire, which takes at least one hour to complete. While the SexKen, SexKen-ID, and Sex-Ken-PD have been used to gather data for several years, it appears that the
SexKen-C was only used once (Fisher et al., 2011). Because the SexKen series is the first of this type of scale to be developed, it is not possible to assess the validity of this scale, according to its author (McCabe, 1999). In addition, the original data are no longer available due to amount of time that has passed since the original study (McCabe, 2011). After reviewing the SexKen-C, it is apparent this questionnaire needs updating. The pictures that are used in the process are very out-of-date and are difficult to decipher. The lack of ability to validate this version of the scale, the hour-long time requirement per person for administration of the questionnaire, the cost of copying the questionnaires, and the outdated pictures result in this scale not being an ideal choice for use in this study. According to Fisher (2011), this scale was also only used in the original study.

Since DSP frequently serve as sex educators for their residents, the possibility of using an instrument to measure how prepared the DSP felt to serve as a sex educator for their residents was explored. The Sex Education Confidence Scale (SECS) for new health educators was examined. The scale, developed by Smith, Balkin, and Kimbrough (2008), was based on the premise that any participant would have at least completed some college courses. In addition, the SECS was intended for use with teacher preparation students and practicing teachers in health and physical education (Smith, Balkin, & Kimbrough, 2008), Since these intended qualifications for participants do not typically exist in the backgrounds of DSP in the selected target population, it was deemed that the SECS instrument was not viable for this study.

The researcher used the services of Amazon to find books and training materials written specifically on the topic of human sexuality for ID populations. Every book that was available under the price ceiling of $100 was purchased. The search criteria used were sexuality, sex education, developmental disabilities, disability, caregiver(s), staff problems, and intellectual
disabilities. Amazon’s feature of recommending similar titles was very useful in finding materials that were not included in the initial searches. The same process was repeated for human sexuality and sex education materials for children, boys, girls, women, and men, since the residents of the group homes frequently function at different developmental levels. However, no potential instruments for a quantitative or mixed methods study were identified. Next, the search engine Google Scholar was utilized to further explore the existing research and resources available on the topic of sexuality and affectionate behaviors in group homes. The search criteria used were sexuality, sex education, developmental disabilities, disability, caregiver(s), staff problems, and intellectual disabilities. Through this search engine an article about a Master’s Thesis Project was found that used a Perception of Sexuality Scale. The purpose of the descriptive study was to determine the perception of DSP toward the sexuality of individuals with ID (Swango-Wilson, 2008). The Perception of Sexuality Scale was used to measure caregiver attitudes (Swango-Wilson, 2008). This scale was reviewed and found to be unsuitable for this study because the instrument was also developed for use by college students (Scotti, Slack, Bowman, & Morris, 1986).

As persons with ID have become increasingly integrated into community settings, their right to sexual expression has become a more important focus of education and service programs. According to Scotti, Slack, Bowman, and Morris (1996a), the perceptions of service providers of the sexual behavior of those with ID can have a significant impact on access to these services by their individual intended recipients. The Perception of Sexuality Scale (POS) was developed to measure the attitudes of service providers (Scotti, Slack, Bowman, and Morris, 1999). However, further analysis of the scale and subsequent research based on the scale once again used undergraduate students as the target population. The participants in the study had
“some contact” with persons with ID, with the mode being contact of only “one to five times per year” (Scotti, et al., 1999, p. 254). In addition, the persons that they had contact with included friends, neighbors, relatives, and acquaintances instead of persons or clients in the workplace. The authors postulated that “college students represent the next generation of service providers, professionals, and policy makers, and thus their opinions of people with ID are in themselves important to assess for application with current service providers in the field of intellectual disability (Scotti, Slack, Bowman, and Morris, 1999, p. 261). The authors also recommended further study of this tenuous connection. Since the present study is not interested in asking employees their personal sex habits and attitudes in comparison with their attitudes about the sexual behaviors of those with ID, which is the basis of the POS Scale, it was determined that this instrument would not be suitable for use here.

Another oft-cited instrument in the field of ID is the Community Attitudes toward the Mentally Ill (CAMI), which was developed by Dear and Taylor (1979) to measure the public’s attitudes toward persons with mental illnesses on several subscales. CAMI is a self-report instrument scored on a five-point-Lickert-type scale. CAMI includes four sub-scales: Authoritarianism, Benevolence, Community Mental Health Ideology, and Social Restrictiveness (Granello, 2003). The scale was used by Wolf, Pathare, Craig, and Leff (1996) to study the effectiveness of a public education campaign to change community attitudes towards mental illness. The same authors conducted a related study to see if the lack of knowledge about mental illness fueled negative attitudes towards people with mental illnesses (1996). Results of the two related studies found that negative attitudes, especially in older people, were fueled by a lack of knowledge, and that public education campaigns should be targeted toward people with children
and non-Caucasians, as these were the groups found to be more likely to object to being around people with mental illness (Wolff, et al., 1996, p. 90 & p. 198).

Granello also utilized CAMI, in his study of 86 participants who were undergraduate students in teacher certification, study skills, and career development courses. Granello simultaneously administered the Hypergender Ideology Scale, a 57-item instrument that uses a 6 point Lickert-type scale for this study. Results indicated that when hypergender scores were statistically controlled for, there were no significant effects on any CAMI subscale score based on participant sex. Biological sex was not significantly related to tolerance, but rather an individual’s personal gender ideological belief system was related to attitudes towards persons with mental illnesses. The results indicated males were significantly more likely to have higher scores on the Hypergender Ideology Scale than females. Participants with higher hypergender scores were more likely to be more authoritarian, more socially restrictive, and less benevolent towards persons with mental illnesses, and more likely to hold less tolerant beliefs about community mental health. The Granello findings indicate that those individuals with extremely traditional gender roles are less likely to express attitudes that are supportive and caring of persons with mental illnesses.

Education about mental illness can increase participants’ willingness to assume some responsibility for assisting persons those afflicted with it, to express higher levels of kindness and benevolence, and to be less willing to view such people as a threat to society (Granello & Pauley, 2000). A large body of literature demonstrates that attitudes are a weak predictor of actual behaviors. Granello felt that society operates under the construct or belief that others should behave in certain socially prescribed ways. This belief results in lowered acceptance of individuals whose behavior deviates from social norms. While the CAMI results of the three
studies denote some interesting patterns of behaviors regarding how people feel towards individuals with mental illness, it does not measure attitudes or beliefs in regards to sexual behavior nor measure what experiences take place in the group home setting by DSP. Granello also studied undergraduate teacher certification students who were not yet in the workforce. Wolff, et al., (1996) studied the general public to develop a public education program for marketing purposes. Since the research goals of the present study are quite different than Wolf and Granello’s, it was deemed that the CAMI scale would not be a usable component of it.

The Knowledge, Comfort, Approach and Attitude towards Sexuality Scale (KCAASS) was developed to assess the training needs and professional skills of staff working in sexuality rehabilitation with spinal cord injury patients (Kendall, Booth, Miller, & Geraghty, 2003). The KCAASS is usually administered by interview, but it can be self-administered. Summary scales for four components of sexuality are calculated through the use of a four-point Lickert scale ranking system for each of the subscales (Kendall, et al., 2003). The purpose of this scale was to help identify specific areas that should be focal points when developing sexual education programs for staff working within the spinal cord population. Since the scale was developed specifically for the spinal cord population, it was not considered a viable option for the present study.

The Attitudes toward the Sexuality of People with Disabilities Scale (ASPDS) measures the attitudes towards the sexuality of people with disabilities of all kinds (Cuskelly & Bryde, 2004). This scale was based on the gender-specific Sexuality of Adults with Intellectual Disabilities Scale (SAIDS), which assessed the attitudes of parents and caregivers towards the sexuality of individuals with intellectual disabilities (Cuskelly & Bryde, 2004). The ASPDS was
adapted for use with three different types of disabilities: schizophrenia, spinal cord injury, and developmental disabilities. It is a 30 question instrument with a five-point Likert-type scale.

The last research tool evaluated for potential use was the Greek Sexuality Attitudes Questionnaire – Learning Disabilities (GSAQ-LD), which is a research instrument developed in Greece to assess the attitudes towards the sexuality of people with and without learning disabilities. The 45-item, Likert-type questionnaire consists of four difference scales – general attitudes towards sex; attitudes towards sexual education; attitudes towards sex education for learning disabled people; and attitudes towards the sexual rights of learning disabled people (Karellou, 2003). Karellou stated her instrument was necessary to develop because “both the SMRAI and the POS previously measured attitudes towards the sexuality of people with LD but the studies were carried out in the United States (U.S.) and were not considered culturally appropriate for use in Greece” (2003a, p. 114). She also stated that the instruments were developed for use with college students and not readily transferable for use with other populations (Karellou, 2003). If the GSAQ-LD was developed specifically for the culture of Greece, it stands to reason that it would not be culturally appropriate for use in the U.S. as well.

Sex in the Workplace

Since the previous searches did not yield viable research instruments for use in this study, the researcher next repeated the search process for the parameters of sex and the workplace. Numerous studies on the topic of sexual harassment were found. However, the only research found to be related to how workers experience sexuality and affectionate behaviors outside of the parameter of sexual harassment was a study completed on the porn industry in Canada. This led to the researcher amending the search parameters to job satisfaction, DSP, staff, workplace, and sexuality. Chou, Kroger, and Lee (2010) conducted a study of job satisfaction in three different
residential models. They found that staffs working in small homes were significantly happier than staff than in other types of facilities. However, the study did not include any sexuality issues (Chou, et al., 2010). Ford and Honner (2000) found that DSPs were concerned about decision-making opportunities, opportunities for advancement, feelings of isolation, and lack of feedback on performance. Again, this study did not address any issues of sexuality or affectionate behaviors (Ford and Honner, 2000). Bell and Espie (2002) conducted a study into staff satisfaction and staff emotions and found that the staff was unhappy with the support from the administrative staff. Finally, Hatton, Rivers, Mason, Mason, Kierman, Emerson, Alborz, and Reeves conducted a study into staff stressors and found in-house conflicts, lack of administrative support, low job-status, and a lack of resources frustrated DSP. All of the studies listed above used self-report questionnaires, which provided a one-time snapshot of the attitudes of DSP in different types of work environments dealing with ID residents. None of the surveys specifically addressed stressors or issues in the workplace in regards to sexuality and affectionate behaviors.

**Gender**

Granello, 2003 investigated the “embodied construct of gender and its influence on attitudes and perceptions held by men and women”, in contrast to previous studies that simply examined the differences in attitudes towards mental illness based on biological sex. In other words, the Granello study added the intervening variable of gender-role adherence—a variable not studied in relation to tolerance towards persons with mental illness in previous studies. The Granello study investigated the attitudes that undergraduate students hold toward individuals with mental illness to identify whether biological sex is a sufficient variable in the prediction of attitudes toward mental illness or whether the students’ views differed according to their gender role adherence.
According to Kaschak (1992), it is not the physical sex of an individual that determines one’s gender identity but rather it is the way in which others interact with and teach the individual how to be appropriately male or female. According to this view, an individual’s gender identity is socially, rather than biologically, constructed (Levant, 1996). Bern (1996) contended the significance of biological differences between men and women depends on their situational context in which they live their lives, not on the physical components themselves.

Granello, (2003), contended that the gender roles to which individuals subscribe, rather than their biological sex, may be the factor that influences their attitudes, opinions, and worldview. Research on social tolerance has found that individuals who adhere to the gender norms of the society are viewed as normal or typical, whereas those individuals who deviate from this subscribed norm are often labeled and judged negatively (Schnittker, 2000). Cormack and Furnham (1998) found that both men and women whose behavior deviated from traditional sex role norms were viewed as more pathological and received more severe negative societal reactions than their gender-norm-adhering counterparts.

An Australian researcher developed resources aimed at creating greater awareness and understanding within the community that LGBT people with ID exist and to provide education and training to disability organizations (Shively, 2012). Sexuality is the lens of being a male or female through which a person views and responds to the world (American Association of Intellectual and Developmental Disability, 2009). Sexuality is an integral part of a person’s adult life and often a part which is inaccessible or denied to adults with ID. Pervasive attitudes towards sexual expression by people with ID revolve around two assumptions – that the person is asexual or if the person is sexual, then they are heterosexual, which is reported to be the dominant sexual identity in Australia. Sexuality is often the source of our deepest oppression; it
is thereby also often the source of our deepest pain (Brown and Pirtle, 2008). There is a
complicated relationship between sexual pleasure and danger; sex can bring gratification as well

Due to life circumstances, many adults with intellectual disability live in supported
accommodations or with their families. Because they may live in shared rooms or houses where
staff members are working, there is a lack of privacy. Many people with ID do not choose with
whom they live, nor with whom they venture out into the community, nor their daily routine,
daily activities, or even clothes (Noonan & Gomez, 2011, p. 176). People with ID have limited
information about sexuality behaviors and limited role models for sexual expression. Individuals
with ID have a hard time generalizing their behaviors from one situation to another, so they need
to have appropriate behaviors reinforced in each environment (Shively, 2012). Attitudes by staff
and family are highly indoctrinating to ID adults. Disability services generally have a lack of
policy about facilitating sexual experiences for people who use their services, and support
workers rarely receive training on sexuality. The sexual development of people with ID is
influenced by a lack of normative learning experiences, segregation, imposed restrictions, lack of
privacy, abuse, overuse of drugs which can inhibit or are administered to inhibit sexual drive,
social attitudes that tend to infantilize individuals with ID or see them as sexually deviant, and a
lack of knowledge about their own sexual rights (Griffiths, Quinsey, & Hingsburger, 1989).
These undeveloped, or diminished, social abilities are likely to affect an individual’s sense of
lovability and capability in terms of social and sexual relationships. All these barriers drive from
top-down service provision wherein the “decision maker” may determine the service structure
and inadvertently or deliberately disallow the person with ID to experience and to make choices
in relation to their own sexuality (Shively, 2012; Noonan & Gomez, 2011). According to
Noonan and Gomez, the delivery of services to people with disability has improved, creating opportunities to broaden their lifestyles (2011, p. 179). The authors recommend greater opportunities for sex education and relationships for all, including the ID population and their caregivers, to promote healthy lifestyles and on-discriminatory living environments wherein an individual can choose the sexual path they wish to take (Noonan & Gomez, 2011, p. 179).

After an extensive, two-year research process, no practical instrument was found to conduct either a quantitative study or a mixed methods study. While several instruments covered job stressors, job satisfaction, sexuality attitudes, or sexuality perceptions, no existing study investigated how DSP directly experience sexuality and affectionate behaviors in the group home or CILA setting. Adapting existing instruments was considered and rejected. The largest problems were:

- many of the studies and instruments were designed for use with undergraduate students
- most studies asked the sexual habits and practices of the participants
- studies that compared personal sexual beliefs to beliefs about ID populations used participants who had little or no experience with ID populations
- most studies were geared towards the needs of the academic realm instead of practical use within the workplace.

Since an extended time period had passed since this research project was originally conceived, an updated literature review was conducted. The results were not much different than the original studies found in earlier literature review efforts. In 2001, a study conducted in Taiwan measured caregiver awareness of reproductive health issues for women with ID. The purpose of the study was to describe caregivers’ awareness of reproductive health issues with
respect to women with ID who are being care for in welfare institutions (Lin, Lin, Hsu, Loh, Lin, Lai, Chien, & Lin, 2011). The study population was composed of staff working in a caregiving role at one of the 267 registered disability welfare institutions in Taiwan. A total of 32 different welfare institutions participated in the research. The study classified awareness of reproductive health issues into four domains: menstrual; menopause; issues of sex education; and reproductive health services. This study administered a mailed questionnaire to caregivers in the 23 institutions and 1,152 respondents participated (Lin, et al., 2011).

The study recommended that service providers offer appropriate reproductive health education to institutional caregivers, and that more attention should be focused on the personal experiences and concerns of ID women in future research. In addition, education programs initiated should consider such factors as the caregiver’s gender, educational level, and experience assisting with reproductive health care issues (Lin, et al., 2011). However, in order to design an educational program to meet those criteria, additional research would have to be completed in order to identify the experiences of DSPs in assisting with reproductive health care issues.

Sexuality in the Workplace – CILA Setting

Role of DSPs

The role of DSPs is invaluable in the day-to-day living of many people with ID (Grieve & McLaren, 2008). Consequently, DSPs can often have substantial influence, although this might not always serve the best interests of the individual. Previous studies have shown significant levels of stigma by DSPs towards people with ID, especially in relation to their sexuality (Grieve & McLaren, 2008). Modern health service personnel typically specialize. They know a great deal about matters that fall within their own field of training, but their perceptions of the people they serve are narrow in other respects (Shontz, 1974, p. 190). Sexual
attitudes are developed through experimentation and reinforcement. DSPs can unwittingly influence the behavior and thoughts of people with ID through the social environments they create, and the spoken and unspoken feedback they give to the behavior and aspirations of their residents (Craft, 1994). Every person lives in a society that enforces predictability of action and thought. Society provides opportunities for personal growth but it also places limits upon the ways in which needs, skills, and personality express themselves. It follows, then, that if one knows to which culture a person belongs, one can say a great deal about how that person is likely to respond. Behavior is predictable because biology, individual consistency, and social pressures establish basic themes for growth and development (Shontz, 1974, p. 188). Numerous biological, psychological, social, and cultural forces interact to influence a person’s sexual development, sexual health, and interpersonal relationships (Alters & Schiff, 2009). These functional emotional skills provide the basis for our intellect and sense of self. Three aspects of a person’s world come together to influence how well he or she masters these functional emotional skills. The first is the person’s biology or the neurological potential or challenges that enhance or impede his or her functioning. The second is the person’s own interactive patterns with his or her parents, teachers, caseworkers, grandparents, and others. The third is the patterns of the family, the culture, and the larger environment (Greenspan & Wieder, 1998, p 4). A multitude of variables exist within those forces that have the potential to influence sexual health—experience, opportunity, knowledge, attitude, age, and physical maturity are a few examples. Staff, as communicating individuals, must be certain their intended meaning is what is received on the other end. The actual meaning often gets lost amid the gestures, body posture, and other nonverbal messages they may not even be aware exist (Neistadt & Freda, 1987, p. 1).
An individual usually formulates a personal value system before adulthood. This value system helps a person identify and classify things as being good or bad, or neither good nor bad. Values guide the reasoning and behavior of a person, especially in sexual decision making (Alters & Schiff, 2009). Any dimension of staff-resident communication about sexuality has the potential to either positively or negatively influence future resident sexual health and sexual decision making. The hesitancy of health professionals to discuss sexuality with clients stems primarily from the discomfort of the professionals in dealing publicly and professionally with a topic most people see as extremely personal and emotionally charged (Neistadt & Freda, 1987, p. ix). This discomfort is often projected onto clients and administrative staff. This process is difficult enough for health professionals and health educators but it can be even more difficult for those not trained in sexuality education. Teaching residents how to communicate and rewarding them for communicating in appropriate ways is critical for the safety of both the residents and the staff (Munster, 2005, p. 119). If handled with unease or difficulty, it could result in a pessimistic form of communication that has the potential to negatively influence future sexuality-based communication, positive sexuality, intimacy, and other aspects of positive sexual health for people living in group homes. This is further complicated by their lower levels of cognitive functioning. In the case of overly affectionate behavior with strangers or people not well known, the goal of the intervention is to eliminate the behavior of hugging or kissing these people without eliminating the affectionate behavior toward appropriate persons (Munster, 2005). The expression of sexuality on the part of ID populations is not a special privilege to be granted only to a select few, but a basic human need and a right (Mitchell, 1985, p. 36).

Therefore, it is essential that administrators and staff advocate that verbal and physical abuses are inappropriate ways to communicate with residents or residents, and that training focus
on teaching staff to reduce resident and resident frustrations by encouraging independent and appropriate ways of expressing themselves (Munster, 2005, p. 119).

**Defining DSP Sexual Attitudes**

What is an attitude? Allport (1935) defined an attitude as a mental or neural state of readiness, organized through experience, exerting a directive or dynamic influence on the individual’s response to all objects and situations to which it is related. A simpler definition of attitude is a mind-set or tendency to act in a particular way toward an object or entity (i.e. a person, place, or thing) due to both an individual’s experience and temperament (Borkowski, 2009). Typically, when one refers to a person’s attitude, it is an attempt to explain his or her behavior. Attitudes are a complex combination of an individual’s personality, beliefs, values, behaviors, and motivations. Attitudes help define how a people see situations, as well as define how people behave toward the situation. Attitude formation is a result of learning, modeling others, and direct experiences with people and situations. Attitudes influence our decisions and guide our behaviors (Borkowski, 2009). Attitudes are formed over a lifetime through an individual’s socialization process. Perception is closely related to attitudes. Perception is the process by which organisms interpret and organize sensation to produce a meaningful experience of the world (Lindsay & Norman, 1977).

Sexual attitudes are developed throughout life through experimentation and reinforcement. Loving someone can be demonstrated through physical contact such as hugging, kissing, and hand-holding. Doing so results in good feelings of acceptance, caring, which reinforce the attitude that physical contact between loved ones is appropriate (Bruess & Greenberg, 2004 p 99). Although an attitude is a predisposition to behave in a particular way, people often behave differently. For example, people who risked showing affection as a child but
were rejected, or those who as infants explored their genitalia and were scolded for it, might hesitate to express affection physically as adults (Bruess & Greenberg, 2004).

Healthy relationships evolve; they do not happen spontaneously. The way IDs interact is greatly influenced by the role models (parents, DSP, media, and friends) they observe. Most adults have never received training in appropriate methods and techniques for building, maintaining, and nurturing a relationship. This lack of skill development limits their ability to serve as healthy role models. Sexuality is a product of the social environment around us (McKinney & Sprecher, 1991, p. 9). One’s perceptions of others influence one’s behavior toward them and members of their group (McKinney & Sprecher, 1991, p. 13). Most sexual activity occurs in interaction with others, whether that is real, imagined, or implied (McKinney & Sprecher, 1991, p. 10). A key component of sexuality is relating to another human being (McKinney & Sprecher, 1991, p. 10).

All too often, people with disabilities are desexualized by doctors, care-givers, friends, family, and in many cases, themselves (Grieve & McLaren, 2008). Individuals with ID have historically been subjected to various efforts to restrict their sexual expression and reproductive capabilities. Assessments of competence can deny individuals legal recognition of their capacity for sexual expression. Although an institution may have a program educating residents about their rights to form intimate relationships, some care staff keeps residents apart from each other (Grieve & McLaren, 2008). Furthermore, research has found that staffs inform residents that it is inappropriate for them to be near each other or to kiss or hold hands (Grieve & McLaren, 2008).

Studies indicate that staff accept masturbation as a normal aspect of sexual development and agree that staff is in need of sex education (Davies & Johnson, 1989). Parents and staff agreed that mandatory premarital counseling should be required as a prerequisite to the marriage
of mentally handicapped person but should not be required for the rest of the population (Davies & Johnson, 1989). Parents favored sex education programs for their handicapped children far more often than they favored sex education programs for non-handicapped people. Staff felt that abortions should be more readily available to pregnant mentally handicapped women. Freedom of choice and the ability for informed consent for the ID population is a highly debated issue, with the topics of abortion and sterilization being the most controversial. Staff seemed to have little difficulty imposing their values on handicapped people (Davies & Johnson, 1989). This study stated the most important need identified was that many staff needed further intensive training so they could feel adequate in providing sex education and counseling to the ID people with whom they work. According to Davies and Johnson, such training needs to be not only factual but also to provide the participants with the opportunity to explore their own feelings about sexual topics as well as to learn some practical and non-directive counseling skills.

A study with nurses explored the behaviors they experienced with patients or clients that they viewed as sexual harassment. Such behaviors ranged from nonverbal leering, smirking, and obscene gestures to verbal sexual innuendoes, off-color jokes, and explicit sexual proposals. Physical behaviors included rubbing, touching, pinching, or grabbing for body parts (Zook, 2000). Nurses participating in the study tended to respond in one of two ways—passively or aggressively. Passive responses included remaining silent, withdrawing from the patient, laughing nervously, trying to joke about the behavior, or even blaming themselves for the patients’ behavior. The other extreme was an aggressive response such as disgust, horror, anger, belittlement, or punishment by refusing to carry out necessary health care (Zook, 2000). Results of the study indicated in order to help the staff cope with sexual behaviors in the workplace, education about the causes of sexually inappropriate behavior was needed as part of the
workplace training requirements (Zook, 2000). A four-tiered program was developed to help the staff assess their own feelings; identify the patient/client defense mechanisms; formulate assertive responses; and demonstrate appropriate limit-setting techniques. The participants had the most difficulty in knowing how to set appropriate limits. Role playing exercises were introduced in order to allow the participants to practice the skills they learned in the new educational trainings. The subsequent training programs were used with nursing staffs, student nurses, assertiveness trainings, and hospital staff overall to reduce situations that could be viewed as sexual harassment and make staff uncomfortable (Zook, 2000).

Harris & Hays (2008) found that sexuality education and supervision experiences are the cornerstone for a therapist’s base level of comfort and willingness to discuss client sexuality with the client. It is through sexuality education that sexuality knowledge is acquired and comfort levels are increased to enable staff to deal with the sexual issues brought to their by their clients. When helping professionals ignore client sexuality, the potential for unintended negative outcomes increase (Harris & Hays, 2008, p. 239). Further, Harris & Hays found few studies have taken place that explored if staff had discussions with their clients about sexuality issues or how the staff felt about serving in the role of a sex educator for their clients (2009). Minimal research also exists on how staff can effectively initiate sexuality-related discussions with clients, despite the fact that many health professionals are not sufficiently trained to work with such concerns. Helping clients talk about sexuality in an open and trusting environment is increasingly important in a society that is barraged with sexual messages, images, and miscommunication (Harris & Hays, 2008). Research has consistently linked sexual knowledge to increased sexual awareness and an ability to work comfortably with clients who have sexual concerns (Yallop & Fitzgerald, 1997; Driscoll, Coble, & Caplan, 1992; Bonner & Gendel, 1989;
Anderson, 1986). Graham and Smith (1984) designed a study to measure the concept of sexuality comfort. High school and college educators (n=32) were interviewed with regard to their thoughts about sexuality comfort. The researchers concluded those teachers who were more anxious about communicating sexual information were less effective educators (Graham & Smith, 1984). The researchers suggested that while knowledge is an important component or relaying sexual information, comfort with sexual material is just as an essential requirement (Harris & Hays, 2008).

Many adults with an intellectual disability live outside the family home in circumstances where their day-to-day lives are influenced by professional carers (Young, Sigafoos, Suttie, Ashman, & Grevell, 1998). Cuskelly and Bryde (2004) found age was the most important influence on attitudes toward the sexuality of individuals with a moderate intellectual disability. Attitudes varied according to age, with younger people being more favorable towards sex education. Older adults had more conservative attitudes about sexual expression than younger adults, for those with and without a disability (Oliver et al., 2002; Murray; Minnes, 1994).

Brown and Pirtle (2008) claimed that sexual behavior is one area where there has historically often been conflict between parents and staff. Typically, parents hold more conservative views of their sons’ and daughters’ sexuality than do staff who are likely to be younger than the parents of adults in their care. Such conflict is likely to lead to some confusion on the part of an adult with a disability (Cuskelly & Bryde, 2004). The differences in attitudes between these two groups are important as parents and professional careers will have substantial influence on the lives of the adults for whom they care. A difference in values around sexuality and its expression may make it difficult for the two groups to work together and may produce a sense of confusion around sexual mores and behavior for individuals with intellectual disability (Cuskelly
Further, this study recommended a research project that would allow for the comparison of attitudes towards the sexuality of persons with an intellectual disability and other groups to identify the level of acceptance of the sexual rights of those with an intellectual disability current in the community. Without this acceptance, appropriate sex education may be withheld or unhelpful (Chapman & Pitcealthy, 1985).

Scotti, Slack, Bowman, and Morris (1996) found that there was substantially less support for a normalized life experience with respect to sexual behavior for individuals with intellectual disability than in other areas. McCabe and colleagues (McCabe & Cummins, 1996; Szollos & McCabe, 1995) have found lower levels of knowledge of sexual matters among those with an intellectual disability than among comparison groups of psychology students. McCabe (1995) also found that staff significantly overestimated their residents’ knowledge in a number of areas related to sexuality. The need for sex education for this population, and the staff that work with them, would seem to be apparent. The ID population frequently has difficulty recognizing social cues, non-verbal cues, and body language cues. Recognizing degrees of relationships can be difficult for the ID, resulting in being overly familiar or overly affectionate with acquaintances, staff, and strangers. This can also result in a diminished awareness of personal space and individual boundaries. Further, ID populations tend to have limited understanding of sexuality, the expectations of adult relationships, and the consequences of affectionate and/or sexual behaviors (Duguay, 2011).

A number of studies of staff attitudes have found that level of disability is seen to be important in determining what is appropriate or necessary with respect to staff responses to sexual behavior (Yool, Landgon & Garner, 2003; Christian, Stinson, & Dotson, 2001). As an
example, informed consent to participate in sexual interactions was believed by staff in the Yool et al., study to be dependent on ability, at least in part (Cuskelley & Bryde, 2004).

**Behavior Theory**

Behaviorism is based on the premise that there is a predictable and reliable link between a stimulus and the response it produces (Schunk, 2008). The rationale for behavior modification is that most behavior is learned—therefore unhealthy behaviors can be unlearned and modified into healthy behaviors. The concept of self is a learned attribute, a progressive concept starting from birth and differentiating steadily through childhood and adolescence (Brammer, Shostrom & Abrego, 1989, p. 30). The development of a self-concept is influenced by an individual’s need for positive regard or approval from his or her parents or primary DSP (Brammer, Shostrom & Abrego, 1989, p. 30). The developing child learns an internalized sense of worth based on his or her perception of the regard received from significant others (Brammer, Shostrom & Abrego, 1989, p. 30).

One’s self-regard comes to depend on the conditions of worth that one has learned through interaction with significant others (Brammer, Shostrom & Abrego, 1989, p. 30). The Social Cognitive Theory (SCT), by psychologist Albert Bandura, states that a person's behavior both influences and is influenced by personal factors and the social environment. Bandura accepts the possibility of an individual's behavior being conditioned through the use of consequences. At the same time he asserts that a person's behavior (and personal factors, such as cognitive skills or attitudes) can impact the environment (Bandura, 1986). Bandura (2001) defines environment as the space outside the person, contrasted with intrapersonal variables. This theory takes note of the social and physical situations in which behaviors take place. Modeling is
a type of social ecology; or the study of the influence of the social context on behavior, including institutional and cultural variables.

SCT extends behaviorism and focuses on the influence that observing others has on behavior. It considers, in addition to behavior and the environment, learners' beliefs and expectations. SCT suggests that reinforcement and punishment affect learners' motivation, rather than directly cause behavior (Bandura, 1986). Modeling lies at the core of SCT. Modeling can be direct (from live models), symbolic (from books, movies, and television), or synthesized (combining the acts of different models). It can cause new behaviors, facilitate existing behaviors, change inhibitions, and arouse emotions. In learning from models, observers go through the processes of attention (observation), retention in memory, reproduction of the observed behavior, and motivation to produce the behavior in the future (Bandura, 1986).

Learners become self-regulated when they set learning goals on their own, monitor their progress toward the goals, and assess the effectiveness of their efforts.

Bandura (1986) described the concept of self-efficacy through the lens of SCT.

According to the social cognitive theoretical framework, individuals learn through the following means: vicarious reinforcement, which is “demonstrated through modeling, imitation, and identification; symbolic activities including language and gestures; forethought activity or cognitive anticipation of consequences; self-reflecting capability or self-evaluation and reflection, self-efficacy or level of confidence, and self-reinforcement” (Malone, 2002, p. 10).

Hackett, Betz, Casas & Rocha-Singh (1992) suggest that experiences gained from vicarious learning significantly increase the potential level of self-efficacy one can attain. Using this perspective, Bandura (2001, 1991, 1986, & 1977) defined self-efficacy as a tool or indicator that provides insight into a person’s perception of their own ability to develop the means and
methods necessary to accomplish a goal for his work with SCT. Therefore, one could argue that
self-efficacy can be a primary motivating factor in the plan of action that individuals choose and
the level of perseverance one is willing to endure in order to successfully overcome obstacles
both within and outside of the academy. SCT states reinforcement is integral to learning
(Bandura, 1986).

Most programs and interventions created by health educators are based on cognitive
behavior theories. Theories of health behaviors help health educators plan, implement, and
evaluate interventions for behavior change (Glanz, Rimer, & Lewis, 2002). SCT has been used
extensively to explain health behaviors (Shafer & Boyer, 2000). As a part of any planning model,
it is necessary to attempt to classify and explain the multitude of factors which influence human
behavior. Behavior change is necessary for health education programs to be successful.

Behaviorism is based on the premise that there is a predictable and reliable link between a
stimulus and the response it produces (Schunk, 2008). The rationale for behavior modification is
that most behavior is learned—therefore unhealthy behaviors can be unlearned and modified into
healthy behaviors (Schunk, 2008).

The goal of a health educator is inform the general population with the information they
need to make healthy choices throughout their health continuum. A behavior is picked out and
either reinforced or constrained to make it more or less common (Schunk, 2008). Health
educators must find a way to tip the scale so the contingencies that will result in the positive
behavior change is reinforced, resulting in a definable reward for the participant. Because of the
diverse population who are sexually active, finding the right intervention to increase supportive
behaviors of staff working with ID populations is important. Traditional outcome goals for health
education programs are to improve personal and community health; decrease incidence,
prevalence, severity, and frequency of health risk behaviors; and to decrease harm and injury from health risk behaviors.

In SCT, perceived efficacy is a key determinant because it affects lifestyle habits both directly and by its influence on other determinants. The stronger the perceived efficacy, the higher the goals people set for themselves, the more they expect their efforts to produce desired outcomes, and the more they view obstacles and impediments to personal change as surmountable (Breslow & Cengage, 2002). This core belief system is the foundation of human motivation and action. It includes self-monitoring, goal setting, and self-reactive influence.

Unless people believe they can produce desired effects by their actions, they have little incentive to act or to persevere in the face of difficulties. Figure 1 shows the relationship between behavior, personal factors, and environmental factors in the SCT. Human behavior is explained using a three-way reciprocal theory in which behavior, personal, and environmental factors continually interact (Pajares, 2002).

Social Cognitive Theory

![Social Cognitive Theory Diagram](image)

**Figure 1** Social Cognitive Theory (Pajares, 2002)

It is easier to prevent detrimental health habits than to try to change them after they have become deeply entrenched as part of a lifestyle. The social cognitive model provides a valuable health tool for group home/CILA workplace efforts to promote the health of its staff and ID residents. Health knowledge can be conveyed readily, but changes in values, attitudes, and health
habits require greater effort (Breslow & Cengage, 2002). Training programs that encompass the essential elements of the self-regulatory model achieve greater success. Social environment include family members, friends and DSP. Cognitive or mental representations of the environment may affect a person’s behavior (Glanz et al., 2002). Observational learning occurs when a person watches the actions of another person and the reinforcements that the person receives (Bandura, 1997). Social cognitive model includes extensive modeling of preferred behaviors. Staff appearing comfortable with ID resident sexuality helps aid in adapting the social norm in regards to the acceptance of sexuality as a healthy choice for ID residents.
<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environment</td>
<td>Factors physically external to the person</td>
<td>Provide opportunities and social support</td>
</tr>
<tr>
<td>Situation</td>
<td>Person’s perception of the environment</td>
<td>Correct misperceptions and promote healthful norms</td>
</tr>
<tr>
<td>Behavioral</td>
<td>Knowledge and skill to perform a given behavior</td>
<td>Promote mastery learning through skills training</td>
</tr>
<tr>
<td>Capability</td>
<td>Anticipatory outcomes of a behavior</td>
<td>Model positive outcomes of healthful behavior</td>
</tr>
<tr>
<td>Expectations</td>
<td>The values that the person places on a given outcome; incentives</td>
<td>Present outcomes of change that have functional meaning</td>
</tr>
<tr>
<td>Expectancies</td>
<td>Personal regulation of goal-directed behavior or performance</td>
<td>Provide opportunities for decision making, self-monitoring, goal setting, problem solving, and self-reward</td>
</tr>
<tr>
<td>Reinforcements</td>
<td>Response’s to a person’s behavior that increase or decrease the likelihood of reoccurrence</td>
<td>Promote self-initiated rewards and incentives</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Confidence in performing a behavior &amp; overcoming barriers in the way</td>
<td>Approach behavior change in small steps to ensure success</td>
</tr>
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</table>

Models and theories are the foundation of many research studies in the field of health education. According to Glanz & Rimer (1995):

Theories [and models] can be used to guide the search for reasons WHY people are or are not following public health and medical advice, or not caring for themselves in healthy ways. They can help pinpoint WHAT you need to know.
before developing or organizing an intervention program. They can provide insight into HOW you shape program strategies to reach people and organizations and make an impact on them. They also help you identify WHAT should be monitored, measured and or compared in the program evaluation (p. _______).

This same method of attack could be used to analyze how social approaches could be used effectively in CILA workplaces. Instead of trying to solve a health problem or issue, we could use this method to help understand the relationship between caseworker behaviors and resident achievement and to reduce any negative impact that relationship may have on resident sexuality.

There are many factors that contribute to a resident's success in affectionate relationships: socioeconomic status (SES), parent or family involvement, peer influence, staff qualification and motivation, resident motivation, resources, educational programs, etc. Each model or theory emphasizes the social component of learning. DSP are essential in order to address the social needs of residents. They play a role in a resident’s motivation, and opportunities to expand their knowledge (Shontz, 1974). Collective efficacy must be in place at the institution. Collective efficacy represents judgments about the performance capability to the social system as a whole; the staff as a whole can organize and execute the actions required to have positive effects on residents. A staff member’s self-efficacy may decrease when they are placed into settings where they are required to teach a subject that is not an area of expertise or comfort. The same to be true if the staff member has little or no understanding of the daily challenges of ID residents.

Administrators need to be aware of the effects that a resident’s home life and staff interaction has on their sexuality. All learning is presumed to have physiological effects (Shontz, 1975, p. 75). Greenspan and Wieder, 1998, stated functional milestones lay a foundation for all
of our learning and development. These functional milestones are the ability to engage in relationships with other people; the ability to engage in two-way communication; the ability to create complex gestures, to string together a series of actions into an elaborate and deliberate problem-solving sequence; and the ability to build bridges between ideas to make them reality-based and logical (p. 3-4). When staffs treat all residents with courtesy and respect, residents associate group home/CILA environments with their caregiver's caring manner and, through classical conditioning, learn to respond to with positive emotions. DSP can also increase residents' feelings of competence by modeling effort and persistence and reinforcing genuine accomplishments. Every action reveals something about the staff person. By gestures, postures, and facial expressions, people communicate or attempt to conceal inner states ranging from depression, contempt, and fear, to joy, affection, and courage (Shontz, 1974, p. 77). Behavioral expectations tend to be translated into pressures to conform. When a person with a disability is treated like a child, he or she may come to evaluate him or herself in those terms. The influence of social expectations and evaluations is especially obvious in childhood, when dependency upon others is high, but these factors are also important in adulthood, even when feelings are not expressed openly. By observing how others react to people with disabilities, one learns attitudes that become part of his or her own response repertoire. Like personality, expressive action is a synergetic enterprise of body and experience; the relationship between the two is the real determinant of human behavior (Shontz, 1974, p. 77).

**Classical Conditioning**

Classical Conditioning is best described as involuntary behavior. A simplistic explanation would be classical conditioning is where one thing is “programmed” into the brain by associating it with another thing—in other words, learned reflexes (Culatta, 2009). A stimulus that already
leads to a response is replaced by a different stimulus. The classic example is Pavlov’s dog training experiment. The initial stimulus was the smell of the dog food, which caused the dog to salivate. The initial stimulus was paired with a new stimulus of a bell. Eventually, just the sound of the bell alone caused the dog to automatically start salivating. Classical conditioning is very concerned with the stimulus-response relationship (Schunk, 2008). The conditioning starts with a reflex. When DSPs provide negative feedback, such as yelling at residents when they exhibit affectionate behaviors, the residents very quickly learn to withdraw socially whenever the caseworker exhibits the same negative behaviors. For example, if a resident gets yelled at whenever they exhibit affectionate behaviors, the resident will learn to associate affection with punishment. This results in a resident who cowers whenever someone yells because they equate yelling with being in trouble.

Operant Conditioning

Operant conditioning is best described as voluntary or deliberate actions. This learning theory was formulated by B. F. Skinner and is based on features from the environment serving as cues for responding (Schunk, 2008). Operant conditioning, also referred to as operant learning, is where something is learned by the consequences of an action. For example, a child gets burnt when he/she puts his/her hand on the hot stove. The child learns that the consequence of touching a hot stove is a burn. Operant conditioning is trial and error learning. The child reacts to stimuli, situations or events in their environment. A behavior is picked out and either reinforced or punished to make it more or less common (Schunk, 2008). It is important to note that research into operant conditioning has shown that rewards work better in obtaining the desired response than punishments. Operant conditioning “operates” on the environment and is maintained by its consequences (Culatta, 2009). For example, if a resident gets a smile from their DSP whenever
they exhibit affectionate behaviors, the resident will learn to associate affection with positive
body language. This will result in a resident who feels positive about exhibiting affectionate
behaviors.

**Differences Between Classical & Operant Conditioning**

Behaviorism is an approach to psychology based on the proposition that behavior can be
researched scientifically through observing behavior (Culatta, 2009). There are several
differences between classical and operant conditioning. One acts to modify or replace the
stimulus that leads to a given response (classical conditioning), and the other to modify or refine
a response (operant conditioning). Both methods have the word conditioning, the acquisition of
specific patterns of behavior in the presence of well-defined stimuli. According to Schunk
(2008), these theories explain learning in terms of environmental events. Classical conditioning
applies to a behavior that is always wanted. In operant conditioning, a behavior can be learned or
extinguished. Both methods are basic forms of learning that separate the “thinking” mind and the
body. In classical conditioning, the learner is automatically reinforced. The reinforcement action
is how one learns to respond to a once neutral stimulus. In operant conditioning, the learner must
provide a correct response in order to receive the reinforcement. Operant conditioning deals with
more cognitive thought process. The key to operant conditioning is reinforcement (Schunk,
2008). Behaviorism is both a psychological movement and a philosophy (Culatta, 2009).

Behaviorism takes a functional view of behavior and that is why it has been a tool utilized in the
institutional setting. The controlled behavior and environment is used by DSP to help residents
learn new skills. Behaviorism defines learning as a change in behavior due to experience and the
association of that experience (stimulus event) and the behavior itself (response event). The
continuous pairing of stimulus with response strengthens learning.
The method of reinforcing the good behaviors and not reinforcing the bad behaviors work particularly well with many types of special needs populations, especially for ones that cause residents to repeat the same behaviors over and over. Problem behaviors can be faded away over time by the consistent lack of reinforcement and positive behaviors can be increased by the consistent use of appropriate reinforcers. Effective practice depends on marshalling the most appropriate theory or theories and practice strategies for a given situation (Glanz, Rimer, & Lewis, 2002).

For most comprehensive health promotion programs, more than one theory or method is used to adequately address the issue necessitating the behavior change (Glanz, Rimer, & Lewis, 2002). Models and methods of behavior change help health educators interpret problem situations and plan feasible interventions. Because they help identify assumptions behind behaviors, they also help identify intervention strategies and steps to assess or evaluate the learner(s). Models and methods of behavior change help to clarify the reasons why health education programs succeed or fail.

**Limitations of Behavioral Methods**

One of the most important issues with behavioral methods is that both classical and operant conditioning models were based on studies completed with animals. Pavlov worked with dogs; and Skinner worked with rats and pigeons (Culatta, 2009). Another limitation of behavioral methods in the CILA setting is that it is easy to forget what true reinforcement is. Frequently staff use what they think should be reinforcing instead of what actually functions as a reinforcer for the resident. Reinforcer effectiveness and preference needs to be assessed constantly in the CILA setting. Something that is usually not a strong reinforcer can become one in certain situations. Conversely, something that is usually a strong reinforcer can lose its
effectiveness as the residents become “satiated.” Too often staffs use the same reinforcer over
and over with resident after resident without assessing the true value of the reinforcer to each
participant. This error is common in staffs that are not fluent in the different components of
behaviorism methods. Too often DSP use bits and pieces of these methods and lack a
comprehensive understanding of how these tools can benefit both the staff and the resident in the
CILA setting. Adequate training, administrative support, and experience can reduce the potential
for this type of problem in the institutional setting.

Maxwell cautioned against ignoring other conceptual resources that may be of equal or
greater importance to a study while conducting a traditional literature review from the academic
focus (2005). He further suggested that the “best introduction to the current status of a research
area is the close association with advisors who know the territory” (2005, p. 34). This led to
conversations with current training officers at organizations serving ID populations such as
group/CILA homes and state institutions. Because of the complexity of the regulation of state
institutions and organizations for housing ID residents, an expert panel will be used in this study
to provide both consultation and expert peer review for the proposed project. The expert panel
will be comprised of the agency director of human resources and training, the agency director for
CILA programs, the director of human resources and training from a state institution for
developmental disabilities, and a tenured-faculty trained in qualitative research methods. These
professionals have the training, research, regulatory, and clinical expertise required to work with
this project.

Many types of group processes can potentially be considered expert panels. Advisory
committees, review committees, stakeholder review boards, and facilitated group processes all
have similarities to expert panels. An expert panel is one qualitative method that can tap expert
knowledge and can be used as a primary analysis method or in conjunction with other tools (Sesking, Still, & Boroski, 2002). For the purposes of this research, an expert panel will be used in an advisory capacity to ensure sufficient depth and detail are being obtained by the researcher and as another layer of member-checking to aid in the quality of the triangulation process. Rather than using triangulation solely as a technique for validation, it may also be used “to ensure a comprehensive and deeper understanding of the subject matter” (Klein & Olbrecht, 2011, p. 343). Expert panels are likely to be useful when it is important to include significant local knowledge about the topic being studied, when a holistic approach is needed, when conflicting societal values are present that may need to be identified and account for, and the impacted area is relatively small. Expert panels are particularly suited to assess impacts in small localized areas (Sesking, Still, & Boroski, 2002), such as CILA home settings.

After all interviews are completed, coded, and major themes have been generated, a summary report will be given to each member of the expert panel. However, each participant’s name and personal identifiers will be removed to maintain confidentiality in the summary report. Each member will be asked to prepare a written reaction to the summary report, indicating their analysis, feedback, and experiences with the issues raised from the interview process. A written analysis will provide the richest information and will aid in the depth of detail required for good qualitative studies (Sesking, Still, & Boroski, 2002). Also, if the panel will be asked to provide only a written analysis of the issues, a smaller panel size (in the range of four to six individuals) is suitable (Sesking, Still, & Boroski, 2002).

Ultimately, no recent studies were found representing the perspective of academic study that would also be of practical use to ID professionals in the workforce. Therefore, a qualitative research method is indicated. An exploratory design based on the premise that an exploration is
needed for one of several reasons: measures or instruments are not available, the variables are unknown, or there is no guiding framework or theory (Creswell & Plano Clark, 2007). This design is best suited for exploring a phenomenon, especially when a researcher wants to explore a phenomenon in depth and then measure its prevalence (Creswell, Plano Clark, 2007).

**Qualitative Research Method**

Qualitative research methods are indicated when a study is geared to understanding the meaning by the participants in the study of specific events, situations, experiences, and actions they are involved with or engage in (Maxwell, 2005). Krepting quotes Sclunid as describing qualitative research as “the study of the empirical world from the viewpoint of the person under study.” It further describes qualitative studies to be naturalistic inquiries. This type of research requires the researcher to access subjective meanings and perceptions of the person(s) under study. Qualitative research is indicated when a researcher is interested not just an accounting of events but rather how the participants in the study make sense of those events and how their understanding influences their behavior (Maxwell, 2005, p. 22). The purpose of this type of study is to create theories or hypotheses. It is used to develop an understanding of a particular phenomenon, concept, or model. Typically, the researcher begins with a single focus (Creswell, 2007).

Qualitative research requires inductive reasoning skills, meaning the researcher moves from the particular to the general. The data is organized into some type of meaningful report that describes what the target population feels, perceives, or is experiencing about the research topic. In other words, generalizations are made based on relationships that have been observed. The researcher looks for and reports patterns. This type of research requires the researcher to use their intuitive skills. Inductive reasoning is used to build theories or create hypotheses.
Qualitative research tends to build on current information and add new facts to existing bodies of knowledge. Qualitative research tends to be dynamic or heuristic, discovering new knowledge from further inquiry of present knowledge (Fetro, 2008).

Krepting describes qualitative research as naturalistic inquiries that study the empirical world from the viewpoint of the person under study (1991). This type of research requires the researcher to access subjective meanings and perceptions of the person(s) under study. Qualitative research takes place in a naturalistic setting; is interactive and authentic; and works towards the understanding human behavior (Creswell, 2007). The purpose of this type of study is to create theories or hypotheses. It is used to develop an understanding of a particular phenomenon, concept, or model. Typically, the researcher begins with a single focus (Creswell, 2007).

Maxwell recommends qualitative research design for projects that are interactive and “unfolding through a process that looks at how a topic influences and is influenced by its environment “(Maxwell, 2005, p. 3). Most important, qualitative research allows for the understanding of the meaning that the phenomena and events have for the people involved in them, and the perspectives that inform their actions (Maxwell, 2005, p. 58).

Qualitative research is the best method for exploring a research topic identified with unanticipated phenomena and influences, and allows for an openness and flexibility in research design to help understand new discoveries and relationships during the data collection process (Maxwell, 2005). Qualitative research methods are used to analyze the process by which events and actions take place (Maxwell, 2005). This method is used when engaging in collaboration and action research with practitioners and is particularly suitable when focusing on particular contexts and their meaning for participants in those contexts (Maxwell, 2005, p. 24). Qualitative
research tends to build on current information and add new facts to existing bodies of
knowledge. Qualitative research tends to be dynamic or heuristic, discovering new knowledge
from further inquiry of present knowledge (Isaac & Michael, 1997).

The first and most important condition for differentiating among the various research
strategies is to identify the type of research questions being asked (Yin, 2003, p. 7). In general,
case studies are the preferred strategy when a “how” or “why” question is being asked about a
contemporary set of events within in some real-life context, over which the investigator has little
or no control (Yin, 2003, p 9). “How” and “why” questions are typically used for explanatory
studies, indicating the use of case studies (Yin, 2003, p. 6). The case study is preferred in
examining contemporary events, especially when the relevant behaviors cannot be manipulated
(Yin, 2003, p. 7). According to Yin, the case study allows investigators to “retain the holistic
and meaningful characteristics of real-life events.” This strategy includes direct observation of
the events being studied and interviews of the persons involved in the events (Yin, 2003, 8). A
strength of the case study is its ability to deal with a variety of evidence—documents, artifacts,
interviews, and observations (Yin, 2003, 8). Historically, the case study was used in the study of
decisions—why they were taken, how they were implemented, and with what result (Yin, 2003,
12).

Sampling and instrumentation decisions actually delimit the settings, actors, processes,
and events to be studied (Miles & Huberman, 1994, p. 23). Participant selection in qualitative
research is not decided or concerned with representativeness, generally because the samples are
too small and bounded in any one qualitative study to meet the requirements of
representativeness (Denzin & Lincoln, 2005). Assessing the DSPs in the agency group homes
will create a sample of participants. Miles and Huberman (1994) identified three key features of
qualitative samples as being small, purposive, and bounded. The core concept of sampling techniques is to find participants to get at characteristics of settings, events, and processes in complex cases (Miles & Huberman, 1994, p. 33). Sampling involves decisions not only about which people to observe or interview, but also about settings, events, and social processes (Miles & Huberman, 1994, p. 30). Qualitative researchers usually work with small samples of people, nested in their context and studies in depth (Miles & Huberman, 1994, p. 27). Qualitative samples tend to be purposive, rather than random (Kuzel, 1992; Morse, 1989) because the initial definition of the universe is more limited and because social processes have logic and coherence that random sampling can reduce to uninterpretable fragments (Miles & Huberman, 1994, p. 27).

Purposeful sampling is a strategy in which particular settings, persons, or activities are selected deliberately in order to provide information that cannot be gotten as well from other choices (Maxwell, 2005, p. 88). Further, with small numbers of cases, random sampling can increase bias (Miles & Huberman, 1994, p. 27). According to Isaac & Michael (1997, p. 198), “small samples are more appropriate for in-depth case studies.” Qualitative research typically includes a small number of individuals to preserve the individuality of each in the analysis process (Maxwell, 2005, p. 22). This is used to better understand how events, actions, and meanings are shaped by the unique circumstances in which these occur rather than collect data from large samples and aggregate the data across situations or larger populations (Maxwell, 2005, p. 22).

The formulation of research questions may precede or follow the development of a conceptual framework. Research questions may be general or particular, descriptive or explanatory. They may be formulated at the outset or later on, and may be refined or reformulated in the course of the fieldwork (Miles & Huberman, 1994, p. 23). Most research
questions do not come out right on the first cut, no matter how experienced the researcher or how
2026 clear the domain of the study (Miles & Huberman, 1994, p. 23). The task is to determine what
2027 the researcher wants to find out about these topics. Formulating too many general research
2028 questions can fragment the collection of data. Having a large number of research questions
2029 makes it harder to see emergent links across different parts of the database and to integrate
2030 findings (Miles & Huberman, 1994, p. 23). A solution to research question proliferation is the
2031 use of major questions, each with sub-questions, for clarity and specificity (Miles & Huberman,
2032 1994, p. 23). Formulating the questions is an iterative process, with each version becoming
2033 sharper and leaner.
2034
2035 Research questions for qualitative studies depend on the method being used to gather the
2036 information. Creswell (2007) advocates four types of research questions for qualitative studies.
2037 They are exploratory, explanatory, descriptive, and emancipator (engage in social action).
2038 Qualitative research questions are open-ended, evolving and non-directional, and are generally
2039 kept to five to seven questions. They generally ask “what” or “how” instead of “why.” Research
2040 questions for quantitative studies typically ask “what,” “who,” “where,” and “when” (Creswell,
2041 2007).
2042
2043 Research questions should be kept in hand and reviewed during fieldwork. This closeness
2044 focuses data collection. Unless something has obvious, direct, or potentially important link to a
2045 research question, it should not appear in field notes.
2046
2047 **Defining Case**

2048 Case studies are intensive analyses and descriptions of a single unit or system bounded by
2049 space and time. Through case studies, researchers hope to gain in-depth understanding of
2047 situations and meaning for those involved (Hancock & Algozzine, 2006, p. 11). Insights gleaned
from case studies can directly influence policy, procedures, and future research (Merriam, 2001).

A case is defined as a phenomenon of some sort occurring in a bounding context. A case study means conducting an empirical investigation of contemporary phenomenon within its natural context using multiple sources of evidence (Yin, 2003). A case study is richly descriptive, because it is grounded in deep and varied sources of information (Hancock & Algozzine, 2006, p. 16). There is a focus, or “heart,” of the study, and a somewhat indeterminate boundary defines the edge of the case: what will not be studied (Miles & Huberman, 1994, p. 25). The case, in effect, is the unit of analysis. The case may be an individual, a role, a small group, a community, a location, temporary events, an episode, an encounter, or a period of time (Miles & Huberman, 1994, p. 25; Hancock & Algozzine, 2006, p. 11). In addition, a case may have subcases embedded within them (Yin, 1984). Single cases are used frequently in qualitative research and can be very vivid and illuminating, especially if they are chosen to be critical, extreme, unique, or revelatory (Yin, 1984). Good cases are developed through the consideration of its conceptual nature, its social size, its physical location, and its temporal extent (Miles & Huberman, 1994, p. 27). The case definition should also include discussion with the organization and professionals involved to add clarity to the definition of the case to be studied (Miles & Huberman, 1994, p. 27). In descriptive studies, information is collected for the purpose of describing a specific group, with no intention of going beyond that group (Hancock & Algozzine, 2006, p. 4).

An exploratory, descriptive research design with aspects of a case study will be used to generate qualitative research and examine the phenomena of sexuality and affectionate behaviors in the group home setting. Yin (p. xiii, 2003) stated: “…case studies continue to be used extensively in social science research—including the tradition disciplines (psychology, sociology, political science, anthropology, history, and economics) as well as practice-oriented...
fields such as urban-planning, public administration, public policy, management science, social
work, and education.” The case study approach allows an intensive study of the background,
current status, and environmental interactions of a given social unit on the level of the individual,
group, institution, and/or community (Isaac & Michael, 1997). The purpose of a case study is to
intensively study the background, current, status, and environmental interactions of a given
social; and individual, group, institution, or community (Isaac & Michael, 1997). Because they
are intensive, they bring to light important variables, processes, and interactions that deserve
further study (Isaac & Michael, 1997). Case study data provide useful examples to illustrate
more generalized statistical findings. According to Isaac and Michael (1997), the case study is
the most preferred method of reporting because it is the most adaptable to emergent multiple
realities (p. 220).

In general, case studies are the preferred strategy when “how” or “why” questions are
being posed, when the investigator has little control over the events, and when the focus in on a
contemporary phenomenon within some real life context (Yin, 2003, p. 1), such as the focus of
this study of the experiences of DSP with sexuality in the workplace setting (group homes). Yin
further stated, “the case study method allows investigators to retain the holistic and meaning
characteristics of real-life events” (2003, p. 2). “How” and “Why” questions are more
explanatory and likely lead to the use of case studies, histories, and experiments as the preferred
research strategies (Yin, 2003, p. 6). The case study is preferred in examining contemporary
events, but when the relevant behaviors cannot be manipulated (Yin, 2003, p. 7). The case
study’s strength is its ability to deal with a full variety of evidence—documents, artifacts,
interviews, and observations (Yin, 2003, p. 8). Yin defines a case study as “an empirical inquiry
that investigates a contemporary phenomenon within its real-life context, especially when the
boundaries between phenomenon and context are not clearly evident” (2003, p. 13). He advocates that the case study be used when the researcher deliberately wants to cover contextual conditions, due to the belief that they might be highly pertinent to the phenomenon under study (Yin, 2003, p. 12). The case study is a comprehensive research strategy that comprises an all-encompassing method—covering the logic of design, data collection techniques, and specific approaches to data analysis (Yin, 2003, p. 14). Case studies need not always to include direct, detailed observations as a source of evidence (Yin, 2003, p. 15).

Research design is the logic that links the data to be collected to the initial questions of the study (Yin, 2003, p. 19). The development of case study designs need to maximize four conditions relation to design quality—construct validity, internal validity (for explanatory or causal case studies only), external validity, and reliability (Yin, 2003, p. 19). Construct validity is defined as establishing correct operational measure for the concepts being studied (Yin, 2003, p. 34). To meet the test of construct validity, the researcher must select the specific types of changes that are to be studied and relate them to the original objectives of the study, and demonstrate that the selected measures of those changes do indeed reflect the specific types of change that have been selected (Yin, 2003, p. 35). Internal validity is used for explanatory or causal studies only, and not for descriptive or exploratory studies. It is defined as establishing a causal relationship, whereby certain conditions are shown to lead to other conditions (Yin, 2003, p. 34). External validity is defined as establishing the domain to which the study’s findings can be generalized (Yin, 2003, p. 34). It is important to note that in regards to external validity, case studies rely on analytical generalization, in contrast to the statistical generalization relied upon by survey research. Further, in analytical generalization, the researcher is striving to generalize a particular set of results to some broader theory (Yin, 2003, p. 37). Reliability is defined as
demonstrating that the operations of the study, such as the data collection procedures, can be repeated, with the same results (Yin, 2003, p. 35). The goal of reliability is to minimize the errors and biases in a study. The objective in a case study is to be sure that if a later researcher followed the same procedures as described by the earlier researcher and conducted the same case study all over again, the later researcher should arrive at the same findings and conclusions (Yin, 2003, p. 37). One prerequisite for allowing this process is the necessity for the first researcher to document the procedures followed in the original case study. Reliability for case studies can be enhanced through the use of a case study protocol and a case study database (Yin, 2003, p. 38).

A research design is a logical plan for getting from here to there, where here may be defined as the initial set of questions to be answered, and there is some set of conclusions (Yin, 2003, p. 20). For a case study, five components of a research design are especially important. The complete design should state what data are to be collected, as indicated by the study’s questions, its propositions, and its unit of analysis. The design should also state what will be done after the data has been collected, as indicated by the logic linking the data to the propositions, and the criteria for interpreting the findings (Yin, 2003, p. 28). Study questions are typically how and why when using the case study research design. Each proposition directs attention to something that should be examined within the scope of study. Defining the unit(s) of analysis directly influences the defining of the case to be studied and is also related to the way the initial research questions were defined (Yin, 2003, p. 24). Once the general definition of the case has been established, other clarifications in the unit of analysis become important. If the unit of analysis is a small group, the persons to be included within the group (the immediate topic of the case study) must be distinguished from those who are outside it (the context for the case study) (Yin, 2003, p. 24). Finally, specific time boundaries are needed to define the
beginning and the end of the case (Yin, 2003, p. 26). All of these types of questions need to be considered and answered to define the unity of analysis and to determine the limits of the data collection and analysis (Yin, 2003, p. 26). Previous literature can become a guide for defining the case and unit of analysis (Yin, 2003, p. 26).

Of equal importance to the structure of a case study design, is the ability of the researcher to adequately conduct the research. According to Yin, there are five essential abilities required by a researcher using the case study method. They are:

1) the ability to ask good questions;
2) the ability to be a good listener;
3) the ability to be adaptive and flexible;
4) the ability to have a firm grasp of the issues being studied;
5) and the ability to be unbiased by preconceived notions (Yin, 2003, p. 59).

Case studies require an inquiring mind during the data collection process, in contrast to the before and after processes required by quantitative research. Gathering data from multiple sources and adapting to the new information gathered in the process requires the researcher to assimilate large amounts of new information without bias (Yin, 2003, p. 60). Very few case studies will end up exactly as planned. Asking the right questions, reading between the lines, pursuing an unexpected lead, and repeating steps as necessary to maintain objectivity and appropriate documentation are important in the case study process. A researcher must be able to balance adaptiveness with rigor, but not rigidity according to Yin (2005).

While several different definitions of qualitative research exist, they each identify several major components. In Krefting’s article, Kirk and Miller (1986) defined qualitative research as “a particular tradition in social science that fundamentally depends on watching people in their
own territory, on their own terms.” For qualitative research the natural setting is generally the
direct source of data, however multiple sources of data are generally collected (Creswell, 2007).
Qualitative research uses purposeful sampling instead of the random sampling methods utilized
by quantitative data collection. It also collects different types of data such as documents,
interviews, journaling, participant observation, and pictures. These types of data can be
categorized into four types: observations, interviews, documents, and audiovisual materials.

Most quantitative researchers recognize and document the worth of a project by assessing
the reliability and validity of the work (Krefting, 1991). Validity means whether something
measures what it claims to measure. Reliability means does something measure what it claims to
be measuring in a consistent fashion. This same standard is much more difficult to achieve with
qualitative research. Krefting stated that the models used to evaluate quantitative research are
seldom relevant to qualitative research. In addition, the term qualitative research is “imprecise
and refers to many dissimilar research methods.” The plurality of qualitative research makes it
more difficult to assess the trustworthiness of this type of research results because the different
data collection methods have different goals. It is also difficult because diverse standards exist
for establishing the quality of qualitative research (Creswell, 2007).

Credibility for qualitative research can be enhanced through the use of prolonged/varied
field experiences, time sampling, reflexivity, triangulation, member checking and peer
examination (Fetro, 2008b). While quantitative research uses reliability, qualitative research
uses consistency as the measure of would the findings be similar and/or consistent if the study
were replicated. Quantitative research uses objectivity and qualitative studies use neutrality as
the term for if the research process and finding have freedom from bias (Fetro, 2008b). Data
analysis for qualitative research is broken down into three major analysis strategies. They are
preparing and organizing the data for analysis; coding the data and condensing the codes into themes; and representing the data through the use of tables, figures, and discussion. Neutens and Robinson include analytical induction, constant comparative method, induction, and models, themes, and concepts as additional data analysis tools. Data analysis for qualitative studies is an ongoing process due to the nature of the data collection, such as re-interviewing after themes develop from the data.

Qualitative research relies on the skill of human perception and is, therefore, influenced by that human “lens” and human bias. Qualitative research is not generalizable in most cases (Fetro, 1991). Data reduction is difficult and qualitative research is very time-consuming. It is very difficult to repeat a qualitative study and the procedures are typically not standardized.

Quantitative research using the experimental method must deal with the cost of the study, the inability to generalize the results of the study if the target group/sample used were not representative of the population, and the difficulty in securing cooperation from those in the experiment and from significant others (parents, administrators, or supervisors). Both types of studies are prone to bias and the researcher must identify potential issues within their written findings.

Summary

The literature review for this proposed case study generates three major reasons why the project is necessary. First, the need for educational programs has been documented by existing research studies, by current experts, and professionals working in the field of ID services. Conversations with current leaders and practitioners in the field resulted in comments such as “you are onto something here”, “there is a need for something to help our staff deal with sexual issues in the workplace but we do not have the time or the expertise to explore it”, “with so much
mandatory training required, we don’t have time for the necessary extras”, and “I wouldn’t even
know where to start” (Institutional Training Officer 1; Institutional Clinical Psychiatrist 1;
Institutional Manager 1; CILA Manager 1; CILA Training Officer 1; & CILA Human Resource
Director 1). Second, most of the studies dealing with staff working with mentally ill or ID
populations looked at staff attitudes towards their own sexuality and personal behaviors in
comparison with how they felt towards the sexuality of ID individuals and their potential
behaviors, instead of what they specifically experienced in the workplace and how those
experiences impacted their overall job experience. Third, most of those studies were extremely
dated (defined by over 10 years old); took place in other countries; and used primarily college
students in teacher preparation or psychological programs. The few studies that used staff
working directly with disabled clients were typically working with clients with physical
disabilities such as spinal cord injuries or mental illnesses such as schizophrenia.

While many studies advocated the need for the development of a sexuality curriculum
specifically for DSP working with the ID population, no single specific study conducted a needs
assessment to identify specifically what sexuality issues exist for DSP working in group homes
in America today and how to address those issues through the development of a sexuality
curriculum especially for DSP. Although many of the recommendations for curriculum
development were also dated, no existing curriculum could be found that had been developed as
a result of those recommendations. In other words, many studies recommended the development
of sexuality curriculums for DSP and staff, but it appears no researcher followed up with the
actual development of the recommended curriculums or explored just what topics should be
included in them. Davies and Johnson, (1989), identified the need for further training for staff so
they could feel adequate in providing sex education and counseling to ID people with whom they
worked. They further recommended the training needed to include not only factual information but also the opportunity to learn some practical and non-directive counseling skills in regards to human sexuality (p. 20).
CHAPTER 3

METHODS

The purpose of this chapter is to describe the research design of the study, as well as the sample and setting. Data collection and analysis procedures will be explained in addition to the importance of establishing trustworthiness in a qualitative research design. Qualitative research methods were chosen for this study because it was unknown a priori what would be found and because the researcher wanted to generate data rich in detail and embedded in context. In-depth interviews and document analysis will be the primary sources of data collection. In addition, job applications, job descriptions, employee training materials, and other handouts will be collected as data. Interviews will be audio and videotaped and field notes will be taken during the interviews as well. The researcher will write analytic memos and contact summaries following each interview.

The purpose of this study is to explore the workplace experiences and training of DSPs, with types of sexual and affectionate behaviors exhibited by intellectually disabled adults in their care in the CILA setting. How well DSPs feel prepared to handle those occurrences and how current training materials assist DSPs in dealing with the human sexuality issues they experience in the workplace will be explored. The experiences, perceptions, emotions, preparation and employee training of DSPs will be investigated. The study will focus on analyzing DSPs thoughts, feelings, and experiences in relation to health and sexuality/affectionate behaviors experienced in the CILA workplace through interviews. This analysis will provide an understanding of what ideas and values DSPs bring to their roles of guiding the sexuality and affectionate behaviors of those residents in their care. If the basic level of sexuality experiences for working with ID populations by DSP can be identified, training programs can be developed.
to build skills in regards to sexuality workplace issues to enhance the CILA experience for both DSP and their residents.

Research Questions

The following research questions direct this study:

1. How do DSPs in CILA settings experience residents’ sexuality and affectionate behaviors?

2. How prepared do DSPs feel to deal with work issues regarding sexuality and affectionate behaviors?

3. How do employee training materials help guide staff behavior in regards to sexuality and affectionate behaviors of residents?

4. How do DSPs perceive their influence on the sexual expression of ID residents in the CILA setting?

Research Design

Qualitative research methods are the best strategy for discovery and exploring a new area (Miles & Huberman, 1994, p. 10). If little is known about an issue, a qualitative approach can be the most useful because qualitative research attempts to explore a host of factors that may be influencing the situation (Hancock & Algozzine, 2006, p. 8). A qualitative approach based on interviews, observations, field notes, and document analysis will be used to provide a context for data collection that challenges participants to discuss topics that may be uncomfortable for them. An exploratory, descriptive research design employing a case study method will be used to generate qualitative data and examine the phenomena of sexuality and affectionate behaviors in the CILA setting. This approach will focus on the expression of the caregiver’s underlying experiences and share a respect for those subjective experiences (Brammer, Shostrom & Abrego,
Further, a this approach will place an emphasis on concepts such as self-actualization, choice, personal responsibility, values, and meaning (Brammer, Shostrom & Abrego, 1989, p. 29).

In-depth interviews will be used to explore and gather descriptions about the phenomena of sexuality and affective behaviors in the group home setting. Best and Kahn (2006) stated that in-depth interviews allow the researcher to get at someone’s experiences, knowledge, opinions, beliefs, and feelings. A qualitative approach based on interviews and document analysis will be used to provide a context for data collection that challenges participants to discuss topics that may be uncomfortable for them. DSPs will be interviewed to determine their perceptions of common sexuality workplace issues working with ID populations and sexuality-related problems within the ID resident population in the group home setting. People interact and interpret the world differently, using social, cultural, religious, economic, and other external factors to impact the way they interpret their world.

By using this approach I can understand the essence of sexuality and affectionate behaviors experienced the workplace at group homes through the social and personal aspects. A qualitative research design based on a case study approach and utilizing the Social Learning Theory (Bandura, 1986) will be used to build an interwoven framework to aid in understanding how sexuality is experienced in the group home setting. For this study, I will be the only person collecting the data. This will allow me to be both adaptive and responsive to situations as they come up within my study. I will be able to process, clarify, and summarize material and data while participating in the interview process and again when completing the data analysis process. By using audio and videotaping during the interview process, I will be able to expand my understanding of the research topic from both verbal and non-verbal communication (Merriam,
Through interaction within our environment, especially our social environment, we can see how DSPs would construct through their societal, cultural, and familial influences their roles as sex educators in the workplace. To limit any personal bias and subjectivities I may have throughout the process, I will utilize an expert panel and a review by a neutral coder trained in qualitative research methods.

**Study Setting**

For qualitative research the natural setting is generally the direct source of data, however multiple sources of data are generally collected (Creswell, 2007). This particular case study is bound by time and place. The duration of this study will be six months during the Fall term of 2014 and the Spring term of 2015. The study will take place in a community in a rural Midwest City that has been the location of programs for the ID since 1969, when a group of committed parents wanted to improve the quality and number of services available to their special needs children. As a result of their efforts, the area has become a national hub for services and organizations for ID populations. Currently there four different organizations providing services such as residential, developmental, vocational, and adult daycare services for ID clients, as well as supportive services to residents who have mild ID who live independently within the community. All of the agencies include group homes called a “Community Integrated Living Arrangement”, or CILA. CILA is a residential program for adults with developmental disabilities. Groups of four to six individuals live in a structured environment that is supervised 24 hours per day. With the support of trained staff, residents work on personal goals for independent living and community integration.

The agency chosen for this study is the one agency within the community that the researcher has the least amount of previous interaction. The community selected for this study is
a rural college town of approximately 25,000 people. The agency selected has other Midwest
locations that will not be included in this study. Only agency CILA homes exclusively serving
moderate to high functioning residents located within the city limits will be included. There are
three CILA homes from the chosen organization that meet those criteria. Each home has a staff
of six to eight employees, and one supervisor, who work in shifts to cover program services 24
hours per day. Six of the employees at each home are DSPs. Residents spend the day at therapy
or at the adult daycare facility. All residents are required to go to bed at 9:00 p.m. Three DSP
are present at each home between the hours of 3:00 p.m. and 9:00 p.m. to work directly with the
residents. All group homes are in neighborhood settings and are designed to have a home-like
atmosphere instead of an institutional environment. Strong family relationships are encouraged
in the CILA process. The corporate office is located within an adult-daycare facility located on
the local town square. The corporate office includes a large training room used for agency
meetings and training sessions. Permission has been granted by the agency to use any necessary
facilities to complete the study.

Selection decisions should also take into account the feasibility of access and data
collection, research relationships with study participants, validity concerns, and ethics. In this
study, potential sensitivity to the research topic (human sexuality) and confidentiality might also
be influenced by the study setting. The agency has granted access to potential study participants
and use of their facilities for the study. One-on-one interviews of participants will be conducted
at a location chosen by the participant. Potential sites are the office of the researcher, a private
conference room located on a university campus, a private conference room located at the
agency worksite, the agency training room, or an alternate location chosen by the participant.
Particular care will be conducted on the part of the researcher to protect confidentiality during
the interview process by adapting the seating arrangements or the logistics within the site chosen by the participant.

**Sampling**

Staff will be identified through a staff list provided by the agency. Each participant will be asked to participate through an introductory letter, followed by a personal visit with the researcher. A total of 18 DSPs are employed in at these three homes. However, DSPs who work directly with the residents between the hours of 3 pm and 9 pm, when the residents are actually in the group homes setting will be considered a priority for this study. DSPs who work at least 30 hours per week will be recruited for participation first, followed by part-time DSPs or those who only work on the weekend. Ideally, at least three of the six DSPs per group home will agree to participate in the interview process. Each DSP will be given the opportunity to participate in the study and will be included in the study if they choose to participate. This study will examine the experiences and training of nine to eighteen DSPs with sexuality and affectionate behaviors in the CILA home setting.

Samples in qualitative studies are usually not wholly prespecified, but can evolve once fieldwork begins. Initial choices of informants may lead to similar and different ones; observing one class of events invites comparison with another; and understanding one key relationship in the setting may reveal facets to be studied in others. This is conceptually-driven sequential sampling. An important question the researcher should ask himself/herself is which activities processes, events, times, and locations, and role partners will he or she sample (Miles & Huberman, 1994, p. 29). It is also important to talk to the people who are not central to the phenomenon but are “neighbors to it, to people who are no longer actively involved, to dissidents and renegades and eccentrics” (Miles & Huberman, 1994, p. 34). Including a component of
Peripheral sampling will allow more depth into the research topic, aid in the discovery of contrasting and comparative information that may help in the understanding of the phenomenon at hand, and help identify the overall culture of the organization being studied (Miles & Huberman, 1994, p. 34). Saturation and sufficiency are two measures used in determining the number of participants to reach a confident analysis level. Saturation occurs at the point “when the generic features of new findings consistently replicate earlier ones” (Denzin & Lincoln, 2005, p. 87). Sufficiency refers to the number of participants necessary to reach saturation in the data, or the point when the data becomes repetitive (Seidman, 1998). If adequate participation cannot be obtained from the DSPs working in CILA homes serving solely moderate and high functioning residents, participants will be solicited from the staff of other CILA homes within the organization that serves a mixture of low and moderate functioning residents. The organization currently employs 54 DSPs—six in each of the nine CILA homes serving low, moderate, and high functioning residents within city limits. Participants will be recruited until at least two DSPs from at least three different CILA homes are interviewed and at least nine different DSPs have participated in the study overall. If all eighteen DSPs working in the three CILA homes serving moderate to high functioning residents agree to participate, the recruitment process will also end.

**Data Collection**

Data collection will include four sources of data—semi-structured interviews, field notes, observation of behavior in interview video tapes, and document analysis. Varying the types of data collection in the research contributes to confident analysis, or trustworthy results (Creswell, 2007). Qualitative data focus on naturally occurring, ordinary events in natural settings, so that society can develop a strong handle on what “real life” is like (Miles & Huberman, 1994, p. 10).
Another characteristic of qualitative data is their richness and holisms, with strong potential for revealing complexity. This detailed data provide “thick descriptions” that are vivid, nested in a real context, and have a ring of truth that has strong impact on the reader. The qualitative data collection process allows the researcher to go beyond “snapshots” of “what” and “how many?” to identify just how and why things happen as they do in an actual setting (Miles & Huberman, 1994, p. 10).

The inherent flexibility of qualitative methods, which allow the data collection times and methods to be varied as a study proceeds, gives further confidence that the researcher has really understood what has been going on in case setting (Miles & Huberman, 1994, p. 10). Qualitative data, with their emphasis on people’s lived experience are fundamentally well suited for “locating meanings people place on the events, processes, and structures of their lives: their perceptions, assumptions, prejudices, or presuppositions and for connecting those meanings to the social world around them (Miles & Huberman, 1994, p. 10). Because the researcher is the primary instrument for data collection and analysis in qualitative research, he or she must spend significant amounts of time in the environment being studied (Creswell, 2007; Hancock & Algozzine, 2006; Merriam, 2009; Stake 2005).

**In-depth individual interviews and field notes.**

The interview is a conversation that has a structure and purpose designated by the interviewer. It is a construction site for knowledge. One belief that is widespread is the assumption that observation is mainly useful for describing behavior and events, while interviewing is mainly useful for obtaining the perspectives of participants (Maxwell, 2005, p. 94). Researchers with good communication skills will be able to easily establish rapport with participants (Creswell, 2007; Seidman, 2006). Building rapport is vital to case study research.
In addition, it is imperative that a good researcher be able to listen and observe. According to Maxwell, the immediate result of observation is description, but that is equally true of interviewing (p. 94).

The purpose of the interviews will be to explore and gather descriptions about how the sexuality and affectionate behaviors of ID residents experienced by DSPs in the workplace impact the DSP and how well the required training prepared the DSPs to deal with those experiences. The aim is to involve a range of DSP who have different experiences with resident sexuality issues within the workplace. According to Best and Kahn (2006), in-depth interviews allow the researcher to get at someone’s experiences, knowledge, opinions, beliefs, and feelings. The in-depth interview questions will allow participants an opportunity to share and express their opinions of what they have experienced, how they dealt with the situation(s), and how well prepared they felt to deal with the situation(s). The exploration to take place in this study is not concerned with the physiology of resident sexuality, but with the emotional, physical, mental, and social essence that surrounds the lived experience of the DSPs that observe sexual and affectionate behaviors and who have to deal with the subsequent issues within their work environment. The way a DSP experiences and interprets the phenomena of sexuality and affectionate behaviors in the workplace setting may affect how he/she will influence resident behavior. The finds will be shared with the agency at the conclusion of the project.

Upon approval from Southern Illinois University's Human Subjects Committee, potential participants will be contacted at their workplace through the use of signs, flyers, phone calls, or individual letters requesting their participation. Each participant will be visited by the researcher in person before the actual interview to help them feel more comfortable with the researcher. Additional DSPs will be identified through the staff list of the participating organization as well
as through the staff listing on the organization’s website. Personal interviews will be conducted
at a time and location of convenience to the interviewees, which will be reserved in advance of
the interview. On the evening prior to the interview appointment, selected participants will
receive a telephone call reminding them of the date, time, and location for the interview. After
signing the consent forms required by IRB, the staff selected will participate in an
audio/videotaped semi-structured interview lasting 45-60 minutes with an agreement that follow
up interviews, if needed, may be conducted. These types of interviews are characterized by a
non-directive style of interviewing to encourage a variety of viewpoints on the topic in focus for
the group (Kvale, 2008). The semi-structured interview includes a mixture of both structured
and less structured interview questions (Merriam, 2009). Questions are used to get participants
involved and are sequenced from general to specific. The interviews will be guided by using a
list of questions and prompts. Interview questions will be designed to aid the DSPs to be
introspective, recall memories of caregiver’s experiences with sexuality and affectionate
behaviors in the workplace, reflect on the social understanding and acceptance of these
behaviors, and give a detailed description of their lived experiences concerning these behaviors
(See Table 3). Member checking will be employed by allowing participants to read their
transcripts and validate the accuracy of the transcription. According to Scientific Research in
Education (2002), collaboration in field-based work can bring a form of intellectual capital to the
research that cannot be obtained in isolation of practice. The way DSPs experience and interpret
the overall occurrence of sexuality workplace issues working with ID populations in the
workplace impacts how they will make the critical decisions of behavioral reactions to those
issues. By using this approach we can understand the essence of sexuality experiences through
the social and personal aspects of the DSPs.

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To support data obtained through interviews, a field log to document the researcher’s observations of the participant during the interview and during the review of the interview video tapes will be maintained. In addition, a reflexivity journal to document the researcher’s thoughts and feelings throughout the investigative process will be maintained (Creswell, 2007). This will allow for increased depth and rich detail that is part of the qualitative research process. It is essential that information is easily identified, well organized, consistent, and maintain clarity (Krueger, 2002, p. 9). Field notes contain notable quotes; key points and themes for each question; follow-up questions that could be asked; big ideas, hunches, or thoughts of the recorder; and other factors such as passionate comments, body language, or non-verbal activity (Krueger, 2002, p. 9).

**Audio/videotape behavior observations.**

Observations of non-verbal behaviors, facial expressions, and comfort levels with discussions topics will be conducted from the video tapes of each interview session. Interview participants sometimes reverse their positions during the timeframe of the interview or follow-up process. When there is a shift in opinion, the researcher typically traces the flow of the conversation to determine clues that may explain the change (Krueger, 2002, p. 11). The interview data are examined for frequency or extensiveness, meaning some topics or issues are brought up more frequently than others. These topics could be considered more important or of special interest to participants. Also to be considered are comments that were not said or only received limited attention. Occasionally, participants will talk about a topic with special intensity or depth of feeling. Interview sessions will be video-taped to aid in the analysis of intensity that may be communicated by the voice tone, speed, emphasis on certain words, and through the body with non-verbal communication cues (Krueger, 2002, p. 11). Intensity may be
difficult to spot with transcripts alone; this is the reason for the video-taping. Specificity is a vital component of data analysis. When interviews have been videotaped, they provide a permanent record that can be coded again and again by investigators with different perspectives (Copland & White, 1991, p. 33).

For this study, observations in the group home setting will not be included because the focus of the study is the DSPs, not the ID residents they serve. Observing the DSPs in the workplace would entail observing the ID residents. While the researcher completed the required background checks to enter the group homes and all legal requirements to become a volunteer within the agency, issues with the resident ability to grant consent to participate in the study and protection of their confidentiality would still remain.

**Document analysis.**

Reviewing documents can add important information to a case study. The types of documents sought for a case study are dependent upon the issue(s) under study (Yin, 2009). Existing documents for this study from the agency to be analyzed will be corporate websites, employee handbook, training schedules, employee training materials, volunteer applications, employment applications, job descriptions, websites from regulatory organizations, employee training materials required by regulatory organizations, sexual incident reports, sex education staff training reports, and sexuality training materials for both staff and residents. The purpose of using document analysis for this study is to explore what types of training DSPs receive on the topics of human sexuality and development, how those materials approach the topic of sex education, and how those materials prepare the DSPs for the sexuality issues that occur in the CILA setting.
Once documents have been found, authenticity should be established by the researcher. Authenticity can be determined by establishing information such as: (a) where documents came from, (b) if they have been edited, and (c) the authors’ sources of information. After authenticity has been established, the researcher will conduct content analysis on the documents and create a coding form that helps the researcher describe the substance of the documents (Creswell, 2007; Bogdan & Biklen, 2007).

**Data Analysis**

Because this study employs the case study method, data analysis will be done through content analysis. The content analysis method is a process that allows for the examination and interpretation of data through reduction, analysis of specific statements, searching for meanings, and is a common theory-development strategy. The interviews will be audio/video-taped and transcribed by a professional court reporter within four weeks of each meeting. Transcripts will be completed for all interviews in a consistent style. The transcripts will be double-spaced, with the comments of the moderator easily identifiable by bold print. Transcripts will be prepared by a court reporter. Moderator statements will be identified in bold print. The interviews will be transcribed word for word, without correction for grammar. If some words are unintelligible, three periods “…” will be used to indicate that words are missing from the transcript. Special or unusual sounds that could help analysis will be noted in the transcript. If there is laughter, loud voices, shouting, or if someone is interrupted, it will be noted in the interview transcript.

Transcripts will be delivered to the court reporter within one week of the finished interview. It is anticipated that the completed transcript will be returned to the researcher within two weeks. A back-up copy of the transcript will also be created as a Microsoft Word file and stored on a
secure computer. Once the completed transcript has been returned to the researcher, it will be
sent to the interviewee for review and confirmation (member-checking).

Thematic coding and inductive analysis will be employed in the data analysis to generate
themes or categories based on the transcribed data. The themes will allow the researcher to gain
an overall perspective about the phenomena of how DSPs experience sexuality and affectionate
behaviors in the workplace. Phase One of data analysis will consist of activities in pre-coding
and descriptive coding. Data analysis for this study will begin with writing notes and memos
during the interview process, which allows not only the capture of analytical thinking of the data
but also facilitates thinking and the stimulation of analytical insights (Maxwell, 2005, p. 96).

Coding will begin as data is collected by jotting down key words or phrases for future references
during the interviews (Saldana, 2013, p 20). The next step will be listening to the interview tapes
and reading the interview transcripts. All transcripts will be read in one setting. This quick read
allows the researcher to view the whole scope and to refresh his or her memory of where
information is located, what information is missing, and what information occurs in abundance.

Transcripts from the interviews will be reviewed and “significant statements” will be
highlighted as well as sentences or quotes that provide an understanding of how DSPs
experienced sexuality and affectionate behaviors within the workplace. Descriptive coding will
be used to identify the basic vocabulary of the data, with the primary goal being to assist the
reader to understand what the study is about and to identify basic categories for further analytic
work (Saldana, 2013, p 88). This initial coding process breaks down the data into discrete parts
for comparison later. Descriptive coding leads primarily to the creation of an index of the data’s
contents. It is essential groundwork for secondary coding and further analysis and interpretation
(Wolcott, 1994, p. 55).
Phase Two of data analysis will employ emotion and value coding methods to analyze the transcripts to develop “clusters of meaning” from the significant statements into themes about their shared experiences and how they felt about them. According to Saldana, “since emotions are a universal human experience, the acknowledgment of them in the research provides deep insight into the participants’ perspective, worldviews, and life conditions” (2013, p 106).

Emotion codes label the emotions recalled and/or experienced by the participant, or inferred by the researcher about the participant and is “especially appropriate for studies that explore intrapersonal and interpersonal participant experiences and actions” (Saldana, 2013, p 105). The transcripts, audio and videotapes will be coded for emotional responses. A textual description will be written to describe what the DSPs experienced.

Value coding is the application of codes onto qualitative data that reflect the participant’s values, attitudes, and beliefs, representing his or her perceptions or worldview. Value coding is particularly suited for case studies that identify intrapersonal and interpersonal participant experiences, and explore cultural values and identity (Saldana, 2013, p. 111). Using multiple sources for value coding (field notes, interview transcripts, and documents) corroborates the coding and enhances trustworthiness of the findings (LeCompte & Preissle, 1993, pp. 264-5) because what a participant states are his or her values, attitudes, or beliefs may not always be truthful or supported by his or her actions.

Phase Three will consist of a review of processes in the workplace and process (or action) coding methods will be used. Process coding is appropriate for studies that search for “ongoing action/interaction/emotion taken in response to situations or problems, often with the goal of handling a problem” (Corbin & Strauss, 2008, pp. 96-7). The processes of human behavior can be “strategic, routine, random, novel, automatic, and/or thoughtful” (Corbin & Strauss, 2008, p
Data will be analyzed specifically for how DSPs respond to the situations they experience in the CILA work environment. Information about the context of the stories will be gathered to help classify the stories in the contextual areas of workplace, personal, time and place. The process of restorying will be used to organize the stories into a framework that makes sense. The qualitative data analysis will be a description of the story and the themes that emerge from it. The study will be a collaborative process, which actively involves participants in the research. This process involves the negotiation as to the meaning of the stories and how DSPs feel sexuality and affectionate behaviors impact their workplace today. The collaboration process results in a validation check to the analysis.

Because of the complexity of the regulation of state institutions and organizations for housing ID residents, an expert panel will be used in this study to provide both consultation and expert peer review for the study. The expert panel will be comprised of the agency director of human resources and training, the agency director for CILA programs, the director of human resources and training from a state institution for developmental disabilities, and a tenured-faculty trained in qualitative research methods. These professionals have the training, research, regulatory, and clinical expertise required to work with this project. For the purposes of this research, an expert panel will be used in an advisory capacity to ensure sufficient depth and detail are being obtained by the researcher and as another layer of member-checking to aid in the quality of the triangulation process. Rather than using triangulation solely as a technique for validation, it may also be used “to ensure a comprehensive and deeper understanding of the subject matter” (Klein & Olbrecht, 2011, p. 343). Expert panels are likely to be useful when it is important to include significant local knowledge about the topic being studied, when a holistic
approach is needed, when conflicting societal values are present that may need to be identified and account for, and the impacted area is relative small. Expert panels are particularly suited to assess impacts in small localized areas (Sesking, Still, & Boroski, 2002), such as CILA home settings.

After all interviews are completed, coded, and major themes have been generated, a summary report will be given to each member of the expert panel. Each participant’s name and personal identifiers will be removed to maintain confidentiality in the summary report. Each participant’s name will be converted to pseudonym for all reporting purposes. Each member will be asked to prepare a written reaction to the summary report, indicating their analysis, feedback, and experiences with the issues raised from the interview process. A written analysis will provide the richest information and will aid in the depth of detail required for good qualitative studies (Sesking, Still, & Boroski, 2002). Also, if the panel will be asked to provide only a written analysis of the issues, a smaller panel size (in the range of four to six individuals) is suitable (Sesking, Still, & Boroski, 2002). Each written reaction report will be read and analyzed to determine if any additional follow-up questions or clarification is required from the participants or if any additional documents need to be obtained for analysis. Data analysis in this stage will include a review to remove any potential bias on the part of the researcher and the use of a tenured-faculty at a state university to review the data analysis process to establish inter-rater reliability.

Phase Four will entail gathering any additional data needed that may be identified by the earlier data analysis processes, an adaptation of the coding process if necessary, and adapting or generating any new themes or categories. A final summary report merging the data from the
interviews, the field notes, document analysis, the audio/videotape observations, the member-  
checking, and the expert panel will be created.

Table 3

Description of Coding Methods

<table>
<thead>
<tr>
<th>Coding Phase</th>
<th>Method</th>
<th>Tool</th>
<th>Action</th>
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</thead>
<tbody>
<tr>
<td>First Cycle</td>
<td>First Cycle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-Coding</td>
<td>Interview/Field Notes</td>
<td>Notes in margins</td>
<td></td>
</tr>
<tr>
<td>Descriptive</td>
<td>Descriptive Coding</td>
<td>Reflective Summaries</td>
<td>Identify Ideas, Concepts, Themes</td>
</tr>
<tr>
<td>Emotion</td>
<td>Emotion Coding</td>
<td>Interview Transcripts</td>
<td>Create Initial Codes</td>
</tr>
<tr>
<td>Value</td>
<td>Value Coding</td>
<td>Document Analysis</td>
<td>Create Categories/Sub-Categories</td>
</tr>
<tr>
<td>Second Cycle</td>
<td>Focused Coding</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Compare Themes</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Compare Categories</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Adapt Categories as necessary</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Adapt Sub-Categories as necessary</td>
</tr>
<tr>
<td>Third Cycle</td>
<td>Bias Check</td>
<td>Self-Reflection</td>
<td></td>
</tr>
<tr>
<td>Coding</td>
<td>Coding Review</td>
<td>Member-Checking</td>
<td>Check for bias</td>
</tr>
<tr>
<td></td>
<td>Expert Panel Review</td>
<td></td>
<td>Compare Themes</td>
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<tr>
<td></td>
<td>Independent Rater Review</td>
<td></td>
<td>Compare Categories</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Adapt Categories/Sub-Categories</td>
</tr>
<tr>
<td>Fourth Cycle</td>
<td>Final Coding</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*NVIVO Qualitative Analysis software will be used if necessary to aid data analysis process.

Ethical considerations.

Risks associated with participation in this study are very low. Participation is voluntary and participants may discontinue the survey at any time without penalty. Every effort will be made to assure participants of their confidentiality. SIUC and EIU Human Subjects Committee approval will be obtained before any participant involvement.
A purposeful sample of DSPs employed by a group home in a rural Midwest community will be utilized for this study. DSPs who are employed as a caregiver of ID residents in the CILA home setting will be interviewed. The DSPs will partake in a semi-structured audio taped interview lasting 60-90 minutes with an agreement that follow up interviews, if needed, may be conducted. Participants who complete the interview process will not receive any incentive for their participation in the study.

Validity/trustworthiness.

Validity is the final component to design. A key concept for validity is validity threat: a way the study might be wrong. Validity, as a component of research, consists of the strategies used to identify and rule out these threats (Maxwell, 2005, p. 106). The main focus of validity in qualitative studies should be how to rule out specific plausible alternatives and threats to my interpretations and explanations, specifically in regard to reactivity and bias (Maxwell, 2005, p. 107). To deal with “reactivity” I will emphasize to participants that I have no stake in how they experience sexuality and affectionate behaviors in the workplace. To deal with bias, I will bring to my awareness my personal perception about sexuality and affectionate behaviors in group home settings and constantly monitor how this may influence how I analyze data.

Case study researchers are particularly at risk for bias due to preconceived positions, since the process requires them to have an understanding of the issues beforehand. The test for this possible bias is the degree to which the researcher is open to contrary findings. The likelihood for this type of bias will be reduced through the use of two raters. Two raters, working independently, will be used establish inter-rater reliability. The raters will be the researcher and one tenured-faculty from a state university. This protocol does not require multiple people to be present during the interviews or observation process, but rather allows the
researcher to share the videotapes and transcripts with other trained experts for review. The
experts may support, refute, or enhance the original conclusions, coding of themes, or original
conclusions (Stake, 2005). To address validity, the data will be checked by two researchers
independently, with the themes being cross-referenced before the results will be combined.
Thematic coding and inductive analysis will be employed by the data analysts to generate themes
or categories based on the transcribed data. A discussion about possible alternative explanations
and suggestions for data collection will be held to identify any potential contrary findings to
reduce bias (Yin, 2003, p. 62.)

Qualitative research uses consistency as the measure of would the findings be similar
and/or consistent if the study were replicated. There are four protocols for triangulation. They
include (a) data source triangulation, (b) investigator triangulation, (c) theory triangulation, and
(d) methodological triangulation (Stake, 2005). Methodological triangulation is the most
common protocol utilized. This protocol uses multiple sources of data to increase confidence
that researchers have in the interpretation of their results. By using a multi-method approach, a
researcher is more likely to clarify or invalidate issues related to the study. Typically, this
method employs the use of in-depth interviews, observations, and document reviews (Merriam,
2009; Yin, 2009; Stake, 2005).

Credibility, or internal validity, is reflective of the rigor in which the researcher pursues
data, and how accurately the research findings reflect the true context of the story as delivered by
the story-teller (Patton, 2002). Triangulation of the data will be obtained through videotape
observations; memos and field notes, transcribed interview data, member-checking, and through
the use of expert panel review. According to Bloomberg and Volpe (2008, p. 64): “triangulation
design is a process where a researcher uses multiple perceptions to clarify meaning”. Analysis
will be conducted through the use of themes and metaphors. Credibility for qualitative research can be enhanced through the use of prolonged/varied field experiences, time sampling, reflexivity, triangulation, member checking and peer examination (Isaac & Michael, 1997). Credibility and confirmability will be maintained through the use of triangulation, peer review, member checking, and clarifying biases.

**Verification techniques.**

The following verification techniques will be used for the qualitative components of this study:

- Member Check (or Respondent Validation); e.g. paraphrase my understanding of something they said and ask them to react to it during the interview.
- Re-read the transcript to see where it supports or conflicts with my findings.
- Triangulation of data (Interview, field notes, transcripts, document analysis)

Data will be analyzed in the following manner:

- The interviews will be audio/video-taped and transcribed by a professional court reporter within two weeks of each meeting. In addition, the researcher will choose two interviews at random to transcribe as well. The two versions of the transcripts of the same interview will be cross-checked for accuracy.
- Qualitative content analysis will be used to develop a series of codes for the interview transcription and the observation notes from the interviews. The content analysis method is a process that allows for the examination and interpretation of data through reduction, analysis of specific statements, searching for meanings, and is a common theory-development strategy. The codes will be used to identify key descriptive
themes within the qualitative data through the use of pre-coding, descriptive, emotion, value, and process coding methods in addition to bias checking and final coding analysis.

- Member-checking will be completed after the interview by giving each participant a transcript of their interview to review and clarify.
- An expert panel will be used in this study to provide both consultation and expert peer review throughout the proposed project.

Demographic data will include sex, level in school, race/ethnicity, age, job title, and length of employment with agency. Data for the qualitative components will be analyzed in the following manner--interviews will be audio-taped and transcribed by a professional court reporter within two weeks of each meeting; Qualitative content analysis will be used to develop a series of codes for the interview transcription. The content analysis method is a process that allows for the examination and interpretation of data through reduction, analysis of specific statements, searching for meanings, and is a common theory-development strategy. The codes will be used to identify key descriptive themes within the qualitative data.

**SUMMARY**

The purpose of this study is to explore the experiences of DSPs with sexuality and affectionate behaviors of intellectually disabled individuals at a mid-size agency providing services for ID residents in a small, rural, mid-western town. The relationship between factors associated with the sexuality behaviors of ID residents in traditional group home settings and the perceptions of DSPs to deal with those behaviors will be analyzed in this qualitative study. The study will examine the perceived sexuality training needs of DSPs and the perceived relevance of such needs as they relate to QRMP responsibilities and competencies. Furthermore the knowledge, attitudes, and behaviors of DSPs and DSPs on the topic of sexuality needs in ID
populations will be analyzed. If the basic level of sexuality experiences for working with ID populations by DSPs can be identified, training programs can be developed to build skills in regards to sexuality workplace issues to enhance the group home experience for DSPs and residents. Chapters four and five will give a detailed account of the findings of the study and appropriate conclusions and recommendations.
CHAPTER 5

DISCUSSION
References


Grieve, A., McLaren, S., Lindsay, W., & Culling, E. (2009). Staff attitudes towards the sexuality of people with learning disabilities: a comparison of different professional groups and


APPENDICES
Appendix A

Definitions of Terms – Comprehensive List


Aberrant Behavior – Behavior that deviates markedly from what is considered typical (Accordo & Whitman, 2011)

Accommodation – An adaptation made to an environment, facility, or task to enhance the performance of an individual with a disability (Accordo & Whitman, 2011).

Acting Out – A psychoanalytic term that refers to expressing feelings, unconscious drives, or impulses through external behavior rather than verbally articulating them. This acting out of feelings is usually expressed in annoying, disruptive, or antisocial ways. Typical acting out behaviors includes fighting, stealing, crying, pouting, hyperactivity, temper tantrums, and verbal threats (Accordo & Whitman, 2011).

Activities of Daily Living (ADLs) – Self-help activities such as bathing, toileting, eating, cooking, being mobile, performing simple health care procedures, and keeping house (Accordo & Whitman, 2011).

Activity-Based Intervention – An early intervention approach that capitalizes on daily caregiver-child transactions. It relies on child-initiated transactions, embeds goals in daily activities, uses logically and naturally occurring antecedents and consequences to develop functional skills that transfer readily to other contexts (Accordo & Whitman, 2011).
Adaptation – The extent to which an individual, group, or community copes with the fluctuating demands of daily life (Accordo & Whitman, 2011).

Adaptive Behavior – A set of skills and behavior, including feeding, dressing, toileting, and higher level social interaction skills, used by individuals with disabilities to cope with the natural and social demands of the environment (Accordo & Whitman, 2011).

Adaptive Education – A general term referring to education that incorporates modified instructional methods, materials, or expectations to address students’ individual differences (Accordo & Whitman, 2011).

Adult Day Care – A continuum of services included sheltered work, day hospital, socialization groups, or custodial services provided to adults who are unable to care for themselves (Accordo & Whitman, 2011).

Adult Protective Services – Social, medical, legal, residential, or custodial services provided to adults who are unable to gain access to such services for themselves. In the event that there is no guardian or significant other, or incases of a guardian or significant other being abusive to the adult with the disability, a public or private agency may provide adult protective and service coordination services (Accordo & Whitman, 2011).

Affectionate Behavior(s) – Hugging, holding hands, sitting side-by-side, and/or kissing

Age-Equivalent (AE) Scores – Ratings derived by determining the average raw score obtained on a test taken by children of various ages (Accordo & Whitman, 2011).

Aggression – A poorly defined set of human behaviors interpreted from physical or verbal behavior directed at others (Accordo & Whitman, 2011).

Agitation – Extreme motor restlessness and an increased activity level associated with anxiety and tension; a sign of mental distress (Accordo & Whitman, 2011).
**Allied Health Professional** – A person with special training who works under the supervision of a health professional to provide direct patient care (Accordo & Whitman, 2011).

**Anxiety** – An internal state of fear in response to actual or perceived danger (Accordo & Whitman, 2011).

**Automatic Processing** – Behavioral sequences that, after prolonged practice, no longer require attention. Automatic processes are rapid and efficient, once learned they are inflexible and hard to change (Accordo & Whitman, 2011).

**Automaticity** – Habitual response to an expected stimulus (Accordo & Whitman, 2011).

**Basic Trust** – In psychoanalyst Erik Erikson’s version of psychosexual development, basic trust is the major achievement of the first developmental stage (basic trust versus mistrust) in the first year of life; repeated interactions with a caregiver provide a foundation of positive predictability, safety, and trust, thus instilling a positive orientation to the world (Accordo & Whitman, 2011).

**Behavioral Capability** – Knowledge and skills necessary to perform behavior

**Behavior Coach** – A one-to-one caregiver for an individual with ID or developmental disabilities (Accordo & Whitman, 2011).

**Behavior Modeling** – A training intervention popularized by social learning theory. A practitioner demonstrates (models) the appropriate behavior or uses a visual representation, and the learner is reinforced for accurate replication of the behavior (Accordo & Whitman, 2011).

**Behavior Modification** – Referring to a set of techniques based on the systematic application of learning theory (Accordo & Whitman, 2011).

**Behaviorism** – A theoretical approach to explaining human behavior. Behaviorism assumes that all human behavior is learned. Learning occurs when the consequences of behavior are pleasant (i.e. responses are repeated when they are reinforced). Reinforcement increases the future
likelihood of behavior occurring, and punishment reduces that likelihood (Accordo & Whitman, 2011).

**Borderline Intellectual Functioning** - An IQ score between 70 and 85 in the absence of functional or adaptive impairment. Educationally speaking, someone with borderline intellectual functioning is a slow learner (Accordo & Whitman, 2011).

**Boundaries** – Emotional and interactional barriers that protect and enhance the integrity of individuals, relationships, and families. Boundaries are unwritten rules that function as invisible lines defending both closeness and distance in a relationship. Boundaries can be too rigid to allow growth, they can be appropriately clear, or they can be too loose to protect the family. The term also has applications in the workplace (Accordo & Whitman, 2011).

**Caregiver** – Any person with physical or legal responsibility for the care of a child, an older adult, or an adult with developmental disabilities (Accordo & Whitman, 2011).

**Choice Making** - Occurs when an individual selects a preferred item or activity from two or more options (Accordo & Whitman, 2011).

**Client** – A social work and human services term denoting an individual, family, group, or community receiving services (Accordo & Whitman, 2011).

**Close Relationship** – a relationship that is personal, interpersonal, significant, intimate, meaningful, loving, or committed (McKinney & Sprecher, 1991, p. 2).

**Cognitive Appraisal** – An individual’s view of a situation. A cognitive appraisal determines whether an event will be perceived as irrelevant, benign, positive, or stressful and threatening (Accordo & Whitman, 2011).

**Common Sense** – Knowledge thought to be widely understood. Generally, common sense is a compilation of cultural traditions or folk knowledge that constitute a body of shared and
relatively standardized interpretations of a variety of phenomena, from natural occurrences to social behavior (Accordo & Whitman, 2011).

**Community of Practice (COP)** – An informal group of people who share an interest, a craft, and/or profession. By sharing information and experiences with the group, members learn from one another (Accordo & Whitman, 2011).

**Concept** – A commonality in events or objects designated by some label (Accordo & Whitman, 2011).

**Coping Skills** – Skills and strategies that provide an individual with the ability to adjust and accommodate to life stressors without unduly interfering with his or her personal, social, or work life functioning (Accordo & Whitman, 2011).

**Criterion** - A predetermined level of performance to be achieved; a targeted standard (Accordo & Whitman, 2011).

**Cultural Bias** - The use of material that is familiar to one social or economic group but remote from the experiences of another group (Accordo & Whitman, 2011).

**Cultural Sensitivity** – Knowledge of cultural differences and the corresponding use of verbal and nonverbal behavior that optimizes interactions with people from a different cultural background (Accordo & Whitman, 2011).

**Deinstitutionalization** – The relocation of people with developmental disabilities and psychiatric illnesses from institutional settings to community placements; one component of normalization (Accordo & Whitman, 2011).

**Dependency** – Behavior characterized by overreliance on another person or system. The reliance can be emotional, physical, or financial. The dependent person fails to use his or her own skills
and abilities, passively leaning on another person or system to care for his or her needs (Accordo & Whitman, 2011).

**Developmental Age (DA)** – The age (in years and months) that best describes a child’s level of performance by equating it to the performance of a typically developing child of that chronological age (CA) (Accordo & Whitman, 2011).

**Developmental Approach** – The theory that people with mild intellectual disability without evidence of physical brain damage behave and learn exactly the same as their typically developing peers except for the impact of personality variables (Accordo & Whitman, 2011).

**DHHS** – Department of Health and Human Services

**Disability** – Any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being (Accordo & Whitman, 2011).

**Direct Reinforcement** – verbal or non-verbal feedback

**Direct Service Personnel** – are people who work directly with people with physical disabilities and/or intellectual disabilities with the aim of assisting the individual to become integrated into his/her community or the least restrictive environment.

**Disabled** – A person with a level of impairment that interferes with their functioning in adult roles, creating difficulties living independently, maintaining employment, completing or advancing their educations, and relating interpersonally with others (Cook, 2000).

**Group Home** – A supported living residence licensed by the state for people with ID, developmental disabilities, and certain mental illnesses. The group home environment tries to be like that of a typical home, encouraging shared responsibility and cooperative social interaction.

To qualify for federal assistance, group homes must adhere to guidelines established by the

Habilitation – The provision of medical, psychological, educational, and family services to people with disabilities in order to maximize their vocational, mental, physical, and social abilities and to facilitate their functioning as independently as possible (Accordo & Whitman, 2011).

Handicap – A disadvantage for a given individual that results from an impairment or disability that limits or prevents the fulfillment of a role that would otherwise be typical for that individual. Except when citing laws or regulations, one should not use the term handicap to describe a disability (Accordo & Whitman, 2011).

Identity – A sense of being male or female, an acknowledgement of the different sexual roles, a preference for heterosexual or homosexual relationships, a molding of different male and female role characteristics (Gardner & Chapman, 1993, p. 199).

Intellectual Disability (ID) – Cognitive impairment. To meet the criteria for having ID under the Individuals with Disabilities Education Act (IDEA) of 1990 (PL 101-476) a student must have an intellectual ability score (IQ) of 70 or below with adaptive and academic skills commensurate with ability. ID replaces the term mental retardation in the United States (Accordo & Whitman, 2011).

Intelligence Quotient (IQ) – A quantitative score that is accepted as reflecting an individual’s cognitive abilities (Accordo & Whitman, 2011).

Interview - An interview is literally an interchange of views between two people conversing about a theme of common interest.
Intimacy – Mental feelings of closeness and caring that accompany sex (Gardner & Chapman, 1993, p. 199).

Locus of Control – Perception of the center of control over reinforcement (internal or external).

Love – A collection of behaviors, thoughts, and emotions that are associated with a psychological attraction toward other individuals (Alters & Schiff, 2009).

Maladaptive Behavior - Recurrent behaviors and behavior patterns that prevent an individual or family from obtaining a desired goal or meeting the demands of the environment (Accordo & Whitman, 2011).

Mental Age (MA) – An age-equivalent score; a measure of mental development as determined by intelligence and achievement tests; expressed as the age for which that level of performance is the average. MA is a “commonsense” concept for helping parents understand the approximate age at which their child functions so that appropriate achievement and behavioral expectations can be used (Accordo & Whitman, 2011).

Model – Subclass of a theory; draw on a number of theories to help people understand a specific problem in a particular setting or context

Modeling – The enacting of a specific behavior or set or behaviors with the intention of having an observer imitate that behavior (Accordo & Whitman, 2011).

Multiple Disabilities – The coexistence of more than one disability in a single individual. The more severe a single disability, the more likely it is that a second disability will be present (Accordo & Whitman, 2011).

Negative Reinforcement – Increasing a behavior when the aversive consequence following it is removed (Accordo & Whitman, 2011).
Normal – conforming to the standard or the common type; not abnormal; regular, natural or serving to establish a standard (Dictionary.com).

Normalization – the belief that ID populations have the right to progress through the normal developmental stages of life and that their decisions must be respected whenever possible (Mitchell, 1985).

Observational Learning – Learning that takes place by observing and remembering how others succeeded or failed (Accordo & Whitman, 2011).

Paraprofessional - An aide or associate-level staff person who has not completed the educational requirements for licensure or certification (Accordo & Whitman, 2011).

Peers – Social equals. In developmental terms, people who are similar in characteristics such as age or developmental level. Children with developmental disabilities are often described as “immature” and as having “poor social skills”, making it difficult for them to associate with their peer groups by age or grade. Peer groups are important for all children in forming modeling for identification (Accordo & Whitman, 2011).

Phenomenology – A philosophical doctrine established by E. Husserl in the 19th century that has had considerable influence in the social sciences. Husserl stressed the rigorously descriptive, but introspective study of how people perceive and understand the world (Vogt, 2005).

QDDP – Qualified Developmental Disability Professional; formerly known as Qualified Mental Retardation Professional or QMRP (qddp.org).

Reciprocal Determinism - Behavior changes result due to interaction between the person and the environment.

Reinforcer – A pleasant event or reward that follows a behavior and that increases the future likelihood of that behavior occurring (Accordo & Whitman, 2011).
Self-Concept – a person’s picture of self and the self-evaluation of this picture (Brammer, Shostrom & Abrego, 1989, p. 29).

Self-Control – gaining control over own behavior through monitoring and adjusting

Self-Efficacy – confidence in ability to perform a certain task

Self-Esteem – An individual’s perception and valuation of his or her worth, especially when compared with a particular reference group, and the feelings that emerge from those judgments (Accordo & Whitman, 2011).

Self-Management – keep record of own behavior, when behavior performed appropriately, then self-reward.

Sexuality – sexual behaviors, arousal, and responses, as well as sexual attitudes, desires, and communication (McKinney & Sprecher, 1991, p. 2).

Social Intelligence (SI) – The ability to understand and deal effectively with social and interpersonal events (Accordo & Whitman, 2011).

Social Learning Theory – A theory of development and learning that emphasizes both the principles of behaviorism and the individual’s internal attributions and thoughts in determining behavior. Social learning theory includes the concepts of modeling, imitation, and self-efficacy.

Social learning is more likely to occur when the model is attractive, is powerful, or possesses other desirable qualities (Accordo & Whitman, 2011).

Temperament – Individual difference in emotional, motor and attentional reactivity and self-regulation consistently displayed in all kinds of settings and situations (Rothbart & Bates).

Vicarious Reinforcement – Observe others reinforced for behaving appropriately

Value – A belief that an idea, object, or action has worth (Alters & Schiff, 2009).
Value System – A collection of beliefs that helps a person identify and classify things as being good or bad, or neither good nor bad (Alters & Schiff, 2009).
Appendix B

Human Subjects Approval Forms

SIUC & EIU
Appendix C

Participant Demographic Information Questionnaire

1. Name: ________________________________________________

2. Age: _________________________________________________

3. Sex: _________________________________________________

4. Race: _____________ ___________________________________

5. Ethnic Origin: _________________________________________

6. Marital Status – Please circle your marital status:
   - Single
   - Married
   - Divorced
   - Widow or Widower
   - Living with Significant Other
   - Prefer Not to Answer

7. Parenting Experience – Please circle how many children you have:
   - No Children
   - 1 Child
   - 2 Children
   - 3 Children
   - 4 Children
   - 5 or more children
   - Guardian of related children
   - Guardian of unrelated children
   - Prefer Not to Answer

8. If you have children, did you attend Lamaze classes? (Please circle your answer)
   - Yes
   - No
   - Not Applicable

9. Education – Please circle your level of education:
   - Graduate Degree
   - Working on Graduate Degree
   - Bachelor’s Degree
   - Senior
   - Junior
   - Freshman
   - Some College
   - High School Diploma
   - GED
   - Never Finished High School
   - Prefer Not to Answer
10. Major – Please write your major and minor here:

11. Degree – Please write your degrees here:

12. Did you have a mandatory health class in junior high or middle school?
(Please circle your answers for questions 11-25)
   Yes
   No

13. Did you have a mandatory health class in high school?
   Yes
   No

14. Have you ever taken a class in child development?
   Yes
   No

15. Have you ever taken a class in human growth and development?
   Yes
   No

16. Have you ever taken a class in human sexuality?
   Yes
   No

17. Have you completed the Department of Human Services Module on preventing sexual abuse?
   Yes
   No

18. Have you ever attended training by SIECUS at your agency?
   Yes
   No

19. Do you have a friend or relative that is intellectually disabled?
   Yes
   No

20. Did you have experience working with intellectually disabled people before you became employed with this agency?
   Yes
   No
21. **Job Appointment Level** – Please circle how your agency classifies your job with the organization:
   - Full time
   - Full time < 9 months
   - Part time
   - Prefer Not to Answer

22. **Job Appointment Level** – Please circle how you classify your job with the organization:
   - Full time
   - Full time < 9 months
   - Part time
   - Prefer Not to Answer

23. **Average Hours Worked Per Week** – Please circle how many hours you typically work each week:
   - Over 40
   - 35-40
   - 30-34
   - 25-29
   - 20-24
   - 15-19
   - 10-14
   - Less than 10
   - Prefer Not to Answer

24. **How long have you worked in this agency?**

25. **Have you ever worked at any other agencies in the group home setting?** If so, for how long did you work there?

26. **Job Enjoyment Level** – Please circle the level in which you enjoy your job with the agency:
   - Minimal
   - Dislike
   - Mildly dislike
   - Neutral
   - Moderately Enjoy
   - Enjoy
   - Intensely Passionate About It
   - Prefer Not to Answer

27. **Please list any additional training or workshops you have attended that have to do with human development, sexuality, or affectionate behaviors:**
Appendix D

Informed Consent Forms for In-Depth Interviews

I am pursuing my Ph.D. in Health Education from Southern Illinois University-Carbondale, and presently am involved in the research portion of my dissertation. This dissertation is a qualitative case study in which I will be interviewing several DSPs who are directly involved with working with ID residents in CILA home settings.

The focus of this study revolves around how DSPs experience training and sexuality and affectionate behaviors in the workplace. The questions asked during the interview will seek to determine your perception of sexuality and affectionate behavior needs of DSPs in group home settings. Your participation will include your participation in one audio/videotaped interview lasting from 45 minutes to one hour. You may end the interview at any time and request the audio/videotapes be erased.

You will not be identified by the position you hold, or by name in the dissertation. Your participation is voluntary. You will receive a hard copy of the interview transcript within two weeks following the interview. You may make any changes you choose. You have the right to withdraw from the study any time up until February 28, 2015. At that point, I will be in the final stages of the writing process and will not be able to remove quotations from the document. At the conclusion and approval of the research project, audio/videotapes will be destroyed.

I appreciate your giving time to this study, which will help me, as well as the agencies, learn more about what we can do to support staff in CILA home settings to better prepare them to deal effectively with resident sexuality and affectionate behaviors in the workplace. If you have any questions, please feel to call me at (217) 549-2989. You may also contact my committee chairperson, Dr. Roberta Ogletree, Professor in the Department of Health Education and Recreation, Mailcode 4632, Southern Illinois University, Carbondale, IL 62901-4632, by email at bobby@siuc.edu, or by telephone at (618) 453-2777. This project has been reviewed and approved by the SIU Human Subjects Committee and the EIU Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Research Development and Administration, Southern Illinois University, Carbondale, IL 62901-4709; Phone (618) 453-4533.)
Thank you in advance for your consideration,

Anita Sego

Please sign below if you are willing to participate in the dissertation project outlined above.

By signing below, the research participant verifies:

I have read the material above, and any questions I asked have been answered to my satisfaction. I understand a copy will be made available to me for the relevant information and phone numbers. I agree to participate in this activity, and I know that my responses will be recorded on audio/videotape. I realize that I may withdraw without prejudice at any time.

Signature________________________________________

Print Name________________________________________

Date________________________________________
# Appendix E

## In-depth Interview Protocol for DSPs

<table>
<thead>
<tr>
<th>Questions</th>
<th>Prompts</th>
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<tbody>
<tr>
<td>1. Describe for me a typical work day in your CILA home.</td>
<td>Prompt #1: workplace setting</td>
</tr>
<tr>
<td></td>
<td>Prompt #2: interactions with your residents</td>
</tr>
<tr>
<td>2. Describe the training you had to complete for your job.</td>
<td>Prompt #1: training times</td>
</tr>
<tr>
<td>3. What is the most stressful thing at your job?</td>
<td>Prompt #1: personally</td>
</tr>
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<td>Prompt #2: professionally</td>
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<tr>
<td>4. When I say the word sexuality what comes to mind?</td>
<td>Prompt #1: perceptions</td>
</tr>
<tr>
<td></td>
<td>Prompt #2: resident</td>
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<tr>
<td>5. Tell me about your experience with sexuality issues at work.</td>
<td>Prompt #1: resident</td>
</tr>
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<td></td>
<td>Prompt #2: other staff</td>
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<td>Prompt #3: parental role</td>
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<td>Prompt #4: educator role</td>
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<tr>
<td>6. How do you feel about your experiences?</td>
<td>Prompt #1: Why or why not?</td>
</tr>
<tr>
<td>7. Do you think your personal attitudes and experiences influence how you interact with your residents?</td>
<td>Prompt #2: How?</td>
</tr>
<tr>
<td>8. What type of training did your employer provide to help prepare you or help you deal with those issues?</td>
<td>Prompt #1: How did it help?</td>
</tr>
<tr>
<td>9. Have you ever served as a sex educator at work?</td>
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<tr>
<td>10. How did that make you feel?</td>
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### Interview Audio/Video Observation Protocol

<table>
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<tr>
<th>DESCRIPTIVE NOTES</th>
<th>REFLECTIVE NOTES</th>
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Appendix G

Document Analysis Protocol

Document analysis will include examining the training materials, records, programs, services, and supports available to support DSP with sexuality and affectionate behaviors & incidents in the workplace.

Name of Document:

Date of Document:

Type of Document (brochure, website, report, training material, etc.):

Author(s):

Intended Audience:

Intended Purpose:
### Perceptions of Sexuality

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<tr>
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<td>Not Natural</td>
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<tr>
<td>SOCINAPP</td>
<td>Socially Inappropriate</td>
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<td>SOCAPP</td>
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</tr>
<tr>
<td>REL</td>
<td>Religious-Based</td>
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<tr>
<td>MOD</td>
<td>Based on Modern Standards</td>
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### Influences on Sexuality/Affectionate Behaviors

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<tbody>
<tr>
<td>POLICY</td>
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<td>CONSENT</td>
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<td>FUNCTIONAL</td>
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<td>LEVEL</td>
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<td>SETTING</td>
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<td>RESPECT</td>
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<td>HONESTY</td>
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<td>COMMUNICATION</td>
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### Trust

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<td>TRSTSCLWRK</td>
<td>Trust in social worker</td>
</tr>
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<td>TRSTN</td>
<td>Trust in nurse/medical staff</td>
</tr>
<tr>
<td>TRSTSPVSR</td>
<td>Trust in supervisors</td>
</tr>
<tr>
<td>TRSTHSTFF</td>
<td>Trust in staff</td>
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<tr>
<td>TRSTSELF</td>
<td>Trust in self</td>
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<td>NOTRSTSCLRK</td>
<td>No trust in social worker</td>
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<td>NOTRSTN</td>
<td>No Trust in nurse/medical staff</td>
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<td>NOTRSTSPVSR</td>
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<td>No Trust in staff</td>
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<td>NOTRSTSELF</td>
<td>No Trust in self</td>
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### Bias/Gender

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### Concept of choice in regards to sexuality

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<td>Concept of Medical/Physical Choice</td>
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<td>INTELCHOICE</td>
<td>Concept of Intellectual Choice</td>
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<tr>
<td>QUALCHOICE</td>
<td>Concept of Quality of Life Choice</td>
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Table 5: Demographic Characteristics of the Participants

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<tr>
<th>Name</th>
<th>Age</th>
<th>Sex</th>
<th>Marital Status</th>
<th># of Kids</th>
<th>Time of Service</th>
<th>Years of Education</th>
<th>Major</th>
<th>Taken Health Class(es)</th>
<th>Family or Friend with ID</th>
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### Table 4

**Family Status and Education of DSPs**

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Table 5

*Employment Status and Level of Job Enjoyment*

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<td>Full time &lt; 9 months</td>
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</table>
VITA

Graduate School
Southern Illinois University

Anita L. Sego
anitalsego@gmail.com

Eastern Illinois University Charleston
Bachelor of Science, Community Health, May 1987

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Special Honors and Awards:
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Dissertation/Thesis/Research Paper Title:
Pending

Major Professor: Dr. Roberta Ogletree

Publications:
Pending